

Patterns of Care at the End of Life for Children and Young Adults with Life-Threatening Complex Chronic Conditions

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Objective To characterize patterns of care at the end of life for children and young adults with life-threatening complex chronic conditions (LT-CCCs) and to compare them by LT-CCC type.

Study design Cross-sectional survey of bereaved parents (n = 114; response rate of 54%) of children with noncancer, noncardiac LT-CCCs who received care at a quaternary care children's hospital and medical record abstraction.

Results The majority of children with LT-CCCs died in the hospital (62.7%) with more than one-half (53.3%) dying in the intensive care unit. Those with static encephalopathy (AOR, 0.19; 95% CI, 0.04-0.98), congenital and chromosomal disorders (AOR, 0.28; 95% CI, 0.09-0.91), and pulmonary disorders (AOR, 0.08; 95% CI, 0.01-0.77) were significantly less likely to die at home compared with those with progressive central nervous system (CNS) disorders. Almost 50% of patients died after withdrawal or withholding of life-sustaining therapies, 17.5% died during active resuscitation, and 36% died while receiving comfort care only. The mode of death varied widely across LT-CCCs, with no patients with pulmonary disorders dying receiving comfort care only compared with 66.7% of those with CNS progressive disorders. A majority of patients had palliative care involvement (79.3%); however, in multivariable analyses, there was distinct variation in receipt of palliative care across LT-CCCs, with patients having CNS static encephalopathy (AOR, 0.07; 95% CI, 0.01-0.68) and pulmonary disorders (AOR, 0.07; 95% CI, 0.01-.09) significantly less likely to have palliative care involvement than those with CNS progressive disorders.

Conclusions Significant differences in patterns of care at the end of life exist depending on LT-CCC type. Attention to these patterns is important to ensure equal access to palliative care and targeted improvements in end-of-life care for these populations. (*J Pediatr* 2017;■■■:■■■-■■■).

Improvements in medical expertise and technology have led to a significant reduction in infant and childhood mortality over the past several decades and many more children are now living with life-threatening complex chronic conditions (LT-CCCs), such as severe congenital anomalies, metabolic disorders, cystic fibrosis, neurodegenerative diseases, and the sequelae of extreme prematurity.¹⁻⁴ Because of their multisystem diseases, technology dependence, and complex medication regimens, children and young adults with LT-CCCs often require a high level of medical care and technological support, even at the end of life (EOL).⁵⁻⁷ Unsurprisingly, large population studies, including a recent cross-national review, demonstrate that the majority of children with LT-CCCs die in the hospital,^{3,7,8} after prolonged periods of inpatient admission⁹ and primarily in an intensive care unit (ICU) setting.^{10,11}

In 2003, The Institute of Medicine's report, *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*, called for more epidemiologic studies documenting the circumstances surrounding deaths during childhood.¹² Since that time, there have been multiple pediatric studies using administrative data and/or characterizing deaths in the inpatient setting.^{1,5,7,9,11,13-16} Additionally, there have been numerous disease-specific studies in cancer¹⁷⁻²² and congenital heart disease.^{23,24} At present, little is known about patterns of care at EOL for children and young adults with LT-CCCs who die across the spectrum of locations, and recent research suggests that hospital use for children with LT-CCCs varies considerably by condition type,⁷ which would suggest that patterns of care at the EOL also may differ. Understanding who these children are, where they die, and the circumstances surrounding their deaths is necessary for health care systems to ensure the provision of efficient and equal access to palliative care for

5Cs	Caring for Children with Complex Chronic Conditions
ACP	Advance care planning
BCH	Boston Children's Hospital
CCC	Complex chronic condition
CNS	Central nervous system
CPR	Cardiopulmonary resuscitation
DNR	Do Not Resuscitate
EOL	End of life
ICU	Intensive care unit
LT-CCCs	Life-threatening complex chronic conditions

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this population¹³ to enhance symptom management, optimize quality of life, help initiate discussions about advance care planning (ACP), aid in discerning patient and family preferences, and provide bereavement support to their families.^{25,26}

Improving knowledge about the patterns of care at the EOL for children and young adults by LT-CCCs type may identify gaps, inform clinical practice, and ultimately improve the quality of EOL care for these children and their families. Therefore, the primary objective of this study was to characterize clinical characteristics and patterns of care at the EOL care for children and young adults with LT-CCCs by chronic condition type, focusing on conditions less well-described in the literature.

Methods

This prospective cross-sectional study is based on a survey of bereaved parents of children and young adults with LT-CCCs. Parents were eligible for participation if (1) they were English speaking, (2) resided in North America with accurate contact information, (3) their child received care at Boston Children's Hospital (BCH) and died between January 2006 and December 2015, (4) at least 12 months had elapsed after their child's death, and (5) their child did not have cancer or congenital heart disease. To identify children and young adults with LT-CCCs, we used the definition of Feudtner et al of complex chronic conditions (CCC) defined as a child or young adult from 1 month of age with a medical condition reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 system severely enough to require specialty pediatric care and some period of hospitalization in a tertiary care hospital.⁹ In this article, we refer to CCCs as life threatening because all children with them in our cohort died. LT-CCCs were then systematically categorized into 5 primary types: central nervous system (CNS) progressive disorders, static encephalopathy, congenital and chromosomal, neuromuscular, and pulmonary disorders, by study investigators using a previously described classification system²⁷ to identify the predominant LT-CCC. Because these children often have multiple CCCs, in a small number of patients where it was difficult to discern the predominant LT-CCC from charting, 2 study investigators adjudicated to identify the primary LT-CCC type. Because many young adults with LT-CCCs continue to receive care at pediatric facilities until the middle of their fourth decade of life, we extended the age range of our cohort, including CCC-related deaths from 1 month up to the 35th birthday. We excluded children with cancer and primary complex congenital heart disease because they likely represent distinct subgroups of LT-CCCs and recent assessments about patterns of care at the EOL exist in the literature.^{20,24,28,29}

Bereaved parents were identified through the hospital bereavement committee database, which includes patients cared for at BCH who died in the hospital, at home, or elsewhere. Eligible parents were sent an introductory letter explaining the purpose of the study and a postage paid opt-out postcard. Three weeks later, a trained study investigator contacted the family by telephone to confirm their desire to

participate and determine their preferred method of survey completion (paper or email). Ten days after distribution of the survey, a combined thank you–reminder card was sent to participating parents. Parents who did not return the survey after the reminder card were called twice—once after 2 weeks and again after 4 weeks. Parents who declined participation were not further approached. This study was approved by the Institutional Review Board at BCH.

The survey *Caring for Children with Complex Chronic Conditions* (5Cs) was adapted from a previously validated instrument, Survey about Caring for Children with Cancer, which measured parental perceptions of EOL care for children with cancer¹⁷ and multiple prior studies have used the Survey about Caring for Children with Cancer or an adaptation of this survey.^{24,28,29} Relevant items were selected and new items related to communication around ACP for children with LT-CCCs were developed de novo on the basis of literature review and the opinions of an advisory board composed of interdisciplinary clinicians and parents of children with LT-CCCs from the Parent Advisory Council at BCH. Cognitive validity, wording, response burden, and willingness to participate were then assessed in a sample (n = 11) of bereaved parents of children with LT-CCCs. The final survey instrument (5Cs), a semistructured 183-item questionnaire, includes parental perspectives on (1) information about the child and their LT-CCC, (2) communication around prognosis after their child's diagnosis or recognition of serious illness, (3) communication and shared decision making around ACP, (4) patient and family experience at the EOL and time of death, (5) bereavement and family support, (6) family characteristics, and (7) parental experience with research participation in this survey. The survey questions and specific survey domains included in this analysis from sections 1, 4, and 6 are detailed in (Table I; available at www.jpeds.com).

Trained research assistants abstracted the medical records of all eligible children to confirm the child's primary diagnosis and date of death, and to determine the child's age, race, sex, insurance type, do not resuscitate (DNR) order status, technology dependence (chronic noninvasive ventilation, tracheostomy and mechanical ventilation, enteral feeding tube, and/or ventriculoperitoneal shunt), and number of hospital admissions, ICU admissions, and hospital duration of stay in the last year of life. Mode of death was classified by study personnel based on chart review and describes the categorization of death along the dimensions of intervention in the immediate EOL period and/or terminal admission as previously described.³⁰ "Died while receiving comfort care" describes those children who died because a decision was made not to initiate any new, life-sustaining interventions during the immediate EOL period or terminal admission. "Died receiving mechanical ventilation and/or cardiopulmonary resuscitation (CPR)" refers to those patients who died while receiving mechanical or noninvasive ventilation or despite active CPR. "Died after withdrawal or withholding of life-sustaining therapies" describes patients who had any life-sustaining therapies in place within the immediate EOL period or terminal admission that, once withdrawn, resulted in the patient's death.

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