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# Circumstances Surrounding the Deaths of Hospitalized Children: Opportunities for Pediatric Palliative Care

Brian S. Carter, MD\*‡; Matthew Howenstein, BS‡; Mary Jo Gilmer, PhD, MBA, RN\*§; Pat Throop, RN, BSN||; Dan France, PhD||; and James A. Whitlock, MD\*‡

**ABSTRACT.** *Objectives.* Little is known regarding the assessment and treatment of symptoms during end-of-life (EOL) care for children. This study was conducted to describe the circumstances surrounding the deaths of hospitalized terminally ill children, especially pain and symptom management by the multidisciplinary pediatric care team.

*Design.* Patients in the neonatal intensive care unit, pediatric critical care unit, or general pediatric units of Vanderbilt Children's Hospital who were hospitalized at the time of death, between July 1, 2000, and June 30, 2001, were identified. Children eligible for the survey had received inpatient EOL care at the hospital for at least 24 hours before death. A retrospective medical record review was completed to describe documentation of care for these children and their families during the last 72 hours of life.

*Results.* Records of children who had received inpatient EOL care were identified (n = 105). A majority (87%) of children were in an intensive care setting at the time of death. Most deaths occurred in the pediatric critical care unit (56%), followed by the neonatal intensive care unit (31%). Pain medication was received by 90% of the children in the last 72 hours of life, and 55% received additional comfort care measures. The presence of symptoms other than pain was infrequently documented.

*Conclusions.* The duration of hospitalization for most children dying in this inpatient setting was sufficient for provision of interdisciplinary pediatric palliative care. Management of pain and other symptoms was accomplished for many children. The documentation of pain and symptom assessment and management can be improved but requires new tools. *Pediatrics* 2004; 114:e361–e366. URL: <http://www.pediatrics.org/cgi/content/full/114/3/e361>; *children, palliative care, pain and symptom management.*

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ABBREVIATIONS. EOL, end of life; NICU, neonatal intensive care unit; PCCU, pediatric critical care unit; VCH, Vanderbilt Children's Hospital; LOS, length of stay; DNR, do not resuscitate.

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From \*Vanderbilt Children's Hospital, ‡Vanderbilt University School of Medicine, §Vanderbilt University School of Nursing, and ||Center for Clinical Improvement, Vanderbilt University Medical Center, Nashville, Tennessee.

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Address correspondence to Brian S. Carter, MD, Department of Pediatrics, Vanderbilt University Medical Center, MCN, A-0126, 21st Ave and Garland St, Nashville, TN 37232-2370. E-mail: [brian.carter@vanderbilt.edu](mailto:brian.carter@vanderbilt.edu)  
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Each year in the United States, ~55 000 children <20 years of age die, and many experience lengthy illnesses. The diagnoses affecting the length of children's lives include prematurity, congenital anomalies, sudden unexpected infant death syndrome, chromosomal defects, trauma, neurodegenerative disorders, cancer, and acquired immunodeficiency syndrome.<sup>1,2</sup> Technologic advances and medical expertise have led to improved outcomes, but incurable conditions continue to lead to premature death. A child's dying is often an intensely painful experience, both emotionally and physically.<sup>3</sup> Studies focusing on the care of children in the terminal stages of their illnesses are limited, and most of the current evidence on the experience of children's deaths is anecdotal.

A recent Institute of Medicine report emphasized the need to address challenges accompanying the care of dying children and their families.<sup>4</sup> Children at the end of life (EOL) are often deprived of the benefits of palliative care because of a lack of coordinated interdisciplinary services. A comprehensive philosophy of palliative care embraces physical, emotional, social, and spiritual elements.<sup>5</sup> Although some studies have described aspects of caring for certain children (eg, oncology patients) at the EOL,<sup>6</sup> there is a paucity of literature examining a comprehensive approach to caring for these children.

In an effort to assess current documentation of EOL care, family and child interdisciplinary support, pain and symptom management, communication, and decision-making, investigators completed a retrospective medical record review for all children who died at Vanderbilt Children's Hospital (VCH) in fiscal year 2001. The purpose of this study was to describe the documentation of care for these children and their families during their EOL experience.

## METHODS

### Data Collection

An automated search of computerized death records was conducted to identify all children at VCH who were hospitalized at the time of death between July 1, 2000, and June 30, 2001. Children admitted to any inpatient unit (neonatal intensive care unit [NICU], pediatric critical care unit [PCCU], or general pediatric units) were included in the survey. Children who died in the emergency department were not included in this review. Patient records eligible for the review included those who received inpatient care at VCH for at least 24 hours before death. Of the 118 records identified, 12 patients were ineligible because they were inpatients for <24 hours. A retrospective review of medical records for the 106 remaining children was completed, with a data

abstraction tool, to determine the aspects of critical and palliative care administered during the last 72 hours of life. Of the 106 eligible medical records, 1 was excluded because of insufficient data.

A medical record abstraction tool was adapted from chart review templates used in similar projects conducted by the City of Hope, the Dana-Farber Cancer Institute, and the Medical University of South Carolina.<sup>6</sup> Minor modifications were made to the VCH tool, to facilitate chart abstraction and to record additional data, such as the use of complementary therapies to relieve pain. The tool was used to investigate 3 categories of palliative care, ie, clinical management, family and child interdisciplinary support, and specific pain and symptom management. Investigation of clinical management included documented patient-family-staff communications, elaboration regarding difficult decision-making, provision of comfort care, and supportive therapies and procedures (eg, art, music, or other child life or expressive therapies, pastoral care, spiritual support or rituals, or therapeutic touch). For this study, comfort care was defined as any measure of active care for patients whose disease was not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems was considered evidence of such care. Examples include the provision of warmth, human touch, swaddling or cuddling, family contact, pacification, secretion control, mouth care, and nonpharmacologic pain management.

The provision of complementary/alternative care was also evaluated. For this study, such care was defined as nonpharmacologic strategies to manage pain and/or symptoms (eg, acupuncture, aromatherapy, guided imagery, hypnotherapy, music therapy, massage, or therapeutic touch). Social work, child life, pastoral care, and behavioral health entries in the medical record were noted as indications of provision of such services for the patient or family. Pain and symptom management provision was evaluated from physician orders, progress note entries, and nursing flowsheet and narrative entries in the final 72 hours before death.

Four reviewers performed the chart review. Inter-reviewer reliability was validated through blinded reabstraction of 10 charts by a second, independent reviewer. Inter-reviewer reliability was >80%.

### Statistical Analyses

Data are reported with descriptive statistics. Subset analysis was performed by separating the study population into cohorts, to evaluate the effects of unit of care (eg, NICU, PCCU, or general pediatric units) on the provision of palliative care services. Approval for this study was obtained from the institutional review board of Vanderbilt University Medical Center.

## RESULTS

### Demographic Characteristics

Of the 105 children whose medical records were reviewed, 55% were male. The median age at death was 68 days (range: 1 day to 18.3 years), and the median length of stay (LOS) was 7 days (range: 1–135 days). When results were evaluated for cohorts from the respective units, age and LOS were as follows: NICU, median age of 7 days and LOS of 7 days; PCCU, median age of 155 days and LOS of 9 days; general pediatric units, median age of 10 years and LOS of 7 days. On the basis of admitting diagnoses, the patients were divided into 6 groups, ie, cardiac diagnoses (33%), congenital defects (14%), neonate-specific diagnoses (14%), infectious diseases (13%), oncologic diagnoses (10%), and trauma (6%) (Fig 1). The relatively large number of deaths resulting from underlying congenital heart disease is likely attributable to VCH being the only children's cardiovascular surgery center in the state. Because of the study design, deaths in the emergency department or in the first 24 hours of hospitalization were not examined.

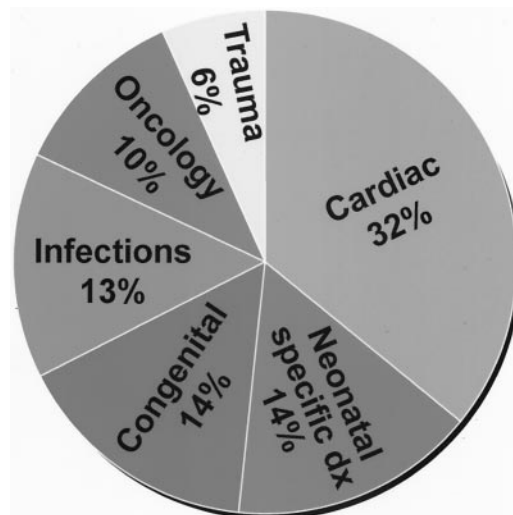


Fig 1. Diagnostic categories for 105 inpatient children who died after 24 hours of hospitalization.

This might have resulted in the small number of deaths attributable to trauma or accidents noted in this study. The majority of patients were being treated in the PCCU at time of death (Table 1).

### Clinical Management

During their final hospitalization, 55% of the children received comfort care services. Nearly 90% received pain medication in the last 72 hours of life. Life-sustaining support (assisted ventilation) was initiated for 98% of the patients, and 63% had assisted ventilation or cardiovascular support withdrawn in the last 48 hours. Nutritional support was initiated for 96% of the children, and 23% of these children had this support withdrawn in their last 48 hours. The vast majority (96%) of children had at least 1 diagnostic, imaging, or laboratory procedure completed within the last 48 hours. However, no information was recorded to indicate whether such procedures were related to life-sustaining or palliative measures.

The health care team documented the discussion of a life-threatening patient situation or disease in 23% of the medical records, but only 1 child received a hospice referral. A do-not-resuscitate (DNR) decision was documented in 42% of the medical records. Given sudden acute deterioration in many circumstances in the PCCU and NICU, a decision to withdraw life support was documented for 64% of the patients. Although >80% of the children were receiving ongoing pain medication as part of their care in the last 72 hours of life, only 26% of those for whom support was withheld or withdrawn received additional analgesia or sedative dosing at the time of such withdrawal. Three percent were receiving neuromuscular blockers at the time of support withdrawal (Table 2).

### Family and Child Interdisciplinary Support

During the final patient hospitalizations, interdisciplinary support for the child and family was infrequently documented (Table 3). When documented,

**TABLE 1.** Demographic Data

Gender, no. (N = 105)	
Male	58
Female	47
Age at death (N = 95)	
Median	68 d
Range	1 d to 18 y
Group medians for PCCU, NICU, wards	155 d, 7 d, 10 y
LOS, d (N = 95)	
Median	7
Range	1–135
Group medians for PCCU, NICU, wards	9, 7, 7
Ethnicity, no. (%) (N = 105)	
Caucasian	52 (55)
African American	19 (20)
Hispanic	4 (4)
Other	3 (3)
ND	22 (23)
Primary language, no. (%) (N = 105)	
English	48 (50)
Spanish	4 (4)
Other	1 (1)
ND	47 (49)
Spanish/other language, no. (%) (N = 5)	
Interpreter used	60 (3)
Interpreter not used	40 (2)
Interpreter ND	0 (0)
Diagnosis, no (%) (N = 105)	
Cardiac	32 (34)
Congenital	14 (15)
Neonatal	14 (15)
Infection	13 (14)
Oncologic	10 (11)
Trauma	6 (6)
Other acute diagnoses	
SIDS	4 (4)
Neurologic	3 (3)
Surgical complication	2 (2)
Other chronic diagnoses	
Metabolic	2 (2)
Location at death, no. (%) (N = 105)	
PICU	56 (59)
NICU	31 (33)
Pediatric ward	10 (10)

ND indicates not determined; SIDS, sudden infant death syndrome.

the social work, child life, and pastoral care services often focused on EOL support for the patient and family; there were few documented instances in which these services were declined.

### Pain and Symptom Management

Physicians documented pain assessment and management in their progress notes in 34% of the medical records. Documentation of pain assessment and postintervention reassessment by the nursing staff during the last 72 hours of life was also low. In addition to pain, shortness of breath and dyspnea were the most commonly occurring symptoms (24%) documented by physicians or nurses during the last 72 hours of life. Pharmacy orders and nursing flow-sheets indicated ongoing pain management for >80% of patients. However, descriptive documentation in physician and staff notes of patient or parental comments regarding pain control or other symptoms being routinely assessed and treated existed for only one-half of these children. Seizures occurred relatively frequently (11%) and were promptly treated. Prolonged crying occurred nearly as frequently (10%), but documentation of specific inter-

ventions (pharmacologic or nonpharmacologic) was uncommon. Overall, physician and nursing documentation of symptom assessment, treatment, and reassessment was sparsely present in the patient medical records (Fig 2).

### DISCUSSION

This study of the circumstances surrounding the deaths of children in a busy academic medical center in 1 year yields 2 major findings. First, consistent with the results of other studies, the majority of inpatient pediatric deaths occurred in an intensive care setting.<sup>7</sup> Given the nature of infant death, death as a consequence of neonatal/perinatal conditions is not uncommon in the NICU or PCCU.<sup>2</sup> Indeed, nearly 90% of inpatient deaths occurred in these 2 units. It is noteworthy that the median age of patients dying in the PCCU was <6 months. Furthermore, death often followed the withdrawal of life-sustaining measures or the withholding of measures such as resuscitation (for patients with a DNR order), both previously reported phenomena.<sup>8–10</sup>

Second, although pediatric deaths may follow sudden, acute, traumatic, or chronic disease states, the median LOS for children dying in this population was  $\geq 1$  week. Such stays afford the opportunity to provide comprehensive EOL care for children and their families, although such services, if provided, were poorly documented. This phenomenon was noted previously in studies from Sweden<sup>11</sup> and Brazil<sup>12</sup> but has been poorly addressed in US reports.

It is possible that neither professional caregivers nor parents foresaw the final hospitalizations studied in this investigation as likely being terminal hospitalizations. However, a considerable number of children had congenital anomalies, cardiac conditions, cancer, or other diagnoses that could well have provided opportunities for communicating the potential illness trajectory and how this might lead to declines in health and premature death.<sup>13,14</sup>

Given the median LOS of children before their deaths, palliative care measures to support both the child and the family could have been provided for a majority of children. Such supportive services as pastoral care, social work, behavioral health, or child life services were used in a minimal number of cases. This may reflect limited awareness of these services and their capacity to help, limited resources (eg, too few supportive staff members), clinical priorities, or a reluctance to direct the goals of care to comfort and quality of life during a child's final days. For this population, community chaplaincy was available, in addition to the services of 1 hospital staff chaplain. Chart entries, as subsequently examined, are not a normative practice for these providers. Social work staff members are unit-based and routinely perform an intake assessment of the child and his or her family at the time of admission. However, documentation may be delayed pending pertinent data or contacts, and it was absent in a large number of the charts examined. It might be that child life specialists were underutilized in the intensive care areas (where most children died), and specific behavioral health referrals, although few, might have reflected staff

**TABLE 2.** EOL Management

	% (Actual Number)			
	Total (N = 105)	PCCU (N = 59)	NICU (N = 33)	Wards (N = 10)
Discussion of life-threatening condition by health care team	76 (80)	90 (53)	64 (21)	50 (5)
Hospice consideration	2 (2)	0 (0)	3 (1)	10 (1)
Hospice referral	1 (1)	0 (0)	0 (0)	0 (1)
Delivery of palliative care	55* (57)	48† (28)	57 (19)	90 (9)
Pain medication ordered	84 (88)	81 (48)	85 (28)	100 (10)
Documented palliative care	49* (50)	43† (25)	49 (16)	80 (8)
Delivery palliative care or pain management	93* (98)	93 (55)	94 (31)	100 (10)
DNR decision	41‡ (43)	39 (23)	36 (12)	80 (8)
Decision made to withdraw life support	63 (66)	68 (40)	69 (23)	30 (3)
Administration of CPR	45 (47)	54 (32)	39 (13)	10 (1)
Initiation of nutritional support	96 (101)	97 (57)	97 (32)	100 (10)
Withdrawal of nutritional support within 48 h of death	23‡ (24)	24 (14)	18 (6)	40 (4)
Initiation of life-sustaining support	98 (103)	100 (59)	100 (33)	90 (9)
Withdrawal of life-sustaining support within 48 h of death	71 (73)*	78 (46)	72 (23)	40 (4)
Pain medication administration at support withdrawal	25 (26)	24 (14)	30 (10)	20 (2)
Neuromuscular blocker present at support withdrawal	3 (3)	4 (2)	3 (1)	0 (0)
Diagnostic tests and imaging performed within 48 h of death	86 (90)	95 (56)	88 (29)	30 (3)

CPR indicates cardiopulmonary resuscitation.

\* N (total) = 103.

† N (PCCU) = 58.

‡ N (total) = 104.

**TABLE 3.** Family and Interdisciplinary Support

	% (Actual Number)			
	Total (N = 105)	PCCU (N = 59)	NICU (N = 33)	Wards (N = 10)
Social worker saw the child/family during admission?	33* (34)	31 (18)	42 (14)	20 (2)
Were any of the visits regarding EOL support?	38 (13)	39 (7)	43 (6)	0 (0)
Declined social work care	2 (2)	3 (2)	0 (0)	0 (0)
Child life worker saw the child family during admission?	9* (9)	12 (7)	0 (0)	20 (2)
Were any of the visits regarding EOL support?	44 (4)	43 (3)	0 (0)	0 (0)
Declined child life care	0 (0)	0 (0)	0 (0)	0 (0)
Pastoral care worker saw the child/family during this admission?	33† (34)	28 (16)	42 (14)	40 (4)
Were any of the visits regarding EOL support?	77 (26)	88 (14)	64 (9)	75 (3)
Were any special concerns regarding religious issues identified?	27 (7)	29 (4)	33 (3)	0 (0)
Declined pastoral care	1 (1)	0 (0)	3 (1)	0 (0)
Psychology/behavioral health worker saw the child/family during admission?	1† (1)	2 (1)	0 (0)	0 (0)
Declined psychology/behavioral health care	0 (0)	0 (0)	0 (0)	0 (0)

\* N (total) = 104.

† N (total) = 103.

members' discomfort with their own ability to assess and refer patients or families for counseling or the fact that there were few psychological support staff members available for consultative services. Case managers know of, and provide referral to, hospice facilities locally and throughout the VCH referral region. Lack of hospice use might well reflect a lack of managing clinician's consideration. Lack of hospice consultation for this inpatient population might also reflect a lack of awareness of or inclination to consult local hospice physicians.

Pain management was addressed consistently among the units during EOL care, for >80% of children. This was reflected in orders for analgesics and medication usage. The fiscal year 2001 study period preceded the current emphasis on pain management, fostered in part by the Joint Accreditation Commission for Hospitals and Health Care Organizations. Pain assessment scales were not routinely incorporated into all unit nursing flowsheets when this cohort was hospitalized. Nurses documented pain as-

essment for only 33% of children receiving EOL care. Physicians noted pain assessment/management in 34% of their daily progress notes. When pain was assessed, the documentation left investigators uncertain regarding whether pain was immediately treated and reassessed. In recent quality improvement surveys at VCH, there have been marked improvements in pain assessment and management. Pain scales are present now on all pediatric units.

Other symptoms among children at the EOL were variably documented (Fig 2). These symptoms have been reported in studies focusing on oncology-related deaths.<sup>6</sup> Treatment of symptoms was inconsistently documented for the population in this study. Specific symptoms, such as fatigue, shortness of breath/dyspnea, and prolonged crying, may warrant greater attention in the provision of comfort for dying children. The lack of validated, objective, scoring systems for symptoms other than pain might have affected clinicians' propensity to document many symptoms.

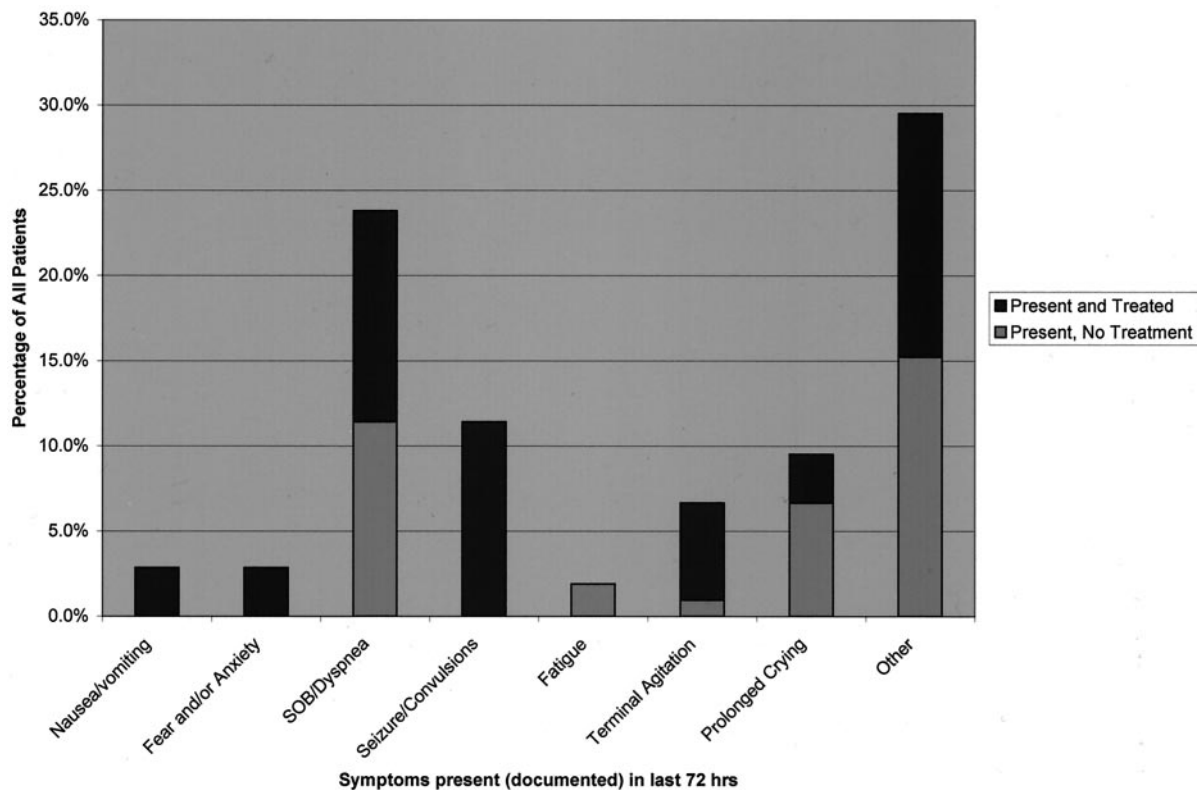


Fig 2. Documentation of symptoms assessed and treated by either nurses or physicians during the 72 hours before death.

Nearly all children had life-sustaining support and nutritional support initiated during their terminal hospitalizations. Although decisions to withdraw life support were common (63% of children), not all of these children had DNR orders written before their death. Cardiopulmonary resuscitation was often administered before death was declared. This might reflect an unexpected death, a tendency on the part of staff members to perform resuscitation in the absence of an appropriate dialogue with the parent/guardian to secure a DNR order, or an insistence on "doing everything" for the child, which might have originated from the family or the staff. Because many of these deaths were likely foreseeable in the final 48 hours, opportunities to make the child comfortable when life support was withdrawn and to not provide what could be described as futile resuscitation efforts might have been missed.<sup>8,15</sup>

Decisions to withdraw nutritional support occurred far less often, compared with other life-sustaining measures. This might reflect the well-recognized emotional, psychological, and symbolic significance assigned to nutrition and hydration as pertaining to the most basic care for children.<sup>16,17</sup> Many of the children in this study died at <1 year of age.

A majority of children underwent diagnostic imaging and laboratory testing in their final 48 hours. This is typical of management in intensive care settings. However, the focus of care toward comfort or palliation may reduce unnecessary, nonbeneficial, and potentially burdensome tests for these children at the EOL. In some instances, these tests helped

direct comfort measures or decisions toward withdrawing care.

This study is limited because of its retrospective design and its dependence on documentation in medical records. Nevertheless, the findings of this study may have significant implications regarding how children and their families receive EOL care in children's hospitals. Opportunities exist to enhance not only the documentation of such care but also overall communication and deliberations regarding the goals of care.<sup>18</sup> Palliative measures may well be appropriate in intensive care units, concomitant with life-saving or -prolonging care that is initially provided as diagnoses are confirmed, initial treatments are offered and patient responses are elicited, and prognoses are considered.<sup>19</sup> Enhanced pain and symptom management and the utilization of supportive, comprehensive, interdisciplinary, palliative care services can be addressed for children whose terminal hospitalizations are generally a number of days in length.

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