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Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study

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Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study

WHAT'S KNOWN ON THIS SUBJECT: During the past decade, pediatric palliative care (PPC) has become an established area of medical expertise. Although the number of hospital-based PPC teams is increasing, scant information exists regarding the patients referred for PPC consultations or their subsequent survival pattern.

WHAT THIS STUDY ADDS: Compared with adult patients, pediatric patients who received hospital-based PPC services had a greater diversity of medical conditions and duration of survival, which underscores the need for PPC teams to be properly resourced to meet the needs of these patients and families.

abstract

OBJECTIVE: To describe demographic and clinical characteristics and outcomes of patients who received hospital-based pediatric palliative care (PPC) consultations.

DESIGN, SETTING, AND PATIENTS: Prospective observational cohort study of all patients served by 6 hospital-based PPC teams in the United States and Canada from January to March 2008.

RESULTS: There were 515 new (35.7%) or established (64.3%) patients who received care from the 6 programs during the 3-month enrollment interval. Of these, 54.0% were male, and 69.5% were identified as white and 8.1% as Hispanic. Patient age ranged from less than one month (4.7%) to 19 years or older (15.5%). Of the patients, 60.4% lived with both parents, and 72.6% had siblings. The predominant primary clinical conditions were genetic/congenital (40.8%), neuromuscular (39.2%), cancer (19.8%), respiratory (12.8%), and gastrointestinal (10.7%). Most patients had chronic use of some form of medical technology, with gastrostomy tubes (48.5%) being the most common. At the time of consultation, 47.2% of the patients had cognitive impairment; 30.9% of the cohort experienced pain. Patients were receiving many medications (mean: 9.1). During the 12-month follow-up, 30.3% of the cohort died; the median time from consult to death was 107 days. Patients who died within 30 days of cohort entry were more likely to be infants and have cancer or cardiovascular conditions.

CONCLUSIONS: PPC teams currently serve a diverse cohort of children and young adults with life-threatening conditions. In contrast to the reported experience of adult-oriented palliative care teams, most PPC patients are alive for more than a year after initiating PPC. *Pediatrics* 2011;127:1094–1101

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KEY WORDS

pediatric care, palliative care, hospice care, chronic illness, technology dependence, polypharmacy

ABBREVIATION

DNR—do not resuscitate

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During the past decade, an increasing number of children's hospitals have created dedicated palliative care services to address the needs of children with advanced life-threatening conditions, their families, and the hospital staff, with specific emphasis on symptom relief, logistics and care coordination, and psychosocial and decision-making support.[1] Little is known, however, about the demographic or clinical characteristics of the children who are referred for palliative care consultation (such as what medical conditions they have or their subsequent life span), or about the focus of the consultation services.[2]

The dearth of pediatric information stands in contrast to the knowledge base regarding adult patient-focused hospital-based palliative care services: several studies have documented that these adult patients, whose mean age ranges from 60 to 82 and most commonly have cancer,[3,4] have a multiplicity of physical and emotional symptoms,[5–7] and typically experience between a 1- and 3-month duration of subsequent survival.[8–11] The numbers of adult palliative care programs has grown in recent years;[12] whereas adult patients who receive inpatient palliative care services are more likely to be discharged to hospice or to home with services,[13] difficulties exist with transitions between inpatient and outpatient care.[14] Extrapolating from these adult-focused studies to the pediatric palliative care population, however, is thought to be inappropriate because of the distinctive patterns of life-threatening medical conditions in childhood.[1,15,16]

We therefore conducted a cohort study of patients who received pediatric palliative care consultative services at 6 major pediatric centers in the United States and Canada with 1-year prospective follow-up.

METHODS

Human Subjects Protections

The protocol for the conduct of this study was approved by The Children's Hospital of Philadelphia's Committee for the Protection of Human Subjects and the institutional review boards of all participating hospitals.

Study Design and Subjects

We conducted an observational cohort study of all patients who received palliative care consultative services between January 1, 2008, and March 31, 2008, with subsequent follow-up observation of patients for 12 months after cohort entry. The study was conducted at 6 hospitals with dedicated pediatric palliative care programs (Children's Hospital of Philadelphia, Children's Hospital Boston/Dana-Farber Cancer Institute, Seattle Children's Hospital, Akron Children's Hospital, Children's Hospitals and Clinics of Minnesota, Canuck Place, and British Columbia Children's Hospital). Data were obtained from review of patients' medical charts.

Data Source

Study coordinators at each site reviewed medical charts of patients at their sites who had received palliative care consultative services, and they entered the abstracted data into their local version of the FileMakerPro database created for this study. Once each site completed data entry, the data were sent to the coordinating principal investigator at The Children's Hospital of Philadelphia who compiled a master database. After the collection of all baseline data, we conducted an audit of the records of 10% of the patients at each site, with an abstractor different from the one who had collected the data originally, and removed from the analysis any data elements that did not have 90% or greater concordance between the abstractors.

Variables

The following variables were abstracted from the records: (1) demographic information (site, patient age, patient gender, patient race, patient ethnicity, patient residence, presence of siblings, and insurance status); (2) clinical information (underlying diagnosis that triggered original referral to palliative care service, medications and medical technology, and current symptoms); (3) characteristics of the palliative care assessment (type of patient, location of patient during consult, persons at consult, goals of consult, and additional recommended interventions); and (4) follow-up information (death, time to death, and location of death).

Age was defined at time of cohort entry on the basis of date of birth and categorized into <1 month, 1 to 11 months, 1 to 9 years, 10 to 18 years, or 19 or older. Race/ethnicity data, as collected by each hospital, was categorized as white, black, Asian, other/mixed, or unknown. Residence was categorized as lives with both parents, lives only/mostly with mother, or other. Payer was categorized as public, private, both, or none. Patient location was categorized as home, hospital ward, hospital ICU (including the NICU, cardiac ICU, and step-down units), hospice facility, outpatient clinic, or other. Duration of survival was calculated from date of cohort entry to date of death for those subjects who died during the 12-month follow-up interval.

Statistical and Graphical Analysis

Using the final compiled master database, descriptive statistics (proportions, means and SDs, medians, and interquartile ranges as appropriate) were used to describe patient characteristics and circumstances at the time of cohort entry. Equivalency of proportions in contingency tables was tested using the χ^2 test or Fisher's exact test when cell sizes were <5.

Kaplan-Meier survival curve and log-rank test were used to describe and compare the survival patterns among groups of patients during the ensuing 12-month follow-up. Statistical analyses were performed by using Stata 11.0 (Stata Corp, College Station, TX). Graphical analysis of the relationship among medications was performed by using Cytoscape 2.8 (available at www.cytoscape.org).

RESULTS

Characteristics of Subjects in the Cohort

Of the children who received a pediatric palliative care consult at 1 of the 6 sites, approximately one-third were 1 to 9 years of age (37.5%), one-third were 10 to 18 years of age (30%), and a number of patients were 19 or older (15.5%) (Table 1). Less than one-fifth of patients were younger than 1 year. Most patients were male (54%), white (69.5%), and lived with both parents (60%). Slightly >20% of patients, however, lived only or mostly with their mother. A majority of patients had siblings (72.6%). At the US sites, about half of patients had public insurance (49.7%), 24.4% had private insurance, 23.5% had both insurance types, and 2.5% of children had no insurance. At the Canadian site, all children had government insurance.

TABLE 1 Demographic Characteristics of Patients in the Cohort

Characteristics	Total, *N* (%)	Early Mortality Within 30 Days, *N* (%)		*P*
		Yes	No	
Total	515 (100)	60 (11.7)	455 (88.4)	
Site				
Akron	163 (31.7)	13 (21.7)	150 (33.0)	<.01
Boston	70 (13.6)	16 (26.7)	54 (11.9)	
Minneapolis	102 (19.8)	8 (13.3)	94 (20.7)	
Philadelphia	38 (7.4)	10 (16.7)	28 (6.2)	
Seattle	67 (13.0)	7 (11.7)	60 (13.2)	
Vancouver	75 (14.6)	6 (10.0)	69 (15.2)	
Age				
<1 mo (and fetal consultations)	24 (4.7)	11 (18.3)	13 (2.9)	<.01
1–11 mo	64 (12.4)	10 (16.7)	54 (11.9)	
1–9 y	193 (37.5)	16 (26.7)	177 (38.9)	
10–18 y	156 (30.0)	17 (28.3)	139 (30.6)	
19 y or older	78 (15.5)	6 (10.0)	72 (15.8)	
Gender				
Female	237 (46.0)	27 (45.0)	210 (46.2)	.87
Male	278 (54.0)	33 (55.0)	245 (53.9)	
Race				
White	358 (69.5)	36 (60.0)	322 (70.8)	.09
Black	46 (8.9)	8 (13.3)	38 (8.4)	
Asian	36 (7.0)	2 (3.3)	34 (7.5)	
Native population	9 (1.8)	1 (1.7)	8 (1.8)	
Mixed	24 (4.7)	5 (8.3)	19 (4.2)	
Other	24 (4.7)	3 (5.0)	21 (4.6)	
Not indicated	18 (3.5)	5 (8.3)	13 (2.9)	
Ethnicity				
Hispanic	38 (7.4)	4 (7.7)	34 (8.2)	.91
Non-Hispanic	477 (92.6)	48 (92.3)	382 (91.8)	
Residence				
With both parents	311 (60.4)	39 (65.0)	272 (59.8)	.38
Only/mostly with mother	113 (21.9)	9 (15.0)	104 (22.9)	
Other[a]	91 (17.7)	12 (20.0)	79 (17.4)	
Siblings				
No	122 (23.7)	12 (20.0)	110 (24.2)	.49
Yes	374 (72.6)	47 (78.3)	327 (71.9)	
Unknown	19 (3.7)	1 (1.7)	18 (4.0)	
US insurance				
Government	218 (49.7)	23 (42.6)	195 (50.7)	.03
Private	107 (24.4)	18 (33.3)	89 (23.1)	
Both	103 (23.5)	9 (16.7)	94 (24.4)	
None	11 (2.5)	4 (7.4)	7 (1.8)	
Canadian insurance				
Government	75 (100)	6 (100)	69 (100)	

[a] Includes institutional facility, foster care, only father, other relatives, alone or with spouse, in hospital since birth, and not yet born.

A majority of patients (55%) had >1 principal diagnosis. The 2 most common principal underlying diagnoses in this cohort of children were genetic or congenital disorders (40.8%) and neuromuscular disorders (39.2%). Twenty percent of children had cancer, nearly equally divided between leukemia (35.3%), brain tumors (28.4%), and solid tumors (35.3%), with 1 child with both leukemia and solid tumor (1%). Less frequent diagnoses included respiratory (12.8%), gastrointestinal (9.9%), cardiovascular (8.3%), metabolic (7.2%), renal (2.7%), and immunologic (2.6%). Ten percent of patients had other diagnoses.

The patients in the cohort had extensive medication profiles: the mean number of medications (both standing daily dosages and as needed usage) was 9.1 (SD 5.5), with a median of 9 and a range from 0 to 18 medications. The most common drugs used by >10% of this cohort are listed in Table 2. All of the medications that the patients were taking at the time of the baseline assessment are depicted in Fig 1. This portrait of the pharmacopeia of pediatric patients who received palliative care consultative services emphasizes the prominent use of certain drugs such as acetaminophen, albuterol, lansoperazole, and lorazepam; the heightened association of certain drugs with

TABLE 2 Clinical Characteristics of Patients in the Cohort

Characteristics	Total, *N*	%	Early Mortality Within 30 Days, *N* (%)		*P*
			Yes	No	
Diagnoses					
Genetic/congenital	210	40.8	17 (28.3)	193 (42.4)	.04
Neuromuscular	201	39.2	22 (36.7)	179 (39.3)	.69
All cancers	102	19.8	18 (30.0)	84 (18.5)	.04
Hematologic	36	7.0	5 (8.3)	31 (6.8)	.66
Solid tumor	36	7.0	6 (10.0)	30 (6.6)	.33
Brain tumor	29	5.6	7 (11.7)	22 (4.8)	.03
Hematologic and solid tumors	1	0.1	0	1 (0.2)	.72
Respiratory	66	12.8	8 (13.3)	58 (12.8)	.90
Other	55	10.7	7 (11.7)	48 (10.6)	.79
Gastrointestinal	51	9.9	4 (6.7)	47 (10.3)	.37
Cardiovascular	43	8.3	10 (16.7)	33 (7.3)	.01
Metabolic	37	7.2	1 (1.7)	36 (7.9)	.08
Renal	14	2.7	2 (3.3)	12 (2.6)	.76
Immunology	12	2.6	0	12 (2.6)	.20
Medications					
Acetaminophen	194	38.0	23 (38.3)	174 (38.2)	.99
Albuterol	126	24.7	8 (13.3)	133 (29.2)	.01
Lansoprazole	126	24.7	10 (16.7)	116 (25.5)	.14
Lorazepam	119	23.2	17 (28.3)	104 (22.9)	.35
Oral antibiotic	83	16.2	9 (15.0)	75 (16.5)	.77
Morphine	78	15.3	21 (35.0)	57 (12.5)	<.01
Ranitidine	78	15.3	10 (16.7)	68 (15.0)	.73
Levetiracetam	78	15.3	7 (11.7)	71 (15.6)	.42
Phenobarbitol	74	14.5	10 (16.7)	64 (14.1)	.60
Ibuprofen	65	12.5	5 (8.3)	60 (13.2)	.29
Polyethylene glycol	57	11.2	5 (8.3)	53 (11.7)	.45
Baclofen (oral)	56	11.0	1 (1.8)	55 (12.1)	.02
Intravenous antibiotic	52	10.2	9 (15.0)	43 (9.5)	.18
Medical technology					
None	105	20.4	8 (13.3)	97 (21.3)	.15
Any feeding tubes	307	59.6	35 (58.3)	272 (59.8)	.83
Gastrostomy tube	250	48.5	21 (35.0)	229 (50.3)	.03
Nastogastric tube	51	9.9	15 (25.0)	36 (7.9)	<.01
Jejunostomy tube	50	9.7	3 (5.0)	47 (10.3)	.19
Central venous catheter	115	22.3	24 (40.0)	91 (20.0)	<.01
Tracheostomy	52	10.1	4 (6.7)	48 (10.6)	.35
Noninvasive ventilation	49	9.5	6 (10.0)	43 (9.5)	.89
Ventilator-dependent	44	8.5	14 (23.3)	30 (6.6)	<.01
Wheelchair	21	4.1	0	21 (4.6)	.09
VP/VJ shunt	15	2.9	2 (3.3)	13 (2.9)	.84

VP/VJ indicates ventriculojugular.

early mortality, such as fentanyl (4 of 13 patients exposed to fentanyl, $P = .03$), furosemide (10 of 35 patients exposed to furosemide, $P = .001$), and morphine (21 of 78 patients, $P < .01$), and less so for methadone (5 of 22 patients, $P = .16$) or oxycodone (6 of 47 patients, $P = .48$); and the proportion of patients exposed to concurrent use of drugs such as acetaminophen and albuterol (15.3% of all patients), morphine and lorazepam (6.6% of all patients), or melatonin and ibuprofen (2.3% of all patients).

Only 1 in 5 children used no medical technology: the majority of children had some type of feeding tube (68.2%), whereas 22.3% had a central venous catheter, and 10.1% had a tracheostomy. Children also had noninvasive ventilation such as bi-level positive airway pressure or high-flow nasal canula (9.5%) and ventilator dependency (8.5%).

The most frequent clinical signs and symptoms at the time of entry into the cohort included cognitive impairment (46.8%), speech difficulties (45.8%), problems with enteral intake (25.6%), seizures (24.5%), and fatigue (23.3%). Other signs and symptoms are shown in Fig 2.

Characteristics of Consultative Service

At the time of entry into the cohort by virtue of receiving a palliative care consultative service (Table 3), most patients (64.3%) were established palliative care patients (that is, the pediatric palliative care teams had been consulted before January 1, 2008) and were cared for in the home (33.2%) or hospital ward (28.4%) at study entry. The remaining patients were cared for in the hospital ICU (17.8%), in a hospice facility (11.4%), at an outpatient clinic (7.4%), or "other" (1.8%), which included a burn unit, a hospital emergency department, and a fetal palliative care consultation.

Most consultation encounters (Table 3) involved a separate meeting with just the patient or family (86.9%), and in 44.2% of these encounters, the palliative care team also met with just the patient's other health care clinicians separately. In 22.1% of consultations, a meeting took place in which both family and clinicians from other clinical services were present. In 30.7% of consultations, the palliative care team met only with the providers. Often (78.4%) there was more than 1 main goal of the consultation. Overall, the main goals of the consultation were symptom management (58.1%), facilitating communication (48.5%) and decision-making (42.1%), assisting with logistics or coordination of care (35.3%), assisting with transition to home (14.4%), and discussion of do-not-resuscitate (DNR) orders (11.8%). Other goals included peri-death recommendations (9.1%)

and parental (6.4%) and sibling (4.5%) bereavement.

The consultative encounter differed in several regards between new and established patients. The palliative care team was more likely to meet with other clinicians ($P < .001$) and more likely to meet jointly with the family and other clinicians ($P < .001$) if the patient was a new palliative care patient. New patients were more likely to have DNR ($P = .004$), peri-death recommendations ($P = .003$), transition to home ($P < .001$), and information ($P = .02$) as goals of the consult. Established patients were more likely to have symptom management ($P = .003$), facilitate decision-making ($P < .001$), and assist with logistics or coordination of care ($P = .01$) as goals of the consult. There was no difference between new and established patients regarding communication or parental or sibling bereavement as goals of the consult.

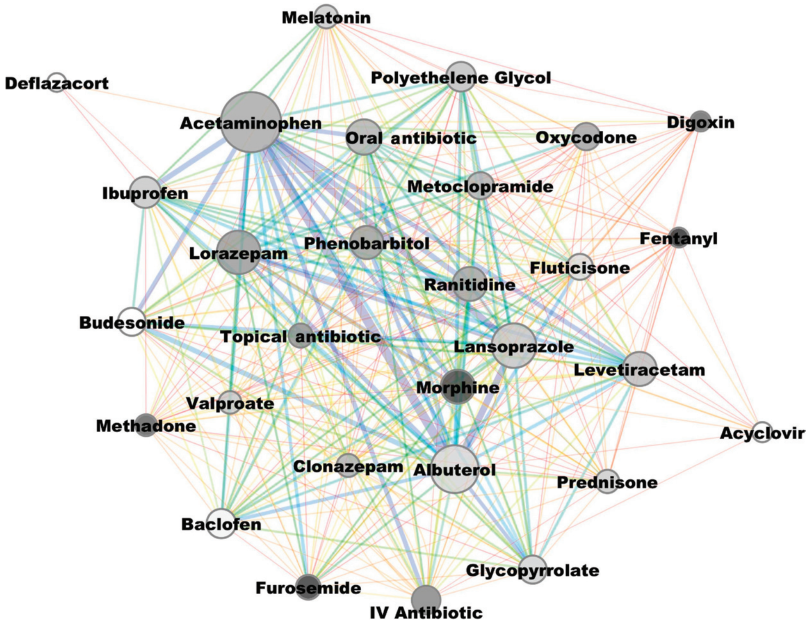


FIGURE 1

Drugs received by patients who received pediatric palliative care consultative service. The size of each node (circle) is proportional to the percentage of all patients who received the drug or class of drugs; the darker grayscale color of each node indicates an increasing proportion of patients who received the drug who experienced early mortality, and the edges (lines) between the drug nodes are color-coded from red (which indicates few patients took both drugs) to blue (which indicates many patients took both drugs).

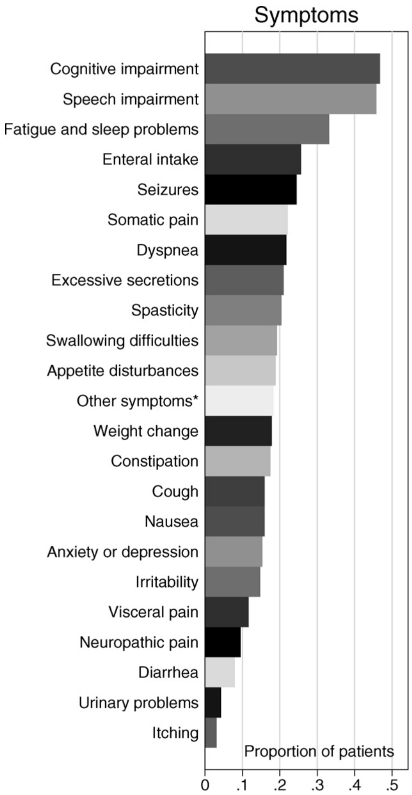


FIGURE 2

Signs and symptoms of patients who received pediatric palliative care consultation services. [a]Other symptoms include paralysis, edema, sepsis, sweating, and dry mouth.

TABLE 3 Palliative Care Consultative Encounter Characteristics

Characteristics	Total, *N*	%	Early Mortality Within 30 Days, *N* (%)		*P*
			Yes	No	Yes
Type of patient					
New	184	35.7	40 (66.7)	144 (31.7)	<.01
Established	331	64.3	20 (33.3)	311 (68.4)	
Location of patient during consult					
Home	170	33.2	7 (11.7)	163 (36.1)	<.01
Hospital ward	145	28.4	16 (26.7)	129 (28.6)	
Hospital ICU[a]	91	17.8	32 (53.3)	59 (13.1)	
Hospice facility	58	11.4	1 (1.7)	57 (12.6)	
Outpatient clinic	38	7.4	2 (3.3)	36 (8.0)	
Other	9	1.8	2 (3.3)	7 (1.6)	
Persons at consult					
Met with patient/family separately	424	86.9	47 (83.9)	377 (87.3)	.49
Met with providers separately	158	42.6	34 (69.4)	124 (38.5)	<.01
Met with patient/family and providers jointly	83	22.1	17 (34.0)	66 (20.3)	.03
Goals of consult					
Symptom management	299	58.1	34 (56.7)	265 (58.2)	.82
Communication	250	48.5	34 (56.7)	216 (47.5)	.18
Decision-making support	217	42.1	37 (61.7)	180 (39.6)	<.01
Logistics/coordination of care	182	35.3	17 (28.3)	165 (36.3)	.23
Transition to home	74	14.4	13 (21.7)	61 (13.4)	.09
Discuss DNR	61	11.8	13 (21.7)	48 (10.6)	.01
Peri-death recommendations	47	9.1	24 (40.0)	23 (5.1)	<.01
Parental bereavement	33	6.4	10 (16.7)	23 (5.1)	<.01
Sibling bereavement	23	4.5	6 (10.0)	17 (3.7)	.03

[a] Includes NICU, cardiac ICU, and the step down unit.

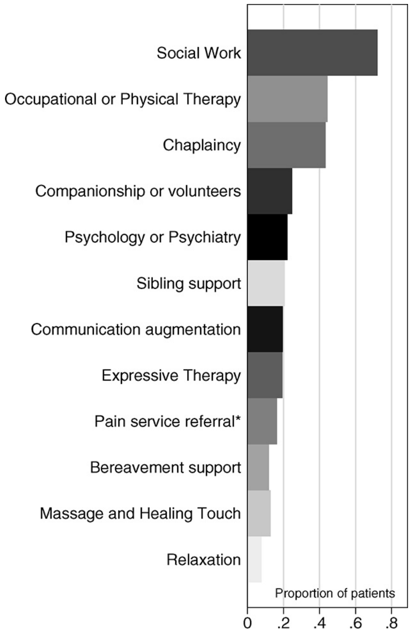


FIGURE 3
Additional interventions recommended by pediatric palliative care consultative service. [a]Excludes Minneapolis, where palliative care and consultative care services are combined into one team.

At the time of the palliative care consultative service that initiated entry into the cohort, the pediatric palliative care team made recommendations regarding additional interventions that would benefit the patient or family, and these most often were for social work (73.2%), occupational or physical therapy (45.3%), chaplaincy (44.1%), and companionship or volunteers (25.2%). At the Minneapolis site, palliative care and pain management services are provided by a single team; among patients at all the other sites (which have separate pain management consultative services), 20.8% of the cohort either were already receiving pain management consultative services or the palliative care consultation made recommendations regarding pain management. Other recommended additional interventions are shown in Fig 3.

Characteristics of Follow-up

During the 12-month follow-up, 30.3% of the cohort died; the median time-to-death was 107 days (Fig 4). Among new patients, 43.5% died with a median time-to-death of 37 days, whereas among established patients, 23% died with a median time-to-death of 85 days. Most patients died in the hospital (62.1%, of whom 56% died in an ICU setting), 28.9% died at home, 7.7% died in a hospice or other residential care facility, and 2 children (1.3%) had missing information on location of death. Among patients who died, those with cancer were more likely to have died at home (45.3%) compared with patients who had other diagnoses (20.4%; $P < .001$).

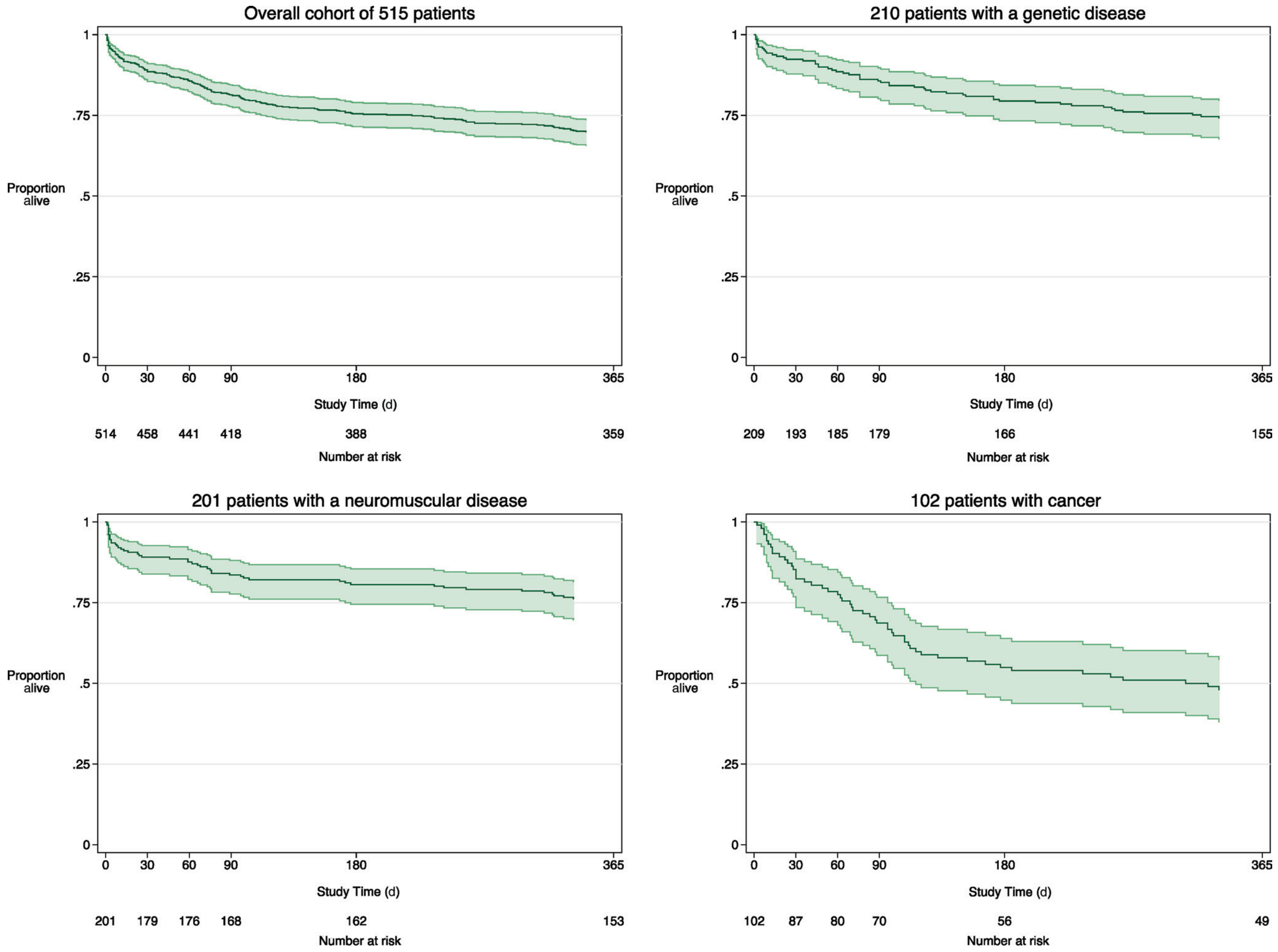
Patients who died within 30 days of entry into the cohort differed in several regards from patients who were still alive a month after the initial consultation or ongoing care as established patients: patients with early mortality were more likely ($P < .05$) to be infants, have cancer or cardiovascular conditions, be receiving morphine, have nasogastric feeding tubes or central venous catheters, or depend on ventilators. Consultations for these patients with early mortality were more likely ($P < .05$) to have occurred in a hospital ICU setting, and the goals of the consult to have been regarding decision-making support, discussion of DNR status, recommendations regarding peri-death care, or parental or sibling bereavement.

DISCUSSION

In this large cohort study of patients who received pediatric palliative care at 6 major children's hospitals in the United States and Canada, patients had a wide variety of underlying medical conditions and a broad age range (including many adults), were often cognitively impaired, had substantial exposure to polypharmacy, and had a highly prevalent reliance on medical technology. The leading 4 goals of the pediatric consultation were managing pain and other symptoms, facilitating communication, supporting decision-making, and helping to coordinate care. A year after entry into the cohort, >2 of 3 patients were still alive. Among those who had died, most had died in the hospital, and patients with early mortality within 30 days of entry into the cohort were more likely to be infants and have either cancer or cardiovascular conditions.

These findings provide an important overview of key characteristics of both the patients and the services involved in the rapidly evolving field of pediatric palliative care. In contrast to what similar epidemiologic profiles have documented for adult palliative care services, pediatric palliative care is not dominated by cancer,[4] various signs and symptoms stemming from neurologic impairment are more common than pain,[5] and the average duration of survival after initiating palliative care services is far longer.[8–11] These differences notwithstanding, the cornerstone goals and activities of palliative care services seem to be consistent across the age-spectrum.

Three major findings warrant emphasis and discussion. First, the prolonged survivorship observed in this cohort of children indicates that palliative care is being introduced to these patients much earlier in their illness experience than is the case for adult patients. Although infants and patients with cancer and cardiovascular conditions were more likely to experience early mortality, 54.2% of infants, 82.4% of patients with cancer, and 76.7% of patients with cardiovascular conditions were still alive a month after cohort entry. The overall pattern of prolonged survival of patients who received palliative care consultative services, with patients often being readmitted to the hospital, implies that pediatric palliative care teams will render service not only to new patients but also to a large group of established



Overall cohort of 515 patients

210 patients with a genetic disease

201 patients with a neuromuscular disease

102 patients with cancer

FIGURE 4

Survival function in the cohort of 515 patients who received pediatric palliative care consultation services and among patients with the 3 most prevalent conditions.

patients, gravely ill but long surviving, and their families. Appropriate staffing for pediatric palliative care teams needs to account, therefore, for both the new as well as the existing patient cases.

Second, the description of this cohort—the clinical characteristics of the patients, their medications and technologies, the services they receive, and their prolonged survivorship—indicates that pediatric palliative care consults emerge most often within the context of a diverse set of complex chronic conditions. Consequently, interdisciplinary palliative care teams caring for these patients, even if only in a consultant role, need a broad understanding of many underlying pediatric medical conditions and the ability to skillfully address the myriad challenges of chronic illness management in addition to the challenges of pain and symptom management and of end-of-life care.

Third, at one end of the age spectrum, only 17.1% of this cohort were younger than a year old, which given the fact that about half of all pediatric mortality occurs during the first year of life, indicates that interdisciplinary palliative care team-based services may be underused among this population. Meanwhile, 15% of patients who received “pediatric” palliative care consultative services were over 18 years of age. This reflects the reality that a fraction of patients treated in children’s hospitals is composed not of children but rather adults whose condition or illness commenced earlier in life, or who as adults had the onset of conditions (for example, certain forms of cancer) that are far more common in childhood. Again, this aspect of the cohort underscores another capacity—namely, the ability to provide care to adult patients—that pediatric palliative care teams must possess.

There are both strengths and weaknesses to this study that should be kept in mind when interpreting the findings. Regarding strengths, the cohort is a complete set of consecutive patients cared for during the study period and thus representative for these 6 geographically diverse sites, and the large sample size provides greater precision in our description of the cohort. Regarding weaknesses, our data collection method relied entirely on review of medical charts, and thus lacked any information gathered directly from the patient or family, and we have no data to analyze the potential impact of the palliative care services on patient or family outcomes. In future observational research studies, researchers should seek to collect more substantial data directly from patients and their families, served by a greater number of different hospitals and pediatric palliative care teams, and assess processes of care and outcomes longitudinally. Second, given the relatively small sample sizes at each of the 6 sites, we did not analyze the data by site (although the sites likely have differences in their patient populations and their consultative practices may differ), leaving for future research the task of assessing the magnitude and implication of such potential differences. Finally, given that the field of pediatric palliative and hospice care is rapidly evolving, the epidemiologic profile provided by this report will likely warrant updating over time.

CONCLUSION

Pediatric palliative care teams serve a diverse cohort of children and young adults with life-threatening and often complex chronic conditions, who typically receive a broad range of services for more than a year. The design, staffing, and support of these interdisciplinary teams need to account for these characteristics of the patients who they serve.

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