Pediatric Palliative Care: A Five-Year Retrospective Chart Review Study

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Abstract

Background: More children are living with serious illness. However, survival and complexity of illnesses have not been described.

Objective: To describe types of illnesses, timing of referral, and time to death following referral to palliative care; to examine the associations between demographics and clinical characteristics and patient survival; and to examine whether average daily pain decreases after referral.

Design: Retrospective chart review of all children ages 2–16 years referred to palliative care at one large children's hospital during the five-year study period from January 1, 2009, through December 31, 2013.

Measurements: The primary outcome was patient survival and the main independent predictor was type of illness. Kaplan–Meier estimation was used to estimate patient survival time following referral, Cox proportional hazards regression was used to build predictive models based on gender, age, race, religion, and types of illnesses, and paired t-test compared the assessment of pain before and after referral.

Results: The cohort consisted of 256 children. Survival experience did not differ significantly based on gender, age, race, or religion ($p \geq 0.05$); however, survival did vary based on referring diagnosis ($\chi^2 = 40.3$, $df = 4$, $p < 0.001$), particularly cancer. Forty-eight children with three days of pain assessments pre- and postreferral had significantly decreased pain postreferral ($t(47) = 1.816$, $p < 0.05$ one tailed), supporting our hypothesis.

Discussion: Results provide important information on the complexity of disease processes for children referred to palliative care, types of illnesses referred, survival, and pain levels. Results reflect earlier referral to palliative care for most children and highlight the medical complexity especially for children with congenital and genetic diagnoses.

Keywords: child; life limiting; life threatening; palliative care; patient survival; pediatric

Background

WITH THE ADVANCEMENT and success of medical science and medical care, a growing number of children are living with long-term and often life-limiting chronic conditions.¹ Children with complex chronic conditions, including cancer, congenital conditions (e.g., hypoplastic left heart syndrome, trisomy 13), respiratory (e.g., cystic fibrosis, asthma), neuromuscular (e.g., muscular dystrophy, brain malformations), hematological (e.g., sickle cell disease, immunodeficiencies, HIV) diseases, require the use of multiple

therapies and patients with these conditions represent the main pediatric candidates for palliative care.^{2,3} An estimated 600,000 to 1,600,000 children younger than 18 years are living with life-threatening/life-limiting conditions; many are technology dependent, and over 180,000 are considered “medically fragile.”^{4–7} These medically fragile children require intense medical and nursing care in the home and often lengthy hospital stays; their care accounts for about 26% of all hospital days and 41% of all hospital charges.⁸ Approximately 53,000 children die each year and about 12,000 deaths result from complex and chronic conditions.⁹ Earlier studies

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TABLE 1. DEMOGRAPHICS OF THE COHORT

<i>Variable</i>	<i>Frequency</i>	<i>Percentage</i>
Gender		
Male	137	53.5
Female	119	46.5
Age groups (at referral)		
Preschool, ages 2 to 4	57	22.3
Early elementary, ages 5 to 8	59	23.0
Late elementary, ages 9 to 12	73	28.5
Adolescents, ages 13 to 16	67	26.2
Race/ethnicity		
White	224	87.5
Black	26	10.2
Hispanic	3	1.2
Asian	1	0.4
Middle Eastern	1	0.4
Not specified	1	0.4
Disposition at the end of the study period		
Alive	158	61.7
Deceased	98	38.3

found that palliative care results in higher healthcare provider and parent satisfaction, better symptom management, higher quality of life, and often longer life; however, the current literature lacks an adequate description of the pediatric population receiving this care or an exploration of sociodemographic or illness characteristics that may be relevant.^{10–14}

Through a longitudinal retrospective chart review, we examined data from all children referred to palliative care between the ages of 2 and 16 years during the five-year period from January 1, 2009, through December 31, 2013, at one children's hospital in western Pennsylvania. The palliative care program at this hospital began in 2003 and has experienced a steady increase in census since its inception with a current census of over 200 patients. Patients, families, and hospital staff report being very satisfied with the palliative care service, which provides 24/7 in-hospital care as well as home and outpatient consultation. The purpose of this study was to describe demographic characteristics, including age and gender distribution, age at diagnosis, and age at referral to palliative care; to describe the types of illnesses that resulted in referral, and which illnesses occurred together; to examine the relationships between patient survival following referral to palliative care and key clinical and socio-demographic variables; and finally, to examine whether pain scores decreased after referral to palliative care.

Methods

Research design and sample selection

This retrospective chart review study examined patients receiving palliative care at a western Pennsylvania children's hospital during a five-year period. A cohort was created by examining records of all patients referred to palliative care during the study period from January 1, 2009, through December 31, 2013. Children were included in the cohort if they were between the ages of 2 and 16 years when they received the referral to palliative care. The minimum age of two years was selected to exclude infant-specific conditions related to short gestation, low birth weight, and lethal congenital conditions.

Procedures

Inpatient and outpatient data were retrieved from the electronic medical record (EMR) and the weekly lists of current patients maintained by the manager of the palliative care service through a combination of programmatic data retrieval and hand data collection. All data were deidentified before analysis. The Institutional Review Board of the University of Pittsburgh and the Steering Committee of the hospital approved this study.

Measurement

The data collected included gender, race, religion, date of birth, date of death (if applicable), last date mentioned in the EMR, date of referral to palliative care, referring diagnosis, and all diagnoses with corresponding International Classification of Disease, 9th or 10th revision (ICD-9, ICD-10) codes found in the medical record. Children were grouped based on age into preschool (ages two to four years), early elementary (ages five to eight years), late elementary (ages 9–12 years), and adolescence (ages 12–16 years). Race was collapsed into white and other. Religion was categorized as Catholic, Protestant, none, other, and unknown. The referring diagnoses were collapsed into categories based on the literature and included cancer, congenital/genetic, transplant, trauma, and other. Categories of all diagnoses were collapsed so that each category contained at least 20% of the total number of children. Two exceptions were mood disorders (any type of anxiety or depression) and technology dependence as these two categories were of particular interest. The primary outcome variable was the total number of days from referral to palliative care until death or the end of the study. Right censoring occurred if a child was lost to follow-up or survived beyond the end of the study period. If a child was lost to

TABLE 2. TIMES TO REFERRAL, DIAGNOSIS, AND DEATH

<i>All children (n = 256)</i>	<i>Mean (SD)</i>	<i>Median</i>	<i>Range</i>
Age at referral to PC	9.5 (4.5) years	9.8 years	2 years–16.9 years
Age at diagnosis of referring illness	5.3 (5.4) years	3.5 years	–13 days to 16.9 years
Time from diagnosis to referral	4.4 (4.9) years	2.3 years	0 days–16.9 years
Children who died during the study period (n = 98)			
Time from diagnosis to death	3.3 (3.5) years	1.8 years	14 days–15.3 years
Time from referral to death	203 days (232)	134 days	4 days–3.7 years

SD, standard deviation.

TABLE 3. DIAGNOSES STATISTICS

Variable	Frequency	Percentage of total
Referring diagnosis (mutually exclusive)		
Cancer	107	41.8
Congenital/genetic	97	37.9
Transplant	23	9.0
Trauma	14	5.5
Other	14	5.5
Categories of diagnosis (not mutually exclusive)		
Pain and painful conditions	155	60.5
Neurological including epilepsy	138	53.9
Congenital and genetic conditions	137	53.5
Pulmonary	131	51.2
Cancer	122	47.7
Liver, kidney, or GI	108	42.2
Ostomies (tracheostomy, gastrostomy, colostomy, ileostomy)	100	39.1
Cardiac	88	34.4
Transplant and transplant complications	65	25.4
Cancer treatment side effects	64	25.0
Vision and hearing disorders	59	23.0
Psychiatric not including mood	52	20.3
Trauma	52	20.3
Technology dependent	49	19.1
Mood disorders	44	17.2

follow-up, the total number of days was calculated using the final visit found in the system. For children who survived beyond the end of the study period, the total number of days was calculated using the end of the study (December 31, 2013).

To compare prereferral pain scores to postreferral pain scores, only children who had pain assessments for three days prereferral and three days postreferral were considered. Pain assessments were recorded from the three scales used by the hospital for these age groups: FLACC (Faces, Legs, Activity, Cry, Consolability), FACES®, and Verbal Numeric Scale (VNS). All three scales use a 0–10 rating scale with 0 being “no pain” and 10 being “worst pain ever.” FLACC has shown to have good construct validity, sensitivity, and

specificity for pain.¹⁵ The FACES pain scale has been used since the early 1980s and validated by numerous studies.^{16,17} The VNS has been validated for ages 8 and older.¹⁸ It has content and construct validity as well as test–retest reliability.¹⁸ Average daily pain scores were calculated for within-participant comparisons.

Data analyses

All data analyses were conducted using IBM SPSS Statistics v22 for Macintosh¹⁹ with $p < 0.05$ as the significance level. Descriptive statistics were computed to characterize the sample, including gender and age distribution, disposition at the end of the study period (alive or deceased), race,

FIG. 1. The most commonly occurring diagnoses (pain, neurological disorders including epilepsy, and congenital or genetic diagnoses plus cancer and mood disorders) with their most common co-occurring diagnoses. The co-diagnoses are shown as a percentage of the illness on the x-axis.

religion, mutually exclusive distribution of five referring illness categories (cancer, congenital/genetic, transplant, trauma, and other), and nonexclusive distribution for 15 diagnosis categories. To test the hypothesis that pain would decrease after palliative care referral, Student *t* tests were used to compare mean daily pain from three days pre- to three days postreferral to palliative care.

The chi-square statistic was used to examine gender, age, religion, race, and referring diagnosis as well as diagnosis categories for differences between children who lived or died during the study period. Kaplan–Meier (KM), or product-limit, estimation was used to estimate the survival function at each distinct time of death from which survival curves were produced. Cox proportional hazards regression was used to find survival curves and build predictive models of survival following palliative care referral based on the covariates of gender, age, race, religion, and disease categories. Univariate analyses considering each predictor one at a time were conducted with KM estimation, and Cox proportional hazards regression was used to estimate hazard ratios using the predictors of patient's gender, age, race, religion, and each disease category separately. The entire set of significant disease covariates was used to fit a full multivariate model with and without interactions.

Results

A total of 256 children were eligible based on the inclusion criteria for the study. Cohort demographics, including sex, age, race/ethnicity, and mortality, are shown in Table 1. Means, medians, and age ranges at referral to palliative care, age at diagnosis of the referring illness, time from diagnosis to referral, time from diagnosis to death, and time from referral to death are shown in Table 2. Children had one diagnosis listed as the main referring diagnosis for palliative care (Table 3). However, most children had more than one diagnosis, ranging from 1 to 13 of the 15 collapsed diagnosis categories considered (Table 3; mean = 5.29, standard deviation [SD] = 2.75, median = 5.0). Breaking down the categories of diagnoses (not mutually exclusive) shows the bigger picture of the complexity of care required for children receiving palliative care (Fig. 1 and Table 4).

Children with a congenital or genetic condition have the most complex overall health issues. Although only 38% of children were referred to palliative care because of a congenital or genetic diagnosis, 54% of children in this cohort have a congenital or genetic diagnosis. Figure 1 shows the six most common single co-diagnosis as a percentage of children with a congenital or genetic diagnosis. In addition, for

TABLE 4. COMORBIDITIES AMONG DIAGNOSIS CATEGORIES

	<i>Frequency</i>	<i>Total sample (%)</i>
Pain (not congenital or genetic)		
Pain + pulmonary	87	34.0
Pain + pulmonary + cardiac	50	35.6
Pain + pulmonary + cancer	34	13.3
Cancer		
Cancer + pain	79	30.9
Cancer + pain + cancer treatment side effects (other than pain)	40	15.6
Cancer + pain + congenital or genetic	34	13.3
Cancer + pain + pulmonary	34	13.3
Congenital or genetic (CG)		
CG + neurological	98	38.3
CG + neurological + pain	63	24.6
CG + neurological + pain + pulmonary	46	18.0
CG + neurological + pulmonary	68	26.6
CG + neurological + ostomies	59	23.0
CG + neurological + ostomies + pain	39	15.2
CG + neurological + ostomies + pulmonary	48	18.7
CG + neurological + ostomies + pulmonary + pain	35	13.7
CG + neurological + technology	36	14.1
CG + neurological + vision or hearing	38	14.8
CG + pain	94	36.7
CG + pain + pulmonary	66	25.8
CG + pain + pulmonary + ostomies	43	16.8
CG + pain + ostomies	50	19.5
CG + pain + liver, kidney or GI	46	18.0
CG + pain + mood	46	18.0
CG + cardiac	59	23.0
CG + cardiac + pain	46	18.0
CG + cardiac + neurological	42	16.4
CG + cardiac + ostomies	35	13.7
CG + cardiac + liver, kidney or GI	34	13.3
CG + cardiac + pulmonary	50	19.5
CG + cardiac + pulmonary + pain	40	15.6
CG + cardiac + pulmonary + neurological	35	13.7
CG + cardiac + pulmonary + ostomies	33	12.9

children with a congenital or genetic diagnosis, 32% of children had vision or hearing difficulties, 30% also had a cancer diagnosis, 26% had a transplant complication, 23% suffered from cancer treatment side effects other than pain, and 23% suffered from a trauma. Children with congenital or genetic conditions often have multiple comorbid diagnoses and medical issues (Table 4).

Based on the chi-square statistic, the time from referral to death did not significantly differ based on gender, age, race, or religion, but was significant for referring diagnosis (Table 5 and Figs. 2 and 3) and illness categories, cancer, congenital/genetic conditions, ostomies, pain and painful conditions, psychiatric disorders not including mood, and trauma. Based on Cox proportional hazards multivariate regression modeling, no significant differences for the time for referral to death were found for gender, age, or race; but there were significant differences for religion, cancer, congenital/genetic conditions, ostomies, pain and painful conditions, psychiatric disorders not including mood, and trauma (Table 6).

Forty-eight children fit the criteria of having three days prereferral and three days postreferral pain assessments. Pain scores were significantly lower postreferral when compared to prereferral, $t(47) = 1.816$, $p < 0.05$, using a one-tailed test, supporting our hypothesis.

Discussion

This retrospective, descriptive study examined the demographics, diagnoses, survival curves, hazard ratios, and pain scores of this large ($N = 256$) cohort of children ages 2 to 16 years receiving palliative care. Relatively few quantitative research studies or review articles have been completed in a pediatric palliative care (PPC) population, most studies are qualitative.²⁰ A search of PubMed using the terms quantitative, research, pediatric, and palliative resulted in only four studies directly exploring PPC in children as a whole. A prospective study involving six children's hospitals with PPC departments by Feudtner et al. conducted in 2008 included a total of 515 children from prenatal to 19 years of age.²¹ The study examined types of diagnoses, medication use, medical technology use, symptoms, family characteristics, type of insurance, mortality, and detailed information about the palliative care consultation. Some differences between the Feudtner et al. cohort and the cohort reported here included a smaller percentage of children with cancer and more non-white children, while other variables in common had similar results, including percentages of male and female children and mortality rates.²¹ Johnston and Vadeboncoeur reported on ages at diagnosis and time to referral, although they

TABLE 5. KAPLAN–MEIER SURVIVAL ESTIMATES FOR CHILDREN RECEIVING PALLIATIVE CARE

Covariate	N deaths	Mean survival time (years)	95% CI		Chi-square (Breslow)	Significance
			Lower	Upper		
Gender	98	5.40	4.82	5.99	2.503	0.114
Male	46	5.83	5.04	6.61		
Female	52	4.82	3.98	5.67		
Age	98	5.40	4.82	5.99	0.455	0.500
Preschool	24	5.08	3.86	6.31		
Early elementary	22	5.31	4.18	6.43		
Late elementary	31	5.00	3.90	6.11		
Adolescent	21	5.84	4.74	6.94		
Religion ^a	89	5.58	4.98	6.18	0.340	0.560
None	23	6.34	5.37	7.30		
Other	33	2.83	1.73	3.93		
Catholic	18	5.69	4.41	6.97		
Protestant	15	6.59	5.54	7.64		
Race ^b	97	5.43	4.84	6.02	1.934	0.164
White	83	5.49	4.86	6.12		
Other	14	4.81	3.24	6.38		
Referring diagnosis ^c	98				24.076	0.000
Cancer	65					
Congenital/genetic	23					
Transplant	8					
Trauma	2					
Other	0					
Diagnosis categories						
Cancer	76	3.29	2.52	4.06	50.564	0.000
Congenital/genetic	42	6.13	5.36	6.91	10.232	0.001
Ostomies	25	6.75	5.91	7.59	12.801	0.000
Pain	50	5.88	5.18	5.59	6.204	0.013
Psychiatric	11	7.31	6.30	8.32	7.367	0.007
Trauma	10	7.22	6.23	8.21	7.664	0.006

^aThere were 11 children with "unknown" religion.

^bThere was one child with "unknown" race.

^cBecause there were no deaths in the category "Other," mean survival time (years) nor a 95% CI could be generated.

FIG. 2. Survival curves for religion, race, age, and gender.

considered only children with cancer. This smaller study ($N=50$) reported a mean age at diagnosis of 7.7 years, a mean time from diagnosis to referral of 1.26 years ($SD=1.53$ years), time from diagnosis to death of 1.76 years ($SD=1.5$ years), and from referral to death was 4.4 months ($SD=6$ months).²² These shorter time frames are likely due to the fact

that all the children had cancer, while the children in our study had a wide variety of diagnoses.

The number and complexity of medical conditions are considerable. Out of 256 children, only 17 (6.6%) had just one illness category. With a mean of 5.29 illness categories each, this cohort requires complex medical management with an interdisciplinary team. These results are echoed in the study by Knapp et al., which examined quality of life in 98 severely impaired children enrolled in a publically funded palliative care program.²³ While the study did not list the illnesses found in the children, it did mention that 1/3 of the children were nonverbal and another 1/3 had severe cognitive impairment.²³ Knapp's results are similar to the results of this study.

Parents' stated religion made a difference in the survival curves of the children. While spiritual support is one of the cornerstones of palliative care, research examining spirituality during PPC is sparse and mainly focused on parental spirituality as a coping mechanism.²⁴⁻²⁶ Wiener et al. in a review of the literature found that culture and religion had a significant impact on decision making for families with children in palliative care and recommended further research in this area.²⁷

Although only a subset of children ($n=48$) was included in the pain assessment analysis, no other study has compared pain scores before and after referral to palliative care. We hypothesized that pain would decrease after referral to palliative care since pain, independent from disease state, is a

FIG. 3. Survival curve for referring diagnosis.

TABLE 6. COX REGRESSION HAZARD RATIOS FOR CHILDREN RECEIVING PALLIATIVE CARE

Covariate	Wald	Significance	Hazard ratio Exp(B)	95% CI for Exp(B)	
				Lower	Upper
Gender (male ^a)	2.276	0.131	1.357	0.913	2.018
Age					
Preschool ^a	1.454	0.693			
Early elementary	0.042	0.838	0.942	0.528	1.680
Late elementary	0.017	0.896	1.036	0.608	1.766
Adolescent	0.926	0.336	0.750	0.417	1.348
Religion					
None ^a	25.407	0.000			
Other	17.704	0.000	3.144	1.877	5.360
Catholic	0.900	0.343	1.348	0.727	2.498
Protestant	0.094	0.759	0.903	0.471	1.731
Race (white ^a)	1.102	0.294	1.355	0.769	2.388
Referring diagnosis					
Cancer ^a	25.599	0.000			
Congenital/genetic	24.886	0.000	0.297	0.184	0.478
Transplant	3.101	0.078	0.517	0.248	1.077
Trauma	5.952	0.015	0.173	0.042	0.709
Other	0.004	0.947	0.000	0.000	5.2E+157
Cancer	43.795	0.000	4.989	3.100	8.031
Congenital/genetic	8.536	0.003	0.550	0.369	0.822
Ostomies	12.601	0.000	0.439	0.278	0.691
Pain	7.515	0.006	0.573	0.385	0.853
Psychiatric	9.064	0.003	0.381	0.203	0.714
Trauma	8.484	0.004	0.378	0.197	0.728

^aReference group.

major cause for the referral to palliative care. Our result provided support for our hypothesis.

This retrospective study is the largest and most comprehensive medical record review for a PPC population to date. This study adds to the body of knowledge for PPC. While many “know” that PPC decreases pain and symptoms and that palliative care is not just for children with an oncology diagnosis, we now have supporting data. No other study has addressed survival or hazard ratios. Children are still not being referred to palliative care until mere days before death. Palliative care is the best of what medicine is meant to be, the team management of complex illnesses leading to a reduction of suffering.

Limitations

The main limitation is that this was a retrospective study. Only the data contained in the chart could be used, leading to some lack of clarity in some of the data. There were 23 children listed as alive who were lost to follow-up who may or may not have been alive at the end of the study period. This leads to an uncertain right censoring date, so both the KM survival models and the Cox regression may be slightly different. The date of death was difficult to find. If no actual date of death was found, the weekly patient lists kept by the manager of the palliative care team were consulted. The date of death was entered as the last week the child appeared on the list. The date of the referring diagnosis was sometimes difficult to find. Physician notes, operative notes, laboratory results, and other clinical notes were searched for a date of diagnosis. In some cases, only a month and year were found.

In this case, the last day of the month was entered for the diagnosis date, giving a more conservative time to referral and/or time to death. The uncertainty of these two dates (date of diagnosis and date of death) and the conservative approach used to quantify them may have resulted in a shorter mean time from diagnosis to referral, from referral to death, and from diagnosis to death than actually occurred resulting in potentially steeper survival curves.

Conclusion

Describing this large ($N=256$) cohort provides important information on the complexity of disease processes for children referred to palliative care, types of illnesses referred, survival curves for demographic and illness variables, and hazard ratios for six of the 15 illness processes: cancer, congenital and genetic conditions, ostomies, pain, psychiatric disorders not including mood, and trauma. Important research has been done but our understanding of the needs of children in palliative care is in the early stages. Research examining the needs of both children and their families with life-threatening and life-limiting illnesses is important for the quality of life of these children and their families. Investigation should include not only symptoms such as pain, anxiety, dyspnea, depression, and stress but also sleep quality and physical function. Future prospective research is needed to provide insight into the unique challenges of PPC.

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