

Associations Between Pediatric Palliative Care Consultation and End-of-Life Preparation at an Academic Medical Center: A Retrospective EHR Analysis

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OBJECTIVES: Our aim in this study was to understand usage patterns of pediatric palliative care (PPC) consultation and associations with end-of-life preparation among pediatric patients who are deceased.

METHODS: We reviewed 233 pediatric mortalities. Data extraction from the electronic health record included determination of PPC consultation by using Current Procedural Terminology codes. Diagnoses were identified by *International Classification of Disease* codes and were classified into categories of life-threatening complex chronic conditions (LT-CCCs). Data analysis included Student's *t* test, Wilcoxon rank test, Fisher's exact test, χ^2 test, and multivariable logistic regression.

RESULTS: The overall PPC consultation rate for pediatric patients who subsequently died was 24%. A PPC consultation for patients admitted to the pediatric ward and PICU was more likely than for patients cared for in the NICU (31% vs 12%, $P < .01$) and was more likely for those with an LT-CCC (40% vs 10%, $P < .01$), particularly malignancy (65% vs 35%, $P < .01$). Also noted were increased completion of Physician Orders for Life-Sustaining Treatment forms (8 vs 0, $P < .01$) and increased documentation of mental health disorders (60% vs 40%, $P = .02$).

CONCLUSIONS: Our findings suggest that PPC consultation for patients in the pediatric ward and PICU is more likely among patients with a greater number of LT-CCCs, and is associated with increased Physician Orders for Life-Sustaining Treatment preparation and documentation of mental health disorders. Patients at risk to not receive PPC consultation are those with acute illness and patients in the NICU.

ABSTRACT



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Dr Stutz conceptualized and designed the study, conducted analysis, drafted the initial manuscript, and edited and incorporated others' edits; Drs Kao and Ross assisted in conceptualizing the study design and analysis, provided guidance on data security, organization, formatting, and processing, and edited the drafted manuscript; Dr Huard assisted in the conceptualization, design, and analysis of the study and edited the manuscript; Mr Grotts provided statistical analysis and consultation and reviewed the manuscript; Mr Sanz extracted data for clinical researchers and reviewed and edited the manuscript; and all authors approved the manuscript as submitted.

Despite the Institute of Medicine's and the American Academy of Pediatrics' guidelines to integrate palliative care as soon as possible after the diagnosis of a life-limiting illness^{1,2} and the known early benefits of palliative care,³ the published rates of pediatric palliative care (PPC) consultations for children vary widely (4%–88%).^{4–7} Similarly, the timing of initial PPC consultation before patient death varies from a median of 8 to 107 days preceding death.^{4,8,9} Because of these variations, we were prompted to examine our institution's practice surrounding PPC use.

To our knowledge, the relationship of PPC consultation to hospital service (pediatric ward and PICU [Pediatrics/PICU] versus NICU), Physician Orders for Life-Sustaining Treatment (POLST) form completion, or detection of mental health disorders (such as depression and anxiety) has not been described in the literature. In this study, we extracted information from our electronic health record (EHR) data

warehouse to address these gaps and describe the usage patterns of PPC at our institution.

METHODS

Setting

This retrospective analysis of EHR-generated data was performed at a pediatric hospital serving 2 locations within an academic health system in urban southern California. Our institution provides care to a medically complex patient population and has 131 pediatric tertiary and quaternary care hospital beds. Patients younger than 18 years of age accounted for ~8012 admissions, 15 815 emergency department visits, and 53 062 ambulatory appointments in a recent year. The PPC consultation team includes 3 attending physicians, a nurse practitioner, a bereavement-focused social worker, a psychologist, and a chaplain. Institutional review board approval was obtained before initiation of the study.

Patients

We included all patients who died before age 18 years between 2013 and 2016, as identified through discrete EHR data elements and pediatric subspecialty divisions' databases for patients who are deceased.

Data Acquisition

The data were extracted from our Epic Systems EHR Clarity database (Epic Systems Corp, Verona, WI). Patient variables that were collected include demographic information (age at time of death, principal payer, sex, race, ethnicity, preferred language, and religion), procedure codes (including billing codes and use of life-sustaining medical technologies), billing and problem list diagnoses, location of death, limitation of resuscitation orders, and the presence of a completed POLST form (Table 1). The initial PPC consultation was identified by the earliest appearance of a Current Procedural

TABLE 1 Comparison of Demographic Information Based on the Presence of Palliative Care Consultation for Patients in Pediatrics/PICU and NICU

	Pediatrics/PICU		<i>P</i>	NICU		<i>P</i>
	(–) PPC Consult (<i>n</i> = 103)	(+) PPC Consult (<i>n</i> = 47)		(–) PPC Consult (<i>n</i> = 73)	(+) PPC Consult (<i>n</i> = 10)	
Mean age at death in months (SD)	85.2 (73.2)	76.8 (72)	.52	0.6 (1.8)	1.6 (2.1)	NA
Sex, <i>n</i> (%)			.86			.73
Female	44 (43)	19 (40)		29 (40)	3 (30)	
Male	59 (57)	28 (60)		44 (60)	7 (70)	
Race and/or ethnicity, <i>n</i> (%)			.81			.23
White	42 (41)	22 (47)		17 (23)	5 (50)	
Other	29 (29)	12 (25)		26 (36)	3 (30)	
Hispanic	32 (31)	13 (28)		30 (41)	2 (20)	
Insurance, <i>n</i> (%)			.42			.40
Commercial	44 (43)	15 (32)		43 (59)	4 (40)	
Government	55 (53)	31 (66)		29 (39)	6 (60)	
International payer	4 (4)	1 (2)		1 (1)	0 (0)	
Language, <i>n</i> (%)			.98			.23
English	87 (84)	41 (87)		58 (80)	8 (80)	
Spanish	12 (12)	5 (11)		6 (8)	2 (20)	
Other	4 (4)	1 (2)		9 (12)	0 (0)	
Religion, <i>n</i> (%)			.32			.03
Catholic	44 (43)	19 (40)		17 (23)	6 (60)	
Protestant	22 (21)	16 (34)		15 (21)	3 (30)	
Other	17 (17)	4 (9)		16 (22)	0 (0)	
None	20 (19)	8 (17)		25 (34)	1 (10)	

–, no PPC consultation present; +, PPC consultation present; NA, not applicable.

Terminology procedure code associated with a unique billing area for PPC consultation.

Measurements and Outcomes

Patient diagnoses were categorized into the following major, life-threatening complex chronic condition (LT-CCC) classes as defined by Feudtner et al⁹: neuromuscular, cardiovascular, respiratory, renal, gastrointestinal, hematologic and/or immunodeficiency, metabolic, congenital or genetic, and malignancy, which were retrieved using *International Classification of Diseases, Ninth Revision* (ICD-9) and *10th Revision* (ICD-10) diagnostic codes.¹⁰ Patients in the Pediatrics/PICU group with at least 1 LT-CCC comprised the “chronically ill” group. Patients in Pediatrics/PICU without LT-CCCs comprised the “acutely ill” group. We also examined the number of LT-CCCs present and the documentation of mental health disorders (such as anxiety, depression, or posttraumatic stress disorder) by the presence of any ICD-9 or ICD-10 code representative of a mental health disorder.

We measured the time from PPC consultation until death in days. Our indicators of end-of-life preparation included life-sustaining medical technology used within 2 days of death, location of death, time between most recent limitation of resuscitation order and death, and the presence of a POLST form on file.

We analyzed patients in the pediatric ward and PICU together because these patients were frequently transferred between the pediatric ward and the PICU. We separated infants who were exclusively cared for and died in the NICU because neonatologists cared for these patients and unique factors potentially influenced end-of-life care decisions.^{11–13}

Statistical Approach

Data were summarized using means with SD, median with interquartile range, or the number of patients in the group, with the percent of the group based on the distribution of the data. Continuous data were tested for significance using a Student’s *t* test or Wilcoxon rank test, and

categorical data were tested using a Fisher’s exact test. A χ^2 test was used to compare proportions. A multivariable logistic regression model was fit to variables that were significant on univariate analysis for patients in Pediatrics/PICU and NICU separately. All tests were 2-sided and a *P* value $\leq .05$ was considered statistically significant. All reported hypothesis testing was bivariable unless explicitly stated. The R Statistical Computing Environment was used for data analysis (The R Foundation, Vienna, Austria).

RESULTS

The entire cohort included a diverse group of 233 children who are deceased (Table 1). Within this group, 198 (198 out of 233, 85%) children had at least 1 LT-CCC (Table 2). The overall rate of PPC consultation was 24% (*n* = 57 out of 233), with PPC consultation rates increasing each year from 16% in 2013 to 38% in 2016 (*n* = 9 out of 57, 16% [2013]; *n* = 17 out of 76, 25% [2014]; *n* = 20 out of 79, 26% [2015]; *n* = 11 out of 29, 38% [2016]; *P* = .031).

TABLE 2 PPC Consultations by LT-CCCs and Number of LT-CCCs

	Pediatrics/PICU		<i>P</i>	NICU		<i>P</i>
	(–) PPC Consult (<i>n</i> = 103), <i>n</i> (%)	(+) PPC Consult (<i>n</i> = 47), <i>n</i> (%)		(–) PPC Consult (<i>n</i> = 73), <i>n</i> (%)	(+) PPC Consult (<i>n</i> = 10), <i>n</i> (%)	
Neuromuscular	3/5 (60)	2/5 (40)	.65	0/0 (NA)	0/0 (NA)	NA
Cardiovascular	18/25 (72)	7/25 (28)	.82	17/21 (81)	4/21 (19)	.26
Respiratory	22/33 (67)	11/33 (33)	.83	5/7 (72)	2/7 (28)	.20
Renal	9/15 (60)	6/15 (40)	.56	5/5 (100)	0/5 (0)	.99
Gastrointestinal	13/20 (65)	7/20 (35)	.80	4/4 (100)	0/4 (0)	.98
Hematologic or immunodeficiency	3/8 (38)	5/8 (62)	.11	4/4 (100)	0/4 (0)	.99
Metabolic	8/10 (80)	2/10 (20)	.73	3/3 (100)	0/3 (0)	.96
Genetic or congenital	40/57 (70)	17/57 (30)	.86	24/31 (77)	7/31 (23)	.28
Malignancy	11/31 (35)	20/31 (65)	<.01	2/2 (100)	0/2 (0)	.98
Transplant	15/27 (56)	12/27 (44)	.11	2/2 (100)	0/2 (0)	.97
Mental health disorder	6/15 (40)	9/15 (60)	.02	NA	NA (NA)	NA
LT-CCC diagnosis count						
0 “acutely ill”	28/31 (90)	3/31 (10)	<.01	3/4 (75)	1/4 (25)	.51
≥ 1 “chronically ill”	75/119 (63)	44/119 (37)	NA	70/79 (89)	9/79 (11)	NA
1	34/45 (66)	11/45 (24)	<.01	42/46 (91)	4/46 (9)	.4
2	20/38 (53)	18/38 (47)	NA	11/12 (92)	1/12 (8)	NA
3	13/25 (52)	12/25 (48)	NA	14/18 (78)	4/18 (22)	NA
>3	8/11 (73)	3/11 (27)	NA	3/3 (100)	0/3 (0)	NA

Hypothesis test was a Fisher’s exact test for the association between those with and without conditions and receiving a PPC consultation. NA, not applicable; –, no PPC consultation present; +, PPC consultation present.

Patients in Pediatrics/PICU

Presence of Chronic Illness

The majority of patients in Pediatrics/PICU were chronically ill (at least 1 LT-CCC, $n = 119$ out of 150, 79%). Those who were acutely ill (no LT-CCC, $n = 31$ out of 150, 21%) died primarily of trauma and sepsis. Among patients in Pediatrics/PICU, PPC consultation was more likely among the chronically ill group than the acutely ill group ($n = 44$ out of 119, 37% vs $n = 3$ out of 31, 10%; $P < .01$). Malignancy was the only category of LT-CCC significantly associated with PPC consultation ($n = 20$ out of 31, 65% vs $n = 11$ out of 35, 35%; $P < .01$). Children with multiple LT-CCCs were more likely to receive PPC consultation than those with a single LT-CCC (33 out of 74, 45% vs $n = 11$ out of 45, 24%; $P < .01$) (Table 2).

Patient End-of-Life Preparation

Patients in Pediatrics/PICU with PPC consultation compared with those without PPC consultation were less likely to receive mechanical ventilation within 2 days of death ($n = 24$ out of 48, 50% vs $n = 76$ out of 102, 74%; $P = .01$). Children who died in the PICU were less likely to have received PPC consultation at any time ($n = 7$ out of 47, 15% vs $n = 72$ out of 103, 70%; $P < .01$). The median time from most recent limitation of resuscitation order to death did not vary between groups (median: 0, range: 0–383.3 days vs median: 0, range: 0–717.4 days; $P = .20$). Patients with a PPC consultation were more likely to have a limitation of resuscitation order placed >1 day before death compared with patients who did not receive a consultation, but this was not statistically significant ($n = 14$ out of 46, 30% vs $n = 19$ out of 96, 20%; $P = .203$). There was a total of 8 POLST forms completed, all of which were for patients who received PPC consultation, and no POLST forms were completed for patients who had not received PPC consultation ($n = 8$ out of 8, 100% vs $n = 0$ out of 8, 0%; $P < .01$).

Mental Health Disorders

Fifteen patients in Pediatrics/PICU ($n = 15$ out of 150, 10%) had documentation of mental health disorders. A greater proportion of children with mental health

disorders had a PPC consultation compared with children without mental health disorders ($n = 9$ out of 15, 60% vs $n = 6$ out of 15, 40%; $P = .02$). The majority ($n = 8$ out of 9, 89%) of mental health disorders were documented after PPC consultation.

Patients in the NICU

Infants cared for exclusively in the NICU accounted for 83 ($n = 83$ out of 233, 36%) of the deaths. Compared with the Pediatrics/PICU group, the PPC consultation rate in the NICU was significantly lower ($n = 10$ out of 83, 12% vs $n = 47$ out of 150, 31%; $P < .01$), and the median time between PPC consultation and death was shorter (median: 85, range: 3–770 days vs median: 24, range: 4–179 days; $P = .02$). A PPC consultation was associated with increased use of limitation of resuscitation orders ($n = 7$ out of 10, 70% vs $n = 17$ out of 73, 23.3%; $P = .01$). The median time from limitation of resuscitation order to death did not vary between groups (median: 0, range: 0–18 days vs median: 0, range: 0–55 days; $P = .27$). A larger percentage of patients received a limitation of resuscitation order >1 day before death with PPC consultation; however, this was not statistically significant ($n = 2$ out of 10, 20% vs $n = 4$ out of 70, 6%; $P = .161$). Seventy-nine infants ($n = 79$ out of 83, 95%) had at least 1 LT-CCC. The presence of or number of LT-CCCs was not significantly associated with increased PPC consultation (Table 2).

Separate multivariable regression models were created for significant variables on the

univariate analysis for the patients in Pediatrics/PICU and NICU to determine covariates associated with PPC consultation (Table 3). Among the children in Pediatrics/PICU, the diagnosis of malignancy (odds ratio [OR]: 3.1, $P = .05$, 95% confidence interval [CI]: 1.0–9.5) was associated with the presence of PPC consultation. Compared with patients who died in the PICU, patients who eventually died at home or in hospice care (OR: 16.6, $P < .01$, 95% CI: 2.4–114.8) or in the inpatient ward (OR: 22.7, $P < .01$, 95% CI: 7.8–66.3) were more likely to have a PPC consult placed.

The patients in the NICU with limitation of resuscitation orders were more likely to have a PPC consultation (OR: 9.3, $P < .01$, 95% CI: 1.7–49.1).

DISCUSSION

This study expands our current understanding of PPC consultation by revealing that consultation for patients who were cared for in the pediatric ward and PICU is associated with chronic illness, differences in end of life preparation (including the completion of POLST forms), and improvement in documentation of mental health disorders. We also found that PPC consultation is less common for those with acute illness as well as less frequent and closer to end-of-life for patients in the NICU.

Rates of PPC consultation at our institution were within the wide range reported previously in the literature but with a

TABLE 3 Multivariable Logistic Regression Model of Significant Variables Associated With Odds of PPC Team Consultation ($P < .05$)

Variable	OR (95% CI)	P
Pediatrics/PICU (acute and chronic)		
Malignancy	3.1 (1.0–9.53)	.05
Patient location at the time of death		
PICU	Reference	$<.01$
Emergency	2.8 (0.6–13.3)	
Home and/or hospice	16.6 (2.4–114.8)	
Inpatient	22.7 (7.8–66.3)	
Ventilator use within 2 d of death	0.6 (0.2–1.9)	.46
Patients in the NICU		
Resuscitation status		
No limitation	Reference	$<.01$
Limitation	9.3 (1.7–49.1)	

longer-than-reported mean time between consultation and death.^{6,7,13–15} Given the American Academy of Pediatrics' and the Institute of Medicine's recommendation that palliative care should be implemented as soon as possible after a life-limiting diagnosis has been made, indicated in the rates we report for chronically ill children is that over half of the opportunities to provide PPC may be missed.^{1,2,10,11,15–17} The benefits of PPC begin well before the end-of-life period, and early PPC consults are imperative to improve the quality of patients' lives long before death.³ Considering the higher rates of PPC consultation for children with multiple LT-CCCs at our institution, we suggest that increased complexity of care may lead to more frequent PPC consultations.

We also found differences in the end-of-life preparation among children with PPC consultation, including reduced frequency of mechanical ventilation use within 2 days of death, location of death, and increased POLST form completion. There was also a nonsignificant trend of increased time from limitation of resuscitation order to time of death. Less invasive technology used at the end of a patient's life could indicate that these families were more prepared for their child's death, but we do not have data about the families' experiences to confirm this assumption. In addition, low POLST form completion rates among patients without PPC consultation may be because of providers' lack of familiarity with POLST forms.^{18,19}

Another notable finding of our study was the relationship between PPC consultation and documentation of mental health disorders. With the documentation of mental health disorders after PPC consultation, it is suggested that PPC consultation may lead to increased identification of mental health disorders, perhaps facilitated when a PPC-trained social worker and/or a psychologist are team members. The percentage of children with mental health disorders was lower than expected given the estimated rate for healthy children is 21%.^{17,20,21} Possible explanations for low rates of mental health disorder identification or documentation include variable levels of

physician confidence in making diagnoses, perceived lack of pediatric psychiatry consultation service, missed opportunities to screen for mental health disorders, patient or parental nondisclosure of symptoms, or attribution of symptoms to primary disease or situation.^{22–24}

In the NICU, PPC consultations were less frequent and occurred closer to death. Intuitively, shorter length of illness in this patient group and unclear prognosis could explain this difference. With higher rates and nonsignificant trends toward earlier entry of limitation of resuscitation orders for patients with PPC consults, it may be indicated that limitation of resuscitation is a major focus of PPC-assisted discussions in the NICU.

Limitations of this study include a small sample size, particularly in the context of subgroup analysis, thereby limiting the power to draw conclusions. Also, this is a retrospective cohort study conducted at a single health system serving a medically complex pediatric population; therefore, our results may not be generalizable to all pediatric programs. Our methods prohibited us from comparing the congruence of patient and/or family preference and the actual location of death. With our data extraction methodology, we rely on adequate documentation of diagnoses in the EHR, and it could lead to an underestimation of the number of LT-CCCs associated with each patient.

On the basis of the findings in this study, we hope to improve PPC consultation by creating EHR-based clinical decision support interventions at our institution. Clinical decision support tools have been proposed for symptom management, with potentially improved outcomes.^{25–26} In our first EHR-based intervention, we aim to improve the completion rate of POLST forms by prompting the provider to complete an electronically generated POLST form at discharge if a patient's resuscitation status has been modified. The next intervention will be to design algorithms to identify patients who qualify for PPC consultation on the basis of clinical criteria. We aim to increase the current usage rate of PPC across all disciplines as well as shorten

the time from LT-CCC diagnosis to PPC consultation.

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