

# Timing of Palliative Consultation for Children During a Fatal Illness

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## ABSTRACT

**BACKGROUND:** The American Academy of Pediatrics recommends palliative care for children at the diagnosis of serious illness. Yet few children who die receive specialty palliative care consultation, and when it is provided, palliative care consultation tends to occur after >75% of the time from diagnosis until death. Focusing on the timing of palliative consultation in relation to the date of diagnosis, we evaluated factors predicting earlier receipt of pediatric palliative care in a cohort of decedents.

**METHODS:** We retrospectively identified patients diagnosed with a life-limiting disease who died at our hospital in 2015–2017 after at least 1 inpatient palliative medicine consultation. Our primary outcome was time from palliative-qualifying diagnosis to earliest receipt of specialty palliative care. A survival analysis was used to describe factors associated with earlier receipt of palliative care.

**RESULTS:** The analysis included 180 patients (median age at diagnosis <1 month [interquartile range (IQR): 0–77]). The median time to first palliative consultation was 7 days after diagnosis (IQR: 2–63), compared with a median of 50 days between diagnosis and death (IQR: 7–210). On the multivariable analysis, palliative consultation occurred earlier for patients who had cardiovascular diagnoses, had private insurance, and were of African American race.

**CONCLUSIONS:** In a cohort of decedents at our institution, palliative consultation occurred much earlier than has been previously reported. We also identify factors associated with delayed receipt of palliative care among children who are dying that reveal further opportunities to improve access to specialty palliative care.



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**TABLE 1** Characteristics Among Patients Included in Study Population (*N* = 180)

Patient Characteristics	<i>n</i> (%)
Girls	70 (39)
Age at diagnosis	
≤30 d	97 (54)
31 d to 1 y	29 (16)
2–6 y	11 (6)
7–12 y	14 (8)
13–18 y	19 (11)
>18 y	10 (6)
Race <sup>a</sup>	
White	116 (73)
African American	29 (18)
Other	14 (9)
Private health insurance	70 (39)
County of residence	
Hospital's county	84 (47)
Contiguous county	33 (18)
Other	63 (35)
Type of palliative care–qualifying diagnosis	
Neuromuscular	12 (7)
Cardiovascular	37 (21)
Pulmonary	20 (11)
Malignancy	23 (13)
Genetic	28 (16)
Renal	4 (2)
Gastrointestinal	4 (2)
Hematologic and/or immunologic	1 (1)
Metabolic	2 (1)
Acute event	49 (27)
Diagnosis met criterion for automatic palliative referral	80 (44)
Location of death	
NICU	63 (35)
PICU	52 (29)
CTICU	36 (20)
Hospital floor	28 (16)
Other location	1 (1)

CTICU, cardiothoracic ICU.

<sup>a</sup> Missing information for 21 patients.

When should children with serious illness receive palliative care? Since 2000, The American Academy of Pediatrics has supported an integrated model “in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether

the outcome ends in cure or death.”<sup>1</sup> Although there is evidence that consultation is welcomed by patients,<sup>2</sup> can lead to better control of symptoms<sup>3–11</sup> and quality of life,<sup>6,7,12–17</sup> and is associated with reduced costs and health care use,<sup>8,9,12–16,18–24</sup> a minority of children in need of such services receive specialty palliative care. In previous analyses of children who have died, between 4% and 38% had received specialty palliative care.<sup>24–26</sup>

In recognizing this unmet need for pediatric palliative care (PPC), both barriers and facilitators to consultation have been identified.<sup>2,27–32</sup> Although researchers have analyzed PPC receipt according to different qualifying conditions<sup>10,33</sup> and although a suggested list of trigger diagnoses for PPC is available,<sup>34</sup> the timing of initial specialty PPC consultation is not well described. Authors of a single study have explicitly sought to define when PPC consultation occurs,<sup>35</sup> and comparable data can be abstracted from other reports (Supplemental Table 4).<sup>5,9,10,24,33,36</sup> Although authors of some studies have reported on late palliative care (defined retrospectively from the date of death<sup>15,19,22</sup>), these data are difficult to translate to the real-time decision about when to consult PPC.

Focusing on the timing of PPC consultation in relation to the date of diagnosis, we propose to evaluate factors that predict earlier receipt of PPC. A better understanding of the timing of PPC will help compare current practice to recommendations about early involvement of palliative care, may highlight opportunities to deliver PPC earlier in the course of a life-limiting illness, and may uncover disparities in patients' access to early PPC. Therefore, our primary aim for the current study is to characterize the timing of PPC consultation relative to diagnosis in a cohort of decedents. Our secondary aim is to determine what factors are associated with delayed receipt of PPC.

## METHODS

The study was approved, and a waiver of informed consent was granted, by the institutional review board (IRB18-00140) at our 476-bed tertiary-academic children's hospital in the Midwestern United States. In

2016, our hospital reported 18 183 inpatient discharges and 1 425 023 total patient visits for patients from all 50 states and from 52 foreign countries.<sup>37</sup> At our hospital, the PPC team (5 attending physicians, 2 nurse practitioners, 1 chaplain, and 1 social worker) has provided inpatient palliative care services since 2009, and our hospital currently staffs >500 consults each year. Using the quality improvement database maintained by the PPC team, we retrospectively identified patients who had received at least 1 inpatient palliative consultation, who had died in the hospital between January 2015 and December 2017, and whose original diagnosis occurred since the PPC team was established. When possible, the date of diagnosis was assigned on the basis of the date of the pathology specimen report or the date recorded in the first PPC consultation note as the date of diagnosis, whichever was earlier. In this way, we might compare our findings with available data (Supplemental Table 4) yet assign diagnosis as the reference point to define timing.

The primary outcome was time from palliative-qualifying diagnosis to earliest receipt of PPC. Covariates included patient age at diagnosis, sex, race and/or ethnicity, private health insurance, place of residence (county where our hospital is located, contiguous counties in the state, or any other place), palliative-qualifying diagnosis (whether an acute event or a type of complex chronic condition<sup>38</sup>), and whether the diagnosis was recommended as an automatic criterion for palliative care consultation, according to proposed PPC referral criteria hosted by the Center to Advance Palliative Care.<sup>34</sup> Except when noted otherwise, patient demographic information was obtained at the date of the final admission.

Continuous data were expressed as medians with interquartile ranges (IQRs), and categorical variables were expressed as counts with proportions. The association of covariates with timing of PPC consultation after diagnosis was assessed through a multivariable Cox proportional hazards regression. A statistical analysis was performed by using Stata/IC 14.2

(Stata Corp, College Station, TX), and 2-tailed  $P < .05$  was considered statistically significant.

## RESULTS

Two hundred patients in the PPC quality improvement database died while hospitalized between January 2015 and December 2017. Twelve patients were excluded because of a diagnosis before 2009, and 8 patients were excluded because of an unavailable date of a palliative care–qualifying diagnosis. The 180 patients in the study cohort (110 boys and 70 girls) had a median age of <1 month (IQR: 0–77), with the majority having had nonprivate insurance and being of white race (73%; Table 1). From the time of diagnosis, a median of 7 days (IQR: 2–63) passed until the earliest specialty palliative care consultation, and the median duration between diagnosis and death was 50 days (IQR: 7–210; Table 2). A Kaplan-Meier plot of first PPC consultation (median) further illustrates that most patients in our cohort received a PPC consultation within a month of diagnosis (Fig 1). Most patients were admitted to the hospital only once since diagnosis, and the median total hospital stay (across all admissions) was 41 days (IQR: 8–112). On average, the earliest PPC visit occurred after 46% of the time had elapsed between diagnosis and death.

An additional 21 patients were excluded from only the multivariable analysis because of missing information on race. Because nearly all these patients were <1 week old (ie, race data were missing predominantly in neonates), we considered that data on this covariate were not missing at random and, therefore, did not pursue multiple imputation of patient race. On the multivariable analysis, when compared with cardiovascular diagnoses, pulmonary (hazard ratio [HR] = 0.5; 95% confidence interval [CI]: 0.2–0.9;  $P = .015$ ) and malignant (HR = 0.5; 95% CI: 0.3–0.96;  $P = .036$ ) diagnoses were associated with delay of earliest PPC consultation (Table 3). Private health insurance (HR = 1.7; 95% CI: 1.1–2.4;  $P = .014$ ) and African American race (HR = 1.7; 95% CI: 1.05–2.9;  $P = .033$ )

**TABLE 2** Outcomes Among Patients Included in Study Population ( $N = 180$ )

Outcomes	Median (IQR)
Time from diagnosis to earliest specialty palliative care, d	7 (2–63)
Time from diagnosis to death, d	50 (7–210)
No. inpatient admissions	1 (1–2)
Total d in the hospital	41 (8–112)
No. inpatient palliative care team consultations	1 (1–2)

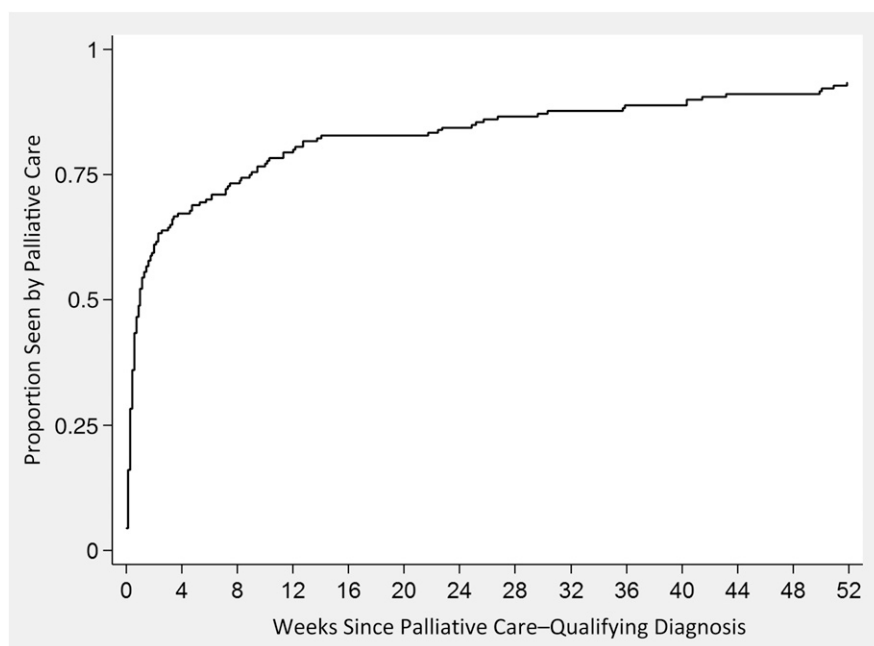
were associated with earlier receipt of PPC.

## DISCUSSION

In our analysis of children who received specialty palliative care and died while hospitalized, the timing of PPC consultation in relation to diagnosis was much earlier (46% of the time from diagnosis to death) than has been previously reported (79%–96%), typically occurring within a month of diagnosis. The multivariable analysis revealed earlier receipt of palliative care for patients with cardiovascular conditions compared with patients with pulmonary or malignant conditions, patients with private health insurance, and patients of African American race. These findings reveal disparities regarding timing of PPC

consultation among a cohort in which PPC consultation was frequently provided soon after diagnosis of a life-limiting illness.

The typically short duration from diagnosis to receipt of specialty palliative care may be explained by our institutional history and workflow of the PPC team at our hospital. Our team benefits from nearly 10 years of experience as an available resource in the institution. With a fully staffed interdisciplinary team, we have the ability to supply palliative care to meet the demand of a large number of patients across a wide range of services. Although many PPC programs have grown out of the hematology and oncology population, cardiovascular diagnosis was the most common specific diagnoses group among patients in our cohort. This likely reflects the high infant



**FIGURE 1** Kaplan-Meier plot of first PPC consultation ( $N = 180$ ).

**TABLE 3** Cox Proportional Hazards Regression of Time From Diagnosis to Earliest Specialty Palliative Care (*N* = 159)

Characteristics	HR	95% CI	<i>P</i>
Girls	1.0	(0.7–1.4)	.824
Age at diagnosis			
≤30 d	Reference	—	—
31 d to 1 y	0.9	(0.6–1.5)	.785
2–6 y	0.7	(0.3–1.7)	.462
7–12 y	0.5	(0.3–1.1)	.089
13–18 y	0.7	(0.4–1.3)	.265
>18 y	1.5	(0.7–3.1)	.307
Race			
White	Reference	—	—
African American	1.7	(1.05–2.9)	.033
Other	1.3	(0.7–2.4)	.454
Private health insurance	1.6	(1.1–2.4)	.014
County of residence			
Hospital's county	Reference	—	—
Contiguous county	1.0	(0.6–1.8)	.919
Other	0.8	(0.5–1.3)	.366
Type of palliative care—qualifying diagnosis			
Cardiovascular	Reference	—	—
Neuromuscular	0.5	(0.2–1.1)	.085
Pulmonary	0.5	(0.2–0.9)	.015
Malignancy	0.5	(0.3–0.96)	.036
Genetic	0.8	(0.4–1.5)	.417
Other	1.5	(1.0–2.5)	.075
Diagnosis met criterion for automatic palliative care referral	0.9	(0.6–1.3)	.562

—, not applicable.

diagnosis. Also, all in-hospital decedents may not be eligible to receive specialty PPC (eg, precipitous death from an acute event in an otherwise well child or PPC not available at all institutions), and further studies should be used to explore methods to compare children receiving PPC with appropriately matched cohorts not receiving PPC.

## CONCLUSIONS

Available evidence supports specialty palliative care as part of the best possible treatment of children with serious illness. Although previous studies have revealed that children with life-limiting conditions often receive PPC (if at all) late in the course of illness, our single-center decedent cohort revealed a pattern of much earlier PPC consultation than what has been previously reported. We also describe factors associated with delayed receipt of PPC. As medicine seeks to provide individualized care, palliation should also be personalized. Specialty PPC is a limited resource and should be provided to those most in need. Our findings (eg, earlier PPC for children with cardiac diagnoses) reveal differences among populations of children who are dying that likely reflect differential disease trajectories and the particular relationship between PPC and the referring service. Future research may be used to build on our findings regarding clinical outcomes and disparities among children who are seriously ill.

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mortality rate of circulatory-system diseases<sup>39</sup> and the well-established process for PPC consultation in our institution's cardiac unit for children with single-ventricle physiology or consideration of a heart transplant.

Our findings reflect current practice at a large academic children's hospital and reveal that patients are being referred to PPC earlier in the course of their disease than reported in previous research. It is unclear to what degree this reflects our local experience or, possibly, increasing acceptance of PPC among referring pediatric providers. Limitations of this study include its retrospective, single-center design and focus on a cohort of children who died in the hospital. Although death was an inclusion criterion so as to benchmark against available data

(Supplemental Table 4) and although cases were not reviewed as to whether the palliative-qualifying diagnosis was also the cause of death, we used diagnosis, rather than death,<sup>15,19,22</sup> as the reference time point to define timing of PPC to better approximate clinical practice. Receipt of palliative care in this analysis refers to specialty, inpatient, consultative care only. It does not account for prenatal palliative care, possible earlier discussions about palliative care, the provision of primary palliative care, or possible requests to delay or decline palliative consultation. Although our analysis revealed patient-level factors associated with differential time from diagnosis to earliest receipt of PPC, further studies may be used to explore these outcomes for all children admitted with a palliative-qualifying

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