

Palliative care is not associated with decreased intensity of care: Results of a chart review from a large children's hospital

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Abstract

Background: Palliative care is an important component of pediatric oncology care, especially for children who will not be cured of their disease. However, barriers remain to integration of this service. One barrier is the perception that it indicates “giving up.” This study examined if palliative care involvement was associated with a decreased intensity of care at the end of life for children with malignancy at a large academic center with a well-established palliative care program.

Procedure: This is a retrospective chart review that measured intensity of care as the number of emergency department visits, hospital days, and intensive care unit days in the last one and three months of life. The data were compared for patients with and without palliative care involvement and with and without hospice involvement.

Results: Palliative involvement was not associated with a decrease in the intensity of care in the last three months of life. Hospice care was associated with a decreased intensity of care. These results held true in analyses adjusted for age at death, gender, and type of malignancy.

Conclusions: These data can reassure patients, families, and providers that palliative involvement does not necessitate decreased intensity of care. Patients and families often choose hospice care to decrease the amount of time spent at the hospital and it was associated with meeting that goal.

KEYWORDS

hospice, oncology, palliative care, treatment intensity

1 | INTRODUCTION

Palliative care, which focuses on managing pain, addressing symptom burden, preventing, and relieving suffering, considering advance care planning, and promoting quality of life, is known to improve the experiences of ill children, especially at the end of life.¹⁻³ The American Academy of Pediatrics, National Academy of Medicine, and World Health Organization have supported the integration of palliative care

services for all children with potentially life-threatening or life-limiting diseases, beginning at the time of diagnosis.⁴⁻⁶ Additionally, palliative care is recommended as part of the psychosocial standards of care for pediatric oncology patients.¹ While palliative care aims to support patients and families throughout the course of their illness,³ concerns remain that palliative care consultation may not be well received by families and can be perceived by some as indicating that providers and families are “giving up” on curative treatment approaches.⁷⁻¹¹ This study examined trends in end-of-life care at a large children's hospital with a well-established palliative care program and active oncology

Abbreviations: ED, emergency department; ICU, intensive care unit.

and bone marrow transplant programs to determine whether palliative care impacts the intensity of medical care, as measured by time spent at the hospital.

2 | METHODS

A chart review was conducted at a large academic medical center after institutional review board approval with a waiver of informed consent. The chart review included patients ≤ 25 years of age receiving oncologic care at the institution who died between January 1, 2012, and February 1, 2017. This data range was selected based on the timing of the institutional shift to the current electronic medical record. The Electronic Medical Record Search Engine, a text searching program, was used to aid data collection in addition to manual chart review.¹²

All known deaths in patients with a malignancy were included unless their end-of-life care was clearly provided at another institution. Palliative care involvement was defined by the presence of at least one note in the patient's chart. The initial consultation performed by palliative care includes an introduction to palliative care principles, evaluation of symptoms, discussion of goals, and several questions to better understand the family's values, supports, and concerns. The start of palliative care involvement was defined as the date of the first note. Hospice involvement was documented if there was notation in the chart that the patient was enrolled. If the chart did not specifically mention hospice enrollment, the patient was considered not to have hospice involvement. As hospice care was external to the institution, the timing of hospice involvement was unclear in the documentation for the majority of patients; therefore, it was not included in the data collection.

Descriptive data were collected from 118 patients. Patients with and without palliative care involvement and patients with and without hospice involvement were compared on clinical variables using two-sided *t* tests, with equal variance assumed, chi-squared tests, and Fisher exact test in cases where cell counts fell below 5. Multiple linear regression was used to assess the association of palliative and hospice involvement with emergency department (ED) visits and hospital days. These outcomes were determined to be sufficiently close to normal distribution for linear regression and *t* tests, using the guideline of skewness greater than -2 and less than 2 , and kurtosis greater than -7 or less than 7 .^{13,14} Due to the highly skewed distribution of intensive care unit (ICU) days, negative binomial regression was used to model this outcome. This was determined to be better-fitting than a Poisson model by the likelihood ratio test ($P < 0.001$). Plots of model residuals were examined to check distributional assumptions, homoskedasticity, and linearity. Multiple regression models included as covariates demographic variables (age at death and gender), as well as type of malignancy to adjust for possible confounding variables. Race was not included due to a large number of missing data points. The number of patients with palliative involvement at a given timepoint was determined by the duration of palliative involvement. For example, if a patient has palliative involvement for 35 days prior to death, that patient's data were included in the analysis as having palliative involve-

TABLE 1 Demographics

	N = 118
Mean age at death	13.5 years (SD 6.8)
Gender	
Male	59 (50%)
Female	59 (50%)
Type of malignancy	
Brain tumor	31 (26%)
Leukemia	38 (32%)
Solid tumor	49 (42%)
Race	
Caucasian	84 (88%)
African American	6 (6%)
Other	6 (6%)
Missing	22
Palliative care involved	
Yes	94 (80%)
No	24 (20%)
Duration of palliative care involvement	
Median	1.4 months
Range	1 day-18.6 months
Hospice involved	
Yes	80 (68%)
No	38 (32%)
Location of death	
Home	73 (62%)
General care	16 (14%)
ICU	24 (20%)
Outside hospital	1 (1%)
Unclear	4 (3%)

ment for the last one month of life and as not having palliative involvement for the last three months. The duration of hospice involvement was unclear so all patients with any hospice involvement were included as having hospice involvement for both time points. A *P* value < 0.05 was considered statistically significant. *P* values were adjusted for multiple comparisons using the Bonferroni correction separately for each group of models, hospice, and palliative involvement. The analysis was performed using R version 4.0.5. Data are available upon request.

3 | RESULTS

One hundred eighteen patients were identified by the chart review (Table 1). The patients averaged 13.5 (SD 6.8) years old at time of death, and the sample was 50% female. Participants were predominantly identified as Caucasian in the chart review (88%) with 22 of the 118 participants missing data for race. Forty-nine patients (42%) had

TABLE 2 End-of-life experiences based on palliative care involvement

Palliative	No	Yes	P value (unadjusted)	P value (adjusted for gender, age at death, type of malignancy, and multiple comparisons)
Involvement				
Any	(n = 24)	(n = 94)		
>30 days before death	(n = 65)	(n = 53)		
>90 days before death	(n = 82)	(n = 36)		
Location of death				
Home	11 (46%)	62 (66%)	0.008	^a
General care	1 (4.2%)	15 (16%)		
ICU	9 (38%)	15 (16%)		
Outside hospital	1 (4%)	0		
Unclear	2 (8%)	2 (2%)		
ED visits in last: mean (SD)				
One month	0.5 (0.8)	0.4 (0.7)	0.354	1.00
Three months	1.0 (1.1)	1.2 (1.8)	0.352	1.00
Hospital days in last: mean (SD)				
One month	12.7 (12.4)	5.3 (8.9)	<0.001	0.008
Three months	26.9 (26.5)	14.2 (22.0)	0.013	0.144
ICU days in last: mean (SD)				
One month	5.2 (8.3)	2.1 (5.5)	0.057	0.272
Three months	7.4 (13.4)	3.9 (11.2)	0.175	0.592
Chemotherapy within last 4 weeks of life (missing data for 6)				
Yes	12 (60%)	47 (51%)	0.634	1.00
No	8 (40%)	45 (49%)		
Hospice involvement				
Yes	12 (50.0%)	68 (72.3%)	0.065	0.368
No	12 (50.0%)	26 (27.7%)		

^aUnable to adjust due to small numbers in each category.

solid tumors, 38 (32%) had leukemia, and 31 (26%) had brain tumors. Palliative care was involved for the majority of the patients ($n = 94$; 80%). Hospice was involved for 80 patients (68%). The majority of patients died at home ($n = 73$; 62%). The median duration of palliative care involvement was 1.4 months (range = 1 day–18.6 months) prior to death (Table 1). The majority of patients who were enrolled in hospice also had palliative care involvement (68/80, 85%).

Palliative care involvement was associated with a lower number of hospital days in the last one month of life in the adjusted and unadjusted analysis. Palliative care involvement was not associated with ICU days or ED visits when adjusted for covariates and multiple comparisons. Additionally, there was no significant difference in the number of patients receiving chemotherapy within four weeks of death based on palliative involvement. Patients with palliative involvement were more likely to die at home (66% vs 46%) and less likely to die in the ICU (16% vs 38%) ($P = 0.008$ for location of death) (Table 2).

Hospice involvement did have a significant association with reduced intensity of care in the last three months of life in both unadjusted and adjusted analyses. Adjusting for demographic and clinical variables, patients with hospice involvement had significantly fewer hospital days in the last one and three months of life (adjusted $P < 0.001$) and ICU days in the last one (adjusted $P < 0.001$) and three months (adjusted $P = 0.007$) of life. Patients with hospice involvement had fewer ED visits in the last one month of life (adjusted $P = 0.008$) (Table 3). The number of patients who received chemotherapy within the last four weeks of life was not significantly decreased by hospice involvement (Table 3).

4 | DISCUSSION

There is increasing evidence to support the integration of pediatric palliative care services when caring for children with a malignancy. Decreased suffering experienced by children with cancer at the end

TABLE 3 End-of-life experiences based on hospice involvement

Hospice involvement	No (n = 38)	Yes (n = 80)	P value (unadjusted)	P value (adjusted for gender, age at death, type of malignancy, and multiple comparisons)
Location of death				
Home	0	73 (91.2%)	<0.001	^a
General care	11 (28.9%)	5 (6.2%)		
ICU	22 (57.9%)	2 (2.5%)		
Outside hospital	1 (2.6%)	0		
Unclear	4 (10.5%)	0		
ED visits in last: mean (SD)				
One month	0.7 (0.9)	0.4 (0.6)	0.012	0.008
Three months	1.4 (1.7)	0.9 (1.1)	0.051	0.152
Hospital days in last: mean (SD)				
One month	20.5 (11.4)	4.1 (6.9)	<0.001	<0.001
Three months	48.8 (26.6)	12.7 (17.7)	<0.001	<0.001
ICU days in last: mean (SD)				
One month	9.2 (9.6)	1.3 (3.9)	<0.001	<0.001
Three months	15.3 (18.6)	2.1 (4.8)	<0.001	0.007
Chemotherapy within last 4 weeks of life (missing data for 6)				
Yes	24 (66.7%)	35 (46.1%)	0.066	1.00
No	12 (33.3%)	41 (53.9%)		
Palliative involvement				
Yes	26 (68.4%)	68 (85.0%)	0.065	0.320
No	12 (31.6%)	12 (15%)		

^aUnable to adjust due to small numbers in each category.

of life, as described by parents, has been reported in the past three decades and is attributed to the delivery of care that incorporates optimal palliative care.² The integration of pediatric palliative care services is also supported by Friedrichsdorf and colleagues, who described children who received pediatric palliative care services as more likely to have fun and experience added meaning to life, contributing to improved quality of life.¹⁵ When evaluating end-of-life communication in a survey of bereaved parents of a child who died of a malignancy, Kassam and colleagues described significantly increased likelihood of discussions about death and dying, guidance on how to talk to children about death and dying, and preparation for medical aspects surrounding death when referred to palliative care services.¹⁶ An evaluation of bone marrow transplant recipients who did not survive also described increased frequency of prognosis and resuscitation status discussions in cases where palliative care was included.¹⁷

It is, therefore, critical that institutions evaluate their own practices and availability of pediatric palliative care services to enhance the experience of children with cancer and their families. We must address barriers and seek solutions to overcome them. Fear that the involvement of palliative care alarms families or indicates that caregivers are “giving up” is often cited as a barrier to beneficial integration of this specialty service.⁷⁻¹¹ The data from our institution found a decrease in hospital days in the last one month of life with pallia-

tive care involvement, but not a significant difference in ED visits, ICU days, or chemotherapy administration in the last four weeks of life. These data suggest that palliative care may lead to more days at home but does not decrease ED visits or ICU days, suggesting that access to care is not limited. This finding may be due to the long standing and strong relationship between the palliative care and oncology teams. The comfort and familiarity between the teams may lead to palliative care involvement prior to and independent of decisions relating to the intensity of care.

Additionally, the interprofessional composition and available inpatient consultation/outpatient services provided by the pediatric palliative care team available at our institution allows for reliable patient access to palliative care services. Weaver et al. described the characteristics of 142 pediatric palliative care teams from centers caring for children with cancer.¹⁸ At the time of this study, just over half (53.4%) of patients had access to pediatric-specific palliative care providers. The composition of the team at our institution includes physicians, nurse practitioners, nurses, social workers, a chaplain, and therapy dog, which contributes to the reach of the services.

Perhaps further contributing to the penetration of palliative care and hospice services in the oncology and blood and marrow transplant population is the dual role of two pediatric palliative care physicians with the local pediatric hospice program and the close relationship

of the palliative care and hospice teams. This awareness of available resources and familiarity in such discussions affords continuity in services when families elect to enroll in hospice services.

The involvement of hospice was associated with a decrease in the number of ED visits and hospital days during the last three months of their lives. Many families pursue hospice care in order to spend less time at the hospital and have less intense care; so these data support that hospice care is associated with that important goal. However, because the duration of hospice involvement is unclear from the data, hospice may not be the direct or sole cause of the decreased time at the hospital.

Notably, a substantial portion of patients received chemotherapy within the last four weeks of life even when hospice was involved, suggesting that families can both continue treatment and receive hospice care if desired. This is consistent with the concurrent care model for pediatric hospice patients stipulated by the Affordable Care Act.¹⁹

There was a significant difference in the location of death when palliative care was involved, with more patients dying at home. The patient's preferred location of death was a variable in the medical record review, but so few charts had that information available that it was not included in analysis. However, previous research suggests that the majority of families who were able to plan a location of death preferred a home death.^{15,20,21} Parents and siblings of children who died at home also had better bereavement outcomes.²⁰ Despite the clear benefits of palliative care for symptom control and psychosocial support, barriers remain to engaging eligible patients and families.^{2,7,11} These data demonstrate that the number of ED visits and ICU days did not vary with palliative care involvement. This finding may help to overcome concerns with engaging palliative care as some patients received high intensity care at the end of life with palliative involvement. Further, Levine et al demonstrated that patients and parents are not opposed to initiating palliative care involvement early in treatment,¹⁰ and it may now be possible to reinforce that perspective with the knowledge that clinical care measures need not be diminished once palliative care is initiated. For patients and families who wish to spend less time in the hospital during end-of-life care, hospice involvement was able to achieve that goal.

This study is limited in that the data are retrospective and medical record documentation may not be fully representative, especially for events that happened outside of the institution. The chart review was conducted as part of a larger research project, and this analysis was designed after data collection. Therefore, a discussion about what would be a clinically meaningful difference in ED visits, hospital days, and ICU days did not occur a priori. It could be surmised that for patients at the end of life, families who wish to spend as much time as possible at home would view any difference as significant.

The duration of hospice involvement was not clear in the medical records; so the changes in ED visits, hospital days, and ICU days may not be related to hospice involvement. It may be related to families who were already interested in less time in the hospital, even before hospice was involved. The number of ED visits, hospital days, and ICU days are widely variable. Although no statistically significant differences

were observed in the mean number of days between the "palliative involvement" and "non-palliative involvement" groups, the sample size may not be sufficient to detect a clinically meaningful difference for all comparisons.

Additionally, the data are also representative of only one institution with a well-established palliative care program and a strong relationship between oncology, bone marrow transplant, and palliative care. Future research focused on prospective data collection regarding palliative involvement and meeting patient and family goals is an appropriate next step.

ACKNOWLEDGMENTS

This work was supported by the Nancy Newton Loeb Pediatric Cancer Award, an intramural grant from the University of Michigan Department of Pediatrics.

CONFLICTS OF INTEREST

None of the authors report a conflict of interest with this work.

LINKED CONTENT

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How to cite this article: Sedig LK, Spruit JL, Southwell J, et al. Palliative care is not associated with decreased intensity of care: Results of a chart review from a large children's hospital. *Pediatr Blood Cancer*. 2022;69:e29391. <https://doi.org/10.1002/pbc.29391>