

1 Palliative Care Is Not Associated with Decreased Intensity of Care: Results of a Chart Review from a
2 Large Children's Hospital

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Brief Running Title: No Decrease in Care Intensity with Palliative Care

Key Words: oncology, palliative care, hospice, treatment intensity

Tables: 3

Figures: 0

Abbreviations	
ED	Emergency department
ICU	Intensive care unit

3 Abstract:

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

10 Procedure: This is a retrospective chart review that measured intensity of care as the number
11 of ED visits, hospital days and ICU days in the last one and three months of life. The data
12 were compared for patients with and without palliative care involvement and with and
13 without hospice involvement.

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

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

21 Introduction:

22 Palliative care, which focuses on managing pain, addressing symptom burden,
23 preventing and relieving suffering, considering advance care planning, and promoting quality
24 of life, is known to improve the experiences of ill children, especially at the end of life.¹⁻³
25 The American Academy of Pediatrics, National Academy of Medicine, and World Health
26 Organization have supported the integration of palliative care services for all children with
27 potentially life-threatening or life-limiting diseases, beginning at the time of diagnosis.⁴⁻⁶
28 Additionally, palliative care is recommended as part of the psychosocial standards of care for
29 pediatric oncology patients.¹ While palliative care aims to support patients and families
30 throughout the course of their illness³, concerns remain that palliative care consultation may
31 not be well received by families and can be perceived by some as indicating that providers
32 and families are “giving up” on curative treatment approaches.⁷⁻¹¹ This study examined
33 trends in end-of-life care at a large children’s hospital with a well-established palliative care
34 program and active oncology and bone marrow transplant programs to determine whether
35 palliative care impacts the intensity of medical care, as measured by time spent at the

36 hospital.

37

38 Methods:

39 A chart review was conducted at a large academic medical center after institutional
40 review board approval with a waiver of informed consent. The chart review included patients
41 ≤ 25 years of age receiving oncologic care at the institution who died between January 1, 2012
42 and February 1, 2017. This data range was selected based on the timing of the institutional
43 shift to the current electronic medical record. The Electronic Medical Record Search Engine,
44 a text searching program, was used to aid data collection in addition to manual chart review.¹²

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

56 Descriptive data were collected from 118 patients. Patients with and without palliative
57 care involvement and patients with and without hospice involvement were compared on

58 clinical variables using two-sided t-tests, with equal variance assumed, chi-squared tests, and
59 Fisher's exact test in cases where cell counts fell below 5. Multiple linear regression was used
60 to assess the association of palliative and hospice involvement with emergency department
61 (ED) visits and hospital days. These outcomes were determined to be sufficiently close to
62 normal distribution for linear regression and t-tests, using the guideline of skewness greater
63 than -2 and less than 2, and kurtosis greater than -7 or less than 7.^{13,14} Due to the highly
64 skewed distribution of intensive care unit (ICU) days, negative binomial regression was used
65 to model this outcome. This was determined to be better-fitting than a Poisson model by the
66 likelihood ratio test ($p < 0.001$). Plots of model residuals were examined to check
67 distributional assumptions, homoskedasticity, and linearity. Multiple regression models
68 included as covariates demographic variables (age at death and gender), as well as type of
69 malignancy to adjust for possible confounding variables. Race was not included due to a
70 large number of missing data points. The number of patients with palliative involvement at a
71 given timepoint was determined by the duration of palliative involvement. For example, if a
72 patient has palliative involvement for 35 days prior to death, that patient's data was included
73 in the analysis as having palliative involvement for the last 1 month of life and as not having
74 palliative involvement for the last 3 months. The duration of hospice involvement was
75 unclear so all patients with any hospice involvement were included as having hospice
76 involvement for both time points. A p value less than 0.05 was considered statistically
77 significant. P values were adjusted for multiple comparisons using the Bonferroni correction
78 separately for each group of models, hospice and palliative involvement. The analysis was
79 performed using R version 4.0.5. Data is available upon request.

80

81 Results:

82 One hundred eighteen patients were identified by the chart review (Table 1). The
83 patients averaged 13.5 (SD 6.8) years old at time of death, and the sample was 50% female.
84 Participants were predominantly identified as Caucasian in the chart review (88%) with 22 of
85 the 118 participants missing data for race. Forty-nine patients (42%) had solid tumors, 38
86 (32%) had leukemia, and 31 (26%) had brain tumors. Palliative care was involved for the
87 majority of the patients (n=94; 80%). Hospice was involved for 80 patients (68%). The
88 majority of patients died at home (n=73; 62%). The median duration of palliative care
89 involvement was 1.4 months (range = 1 day-18.6 months) prior to death. (Table 1). The
90 majority of patients who were enrolled in hospice also had palliative care involvement
91 (68/80, 85%).

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

99 Hospice involvement did have a significant association with reduced intensity of care
100 in the last three months of life in both unadjusted and adjusted analyses. Adjusting for
101 demographic and clinical variables, patients with hospice involvement had significantly
102 fewer hospital days in the last one and three months of life (adjusted $p < .001$) and ICU days

103 in the last one (adjusted $p < 0.001$) and three months (adjusted $p = 0.007$) of life. Patients with
104 hospice involvement had fewer ED visits in the last one month of life (adjusted $p = 0.008$)
105 (Table 3). The number of patients who received chemotherapy within the last four weeks of
106 life was not significantly decreased by hospice involvement (Table 3).

107

108 Discussion:

109 There is increasing evidence to support of integration of pediatric palliative care
110 services when caring for children with a malignancy. Decreased suffering experienced by
111 children with cancer at the end of life, as described by parents, has been reported in the past
112 three decades and is attributed to the delivery of care that incorporates optimal palliative
113 care.² The integration of pediatric palliative care services is also supported by Friedrichsdorf
114 and colleagues, who described children who received pediatric palliative care services as
115 more likely to have fun and experience added meaning to life, contributing to improved
116 quality of life.¹⁵ When evaluating end-of-life communication in a survey of bereaved parents
117 of a child who died of a malignancy, Kassam and colleagues described significantly increased
118 likelihood of discussions about death and dying, guidance on how to talk to children about
119 death and dying, and preparation for medical aspects surrounding death when referred to
120 palliative care services.¹⁶ An evaluation of bone marrow transplant recipients who did not
121 survive also described increased frequency of prognosis and resuscitation status discussions
122 in cases where palliative care was included.¹⁷

123 It is, therefore, critical that institutions evaluate their own practices and availability of
124 pediatric palliative care services to enhance the experience of children with cancer and their

125 families. We must address barriers and seek solutions to overcome them. Fear that the
126 involvement of palliative care alarms families or indicates that caregivers are “giving up” is
127 often cited as a barrier to beneficial integration of this specialty service.⁷⁻¹¹ The data from our
128 institution found a decrease in hospital days in the last one month of life with palliative care
129 involvement, but not a significant difference in ED visits, ICU days or chemotherapy
130 administration in the last four weeks of life. These data suggest that palliative care may lead
131 to more days at home but does not decrease ED visits or ICU days, suggesting that access to
132 care is not limited. This finding may be due to the long standing and strong relationship
133 between the palliative care and oncology teams. The comfort and familiarity between the
134 teams may lead to palliative care involvement prior to and independent of decisions relating
135 to the intensity of care.

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

144 Perhaps further contributing to the penetration of palliative care and hospice services
145 in the oncology and blood and marrow transplant population is the dual role of two pediatric
146 palliative care physicians with the local pediatric hospice program and the close relationship
147 of the palliative care and hospice teams. This awareness of available resources and

148 familiarity in such discussions affords continuity in services when families elect to enroll in
149 hospice services.

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

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

160 There was a significant difference in the location of death when palliative care was
161 involved, with more patients dying at home. The patient's preferred location of death was a
162 variable in the medical record review, but so few charts had that information available that it
163 was not included in analysis. However, previous research suggests that the majority of
164 families who were able to plan a location of death preferred a home death.^{15,20,21} Parents and
165 siblings of children who died at home also had better bereavement outcomes.²⁰ Despite the
166 clear benefits of palliative care for symptom control and psychosocial support, barriers
167 remain to engaging eligible patients and families.^{2,7,11} This data demonstrates that the number
168 of ED visits and ICU days did not vary with palliative care involvement. This finding may
169 help to overcome concerns with engaging palliative care as some patients received high

170 intensity care at the end of life with palliative involvement. Further, Levine et al
171 demonstrated that patients and parents are not opposed to initiating palliative care
172 involvement early in treatment¹⁰ and it may now be possible to reinforce that perspective with
173 the knowledge that clinical care measures need not be diminished once palliative care is
174 initiated. For patients and families who wish to spend less time in the hospital during end-of-
175 life care, hospice involvement was able to achieve that goal.

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

183 The duration of hospice involvement was not clear in the medical records; so the
184 changes in ED visits, hospital days and ICU days may not be related to hospice involvement.
185 It may be related to families who were already interested in less time in the hospital, even
186 before hospice was involved. The number of ED visits, hospital days, and ICU days are
187 widely variable. Although no statistically significant differences were observed in the mean
188 number of days between the "palliative involvement" and "non-palliative involvement"
189 groups, the sample size may not be sufficient to detect a clinically meaningful difference for
190 all comparisons.

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

196

197 Conflict of Interest:

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

199

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203

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266 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%)

267

268 Table 2: End of life experiences based on palliative care involvement

Palliative Involvement	No	Yes	p value (unadjusted)	p value (adjusted for gender, age at death, and type of malignancy and multiple comparisons)
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	*
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)				
1 month	0.5 (0.8)	0.4 (0.7)	0.354	1.00
3 months	1.0 (1.1)	1.2 (1.8)	0.352	1.00
Hospital days in last: mean (SD)				
1 month	12.7 (12.4)	5.3 (8.9)	<0.001	0.008
3 months	26.9 (26.5)	14.2 (22.0)	0.013	0.144
ICU days in last: mean (SD)				
1 month	5.2 (8.3)	2.1 (5.5)	0.057	0.272
3 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%)		

269 *unable to adjust due to small numbers in each category

270 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	*
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)				
1 month	0.7 (0.9)	0.4 (0.6)	0.012	0.008
3 months	1.4 (1.7)	0.9 (1.1)	0.051	0.152
Hospital days in last: mean (SD)				
1 month	20.5 (11.4)	4.1 (6.9)	<0.001	<0.001
3 months	48.8 (26.6)	12.7 (17.7)	<0.001	<0.001
ICU days in last: mean (SD)				
1 month	9.2 (9.6)	1.3 (3.9)	<0.001	<0.001
3 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%)		
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271 *unable to adjust due to small numbers in each category

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Caucasian	84 (88%)
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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	
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ICU	24 (20%)
Outside hospital	1 (1%)
Unclear	4 (3%)

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278

Palliative Involvement	No	Yes	p value (unadjusted)	p value (adjusted for gender, age at death, and type of malignancy and multiple comparisons)
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>90 days before death	(n = 82)	(n = 36)		
Location of death				
Home	11 (46%)	62 (66%)	0.008	

General care	1 (4.2%)	15 (16%)		
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Outside hospital	1 (4%)	0		
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ED visits in last: mean (SD)				
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1 month	5.2 (8.3)	2.1 (5.5)	0.057	0.272
3 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%)		

279

280

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)
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General care	11 (28.9%)	5 (6.2%)		
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ICU days in last: mean (SD)				
1 month	9.2 (9.6)	1.3 (3.9)	<0.001	<0.001
3 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%)		

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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%)

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Palliative Involvement	No	Yes	p value (unadjusted)	p value (adjusted for gender, age at death, and type of malignancy and multiple comparisons)
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	*
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)				

1 month	0.5 (0.8)	0.4 (0.7)	0.354	1.00
3 months	1.0 (1.1)	1.2 (1.8)	0.352	1.00
Hospital days in last: mean (SD)				
1 month	12.7 (12.4)	5.3 (8.9)	<0.001	0.008
3 months	26.9 (26.5)	14.2 (22.0)	0.013	0.144
ICU days in last: mean (SD)				
1 month	5.2 (8.3)	2.1 (5.5)	0.057	0.272
3 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%)		

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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	*
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)				
1 month	0.7 (0.9)	0.4 (0.6)	0.012	0.008
3 months	1.4 (1.7)	0.9 (1.1)	0.051	0.152
Hospital days in last: mean (SD)				
1 month	20.5 (11.4)	4.1 (6.9)	<0.001	<0.001
3 months	48.8 (26.6)	12.7 (17.7)	<0.001	<0.001
ICU days in last: mean (SD)				
1 month	9.2 (9.6)	1.3 (3.9)	<0.001	<0.001
3 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%)		

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