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Does palliative care involvement influence location of death?

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Does pediatric palliative care involvement influence location of death?

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Describe role of Submitting/Presenting Trainee in this project (limit 150 words): I, Joy Solano, with significant mentorship from Jenni Linebarger, participated in the design of this research project, built the RedCap data collection tool, performed the first review of half of the charts (approximately 300 charts) and performed the second review of the other 300 charts. We met or emailed frequently to resolve disagreements in the data collection process. Data collection lasted just over a year and was completed in December 2018. Since then, I have met repeatedly with our statistician (Ashley Sherman) for data analysis. I conceptualized and drafted this abstract and submitted it for review/revision to Jenni Linebarger prior to submission to CMH Research Days.

Background, Objectives/Goal, Methods/Design, Results, Conclusions limited to 500 words

Background: In 2003, the Institute of Medicine called for more research focused on improving end of life care for pediatric patients. Multiple studies describe circumstances surrounding the deaths of hospitalized children; some suggest a home death is preferred by patients and their caregivers. A few studies have examined the influence of palliative care teams on end of life care in the pediatric population, but those studies have not included deaths from both inpatient and outpatient settings.

- Write a couple lines about location of death and home address/race/gender (only seen one study that looked at income level, not distance from hospital)

Objectives/Goal: We sought to describe the influence of a palliative care team on the circumstances surrounding the deaths of children over time, paying particular attention to the location of death, whether the location was discussed with the patient and/or caregiver(s) and whether home address was associated with location of death.

Methods/Design: This retrospective chart review was based on a report identifying all patients cared for at one quaternary children's hospital who died in the year 2005, 2010, or 2015. Data collection included demographic data, locations of death, whether the location of death was discussed and documented, and whether palliative care was involved. Descriptive statistics were analyzed, and chi-square and Kruskal Wallis tests were used to look for significant differences in the data.

Results: A total of 600 patients were identified. A majority of the patients were <1 year of age, male, white, English-speaking, Christian and used public insurance (Table 1). The palliative care team involvement increased significantly over time. The majority of patients from all years died in an intensive care unit (ICU), yet ICU deaths decreased significantly over time (Table 2). Discussions about location of death were documented for 38.9% of patients and increased over time. Of patients with such discussion documented, 8.1% died in the pediatric ICU (PICU) compared with 55.5% of those without a discussion ($p<0.0001$). Patients followed by the palliative care team were more likely to have documented discussions about location of death (59.8% vs 26.5%, $p<0.0001$), were less likely to die in the PICU (28.3% vs. 41.9%, $p<0.0001$) and more likely to die at home (20.3% vs. 10.5%, $p<0.0001$).

Conclusions: A discussion about location of death is significantly more likely to occur if a palliative care team is involved, and patients are more likely to die at home and less likely to die in the PICU if the location of death is discussed.

Table 1 Demographics & Select Clinical Characteristics of Population

Characteristic	Result, n (%)
Age (N=600)	
<1 month	160 (26.7)
1 month-1 year	143 (23.8)
1-4 years	94 (15.7)
5-9 years	76 (12.7)
10-14 years	49 (8.2)
15-17 years	42 (7)
>17 years	36 (6)
Sex (N=599)	
Male	350 (58.4)
Female	249 (41.6)
Race/Ethnicity (N=596)	
White/Caucasian	380 (63.8)
Black/African American	106 (17.8)
Hispanic	53 (8.9)
Other	57 (9.6)
Spoken Language (N=598)	
English	558 (93.3)
Spanish	29 (4.9)
Other	11 (1.8)
Religion (N=541)	
Christian	364 (67.3)
Other	22 (4.1)
None	155 (28.7)
Primary Insurance (N=567)	
Public	309 (54.5)
Private	203 (35.8)
Military	15 (2.7)
None/Self-Pay	40 (7.1)
Disease Category, Top 5 (N=600)	
Hematologic/Oncologic	92 (15.3)
Neonatal	73 (12.2)
Cardiac	84 (14)
Neurologic/Neuromuscular	67 (11.2)
Trauma	66 (11)
Other/unknown	218 (36.3)
Palliative Care Involved? (N=600)	
Yes	200 (33.3)
No	400 (66.7)
Location of Death (N=519)	
Pediatric ICU	192 (37)
Intensive Care Nursery	145 (27.9)
General Ward	31 (6)
Emergency Department	41 (7.9)
Off Unit*	12 (2.3)
Home	73 (14.1)
Other**	25 (4.8)
Location Discussed? (N=529)	
Yes	206 (38.9)
No	323 (61.1)

* Off unit includes the operating room or chapel.

** Other includes hospice house, other hospital, and ambulance.

Table 2 Differences in Location of Death, Location Discussions, & Palliative Care Involvement Over Time

Variable	2005, n (%)	2010, n (%)	2015, n (%)	p
Location of Death	N=152	N=180	N=187	<0.0001
Pediatric ICU	64 (42.1)	69 (38.3)	59 (31.6)	
Intensive Care Nursery	45 (29.6)	54 (30)	46 (24.6)	
General Ward	18 (11.8)	6 (3.3)	7 (3.74)	
Emergency Department	10 (6.6)	15 (8.3)	16 (8.6)	
Off Unit*	1 (0.7)	1 (0.6)	10 (5.4)	
Home	13 (8.6)	26 (14.4)	34 (18.2)	
Other**	1 (0.7)	34 (18.2)	15 (8)	
Location Discussed	N=156	N=180	N=193	<0.0001
Yes	52 (33.3)	54 (30)	100 (51.8)	
No	104 (66.6)	126 (70)	93 (48.2)	
Palliative Care Involvement	N=191	N=192	N=217	<0.0001
Yes	42 (22)	61 (31.8)	97 (44.7)	
No	149 (78)	131 (68.2)	120 (55.3)	

* Off unit includes the operating room or chapel.

** Other includes hospice house, other hospital, and ambulance.