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DISPARITIES IN END-OF-LIFE CARE IN CHILDREN DYING OF CANCER IN ALABAMA: A CROSS SECTIONAL STUDY

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A THESIS

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DISPARITIES IN END-OF-LIFE CARE IN CHILDREN DYING OF CANCER IN ALABAMA: A CROSS SECTIONAL STUDY

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MASTER OF SCIENCE IN PUBLIC HEALTH

ABSTRACT

Regional studies show that children dying of cancer receive medically intense end-of-life care but there is limited information about end-of-life care in the Deep South and limited information about hospice and palliative care involvement at EOL.

We conducted a retrospective electronic medical record review of children (0-x years) that died of cancer between 2010-20199 who received cancer directed therapy at Children's of Alabama. We collected patient clinical and sociodemographics factors, including sex, race, and area deprivation index, cancer diagnosis and treatment, palliative care and hospice involvement, location of death, and medical care in the last 30d of life, including chemotherapy use, intubation, and ICU admission.

Of 233 patients, median age at death was 11.0 (IQR) and 38% belonged to a racial/ethnic minority. Forty-one percent had a non-CNS solid tumor. Forty-nine percent died in the hospital and 37% received medically intense care in the last 30d of life (intubation, ICU admission, hemodialysis, or CPR). Fifty-eight percent received a palliative care consult, which occurred >30 days before death (early) in 36%. Although palliative care involvement was associated with both more acute care (hospital and ICU) and hospice utilization (61%), children who received early palliative spent less days in the ICU (OR, 95% CI=1.2, 1.0-1.3) and had greater odds of enrolling in hospice (2.6, 1.3-5.0) than those who received late palliative care. Additionally, end-of-life care varied with race/ethnicity and diagnosis.

For children who die of cancer in Alabama, care varies significantly by palliative care involvement, diagnosis, and race. It is important to understand whether this variation due to differences in patient and family preferences or systemic factors such as variation in hospice access.

Keywords: pediatric cancer, end-of-life care, palliative care, hospice

DEDICATION

This work is dedicated to Michelle B. Davis, Dr. David Knight, Mary B. Davis, Dr. Adam M. Goodman, Amanda L. Segars, Dr. Huifeng Yun, and Dr. Emily E. Johnston.

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LIST OF ABBREVIATIONS

AND	allow natural death
AOR	adjusted odds ratio
ARR	adjusted relative risk
CNS	central nervous system
CPR	cardiopulmonary resuscitation
DNI	do not intubate
DNR	do not resuscitate
DOD	date of death
ED	emergency department
EOL	end-of-life
ICU	intensive care unit

INTRODUCTION

Nearly 2,000 US children die from cancer each year (1), yet there remain many unknowns regarding medical intensity of end-of-life (EOL) care, palliative care use, and hospice enrollment at EOL – particularly in minority populations. Adults dying from cancer do not want to die in the hospital or receive medically intense care [mechanical ventilation/intubation, intensive care unit (ICU) admission, and cardiopulmonary resuscitation (CPR)] at EOL. (2–5) Additionally, such medically intense EOL care in adults is associated with poor patient quality of life and worse bereaved caregiver outcomes. (2,6,7) Instead, high quality EOL care for adults with cancer includes early palliative care involvement and hospice enrollment. (7–10) Hence, the National Quality Forum has endorsed measures related to avoidance of medically intense interventions at EOL life care and hospice involvement at EOL as measures of high-quality end-of-life care for adults with cancer. (11)

There is a growing body of evidence that children dying from cancer and their families also do not want medically intense care at the EOL (2,12,13) and prefer home death. (12–14) However, 40-65% of children dying of cancer receive at least some medically intense end-of-life care and 43-63% die in the hospital. (15,16) This discrepancy between child and family wishes and reality raises concerns about whether children with cancer and their families are receiving goal concordant EOL care.

There are significant disparities in EOL care in pediatric oncology. Notably, children with hematologic malignancies are more likely to receive medically intense EOL care and die in the hospital than those with solid tumors (15,16) and minority children are more likely to die in the hospital. (15) Further, prior studies in EOL care in children dying with cancer and other complex chronic conditions have found that EOL also varies with type of insurance, (15) income, (16,17) and distance from home to the hospital. (15–17) However, patterns of EOL care of children dying of cancer in the Deep South are unknown, which is a critical gap as there are known disparities in end-of-life care for African Americans adults. (18–21) Additionally, few studies have examined palliative care and hospice utilization at end-of-life for children with cancer. Thus, the present study sought to determine rates and disparities in medical intensity of EOL care, palliative care, and hospice use in children dying of cancer in Alabama and how palliative care influences end-of-life practices.

METHODS

Study Design and Population

We conducted a retrospective cross-sectional study via electronic medical record review. We examined EOL care in children with cancer (0-19 years of age at diagnosis) that died 2010 to 2019 while receiving care at Children's of Alabama in Birmingham, AL. Children without end-of-life information were excluded. This study was considered non-human subjects research by the UAB IRB.

Independent Variables

Clinical variables included: date of birth, sex, primary cancer diagnosis, date of primary diagnosis, relapse information, treatment information (including Phase 1 clinical trial enrollment), and date of death (DOD). Additionally, we calculated age at death and time between primary cancer diagnosis and DOD. Sociodemographic variables included race/ethnicity, insurance at the time of death, area deprivation index, and distance to Children's of Alabama from patient's primary residence. Distance to the hospital and area deprivation index were calculated based on residence at time of death. If address at time of death was unknown, the last known address was used. Driving distance between Children's of Alabama and residence at time of death was calculated using address latitude and longitude (from SAS Proc Geocode). (22) The area deprivation index is a measure that uses American Community Survey data to rank US census-based regions by disadvantage at both the state and national level. (23–25) It consists of 17 variables including median family income, percent of families below the poverty level, and percent of population below 150% of the poverty threshold. Higher scores represent greater area deprivation (poorer areas) and range from 0 to 100. (24) The national-level area deprivation index was used for this study as patients were from multiple sites.

Dependent Variables

Dependent variables included 1) medically intense EOL care, 2) supportive EOL care, 3) circumstances at time of death, and 4), and location of death.

Intense EOL indicators included receiving mechanical ventilation/intubation, CPR, hemodialysis, tracheostomy or gastronomy tube placement, cancer directed therapy, emergency department (ED) visits, or ICU admission during the last 30 days of life, and hospital death. (15–17,26) We calculated individual rates of intense care and composite measures including: 1) any medically intense intervention (mechanical ventilation/intubation, CPR, renal dialysis, or ICU admission) (15,26), 2) cancer directed-therapy (chemotherapy and/or radiation), and 3) ED visits. Number of days admitted and number of days admitted to the ICU in the last 30d of life were also calculated. Further, we created a composite measure of high utilization in the last 30d based on median length of stays that included any of the following: 1) >15 days of hospital admission, 2) >5 days of ICU admission, 3) any ED visit.

Supportive care measures included 1) palliative care involvement, 2) early palliative care involvement (>30 days before death), 3) days between initial palliative care encounter and DOD, 4) hospice enrollment, 5) early hospice enrollment (>5 days before death) and 6) days enrolled in hospice. Thirty days was selected for early palliative care as palliative care consult before 30 days of death has been shown to change end-of-life trajectories. Five days was selected for early hospice enrollment as a recent expert panel endorsed hospice enrollment for more than 5 days as a marker of high-quality end-of-life care for children with cancer. (27)

Circumstances at the time of death included 1) final resuscitation status, 2) number of days between AND/DNR/DNI and DOD, 3) whether the patient died: during CPR, after withdrawal of life-sustaining interventions, while receiving mechanical ventilation, or while receiving comfort care, 4) location of death.

Statistical Analyses

We calculated descriptive statistics for each independent and dependent variable. We used chi-square (for categorical variables) and Wilcoxon rank sum tests (for continuous variables) to examine sociodemographic, clinical, and EOL measure differences between children that received palliative care vs those that did not. Multiple multivariable regressions were conducted to determine sociodemographic and clinical factors associated with medically intense care: (1) any medically intense care, (2) hospital death, 3) number of admission days in the last 30d of life, and 4) number of days spent in the ICU in the last 30d of life; and supportive EOL care including: 1) palliative care involvement, 2) early palliative care involvement (>30days before death), 3) number of days between initial palliative care consult and DOD, 4) hospice enrollment, 5) early hospice enrollment (>5days before death), and 6) number of days of hospice enrollment. Logistic regressions were used for binary outcomes and Poisson regressions were used for count variables.

We used chi-square analyses and Wilcoxon rank sum tests to examine demographic differences between those included and excluded (due to lack of end-of-life data).

All statistical analyses were conducted using SAS 9.4 (SAS Institute, Inc., Cary, NC).

RESULTS

Study Design and Population

Of the 238 children who met inclusion criteria, median age at death was 11.0 (Q1-Q3=5-16) (Table 1). A majority of patients were male (53%) and non-Hispanic white (62%). Primary cancer diagnoses consisted of non-central nervous system (CNS) solid tumors (41%), CNS tumors (39%), and hematologic malignancies (21%). Additionally, 55% of patients were publicly insured and 48% had private insurance. Thirty one percent of children had area deprivation above the median, reflecting greater neighborhood disadvantage. Finally, 45% of children lived within 65 miles of Children of Alabama. Only age at death was associated with palliative care involvement such that a larger proportion of children that died between 0-5 did not receive palliative care (p=0.05).

We compared demographic differences between children included and those excluded due to lack of EOL information. There were no significant differences in sex (p=0.10), race (p=0.75), primary cancer diagnosis (p=0.51), non-Medicaid insurance (p=0.65), area deprivation index (p=0.59), or distance from address at time of death to Children's of Alabama (p=0.27). However, there were significant differences in years from primary cancer diagnosis to death (p<0.0001), age at death (p<0.001), year of death (p<0.01), Medicaid insurance (p=0.03), and unknown insurance (p<0.0001).

Table 1. Patient demographics

	Total Population (n=233)	**Palliative Care (n=135)**	**No Palliative Care (n=98)**	**p-value**
Age at Death (Years)				
0-5	66 (28.3)	29 (21.5)	37 (37.8)	**0.05**
6-11	54 (23.2)	32 (23.7)	22 (22.5)	
12-16	63 (27.0)	41 (30.4)	22 (22.5)	
≥17	50 (21.5)	33 (24.4)	17 (17.4)	
Year of Death				0.12
2010-2014	112 (48.1)	59 (43.7)	53 (54.1)	
2015-2019	119 (51.9)	76 (56.3)	45 (45.9)	
Sex				0.20
Male	123 (53.3)	67 (49.6)	57 (58.2)	
Race				
Non-Hispanic White	145 (62.2)	78 (57.8)	67 (68.4)	0.13
Black	81 (34.8)	51 (37.8)	30 (30.6)	
Other	7 (3.0)	6 (4.4)	1 (1.0)	
Diagnosis				0.23
Leukemia/Lymphoma	48 (20.6)	29 (21.5)	19 (19.4)	
CNS Tumors	90 (38.6)	46 (34.1)	44 (44.9)	
Non-CNS Solid Tumors	95 (40.8)	60 (44.4)	35 (35.7)	
Years from Primary Diagnosis to DOD Median (IQR)	1.0 (2.0)	1.0 (0.0-3.0)	1.0 (0.0-2.0)	0.80
Relapse				
Yes	102 (43.8)	58 (43.0)	44 (44.9)	0.77
Phase 1 Study Enrollment				
Yes	47 (21.0)	29 (22.3)	18 (19.2)	0.57

Insurance				
Medicaid/CHIP	128 (54.9)	80 (59.3)	48 (49.0)	0.12
Non-Medicaid/CHIP	113 (48.5)	63 (46.7)	50 (51.0)	0.51
Other/Unknown	2 (0.9)	1 (0.7)	1 (1.0)	0.82
Area Deprivation Index				
Low (0-67)	82 (35.2)	49 (36.3)	33 (33.7)	0.82
High (68-100)	71 (30.5)	39 (28.9)	32 (32.7)	
Unknown	80 (34.3)	47 (34.8)	33 (33.7)	
Distance from Home to COA (miles)	105 (45.1)	61 (45.2)	44 (44.9)	1.00
Low (0-65)	102 (43.8)	59 (43.7)	43 (43.9)	
High (>65)	26 (11.2)	15 (11.1)	11 (11.2)	
Unknown				

Medically Intense End-of-Life Care

Medically Intense Care

Thirty seven percent of children received some medically intense intervention in the last 30d of life (Table 2). The most common intense interventions were ICU admission (36%) and mechanical ventilation/intubation (26%). Medically intense care did not vary with palliative care in either Chi-squared (Table 2) or multivariable analysis (Table 3).

Several sociodemographic and clinical factors were associated with medically intense EOL care (Table 3). Specifically, minority children (AOR, 95% CI: 2.2, 1.1-4.2, ref: non-Hispanic white), children with hematologic malignancies (AOR, 95% CI: 4.0, 1.7-9.6, ref: non-CNS solid tumors), and children that did not enroll in a phase 1 study (AOR, 95% CI: 2.6, 1.3-7.6, ref: children that did enroll in a phase 1 study) had greater odds of receiving medically intense care in the last 30d of life than their peers.

Table 2. Rates of various end-of-life care measures

	Total Population (n=233)	**Palliative Care**	**No Palliative Care**	**p-value**

		(n=135)	**(n=98)**	
Intense Interventions in Last 30 Days of Life				
ICU Admission	81 (34.8)	53 (39.3)	28 (28.6)	0.09
Mechanical Ventilation/Intubation	59 (25.3)	36 (26.7)	23 (23.5)	0.58
Hemodialysis	16 (6.9)	9 (6.7)	7 (7.1)	0.89
CPR	21 (9.0)	9 (6.7)	12 (12.2)	0.14
Any Medically Intense Care	87 (37.3)	56 (41.5)	31 (31.6)	0.13
Healthcare Utilization in Last 30 Days of Life				
Admission	168 (72.1)	113 (83.7)	55 (56.1)	**<0.0001**
# Admission Days				**<0.0001**
Median (Q1-Q3)	7 (1.0-27.0)	13.0 (3.0-30.0)	2 (1.0-11.0)	
ICU Admission	81 (34.8)	53 (39.3)	28 (28.6)	0.09
# Days in ICU				
Median (Q1-Q3)	1.0 (1.0-2.0)	1.0 (1.0-3.0)	1.0 (1.0-1.0)	0.13
ED Visit	70 (30.0)	45 (33.3)	25 (25.5)	0.20
High Utilization	143 (61.4)	97 (71.9)	46 (46.9)	**0.0001**
Cancer-Directed Therapy in the Last 30 Days of Life				
Any Cancer Directed Therapy	94 (40.3)	58 (43.0)	36 (36.7)	0.34
Chemotherapy	89 (38.2)	53 (39.3)	36 (36.7)	0.70
Radiation	18 (7.8)	14 (10.4)	4 (4.1)	0.08
Supportive Care Services				
Palliative Care	135 (57.9)	-	-	-
Early Palliative Care Involvement (>30 days before death)	83 (35.6)	-	-	-
# Days from First Palliative Care Encounter to Death Median (Q1-Q3)	50 (141.0)	-	-	-
Hospice Enrollment	96 (41.2)	65 (48.2)	31 (31.6)	**0.01**
Early Hospice Enrollment (>5 days before death)	75 (32.2)	52 (38.5)	23 (23.5)	**0.02**
# Days from Hospice Enrollment to Death Median (Q1-Q3)	25 (7.0-44.0)	25.0 (7.0-42.0)	24 (10.0-45.0)	0.74

Hospital Death

Forty nine percent of children died in the hospital with 28% dying on the hospital floor and 22% dying in the ICU (Table 2). Bivariate analyses revealed that hospital death varied with palliative care involvement (p<0.001). Children who received palliative care were more likely to die in the hospital than those who did not receive palliative care in bivariate analysis (57% versus 40%, p<0.001) (Table 2). However, that was largely driven by more floor deaths in the palliative care population. That association held true in multivariable logistic with children who received palliative care being less likely to die in the hospital (AOR, 95% CI=0.5, 0.3-0.9).

Other factors associated with hospital death year of death, diagnosis and phase 1 clinical trial enrollment (Table 3). Specifically, children that died in 2010-2014 (AOR, 95% CI=2.2, 1.2-4.1, ref: 2015-2019), patients with hematologic malignancies (AOR, 95% CI=3.9, 1.6-9.6, ref: non-CNS solid tumors), and children that did not enroll in a phase 1 study (AOR, 95% CI=2.7, 1.2-5.7, ref: children enrolled in a phase 1 study) (Table 4) had greater odds of dying in the hospital than their peers.

Hospital Admission

Seventy-two percent of children had at least one hospital admission and those admitted spent a median of 7 (Q1-Q3=1.0-27.0) days in the hospital in the last 30d of life (Table 2). Chi-square analysis revealed that hospital admission was associated with palliative care such that a larger proportion of children that received palliative care were admitted to the hospital in the last 30d of life ($p<0.001$). Additionally, a Wilcoxon rank sum test revealed that the number of days of admission varied with palliative care involvement ($p<0.0001$). Specifically, children that received palliative care spent a greater number of days in the hospital (median, Q1-Q3=13.0, 3.0-30.0) than children that did not receive palliative care (ARR, 95% CI=2.0, 1.0-11.0).

Multivariable Poisson regression revealed that the number of days spent in the hospital also varied with age at death, sex, race, diagnosis, relapse, phase 1 study enrollment, insurance, area deprivation index, and distance to Children's of Alabama (Table 4). Specifically, children aged 0-5 years at time of death (ARR, 95% CI=1.3, 1.0-

1.3, ref: 17+ years), females (ARR, 95% CI=1.5, 1.4-1.6, ref: male), minorities (ARR, 95% CI=1.2, 1.1-1.3, ref: non-Hispanic white), children with CNS tumors (ARR, 95% CI=1.4, 1.2-1.5), children with hematologic malignancies (ARR, 95% CI=2.3, 2.1-2.6, ref: non-CNS solid tumors), children had not relapsed (ARR, 95% CI=1.2, 1.1-1.3, ref: children that relapsed), children that did not enroll in a phase 1 study (2.0, 1.7-2.3, ref: children that did enroll in a phase 1 study), and children with low area deprivation (reflecting less neighborhood disadvantage) (ARR, 95% CI=1.3, 1.1-1.6, ref: high area deprivation) spent more days in the hospital in the last 30d of life. Conversely, children that did not receive palliative care (ARR, 95% CI=0.7, 0.7-0.8, ref: children that did receive palliative care), children with non-Medicaid insurance (ARR, 95% CI=0.9, 0.8-0.9), and children that lived closer to Children's of Alabama (ARR, 95% CI=0.9, 0.8-1.0) spent fewer days in the hospital.

ICU Admission

Thirty six percent of children were admitted to the ICU and spent a median of 1.0 (Q1-Q3=1.0-2.0) days in the ICU in the last 30d of life (Table 2). Bivariate analyses revealed no significant differences in ICU admission or number of days spent in the ICU between children that received palliative care compared to children that did not receive palliative care. However, multivariable analyses revealed that children who received palliative care were at less risk for spending more days in the ICU (ARR, 95% CI=0.9, 0.8-1.0) (Table 4).

Other clinical and sociodemographic factors associated with the number of days spent in the ICU, included age at death, race, diagnosis, relapse, phase 1 study enrollment, insurance, area deprivation index, and distance from home to Children's of Alabama (Table 4). Specifically, children between 12-16 (ARR, 95% CI=0.6, 0.5-0.8, ref: 17+ years) at time of death, children insured by Medicaid (ARR, 95% CI=0.6, 0.5-0.7, ref: children not insured by Medicaid), and children that lived closer to Children's of Alabama (0.7, 0.6-0.8, ref:>65 miles) were less likely to spend more days in the ICU in the last 30d of life. Additionally, children that died between 2010-2014 (ARR, 95% CI=1.3, 1.2-1.5, ref: 2015-2019), female children (ARR, 95% CI=1.2, 1.0-1.4, ref: male) minority children (ARR, 95% CI=1.4, 1.2-1.6, ref: non-Hispanic white), children with CNS tumors (ARR, 95% CI=1.5, 1.2-1.7, ref: non-CNS solid tumors), children with hematologic malignancies (ARR, 95% CI=3.7, 3.1-4.4, ref: non-CNS solid tumors), children that relapsed (ARR, 95% CI=1.7, 1.5-2.0, ref: children that did not relapse), children that enrolled in a phase 1 study (ARR, 95% CI=1.7, 1.4-2.2, ref: children that did not enroll in a phase 1 study), and children with low area deprivation (ARR, 95% CI=1.3,1.0-1.5, ref: low (0-67) were at greater risk for spending more days in the ICU.

Table 3. Factors associated with intense end-of-life care

Category (Reference)	**Medically Intense Care**	**Hospital Death**	**# Days of Admission in Last 30 Days of Life**	**# Days in ICU in Last 30 Days of Life**
	AOR (95% CI)	AOR (95% CI)	ARR (95% CI)	ARR (95% CI)
Age at Death (17+ years)				
0-5 years	1.8 (0.7-5.1)	1.1 (0.5-2.5)	**1.3 (1.1-1.4)**	0.9 (0.7-1.1)
6-11 years	1.8 (0.7-4.8)	1.2 (0.5-2.7)	1.1 (1.0-1.3)	1.1 (0.9-1.4)
12-16 years	2.1 (0.8-5.5)	1.2 (0.5-3.1)	0.9 (0.8-1.0)	**0.6 (0.5-0.8)**
Year of Death (2015-2019)				
2010-2014	1.1 (0.6-2.0)	**2.2 (1.2-4.1)**	1.0 (1.0-1.1)	**1.3 (1.2-1.5)**
Sex (Male)				
Female	1.0 (0.6-1.9)	1.3 (0.7-2.4)	**1.5 (1.4-1.6)**	**1.2 (1.0-1.4)**
Race (White)				
Minority	**2.2 (1.1-4.2)**	1.2 (0.6-2.2)	**1.2 (1.1-1.3)**	**1.4 (1.2-1.6)**
Diagnosis (Non-CNS Solid Tumors)	0.9 (0.5-1.8)	1.1 (0.6-2.2)	**1.4 (1.2-1.5)**	**1.5 (1.2-1.7)**

CNS Tumors	**4.0 (1.7-9.6)**	**3.9 (1.6-9.6)**	**2.3 (2.1-2.6)**	**3.7 (3.1-4.4)**
Hematologic Malignancies				
Years from Primary Diagnosis to DOD	1.1 (1.0-1.3)	1.0 (0.9-1.2)	1.0 (1.0-1.0)	**1.1 (1.1-1.1)**
Relapse (Yes)				
No	1.9 (0.9-4.0)	1.7 (0.9-3.3)	**1.2 (1.1-1.3)**	**1.7 (1.5-2.0)**
Palliative Care (No)				
Yes	0.7 (0.3-1.2)	**0.5 (0.3-0.9)**	**0.6 (0.5-0.6)**	**0.9 (0.8-1.0)**
Phase 1 Study Enrollment (Yes)				
No	**2.6 (1.1-6.1)**	**2.7 (1.2-5.7)**	**1.9 (1.6-2.1)**	**1.7 (1.4-2.2)**
Insurance (Medicaid/CHIP)				
Non-Medicaid/CHIP	0.8 (0.4-1.6)	0.6 (0.3-1.1)	**0.9 (0.8-1.0)**	**0.6 (0.5-0.7)**
Area Deprivation Index [High (68-100)]	2.1 (1.0-4.7)	1.6 (0.7-3.3)	**1.4 (1.2-1.5)**	**1.3 (1.0-1.5)**
Low (0-67)	1.6 (0.7-3.5)	1.4 (0.6-2.9)	**1.2 (1.1-1.3)**	1.1 (0.9-1.3)
Unknown				
Distance from Home to COA [High (>65 miles)]	1.0 (0.5-2.0)	1.8 (0.9-3.5)	**0.9 (0.8-1.0)**	**0.7 (0.6-0.8)**
Low (0-65 miles)	1.5 (0.6-4.3)	1.0 (0.4-2.8)	**1.2 (1.0-1.3)**	0.8 (0.7-1.1)
Unknown				

Supportive Care at the End-of-Life

Palliative Care

Fifty-eight percent of children had a palliative care consult and 36% of those children first saw palliative care >30 days before death (Table 2).

Age at death was associated with palliative care involvement such that children 0-5 years at time of death were less likely (AOR, 95% CI=0.3, 0.1-0.8) to receive palliative care than children 17+ years of age at time of death (Table 3).

Additionally, age at death, year of death, and diagnosis were associated with early palliative care involvement (Table 4). Specifically, children between 0-5 years at time of death (AOR, 95% CI=0.3, 0.1-0.8, ref: 17+ years) and children that died between 2010-2014 (AOR, 95% CI=0.4, 0.2-0.8, ref: 2015-2019) were less likely to have early palliative care involvement for more than 30 days. Alternatively, children with CNS tumors were more likely (AOR, 95% CI=2.8, 1.4-5.6) to have early palliative care involvement compared to children with non-CNS solid tumors.

Multivariable Poisson regression demonstrated that the number of days between initial palliative care consult and DOD was associated age at death, years of death, sex, race, diagnosis, years from primary diagnosis to DOD, relapse, phase 1 study enrollment, area deprivation, and distance from home to Children's of Alabama (Table 5). Specifically, children 6-11 (ARR, 95% CI=1.8, 1.8-1.9) and 12-16 (ARR, 95% CI=1.1, 1.0-1.1) years at time of death were more likely to have more days from initial palliative care consult to DOD than children 17+ years at time of death. Additionally, children that died between 2010-2014 (ARR, 95% CI=0.4, 0.3-0.4, ref: 2015-2019), minority children (ARR, 95% CI=0.7, 0.7-0.7, ref: non-Hispanic white), children with hematologic malignancies (ARR, 95% CI=0.5, 0.5-0.6, ref: non-CNS solid tumors), children with low area deprivation (ARR, 95% CI=0.7, 0.6-0.7, ref: high area deprivation), and children that lived closer to Children's of Alabama (ARR, 95% CI=0.5, 0.5-0.6, ref: >65 miles) had shorter periods of palliative care involvement. Additionally, each subsequent year after diagnosis to DOD was associated with a greater number of days (ARR, 95% CI=1.1, 1.1-1.1) between initial palliative care visit and DOD (Table 5). Finally, children with CNS tumors (ARR, 95% CI=1.2, 1.2-1.3, ref: non-CNS solid tumors) children that did not enroll in a phase 1 study (ARR, 95% CI=1.2, 1.2-1.3, ref: children that did enroll in a phase 1 study) were more likely to have more days between initial palliative care note and DOD (Table 4).

Hospice

Forty one percent of children dying of cancer enrolled in hospice care, and 32% of those children were enrolled for >5days (Table 2). Additionally, 9% enrolled in hospice but ultimately returned to the hospital to die (Table 5). A larger proportion of children that enrolled in hospice also received palliative care (48% enrolled vs 32% than did not receive palliative care) (p=0.01). However, children that did not receive palliative care had lower odds of enrolling in hospice (AOR, 95% CI=0.4, 0.2-0.7) and were at greater risk for spending fewer days on hospice (ARR, 95% CI=0.4, 0.2-0.8). Further, a larger number of children that received palliative care enrolled in hospice more than 5 days before death (39% enrolled in hospice early vs 23% that did not receive palliative care) (p=0.02).

Additional sociodemographic and clinical factors associated with hospice enrollment that include diagnosis, phase 1 study enrollment, and area deprivation index (Table 4). Specifically, children with hematologic malignancies (AOR, 95% CI=0.2, 0.1-0.5, ref: non-CNS solid tumors), children that did not enroll in a phase 1 study (AOR, 95% CI=0.4, 0.2-0.8, ref: children that did enroll in a phase 1 study), and children with low area deprivation scores (AOR, 95% CI=0.3, 0.1-0.7, ref: high) had decreased odds of enrolling in hospice.

Multivariable logistic regression revealed clinical and sociodemographic factors associated with early hospice enrollment (Table 4). Specifically, children with hematologic malignancies (AOR, 95% CI=0.2, 0.1-0.7, ref: non-CNS solid tumors), , and children that did not enroll in a phase 1 study (AOR, 95% CI=0.4, 0.2-0.8, ref: children that did enroll in a phase 1 study) had decreased odds of enrolling in hospice more than 5d before death.

Factors associated with length of time on hospice include age at death, year of death, race, diagnosis, years from primary diagnosis to DOD, relapse, phase 1 study enrollment, insurance, area deprivation, and distance to Children’s of Alabama (Table 4).

Specifically, children aged 0-5 had shorter hospice enrollments than children 17+ at time of death (ARR, 95% CI=0.7, 0.6-0.8), while children between 6-11 years at time of death had longer hospice enrollments than those 17+ (ARR, 95% CI=1.7, 1.5-1.8). Further, children that died between 2010-2014 (ARR, 95% CI=1.1, 1.0-1.2), minority children (ARR, 95% CI=1.6, 1.5-1.8), children that did not enroll in a phase 1 study (ARR, 95% CI=1.8, 1.6-1.9), children insured by Medicaid (ARR, 95% CI=1.5, 1.4-1.7, ref: non-Medicaid insurance) and children with low area deprivation (ARR, 95% CI=1.5, 1.3-1.6) were more likely to spend more days on hospice (Table 4). Finally, children with CNS tumors (ARR, 95% CI=0.5, 0.4-0.5, ref: non-CNS tumors), children with hematologic malignancies (ARR, 95% CI=0.2 (0.2-0.3, ref: non-CNS solid tumors) and children that lived closer to Children's of Alabama (ARR, 95% CI=0.7, 0.7-0.8, ref: >65 miles) had shorter hospice enrollments than their peers.

Table 4. Factors associated with supportive end-of-life care

Category (Reference)	**Palliative Care Involvement**	**Early Palliative Care Involvement**	**# Days from Initial Palliative Care Visit to DOD**	**Hospice Enrollment**	**Early Hospice Enrollment**	**# Days Hospice Enrollment**
	AOR (95% CI)	AOR (95% CI)	ARR (95% CI)	AOR (95% CI)	AOR (95% CI)	ARR (95% CI)
Age at Death (17+ years)						
0-5 years	**0.3 (0.1-0.8)**	**0.3 (0.1-0.8)**	1.0 (0.9-1.0)	1.2 (0.4-3.2)	0.9 (0.3-2.5)	**0.7 (0.6-0.8)**
6-11 years	0.6 (0.2-1.5)	0.6 (0.2-1.4)	**1.8 (1.8-1.9)**	2.5 (0.9-6.3)	2.0 (0.8-5.1)	**1.7 (1.5-1.8)**
12-16 years	0.8 (0.3-1.9)	0.8 (0.4-2.0)	**1.1 (1.0-1.1)**	1.4 (0.6-3.7)	1.3 (0.5-3.3)	1.0 (0.9-1.2)
Year of Death (2015-2019)						
2010-2014	0.6 (0.3-1.1)	**0.4 (0.2-0.8)**	**0.4 (0.3-0.4)**	0.6 (0.3-1.2)	0.8 (0.4-1.5)	**1.1 (1.0-1.2)**
Sex (Male)						
Female	1.5 (0.8-2.7)	1.1 (0.6-2.0)	**1.0 (1.0-1.1)**	0.9 (0.5-1.7)	1.1 (0.6-2.0)	1.0 (0.9-1.1)
Race (White)						

Minority	1.5 (0.8-2.8)	0.7 (0.3-1.4)	**0.7 (0.7-0.7)**	0.7 (0.4-1.4)	1.1 (0.6-2.2)	**1.6 (1.5-1.8)**
Diagnosis (Non-CNS Solid Tumors)						
CNS Tumors	1.7 (0.9-3.1)	**2.8 (1.4-5.6)**	**1.2 (1.2-1.3)**	0.8 (0.4-1.6)	0.7 (0.4-1.4)	**0.5 (0.4-0.5)**
Hematologic Malignancies	1.6 (0.7-3.6)	1.2 (0.5-2.9)	**0.5 (0.5-0.6)**	**0.2 (0.1-0.5)**	**0.2 (0.1-0.7)**	**0.2 (0.2-0.3)**
Years from Primary Diagnosis to DOD	0.9 (0.8-1.0)	1.0 (0.9-1.1)	**1.1 (1.1-1.1)**	1.0 (0.9-1.1)	1.0 (0.8-1.1)	**1.2 (1.1-1.2)**
Relapse (Yes)						
No	1.1 (0.6-2.0)	1.1 (0.6-2.2)	1.1 (1.0-1.1)	0.9 (0.4-1.7)	0.9 (0.4-1.7)	**0.8 (0.7-0.8)**
Palliative Care (Yes)						
No	-	-	-	**0.4 (0.2-0.7)**	**0.4 (0.2-0.8)**	1.1 (1.0-1.2)
Phase 1 Study Enrollment (Yes)						
No	0.8 (0.4-1.7)	1.2 (0.6-2.7)	**1.4 (1.4-1.5)**	**0.4 (0.2-0.8)**	**0.4 (0.2-0.8)**	**1.8 (1.6-1.9)**
Insurance (Medicaid/CHIP)						
Non-Medicaid/CHIP	0.7 (0.4-1.2)	0.9 (0.5-2.7)	1.0 (0.9-1.0)	1.8 (0.9-3.4)	1.6 (0.8-3.0)	**1.5 (1.3-1.6)**
Area Deprivation Index [High (68-100)]						
Low (0-67)	1.4 (0.7-2.9)	1.3 (0.6-2.8)	**0.9 (0.9-1.0)**	**0.3 (0.1-0.7)**	0.5 (0.2-1.2)	**1.5 (1.4-1.7)**
Unknown	1.3 (0.6-2.7)	0.8 (0.3-1.7)	**0.6 (0.6-0.7)**	0.6 (0.3-1.4)	0.7 (0.3-1.7)	**0.8 (0.7-0.8)**
Distance from Home to COA [High (>65 miles)]						
Low (0-65 miles)	1.0 (0.5-2.0)	1.1 (0.5-2.2)	**0.5 (0.5-0.6)**	1.7 (0.8-3.5)	1.6 (0.8-3.3)	**0.7 (0.7-0.8)**
Unknown	1.0 (0.4-2.6)	0.6 (0.2-1.7)	**0.3 (0.3-0.3)**	0.4 (0.1-1.2)	0.8 (0.3-2.4)	**0.5 (0.4-0.6)**

Circumstances at Time of Death

Final Resuscitation Status

Sixty-eight percent of children had an allow natural death (AND), do not resuscitate (DNR), or do not intubate (DNI) order as their final resuscitation status, while 9% remained a full code (Table 5). Further, a larger proportion of individuals that received palliative care had an AND, DNR, or DNI (79%) than those that did not receive palliative care (54%). The median number of days between AND, DNR, or DNI orders was 6 days (Q1-Q3=2.0-20.0) and did not vary with palliative care.

Interventions at Time of Death

Sixty-eight percent of children died while receiving comfort care only (Table 5). However, 5% died during CPR, 14% died after the withdrawal of life sustaining interventions (e.g. mechanical ventilation, CPR), and 8% died while receiving mechanical ventilation/intubation. Bivariate analyses revealed significant difference in the proportion of children that died while receiving comfort care only such that a larger number of children that received palliative care died while receiving comfort care only (79%) compared to children that did not receive palliative care (53%) (p<0.0001).

Location of Death

Forty-nine percent of children died in the hospital, 28% of which were on the general floor and 22% in the ICU (Table 5). A greater proportion of children that received palliative care died in the hospital general floor than children that did not receive palliative care (p<0.0001). Additionally, only 35% of children died at home or on hospice. Finally, 9% of children enrolled in hospice but returned to the hospital to die.

Table 5. Circumstances at time of death

	Total Population (n=233)	**Palliative Care (n=135)**	**No Palliative Care (n=98)**	**p-value**
Final Resuscitation Status				**<0.0001**
Full Code	22 (9.4)	10 (7.4)	12 (12.2)	
AND/DNR/DNI	159 (68.2)	106 (78.5)	53 (54.1)	
Compassionate Extubation	17 (7.3)	11 (8.2)	6 (6.1)	
Unknown	35 (15.0)	8 (5.9)	27 (27.8)	

# Days Between AND/DNR/DNI and DOD Median (Q1-Q3)	6.0 (2.0-20.0)	7.0 (2.0-21.5)	3.0 (2.0-15.0)	0.23
Died during CPR	12 (5.2)	5 (3.7)	7 (7.1)	0.24
Died after Withdrawal of Life Sustaining Interventions	32 (13.9)	22 (16.3)	11 (11.2)	0.27
Died while Mechanically Ventilated/Intubated	18 (7.8)	8 (5.9)	10 (10.2)	0.23
Died while Receiving Comfort Care Only	158 (68.4)	107 (79.3)	52 (53.1)	<0.0001
Location of Death				**<0.0001**
Hospital General Floor	64 (27.5)	47 (34.8)	17 (17.4)	
Intensive Care Unit	52 (22.3)	30 (22.2)	22 (22.5)	
Home/Hospice	81 (34.8)	51 (37.8)	30 (30.6)	
Unknown	36 (15.5)	7 (5.2)	29 (30.0)	
Enrolled in Hospice but Died in Hospital	22 (9.4)	18 (13.3)	4 (4.1)	**0.02**

*AND=Allow Natural Death, DNR=Do Not Resuscitate, DNI=Do Not Intubate

DISCUSSION

This first study to examine end-of-life care for children with cancer in the Deep South revealed high rates of medically intense care and significant clinical and sociodemographic disparities in EOL. In particular, 36% of children were admitted to the ICU, 49% died in the hospital, and 42% never saw palliative care. Care varied with sociodemographic and clinical factors. For example, minority children and children with hematologic malignancies were at greater risk for spending more days admitted in the last 30d of life. Further, area deprivation was associated with hospice enrollment, number of days spent on hospice, and number of days from initial palliative care consult to DOD. We establish rates and disparities in EOL care in children with cancer in Alabama. Further studies need to be conducted to determine whether these observations represent goal concordant care or systemic factors such as hospice and palliative care access.

Palliative care involvement was associated with both more acute care use (hospital and ICU) and hospice enrollment. This apparent increase in both medically intense and supportive care services may reflect two populations of patients receiving palliative care: those with early and late palliative care. Children who had palliative care more than 30 days before death had less ICU days and more (and longer) hospice enrollment than those who had palliative care involved for less than 30 days. This is consistent with adult literature showing end-of-life conversations more than 30 days before end-of-life change end-of-life trajectories. Additionally, of children who died in the hospital, those who received palliative care were more likely to die on the general ward than patients without palliative care. As early palliative care appears to change end-of-life trajectories it is essential to examine why younger children and those with non-CNS tumors are less likely to have early palliative care involvement.

The present study found that minority patients (which were primary black) received more medically intense care and less supportive care than their non-Hispanic white peers: they spent more days in the hospital and ICU and had shorter periods with palliative care involvement. However, when they enrolled on hospice, minorities actually had longer hospice enrollment periods than their white peers. These results are consistent with prior work demonstrating that minority children are more likely to experience medically intense care (15,16,28,29), and expands on these works by demonstrating further disparities regarding the number of days spent in the hospital or ICU, number of days spent on hospice, and the number of days from initial palliative care visit to DOD. These results are consistent with prior work demonstrating that minority children are more likely to experience medically intense care (15,28,29) and expands on these works by demonstrating further disparities regarding the number of days spent in the hospital or ICU, number of days spent on hospice, and the number of days from initial palliative care visit to DOD. However, underlying reasons for these disparities need to be examined and could be due to differences in prognostic awareness, how end-of-life wishes are enacted, and palliative care involvement. For instance, a survey of parents of children with a poor cancer prognosis revealed parents belonging to an ethnic minority were less likely to understand and recognize their child's poor prognosis, and their children were more likely to experience medically intense care. (28) Additionally, minority adults with cancer are less likely to have their end-of-life wishes enacted than white patients with cancer. (30) The shorter periods of palliative care involvement found in this study raises the question of whether palliative care involvement may help mediate these factors. Thus, it is critical to examine whether minority children are experiencing goal concordant EOL care and how palliative care may impact goal concordant care for minority children with cancer and their families.

Children with hematologic malignancies were more likely to receive medically intense care and die in the hospital, spent more time in the ICU, and were less likely to enroll in hospice and had less time with palliative care than those with solid tumors, consistent with prior works in EOL care in children dying with cancer. (15,16,31) This study expands on those works by demonstrating additional diagnostic disparities in EOL care in children dying from cancer such that children with hematologic malignancies receive more intense care. (15,16) Similarly, Hoell et al., found that children with hematologic malignancies had advanced disease at the start of palliative care. (32) These results may reflect challenges regarding when to initiate EOL discussions in children dying of from hematologic malignancies. (33–35) Prior adult survey studies revealed that physicians reported EOL discussions that occurred “too late” (35) in patients with hematologic malignancies, and physicians have also reported struggling to determine when adults with hematologic malignancies are in their EOL stage. (34) Finally, lack of transfusion support in hospice may prevent some adult with hematologic malignancies from enrolling in hospice.(34) Similar reasons may hold true in pediatric EOL care, as children with hematologic malignancies also have multiple options for salvage therapy available and could benefit from transfusion support at end-of-life. (32) Taken together, these results demonstrate the need for further study of parent-physician EOL discussions for children and barriers to hospice and palliative care involvement for children with hematologic malignancies.

Children dying of cancer in Alabama receive intense care at the EOL, which appears to be more medically intense than other regions of the US and Canada. Specifically, 37% received medically intense care in the last 30d of life. These rates are higher than a California-based study (23% with ≥ 2 intensity indicators and 22% with medically intense care), demonstrating regional differences in EOL care in children with cancer in the US. (15) Further, rates of individual intensity indicators differed between this study and other previous studies. For instance, ICU admission in the present study (36%) was higher than both the California study and another previous study conducted in Ontario, which had ICU admission rates of 20 and 22% respectively. (15,16) However, hospital death rates were similar in Alabama (49%) and Ontario (43%) (16) but higher in

California (63%). (15) These results demonstrate variation in pediatric oncology end-of-life care across North America. A study of regional variation in EOL care and preferences among Medicare patients demonstrated that regional variations in end-of-life care did not correspond with regional variation in end-of-life care preferences. (36) Thus, it is important to further study whether this apparent regional variation in EOL care for children with cancer reflects regional variation in patient preferences or regional variation in hospice and palliative care access, how providers approach end-of-life conversations, or other systemic factors.

These results reveal high rates of medically intense EOL care in children with cancer in Alabama with disparities related to race, diagnosis, and area deprivation. This study highlights the high-risk groups that need to be included in studies of end-of-life preferences, the need to better understand regional variation in EOL care for children with cancer, and to determine if the patterns identified here represent goal concordant care or factors such as provider bias regarding when to initiate end-of-life conversations, disparities in how wishes are enacted, access to quality hospice, or other systemic issues. Only then can we ensure that all children dying of cancer have access to goal concordant end-of-life care potentially through triggered palliative care consults, policy change, and physician education

Although this study lays important groundwork needed to ensure all children with cancer receive goal concordant end-of-life care, it has limitations to consider. First, this study was conducted on children that received primary cancer-directed therapy at Children’s of Alabama and may not represent all children that died of cancer in Alabama. However, Children’s of Alabama cares for the vast majority of children with cancer in

Alabama so is representative of care in the state. Second, this study examines rates and disparity in end-of life care but not patient and parent preference. However, uncovering disparities allows for future studies to examine if those disparities represent goal concordant care. Finally, end-of-life data was not available for some children, specifically those that died at home or in a community hospital. However, we only excluded 8.3% of children due to lack of end-of-life information.

Conclusion

In the Deep South, children with cancer are receiving medically intense EOL care and how EOL care varies with palliative care involvement, timing of palliative care involvement, diagnosis, race, and area deprivation. Further studies need to examine whether these differences are consistent with patient and parent preference or various structural barriers to care such as lack of hospice access.

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