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Race, ethnicity, and goal-concordance of end-of-life palliative care in pediatric oncology

Running title: Goal-concordance of pediatric EOL care

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Precis: In a cohort of pediatric oncology patients receiving subspecialty palliative care, non-white children were more likely to die in the hospital than white children. These differences were goal-concordant suggesting these are race-associated differences rather than disparities in end-of-life care.

Abstract

Background: Racial and ethnic minority children with cancer disproportionately receive intensive care at the end-of-life. It is not known whether these differences are goal-concordant or disparities. We sought to explore patterns of pediatric palliative care (PPC) and health care utilization in pediatric oncology patients receiving subspecialty palliative care at the end-of-life (last 6-months) and to examine goal-concordance of location of death in a subset of these patients.

Methods: This was a retrospective cohort study of pediatric oncology patients receiving subspecialty palliative care at a single large tertiary care center who died between January 2013 and March 2017.

Results: A total of 115 patients including 71 white, non-Hispanic patients and 44 non-white patients (including 12 Black patients and 21 Hispanic patients) were included in the analytic cohort. There were no significant differences in oncologic diagnosis, cause of death, or health care utilization in the last 6 months of life. White and non-white patients had similar PPC utilization including time from initial consult to death and median number of PPC encounters. Non-white patients were significantly more likely to die in the hospital compared to white patients (68% vs. 46%, p=0.03). Analysis of a sub-cohort with documented preferences (n = 45) revealed that 91% of white patients and 93% of non-white patients died in their preferred location of death.

Conclusion: While non-white children with cancer were more likely to die in the hospital, this difference was goal-concordant in our cohort. Subspecialty PPC access may contribute to the achievement of goal-concordant end-of-life care.

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Background

Subspecialty pediatric palliative care (PPC) aims to improve quality of life and reduce symptom burden in seriously ill children through the provision of goal-concordant care. Children who are racial and ethnic minorities disproportionately receive intensive end-of-life care, including hospital or ICU-level care, active resuscitation, and in-hospital death.[1–6] It is not known whether these observed differences in pediatric patients are goal-concordant or represent disparities in care among racial and ethnic minority patients.

Race-based disparities in quality palliative care at the end-of-life are well-documented in adult patients. Specifically, adult Black patients are more likely to die in the hospital and receive intensive and life-prolonging care[7–10] that may be discordant with their expressed preferences.[11] Current quality metrics in palliative care are based on data that adults of all race/ethnicities have a strong preference for care focused on comfort at the end-of-life and death at home[12,13] and that

intensive EOL care is associated with poor quality of life and caregiver outcomes.[14,15] Consequently, in-hospital death, peri-death ICU admissions, and short or no hospice enrollment are deemed poor quality care at the end-of-life.[16,17] Given the dearth of preference data for pediatric patients, it is not clear that these quality metrics should be applied to pediatric patients. Ensuring the provision of high quality PPC at end-of-life requires understanding whether racial and ethnic differences in end-of-life care for children with cancer reflect family preferences or outcome disparities.

One critical and intervenable end-of-life outcome is ensuring that pediatric location of death is consistent with expressed patient and family preferences. Despite identified differences in pediatric location of death by race and ethnicity, data on family preferences among non-white pediatric patients are lacking.[18,19] To address this critical gap, we aimed to explore racial and ethnic differences in patterns of PPC and end-of-life care utilization over the last 6-months of life in a cohort of pediatric oncology patients receiving palliative care at a large referral center. A key secondary aim was to explore concordance between location of death and expressed family preferences.

Methods

This was a retrospective cohort study at a single large tertiary pediatric care center. This study was approved by the Dana-Farber Cancer Institute Institutional Review Board.

Study cohort

The study cohort was derived from the Dana-Farber/Boston Children Hospital (DF/BCH) Pediatric Palliative Care Database which systematically tracks all patients receiving palliative care at DF/BCH. The analytic cohort included all children with available race/ethnicity data who had a primary cancer diagnosis, received both primary oncology and PPC care at DF/BCH during the last six months of life and died between January 1, 2013 and March 15, 2017. At DF/BCH, 80% of pediatric oncology patients who die receive PPC at least 1 month prior to death. To minimize heterogeneity, foreign-national patients receiving care via embassy pay were excluded (n=7). The final analytic cohort included 115 patients.

Data collection

Demographic, disease, and care utilization data were extracted from electronic medical records into a REDCap database. Data elements were obtained via electronic data capture and manual abstraction from free text clinical note content. Primary data abstraction was completed by one study investigator (PU). Unclear data element coding was discussed with another investigator (KB) and final consensus was reached by both investigators.

Exposures

Racial and/or ethnic minority status was the primary exposure of interest due to previously described racial and ethnic disparities in palliative care. Race/ethnicity was dichotomized as white versus non-white. Exploratory analyses examining socioeconomic status were performed *post* hoc. Socioeconomic status was characterized at the neighborhood-level by linkage of a child's residential ZIP code at death with U.S. Census data from the 2012-2016 American Community Survey.[20] ZIP codes were *a priori* defined as high-poverty (≥ 20% of the population lived below 100% federal poverty level (FPL)) versus low-poverty if (<20% of the population lived below 100% FPL) based on Census definition.[21]

Covariates

Demographics

Demographic data include age at death, sex (male or female), primary language (English, Spanish, or other), religion (identified religious affiliation or none), and insurance at death (public, private, or both).

Disease and treatment variables

Disease variables included date of first cancer diagnosis, disease type (hematologic malignancy, extracranial solid tumor, brain tumor), number of relapses, number of stem cell transplants, phase I or phase II clinical trial enrollment (yes or no), and cause of death (progressive disease, treatment-related or other).

Care Utilization Variables

Hospital utilization variables in the last 6-months of life included number of days in-hospital, number of unplanned hospitalizations (defined as admissions not for chemotherapy or planned surgeries) and number of ICU admissions. PPC utilization variables in the last 6-months of life included date, location (inpatient (non-ICU), ICU, outpatient, other), and indication (advance care planning, goals of care, decision-making, psychosocial support, symptom management, logistics/coordination of care, transition to home, parental/sibling bereavement, quality of life, other) for initial PPC consult, content of initial PPC consult (advance care planning, goals of care, resuscitation status, and symptom burden), total PPC encounters, hospice enrollment (yes or no) and date if applicable, and documented MOLST form (yes or no).

EOL Care Intensity Variables

EOL variables included primary decision-maker (assumed to be parent if not documented and patient < 18 years), date of death, location of death (hospital or home/hospice), mode of death (active resuscitation, discontinuation of life-sustaining therapies (LST), or comfort-focused care), date and content of first documented resuscitation status order, resuscitation status at death (full code or limited resuscitation), medical interventions in last 7 days of life (CPR, intubation, IV inotropes).

Outcomes

The primary outcome of interest was EOL patterns of care (including timing of PPC consult, medical interventions in the last 7 days of life, location of death, and resuscitation status at death) stratified by race/ethnicity. We additionally explored goal-concordant location of death stratified by race/ethnicity for a subset cohort with available data. Children for whom documented free text preferred location of death most proximal to date of death matched actual location of death were considered to have experienced goal-concordant location of death. When disagreement was noted in preference for location of death between child and parents (n = 1), child's preference of death was recorded as preferred location of death.

Statistical Analysis

Patient demographics, disease and care utilization were summarized for the overall cohort, and by race/ethnicity using descriptive statistics including medians, interquartile ranges for

continuous measures, frequencies and proportions for categorical measures. Baseline characteristics were compared between race/ethnicity groups with the Chi-square and Wilcoxon tests for categorical and continuous variables, respectively. Due to the small sample size, we *a priori* chose to perform univariate tests of association only for the EOL patterns of care (including timing of PPC consult, medical interventions in the last 7 days of life, location of death, and resuscitation status at death) as the primary outcomes of interest using Wilcoxon rank sum test for continuous outcomes and Fisher's exact test for categorical outcomes. All analyses were performed using SAS version 9.4 (SAS Institute Inc., Cary, NC). Two-sided p-values<0.05 were considered statistically significant.

Results

Study population characteristics

A total of 115 patients were included in analysis with a median age at death of 13.5 years (interquartile range [IQR]=6-17.2) (Table 1). Over a third (38%) were non-white including 12 (10%) Black and 21 (18%) Hispanic (2 patients identified as both). Twenty-one patients (18%) lived in a high-poverty neighborhood, and 46 patients (40%) had public insurance alone. Children living in high-poverty neighborhoods or with public insurance were disproportionately non-white. Disease characteristics did not differ significantly by race/ethnicity. Progression of disease was the primary cause of death in both white (90%) and non-white patients (93%).

PPC utilization

Children had a median of 12 total PPC encounters (IQR = 5-23) prior to death (Table 2). Initial PPC consults occurred a median of 3-months (IQR=1.2-6.4) before death overall and this did not differ between white and non-white patients (2.6 vs. 3.3 months, p = 0.87) (Table 4). Initial PPC consults were more likely to occur in the outpatient setting for white patients (49% white vs. 25% non-white). The content of initial PPC encounters did not vary by race/ethnicity and included goals of care discussion for a majority of patients (90% white vs. 86% non-white), and advance care planning for a minority of patients (27% for both white and non-white patients). At the time of initial PPC consult, resuscitation status was Full Code for a majority of patients (84% white vs. 73% non-white). Patterns of care utilization were also compared across patients living in high and low-poverty neighborhoods and did not differ significantly from white vs. non-white

patient comparisons, likely reflective of the fact that most patients living in high-poverty areas in our cohort were non-white.

Care utilization in the last 6-months of life

Patients were hospitalized for a median of 22 days (IQR=9-58), including a median of 2 unplanned admissions in the last 6-months of life (Table 3). Nearly a quarter (24%) of the cohort enrolled on a Phase I or II trial (Table 1). Overall healthcare utilization was comparable by race/ethnicity.

Patterns of end-of-life care

Location of death differed significantly between white and non-white patients (Table 4). Non-white patients were significantly more likely to die in-hospital compared to white patients (68% vs. 46%; p=0.03). Differences in high-intensity EOL care as measured by utilization of CPR, intubation, or IV inotropes in last 7 days did not reach significance comparing white patients to non-white patients (30% vs 17%, p=0.11). There was no difference in resuscitation status at time of death by race/ethnicity (p=1.0).

Concordance of location of death with patient/family preferences: Sub-cohort

Forty-five (39%) patients in the analytic cohort had documented preference for location of death available for analysis, with a similar proportion of non-white (14/44, 32%) and white (31/71, 44%) patients as in the overall cohort. The sub-cohort did not differ significantly from the overall cohort in terms of key sociodemographic covariates including language, insurance status, and proportion living in high-poverty neighborhoods. Similar to the overall cohort, non-white patients in this sub-cohort remained more likely to die in the hospital than white patients (64% vs. 29%). Location of death was concordant with expressed preference in a majority of both non-white and white patients (93% vs. 91% respectively) (Figure 1). Among non-white patients, 9/9 (100%) in-hospital deaths were goal-concordant, while 4/5 (80%) home deaths were goal-concordant. Similarly, among white patients, 21/22 (95%) home deaths were goal-concordant, and 8/9 (89%) in-hospital deaths were goal-concordant. In this sub-cohort, public insurance, high poverty zip code, and non-English primary language were also associated with higher

proportions of in-hospital death (58%, 70%, and 80%, respectively); all of these in-hospital deaths were goal-concordant.

Discussion

Non-white pediatric oncology patients receiving subspecialty PPC were significantly more likely than white patients to die in-hospital (68% vs 46%, p=0.03), similar to previously published data.[1–4,6] This race/ethnicity-associated difference appears to be goal-concordant based on sub-cohort analysis of documented family preferences. Specifically, among those with documented preferences, 91% of white patients and 93% of non-white patients died in their preferred location of death. While fewer non-white patients in our cohort preferred to die at home, all of those who expressed this preference successfully achieved goal-concordant location of death. We identified no differences between white and non-white patients with regard to PPC patterns of care including frequency of PPC encounters, or content of initial PPC consultation and this finding is consistent with prior studies.[22,23] Uniform PPC access in our cohort may have contributed to the fact that there were also no differences between non-white and white patients in intensity of end-of-life care or resuscitation status in the last 7 days of life. It may have also led to goal-concordant locations of death for the patients in our sub-cohort.

These data contribute substantially to the existing data regarding family and patient preferences for location of death in children which include largely white populations. Prior studies identified death at home as preferred among adolescents[18] and parents of children with cancer.[19] However, a majority of adolescents and parents were white. Our data suggest that pediatric race-associated differences in location of death may in fact be goal-concordant and thus reflective of different preferences, not inequitable care. The implications of this for PPC research and care delivery are significant. Research to date has relied on adult metrics to interpret pediatric data, including a cohort study of pediatric oncology patients across California that reported disparities in the intensity of end-of-life care among white and non-white patients.[2] Though non-white patients were more likely to die in the hospital in this cohort, other measures of intensity did not vary significantly between white and non-white patients. Interpreted in the context of our concordance data, these results may, in fact, reflect differential preferences rather than disparities. Importantly, these data suggest that the application of adult quality metrics to children with

cancer may be inappropriate[24] and recent efforts to define high quality pediatric end-of-life care highlight the importance of death in a preferred location, rather than in the hospital.[25]

There are several reasons that non-white pediatric patients and their families may prefer to die in the hospital. First, race is a social construct,[26] and may serve as a proxy for multiple other factors (culture, religion, language, perceived trustworthiness of the healthcare system) that shape family preferences. These factors may differ between racial and ethnic groups (e.g. Black vs. Hispanic). For example, a recent study suggests that Spanish-speaking bereaved parents preferred death at home,[27] though preferences in hindsight during bereavement may differ from those prior to the death of a child. Notably, the parents in that study additionally expressed that home death was only preferable only if there were adequate resources to support their child at home. Our sample size limits our ability to analyze differences between these groups. Second, observed differences may reflect the downstream effects of structural racism leading to ongoing economic disadvantage for some racial and ethnic groups. Non-white patients in our cohort were more likely to live in high-poverty neighborhoods. Families living in high-poverty neighborhoods are more likely to be low-income and experience material hardship—for example difficulty putting food on the table, keeping the heat or electricity on or unstable housing.[29,30] They may also have less access to hospice or home services. It is possible that observed racial/ethnic differences in preferred location of death reflect resource and access needs that parents may perceive as barriers to a quality death at home. Finally, while the timing and frequency of PPC was similar between white and non-white patients, we were unable to assess the quality of communication, as well as implicit and explicit biases, in these encounters. It has previously been demonstrated that providers believe that Black and Hispanic parents are less interested in prognostic communication, though a majority of Black and Hispanic families desire detailed prognostic information.[28] Differences in communication may contribute to the finding that though the frequency of end-of-life discussions between Black and white patients is similar, Black patients have less terminal illness awareness.[11] Next steps to providing equitable, goal-concordant care at the end-of-life will involve understanding the primary drivers of these preferences. While our data suggests that public insurance, high poverty neighborhood, and non-English primary language were also associated with a preference for hospital death, focused research efforts to

explore the perspectives of non-white racial and ethnic groups are necessary to learn how these factors and their intersectionality influence parent preferences.

Our study had several limitations. Our cohort derives from a single large, tertiary care center, which may limit generalizability of these findings. The retrospective nature of this study limits a broader understanding of family and patient preferences which were abstracted from the medical record. Provider documentation may not clearly reflect all discussions relevant to the full scope of patient and family preferences. Additionally, concordance data were available only for a subset of our analytic cohort and may represent a biased sample of families particularly skilled at advocating for their preferences at EOL. Compared to location of death for the entire cohort, a smaller percentage of white patients in the concordance sub-cohort died in the hospital (46% vs. 29%) while a similar number of non-white patients died in the hospital (68% vs 64%). This said, all patients in this cohort had active PPC involvement which may mitigate this potential bias by offering patients the opportunity to discuss hopes and worries in the context of advanced illness.

Among a cohort of pediatric oncology patients receiving subspecialty PPC, race and ethnicity-associated differences in location of death were concordant with family preferences. As such, in-hospital death in our pediatric cohort appears to reflect quality—not poor—PPC care delivery. Further investigation exploring the factors that inform racial/ethnic differences in family goals for EOL care are clearly needed to ensure the provision of equitable and goal-concordant PPC.

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Figure Legend

Figure 1: Proportion of white and non-white patients with goal-concordant location of death are shown.

Table 1: Demographic and disease characteristics by race/ethnicity				
	Total (N=115) n (%)	White (N=71) n (%)	Non-white (N=44) n (%)	P-value
Median (IQR) age at death (years)	13.5 (6, 17.2)	13.6 (6.0, 17.4)	13.1 (6.6, 17.0)	0.61
Female sex	56 (49)	39 (55)	17 (39)	0.12
Primary language				<0.0001
English	97 (84)	70 (99)	27 (61)	
Spanish	10 (9)	0 (0)	10 (23)	
Other	8 (7)	1 (1)	7 (16)	
Religious Affiliation (N=96)		(N=58)	(N=38)	0.80
Yes	76 (79)	45 (78)	31 (82)	
No	20 (21)	13 (22)	7 (18)	
Insurance status at death				0.005
Public	46 (40)	20 (28)	26 (59)	
Private	31 (27)	23 (32)	8 (18)	
Mixed	38 (33)	28 (39)	10 (23)	
Diagnosis				0.78
Hematologic malignancy	25 (22)	14 (20)	11 (25)	
Solid tumor	51 (44)	33 (46)	18 (41)	
Brain tumor	39 (34)	24 (34)	15 (34)	
Number of relapses				0.88
0	58 (50)	35 (49)	23 (52)	
1	27 (23)	18 (25)	9 (20)	
2+	30 (26)	18 (25)	12 (27)	
Enrolled in phase I or phase II clinical trial	28 (24)	17 (24)	11 (25)	>0.99
Living in high poverty neighborhood	21 (18)	2 (3)	19 (43)	<0.0001
Cause of death				0.28
Treatment-related	9	7(10)	2 (5)	
Progressive disease	105	64 (90)	41 (93)	
Other	1	0 (0)	1 (2)	

Table 2: Palliative care utilization by race/ethnicity			
	Total (N=115) n (%)	White (N=71) n (%)	Non-white (N=44) n (%)
Indications for initial PPC consult		(N=69)	
Decision support	53 (46)	28 (39)	25 (57)
Psychosocial support	52 (46)	34 (49)	18 (41)
Symptom management	64 (57)	38 (54)	26 (59)
Logistics	8 (7)	6 (8)	2 (5)
Parental/sibling bereavement	0 (0)	0 (0)	0 (0)
Goals of care discussed at initial encounter	102 (89)	64 (90)	38 (86)
Advanced care planning discussed at initial encounter	31 (27)	19 (27)	12 (27)
Resuscitation status at initial consult			
Full code	93 (81)	60 (85)	33 (75)
Limited resuscitation	22 (19)	11 (15)	11 (25)
Location of initial consult			
Inpatient, non-ICU	50 (43)	24 (34)	26 (59)
ICU	14 (12)	9 (13)	5 (11)
Outpatient	46 (40)	35 (49)	11 (25)
Other*	5 (4)	3 (4)	2 (6)
Median number of total PPC encounters (IQR)	12 (5, 23)	11 (5, 23)	13 (7.5, 32)

*Four initial palliative care consults occurred at home and one occurred at a local rehabilitation center.

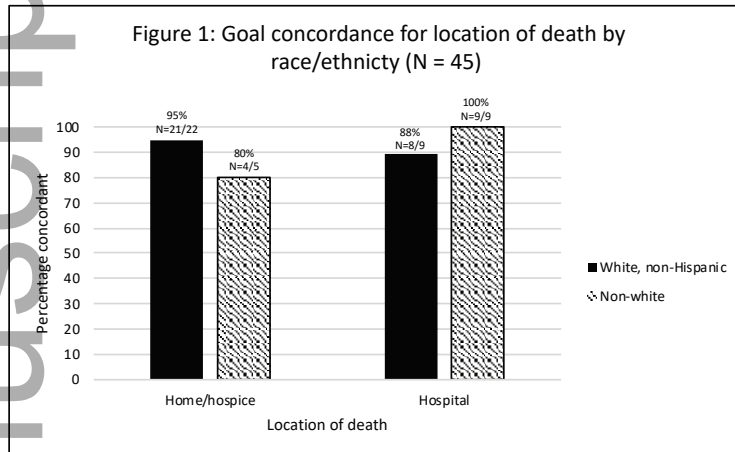| Table 3: Health care utilization by race/ethnicity			
	Total (N = 115) n (%)	White (N=71) n (%)	Non-white (N=44) n (%)
Mode of death			
Active resuscitation	7 (6)	4 (6)	3 (7)
Discontinuation of LST	18 (16)	9 (13)	9 (20)
Comfort care	90 (78)	58 (82)	32 (73)
MOLST form present	59 (52)	38/70 (56)	21 (48)
Hospice involved	57 (50)	40/70 (56)	17 (40)
Median days hospitalized in last 6 months of life	22 (9, 58)	19.0 (4, 53)	36.5 (16.5, 86.0)

Median number of unplanned admissions	2 (1, 3)	2 (1, 3)	2.5 (1, 4)
Number of ICU admissions in last 6 months			
0	49 (43)	33 (46)	16 (36)
1+	66 (57)	38 (54)	28 (64)
Resuscitation status changed in last 7 days	42 (37)	24 (34)	18 (41)
Radiation received in last 7 days	2 (2)	0 (0)	2 (5)
Chemotherapy received in last 7 days	24 (21)	16 (23)	8 (18)
ICU admission in last 7 days	18 (16)	8 (11)	10 (24)
Median (IQR) length of final admission if death in hospital (days)	11 (5.5, 31.5)	11 (6, 30)	14 (3, 32)

Table 4: End of life care by race/ethnicity				
	Total (N = 115) n (%)	White (N=71) n (%)	Non-white (N=44) n (%)	P-value
Location of death (N=114)*				0.03
Hospital	62 (54)	32/70 (46)	30 (68)	
Home/hospice	52 (46)	38/70 (54)	14 (32)	
Resuscitation status at death (N=114)*				1.0
Full code	13 (11)	8 (11)	5 (11)	
Limited resuscitation	101 (89)	62 (89)	39 (89)	
Interventions received in the last 7 days	25 (22)	12 (17)	13 (30)	0.11
CPR	7 (6)	4 (6)	3 (7)	
Intubation	23 (20)	12 (17)	11 (26)	
IV inotropes	13 (11)	7 (10)	6 (14)	
Median (IQR) time from initial PPC encounter to death (months)	3 (1.2, 6.4)	2.6 (1.2, 8.1)	3.3 (1.1, 6.2)	0.87

*One patient died in FL on a Make-A-Wish trip and was excluded from analysis

Figure 1: Goal concordance for location of death by race/ethnicty (N = 45)

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