Intensity of End-of-Life Care for Patients with Hematologic Malignancies and the Role of Race/Ethnicity

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Abstract

Background: Racial/ethnic minority patients with nonhematologic malignancies (non-HM) have lower rates of hospice care, advance directive use, and palliative care utilization than non-Hispanic white (NHW) patients. Less is known regarding racial/ethnic minority patients with hematologic malignancies (HM).

Objectives: To study hospital utilization among racial/ethnic minority patients with HM and compare end-of-life outcome measures to patients with non-HM.

Methods: We performed a retrospective cohort study (2010–2015) using electronic health records from an integrated academic health center to study differences in hospital utilization patterns and documentation of advance care planning between patients with HM and non-HM. In the subgroup with hematologic malignancy, we examined outcomes associated with racial/ethnic minority status.

Results: Among all patients in the last 30 days of life, those with HM had higher rates of inpatient care (odds ratio [OR], 1.96; 95% CI: 1.74–2.20; $p < 0.001$) and intensive care unit (ICU) care (OR, 3.50; 95% CI: 3.05–4.03; $p < 0.001$). Patients with HM were more likely to die in a hospital (OR, 2.75; 95% CI: 2.49–3.04; $p < 0.001$) than those with non-HM. Furthermore, during the last 30 days of life, among patients with HM, racial/ethnic minority patients were more likely to have more than one emergency room visit (OR, 6.81; 95% CI: 1.34–33.91; $p = 0.02$), 14+ days of inpatient care (OR, 1.60; 95% CI: 1.08–2.35; $p = 0.02$), longer stays in the ICU (OR, 1.26; 95% CI: 1.04–1.52; $p = 0.02$), and lower rates of advance directive documentation (OR, 0.60; 95% CI: 0.44–0.82; $p < 0.01$) than NHWs.

Conclusion: Our findings suggest that racial/ethnic minority patients with HM have higher utilization of care at the end-of-life and lower rates of advance directives compared with NHW patients.

Keywords: advance directives; hospital utilization in cancer patients; oncology issues in palliative care; palliative care in HM

Introduction

IN RECENT YEARS, clinicians and researchers have identified unique needs that patients with hematologic malignancies (HM) have at the end of life compared with patients with non-hematologic malignancies (non-HM). They have described receipt of more intensive and aggressive end-of-life care, as well as poorer quality of life, for patients with HM compared with those with non-HM.[1–3] These differences in care may be attributed to unique disease features that characterize the course and treatment for patients with HM versus patients with non-HM: patients with HM often have a continued possibility of cure despite advanced disease, hematologic oncologists have difficulty identifying the end-of-life phase of patients with HM,[4] and hematologists who treat these diseases are more likely to favor prescribing systemic therapy even if there is thought to be no survival benefit.[5] Furthermore, despite an increasing awareness of racial disparities in patients with HM,[6] less is known about disparities in end-of-life care in racial/ethnic minority patients with HM. In patients with acute myeloid leukemia (AML), some data suggest that nonwhite status is an independent predictor of admission to the intensive care unit (ICU) and higher use of chemotherapy at the end of life.[7]

We were interested in exploring the differences in end-of-life care and documentation of advance care planning between

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patients with HM and those with non-HM, as well as exploring differences among those with HM based on patient race/ethnicity. We performed a retrospective cohort study of patients cared for in a large multihospital healthcare system, examining end-of-life outcomes and documentation of advance care planning for these groups. Among patients with HM, we then examined these same outcomes for racial/ethnic minority patients compared to non-Hispanic white (NHW) patients.

Methods

Setting and study population

The setting was an integrated academic healthcare system, which included diverse academic and community sites: University of Washington (UW) Medical Center, Harborview Medical Center, Seattle Cancer Care Alliance, and UW Neighborhood Clinics. The study population was selected from patients cared for in one of these four settings and who died in Washington State from 2010 to 2015. The patients were at least 18 years of age, had either HM or non-HM (but not both types) as defined by ICD-9 and ICD-10 codes, and did not die as a result of an external event defined in death certificates as "injury or poisoning emanating from an accident, suicide, homicide, or an undetermined source." Our data did not indicate whether the patient's cancer was the attributed cause of death. To be included in our analysis, a patient must have had at least one nonsurgical inpatient visit in the 2 years before death or at least two outpatient visits at the same UW Medicine site in the last 32 months of life, with at least one visit occurring during the last 24 months of life. The criteria for healthcare system attribution were adapted from the Dartmouth Atlas methodology[8] to capture patients treated within a particular healthcare system and exclude those referred for a surgical procedure or a second opinion.

Data sources

Data were extracted from the UW Medicine electronic health records (EHRs) and from Washington State death certificates. Data extracted from the EHR included birthdate, health insurance status, medical diagnoses, advance directive documentation, and UW Medicine system utilization. Death certificate data provided information on gender, race/ethnicity, level of education, location, and date of death.

Outcomes

We analyzed nine end-of-life utilization outcomes, all occurring in the last 30 days of life. Two outcomes were related to emergency department (ED) use (i.e., any ED visit, at least two ED visits), four outcomes related to inpatient care (i.e., any inpatient care, number of days of inpatient care, at least 14 days of inpatient care, at least two inpatient admissions), two outcomes associated with ICU care (i.e., any ICU care, number of days of ICU care), and one outcome related to place of death (i.e., death in a hospital). In addition, we examined three outcomes associated with EHR documentation of advance care planning (including living wills or healthcare directives, durable power of attorney for healthcare, and Physician Orders for Life-sustaining Treatments): any documentation of advance care planning, documentation of advance care planning that occurred more than 30 days

before death, and documentation of advance care planning that occurred during the last 30 days of life.

Predictor and potential confounders

The first tested predictor of interest was cancer type: HM versus non-HM. We tested seven variables as potential confounders of the association between cancer type and each outcome: (1) age at death; (2) patient gender; (3) racial/ethnic minority status (NHW versus nonwhite or Hispanic); (4) level of education (ordinal categories: 8th grade or less; 9–12 years without diploma; high school diploma or equivalent; some college with no degree; associate's degree; bachelor's degree; master's degree; or doctorate/professional degree), (5) insurance type (private, Medicare, Medicaid, military, other, or no documented insurance); (6) attributed healthcare facility; and (7) number of chronic conditions as defined by the Dartmouth Atlas (cancers with poor prognoses, chronic pulmonary disease, coronary artery disease, heart failure, severe chronic liver disease, chronic renal failure, dementia, diabetes with end-organ damage, and peripheral vascular disease).[8]

The second tested predictor of interest was racial/ethnic minority status among patients with HM. We tested the same potential confounders, excluding racial/ethnic minority status, which was the predictor.

Statistical analysis

We assessed the associations between cancer type (0 = non-HM, 1 = HM) and each of the 12 outcomes with regression models: logistic regression for binary outcomes and negative binomial regression for count outcomes (days of inpatient care and days of ICU care). For the days-of-care outcomes, we included only patients who had one or more days of the relevant type of care. A variable was considered a confounder and included as a covariate in the final model if its addition to the bivariate model changed the coefficient for cancer type by at least 10%.[9–11] All estimations were done with restricted maximum likelihood.

In addition, within the HM subgroup, we used this same analytic method to assess associations between racial/ethnic minority status (0 = white non-Hispanic, 1 = minority or mixed race/ethnicity) and the 12 outcomes.

Results

The full cohort included 9468 patients of whom 71% (n = 6678) had non-HM, 84% (n = 6955) were white, and 42% (n = 3992) were female. Racial and gender makeup was similar for patients with non-HM versus HM, with both groups consisting of more than 80% white and ~40% female patients. The insurance types were also similar for the two groups, with hematologic cancer patients having 42% private insurance, 31% Medicare, and 16% Medicaid and non-HM patients having 40% private insurance, 32% Medicare, and 19% Medicaid (Table 1).

In the last 30 days of life, decedents with HM were significantly more likely to have received inpatient care, been hospitalized for 14 or more days, had multiple hospital admissions, and had more days of hospital care once admitted than were those with non-HM (Table 2). They were also significantly more likely in the last 30 days of life to have

received ICU care, spent more time in the ICU once admitted, and died in a hospital. Cancer type was not significantly associated with ED use in the last 30 days of life (Table 2). HM patients were more likely than non-HM patients to have had EHR documentation of some advance care planning ($p < 0.001$), as well as documentation during each of two time periods: more than 30 days before death ($p = 0.001$) and within the last 30 days of life ($p = 0.028$).

Within the HM subpopulation, racial/ethnic minority status was associated with a higher likelihood of 2+ ED visits, 14+ days of inpatient care, and with lengthier hospital and ICU stays, once admitted. Racial/ethnic minority status was also associated with a lower rate of documentation of advance care planning overall, as well as documentation of advance care planning more than 30 days before death. However, rates of advance care planning within the last 30 days of life were roughly equal for the two racial groups (Table 3).

Discussion

In this cohort, we found that patients with HM received more intensive care at the end of life than did patients with non-HM. These patients had more inpatient care, more ICU care, and a higher likelihood of dying in the hospital than patients with non-HM. The high intensity of care at the end of life for patients with HM has been documented in other studies.[1,12,13] The unique healthcare needs for patients with HM likely contribute to this trend. For example, the potential need for transfusion support can be a barrier to hospice referral for patients with HM.[14] Transfusion services are sometimes unavailable in hospices because of reimbursement policies, and many times a choice is made between continuing transfusions or enrolling in hospice.

Studies have also shown that the lack of a clear transition point between curative and palliative treatments can be a barrier to accurate prognostication and palliative care management.[15–17] Patients with HM receiving aggressive chemotherapy are usually doing so in hopes of cure or longer survival. Thus, aggressive care may be appropriate because if they do not succumb to complications of treatment, they may experience an extended period of good health. Measuring palliative care outcomes in these circumstances is difficult in that this care might only be judged ''aggressive'' if treatment is unsuccessful and the patient dies. Therefore, outcome measures consistent with high-quality palliative care that is

TABLE 1. CHARACTERISTICS OF DECEDENTS

Characteristic	Total sample		Nonhematologic malignancy		Hematologic malignancy	
	n	Statistic[a]	Valid, n	Statistic[a]	Valid, n	Statistic[a]
Cancer type	9468					
Nonhematologic		6678 (70.5)				
Hematologic		2790 (29.5)				
Age at death, median (IQR)	9468	64 (56–64)	6678	64 (57–73)	2790	65 (56–74)
Female	9468	3992 (42.2)	6678	2936 (44.0)	2790	1056 (37.8)
Race	8262		6014		2248	
White		6955 (84.2)		4997 (83.1)		1958 (87.1)
Black		400 (4.8)		304 (5.1)		96 (4.3)
Native American		98 (1.2)		79 (1.3)		19 (0.8)
Asian		531 (6.4)		431 (7.2)		100 (4.4)
Pacific Islander		43 (0.5)		36 (0.6)		7 (0.3)
Hispanic		141 (1.7)		106 (1.8)		35 (1.6)
Other or mixed race		94 (1.1)		61 (1.0)		33 (1.5)
Education	8172		5941		2231	
8th grade or less		258 (3.2)		187 (3.1)		71 (3.2)
9–12 years, no diploma		482 (5.9)		351 (5.9)		131 (5.9)
High school diploma or equivalent		2556 (31.3)		1891 (31.8)		665 (29.8)
Some college, no degree		1688 (20.7)		1239 (20.9)		449 (20.1)
Associate's degree		701 (8.6)		510 (8.6)		191 (8.6)
Bachelor's degree		1506 (18.4)		1081 (18.2)		425 (19.0)
Master's degree		692 (8.5)		487 (8.2)		205 (9.2)
Doctorate or professional degree		289 (3.5)		195 (3.3)		94 (4.2)
Insurance type	9468		6678		2790	
Private		3815 (40.3)		2650 (39.7)		1165 (41.8)
Medicare		3013 (31.8)		2143 (32.1)		870 (31.2)
Medicaid		1716 (18.1)		1277 (19.1)		439 (15.7)
Military		379 (4.0)		241 (3.6)		138 (4.9)
Other type		260 (2.7)		159 (2.4)		101 (3.6)
No documented insurance		285 (3.0)		208 (3.1)		77 (2.8)
Number of Dartmouth Atlas conditions with which patient had been diagnosed, median (IQR)	9468	1 (1–2)	6678	1 (1–2)	2790	1 (0–2)

[a]Unless otherwise specified, the statistic provided is the number of cases with the characteristic (percentage of valid cases).
IQR, interquartile range.

TABLE 2. ASSOCIATION OF HEMATOLOGIC MALIGNANCY WITH END-OF-LIFE OUTCOMES

Outcome	Multivariable analysis (odds ratio or incidence rate ratio)[a]	95% CI	p
Any ED visits[b]	0.89	0.65–1.21	0.447
2+ ED visits[c]	0.67	0.27–1.63	0.371
Any inpatient care[d]	1.96	1.74–2.20	**<0.001**
14+ days of inpatient care[d]	3.20	2.67–3.83	**<0.001**
Days of inpatient care (if 1+ days)[e]	1.30	1.23–1.38	**<0.001**
2+ inpatient admits[d]	2.06	1.64–2.59	**<0.001**
Any ICU care[d]	3.50	3.04–4.03	**<0.001**
Days of ICU care (if 1+ days)[e]	1.46	1.34–1.60	**<0.001**
Death in a hospital[e]	2.75	2.49–3.04	**<0.001**
EHR documentation of advance care planning[f]			
Any advance care planning[g]	1.22	1.10–1.36	**<0.001**
Advance care planning more than 30 days before death[g]	1.21	1.08–1.36	**0.001**
Advance care planning in last 30 days before death[h]	1.24	1.02–1.50	**0.028**

Each outcome of interest was tested separately, using cancer type as the predictor of interest (0 = nonhematologic malignancy only, 1 = hematologic malignancy) and adjusting for any variables that changed the coefficient for cancer type by 10% or more. Binary outcomes were tested with logistic regression; count outcomes, with negative binomial regression.

[a]For binary outcomes, the ratio is an odds ratio; for count outcomes it is an incidence rate ratio.

[b]Adjusted for confounding by racial/ethnic minority status, number of Dartmouth Atlas diagnoses, insurance type/status, and the facility to which patient was attributed.

[c]Adjusted for confounding by racial/ethnic minority status and insurance type/status.

[d]Adjusted for confounding by number of Dartmouth Atlas diagnoses and the facility to which patient was attributed.

[e]Bivariate model; there was no confounding.

[f]Defined as presence of a living will (or healthcare directive), durable power of attorney for healthcare, or Physicians Order for Life-sustaining Treatments.

[g]Adjusted for confounding by gender, number of Dartmouth Atlas diagnoses, insurance type/status, and the facility to which patient was attributed.

[h]Adjusted for confounding by gender, racial/ethnic minority status, number of Dartmouth Atlas diagnoses, insurance type/status, and the facility to which patient was attributed.

ED, emergency department; EHR, electronic health record; ICU, intensive care unit.

Bold text indicates a statistically significant correlation.

TABLE 3. ASSOCIATION OF RACIAL/ETHNIC MINORITY STATUS WITH END-OF-LIFE OUTCOMES AMONG PATIENTS WITH HEMATOLOGIC MALIGNANCY

Outcome	Multivariable analysis (odds ratio or incidence rate ratio)[a]	95% CI	p
Any ED visits[b]	1.52	0.78–2.93	0.22
2+ ED visits[c]	6.81	1.37–33.91	**0.02**
Any inpatient care[b]	1.19	0.89–1.60	0.23
14+ days of inpatient care[d]	1.59	1.08–2.25	**0.02**
Days of inpatient care (if 1+ days)[e]	1.16	1.00–1.35	**<0.05**
2+ inpatient admits[f]	0.93	0.51–1.68	0.80
Any ICU care[b]	1.18	0.85–1.62	0.32
Days of ICU care (if 1+ days)[g]	1.26	1.04–1.52	**0.02**
Death in a hospital[h]	1.29	1.00–1.68	0.052
EHR documentation of advance care planning[i]			
Any advance care planning[c]	0.60	0.43–0.82	**<0.01**
Advance care planning more than 30 days before death[j]	0.59	0.42–0.83	**<0.01**
Advance care planning in last 30 days before death[k]	1.00	0.64–1.57	0.994

Each outcome of interest was tested separately, using racial/ethnic minority status as the predictor of interest (0 = white non-Hispanic, 1 = minority or mixed race/ethnicity) and adjusting for any variables that changed the coefficient for minority status by 10% or more. Binary outcomes were tested with logistic regression; count outcomes, with negative binomial regression.

[a]For binary outcomes, the ratio is an odds ratio; for count outcomes it is an incidence rate ratio.

[b]Adjusted for patient age; insurance type, and facility.

[c]Adjusted for insurance type and facility.

[d]Adjusted for patient age and education.

[e]Adjusted for patient age, education, insurance type, and facility.

[f]Adjusted for patient age, gender, education, insurance type, facility, and number of diagnoses.

[g]Adjusted for patient age, education, and facility.

[h]Adjusted for patient age and insurance type.

[i]Defined as presence of a living will (or healthcare directive), durable power of attorney for healthcare, or Physicians Order for Life-sustaining Treatments.

[j]Adjusted for facility.

[k]Adjusted for patient education, insurance type, and facility.

Bold text indicates a statistically significant correlation.

appropriate for patients with advanced incurable non-HM may be less applicable to patients with HM. This is an important question that needs to be more thoroughly considered by the community of patients with HM and the clinicians taking care of them at the end of life.

Among the subgroup of patients with HM, our data showed that racial/ethnic minority patients received more intensive care at the end of life and were less likely to complete advance care planning than were NHW patients. Other researchers have reported that racial/ethnic minority patients with non-HM receive more intensive end-of-life care than their white counterparts,[18] but less is known about this trend for racial/ethnic minority patients with HM. Furthermore, although some studies have reported that African Americans, Hispanics, and Asians are less likely than their white counterparts to be knowledgeable about and complete advance directives,[19–23] we are unaware of data on advance care planning involving racial/ethnic minority patients with HM. Several factors may explain the differences by race/ethnicity in early advance care planning, including poor patient–provider communication,[24,25] low health literacy,[26] provider or patient bias,[27] unique cultural needs not addressed by the current infrastructure,[28] and patient preferences for more intensive care.

Our study findings must be considered within the context of a number of limitations. First, although we used ICD9/10 codes to identify eligible patients by diagnosis, our data sources did not specify the cause of death. Therefore, it is unclear whether the patients who died did so as a direct result of their cancer or as a result of another cause. Second, the numbers of racial/ethnic minority patients in our study were not large enough to analyze by specific racial and ethnic groups. Future studies should explore whether differences exist among these groups. Furthermore, given that our study reflects a population from a single geographic region, the generalizability of the race/ethnicity findings may be limited to other locations where the breakdown of specific racial/ethnic groups is similar. Third, our data sources did not document language barriers, provider biases, and the quality of provider–patient communication, which could each influence planning for end-of-life care. A systematic review found that patients with limited English proficiency had worse quality end-of-life care and goals-of-care discussions when professional interpreters were not used, highlighting the importance of language in realizing optimal end-of-life care.[29] Finally, our sample was restricted to deceased patients and may actually have underestimated the differences in intensive care between the two cancer groups. It is possible that the subset of patients who had many hospital admissions as well as ED and ICU utilization survived and thus were not included in our analysis; this group would presumably be larger for HM than for those with non-HM.

In summary, our study has several important findings. First, we confirm that patients with HM receive higher intensity of care at the end of life than those with non-HM. Second, we also show that among patients with HM, patients from racial/ethnic minority groups receive higher intensity care and are less likely to have documentation of early advance care planning in the EHR. Given this discrepancy in advance care planning documentation among racial/ethnic minority patients with HM, it is important that providers are educated about the need for culturally sensitive communication that will engage their patients from different backgrounds.[30] In addition, it is important to acknowledge that standard definitions of high intensity care at the end of life may not have the same meaning for patients with HM, given that chemotherapy regimens for these diseases tend to require more inpatient admissions and also because the persistent prospect of cure remains, even in advanced disease. More observational studies of patient-reported outcomes of patients with HM at the end of life are needed to gain a better understanding of the unique needs of this patient population. A special emphasis on racial/ethnic minority patients with HM is also important to minimize potential barriers to high-quality end-of-life care.

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