blood advances

Disparities in place of death for patients with hematological malignancies, 1999 to 2015

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Key Points

- Despite overall improvements, patients with HMs in the United States remain more likely to die in the hospital than at home.

- Concerning place of death disparities exist along age, marital status, cancer subsite, race, and ethnic lines.

Patients with hematologic malignancies (HMs) often receive aggressive end-of-life care and less frequently use hospice. Comprehensive longitudinal reporting on place of death, a key quality indicator, is lacking. Deidentified death certificate data were obtained via the National Center for Health Statistics for all HM deaths from 1999 to 2015. Multivariate regression analysis (MVA) was used to test for disparities in place of death associated with sociodemographic variables. During the study period, there were 951 435 HM deaths. Hospital deaths decreased from 54.6% in 1999 to 38.2% in 2015, whereas home (25.9% to 32.7%) and hospice facility deaths (0% to 12.1%) increased (all $P < .001$). On MVA of all cancers, HM patients had the lowest odds of home or hospice facility death (odds ratio [OR], 0.55; 95% confidence interval, 0.54-0.55). Older age (40-64 years: OR, 1.34; ≥65 years: OR, 1.89), being married (OR, 1.62), and having myeloma (OR, 1.34) were associated with home or hospice facility death, whereas being black or African American (OR, 0.68), Asian (OR, 0.58), or Hispanic (OR, 0.84) or having chronic leukemia (OR, 0.83) had decreased odds of dying at home or hospice (all $P < .001$). In conclusion, despite hospital deaths decreasing over time, patients with HMs remained more likely to die in the hospital than at home.

Introduction

More than 50 000 people die annually from hematological malignancies (HMs) in the United States.[1] Surveys suggest that only 1% of patients with cancer prefer an in-hospital death[2]; most want to die at home.[3] However, patients with HMs more frequently receive aggressive end-of-life care,[4] and home hospice is seldom used.[5] They are up to 4 times more likely to die in the hospital than those with solid tumors[6] and, if referred to hospice, are more often enrolled in the last 24 hours of life.[7]

However, more comprehensive modern evaluation of place of death in the United States is limited, because prior research was based on Medicare data[8] (therefore, only patients age ≥65 years) or institutional reporting.[9] We therefore sought to evaluate changes in place of death for the HM population over time, using a more inclusive data set, and to describe any associated health care disparities.

Methods

Deidentified death certificate data were obtained from the National Center for Health Statistics. The National Center for Health Statistics is part of the Centers for Disease Control and Prevention and provides national statistical information to help guide policies to improve health in the United States. We included all deaths resulting from HMs from 1999 to 2015. Place and year of death were documented along with sociodemographic information including age, sex, race, ethnicity, marital status, and education. HM deaths were compared with those resulting from solid tumors and then with one another based on subtype (acute leukemia, chronic leukemia, aggressive lymphoma, nonaggressive lymphoma, myeloma).

Figure 1. Trends in place of death resulting from HMs (1999-2015). Location by primary site (A) and by race and ethnicity (B).

Using data from all years with full place-of-death reporting (2003-2015), multivariate logistic regression was used to test for disparities in place of death. Statistical analyses were performed using SPSS software (version 21; Armonk, NY). All comparisons were 2 tailed. The Duke University Medical Center Institutional Review Board provided a waiver (Pro00045337) for this study.

Results

There were 951 435 deaths resulting from HMs in the study period. A majority of those who died were male (54.9%), white (88.0%), and non-Hispanic (93.9%); 9.6% were black or African American, 2.1% were Asian, and 0.4% were American Indian. Most were age ≥65 years at time of death (73.9%), with median age of 72 years (interquartile range, 63-81 years). Acute leukemia caused the most deaths (21.7%), followed by myeloma (20.0%) and chronic leukemia (10.5%).

Between 1999 and 2015, hospital (54.6% to 38.2%) and nursing facility deaths (13.1% to 11.9%) both decreased, whereas home (25.9% to 32.7%) and hospice facility deaths (0% to 12.1%) increased (all $P < .001$). Comparing states with the highest and lowest rates, New York had the highest rate of hospital death (61.6%), almost twice the lowest rate in Utah (32.5%). Utah had the highest home death rate (50.0%), almost 3 times the rate in South Dakota (17.5%). Florida had the highest hospice facility death rate (20.2%); it was >20 times the lowest rate in Utah (≤0.2%). Eleven states (Maryland, Idaho, Colorado, Hawaii, Alaska, Massachusetts, Virginia, North Dakota, West Virginia, Utah, Alabama) had aggregate hospice facility utilization of <2% since 2003, the first available year for this data element in the data set.

There was also significant variation in place of death by cancer subtype (Figure 1A) and race (Figure 1B). There was an overall

Table 1. Univariate and multivariate analysis–modeled results: death resulting from HMs at home or in hospice facility (vs death in another location)

	Univariate analysis		Multivariate analysis	
	OR (95% CI)	P	OR (95% CI)	P
All cancers (HMs and solid tumors)				
Year of death (continuous variable)	1.058 (1.058-1.058)	<.001	1.047 (1.046-1.047)	<.001
Age, y				
Age (continuous variable)	0.997 (0.0997-0.998)	<.001	—	<.001
0-39	1.000		1.000	
40-64	1.366 (1.351-1.381)	<.001	1.095 (1.077-1.112)	<.001
≥65	1.295 (1.281-1.309)	<.001	1.050 (1.034-1.067)	<.001
Sex				
Female (reference)	1.000		1.000	
Male	1.030 (1.027-1.033)	<.001	0.930 (0.926-0.934)	<.001
Marital status*		<.001		<.001
Single (reference)	1.000		1.000	
Married	2.027 (2.058-2.082)	<.001	1.997 (1.982-2.013)	<.001
Divorced/separated	1.361 (1.352-1.370)	<.001	1.284 (1.273-1.296)	<.001
Widowed	1.411 (1.403-1.419)	<.001	1.388 (1.376-1.400)	<.001
Education level†				<.001
Some high school or less (reference)	1.000	<.001	1.000	
High school graduate (≥4 y)	1.047 (1.042-1.052)	<.001	0.976 (0.970-0.981)	<.001
Some college/associates degree	1.174 (1.167-1.181)	<.001	1.068 (1.061-1.076)	<.001
College graduate (≥4 y)	1.163 (1.155-1.171)	<.001	1.055 (1.047-1.063)	<.001
Advanced degree	1.206 (1.196-1.216)	<.001	1.092 (1.082-1.102)	<.001
Race		<.001		<.001
White (reference)	1.000		1.000	
Black or African American	0.669 (0.666-0.672)	<.001	0.693 (0.731-0.757)	<.001
Asian or Pacific Islander	0.776 (0.768-0.783)	<.001	0.636 (0.629-0.644)	<.001
American Indian or Alaska Native	0.888 (0.869-0.906)	<.001	0.859 (0.836-0.883)	<.001
Ethnicity				
Non-Hispanic (reference)	1.000		1.000	
Hispanic	1.089 (1.082-1.096)	<.001	0.954 (0.946-0.962)	<.001
Primary cancer diagnosis				
Solid tumor (reference)	1.000		1.000	
HM	0.570 (0.567-0.573)	<.001	0.547 (0.543-0.551)	<.001
HMs only				
Year of death (continuous variable)	1.058 (1.058-1.058)	<.001	1.053 (1.051-1.055)	<.001
Age, y				
Age (continuous variable)	0.997 (0.0997-0.998)	<.001	—	<.001
0-39	1.000		1.000	
40-64	1.366 (1.351-1.381)	<.001	1.335 (1.281-1.390)	<.001
≥65	1.295 (1.281-1.309)	<.001	1.888 (1.814-1.965)	<.001
Sex				
Female (reference)	1.000		1.000	
Male	1.030 (1.027-1.033)	<.001	0.990 (0.977-1.003)	.133

*Martial status is unknown in 0.7% of the 2003-2015 data file.

†Education level is unknown in 38.5% of the 2003-2015 data file.

‡Acute leukemia includes acute myeloid and acute lymphocytic leukemias; chronic leukemia includes chronic myeloid and chronic lymphocytic leukemias; aggressive lymphoma includes diffuse large B-cell and Burkitt's lymphomas; nonaggressive lymphoma includes Hodgkin disease and follicular lymphoma; and myeloma includes multiple myeloma, plasma cell leukemia, and plasmacytoma.

Table 1. (continued)

	Univariate analysis		Multivariate analysis	
	OR (95% CI)	P	OR (95% CI)	P
Marital status*		<.001		<.001
Single (reference)	1.000		1.000	
Married	2.027 (2.058-2.082)	<.001	1.612 (1.570-1.655)	<.001
Divorced/separated	1.361 (1.352-1.370)	<.001	1.241 (1.204-1.280)	<.001
Widowed	1.411 (1.403-1.419)	<.001	1.417 (1.377-1.458)	<.001
Education level†		<.001		<.001
Some high school or less (reference)	1.000		1.000	
High school graduate (≥4 y)	1.047 (1.042-1.052)	<.001	0.969 (0.952-0.986)	<.001
Some college/associates degree	1.174 (1.167-1.181)	<.001	1.030 (1.010-1.051)	.004
College graduate (≥4 y)	1.163 (1.155-1.171)	<.001	0.984 (0.963-1.007)	.174
Advanced degree	1.206 (1.196-1.216)	<.001	1.000 (0.974-1.026)	.991
Race		<.001		<.001
White (reference)	1.000		1.000	
Black or African American	0.669 (0.666-0.672)	<.001	0.680 (0.664-0.695)	<.001
Asian or Pacific Islander	0.776 (0.768-0.783)	<.001	0.575 (0.552-0.599)	<.001
American Indian or Alaska Native	0.888 (0.869-0.906)	<.001	0.884 (0.804-0.972)	.011
Ethnicity		<.001		<.001
Non-Hispanic (reference)	1.000		1.000	
Hispanic	1.089 (1.082-1.096)	<.001	0.843 (0.824-0.864)	<.001
Primary cancer diagnosis‡		<.001		<.001
Acute leukemia (reference)	1.000		1.000	
Chronic leukemia	0.887 (0.870-0.904)	<.001	0.829 (0.810-0.849)	<.001
Aggressive lymphoma	1.244 (1.209-1.279)	<.001	1.141 (1.103-1.180)	<.001
Nonaggressive lymphoma	1.077 (1.044-1.110)	<.001	1.181 (1.136-1.227)	<.001
Myeloma	1.325 (1.305-1.344)	<.001	1.338 (1.313-1.364)	<.001
Other leukemia/lymphoma	1.155 (1.140-1.169)	<.001	1.133 (1.115-1.152)	<.001

*Martial status is unknown in 0.7% of the 2003-2015 data file.

†Education level is unknown in 38.5% of the 2003-2015 data file.

‡Acute leukemia includes acute myeloid and acute lymphocytic leukemias; chronic leukemia includes chronic myeloid and chronic lymphocytic leukemias; aggressive lymphoma includes diffuse large B-cell and Burkitt's lymphomas; nonaggressive lymphoma includes Hodgkin disease and follicular lymphoma; and myeloma includes multiple myeloma, plasma cell leukemia, and plasmacytoma.

downtrend in hospital death for each category. Patients with acute leukemia and Asian race had the highest rates of hospital death. Black or African American patients and those with chronic leukemia were the least likely to die at home. Compared with solid tumor deaths, HM deaths were more likely to occur in the hospital and less likely to occur at home. By 2015, patients with HMs were still 65% more likely to die in the hospital (HMs, 38.2% vs non-HMs, 23.2%) and 25% less likely to die at home (32.7% vs 43.6%; both $P < .001$).

Place of death either at home or in a hospice facility was examined; all assessed categories were associated on univariate analysis ($P < .05$) and included in the final model. On multivariate analysis of all cancers, HM diagnosis had the strongest negative association with home/hospice facility death (odds ratio [OR], 0.55; 95% confidence interval [CI], 0.54-.055; Table 1). On multivariate analysis limited to HMs, older age (age 40-64 years: OR, 1.34; 95% CI, 1.28-1.39; age ≥65 years: OR, 1.89; 95% CI, 1.81-1.97), being married (OR, 1.62; 95% CI, 1.57-1.66), and having myeloma (OR, 1.34; 95% CI, 1.31-1.36) were associated with home/hospice facility death. Black or African American (OR, 0.68; 95% CI, 0.66-0.70) and Asian patients (OR, 0.58; 95% CI, 0.55-0.60), those of Hispanic ethnicity (OR, 0.84; 95% CI, 0.82-0.86), and those with a diagnosis of chronic leukemia (OR, 0.83; 95% CI, 0.81-0.85) had decreased odds of dying at home or hospice (Table 1).

Discussion

In this study of all hematological cancer deaths over the past 17 years in the United States, hospital deaths decreased by 30%, with a corresponding rise in home and hospice facility deaths. Despite this overall trend, patients with HMs remained more likely to die in the hospital than patients with solid tumors.

Hospital death has been associated with worse outcomes, with unmet symptom needs for patients[10] and prolonged grief disorder for caregivers.[11] Appropriate hospice referral and clinician-led shared decision making for end-of-life care can improve goal attainment[12] and reduce hospital deaths.[13] Unfortunately, patients with HMs have lower palliative care utilization, and surveys show that hematological oncologists may harbor more philosophical

resistance to making referrals.[14] They may also be less comfortable having goals-of-care discussions,[15] especially with those with chronic/indolent lymphomas.[16] Additionally, patients themselves may have unrealistic treatment expectations[16] and prefer aggressive care, with 28% stating a preference to die in the hospital.[17]

Obstacles to palliative care and hospice enrollment may stretch beyond patient and physician perceptions and resistance. Patients with HMs can have uncertain disease trajectories, making it difficult to appropriately identify when to transition away from active treatment.[16] There is also evidence that patients with HMs have higher symptom burden,[18] which sometimes warrants blood products for palliation; a recent study showed that the rate of transfusion dependence at death or hospice enrollment was 20%.[19] Financial constraints driving transfusion exclusion in hospice policies may ironically end up driving up overall health care costs, as patients ultimately end up requiring more costly hospitalizations at the end of life.

Despite these barriers, there have been reports of increased rates of hospice admission and home deaths,[20] consistent with our study findings. This overall positive trend may reflect the national shift toward considering palliative care vital to the cancer care continuum. Proliferation of the hospice industry has improved access, although there is still geographic variability,[21] which may partially explain the significant state-to-state variation seen in this study. Given the stark regional disparities in place of death, however, there are also likely important social and demographic differences at play. Utah, for example, has the highest rate of home death and the lowest rate of hospice facility death; this may reflect both a population with strong family units (and thus the capacity to care for loved ones at home) and potential religious objection to care in a hospice facility, which may be associated with "giving up." Alternatively, Florida, with >1 in 5 patients dying in a hospice facility, may reflect the coexistence of an aging retirement population and readily available care facilities.

Our study highlights important racial disparities in end-of-life care, with nonwhite and Hispanic patients much less likely to die at home or in a hospice facility. Although there were important decreases in hospital death rates across all races over time, the utilization gap remained grossly stable. This means that the relative disparity between, for example, white and black or African American patients actually grew with time. These findings are consistent with prior research showing that these populations are at risk for health care disparities,[22,23] either because of a desire for more aggressive end-of-life care, distrust of the health care system, or decreased referral by providers to palliative care services.

Likewise, significant variation based on cancer subtype identifies patients for whom palliative care services may not be optimally deployed. Whereas patients with myeloma have high hospice enrollment and limited late enrollment,[24] patients with acute leukemia are at high risk for aggressive care and hospital death.[8,9] This may be due to initial presentation for patients with acute leukemia, where both diagnosis and death may occur in the same hospitalization, or to the increased risks for bleeding and infection that come with standard induction chemotherapy regimens, which may require prolonged hospital stays. Patients with chronic leukemia may have the lowest rate of home death because, as an older population, they require more significant care needs and thus disproportionately die in nursing facilities.

Our study has several limitations. Inaccuracy of death certificates may have led to potential discrepancies, although an expert panel found high fidelity in a retrospective review.[25] Access to and utilization of hospice care vary widely by income, insurance, and county-level resources, data on which were not available for this analysis. Finally, this place-of-death study may not accurately reflect the intensity of end-of-life care, because patient death on a palliative care service in a hospital would still be coded as "hospital death" in this study.

In conclusion, despite overall improvements, patients with HMs in the United States remain more likely to die in the hospital than at home. Concerning disparities exist along age, marital status, cancer subsite, race, and ethnic lines. Continued efforts are needed to improve the provision of quality end-of-life care in hematology.

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