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Racial and Ethnic Differences in End-of-Life Care in Fee-for-Service Medicare Beneficiaries with Advanced Cancer

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Abstract

OBJECTIVES—To examine racial and ethnic variation in use of hospice and high-intensity care in patients with terminal illness.

DESIGN—Retrospective, secondary data analysis.

SETTING—Surveillance, Epidemiology, and End Results-Medicare Database from 1992 to 1999 with follow-up data until December 31, 2001.

PARTICIPANTS—Forty thousand nine hundred sixty non-Hispanic white, non-Hispanic black, Asian, and Hispanic fee-for-service Medicare beneficiaries aged 65 and older with advanced-stage lung, colorectal, breast, and prostate cancer.

MEASUREMENTS—Hospice use and indicators of high-intensity care at the end of life.

RESULTS—Whereas 42.0% of elderly white patients with advanced cancer enrolled in hospice, enrollment was lower for black (36.9%), Asian (32.2%), and Hispanic (37.7%) patients. Differences between white and Hispanic patients disappeared after adjustment for clinical and sociodemographic factors. Higher proportions of black and Asian patients than of white patients were hospitalized two or more times (11.7%, 15.0%, 13.7%, respectively), spent more than 14 days hospitalized (11.4%, 17.4%, 15.6%, respectively), and were admitted to the intensive care unit (ICU) (12.0%, 17.0%, 16.2%, respectively) in the last month of life and died in the hospital (26.5%, 31.3%, 33.7%, respectively). Unadjusted differences in receipt of high-intensity care according to race or ethnicity remained after adjustment.

CONCLUSION—Black and Asian patients with advanced cancer were more likely than whites to be hospitalized frequently and for prolonged periods, be admitted to the ICU, die in the hospital, and

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be enrolled in hospice at lower rates. Further research is needed to examine the degree to which patient preferences or other factors explain these differences.

Keywords

racial and ethnic disparities; end-of-life care; hospice; high-intensity care; cancer

Patients with terminal illness increasingly face challenging choices about use of high-intensity care and palliative services such as hospice. Hospice has been shown to improve the quality of end-of-life care,¹ whereas death in a hospital has been associated with lower ratings of care and unmet emotional, informational, and symptom needs.² Decisions about care at the end of life are often complex, however, and may be heavily influenced by factors such as understanding of prognosis, preferences for life-prolonging treatment, caregiver or family hopes and beliefs, patient–physician communication, and culture.³

Recent research suggests considerable racial and ethnic variation in the structures and processes of care that might affect the care choices and experiences of patients with terminal illness. For example, availability of opioids has been shown to be lower in pharmacies in predominantly nonwhite neighborhoods than in white neighborhoods,⁴ and rates of opioid prescribing for pain in emergency departments (EDs) remain persistently lower for racial and ethnic minority patients than for whites.⁵ For patients with cancer, racial and ethnic disparities in screening, surgery, chemotherapy, morbidity, and mortality have been well documented.⁶ Racial and ethnic differences in end-of-life care have received less attention, leading the Institute of Medicine to call for more research in this area.⁷ Previous research has not considered hospice and intensive life-prolonging care in a single population and has focused predominantly on comparisons between African Americans and whites, with little attention to other racial and ethnic minorities. Such studies limit the ability of clinicians and policy makers to formulate a national understanding of racial and ethnic differences in care for patients at the end of life across multiple races and ethnicities and care options. In this context, the present study examines racial and ethnic differences in hospice and high-intensity care at the end of life in non-Hispanic white, Hispanic, non-Hispanic black, and Asian/Pacific Islander Medicare beneficiaries newly diagnosed with advanced cancer.

METHODS

Data Source

Patients newly diagnosed with advanced cancer were analyzed using the Surveillance, Epidemiology, and End Results (SEER) Medicare database. The database contains cancer information on patients aged 65 and older from the National Cancer Institute's SEER Program and Medicare enrollment and utilization information from the Centers for Medicare and Medicaid Services.⁸ Medicare files include claims for hospice use, inpatient and outpatient care, and physician billing. Medicare claims were available through December 31, 2001.

Study Sample

The study sample included 40,960 non-Hispanic white (white), Hispanic, non-Hispanic black (black), Asian American/Pacific Islander (Asian) patients aged 65 and older with first primary diagnosis of advanced cancer and fee-for-service Medicare insurance who died between January 1, 1992, and December 31, 1999. This sample included patients with stage IIIB/IV non-small-cell lung cancer (NSCLC) (n = 21,413); extensive-stage small-cell lung cancer (n = 4,525); and stage IV colorectal cancer (n = 8,076), female breast cancer (n = 1,995), and prostate cancer (n = 4,951). These diagnoses include the four most commonly diagnosed cancers in elderly people.⁹ SEER abstracts patient charts for information on race, and a surname

matching algorithm is used to determine Hispanic ethnicity. Consistent with previous studies, beneficiaries with managed care insurance were not included, because Medicare claims for hospital-based services (measures of high-intensity care) are not available for patients with managed care insurance.^{10,11}

Outcomes of Interest

Ethnic and racial differences in receipt of hospice or high-intensity care were examined using previously developed measures.^{10–13} All patients were followed from diagnosis until death or the end of the follow-up period (December 31, 2001). Details of the study samples used for each outcome of interest are described below.

Hospice—Three measures of hospice use were used to characterize differences in hospice use: hospice enrollment, hospice length of stay (LOS), and hospice enrollment within 3 days of death.^{10–13} Rates of hospice enrollment were examined using survival methods.¹² Time to hospice enrollment was defined as time from diagnosis to hospice entry or December 31, 2001, whichever came first. Those patients who never enrolled in hospice were considered censored observations. Hospice LOS was defined as the time from hospice entry to death in hospice or discharge from hospice. Hospice enrollment within 3 days of death was used as a potential measure of lower-quality end-of-life care.^{10,11} Analyses of hospice LOS and hospice enrollment within 3 days of death were conducted only in patients who enrolled in hospice.

High-Intensity Care at the End of Life—Specific indicators of intensity of care at the end of life were examined, including two or more hospitalizations in the last month of life (a measure of frequent hospitalizations), more than 14 days in the hospital in the last month of life (a measure of prolonged hospitalization), death in the hospital (death in a high-intensity institutional setting), intensive care unit (ICU) use in the last month of life, receipt of chemotherapy in the last 14 days of life, and two or more ED visits in the last month of life (the latter 3 being markers for receipt of high-intensity treatment).^{10,11}

Covariates

Data on sociodemographic and clinical characteristics previously shown to be associated with the outcomes of interest were obtained. Sociodemographic and geographic characteristics at diagnosis were age, sex, marital status, foreign-born status, income, urban or metropolitan area of residence, and SEER registry. Two measures of socioeconomic status were used. First, 1990 census tract-level data were used to group patients into quintiles of median household income, substituting ZIP code level data for patients with missing census track. Second, a history of state buy-in during the year preceding diagnosis was used as a proxy for individual low-income status. The state buy-in variable generally indicates whether a beneficiary was enrolled in a state-administered Medicaid program. Clinical characteristics included site of primary cancer, tumor grade at diagnosis, year of diagnosis, and comorbidity score. Charlson Comorbidity Index was calculated using claims for services provided in the year before diagnosis, ending 1 month before diagnosis to ensure that the condition was present before diagnosis rather than a complication of care.¹⁴

Statistical Analysis

Bivariable associations between race and ethnicity and receipt of hospice care are presented. To determine whether racial and ethnic differences in rates of hospice enrollment remained significant after adjustment for sociodemographic and clinical factors, multivariable Cox proportional hazards models were fitted to determine the relationship between race and ethnicity and hospice enrollment rate. These models were adjusted for age, sex, marital status, median household income, state buy-in status, foreign-born status, site of primary cancer,

tumor grade, year of diagnosis, and comorbidity score and were stratified according to SEER registry. Bivariable analyses were used to estimate unadjusted associations between race and ethnicity and each indicator of high-intensity care. Multivariable logistic regression was used to estimate the association between race and ethnicity and each indicator of high-intensity care, after adjustment for age, sex, marital status, median household income, state buy-in status, foreign-born status, site of primary cancer, tumor grade, year of diagnosis, comorbidity score, and SEER registry.

Although *P*-values are presented, small differences may be statistically significant because of the large sample size but may not be clinically meaningful. All analyses were performed using SAS version 9.1 (SAS Institute, Inc., Cary, NC).

RESULTS

Sample Characteristics

Sample characteristics of the patients with advanced cancer are presented in Table 1. This cohort was elderly, with a mean age at diagnosis overall of 74.7. Because of the patient mix according to site of cancer, a greater proportion of whites than of blacks, Asians, and Hispanics were female (Table 1). As expected, mortality was high, with 51.0% of patients dying within 6 months of diagnosis.

Hospice Enrollment and Length of Stay

The proportion of elderly patients with advanced cancer who enrolled in hospice was highest in whites (42.0%), lower in Hispanics (37.7%) and blacks (36.9%), and lowest in Asians (32.2%) (Table 2). After adjustment for age, sex, marital status, median household income, state buy-in status, foreign-born status, site of primary cancer, tumor grade, year of diagnosis, comorbidity score, and SEER registry, lower rates of hospice enrollment persisted for black and Asian but not Hispanic patients compared to whites (black: adjusted hazard ratio (aHR) = 0.91, 95% confidence interval (CI) = 0.85–0.97; Asian: aHR = 0.76, 95% CI = 0.69–0.84; Hispanic: aHR = 1.01, 95% CI = 0.92–1.11). Median length of stay in hospice and the proportion of patients who enrolled in hospice within 3 days of death were similar according to race and ethnicity (Table 2).

High-Intensity Care at the End of Life

Use of high-intensity care at the end of life according to race or ethnicity is depicted in Figure 1. Trends evident in the unadjusted proportions remained significant after adjustment for age, sex, marital status, median household income, state buy-in status, foreign-born status, site of primary cancer, tumor grade, year of diagnosis, comorbidity score, and SEER registry. Black and Asian patients with advanced cancer were more likely than white patients to be hospitalized two or more times (black: adjusted odds ratio (aOR) = 1.26, 95% CI = 1.14–1.41; Asian: aOR = 1.17, 95% CI = 1.01–1.34), spend more than 14 days hospitalized (black: aOR = 1.54, 95% CI = 1.39–1.71; Asian: aOR = 1.45, 95% CI = 1.28–1.68), and die in the hospital (black: aOR = 1.12, 95% CI = 1.11–1.32; Asian: aOR = 1.38, 95% CI = 1.24–1.53). Blacks were also more likely than whites to have two or more ED visits in the last month of life (aOR = 1.60, 95% CI = 1.40–1.83). With the exception of ICU admission, Hispanics received high-intensity care as often as whites. Admission to the ICU in the last month of life was higher for all minority patients than for whites (Hispanic: aOR = 1.33, 95% CI = 1.15–1.54; black: aOR = 1.15, 95% CI = 1.04–1.27; Asian: aOR = 1.30, 95% CI = 1.13–1.48). Black patients were slightly less likely than whites to receive chemotherapy in the last 14 days before death (aOR = 0.72, 95% CI = 0.60–0.86).

DISCUSSION

Older black and Asian patients with advanced cancer were less likely than whites to enroll in hospice and more likely to receive high-intensity care at the end of life. Black and Asian patients were more likely to be hospitalized frequently and for prolonged periods and to be admitted to the ICU in the last month of life than whites; they were also more likely to die in the hospital. Hispanic patients enrolled in hospice and used high-intensity care at the end of life at rates similar to whites.

The primary question that these findings raise is the extent to which these differences are due to differences in patient preferences or to disparities resulting from inequities in access to hospice or bias within the healthcare system. A significant body of literature suggests that black patients have a greater preference for high-intensity care at the end of life and a lesser preference for hospice.^{15–18} Patient preferences may fully or partly explain differences found in the current study, although other studies found that preferences did not account for racial and ethnic differences of advance care planning.^{17,18} Clarifying the extent to which racial and ethnic differences in end-of-life care are due to cultural differences in care preferences rather than to inequities is important, because the implications for intervention differ depending on the underlying explanation. Finding that differences in end-of-life care are due to patient preferences would suggest the need to develop educational initiatives about cultural differences, whereas finding that differences result from inequities in access to hospice and palliative services would suggest the need to promote access to these services for underserved populations.

These findings build on previous research suggesting lower rates of hospice enrollment for black and Asian patients with cancer than for whites and similar rates for Hispanics and whites.^{13,19,20} These previous studies examined decedent cohorts of patients diagnosed with all stages of cancer, including those with limited-stage disease. The validity of such retrospective studies have been questioned, because clinicians sometimes find it difficult to predict the end of life with certainty.²¹ This study, in contrast, used an incident cohort of patients diagnosed with serious life-threatening illness and examined outcomes at the end of life. The consistency of the findings presented here with previous research lends strength to the validity of both approaches.²²

Trends established before the end of life may influence these indicators of high-intensity care. For example, blacks are less likely to receive multiple forms of cancer treatment, including surgery for resectable disease, radiotherapy when indicated, and chemotherapy.⁶ The finding of lower rates of chemotherapy for black than for white patients within 14 days of death may reflect inequities in access to treatment that persist throughout the continuum of care, including the end of life. Similarly, possibly reflecting a long history of poorer access to care, black patients are more likely to identify the ED as their usual source of care;²³ 10% of black patients with advanced cancer used the ED frequently (≥ 2 times) in the last month of life, rates higher than any other racial or ethnic group. This finding may reflect greater use of high-intensity care, as well as a trend toward greater use of the ED for care throughout life for black patients. Greater use of the ED for terminal care in blacks is of particular concern given persistent racial disparities in wait times to see a physician and opioid prescribing and in U.S. EDs.^{5,24}

Asian Americans are one potentially vulnerable ethnic group that is understudied with respect to end-of-life care. Little is known about the dying experience of Asians with cancer. A previous study found that Asians dying of cancer were substantially less likely to receive hospice care than whites, especially if they were foreign born.¹⁹ A subsequent study showed that hospice enrollment and length of stay varied significantly across Asian/Pacific Islander ethnic subgroups.²⁵ The present study confirms these findings in an incident cohort while also

establishing greater usage of high-intensity care at the end of life for Asians with advanced cancer than for whites. The underlying reasons for these differences are poorly understood. One study found that Korean Americans had a more-positive attitude toward life-sustaining treatment than European Americans but had a lower personal desire to receive these treatments.²⁶ Studies of cancer patients in Taiwan suggest considerable discrepancy between patients' and caregivers' preferences for end-of-life care.²⁷

In contrast to the experiences of black and Asian patients with advanced cancer, similarities in end-of-life experiences of Hispanic and white patients are noteworthy. The Medicare Hospice Benefit requires the presence of a fulltime caregiver in most cases. Because of strong kinship ties within the Hispanic community,²⁸ this requirement may be less of a barrier for families of Hispanic patients than black or Asian patients, although this hypothesis requires further exploration. Racial and ethnic differences in cultural attitudes toward death in the home versus an institutional setting may partly explain these findings.

This study has several limitations. First, as discussed above, no information on patient preferences, which may have guided care decisions at the end of life, was available. Second, outcomes for seriously ill patients diagnosed initially with limited-stage cancer that subsequently progressed were not examined. Third, the cohort studied was composed of advanced cancers with varying survival times. Six-month survival was higher for patients with stage IV prostate cancer than for patients with stage IIIB or IV lung cancer, for example. Fourth, the study sample did not include the approximately 20% of patients with managed care insurance, because claims for managed care beneficiaries used to study high-intensity care at the end of life are not available. That managed care beneficiaries are more likely to enroll in hospice has been well established;¹² less is known about how use of high-intensity care at the end of life differs between Medicare and fee-for-service beneficiaries. Fifth, although some of these data are from late 2001, much of the data are from the 1990s, and trends may have changed in the intervening years. For example, there is some evidence that the difference in hospice enrollment between blacks and whites has decreased over time.²⁹ Sixth, the implications of these findings for patients with noncancer illnesses are unclear. Although black patients are more likely to enroll in hospice with a diagnosis of human immunodeficiency virus/acquired immunodeficiency syndrome than white patients,²⁹ in the absence of large-scale population-based studies of patients with noncancer diagnoses, comparing the use of services at the end of life according to diagnosis alone is problematic, because there is no denominator for comparison. Finally, SEER-Medicare may not be a closed system. Some of these elderly advanced cancer patients, particularly Hispanic and Asian patients, may be returning to their country of ethnic origin to die.³⁰

In conclusion, this study is an important step toward understanding the magnitude and scope of racial and ethnic differences in the end-of-life experience for older adults with advanced cancer. Additional research is needed to investigate the factors for which these "racial" and "ethnic" differences are a proxy. There needs to be a better understanding of the ways in which patient preferences and healthcare system factors contribute to observed racial and ethnic differences in use of hospice and high-intensity care at the end of life. Improved understanding will hopefully lead to interventions that improve end-of-life care for all patients with advanced cancer.

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Indicators of High-Intensity Care at the End of Life by Race/Ethnicity, Unadjusted (n=40,960)

Figure 1.

For each measure of high-intensity care at the end of life, $P < .001$ for differences according to race or ethnicity.

Table 1

Sample Characteristics According to Race or Ethnicity*

Characteristic	Overall Sample (N = 40,960)	Non-Hispanic White (n = 33,293)	Hispanic (n = 1,520)	Non-Hispanic Black (n = 4,095)	Asian (n = 2,052)	P-Value [†]
Patient characteristics						
Age at diagnosis, mean (SD)	74.7 ± 6.6	74.4 ± 6.5	73.9 ± 6.7	73.5 ± 6.4	74.7 ± 6.6	
Female, n (%)	17,066 (41.7)	14,251 (42.8)	576 (37.9)	1,525 (37.2)	714 (34.8)	<.001
Married at diagnosis, n (%)	21,719 (53.0)	18,074 (54.3)	776 (51.1)	1,546 (37.8)	1,323 (64.5)	<.001
Foreign born, n (%)	3,529 (8.6)	2,215 (6.7)	357 (23.5)	40 (1.0)	917 (44.7)	<.001
State buy in, n (%)	5,898 (14.4)	3,126 (9.4)	629 (41.4)	1,281 (31.3)	862 (42.0)	<.001
Income: lowest quintile, n (%)	8,344 (20.4)	4,815 (14.5)	513 (33.8)	2,468 (60.3)	548 (26.7)	<.001
Clinical characteristics, n (%)						
Cancer type						
Stage IIb, IV non-small-cell lung	21,413 (52.3)	17,412 (52.3)	733 (48.2)	2,037 (49.7)	1,231 (60.0)	
Extensive-stage small	4,525 (11.1)	3,949 (11.9)	127 (8.4)	771 (18.8)	362 (17.6)	
Stage IV colorectal	8,076 (19.7)	6,621 (19.9)	322 (21.2)	223 (5.5)	62 (3.0)	<.001
Stage IV breast	1,995 (4.9)	1,633 (4.9)	77 (5.1)	769 (18.8)	243 (11.8)	
Stage IV prostate	4,951 (12.1)	3,678 (11.1)	261 (17.2)	295 (7.2)	154 (7.5)	
Area characteristics, n (%)						
Died within 6 months of diagnosis	20,889 (51.0)	17,192 (51.6)	718 (47.2)	2,022 (49.4)	957 (46.6)	<.001
Tumor grade, poorly differentiated	13,456 (32.9)	10,778 (32.4)	535 (35.2)	1,362 (33.3)	781 (38.1)	<.001
Charlson Comorbidity Index ≥2	4,616 (11.3)	3,634 (10.9)	182 (12.0)	575 (14.0)	225 (11.0)	<.001
Area characteristics, n (%)						
Residence in large metropolitan area	25,338 (61.9)	19,366 (58.2)	1,031 (67.8)	3,779 (92.3)	1,162 (56.6)	<.001
Registry						

Characteristic	Overall Sample (N = 40,960)	Non-Hispanic White (n = 33,293)	Hispanic (n = 1,520)	Non-Hispanic Black (n = 4,095)	Asian (n = 2,052)	P-Value [†]
Atlanta	2,376 (5.8)	1,732 (5.2)	15 (1.0)	622 (15.2)	7 (0.3)	
Connecticut	5,727 (14.0)	5,398 (16.2)	68 (4.5)	246 (6.0)	15 (0.7)	
Detroit	7,652 (18.7)	5,787 (17.4)	30 (2.0)	1,812 (44.3)	23 (1.1)	
Hawaii	1,147 (2.8)	317 (1.0)	10 (0.7)	[‡]	815 (39.7)	
Iowa	6,172 (15.1)	6,085 (18.3)	17 (1.1)	64 (1.6)	6 (0.3)	
Los Angeles	6,066 (14.8)	4,146 (12.5)	632 (41.6)	760 (18.6)	528 (25.7)	<.001
New Mexico	1,449 (3.5)	1,074 (3.2)	346 (22.8)	25 (0.6)	[‡]	
San Francisco	3,267 (8.0)	2,293 (6.9)	180 (11.8)	404 (9.9)	390 (19.0)	
San Jose	1,658 (4.1)	1,310 (3.9)	158 (10.4)	37 (0.9)	153 (7.5)	
Seattle	4,227 (10.3)	3,988 (12.0)	30 (2.0)	110 (2.7)	99 (4.8)	
Utah	1,219 (3.0)	1,163 (3.5)	34 (2.2)	10 (0.2)	12 (0.6)	

* Percentages may not add up to 100 because of rounding.

[†] Chi-square *P*-value for difference according to race or ethnicity.

[‡] Data not shown because cell sizes <5.

Table 2

Unadjusted Hospice Enrollment and Length of Stay According to Race or Ethnicity

Hospice Enrollment and Length of Stay	Non-Hispanic White	Hispanic	Non-Hispanic Black	Asian	P-Value*
Hospice enrollment, % (n = 40,930) [†]	42.0	37.7	36.9	32.2	<.001
Hospice length of stay, median days (n = 16,628) [‡]	19	21	21	17	.32
Hospice length of stay 3 or fewer days, % (n = 16,628) [‡]	10.8	10.9	11.2	12.2	.69

* P-values for hospice enrollment based on chi-square test for hospice enrollment and length of stay 3 or fewer days and on Wilcoxon test for median length of stay.

[†] Sample for analysis of hospice enrollment does not include 30 patients with hospice claims before diagnosis.

[‡] Sample for analyses of hospice length of stay and length of stay 3 or fewer days includes patients who were admitted to hospice, excluding 87 patients whose date of death preceded their last hospice claim.