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Racial Disparities in Hospice Outcomes: A Race or Hospice-Level Effect?

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Abstract

Background/objectives—Black Americans receive more intensive and higher cost care at the end of life including higher rates of hospitalization and lower rates of hospice enrollment. We sought to determine if racial variation exists among hospice enrollees in rates of hospitalization and hospice disenrollment and whether variation is explained by systematic differences in hospice provider patterns.

Design—Longitudinal cohort study.

Participants—Medicare beneficiaries (N= 145,038) enrolled in a national random sample of hospices (N=577) from the National Hospice Survey and followed until death (2009–2010).

Measurements—We used Medicare claims data to identify the following after hospice enrollment: hospital admission, emergency department visits (ED), and hospice disenrollment. We estimated a series of hierarchical models including hospice-level random effects to compare outcomes between blacks and whites.

Results—In unadjusted models, black hospice patients were significantly more likely than white patients to be admitted to the hospital (14.9% vs 8.7%, OR =1.84, 95%CI=1.74–1.95), visit the ED (19.8% vs. 13.5%, OR=1.58, 95%CI=1.50–1.66), and disenroll from hospice (18.1% vs. 13.0%, OR=1.48, 95%CI=1.40–1.56). These results were largely unchanged after accounting for patient clinical and demographic covariates and hospice-level random effects. In adjusted models, blacks were at higher risk for hospital admission (OR =1.75, 95%CI=1.64–1.86), ED visits (OR=1.61, 95%CI=1.52–1.70), and hospice disenrollment (OR=1.54, 95%CI=1.45–1.63).

Conclusions—Racial differences in intensity of care at the end of life are not attributable to hospice-level variation in intensity of care. Differences in patterns of care between black and white hospice enrollees persist within the same hospice.

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Introduction

Multiple studies find disparities between blacks and whites in the intensity of care at the end of life. Black patients receive more intensive and higher cost treatments at the end of life including greater rates of hospital admission, Emergency Department (ED) visits, Intensive Care Unit (ICU) stays, gastrostomies for artificial nutrition, mechanical ventilation, and cardiopulmonary resuscitation.^{1–6} Consistent with this pattern, blacks are less likely to enroll in hospice compared with non-minorities, despite the growth of hospice across the country during the past decade.^{7–9} For example, using data from 2014, an estimated 76% of all hospice patients were white and only 7.6% were black.⁷ In this same year, an estimated 47% of white patients died while under the care of hospice compared with 31% of black patients.¹⁰ Even after enrolling in hospice, black patients are more likely to disenroll in order to seek curative treatment not covered under hospice care.¹¹ The greater use of high intensity healthcare at the end of life by blacks has been shown to be independent of sex, education, marital status, existence of a living will, income, religiosity, and neighborhood socioeconomic status.^{9, 12–13} This pattern of healthcare use at the end of life for blacks compared with whites may be due to preferences not captured by these characteristics or to lack of knowledge of hospice.^{8–9, 14–15}

Evidence suggests that for some outcomes, however, racial disparities in care are more likely rooted at the provider level rather than in patient-level differences in preferences for care. For example, a study of end-of-life ICU use found that the majority of observed differences in ICU use during terminal admissions among black and Hispanic patients compared with whites was attributed to their use of hospitals with a higher ICU use overall.¹⁶ The impact of provider-level variation on intensity of end-of-life care may be particularly important in understanding the intensity of care for hospice enrollees. Recent studies indicate substantial variation across hospices in certain patient outcomes. Specifically, there is substantial hospice-level variation in the proportion of hospice enrollees who use the hospital (from 0% of patients at some hospices to 55.6% of patients at other hospices), ED (from 0% of patients at some hospices to 72.7% of patients at others), and ICU (from 0% of patients at some hospices to 26.6% of patients at others).¹⁷ Similarly, the proportion of hospice enrollees who disenroll from hospice was found to range from 0% of patients at some hospices to 38% of patients at others.¹⁸ Some of this hospice provider-level variation is associated with differences in hospice practices, ownership, and size,^{17–18} including evidence that for-profit hospices and hospices that spend less on direct patient care (e.g., home visits) are more likely to be in the highest quartiles of these utilization outcomes.¹⁹

Although previous studies have found that black patients have higher rates of hospitalization after enrolling in hospice than white patients,^{20–23} without accounting for provider level variation, the conclusions of these studies are limited. Specifically, it is unknown if blacks tend to be cared for by hospices with higher rates of hospital utilization and hospice

disenrollment *for all patients* or if racial differences in outcomes are due to within hospice differences by race. Accordingly, we examined the relationship between race and hospitalizations and ED visits following hospice enrollment and disenrollment from hospice. We estimated the extent to which observed differences in outcomes are attributable to blacks' enrollment in hospices with higher rates of hospital utilization and disenrollment rather than racial differences in these outcomes within the same hospice. Discerning these patterns is essential to understanding racial differences in end-of-life healthcare and ensuring access to optimal care for all patients.

Methods

Study Design and Sample

We used data from a longitudinal cohort study of Medicare beneficiaries (N= 213,495) enrolled in a national random sample of hospices (N=591) from the National Hospice Survey and followed until death (2009–2010). As reported elsewhere,^{17, 24–26} we chose the random sample of hospices from the Medicare Provider of Services files, which includes all hospices that participate in the Medicare program. We collected completed surveys from 591 hospices, representing an 84% response rate. We linked 577 of these hospices (98%) to the Medicare claims data for beneficiaries; the claims data was unavailable for 14 of these hospices due primarily to these hospices having merged or closed during the survey period. This sample represents approximately 20% of all Medicare-certified hospices in the United States that were operating in 2009.

From this group, we excluded patients younger than 66 (N=15,003) to ensure individuals were eligible for Medicare in the year before hospice enrollment so that we could access data on preexisting chronic conditions. We excluded patients not eligible for both Medicare Parts A and B (N=2,111) or who were enrolled in a managed care organization (N=46,567). Race was collected from the Medicare claims data where it is recorded as one of six values (White, Black, Asian, North American Indian, Hispanic, Other, and unknown). A patient's race is populated in the Medicare enrollment database as it was voluntarily self-reported to the Social Security Association upon applying for or renewing a Social Security number.²⁷ Medicare claims data for black and white beneficiaries is considered more sensitive and less vulnerable to the biases and inaccuracies of coding recognized among the relatively smaller racial and ethnic groups.²⁷ We excluded patients who did not report their race and those who reported a race or ethnicity other than white or black (N= 4,776). After applying exclusion criteria, our total sample included 145,038 patients from 577 hospices.

Measures

For this analysis, we included questions regarding descriptive characteristics of hospices collected in this survey including: ownership (for profit, nonprofit, government/other), whether the hospice was part of a chain of hospices, size (number of patients per day in the past 12 months), whether the hospice was in an urban area, and the census region of the hospice.

From the Medicare claims data, we obtained patient demographic and clinical information including sex (male, female), age (categorized as 65–69, 70–74, 75–79, 80–84 and 85 years and above), and primary diagnosis based on International Classification of Diseases, Ninth Revision (ICD-9) codes. We obtained information regarding the number of chronic conditions by examining all Medicare hospital inpatient and outpatient claims for each individual for the 12 months before their hospice enrollment. We measured hospice length of stay for each patient using Medicare hospice claims data.

For our dependent variables, we measure the following utilization based outcomes, gathered from Medicare claims data, from the time of a beneficiary's hospice enrollment to his/her death: 1 hospitalization, 1 ED visits, and disenrollment from hospice (including those who voluntarily disenroll from hospice and those who no longer meet hospice eligibility criteria and are disenrolled by the hospice).

Statistical analysis

We estimated the association between race and demographic and clinical characteristics using chi-squared tests. We estimated the proportion of each hospice's patients who experienced the following utilization-based outcomes from the time of their hospice enrollment to their death: one or more hospitalizations, one or more ED visits, and hospice disenrollment. We compared the unadjusted proportion of black versus white hospice enrollees with each of these outcomes.

We undertook a series of steps to graphically depict hospital utilization and hospice disenrollment patterns across hospice providers and by race, paralleling prior research in racial disparities.¹⁶ First, we calculated the proportion of patients hospitalized among white hospice enrollees at each hospice and arrayed hospices by decile from lowest to highest white hospitalization rate. We conducted an ordered logistic regression model to estimate the association between race and deciles of hospitalization rate. Second, using hospices with at least 5 black hospice enrollees (n=360 hospices), we determined the proportions of black and white hospice enrollees admitted to hospices within each decile. Third, we calculated the black and white hospitalization rates within each decile for comparison. We repeated these steps for the outcome of ED visits and the outcome of hospice disenrollment.

We used sequential hierarchical models to address the clustering of patients within hospices. We first estimated an unadjusted logistic regression model including only hospice enrollee race (black compared with white). Next, we estimated a hierarchical model including race and hospice random effects to adjust for unobserved hospice-level factors omitted from the model that systematically raise or lower utilization of all enrollees in that hospice. We then estimated a fully-adjusted model including race, hospice random effects, patient clinical and demographic characteristics (i.e., age, gender, cancer as a primary diagnosis, number of chronic conditions, and length of hospice stay). All analyses were performed in Stata Version 14 software (StataCorp LP, College Station, TX).

Results

Study Population

Our sample of Medicare beneficiaries was composed of 133,996 (92.4%) white patients and 11,072 (7.6%) black patients who were enrolled in the 577 hospices that responded to the National Hospice Survey. Approximately half of hospices were for profit, providing care to about one third of the population of patients in the sample, and approximately half of the hospices had <50 patients per day on average. About a quarter of hospices were members of a chain of hospices. Approximately 90% of patients were served in hospices in an urban area, representing about two thirds of hospices. Demographic and clinical characteristics of the black and white patients in the sample and the characteristics of the hospices they utilized can be found in Supplementary Table 1. Black patients were significantly more likely to be younger, female, and have a primary diagnosis of neoplasm than white patients in the sample. Black patients were more likely to be admitted to hospices that were larger, for-profit, and located in an urban area than white patients.

Hospice Admission Patterns

In examining hospice admission patterns, black hospice enrollees were not disproportionately cared for by hospices with higher rates of hospital admission, ED use, or hospice disenrollment (Supplementary Figure 1). The magnitudes of differences in black and white proportions across decile categories are fairly small and inconsistent in direction. Specifically, the largest difference between proportions of black and white patients in any one decile was 2.6 percent for hospital admission, 5.4 percent for ED visits, and 3.2 percent for hospice disenrollment. In addition, there are slightly higher proportions of black patients compared with white patients in both the highest and lowest deciles for each outcome. Quantitative comparison of the association between race and decile using ordered logistic regression was not statistically significant for any of the study outcomes. Yet within deciles of hospital admission, ED use, and hospice disenrollment, the rates among blacks are significantly higher than the rates among whites (Figure 1).

Hospital Utilization and Hospice Disenrollment Outcomes

Overall, 11,611 (8.7%) white patients in our sample were admitted to the hospital, 18,085 (13.5%) visited the ED, and 17,400 (13.0%) disenrolled from hospice, compared with 1,649 (14.9%) black patients admitted to the hospital, 2,191 (19.8%) visited the ED, and 2,001 (18.1%) disenrolled from hospice (Figure 2) ($p<0.01$ for each comparison). In unadjusted models (Table 1, Model 1), black hospice patients were significantly more likely than whites to be admitted to the hospital (OR = 1.84, 95%CI=1.74–1.95), visit the ED (OR=1.58, 95%CI=1.50–1.66), and disenroll from hospice during the course of their care (OR=1.48, 95%CI=1.40–1.56). In models accounting for hospice random effects (Table 1, Model 2), black patients remained more likely than whites to have each measured outcome: hospital admission (OR=1.72, 95%CI=1.62–1.83), ED visits (OR=1.53, 95%CI=1.46,1.64), and hospice disenrollment (OR= 1.45, 95%CI=1.37, 1.53). Similarly, in the fully adjusted model including hospice random effects as well as demographic and clinical characteristics (Table 1, Model 3), blacks had higher odds of hospital admission (OR =1.75, 95%CI=1.64–1.86),

ED visits (OR=1.61, 95% CI=1.52–1.70), and disenrollment from hospice (OR=1.54, 95% CI=1.45–1.63).

Discussion

In a large, national sample of hospice users, blacks had significantly higher rates of hospital admission, ED visits, and hospice disenrollment at the end of life. Our results suggest that these higher rates of hospital utilization and hospice disenrollment by blacks compared with whites are attributable to racial differences *within* the same hospice rather than systematic differences between hospices in hospital utilization and hospice disenrollment rates.

There are a number of important potential explanations for our findings. First, a commonly proposed explanation for differences in intensity of end-of life care by race is differences in patient preferences. Black patients are more likely to have a preference for life-sustaining therapies and to hold spiritual beliefs that may conflict with the goals of hospice care than white patients.^{11, 28–29} This preference is often attributed to a general distrust in the healthcare system based on the history of racism in medical research and persistent health disparities.³⁰ However, while it is true that blacks are more likely to prefer intensive treatment at the end of life, the majority still prefer to die at home.³¹

Second, our finding of patient-level difference between black versus white patients at the same hospice may also reflect differences in the patterns of communication between black versus white patients regarding hospice that result in a lack of understanding of hospice care and potentially inappropriate hospice enrollment. In a study of chronic kidney disease patients, blacks were less likely than whites to understand hospice or to have had end of life discussions with healthcare providers.³² In the last year of life, blacks are less likely than whites to visit a primary care doctor, which has been associated with higher hospitalization rates and in-hospital deaths for these patients.³³ Poor interpersonal communication between doctors and their black patients has been proposed as a reason for their lack of trust in the healthcare system.³⁴ It is possible that improving provider communication and patient understanding of hospice could reduce these disparities.

A third potential explanation for our finding of higher rates of hospitalization and disenrollment for blacks compared with whites is differing availability of resources. Given that hospice care is primarily provided in a patient's home, the quality of care may be largely dependent on the resources of caregivers and availability of support at or near the home of the patient. Evidence suggests that black hospice patients may have a more difficult time accessing appropriate resources.^{15, 35–38} Specifically, their local pharmacy may be less likely to stock adequate pain medication and they are less likely to receive regular visits by a health aide or other health professional.^{35–37} Black patients may face particularly high barriers to access to certain resources, even when compared to white patients at the same hospice, causing them to resort to the hospital or disenroll from hospice.^{15, 38}

Although many of the above factors are often cited as contributing to lower rates of hospice enrollment for blacks compared with whites, it is plausible that these same factors may contribute to differences in patterns of care after hospice enrollment. The specific individual

and family level causes of hospitalization after hospice enrollment and hospice disenrollment are not well known. A recent qualitative study asked hospice care providers why their patients were hospitalized after hospice enrollment and these providers cited the families' lack of understanding of hospice, caregiver burden, slow hospice response time compared to 911, and a preference for more intensive treatment.³⁹ A related study that interviewed family caregivers had similar findings.⁴⁰ Finally, it is important to note that although hospice provider level effects do not explain racial differences in study outcomes, the similar increase in proportions for each outcome across deciles for both whites and blacks depicted in Figure 1 suggests that hospice provider level effects impact these outcomes. This is consistent with existing evidence^{17–19, 24–26} regarding provider level variation in hospital utilization and hospice disenrollment of hospice enrollees.

There are several limitations to our study. First, it is possible that differences in utilization outcomes are a result of unmeasured aspects of the patients' clinical or socioeconomic characteristics. Although our models adjusted for multiple characteristics of patients known to be associated with utilization outcomes, it is possible that there are unmeasured confounders.¹⁵ Second, our analysis does not include information regarding patient or family preferences for care or if these preferences were met, including whether hospice disenrollment was voluntary or initiated by the hospice. Nor do we have information on patient or family satisfaction or quality of life. Understanding the extent to which high intensity outcomes align with patient and family preferences is essential for determining if and how to shape interventions to better align patient preferences and outcomes for black and white hospice patients. Third, our results are not generalizable to the hospices in the United States that do not participate in the Medicare program (approximately 7%), hospice patients who are not Medicare beneficiaries, or hospice patients who were enrolled in managed care organizations. Finally, our sample only analyzed black patients compared with white patients and does not provide information on hospice outcomes for patients of other races. While little is known about the end-of-life care of other races in America, some evidence suggests that Hispanic patients have higher healthcare costs and higher use of intensive care at the end of life than white or black patients.^{2, 32} Less is known about Asian, Pacific Islander, or Native American patients warranting future research in these populations.

Our findings underscore the need to better understand racial disparities in outcomes after hospice enrollment. Differences in rates of hospital admission, ED visits, and hospice disenrollment are not driven by differential enrollment in hospices with varying rates of these outcomes. Rather, our findings suggest that blacks have higher hospital utilization and hospice disenrollment regardless of whether the hospice caring for them has high or low rates of these outcomes. In addition to increasing the financial costs of end-of-life care, greater use of the hospital and higher hospice disenrollment by black patients may adversely impact the quality of the end of their life and increase caregiver burden. Culturally sensitive interventions that increase understanding of hospice, address shortcomings in provider communication, and improve caregiver resources could help decrease these persistent differences in outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Hospital Utilization and Hospice Disenrollment among Hospice Patients by Decile of Hospice Treatment Intensity

We grouped hospices into deciles arrayed from hospices with the lowest to highest rates of hospital admission (A), Emergency Department visits (B), and hospice disenrollment (C). Each panel compares the percent of black and white patients with each outcome in each decile. Error bars represent 95 percent confidence intervals around the decile rate estimate.

Figure 2.
Unadjusted Differences in Hospital Utilization and Hospice Disenrollment between Black and White Patients

Table 1

Hospital Utilization and Hospice Disenrollment:
Black Patients Compared to White Patients

	Model 1 OR (95% CI)	Model 2 OR (95% CI)	Model 3 OR (95% CI)
Hospital Admission	1.84 (1.74, 1.95)	1.72 (1.62, 1.83)	1.75 (1.64, 1.86)
ED Visits	1.58 (1.50, 1.66)	1.53 (1.46, 1.62)	1.61 (1.52, 1.70)
Disenrollment	1.48 (1.40, 1.56)	1.45 (1.37, 1.53)	1.54 (1.45, 1.63)

Model 1: Unadjusted

Model 2: Adjusted only for hospice random effects

Model 3: Adjusted for hospice random effects, average age, percent female, percent with cancer as a primary diagnosis, average number of chronic conditions and median length of hospice stay