

# Lower Use of Hospice by Cancer Patients who Live in Minority Versus White Areas

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**BACKGROUND:** Although hospice care can alleviate suffering at the end of life for patients with cancer, it remains underutilized, particularly by African Americans and Hispanics.

**OBJECTIVE:** To examine whether the racial composition of the census tract where an individual resides is associated with hospice use.

**DESIGN:** Retrospective analysis of the Surveillance, Epidemiology, and End Results–Medicare file for individuals dying from breast, colorectal, lung, or prostate cancer ( $n=70,669$ ).

**MEASUREMENTS:** Hospice use during the 12 months before death.

**RESULTS:** Hospice was most commonly used by individuals who lived in areas with fewer African-American and Hispanic residents (47%), and was least commonly used by individuals who lived in areas with a high percentage of African-American and Hispanic residents (35%). Hispanics (odds ratio 0.51, 95% confidence interval 0.29–0.91) and African Americans (0.56, 0.44–0.71) were less likely to use hospice if they lived in a census tract with a high percentage of both African Americans and Hispanics than if they lived in a low minority tract. African Americans and whites were less likely to receive hospice care if they lived in a census tract with a high percentage of Hispanics than if they lived in a low minority area.

**CONCLUSIONS:** Increasing hospice use may require interventions to improve the delivery of hospice care in minority communities.

**KEY WORDS:** race; ethnicity; hospice; segregation.

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## INTRODUCTION

Hospice care, palliative care, and supportive services for patients and their families is a cornerstone of end-of-life care

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for patients with cancer and has been associated with less suffering and better satisfaction than conventional hospital care.<sup>1,2</sup> Medicare has provided coverage for hospice services since 1983.<sup>2,3</sup> Although the use of hospice care has been increasing over time, it remains underutilized, particularly for African Americans and perhaps Hispanics.<sup>3–8</sup>

There are theoretically 3 ways in which the characteristics of the area where an individual resides may influence the use of hospice care, which is typically provided at home rather than an institutional setting: the availability of necessary services and resources (e.g., pharmacies, home care services), the presence of caregivers and social support networks for a dying patient, and familiarity with and acceptance of hospice care. Although there are several potential reasons for racial and ethnic disparities in hospice use, shortages of necessary services and resources as well as more limited social acceptance of and familiarity with hospice care in areas with large minority populations may contribute. For example, the concentrated poverty that frequently occurs in minority neighborhoods may lead to fragile social networks.<sup>9</sup>

The purpose of this study is to examine whether the racial composition of the local area where an individual resides is associated with the use of hospice care at the end of life for non-Hispanic African Americans (hereafter, called African Americans), non-Hispanic whites (hereafter, called whites), and Hispanics with four common cancers.

## METHODS

### Data

This analysis is based on data from the Surveillance, Epidemiology, and End Results (SEER)–Medicare file. These data include Medicare claims for persons with cancer residing in SEER program areas (states of Connecticut, Hawaii, Iowa, New Mexico, and Utah and the metropolitan areas of Detroit, San Francisco, Atlanta, Seattle, Los Angeles, and San Jose). At the time of this analysis, data were available for individuals diagnosed with cancer from 1992 to 1999 with Medicare claims data available through 2001. The SEER program sites collect information on all incident cancer cases. These data have been linked by the National Cancer Institute to Medicare claims. A restricted access version of these data was obtained so that the characteristics of each individual's census tract of residence, from the 1990 U.S. Census, could be appended.

This study was reviewed and approved by the Institutional Review Board of Brigham and Women's Hospital.

## Sample

We included individuals who had died from cancer between 1992 and 2000, who were at least 66 years of age at the time of death, and who had been diagnosed with breast, colorectal, lung, or prostate cancer before death. We excluded individuals less than 66 years of age to ensure access to at least a full year of Medicare claims. Because our analysis was focused on the role of residential characteristics, we excluded 1,016 individuals with a missing census tract identifier.

The sample was limited to individuals whose race/ethnicity was reported as white, African-American, or Hispanic. Although the racial designation of whites and blacks in these data is reasonably sensitive and specific,<sup>10</sup> the designation of Hispanic ethnicity is less so. However, prior analyses have used Medicare data to identify individuals of Hispanic ethnicity.<sup>11,12</sup> Our final dataset included 70,669 individuals.

## Variables

The principal outcome was whether an individual had used hospice care during the 12 months before death. Because the Medicare benefit requires that hospice patients forgo curative treatments, individuals may disenroll or reenroll in hospice care. We therefore defined our outcome as any hospice claim, either at home or in an institutional setting, during this period.

Our principal independent variable was the racial composition of the area where each individual resided at the time of diagnosis, measured by the percentage of African-American and Hispanic residents within the census tract. We categorized areas as: (1) high African-American and high Hispanic, where each group was at least 30% of the population; (2) high African-American only, where the percentage of African-American residents was at least 30% and the percentage of Hispanics was less than 30%; (3) high Hispanic only, where the percentage of Hispanic residents was at least 30% and the percentage of African Americans was less than 30%; and (4) low African-American and low Hispanic, where the percentage of both groups was less than 30%.<sup>13,14</sup> To test the robustness of our findings, we also used cut points of 25% and 35%.

Other census tract-level covariates included quintiles for median household income and the percentage of individuals who had graduated from college.

Individual-level independent variables included age (categorized as 66–74, 75–84, or at least 85 years), sex, race/ethnicity (white, African-American, or Hispanic), marital status (married or not married), site of cancer (breast, colorectal, prostate, or lung), stage at diagnosis (unstaged, local or regional, or distant), number of comorbid conditions (none, 1, 2, 3, or more), whether an individual was of “low income” (based on eligibility for state assistance with Medicare premiums and copayments), year of death, and indicators of whether someone was enrolled in a Medicare-managed care plan within the 13 months before diagnosis, at any time after diagnosis, or without Medicare coverage within 13 months before diagnosis (these indicators were used to adjust for individuals who may have less complete information about comorbid conditions). Information about hospice use is recorded for individuals with a Medicare-managed care plan as these services are paid directly by Medicare.

## ANALYSIS

Rates of hospice use were compared by independent variables using chi-square tests. Multilevel logistic regression models, clustered by census tract, were performed using SAS version 9 (SAS Institute, Carey, NC). Variables that were significantly associated with hospice use in bivariate analyses were included. These models adjusted for the individual- and area-level factors described above. Because we believed that the effect of neighborhood racial characteristics could differ for individuals of different race/ethnicity, we examined separate models for whites, African Americans, and Hispanics. Dummy variables for missing data were used in the regression models for marital status ( $n=2,123$ ). There were no other missing data.

## RESULTS

### Characteristics of the Sample

Forty-six percent of these individuals dying with cancer used hospice care during the 12 months before death. African Americans (42.5%) and Hispanics (44.5%) were significantly less likely than whites (46.5%) to use hospice care. Hospice care was significantly more common among women (48.2%) than men (44.6%), and individuals who were married (48.2%) than not married (44.3%). Hospice care was significantly less

Table 1. Census tract characteristics and hospice use

	Sample size	Ever used hospice during the year before death, % (n)
Racial/ethnic composition of census tract*		
African-American and Hispanic $\geq 30\%$	1,023	34.9 (357)
African-American <sup>†</sup>	775	33.7 (261)
Hispanic <sup>‡</sup>	80	27.5 (22)
White <sup>†</sup>	168	44.1 (74)
African-American $\geq 30\%$ and Hispanic $\geq 30\%$	6,676	44.3 (2,954)
African-American <sup>†</sup>	4,784	44.7 (2,140)
Hispanic <sup>‡</sup>	88	38.6 (34)
White <sup>†</sup>	1,804	43.2 (780)
African-American <30% and Hispanic >30%	6,921	43.0 (2,978)
African-American <sup>†</sup>	393	31.3 (123)
Hispanic <sup>‡</sup>	1,980	43.2 (855)
White <sup>†</sup>	4,548	44.0 (2,000)
Low minority	56,049	47.1 (26,378)
African-American <sup>†</sup>	1,167	43.2 (504)
Hispanic <sup>‡</sup>	1,405	47.8 (672)
White <sup>†</sup>	53,477	47.1 (25,202)
Median income quintile of census tract*		
$\leq *23,950$	14,159	42.2 (5,978)
*23,951–*30,950	14,208	45.6 (6,478)
*30,951–*37,593	14,176	47.9 (6,787)
*37,954–*46,882	14,146	47.7 (6,757)
>*46,882	13,980	47.7 (6,667)
Percent of college graduates in census tract*		
$\leq 9.9\%$	14,163	44.5 (6,309)
10.0–15.4%	14,153	45.8 (6,484)
15.5–23.0%	14,099	47.2 (6,653)
23.0–35.6%	14,141	46.0 (6,503)
>35.6%	14,113	47.6 (6,718)

\*P value of  $\chi^2$  test for racial/ethnic composition, median income and percent of high school graduates in census tract <.0001.

<sup>†</sup>P value of  $\chi^2$  test for racial/ethnic group <.0001.

common among low-income individuals (36.9%) than higher income individuals (48.7%).

Hospice care was less commonly used by individuals who lived in areas with a high percentage of African-American and Hispanic residents (35%) and most commonly used in low minority areas (47%—Table 1). Within each of these categories for the racial/ethnic composition of the census tract, there was variation in hospice use by personal race/ethnicity. For example, in high African-American and high Hispanic census tracts, 34% of African Americans, 28% of Hispanics, and 44% of whites used hospice care. Most individuals lived in areas with others of similar race/ethnicity.

### Area Racial Composition and Hospice Use

After adjustment for individual and area socioeconomic characteristics, Hispanics and African Americans who lived in a census tract with at least 30% African Americans and Hispanics were less likely to have used hospice care than individuals of similar race/ethnicity who lived in a low minority neighborhood (Table 2). No differences were observed for whites who lived in a high African-American and high Hispanic area, although there were few whites in these high minority areas ( $n=168$ ). African Americans and whites who lived in a Hispanic neighborhood were less likely to receive hospice care than individuals of similar race/ethnicity in a low minority area, whereas similar differences were not observed for Hispanics. There were no significant differences for whites, African

Americans, or Hispanics who lived in a high African-American area compared with those who lived in a low minority area, although few Hispanics lived in these neighborhoods ( $n=88$ ). The significance of our findings did not differ when we used alternative definitions for our areas (i.e., cut points for racial composition of 25% and 35% compared with 30%).

### CONCLUSIONS

Although prior work has demonstrated that hospice care is underutilized by African Americans and perhaps by Hispanics,<sup>3-8</sup> this paper shows that among elderly Medicare beneficiaries with cancer, individuals who live in census tracts with a greater percentage of minorities are less likely to use hospice care than individuals who live in areas with fewer minorities, independent of individual socioeconomic and clinical characteristics.

These findings suggest that there may be inadequate resources and services for the provision of hospice care in minority neighborhoods. Minority neighborhoods may have less of the medical infrastructure necessary to provide home hospice. For instance, pharmacies may not stock quantities of opioids needed to treat the severe pain that is often experienced by cancer patients at the end of life.<sup>15,16</sup> Hospice workers may also be less willing to go to minority neighborhoods to provide home hospice care. Institutional hospice care may be an important option for African Americans, who are less likely to have the caregiver support required for home

Table 2. Use of hospice by race/ethnicity

	Hispanic			African-American			White		
	Adjusted* odds ratio (95% confidence interval)			Adjusted* odds ratio (95% confidence interval)			Adjusted* odds ratio (95% confidence interval)		
Individual characteristics									
Male	0.70	0.62	0.80	0.78	0.65	0.92	0.76	0.73	0.80
Not married	0.97	0.86	1.09	0.77	0.65	0.90	0.86	0.82	0.89
Low income	0.78	0.69	0.87	0.77	0.65	0.91	0.72	0.68	0.77
Cancer type									
Breast cancer	0.77	0.63	0.94	0.86	0.64	1.16	0.79	0.74	0.85
Prostate cancer	1.03	0.89	1.19	1.03	0.82	1.29	0.99	0.93	1.05
Colorectal cancer	1.18	1.04	1.35	1.01	0.85	1.20	0.96	0.92	1.00
Lung cancer	Reference			Reference			Reference		
Stage at diagnosis									
Unstaged	0.98	0.83	1.17	0.98	0.76	1.26	1.06	1.00	1.13
Distant	1.24	1.11	1.38	1.17	1.00	1.37	1.14	1.10	1.19
Localized/regional	Reference			Reference			Reference		
Area racial composition									
African-American and Hispanic $\geq 30\%$	0.51	0.29	0.91	0.56	0.44	0.71	0.85	0.59	1.22
African-American $\geq 30\%$ and Hispanic $\leq 30\%$	0.70	0.43	1.14	1.08	0.92	1.28	0.95	0.85	1.07
African-American $\leq 30\%$ and Hispanic $\geq 30\%$	0.88	0.72	1.08	0.52	0.40	0.69	0.81	0.75	0.88
Low minority	Reference			Reference			Reference		
Median income quintile of census tract									
$\leq *23,950$	Reference			Reference			Reference		
*23,951–*30,950	0.91	0.78	1.07	0.95	0.77	1.18	1.15	1.06	1.24
*30,951–*37,593	1.08	0.89	1.30	0.87	0.69	1.10	1.21	1.11	1.31
*37,954–*46,882	0.73	0.57	0.93	0.96	0.75	1.24	1.18	1.08	1.28
>*46,882	0.80	0.59	1.08	0.83	0.60	1.14	1.16	1.06	1.27
Percent of college graduates in census tract									
$\leq 9.9\%$	Reference			Reference			Reference		
10.0–15.4%	0.98	0.84	1.16	1.22	0.98	1.51	0.90	0.83	0.97
15.5–23.0%	0.99	0.82	1.18	1.18	0.93	1.49	0.89	0.82	0.96
23.0–35.6%	0.97	0.78	1.20	1.14	0.88	1.49	0.81	0.75	0.89
>35.6%	1.07	0.82	1.40	1.26	0.91	1.74	0.84	0.77	0.92

\*Adjusted for variables listed above and age at death, number of comorbid conditions ever in Medicare HMO after diagnosis, in HMO or without Medicare in 13-month period before diagnosis, and year of death.

hospice care.<sup>17,18</sup> However, hospice services may be less likely to locate in minority neighborhoods, or more likely to close their doors, as has been shown for hospitals.<sup>19,20</sup>

These findings also suggest that there may be limited understanding or social acceptance of hospice care in these neighborhoods. The local culture may be less “accepting” of hospice care because of personal values or less access to information about palliative care or hospice programs.<sup>18,21</sup> Knowledge of research on past disparities in death rates from cancer and the mistreatment of minorities in medical care may lead African Americans to be wary of any suggestion to forego curative treatments required by hospice programs.<sup>21–23</sup> In Hispanic communities, language barriers between hospice providers and residents and cultural and religious differences may contribute to the lower use of hospice care.<sup>21</sup>

We selected the census tract as the geographic unit for this analysis because we wanted to approximate the local availability of resources that may be important for hospice services. Because our sample includes few African Americans in rural areas, we cannot examine whether there are differences in use of hospice care between urban and rural areas. We do not have data about the characteristics of minority neighborhoods that could contribute to the differences in hospice use that we observed in this sample (e.g., pharmacies, knowledge and beliefs about end-of-life care). Future studies should explore the availability of hospice care in areas with high minority populations as well as views of minority populations on hospice care. New strategies to increase the utilization of hospice care in minority neighborhoods might include financial incentives for pharmacies and hospices that locate in minority neighborhoods<sup>24</sup> and the training of neighborhood “opinion leaders” who are educated in options for end-of-life care.

Among individuals dying from cancer, those who live in minority neighborhoods are less likely to receive hospice care than those who live in predominantly white neighborhoods. These differences in hospice use may contribute to disparities in suffering at the end of life and caregiver burden. Increasing the use of hospice care in the United States may require interventions to improve resources as well as the social acceptance of hospice care in minority communities.

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