# DISPARITIES IN HOSPICE UTILIZATION AMONG AMERICAN INDIAN MEDICARE BENEFICIARIES DYING OF CANCER

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**Objective:** We sought to compare hospice utilization for American Indian and White Medicare beneficiaries dying of cancer.

**Methods:** We used the Surveillance, Epidemiology, and End Results (SEER)-Medicare linked databases to analyze claims for 181,316 White and 690 American Indian patients dying of breast, cervix, colorectal, kidney, lung, pancreas, prostate cancer, or stomach cancer from 2003 to 2009.

**Results:** A lower proportion of American Indians enrolled in hospice compared to White patients (54% vs 65%, respectively; $P<.0001$). While the proportion of White patients who used hospice services in the last 6 months of life increased from 61% in 2003 to 68% in 2009 ($P<.0001$), the proportion of American Indian patients using hospice care remained unchanged ($P=.57$) and remained below that of their White counterparts throughout the years of study.

**Conclusion:** Continued efforts should be made to improve access to culturally relevant hospice care for American Indian patients with terminal cancer. (*Ethn Dis*. 2014;24[4]:393–398)

**Key Words:** American Indian, Hospice Utilization, Disparities, Medicare Beneficiaries, End of Life

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## INTRODUCTION

Since the Medicare Hospice benefit was created in the 1980s, enrollment has steadily increased among Medicare beneficiaries with both cancer and non-cancer diagnoses.[1] However, multiple studies have shown racial disparities with respect to access of hospice care.[2] With respect to hospice care among cancer patients specifically, investigators have previously analyzed SEER-Medicare data to assess hospice utilization by race. Reports have consistently shown that hospice utilization was lower among Black cancer patients compared to their White counterparts,[3,4] and some have found lower utilization of hospice among Hispanic and Asian patients dying of cancer as well.[5] To our knowledge, no study has looked at population-based data to compare hospice enrollment among American Indian cancer patients. We hypothesized that hospice enrollment among American Indian Medicare beneficiaries dying of cancer would be less than that of their non-Hispanic White counterparts. Furthermore, we sought to ascertain whether the trend of increasing hospice utilization at the end of life seen in White patients dying of cancer also held for American Indian patients dying of cancer.

*We hypothesized that hospice enrollment among American Indian Medicare beneficiaries dying of cancer would be less than that of their non-Hispanic White counterparts.*

## METHODS

We analyzed data in the Surveillance, Epidemiology, and End Results (SEER) Medicare database and identified 181,316 White and 690 American Indian patients aged ≥65 years who died of breast, cervical, colorectal, lung, kidney, pancreatic, prostate, or stomach cancer. We chose these cancers because breast, colorectal, lung, pancreatic, and prostate cancer deaths comprise the top five cancer causes of death nationwide;[6] and American Indians have relatively higher rates of cervical, kidney, and stomach cancers than non-Hispanic Whites.[7] We analyzed administrative data for patients who died from these cancers between January 1, 2003 and December, 31, 2009. We excluded patients who did not have pathologic confirmation of cancer or whose diagnosis of cancer occurred upon death or autopsy. To capture complete claims data, we excluded patients who were not continuously enrolled in Medicare Part A and B or who were enrolled in an HMO in the last 6 months of life.

The SEER program (a National Cancer Institute-supported database) includes tumor registries in 17 geographic areas (Greater California, San Francisco-Oakland, Los Angeles, San Jose, Connecticut, Detroit, Seattle-Puget Sound, Atlanta/Rural Georgia, Iowa, Louisiana, New Jersey, New Mexico, Utah, Hawaii, Kentucky,

Louisiana and New Jersey) and covers approximately 25% of the US population.[8] The Medicare program files provide data regarding claims for hospital, physician, and outpatient medical services for 97% of US citizens aged ≥65 years.[9,10] The SEER registry files are linked via a de-identified denominator file (PEDSF) to the Medicare claims files. No protected health information could be linked to identifiable individual patients, and M.D. Anderson's institutional review board exempted this study.

We identified hospice utilization using the Medicare hospice claims as any hospice admission and/or service date in that claims file within the last 6 months of life. Analysis of claims data was performed using the SAS Systems software for Windows (version 9.3). We used the chi-square statistic to test for differences between proportions of patients using hospice by race. We performed a Cochrane Armitage test for trend to evaluate significance of any change in the proportion of patients with any hospice utilization in the last 6 months of life among patients who died of cancer in the years encompassed by this study (Figure 1a). We also compared hospice utilization among American Indian patients vs non-Hispanic White patients by employing a simple random sampling approach based on a 4:1 random sampling of White vs American Indian patient ratio to generate a potentially less unbalanced cohort. We performed random sampling 10 times and in the relevant tables, proportions enrolling in hospice reflect the average percentage hospice enrollment over these 10 samples (Figure 1b).

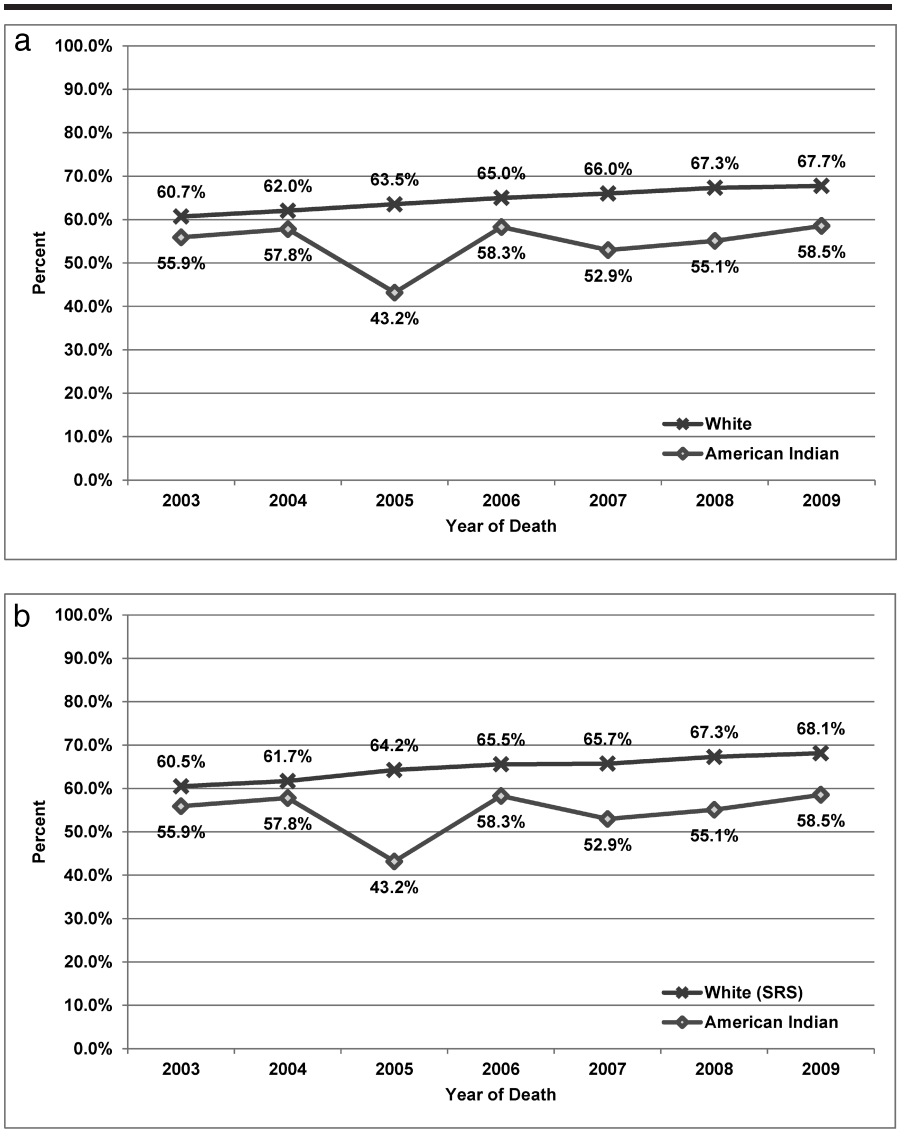


**Fig 1. Percent of patients enrolling in any hospice care in the last six months of life by race for the entire cohort (all SEER regions, 1.a entire White cohort, 1.b random sampling on White cohort with 1:4 ratio)**

## RESULTS

Overall, a lower proportion of American Indians enrolled in hospice compared to White patients (54% vs. 65%, respectively; $P<.0001$). Figures 1a and 1b show the proportion of patients with any hospice utilization in the last 6 months of life by race (White vs. American Indian) throughout the years of study. While the proportion of White patients dying of cancer who used any hospice services in the last 6 months of life steadily increased from 61% in 2003 to 68% in 2009 ($P<.0001$), the proportion of American Indian patients using hospice care in the last 6 months of life did not change ($P=.57$). The vast majority of the American Indian patients in this cohort resided in the Western SEER region (California, Hawaii, New Mexico, Utah, Washington state; $n=587$; Table 1). When analyzed by region, the proportion of American Indian patients enrolling in hospice in the Western SEER registries increased over the years of study, but not significantly ($P=.18$) Also, American Indian hospice use remained below that of White patients whose enrollment did increase significantly over the years of study ($P<.0001$) as shown in Figure 2.

We performed multivariable modeling to ascertain whether the disparity in

**Table 1. Univariate analysis on diagnosis, sociodemographic, and health services characteristics**

| Characteristic | Total | White (*N* =181316) | | American Indian (*N* =690) | | *P* |
|---|---|---|---|---|---|---|
| | | *n* | % | *n* | % | |
| Year of death | | | | | | <.01 |
| 2003 | 26146 | 26078 | 14.4 | 68 | 9.9 | |
| 2004 | 26313 | 26223 | 14.5 | 90 | 13.0 | |
| 2005 | 27081 | 26986 | 14.9 | 95 | 13.8 | |
| 2006 | 26550 | 26447 | 14.6 | 103 | 14.9 | |
| 2007 | 26132 | 26013 | 14.4 | 119 | 17.3 | |
| 2008 | 25615 | 25506 | 14.1 | 109 | 15.8 | |
| 2009 | 24169 | 24063 | 13.3 | 106 | 15.4 | |
| Hospice care | | | | | | <.0001 |
| No | 64612 | 64298 | 35.5 | 314 | 45.5 | |
| Yes | 117394 | 117018 | 64.5 | 376 | 54.5 | |
| Age at diagnosis | | | | | | <.0001 |
| 65–69 | 31317 | 31145 | 17.2 | 172 | 24.9 | |
| 70–74 | 37908 | 37725 | 20.8 | 183 | 26.5 | |
| 75–79 | 41859 | 41719 | 23.0 | 140 | 20.3 | |
| ≥80 | 70922 | 70727 | 39.0 | 195 | 28.3 | |
| Sex | | | | | | .33 |
| Male | 93301 | 92960 | 51.3 | 341 | 49.4 | |
| Female | 88705 | 88356 | 48.7 | 349 | 50.6 | |
| Marital status | | | | | | <.0001 |
| Single | 25796 | 25666 | 14.2 | 130 | 18.8 | |
| Married | 88336 | 88076 | 48.6 | 260 | 37.7 | |
| Other | 67874 | 67574 | 37.3 | 300 | 43.5 | |
| Cancer type | | | | | | <.0001 |
| Colorectal | 27437 | 27332 | 15.1 | 105 | 15.2 | |
| Lung | 91307 | 91007 | 50.2 | 300 | 43.5 | |
| Breast | 18415 | 18361 | 10.1 | 54 | 7.8 | |
| Prostate | 16137 | 16077 | 8.9 | 60 | 8.7 | |
| Pancreatic | 15804 | 15726 | 8.7 | 78 | 11.3 | |
| Stomach | 6422 | 6379 | 3.5 | <44 | [a] | |
| Kidney | 5668 | 5624 | 3.1 | 44 | 6.4 | |
| Cervix | 816 | 810 | 0.5 | <44 | [a] | |
| Comorbidity score | | | | | | .57 |
| 0 | 74861 | 74592 | 41.1 | 269 | 39.0 | |
| 1 | 42497 | 42323 | 23.3 | 174 | 25.2 | |
| ≥2 | 34356 | 34228 | 18.9 | 128 | 18.6 | |
| Unknown | 30292 | 30173 | 16.6 | 119 | 17.3 | |
| Region | | | | | | <.0001 |
| West | 71125 | 70538 | 38.9 | 587 | 85.1 | |
| Northeast | 39406 | 39376 | 21.7 | 30 | 4.4 | |
| Midwest | 27509 | 27467 | 15.2 | 42 | 6.1 | |
| South | 43966 | 43935 | 24.2 | 31 | 4.5 | |
| Urban/rural | | | | | | .51 |
| Urban | 160276 | 159674 | 88.1 | 602 | 87.3 | |
| Rural | 21730 | 21642 | 11.9 | 88 | 12.8 | |
| Median household income | | | | | | <.0001 |
| Lowest quartile | 42540 | 42232 | 23.3 | 308 | 44.6 | |
| 2nd quartile | 42520 | 42347 | 23.4 | 173 | 25.1 | |
| 3rd quartile | 42527 | 42404 | 23.4 | 123 | 17.8 | |
| Highest quartile | 42522 | 42467 | 23.4 | 55 | 8.0 | |
| Unknown | 11897 | 11866 | 6.5 | 31 | 4.5 | |
| Education (<12 years) | | | | | | <.0001 |
| Lowest quartile | 43123 | 43051 | 23.7 | 72 | 10.4 | |
| 2nd quartile | 43049 | 42910 | 23.7 | 139 | 20.1 | |
| 3rd quartile | 43216 | 43036 | 23.7 | 180 | 26.1 | |
| Highest quartile | 42878 | 42634 | 23.5 | 244 | 35.4 | |
| Unknown | 9740 | 9685 | 5.3 | 55 | 8.0 | |

[a] Indicates cell value cannot be disclosed in order to preserve confidentiality of individuals per the SEER-Medicare Data user agreement that prohibits reporting of cell values below a certain cutpoint. Two values in any column must be obscured to prevent inference of the values from sums or proportions.

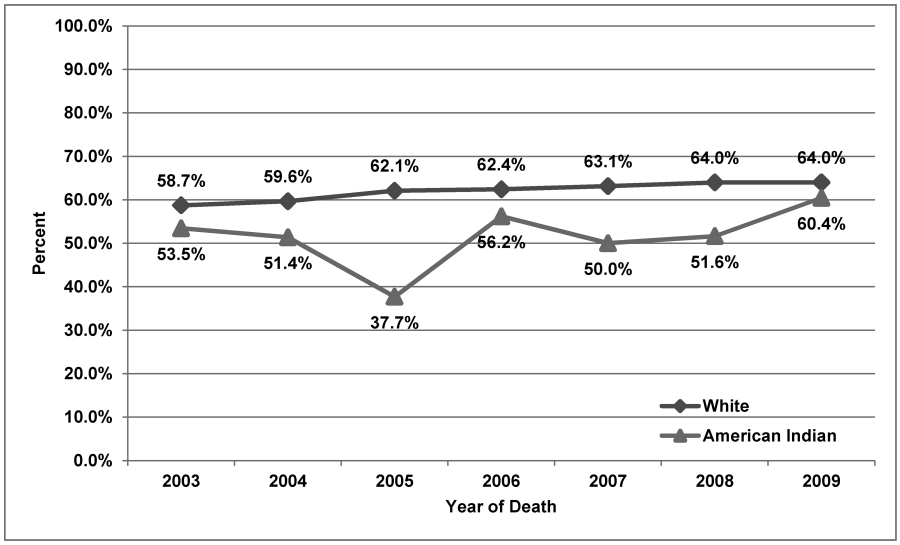


**Fig 2. Percent of patients in the Western SEER regions (California, Hawaii, New Mexico, Utah, Washington state) enrolling in any hospice care by race**

hospice enrollment persisted when adjusting for tumor and sociodemographic characteristics. This analysis with the original cohort (Table 2) showed that non-Hispanic White patients dying of cancer were significantly more likely to enroll in hospice care than American Indian patients in the last 6 months of life, even when adjusting for potential confounding characteristics (odds ratio=1.35, 95% confidence interval: 1.16–1.57). Other demographic and tumor related factors that were significantly associated with greater likelihood of hospice care enrollment included older age (> 69 years), female sex, having no comorbidities, and death from prostate, pancreatic, kidney, or stomach cancers. Patients living in the Midwest or Southern SEER regions were significantly more likely to enroll in hospice care as were patients who lived in any urban area of residence compared to those living in rural areas of residence. To serve as a sensitivity analysis for our finding of significantly increased likelihood of non-Hispanic White patient hospice enrollment being higher than that of American Indian patients, we also performed multivariable modeling using the balanced cohort generated from the 4:1 random sampling. The model fit was poor due to loss of model power, but the results were similar in that the non-Hispanic White patients were more likely than American Indian patients to enroll in hospice care in the last 6 months of life (odds ratio=1.37, 95% confidence interval: 1.14–1.66) (data not shown).

## DISCUSSION

In this population-based cohort, we observed that a lower proportion of American Indian Medicare beneficiaries dying of cancer in recent years enrolled in hospice during the last six months of life than their White counterparts. Furthermore, while the proportion of White patients enrolling in hospice significantly increased during those years, the proportion of American Indian doing so did not. The reasons for lower hospice enrollment may reflect the relative lack of Centers for Medicare and Medicaid Services (CMS)-accredited or Indian Health Service and tribally operated hospice programs in or near American Indian reservations.[11,12] This reasoning is partially supported by our finding in the adjusted analysis of decreased hospice enrollment among patients with rural residence where patients may be geographically remote from hospice care services. Many reservations are inherently rural and relatively concentrated in the Western United States where we also observed hospice enrollment to be significantly lower compared to other regions. There may also be culturally-based barriers to provision of effective end of life care for American Indians. These may arise when health care providers lack culturally responsive tools and training to broach discussion of end-of-life care with American Indian patients. Additionally, historical trauma and attendant perceived discrimination,[13] especially as relates to the withdrawal of curative or aggressive treatments, as well as culturally-rooted negative perceptions about discussion of eminent death may hinder communication about end-of-life care planning and referral to hospice among American Indian patients.[14] Programs like the Palliative Care Consultation Service at the University of New Mexico have demonstrated that effective palliative care can be administered to American Indian patients through culturally-tailored communication techniques and supporting consultation with traditional healers; subsequently mitigating disparities in hospice utilization in this population.[15] In addition, the Indian Health Care

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**Table 2. Multivariable analysis of predictors of use of hospice care in the last 6 months of life after metastatic cancer diagnosis for the non-Hispanic White and American Indian cohort**

| Predictors | Odds Ratio | 95% CI | | *P* |
|---|---|---|---|---|
| Race | | | | |
| American Indians[a] Non-Hispanic White | 1.35 | 1.16 | 1.57 | .0001 |
| Year of death | | | | |
| 2003[a] | | | | |
| 2004 | 1.06 | 1.03 | 1.10 | <.001 |
| 2005 | 1.13 | 1.09 | 1.17 | <.0001 |
| 2006 | 1.21 | 1.17 | 1.25 | <.0001 |
| 2007 | 1.27 | 1.22 | 1.31 | <.0001 |
| 2008 | 1.35 | 1.30 | 1.40 | <.0001 |
| 2009 | 1.38 | 1.33 | 1.43 | <.0001 |
| Age at diagnosis | | | | |
| 65–69[a] | | | | |
| 70–74 | 1.09 | 1.06 | 1.13 | <.0001 |
| 75–79 | 1.17 | 1.14 | 1.21 | <.0001 |
| ≥80 | 1.30 | 1.26 | 1.34 | <.0001 |
| Sex | | | | |
| Male[a] | | | | |
| Female | 1.30 | 1.27 | 1.33 | <.0001 |
| Marital status | | | | |
| Single[a] | | | | |
| Married | 1.09 | 1.06 | 1.12 | <.0001 |
| Other | 1.10 | 1.06 | 1.13 | <.0001 |
| Cancer Type | | | | |
| Colorectal[a] | | | | |
| Lung | .99 | .97 | 1.02 | .69 |
| Breast | 1.01 | .97 | 1.05 | .74 |
| Prostate | 1.22 | 1.17 | 1.28 | <.0001 |
| Pancreatic | 1.51 | 1.45 | 1.58 | <.0001 |
| Stomach | 1.09 | 1.03 | 1.16 | <.01 |
| Kidney | 1.27 | 1.19 | 1.36 | <.0001 |
| Cervix | 1.13 | .97 | 1.31 | .12 |
| Comorbidity score | | | | |
| 0[a] | | | | |
| 1 | .93 | .90 | .95 | <.0001 |
| ≥2 | .81 | .79 | .84 | <.0001 |
| Unknown | .96 | .94 | .99 | .01 |
| Region | | | | |
| West[a] | | | | |
| Northeast | .92 | .90 | .95 | <.0001 |
| Midwest | 1.71 | 1.66 | 1.77 | <.0001 |
| South | 1.49 | 1.45 | 1.53 | <.0001 |
| Urban/rural | | | | |
| Urban[a] | | | | |
| Rural | .80 | .77 | .82 | <.0001 |
| Education (<12 years) | | | | |
| Lowest quartile[a] | | | | |
| 2nd quartile | .94 | .91 | .97 | <.0001 |
| 3rd quartile | .88 | .85 | .90 | <.0001 |
| Highest quartile | .78 | .76 | .80 | <.0001 |
| Unknown | .97 | .92 | 1.02 | .19 |

[a] Reference.

Improvement Act was made permanent in 2010 and has also resulted in new authorities for the Indian Health Service, which specifically include improvements in palliative and hospice care among American Indians.[16] Our findings emphasize that initiatives such as these should continue to receive policy and funding priority on both local and national levels.

Hospice care has been shown to improve quality of life[17,18] and, in some studies,[19] survival for patients with advanced cancer. Our finding of disparate hospice use among American Indian Medicare beneficiaries highlights the need for continued efforts to increase access to culturally relevant hospice care among American Indian cancer patients.

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