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HEALTH SERVICES RESEARCH

Racial and Ethnic Differences in Hospice Use and End-of-life Hospitalizations among Medicare Beneficiaries with Dementia

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Abstract

Background: The pool of studies examining ethnoracial differences in hospice use and end-of-life hospitalizations among patients with dementia is limited and results are conflicting. This study examined how dementia end-of-life care utilization and patient treatment preferences differ by race and ethnicity.

Methods: Using U.S. national survey data from the Health and Retirement Study linked with Medicare and Medicaid claims, our sample included 5,058 beneficiaries aged ≥65 years diagnosed with dementia who died in 2000-2016. We examined the frequency and costs of hospice care, emergency department (ED) visits, and hospitalizations during the last 180 days of life among Medicare decedents with dementia. We analyzed the proportion of dementia decedents with advance care planning and their end-of-life care preferences.

Results: Less than half of beneficiaries with dementia in our sample (48%) used hospice in the last 180 days of life; of these, one in three hospice users received the service for seven days or less. In adjusted analysis, non-Hispanic (NH) Blacks, nursing home residents, and survey respondents represented by a proxy were less likely to use hospice, whereas older age, females, higher education, more severe cognitive impairment, and more IADL limitations were associated with higher hospice enrollment. Among dementia decedents, NH Blacks and Hispanics used more ED and inpatient services and incurred >50% higher inpatient expenditures at the end of life, compared with NH whites. More NH Black and Hispanic beneficiaries with dementia enrolled in hospice were subsequently admitted to the ED or hospital before death. The proportion of dementia beneficiaries completing advance care planning was significantly lower among NH Blacks and Hispanics compared with NH whites (21% and 21% vs. 57%, p<0.01). More NH Black and Hispanic decedents with dementia had written instructions choosing all care possible to prolong life, whereas more NH whites preferred to limit care in certain situations, withhold treatments, and forgo extensive life-prolonging measures.

Conclusion: Our results highlighted substantial unmet end-of-life care needs among older adults with dementia, especially among NH Blacks and Hispanics. Medicare should consider alternative payment models to promote culturally competent end-of-life care and reduce low-value interventions and costs among the population with dementia.

Figure 1: Cumulative hospice days in the last 180 days of life among dementia beneficiaries enrolling in hospice care, by race and ethnicity

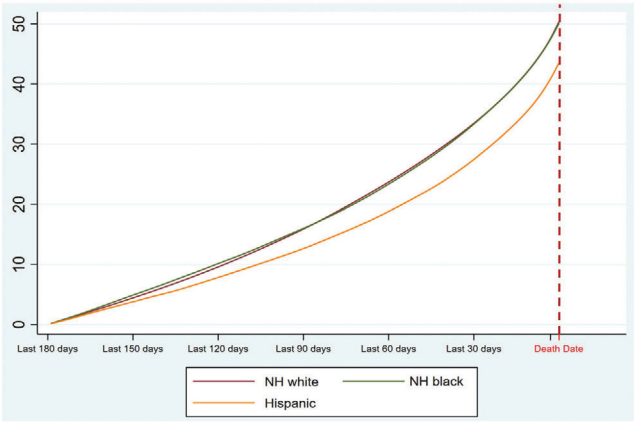
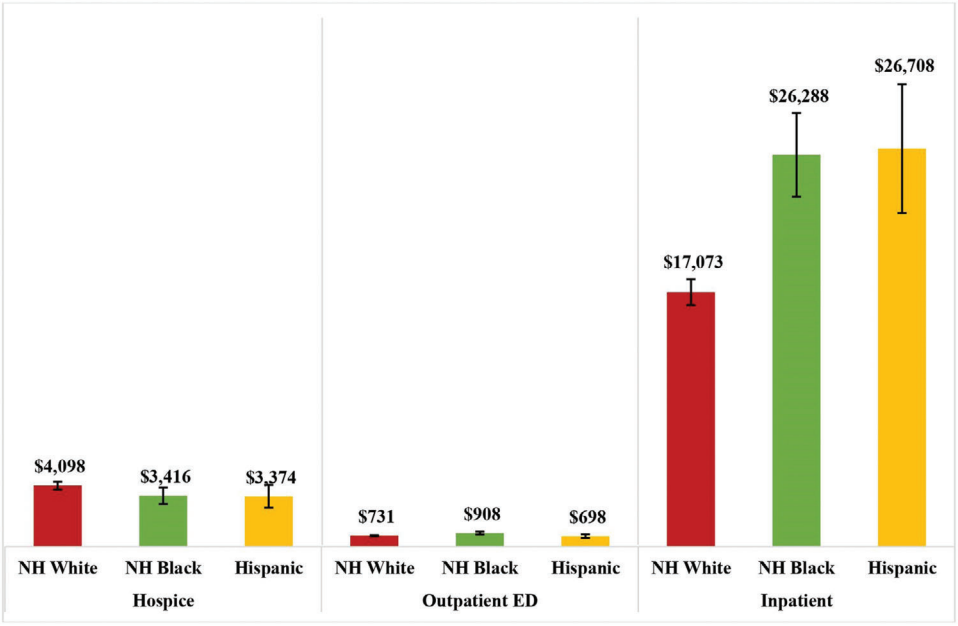


Figure 2: Estimated mean Medicare expenditures per dementia decedent: hospice, outpatient emergency department, and inpatient care in the last 180 days of life[1]



[1]Model adjusted for race/ethnicity, age, gender, education, cognition, functional limitations, comorbidities, Medicare-Medicaid dual eligibility, nursing home status, and proxy respondent.

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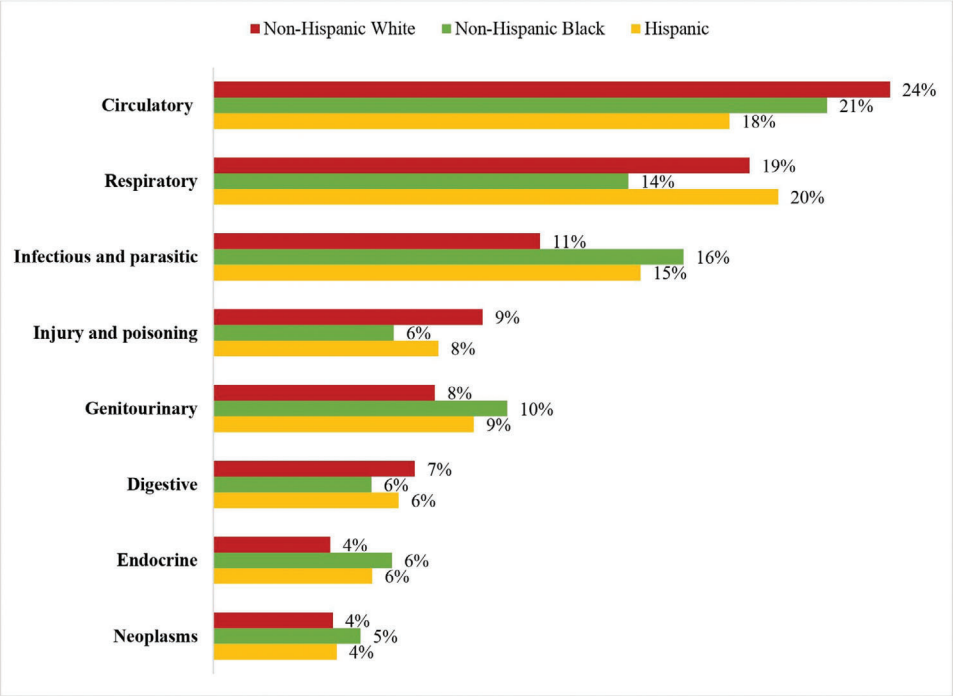
Figure 3: Major causes of hospitalizations in the last 180 days of life among dementia beneficiaries, by race and ethnicity



The figure is restricted to major causes of hospitalizations accounting for ≥5% of admissions in any of the racial/ethnic group. We used principal discharge diagnoses to categorize causes of hospitalizations based on the Agency for Healthcare Research and Quality (AHRQ) Clinical Classifications Software (CCS) for ICD-9-CM codes and the Clinical Classifications Software Refined (CCSR) for ICD-10-CM codes.