

UCSF

UC San Francisco Previously Published Works

Title

The Association Between Race and Place of Death Among Persons With Dementia.

Permalink

<https://escholarship.org/uc/item/1bq3442q>

Journal

Journal of Pain and Symptom Management, 64(3)

Authors

Mayan, Inbal
Hunt, Lauren
Yaffe, Kristine
et al.

Publication Date

2022-09-01

DOI

10.1016/j.jpainsymman.2022.05.010

Peer reviewed



Published in final edited form as:

J Pain Symptom Manage. 2022 September ; 64(3): e109–e114. doi:10.1016/j.jpainsymman.2022.05.010.

The Association Between Race and Place of Death Among Persons With Dementia

Inbal Mayan, MD,

Global Brain Health Institute (I.M.), University of California, San Francisco, CA, USA; Tel Aviv University Sackler School of Medicine (I.M.), Ramat Aviv, Israel

Kristine Yaffe, MD,

Departments of Psychiatry and Behavioral Science (K.Y.), Neurology and Epidemiology and Biostatistics, UCSF, San Francisco, CA, USA

Jennifer James, PhD, MS, MSW,

Departments of Psychiatry and Behavioral Science (J.J.), Neurology and Epidemiology and Biostatistics, UCSF, San Francisco, CA, USA

Lauren J. Hunt, PhD, RN, FNP-BC

Department of Physiological Nursing (L.J.H.), University of California, San Francisco, CA, USA

Abstract

Context.—Little is known about racial differences in place of death for persons with dementia (PWD), who may be especially vulnerable to receiving care at end of life that is not concordant with their goals or that places higher burden on caregivers.

Objectives.—To determine if there are racial and ethnic differences in place of death among PWD.

Methods.—We analyzed data from the nationally representative National Health and Aging Trends study. Participants were included if they had probable dementia as defined by a previously validated algorithm and died between 2012 and 2020. Race and ethnicity were self-reported. Place of death was obtained from post-mortem interviews with bereaved caregivers.

Results.—The sample included 993 decedents with dementia (81.4% white; 11.0% black, 7.6% hispanic). A higher percentage of black and hispanic decedents died in the hospital (30.3% and 32.8%, respectively) compared to white decedents (19.0%). A higher percentage of white decedents died in the nursing home (31.0%) than black (22.4%) or hispanic decedents (15.0%) In adjusted analyses, black decedents had a higher odds of hospital death (AOR 1.50; 95% CI 1.01, 2.24) compared to white decedents, with similar trends found for hispanic decedents.

Address correspondence to: Inbal Mayan, MD, 2522 Lanier Pl, Durham, NC USA. Inbal.Mayan@gbhi.org.

Author Contributions

I.M contributed to the design of the research, to the analysis of the results and to the writing of the manuscript. K.Y contributed to the writing of the manuscript. J.J contributed to the writing of the manuscript. L.J.H contributed to study design, analysis and writing the manuscript.

The authors declare no conflicts of interest.

Conclusion.—We found racial and ethnic differences in location of death for PWD, with black and hispanic PWD more likely to die in the hospital compared to white PWD. More research is needed to determine if the differences found represent goal concordant care or rather lack of access to high quality of care at the end of life.

Keywords

Place of death; Racial disparities; Dementia

Introduction

Significant shifts in place of death have been documented in the US in the past decades. Recent studies have shown a decrease in death in the hospital and an increase in death at home or at hospice facilities.¹ These trends extend to people dying with or from dementia, who now comprise 30%–40% of all decedents 65 and older in the U.S.² Most Americans state that they prefer to die at home, and evidence suggests that site of death should be considered a quality measure for end-of-life.³ Yet, dying at home is possible only with the appropriate resources and may not be equally preferred across all racial and ethnic groups.⁴ For people with dementia (PWD), who often experience a prolonged period of time in a dependent state, dying at home usually requires a dedicated caregiver and significant medical and social support.^{5–7}

Previous studies have documented differences in place of death among racial and ethnic minorities compared to whites. These indicate that racial and ethnic minorities are more likely to die in the hospital and home, while white decedents are more likely to die in nursing homes.⁸ Yet, despite the fact that PWD comprise a large and growing percentage of decedents and racial and ethnic minorities are at greater risk of developing dementia, little is known about racial and ethnic differences in place of death among PWD.^{4,6,8} This knowledge could have important implications for ensuring that racial and ethnic minority PWD are receiving appropriate supports at end of life and their place of death is aligned with their goals of care.

Our study aims to assess the association between race, ethnicity and place of death for people with dementia using data from the nationally-representative National Health and Aging Trends Study (NHATS).

Methods

Data Sources and Participants

NHATS is a nationally representative sample of Medicare beneficiaries ages 65 or older in the U.S., with oversampling of non-hispanic black persons and adults 85 and older. In total, 8,245 participants were included in the initial 2011 survey (Round 1) and a replenishment cohort was added in 2015. Annual assessments include verbal questionnaires and performance-based metrics of cognitive and physical capacity. Additionally, NHATS administers a “Last Month of Life” survey to proxy respondents familiar with the participants’ end-of-life care, usually a family member.⁹ Response rates were high at 71%

for Round 1, 86%–95% for follow-up assessments, and 94%–96% for the last month of life interview. Our cohort included participants from the 2011 cohort who died and had a last month life interview between 2012 and 2019 ($n = 2862$).

Measures

Dementia status: Dementia status of decedents was established using a validated algorithm¹⁰ that classifies participants as having no dementia, possible dementia, and probable dementia. The algorithm is based on 1) Self or proxy report of physician's diagnosis of dementia; a positive response places that person in the possible dementia category 2) Scoring of cognitive testing in multiple domains, a score of 1.5 standard deviations below the mean in two domains places that person in the probable dementia group, while a score of 1–1.5 standard deviation below the mean places that person in the probable dementia group; and 3) score on the AD8, a multidimensional dementia screening questionnaire administered to all proxy respondents. A score of 2 or above, which meets criteria for likely dementia, places that person in the probable dementia group. Sensitivity and specificity of this approach for identifying probable dementia are 65.7% and 87.2%, respectively.^{10,11} We assigned dementia diagnosis based on the survey before the reported death. We excluded participants who were missing dementia classification in the year before death. For our analysis, we included only participants with probable dementia.

Race and ethnicity: Race and ethnicity were self-reported and taken from the initial recruitment interview to NHATS performed in 2011. Participants are asked if they consider themselves to be white, black, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, or Other and are asked to identify a primary race if they select more than one category. They are then asked if they consider themselves to be hispanic or Latino. From this information, NHATS creates a derived variable that categorizes participants based on the primary race selected as non-Hispanic white, non-hispanic black, hispanic, or non-Hispanic Other (American Indian/Asian/Native Hawaiian, Pacific Islander, or other). We included non-hispanic white, non-hispanic black, and hispanic participants and excluded participants identified as Other ($n = 59$).

Place of death: Place of death was established by proxy answer in the Last Month of Life interview. Place of death was categorized as home, hospital, nursing home, a hospice facility or other (in an ambulance or somewhere else). There is no information in the NHATS dataset on preferences regarding place of death and decedents regional availability of services such as hospitals or nursing homes.

Covariates: Covariates included categorical age at time of death (65-74/75-84/85+), sex (female/male), education (less than high school/High school graduate/ Bachelor's degree or higher), marital status in the year before death (Married/ Separated divorced or never married/ Widowed/ Unknown), number of chronic conditions (0-1/2-3/4+); and income (median yearly in USD).

Analysis

We used summary statistics to describe our sample by race and ethnicity. We calculated unadjusted odds ratios to compare place of death by race and ethnicity. For these analyses, we used logistic regression to assess the odds of dying for each place of death compared to all other possible locations using white PWD as the reference category. For example, we examined the odds of dying at home versus all other locations (hospital, nursing home, hospice facility). We then created adjusted models with all covariates included. We used NHATS survey weights that provide nationally representative estimates for deceased participants considering differential probabilities of selection and nonresponse. All analyses were performed using STATA, version 16.

Results

Sample Characteristics

Our sample included 993 NHATS participants enrolled in NHATS Round 1 who died during the 9 years of follow-up and had probable dementia in the interview prior to death. Hispanic decedents with dementia were less likely to be female (55.2%) compared to white (61.5%) and black (62.9%) decedents. White decedents were more likely to be 85 and older (73.2%) compared to black (60.2%) and hispanic (61.2%) decedents. Most white decedents were high school graduates while the majority of black and hispanic decedents had less than high school education. Most of the participants in all racial and ethnic groups were widowed. The median income for white decedents was higher than for black and hispanic decedents (Table 1)

Association Between Race and Place of Death

Frequency of place of death by race and ethnicity is shown in Fig. 1. A higher proportion of white PWD died in a Nursing Home (31%) versus black PWD (22.4%) or hispanic PWD (15.0%). A higher proportion of hispanic PWD (43.3%) died at home compared to white (36.0%) and black 37%) PWD and a higher proportion of black (30.3%) and hispanic (33%) PWD died in the hospital compared to white PWD (19%). In adjusted analyses, black (AOR 1.50, 95% CI 1.0–2.2) and hispanic (AOR 1.80, 95% CI 1.0–3.2) PWD had higher odds of hospital death versus all other locations and a lower odd of dying in the nursing home (AOR 0.70, 95% CI 0.5–0.98 for black PWD and AOR 0.40, 95% CI 0.2–0.9 for hispanic PWD) (Table 2). Hispanic PWD had a higher odd of dying at home versus all other locations, but the estimate included the possibility that there was no difference (AOR 1.43, 95% CI 0.9-2.6).

Discussion

Our findings show important differences in place of death associated with race and ethnicity. Black and hispanic PWD are more likely to die in the hospital than white PWD and less likely to die in a nursing home than white PWD. These findings have key implications for the care of the diverse population of PWD at the end-of-life.

Our findings are in line with the growing body of literature demonstrating differences in place of death by race and ethnicity and extends this to PWD.^{8,12,13} These studies consistently find that racial and ethnic minority groups are more likely to die in the hospital and/or at home. Our findings are consistent with the one study we are aware of that included race and ethnicity as a variable in looking at place of death among PWD (Cross et al).⁶ However, this study was limited in that they used death certificates to identify dementia cases, which likely underreported dementia deaths, whereas we used a validated algorithm to identify dementia cases.

The relationship between structural racism in healthcare, cultural preferences, and end-of-life outcomes is complex and multifaceted.¹⁴ Differences found in place of death, especially a larger percentage of black and hispanic PWD dying in the hospital compared to white PWD, has often been assumed to be a reflection of cultural/religious preferences of receiving more “aggressive” care toward the end of life.^{4,15–18} However, differences may also reflect lower access to care for black and hispanic PWD and lack of resources necessary to avoid transitions in the end of life^{19,20} or could be attributed to cultural preferences for caring for elders in the home and not in nursing homes, which is also more common in minority populations.^{21,22} While it is known that PWD need significant care for long periods of time and that caregiver burden is very high for people supporting this population, it is still unknown what role this factor plays in determining place of death for a diverse population of PWD. Low access to medical support and the financial burden of living in a nursing home may cause minoritized populations to have a higher hospital death rate, but this cannot be definitively stated based on the available data. Further, a higher proportion of black and hispanic Medicare recipients report a preference to die in the hospital.⁴ This may demonstrate that Patients across racial and ethnic groups may have a similar likelihood of dying in their preferred location. However, it is not well understood if or how systemic racism within the healthcare system, cultural and religious norms, and existing health disparities may drive individual preference.

If it is this case that reduced access to medical and other supports are driving higher hospital deaths, it is important to ensure that supports are expanded and adapted to the cultural, language, and religious preferences of PWD from racial and ethnic minoritized groups. Expansion of home-based palliative care models could provide an additional layer of support to PWD from racial and ethnic minority groups who do not meet prognostic eligibility criteria for hospice or do not wish to enroll in hospice. Expanding access to such programs, which are not currently covered under Medicare, is vitally important to improving end-of-life care for diverse PWD moving forward.

There are several limitations to this study. First, the sample sizes of hispanic PWD were small and limited the ability to detect an effect in our estimates. Second, we only assessed the final place of death and did not consider transitions that occurred in the weeks and months leading up to death. We did not have information on Patient’s preferred location of death and whether their actual place of death aligned with preferences. Third, place of death was self-reported by proxies and was not confirmed with medical records. We did not have information on the regional availability of hospice, nursing homes, and hospitals in the PWD’s vicinity, which may have affected options for place of death. Fourth, NHATS

categorization of race and ethnicity is somewhat limited, with participants asked to define a primary race category. We included only three race and ethnic categories caused by the size of the cohort. Finally, we did not assess Medicare Hospice use prior to death, which is an important area for further research. It is well-documented that racial and ethnic minoritized groups are less likely to access hospice prior to death, and home-based support that hospice provides may increase the likelihood of death at home. Racial and ethnic disparities in hospice use, which has been shown to decrease likelihood of hospital death, may in part explain differences in place of death seen in our study.^{23–25} Future research should explore the relationship between hospice use, race and ethnicity, and place of death and the role of Patient preferences and systemic factors, such as regional healthcare markets, and their influence on racial disparities in place of death for PWD.

In conclusion, it is critical that care received at end of life for racial and ethnic minority PWD, including place of death, is aligned with goals of care of the PWD and their caregiver. Given that racial and ethnic minorities are more likely to care for PWD through the end of life at home, there needs to be greater access to home-based clinical care and other supports and services that are adapted to the unique needs of diverse populations.

Disclosures

Dr. Lauren Hunt: National Center for Advancing Translational Sciences of the NIH(KL2TR001870), National Palliative Care Research Center.

Dr. Kristine Yaffe: Population Based Research for Alzheimer's Innovation (POP BRAIN) NIH R35AG071916.

References

1. Cross SH, Warraich HJ. Changes in the place of death in the United States. *N Engl J Med* 2019;381:2369–2370. [PubMed: 31826345]
2. Xu W, Wu C, Fletcher J. Assessment of changes in place of death of older adults who died from dementia in the United States, 2000-2014: a time-series cross-sectional analysis. *BMC Public Health* 2020;20:765. 10.1186/s12889-020-08894-0. [PubMed: 32522179]
3. Arnold E, Finucane AM, Oxenham D. Preferred place of death for patients referred to a specialist palliative care service. *BMJ Support Palliat Care* 2015;5:294–296. 10.1136/bmjspcare-2012-000338.
4. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med* 2009;24:695–701. 10.1007/s11606-009-0952-6. [PubMed: 19387750]
5. Wiggins N, Dronney J, Mohammed K, Riley J, Sleeman KE. Understanding the factors associated with patients with dementia achieving their preferred place of death: a retrospective cohort study. *Age Ageing* 2019;48:433–439. 10.1093/ageing/afz015. [PubMed: 30806452]
6. Cross SH, Kaufman BG, Taylor DH, Kamal AH, Warraich HJ. Trends and factors associated with place of death for individuals with dementia in the United States. *J Am Geriatr Soc* 2020;68:250–255. 10.1111/jgs.16200. [PubMed: 31609481]
7. Burge F, Lawson B, Johnston G, et al. Preferred and actual location of death: what factors enable a preferred home death? *J Palliat Med* 2015;18:1054–1059. 10.1089/jpm.2015.0177. [PubMed: 26398744]
8. Iwashyna TJ, Chang VW. Racial and ethnic differences in place of death: United States, 1993. *J Am Geriatr Soc* 2002;50:1113–1117. 10.1046/j.1532-5415.2002.50269.x. [PubMed: 12110074]

9. NHATS_User_Guide_R10_Beta_Release_04_30_2021_0.pdf. Available from: https://www.nhats.org/sites/default/files/2021-04/NHATS_User_Guide_R10_Beta_Release%2004_30_2021_0.pdf. Accessed July 7, 2021.
10. DementiaTechnicalPaperJuly_2_4_2013_10_23_15.pdf. Available from: https://www.nhats.org/sites/default/files/inline-files/DementiaTechnicalPaperJuly_2_4_2013_10_23_15.pdf. Accessed June 24, 2021.
11. NHATS_Addendum_to_Technical_Paper_5_STATA_Programming_Statements_Jul2013_0.pdf. Available from: https://www.nhats.org/sites/default/files/inline-files/NHATS_Addendum_to_Technical_Paper_5_STATA_Programming_Statements_Jul2013_0.pdf. Accessed July 7, 2021.
12. Kwak J, Haley WE, Chiriboga DA. Racial differences in hospice use and in-hospital death among Medicare and Medicaid dual-eligible nursing home residents. *Gerontologist* 2008;48:32–41. 10.1093/geront/48.1.32. [PubMed: 18381830]
13. Flory J, Yinong YX, Gurol I, et al. Place of death: U.S. trends since 1980. *Health Aff Proj Hope* 2004;23:194–200. 10.1377/hlthaff.23.3.194.
14. Wicher CP, Meeker MA. What influences African American end-of-life preferences? *J Health Care Poor Underserved* 2012;23:28–58. [PubMed: 22643461]
15. Johnson KS, Kuchibhatla M, Tanis D, Tulsy JA. Racial differences in hospice revocation to pursue aggressive care. *Arch Intern Med* 2008;168:218–224. 10.1001/archinternmed.2007.36. [PubMed: 18227371]
16. Song MK, Hanson LC. Relationships between psychosocial-spiritual well-being and end-of-life preferences and values in African-American dialysis patients. *J Pain Symptom Manage* 2009;38:372–380. 10.1016/j.jpainsymman.2008.11.007. [PubMed: 19356896]
17. Johnson KS, Elbert-Avila KI, Tulsy JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans: a review of the literature. *J Am Geriatr Soc* 2005;53:711–719. 10.1111/j.1532-5415.2005.53224.x. [PubMed: 15817022]
18. Balboni TA, Balboni M, Enzinger AC, et al. Provision of spiritual support to patients with advanced cancer by religious communities and associations with medical care at the end of life. *JAMA Intern Med* 2013;173:1109–1117. 10.1001/jamainternmed.2013.903. [PubMed: 23649656]
19. Loggers ET, Maciejewski PK, Jimenez R, et al. Predictors of intensive end-of-life and hospice care in Latino and white advanced cancer patients. *J Palliat Med* 2013;16:1249–1254. 10.1089/jpm.2013.0164. [PubMed: 24053593]
20. Noh H, Schroepfer TA. Terminally ill African American elders' access to and use of hospice care. *Am J Hosp Palliat Care* 2015;32:286–297. 10.1177/1049909113518092. [PubMed: 24413609]
21. Jenkins C, Lapelle N, Zapka JG, Kurent JE. End-of-life care and African Americans: voices from the community. *J Palliat Med* 2005;8:585–592. 10.1089/jpm.2005.8.585. [PubMed: 15992200]
22. Thomeer MB, Mudrazija S, Angel J. How and why does nursing home use differ by race and ethnicity? *J Gerontol Ser B* 2018;73:e11–e12. 10.1093/geronb/gbv056.
23. Johnson KS, Payne R, Kuchibhatla MN, Tulsy JA. Are hospice admission practices associated with hospice enrollment for older African Americans and Whites? *J Pain Symptom Manage* 2016;51:697–705. 10.1016/j.jpainsymman.2015.11.010. [PubMed: 26654945]
24. Johnson KS. Racial and ethnic disparities in palliative care. *J Palliat Med* 2013;16:1329–1334. 10.1089/jpm.2013.9468. [PubMed: 24073685]
25. Johnson KS, Kuchibhatla M, Payne R, Tulsy JA. Race and residence: intercounty variation in Black-White differences in hospice use. *J Pain Symptom Manage* 2013;46. 10.1016/j.jpainsymman.2012.12.006.

Key Message

We found that PWD who define themselves as black or hispanic are more likely to die in the hospital than PWD who define themselves as white.

This may represent lack of access to high quality of care at the end of life for racial and ethnic minority groups.

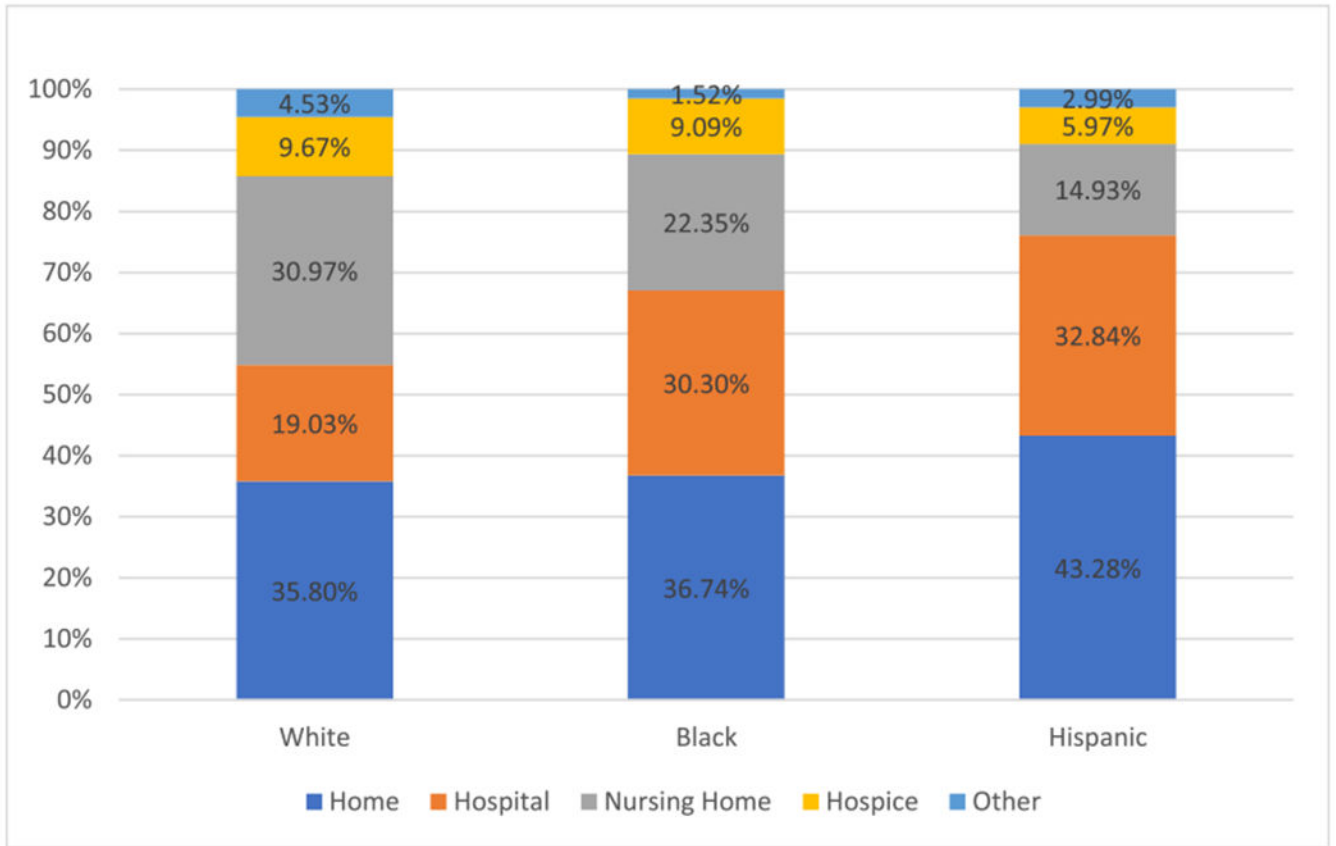


Fig. 1. Place of death among decedents with dementia by race and ethnicity.

Table 1

Sample Characteristics of the 993 Decedents with Dementia by Race

Characteristic	White N = 662 (81.3%)	Black N = 264 (11.1%)	Hispanic N = 67 (7.6%)
<i>Sex</i>			
Female	407 (61.5%)	166 (62.9%)	37 (55.2%)
Male	255 (38.5%)	98 (37.1%)	30 (44.8%)
<i>Age at death</i>			
65–74	19 (2.9%)	21 (8.0%)	4 (6.0%)
75–84	158 (23.9%)	84 (31.8%)	22 (32.8%)
85+	485 (73.2%)	159 (60.2%)	41 (61.2%)
<i>Education</i>			
Less than high school	196 (29.6%)	161 (61.0%)	47 (70.1%)
High school graduate	348 (52.6%)	83 (31.4%)	15 (22.4%)
Bachelor's degree or higher	118 (17.8%)	20 (7.6%)	5 (7.5%)
<i>Number of chronic Conditions</i>			
0–1	135 (20.4%)	51 (19.3%)	12 (17.9%)
2–3	280 (42.3%)	120 (45.5%)	26 (38.8%)
>4	247 (37.3%)	93 (35.2%)	29 (43.3%)
<i>Marital status</i>			
Married or living with partner	186 (28.1%)	51 (19.3%)	22 (32.8%)
Separated/Divorced/Never Married	60 (9.1%)	51 (19.3%)	8 (12.0%)
Widowed	396 (59.8%)	153 (58.0%)	35 (52.2%)
Unknown	20 (3.0%)	9 (3.4%)	2 (3.0%)
<i>Income, \$, median (interquartile range)</i>	21000 (9500–32500)	12000 (6000–18000)	12000 (5664–18336)

All analyses take into account complex survey design.

Table 2

Unadjusted and Adjusted Odds Ratio for Place of Death of black and hispanic Compared to white Decedents With Dementia Enrolled in the National Health and Aging Trends Study (n=993)

	Hospital vs. all Others		Home vs. all Others		Nursing Home vs. all Others		Hospice Facility vs. all Others	
	Unadjusted (95% CI)	Adjusted (95% CI)	Unadjusted (95% CI)	Adjusted (95% CI)	Unadjusted (95% CI)	Adjusted (95% CI)	Unadjusted (95% CI)	Adjusted (95% CI)
Black	1.72 (1.19–2.50)	1.50 (1.01–2.24)	1.02 (0.71–1.45)	1.13 (0.79–1.62)	0.69 (0.49–0.98)	0.70 (0.46–0.98)	0.90 (0.55–1.46)	0.91 (0.53–1.58)
Hispanic	2.21 (1.25–3.90)	1.80 (1.01–3.20)	1.25 (0.71–2.21)	1.43 (0.79–2.61)	0.35 (0.15–0.84)	0.36 (0.15–0.87)	0.60 (0.18–1.97)	0.52 (0.16–1.74)

Adjusted for age, sex, education level, chronic disease level, income, marital status.

All analyses take into account complex survey design.

CI = Confidence Interval.