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Racial/Ethnic Disparities in Length of Life after Dementia Diagnosis: an 18-Year Follow-up Study of Medicare Beneficiaries

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Summary

Background—This study quantifies survival time after dementia diagnosis and assesses mechanisms driving differences across race/ethnicity to inform care and financial planning.

Methods—Using 100% Medicare claims data, we identified 670,955 beneficiaries with incident dementia diagnosis in 2001 and followed them through 2018. We quantified racial/ethnic differences in post-diagnosis survival and for subgroups defined by sex, age at diagnosis, socio-economic status, and geography. Additionally, we investigated racial/ethnic time trends in 5-year mortality risk of 8,080,098 beneficiaries with incident dementia in years 2001–2013.

Findings—Hispanics and Asians diagnosed with dementia had 40% lower mortality risk and African Americans had 13% lower mortality risk than Whites. There was no difference between American Indians/Alaska Natives and Whites. Racial/ethnic differences were of similar size in sex, age at diagnosis, and urban/rural subgroups; however, the survival advantage between non-Whites and Whites was larger among low-income beneficiaries. State differences in mortality among Blacks were consistent with a Southern divide but not for Asians and Hispanics. The Asian-White and Hispanic-White mortality differences decreased 2001 to 2013.

Interpretation—Racial/ethnic survival differences after dementia diagnosis have implications for magnitude of financial impact of dementia on individuals and families. Quantifying survival

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Contributors

All authors who contributed significantly to the work are listed as authors. JMZ conceived the study. YC and PF performed the analysis. EC and JMZ provided interpretation of results. JMZ, YC prepared the manuscript and all authors contributed significantly to its revision. JMZ and PF who had data access verified the underlying data.

Declaration of interest

The authors have no conflicts.

Data sharing statement

The data used in this study is not publicly available due to the data user agreement with the Centers for Medicare and Medicaid Services.

Requests can be made through ResDAC (RESDAC@UMN.EDU) and more information can be found at: https://www.nia.nih.gov/research/dbsr/obtaining-cms-data-your-research

Supplementary materials

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differences and changes over time informs family, community, and societal level long-term care planning for a large and growing population of persons living with dementia. Variation in the size of racial/ethnic differences by economic status and geographic location provides opportunities for targeted strategies to reduce economic consequences and improve care and quality of life after dementia diagnosis.

Keywords

dementia; racial/ethnic disparities; mortality; mechanisms

Introduction

Several studies have documented significant differences in survival after dementia diagnosis across racial and ethnic groups.[1–6] The size of differences varies considerably across studies. For example, Hispanics with dementia outlive non-Hispanic Whites by one year as reported by Mayeda and colleagues,[3] while the Hispanic-White disparity is roughly four times as large in Helzner et al.'s work.[4] It is also inconclusive whether Asians diagnosed with dementia live longer than White counterparts or not.[3,5] Cross-study differences in these estimates are driven partly by studies based on regional samples, with limited sample sizes for racial/ethnic groups and insufficient observed follow-up time after dementia onset.[6] Quantifying length of life after dementia diagnosis and understanding mechanisms driving these subpopulation differences informs care, end of life and financial planning for diverse groups of persons living with dementia and their families, their health care providers, and public health policy leaders.

Potential mechanisms driving racial/ethnic differences in post-diagnosis survival are proposed but not explicitly tested. Hispanics and African Americans have more competing risks for mortality associated with their higher prevalence of other conditions (e.g. hypertension, diabetes) before and after dementia diagnosis.[3,7] Risks may be related to differences in age at dementia onset or at diagnosis of dementia, with studies showing delayed dementia diagnosis of Hispanics and Blacks relative to Whites.[8,9] Non-Whites with dementia are more likely than whites to be undiagnosed leading to a selection of minorities diagnosed with dementia based on health and/or economic status that may in part explain disparities in mortality risk.[8] Higher education, less common among members of minorities, is associated with greater cognitive reserve resulting in later-stage diagnosis of dementia and paradoxically faster mortality.[4,10] However, a resource advantage associated with higher socio-economic status (SES) may offset the relatively later diagnosis, via better access to and quality of care, as in the general population.[11,12] Location plays a role in driving racial/ethnic disparities. Larger percentages of minorities live in urban areas than rural areas and rural-urban differences in dementia detection and care has been documented.[13] State policy regarding health benefits, immigration, environment, labor, and others, have also been linked to longevity. [14,15] Over time, racial/ethnic differences in post-diagnosis survival may change due to secular trends in these factors.

This study aimed to quantify years of life lived after dementia diagnosis for racially/ethnically diverse populations, and to understand factors driving the differences. We quantify

survival using large representative samples of older African Americans, American Indians/Alaska Natives, Asians/Pacific Islanders, Hispanics, and non-Hispanic Whites enrolled in traditional Medicare. Estimates were not biased by censoring because beneficiaries were followed for 18 years after diagnosis at which point all but 1% of persons living with dementia had died. Leveraging Medicare claims data, we analyzed multiple hypotheses for racial/ethnic disparities including age at diagnosis, SES, geographic location, and year of dementia diagnosis for empirical evidence of their relevance.

Methods

Data and study population

The main study population was drawn from a 100% sample of Medicare beneficiaries aged 65 or older and enrolled in traditional fee-for-service (FFS) Medicare in 2001 (N=32,030,540). To capture incident dementia diagnosis, we restricted analysis to those continuously enrolled in FFS from 1999 to 2001 to ensure a two-year 'wash-out' period with no dementia diagnosis to 2001 (N=21,882,461). We identified incident dementia in 2001 for 670,955 beneficiaries composed of African Americans (n=62,488), American Indians/Alaska Natives (n=1,941), Asians/Pacific Islanders (n=5,206), Hispanics (n=17,214), non-Hispanic Whites (n=578,901), missing races (n=2,564), and other races (n=2,641). The cohort, including those who in any year after 2001 switched from FFS to Medicare Advantage (n=32,362 or 4.8%), was followed from date of incident dementia diagnosis in year 2001 to December 31, 2018, or death. Only 1.1% (n=7,407) of the sample remained alive at the end of 2018.

For analysis of time trends in racial/ethnic disparities, we identified cohorts of individuals with an incident dementia diagnosis in each year from 2001 to 2013 (N=8,080,098) and estimated mortality risk for each of the 13 cohorts. Prior exclusion restrictions apply to this sample. We also pooled this cohort sample of individuals with incident dementia diagnosis in any year during 2001–2013 to provide sufficient sample size for analyses of geographic variations in mortality risk across states for each racial/ethnic group.

Dementia measure

Incident dementia diagnosis was identified as a dementia diagnosis in 2001 and no diagnosis in the prior two years (incident). To account for rule-out diagnoses, we required a second dementia diagnosis over the next two years, or death within one year.[16] Dementia diagnoses were ascertained using the following International Classification of Diseases, Ninth Revision, Clinical Modification codes (ICD-9-CM): Alzheimer's disease (331.0), Pick's disease (331.11), other frontotemporal dementia (331.19), senile dementia (290.0, 290.20, 290.21, 290.3, 331.2, 797), presenile dementia (290.10, 290.11, 290.12, 290.13), vascular dementia (290.40, 290.41, 290.42, 290.43), dementia classified-elsewhere (294.0, 294.10, 294.11, 294.8, 331.7), and unspecified dementia (294.20, 294.21).

Mortality

The main outcome, mortality, was measured using the death date provided in the Medicare data, sourced from the claims, online date of death provided by family members, or

benefit information collected from the Railroad Retirement Board and the Social Security Administration. The date of death has been validated for about 99% of beneficiaries.[17]

Race/ethnicity and other covariates

Race/ethnicity, self-reported in claims based on Social Security records, was refined based on Research Triangle Institute's algorithm that uses first and last name to increase accurate identification of Hispanics and Asians in Medicare claims.[18] Age and sex were retrieved from the Master Beneficiary Summary File. Low SES was indicated by identifying those eligible for both Medicare and Medicaid, 'dual-eligibles,' in any month of incidence year. Urbanicity was obtained from mapping Federal Information Processing System (FIPS) county codes to the Rural-Urban Continuum codes developed by the United States Department of Agriculture. State of residence was identified from FIPS state codes. Disease complexity was measured using the Charlson Comorbidity Index (CCI), an integer score that predicts one-year mortality based on the presence of one or multiple comorbid conditions.[19] Using ICD-9-CM codes in claims, we generated indicators of diagnosed comorbid health conditions, including hypertension, hyperlipidemia, acute myocardial infarction, atrial fibrillation, stroke, and diabetes. All covariates were measured in the year of incident dementia diagnosis.

Statistical analysis

We calculated years of survival by race/ethnicity among persons with incident dementia diagnosis in 2001 using longitudinal data files and date of death. We then used Cox proportional hazards models to estimate racial/ethnic differences in time to death with covariate controls for age and age-squared at diagnosis, sex, CCI and CCI-squared, health condition indicators, and indicator for dual-eligibility status. To assess if any of the hypothesized factors differentially affected survival across race/ethnicity, we estimated stratified hazard models separately by sex; age bands 65–75, 76–80, 81–85, and 86 and older; dual-eligibility status; rural/urban living. The stratified models are adjusted for all the controls listed above and we applied Bonferroni correction to p-values.

For analyses of time trends in survival, we estimated 5-year mortality risk by race/ethnicity using Cox proportional hazards models stratified by year of diagnosis (2001 to 2013) and adjusting for previously described covariate controls.

To study the impact of state of residence on racial differences, we pooled the sample of persons with incident dementia 2001–2013 and used Cox models to estimate 5-year mortality risk separately for each racial/ethnic population including state indicators and all other control variables. We reported hazard ratios for the five most populous states for each racial/ethnic group relative to CA, which is a top 5 most populous state for all racial/ethnic groups.

We assessed the proportionality assumption of the models with Schoenfeld residuals and examined robustness of estimates to alternative models. For the analysis of cohort with incident diagnosis in 2001, we estimated log-linear models of survival years with Ordinary Least Squares (OLS) multivariate regression. For the analysis of time trend and state of

residence, we estimated multivariate logistic regression of 5-year mortality. All analyses were conducted in SAS Enterprise Guide 7.100.5.6214.

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Results

Descriptive statistics

Table 1 reports sample characteristics measured in 2001, year of dementia diagnosis. Mean age of diagnosis was 82.2 years. Hispanics had the youngest age at diagnosis (79.4 years), while non-Hispanic Whites had the oldest (82.4 years). On average African Americans or Asian Americans were diagnosed at the age of 81. Females had higher rate of dementia diagnosis (66.0%) than males. Rates of hypertension and stroke were 75.1% and 29.8%, respectively, and prevalence of comorbidities varied by race/ethnicity. African Americans had the highest comorbidity index (1.7) and higher prevalence of hypertension and stroke than other groups. Almost one quarter (24.0%) of beneficiaries with incident dementia were eligible for both Medicare and Medicaid. Over half of racial/ethnic minorities received both Medicare and Medicaid benefits compared to 20% of non-Hispanic Whites. Seventy-five percent of persons with an incident dementia diagnosis lived in urban areas.

Distribution of years of survival after diagnosis by race/ethnicity

Following dementia diagnosis, Whites survived the shortest length of time on average (3.5 years) and at median (2.3 years) (Table 2). Hispanics (6.2 years) followed by Asians/Pacific Islanders (5.5 years) had the longest mean and median survival (5.5 and 4.1 years, respectively). African Americans' mean survival (3.8 years) and that for American Indians/Alaska Natives (3.6) was at or close to the average for Whites. Ten percent of individuals lived at least 8.9 more years after diagnosis (Table 2). The 90^{th} percentile of survival time was higher for non-Whites than Whites. Among Asians/Pacific Islanders, 10% lived at least 14.3 years and similarly among Hispanics, 10% lived over 13.8 years, which were roughly 5 years longer than that among Whites (8.6 years). African Americans and American Indians/Alaska Natives had similar but slightly higher post-diagnosis life expectancy as Whites, both on average and at median; however, at the 90^{th} percentile, African Americans outlived Whites by over one year.

Racial/Ethnic difference in survival with additional controls

After adjusting for age, age-squared, sex, comorbid conditions, CCI, and dual eligibility status, all racial/ethnic minorities but American Indians/Alaska Natives had lower mortality risks than Whites (Table 3 Panel A). Being Asian/Pacific Islander (HR=0.60, 95%CI: 0.59—0.62) or Hispanic (HR=0.59, 95%CI: 0.58—0.60) reduced the hazard by about 40% relative to White. African Americans experienced a 13% reduction in mortality risk than Whites (HR=0.87, 95%CI: 0.86—0.88).

Racial/Ethnic difference in survival by sex and age at diagnosis

Table 3 Panel B reports hazard ratios for each racial/ethnic group from models stratified by sex and including all other covariates. Compared to White females, African American females had a 16.5% (HR=0.84, 95%CI: 0.83—0.85) lower hazard of death, and African American males had a 7% lower hazard (HR=0.93, 95%CI: 0.92—0.94) relative to White males. There was little sex difference in the American Indian/Alaska Native, Asian, and Hispanic groups.

Racial differences in age at diagnosis did not explain the mortality differences by race/ethnicity. That is, mortality difference by race/ethnicity persisted across age bands (Table 3 Panel C). An exception was the higher hazard ratio among Asians/Pacific Islanders diagnosed at age 86 and older (HR=0.75, 95%CI: 0.71—0.80).

Racial/Ethnic difference in survival by SES

When stratified by dual eligibility status, a proxy for low SES (Table 3 Panel D), the lower mortality risk of African Americans, Asian/Pacific Islanders and Hispanics compared to Whites remained and was larger among the dual-eligibles than among non-dual-eligibles. A notable difference was among American Indians/Alaska Natives. Although there was no difference than Whites among all American Indians/Alaska Natives, among the dual-eligible, mortality risk relative to Whites was 8% lower (HR=0.92, 95%CI: 0.86—0.98).

Racial/Ethnic difference in survival by geographic location

Rural versus urban location did not explain racial/ethnic differences in survival after a dementia diagnosis for most groups. Differences in mortality risk of African Americans, American Indians/Alaska Natives and Hispanics relative to Whites was similar among rural and urban beneficiaries (Table 3 Panel E). Mortality risk of Asians/Pacific Islanders relative to Whites residing in non-urban areas (HR=0.59, 95%CI: 0.58—0.61) was lower than the Asian-White difference in urban areas (HR=0.79, 95%CI: 0.71—0.87).

There were differences in post-diagnosis mortality within a racial/ethnic population by state of residence (Table 4 and Supplementary Table S2). California (CA) is among the top five most populous states for all racial/ethnic groups and Table 4 reports hazard ratios for four other most populous states for each race/ethnicity relative to CA. African Americans residing in NY had a lower mortality risk compared to African Americans in CA (HR=0.98, 95%CI: 0.96—1.00), while those living in GA faced an elevated risk of death (HR=1.09, 95%CI: 1.07—1.12). American Indians/Alaska Natives living in AZ had a 11% lower hazard of death relative to CA but those living in OK had a 9% elevated risk. Asians/Pacific Islanders living in HI, NJ, NY, TX had higher hazards of death relative to those in CA. Hispanics living in FL (6%) and NY (8%) had lower hazards relative to Hispanics living in CA. Non-Hispanic Whites in FL, NY, and PA had lower risks of death after dementia diagnosis relative to Whites in CA but no difference for those in TX.

Racial/Ethnic difference in survival by year of dementia diagnosis

Figure 1 shows the adjusted hazard ratios of 5-year mortality risk for each racial/ethnic group relative to Whites from different models stratified by year of incident dementia

diagnosis during 2001–2013. Asians and Hispanics saw a decreasing mortality advantage over Whites from 2001 to 2006, which became stable from 2006 onward (Figure 1 and Supplementary Table S3). The gap in survival time between African Americans and Whites remained constant over time. American Indians/Alaska Natives had similar mortality risk as Whites across most years but trended up over time and by 2013 they had a higher mortality risk relative to Whites.

Discussion

Using 100% sample of Medicare beneficiaries, this is the first study to quantify racial/ethnic disparities in survival time following dementia onset, for all older Americans in traditional Medicare. Compositional differences within race/ethnic groups from regional studies particularly Latinos, resulted in different findings regarding survival after dementia diagnosis.[3–5] Distinct from prior studies, we found a large survival advantage among Hispanics relative to Whites: a 40% reduction in mortality risk. Only two prior studies provided estimates of disparities in survival for American Indians/Alaska Natives and Asian Americans compared to Whites, although estimates were imprecisely measured due to small sample sizes,[5] especially when stratified by age.[3] In the model adjusted for differences in health, SES, and demographics, we found no difference of American Indians relative to Whites (HR=0.97, 95%CI: 0.93—1.01). We documented a large survival advantage among Asian Americans compared to Whites (HR=0.60, 95%CI: 0.59—0.62) that is substantially larger than estimates reported previously.

A second strength of this study is the long follow-up. This is the first study to follow individuals for up to 18 years, including those who move to Medicare Advantage, which reduces time censoring bias and selection bias associated with changes in Medicare plan type. Reducing censoring is important. Mean survival among all was 3.6 years and over one year higher than the median (2.4 years) reflecting the skewed distribution: 5% live at least 11 more years after diagnosis. More than 10% of Asians and Hispanics lived more than 13 years, the length of censored follow-up in an earlier study.[3] African Americans had a slightly higher mean and median survival years relative to Whites; however, 10% survived at least one year longer than non-Hispanic Whites.

A third strength of this study is the analysis of contributing factors of socioeconomics, geographical location, and time trends in who is diagnosed to disparities in survival. The addition of this information along with large samples of racially/ethnically diverse populations and long follow up has not been possible in prior studies. We analyzed whether the average higher SES of non-Hispanic Whites compared to non-Whites is a factor driving disparities by separately modeling disparities in survival by Medicaid and Medicare dual-eligibility status - a proxy for low SES. The cognitive reserve hypothesis is consistent with higher mortality risk of Whites compared to non-Whites. According to the cognitive reserve hypothesis,[10] cognitive reserve delays symptom onset despite progression of disease pathology and thus diagnosis occurs at later stages in disease and once diagnosed, decline is faster, and longevity is compressed. The hypothesized racial disparities may be reduced in resource constrained populations if disparities are in part driven by low SES associated with delayed diagnosis and thus more severe disease at diagnosis. We did not find evidence

favoring this hypothesis. Within the sample of beneficiaries who are dual-eligible we found the survival advantage of non-Whites compared to Whites persisted and at a similar albeit slightly larger magnitude than among non-dual eligible beneficiaries.

The differential location of racial/ethnic groups across urban and non-urban areas may contribute to disparities in survival differences after a dementia diagnosis. In the general population, mortality rate is higher in rural areas and the gap has widened over the last 40 years with larger risk reductions in metro areas.[20] In the context of dementia, missed and delayed diagnoses may be more common in rural areas where primary and specialty care are undersupplied and underused.[21,22] As such, rural Americans tend to be diagnosed at more advanced stage of dementia thus facing shorter survival than urban counterparts. We found similar racial/ethnic disparities in survival after diagnosis in both urban and non-urban areas except for Asians/Pacific Islanders. The magnitude by which non-urban Asians outlived non-urban Whites was greater than that of urban Asians and Whites. This may in part be explained by compositional differences in Asians who live in urban and non-urban areas.

Prior studies of racial/ethnic differences in survival differences have largely focused on explanations such as individual health behaviors to the neglect of contextual factors such as state health policies, access to and supply of physicians and dementia specialists,[23] diagnostic practice,[24] and other institutional factors that shape health and mortality.[14,15] Consistent with a prior study investigating Black-White disparities by state, we found elevated mortality risk for African Americans residing in southern states as well as lower risk for Whites in Middle Atlantic states.[24] We also added differences in survival by state of residence for American Indians/Alaska natives, Asians/Pacific Islanders, and Hispanics to this scant literature. Findings for Hispanics did not follow a similar southern versus non-southern state divide. In states with significant populations of American Indians/Alaska natives such as AZ, CA and OK, we reported statistically different mortality hazards with both increased rates in OK (9%) and decreased in AZ (12%) relative to CA. The four most populous states with Asians/Pacific Islanders besides CA were associated with higher mortality risk for this group. Understanding origins of these state disparities in survival provides opportunities to reduce mortality risk across diverse populations.

We analyzed mortality risks of persons first diagnosed in each year 2001–2013 and found a narrowing gap between Asians and Whites and Hispanics and Whites and an increasing gap between American Indians/Alaska Natives and Whites. This may be explained by changing characteristics (not measured in claims data such as functional limitations) of different racial/ethnic populations who were being diagnosed in 2001 compared to 2013. Indeed, diagnosis of incident dementia increased over time for American Indians/Alaska Natives, Asians/Pacific Islanders, and Hispanics and declined among Whites. As more non-White persons with dementia receive a diagnosis, this changes the health and functional profile of the populations who are diagnosed.

We observed persistent survival advantage of non-Whites after accounting for hypothesized factors that were measurable in our Medicare claims data. Other explanations include racial/ethnic differences in dementia etiology, which can affect progression of disease and likely survival.[13,14] Some autopsy evidence suggests differences in pathology among

African Americans, Hispanics,[5] and Whites,[25,26] however the distribution of etiologic subtype by race/ethnicity is not well identified in administrative claims. A prior study finds 85% of dementia diagnoses are by non-dementia specialists who are more likely to code “unspecified dementia” compared to dementia specialists who are more likely to specify subtypes of dementia.[23] Hispanics and Asians have fewer visits with dementia specialists thus the etiology of their disease may be less well understood. Second, faster progression of dementia is associated with pre-diagnosis vascular risks, including diabetes and cholesterol level.[4] In our sample we observed higher prevalence of diabetes and hyperlipidemia among non-whites suggesting a faster decline inconsistent with their longer survival compared to Whites. Third, greater contribution of impairment to death among African Americans than among Whites has been reported.[27] Finally medical and informal care matters. Studies found less use of dementia care specialists and drug treatments among racial/ethnic minorites.[23,28,29] Hispanics also have a lower likelihood of placement into nursing homes.[30,31] If institutionalization increases mortality risks, then lower nursing home use by Hispanics may in part explain their survival advantage.

There are limitations to the study. The study population of all Medicare beneficiaries in traditional Medicare excludes those enrolled in Medicare Advantage at time of diagnosis. However, this was less than 13% of all beneficiaries in Medicare in 2001, and the study does include those who switch to Medicare Advantage plans after 2001. We identified dementia from claims with dementia diagnostic codes and non-whites with dementia are at higher risk of being undiagnosed relative to whites,[8] and despite adjusting for health conditions and CCI, there may be a selection bias on unobserved health factors. Cause of death may in part explain racial/ethnic disparities in survival but is not measured in these data. Differences in morality risk after diagnosis across states and within a racial/ethnic group may be driven by state policies, programs, and other state-specific factors and/or selection into those states on individual characteristics and factors that we did not observe. We reduced the likelihood that results are driven by primarily selection, by analyzing states with large populations of each racial/ethnic group. Indeed, we find much larger cross-state differences within a racial ethnic group when comparing states with small populations of a racial ethnic group (Supplementary Table S2). For example, the highest and the lowest hazard ratios for African Americans were Vermont (HR=1.35) and Maine (HR=0.76). We report estimates from Cox proportional hazard models for comparability to other studies. Assessment of proportionality assumption indicated violation for some covariates. The reported racial/ethnic differences in survival were robustness to alternative modeling and estimation approaches utilizing OLS estimation of log-linear models of survival years (Supplementary Table 4) and logistic regression of 5-year mortality risk (Supplementary Table 5 and Supplementary Figure 1). For instance, African Americans with a 13% lower risk of mortality in Cox models experienced 7.6% increase in years of survival using OLS models. Conclusions drawn from these models were consistent with those reported based on Cox models.

Racial/ethnic minorities diagnosed with dementia live many more years, requiring a decade or more of care. Variation in the size of racial/ethnic differences by economic status and geographic location provides opportunities for targeted strategies to reduce economic consequences and improve care and quality of life after dementia diagnosis. Measurement of these survival differences and understanding how and why they are changing over time will

inform community and societal level care and long-term support planning for a large and growing population of persons living with dementia.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Lewis G, Werbeloff N, Hayes JF, Howard R, Osborn DPJ. Diagnosed depression and sociodemographic factors as predictors of mortality in patients with dementia. Br J Psychiatry 2018;213(2):471–476. [PubMed: 29898791]
2. Ornstein KA, Zhu CW, Bollens-Lund E, et al. Medicare expenditures and health care utilization in a multiethnic community-based population with dementia from incidence to death. Alzheimer Dis Assoc Disord 2018;32(4):320–325. [PubMed: 29734263]
3. Mayeda ER, Glymour MM, Quesenberry CP, Johnson JK, Pérez-Stable EJ, Whitmer RA. Survival after dementia diagnosis in five racial/ethnic groups. Alzheimers Dement 2017;13(7):761–769. [PubMed: 28174069]
4. Helzner EP, Scarmeas N, Cosentino S, Tang MX, Schupf N, Stern Y. Survival in Alzheimer disease: a multiethnic, population-based study of incident cases. Neurology 2008;71(19):1489–1495. [PubMed: 18981370]
5. Mehta KM, Yaffe K, Pérez-Stable EJ, et al. Race/ethnic differences in AD survival in US Alzheimer's Disease Centers. Neurology 2008;70 (14):1163–1170. [PubMed: 18003939]
6. Co M, Couch E, Gao Q, Martinez A, Das-Munshi J, Prina M. Differences in survival and mortality in minority ethnic groups with dementia: a systematic review and meta-analysis. Int J Geriatr Psychiatry 2021:1–24.
7. Chen C, Zissimopoulos JM. Racial and ethnic differences in trends in dementia prevalence and risk factors in the United States. Alzheimers Dement (N Y) 2018;4(1):510–520. [PubMed: 30364652]
8. Chen Y, Tysinger B, Crimmins E, Zissimopoulos JM. Analysis of dementia in the US population using Medicare claims: Insights from linked survey and administrative claims data. Alzheimers Dement (N Y) 2019;5(1):197–207. [PubMed: 31198838]
9. Cooper C, Tandy AR, Balamurali TBS, Livingston G. A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. Am J Geriatr Psychiatry 2010;18 (3):193–203. [PubMed: 20224516]
10. Stern Y Cognitive reserve in ageing and Alzheimer's disease. Lancet Neurol 2012;11(11):1006–1012. [PubMed: 23079557]
11. Hamad R, Penko J, Kazi DS, Coxson P, Guzman D, Wei PC, Mason A, Wang EA, Goldman L, Fiscella K. Bibbins-Domingo K. Association of low socioeconomic status with premature coronary heart disease in US adults. JAMA cardiology 2020 Aug 1;5(8):899–908. [PubMed: 32459344]
12. Adler NE, Stewart J. Health disparities across the lifespan: meaning, methods, and mechanisms. Annals of the New York Academy of Sciences 2010 Feb;1186(1):5–23. [PubMed: 20201865]
13. Weden MM, Shih RA, Kabeto MU, Langa KM. Secular trends in dementia and cognitive impairment of U.s. rural and urban older adults. Am J Prev Med 2018;54(2):164–172. [PubMed: 29246677]
14. Montez JK, Beckfield J, Cooney JK, et al. US state policies, politics, and life expectancy. Milbank Q 2020;98(3):668–699. [PubMed: 32748998]

15. Montez JK, Zajacova A, Hayward MD, Woolf SH, Chapman D, Beckfield J. Educational disparities in adult mortality across U.s. states: How do they differ, and have they changed since the mid-1980s? Demography 2019;56(2):621–644. [PubMed: 30607779]
16. Thunell J, Ferido P, Zissimopoulos J. Measuring Alzheimer's disease and other dementias in diverse populations using Medicare claims data. J Alzheimers Dis 2019;72(1):29–33. [PubMed: 31524159]
17. Death Information in the Research Identifiable Medicare Data. Research Data Assistance Center 2018 (online). Available at: http://www.resdac.org/articles/death-information-research-identifiablemedicare-data. Accessed April 30, 2021.
18. Eicheldinger C, Bonito A. More accurate racial and ethnic codes for Medicare administrative data. Health Care Financ Rev 2008;29(3):27–42. [PubMed: 18567241]
19. Charlson M, Szatrowski TP, Peterson J, Gold J. Validation of a combined comorbidity index. J Clin Epidemiol 1994;47(11):1245–1251. [PubMed: 7722560]
20. Cosby AG, McDoom-Echebiri MM, James W, Khandekar H, Brown W, Hanna HL. Growth and persistence of place-based mortality in the United States: The rural mortality penalty. Am J Public Health 2019;109(1):155–162. [PubMed: 30496008]
21. Adornato BT, Drogan O, Thoresen P, et al. The practice of neurology, 2000–2010: report of the AAN Member Research Subcommittee. Neurology 2011;77(21):1921–1928. [PubMed: 22031533]
22. Lin CC, Callaghan BC, Burke JF, et al. Geographic variation in neurologist density and neurologic care in the United States. Neurology 2021;96(3):e309–e321. [PubMed: 33361251]
23. Drabo EF, Barthold D, Joyce G, Ferido P, Chang Chui H, Zissimopoulos J. Longitudinal analysis of dementia diagnosis and specialty care among racially diverse Medicare beneficiaries. Alzheimers Dement 2019;15(11):1402–1411. [PubMed: 31494079]
24. Gillum RF, Obisesan TO. Differences in mortality associated with dementia in U.S. blacks and whites. J Am Geriatr Soc 2011;59 (10):1823–1828. [PubMed: 22091495]
25. Graff-Radford NR, Besser LM, Crook JE, Kukull WA, Dickson DW. Neuropathologic differences by race from the National Alzheimer's Coordinating Center. Alzheimers Dement 2016;12(6):669–677. [PubMed: 27094726]
26. Barnes LL, Leurgans S, Aggarwal NT, et al. Mixed pathology is more likely in black than white decedents with Alzheimer dementia. Neurology 2015;85(6):528–534. [PubMed: 26180136]
27. Wilson RS, Aggarwal NT, Barnes LL, Bienias JL, Mendes de Leon CF, Evans DA. Biracial population study of mortality in mild cognitive impairment and Alzheimer disease. Arch Neurol 2009;66 (6):767–772. [PubMed: 19506138]
28. Barthold D, Joyce G, Ferido P, et al. Pharmaceutical treatment for Alzheimer's disease and related dementias: Utilization and disparities. J Alzheimers Dis 2020;76(2):579–589. [PubMed: 32538845]
29. Mehta KM, Yin M, Resendez C, Yaffe K. Ethnic differences in acetylcholinesterase inhibitor use for Alzheimer disease. Neurology 2005;65(1):159–162. [PubMed: 16009909]
30. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. JAMA 2004;292(8):961–967. [PubMed: 15328328]
31. Yaffe K, Fox P, Newcomer R, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. JAMA 2002;287(16):2090–2097. [PubMed: 11966383]

Research in context

Evidence before this study

Accurate estimates of life expectancy after dementia diagnosis and drivers of differences in diverse groups informs their care and financial planning. Prior studies on post-diagnosis survival have not yielded population representative estimates for different racial/ethnic populations because of limitations in sample size, representativeness of racial/ethnic groups, and length of follow up. We searched PubMed on July 1, 2021, using search terms: (“Alzheimer’s” OR “dementia” OR “cognitive”) AND (“mortality” OR “survival” OR “death” OR “life expectancy”) AND (“race” OR “ethnicity”). From the 988 records returned, we identified 20 studies characterizing racial/ethnic differences in survival time after dementia incidence in the U.S. A recent meta-analysis found most U.S. studies (13 out of 17) reported survival advantage for non-Whites relative to Whites, with a pooled hazard ratio of 0.79 (95%CI: 0.74–0.84) and significant heterogeneity across racial/ethnic populations and across studies.

Added value of this study

Using a 100% sample of beneficiaries in traditional Medicare with 18 years of follow-up data after incident dementia diagnosis, this study provides estimates of racial/ethnic differences in years of life lived after diagnosis. This study also contributes to the understanding of heterogeneity in racial/ethnic survival differences by analysis of demographic, economic, geographic, and temporal factors.

Implications of all the available evidence

We find longer length of life following dementia diagnosis for African Americans, Asians, and Hispanics compared to Whites and no difference for American Indians/Alaska Natives compared to Whites. Large differences in survival after dementia diagnosis have meaningful implications for financial impact of, and care planning for, dementia for both families and society. Economic, temporal and geographic drivers of racial/ethnic disparities provide opportunities for targeted strategies to reduce economic consequences and improve care and length and quality of life after dementia diagnosis in a large and growing population of persons living with dementia.

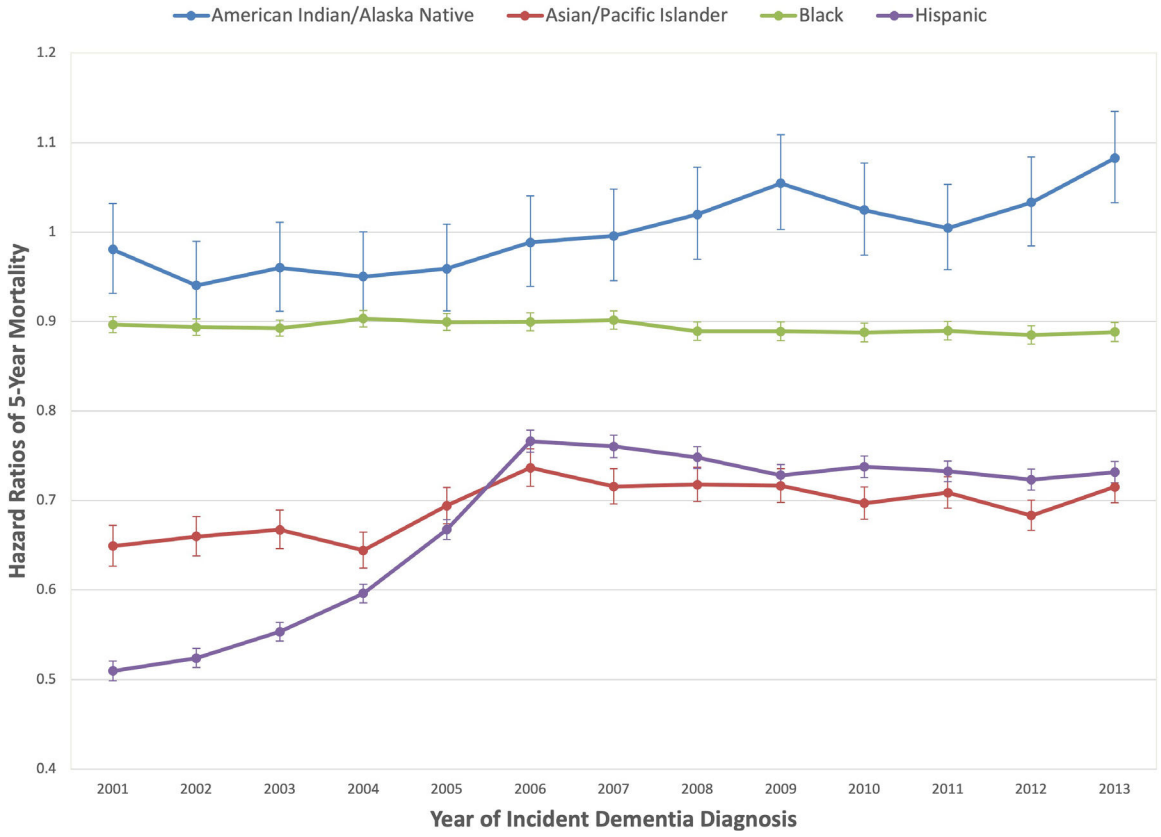

Figure 1.
Five-Year Mortality Risk by Race/Ethnicity (Relative to Whites), 2001–2013.

Table 1:

Sample characteristics of Medicare Beneficiaries with Incident Dementia Diagnosis in 2001 and by Race/Ethnicity.

	All	African American	American Indian/Alaska Native	Asian/Pacific Islander	Hispanic	Non-Hispanic White
N	670,955	62,488	1,941	5,206	17,214	578,901
Mean Age, years	82.2	81.0***	80.1***	80.9***	79.4***	82.4
Female, %	66.0%	66.9%***	62.6%***	60.2%***	64.7%***	65.9%
Mean CCI	1.3	1.7***	1.6***	1.4***	1.4***	1.3
Hypertension, %	75.1%	86.3%***	74.9%	78.7%***	78.3%***	73.7%
Hyperlipidemia, %	29.9%	24.7%***	22.3%***	41.3%***	44.5%***	30.0%
AMI, %	5.7%	5.6%*	5.9%	5.0%*	4.7%***	5.8%
ATF, %	21.3%	13.5%***	14.6%***	15.1%***	10.8%***	22.6%
Diabetes, %	28.4%	41.5%***	40.3%***	36.7%***	45.8%***	26.4%
Stroke, %	29.8%	34.3%***	29.3%	31.4%***	31.0%***	29.2%
Depression, %	27.1%	17.8%***	25.5%*	20.3%***	27.5%	28.1%
Anxiety, %	11.6%	7.3%***	10.7%*	7.5%***	12.5%	12.1%
Dual eligibility, %	24.0%	53.1%***	48.0%***	59.7%***	50.6%***	19.6%
Urban, %	75.0%	80.8%***	44.7%***	92.3%***	66.4%***	74.6%

T-tests are performed for differences in means of covariates of a given non-White race/ethnicity compared to those of Whites.

*** p<0.001

** p<0.01

* p<0.05.

CCI=Charlson Comorbidity Index. CCI is calculated using one year of claims prior to dementia diagnosis; each beneficiary is given a weighted score of comorbidities. A score of 0 means the lack of comorbidity; a higher score indicates higher mortality in the next year. CCI coding macro available from the National Cancer Institute https://healthcaredelivery.cancer.gov/seermedicare/privacy/. AMI=acute myocardial infarction. ATF=atrial fibrillation. This sample excludes 5,205 beneficiaries with missing/other race/ethnicity.

Table 2:

Distribution of Years of Survival After Dementia Diagnosis by Race/Ethnicity.

Race/Ethnicity	All	African American	American Indian/Alaska Native	Asian/Pacific Islander	Hispanic	Non-Hispanic White
Mean	3.6	3.8	3.6	5.5	6.2	3.5
Standard Deviation	3.8	4.1	3.8	5.2	4.9	3.6
5th Percentile	0.0	0.0	0.0	0.1	0.1	0.0
10th Percentile	0.1	0.1	0.1	0.2	0.4	0.1
25th Percentile	0.6	0.6	0.6	1.1	1.9	0.6
Median	2.4	2.4	2.4	4.1	5.5	2.3
75th Percentile	5.3	5.6	5.2	8.3	9.1	5.1
90th Percentile	8.9	9.6	8.9	14.3	13.8	8.6
95th Percentile	11.4	12.5	11.3	17.2	17.1	11.0
99th Percentile	17.1	17.4	17.1	17.8	17.8	16.5

The table excludes results for missing/other race/ethnicity (n=5,205). Percent of respondents who were still alive in 2018: non-Hispanic White (0.87%), African American (1.66%), Asian/Pacific Islander (6.45%), Hispanic (5.37%), American Indian/Alaska Native (1.13%).

Table 3:

Adjusted Hazard Ratios of Mortality Risk for All Medicare Beneficiaries with Dementia Diagnosis in 2001 and by Factors (Relative to Non-Hispanic Whites).

Hazard Ratio (95% CI)	African American	American Indian/Alaska Native	Asian/Pacific Islander	Hispanic
Panel A. All				
All	0.87*** (0.86–0.88)	0.97 (0.93–1.01)	0.60*** (0.59–0.62)	0.59*** (0.58–0.60)
Panel B. By Sex				
Male	0.93*** (0.92–0.94)	0.93 (0.86–0.99)	0.62*** (0.59–0.64)	0.59*** (0.58–0.61)
Female	0.84*** (0.83–0.85)	1.00 (0.95–1.06)	0.61*** (0.58–0.63)	0.59*** (0.57–0.60)
Panel C. By Age at Diagnosis				
65–75	0.90*** (0.88–0.91)	0.94 (0.87–1.02)	0.52*** (0.49–0.55)	0.56*** (0.55–0.58)
76–80	0.87*** (0.86–0.89)	0.99 (0.91–1.09)	0.55*** (0.52–0.59)	0.60*** (0.58–0.62)
81–85	0.85*** (0.84–0.87)	0.99 (0.90–1.09)	0.60*** (0.57–0.64)	0.62*** (0.60–0.64)
86+	0.85*** (0.83–0.86)	0.94 (0.85–1.03)	0.75*** (0.71–0.80)	0.57*** (0.55–0.59)
Panel D. By Socioeconomic Status				
Non-Dual Eligibility	0.90*** (0.89–0.91)	1.01 (0.95–1.07)	0.69*** (0.66–0.72)	0.60*** (0.59–0.61)
Dual Eligibility	0.84*** (0.83–0.85)	0.92* (0.86–0.98)	0.56*** (0.54–0.58)	0.57*** (0.56–0.59)
Panel E. By Rural/Urban Living				
Urban	0.85*** (0.83–0.87)	0.95 (0.90–1.01)	0.79*** (0.71–0.87)	0.58*** (0.57–0.60)
Rural	0.87*** (0.86–0.88)	0.99 (0.93–1.06)	0.59*** (0.58–0.61)	0.58*** (0.57–0.60)

*** p<0.001

** p<0.01

* p<0.05.

All p-values were corrected using Bonferroni method, to adjust for multiplicity. Models were adjusted for age at diagnosis and age-squared, sex, comorbid condition indicators (for hypertension, hyperlipidemia, acute myocardial infarction, atrial fibrillation, stroke, and diabetes), Charlson Comorbidity Index, Charlson Comorbitidy Index squared, and Medicare Medicaid dual eligibility status. The sample contained 670,955 beneficiaries with incident dementia diagnosis in 2001.

Table 4:

Five-Year Mortality Risk in Top 5 Populous States by Race/Ethnicity (Relative to California).

	African American	American Indian/Alaska Native	Asian/Pacific Islander	Hispanic	Non-Hispanic White
AZ		0.889***			
AK		1.116**			
FL				0.938***	0.984***
GA	1.094***				
HI			1.078***		
IL			1.116***		
NC	1.078***				
NJ				0.904***	
NM		0.918*			
NY	0.979*		1.044**	0.915***	0.946***
OK		1.094**			
PA					0.960***
TX	1.025**		1.130***	1.044***	1.004

*** p<0.001

** p<0.01

* p<0.05.

The sample contained 8,080,098 beneficiaries with incident dementia diagnosis in any year from 2001 to 2013. Models were adjusted for age, age-squared, sex, comorbid condition indicators (for hypertension, hyperlipidemia, acute myocardial infarction, atrial fibrillation, stroke, and diabetes), Charlson Comorbidity Index, Charlson Comorbidity Index squared, and Medicare Medicaid dual eligibility status. The sample contained 8,080,098 beneficiaries with incident dementia diagnosis in any year from 2001 to 2013.