Regional variation in U.S. dementia trends from 2000-2012

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\textbf{A B S T R A C T}

Although recent studies report a decline in dementia prevalence among U.S. older adults, national trends may mask subnational variation, particularly given large health and social inequalities linked to geography. To address this gap, we determined if there was subnational variation in reported national dementia trends and if region-specific trends were explained by sociodemographic and health characteristics. Data come from the 2000 (n = 10,447) and 2012 (10,426) waves of the Health and Retirement Study. We used validated methods for dementia classification using proxy and self-respondents. Logistic regression models, adjusted for within-person clustering over time, estimated trends in dementia prevalence by region and census division. We found subnational variation in dementia prevalence in both 2000 and 2012, as well as in change in dementia prevalence during this period. In 2000, dementia prevalence was lowest in the West (8.6%), higher in the Midwest (10.0%) and Northeast (11.1%), and highest in the South (14.6%). Dementia prevalence declined over time across all regions of the U.S. from 2000 to 2012 but remained highest in the South (10.7%) compared to the other regions (7.0–7.8%). Despite downward trends in dementia across the U.S., the prevalence of dementia in the South in 2012 approximated levels found in other regions in 2000. There was relatively less change over time in the West compared to other regions, but dementia prevalence was already quite low in the West in 2000. Within region, trends in dementia prevalence between 2000 and 2012 also varied slightly across census divisions. Subnational variation in changes in dementia prevalence were largely explained by education and health status. Variation in baseline prevalence, as well as differential rates of change, highlight the importance of examining subnational variation in dementia trends.

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inequality in mortality from neurological disorders, which largely consists of AD-related deaths, increased from 2000 to 2014, with the most pronounced changes occurring in counties located in the U.S. South and industrial Midwest. Taken together, these studies indicate the existence of a “Dementia Belt” that overlaps with the well-documented “Stroke Belt” in the regional South. We do not know, however, if recently observed declines in dementia prevalence at the national level have occurred at similar rates across U.S. regions, including in the Dementia Belt.

National trends in dementia prevalence have been attributed to historical changes in the factors known to influence risk for dementia across successive cohorts of older adults (Langa et al., 2017; Satizabal et al., 2016; Wu et al., 2017). These historical shifts have varied across U.S. regions, suggesting potential differential geographic patterning in trends. For example, educational attainment, one of the most important risk factors for dementia, increased significantly during the 20th century. At the national level, about a quarter of U.S. adults over age 25 had completed a high school education in 1940. By 1960, approximately 41% had done so, representing a relative increase of 64% within just two decades. Improvements in education, however, have not been uniform across the country. The Northeast and Midwest regions, for example, reported similar rates and trends in high school completion as documented nationally, whereas the South reported lower rates of high school completion in 1940 (20%) and 1960 (35%) and the West reported higher rates in those periods (35% and 51%, respectively) (U.S. Census Bureau, 2020).

Researchers have also documented stark geographic divides in the health of the U.S. population, with people living in certain parts of the U.S. falling behind on several health indicators implicated in dementia risk. Smoking, a known risk factor for dementia (Rusakan et al., 2010, 2011), has been cited as a major contributor to geographic divergence in mortality (Fenelon, 2013), but although smoking rates have declined nationally, the decline has been greater in the West and less pronounced in the South (Dwyer-Lindgren et al., 2014; Fenelon, 2013). Cardiovascular disease (CVD), another important risk factor for dementia (Alonso et al., 2009; Whitmer et al., 2005), also declined markedly during this same period at a national level; however, clear geographic disparities in CVD emerged. As a result, cardiovascular mortality is now concentrated in the South, where mortality improvements have not kept pace with other regions of the country (Dwyer-Lindgren et al., 2017). Overall disease burden is also a risk factor for dementia. Researchers have found persistent regional differences in chronic disease burden, with higher morbidity found in the South and lower morbidity found in the West and Northeast (Nowakowski et al., 2019). It has become abundantly clear that parts of the U.S. lag behind national health improvements, that some regions are consistently disadvantaged relative to others, and that national trends showing improved population health likely masks geographic disparities.

Given known persistent economic, social, and health inequalities, it is unlikely that declining dementia has been experienced equally across U.S. regions. Although recent studies report an overall decline in dementia prevalence in the U.S. older adult population (Chen & Zissimosoulos, 2018; Langa et al., 2017), it remains unknown if there were subnational differences in this trend. We build on prior work of Langa et al. (2017) by examining subnational variation in dementia trends in the same population of adults ages 65 and older and across the same period spanning 2000 to 2012 and hypothesize that the national trend they observed differs across U.S. regions. We further hypothesize that there is subnational variation in the extent to which trends in dementia prevalence are explained by differences in the sociodemographic and health characteristics of the individuals residing in different regions of the U.S.

2. Methods

2.1. Data and sample

We used data from the 2000 and 2012 waves of the Health and Retirement Study (HRS). The HRS is a nationally representative, longitudinal study of U.S. adults over age 50 (Sonnega et al., 2014). Since 1992, the HRS has conducted core interviews with age-eligible respondents and their spouses approximately every two years. The HRS is a multi-stage area probability sample of age-eligible households selected from primary sampling units chosen from U.S. Metropolitan Statistical Areas (MSAs) and non-MSA counties, with an oversampling of minorities and the oldest-old. This complex sampling design allows for nationally representative analysis of census regions to be performed at the population level. We use data from the Langa-Weir Classification in the Cognitive Function File v2 provided by the HRS and the RAND HRS (Langa et al., 2020; RAND, 2020).

Our sample includes HRS respondents aged 65 and older, residing in one of the designated U.S. Census Regions, who were living in the community or a nursing home in 2000 or 2012. The 2000 cohort included 10,447 respondents and the 2012 cohort included 10,426 respondents after we excluded 282 (2.6%) and 296 (2.8%) respondents in 2000 and 2012, respectively, due to missing data on 1 or more analytic variables. Because HRS uses a steady-state design to replenish the sample with younger cohorts every 6 years, our analytic sample includes 3,984 respondents who provided data in both 2000 and 2012, 6,463 respondents who provided data only in 2000, and 6,442 respondents who provided data only in 2012. Of respondents who provided data in both years, 174 moved from one region of the U.S. to another.

2.2. Measures

2.2.1. Dementia

HRS uses information from respondents, proxies, and interviewers to identify cognitive impairment and classify individuals as having no cognitive impairment, having impairment with no dementia, or as having dementia. Respondents are administered the Telephone Instrument for Cognitive Status or TICS to assess cognitive function either by phone or in face-to-face interviews. The cognitive assessment consists of tests that evaluate the respondent’s memory, using 10 word immediate and delayed recall, and attention and processing speed, using a serial 7s subtraction test of working memory and counting backwards. Scores from all items in the cognitive assessment are summed into a composite score of cognitive functioning that ranges from 0 to 27. We used cut-points defined by Langa-Weir (Langa et al., 2020), which classifies respondents with a score of 0–6 as having cognitive impairment consistent with dementia. Dementia classification was also determined for respondents who did not take the cognitive assessment by using their proxy’s assessment of their memory and limitations in five instrumental activities of daily living (IADL), as well as the interviewer’s assessment of the respondent’s level of difficulty in completing the interview due to cognitive limitation. Scores on this assessment range from 0 to 11, with scores of 6 to 11 indicating functioning consistent with dementia. This categorization has good predictive ability when compared with classification from a consensus panel of experts in neuropsychiatric assessments of dementia (Crimmins et al., 2011). We created a binary indicator for those who were classified as having dementia versus those who were not classified as having dementia (the latter includes those with no cognitive impairment as well as those with cognitive impairment but no dementia).

2.2.2. Region

We use U.S. Census Bureau definitions of statistical regions and divisions to assign states to one of four regions and nine divisions, as shown in Table 1.
Estimates weighted for complex sample design and to represent the population. Standard deviations (SD) shown in parentheses.

### Table 1
U.S. Census regions, divisions, and states.

| Region       | Northeast | New England: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont | Mid-Atlantic: | New Jersey, New York, Pennsylvania | Midwest | East North Central: Illinois, Indiana, Michigan, Ohio, Wisconsin | Central: Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota | South Dakota | South Atlantic: Delaware, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, West Virginia | Central: Alabama, Kentucky, Mississippi, Tennessee | Central: Arkansas, Louisiana, Oklahoma, Texas | Central: West South Central: Colorado, New Mexico, Utah, Wyoming, | West Mountain: Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, Wyoming, | Pacific: Alaska, California, Hawaii, Oregon, Washington |
|--------------|-----------|-----------------------------------------------------------------------------------|-------------|------------------------------------|---------|----------------------------------------------------------------|--------------------------------|-----------------|------------------------------------------------|--------------------------------|-----------------|------------------------------------------------|------------------------------------------------|-----------------|

#### 2.2.3. Covariates
Demographic covariates included age (in years), self-reported gender (female or male), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, or Other), and nativity (foreign-born or US-born). Socio-economic status (SES) was measured using years of schooling (<12 years, 12 years, 13–15 years, and 16 or more years) and household net worth (excluding second residences) calculated as total wealth minus total debt and adjusted to 2000 dollars and categorized into quartiles. Health conditions included respondent reported doctor diagnosed cardiovascular risk factors (stroke, diabetes, heart disease, hypertension), current smoking status (current smoker, former smoker, never smoker), and body mass index calculated from self-reported height and weight and classified as underweight (<18.5), normal weight (18.5–24.9), overweight (25.0–29.9), and obese (≥30.0).

#### 2.3. Analysis plan
First, we examined how demographic characteristics, SES, and health conditions varied by region and changed over time. Next, we estimated age- and sex-adjusted dementia prevalence by census region and division in 2000 and 2012, and the relative and absolute change in dementia from 2000 to 2012. Finally, using logistic regression models we estimated trends in dementia prevalence from 2000 to 2012 stratified by census region and division. Because some respondents were present in both time periods, we report robust standard errors that account for within-person clustering over time (see Section 2.1), and also report the number of person-period observations in addition to the number of respondents in each region and division. Model 1 adjusted for

### Table 2
Sample characteristics by Region, 2000 and 2012, HRS.

|                     | Northeast 2000 | Northeast 2012 | Midwest 2000 | Midwest 2012 | South 2000 | South 2012 | West 2000 | West 2012 |
|---------------------|---------------|---------------|-------------|--------------|------------|------------|-----------|-----------|
| **Age, y**          |               |               |             |              |            |            |           |           |
| 65-74               | 52.8          | 52.7          | 50.6        | 51.4         | 53.7       | 59.3       | 53.3      | 53.7      |
| 75-84               | 35.0          | 33.3          | 37.9        | 32.4         | 35.0       | 29.1       | 36.0      | 33.1      |
| ≥85                 | 12.1          | 14.0          | 11.5        | 16.2         | 11.3       | 11.6       | 10.7      | 13.2      |
| **Female, %**       |               |               |             |              |            |            |           |           |
| White               | 88.0          | 84.6          | 92.0        | 90.8         | 77.9       | 76.8       | 84.4      | 79.1      |
| Black               | 7.6           | 8.0           | 6.5         | 6.6          | 13.4       | 12.8       | 2.8       | 3.1       |
| Hispanic            | 3.0           | 5.1           | 0.8         | 1.3          | 6.8        | 8.1        | 9.1       | 13.8      |
| Other               | 1.5           | 2.2           | 0.7         | 1.2          | 1.9        | 2.2        | 3.7       | 4.0       |
| **Foreign born, %** |               |               |             |              |            |            |           |           |
| <12 yrs             | 32.8          | 19.8          | 28.9        | 16.0         | 40.6       | 26.2       | 22.3      | 16.0      |
| 12 yrs              | 36.7          | 39.3          | 41.4        | 41.9         | 27.9       | 30.5       | 30.3      | 26.6      |
| 13-15 yrs           | 14.2          | 18.4          | 16.9        | 21.1         | 15.5       | 19.5       | 23.9      | 28.2      |
| ≥16 yrs             | 16.2          | 22.5          | 12.8        | 21.1         | 16.1       | 23.7       | 23.4      | 29.2      |
| **Mean (SD)**       |               |               |             |              |            |            |           |           |
| <12 yrs             | 11.8 (3.0)    | 12.8 (2.7)    | 11.9 (2.7)  | 12.9 (2.6)   | 11.2 (4.2) | 12.5 (3.7) | 12.6 (3.2) | 13.3 (3.1) |
| **Net worth (year 2000 $)**, % | | | | | | | | |
| Quartile 1 - lowest | 27.2          | 28.5          | 20.4        | 22.1         | 30.4       | 28.8       | 19.9      | 23.4      |
| Quartile 2          | 24.6          | 17.1          | 24.3        | 25.6         | 28.0       | 27.5       | 21.5      | 17.1      |
| Quartile 3          | 26.7          | 25.5          | 23.2        | 21.3         | 21.3       | 21.1       | 24.9      | 22.8      |
| Quartile 4 - highest| 21.4          | 28.9          | 27.1        | 28.3         | 20.3       | 22.6       | 33.7      | 36.7      |
| **Median**          | 134,500       | 171,088       | 176,000     | 162,060      | 104,000    | 111,370    | 204,000   | 229,151   |
| **Cardiovascular risk factors, %** | | | | | | | | |
| Stroke              | 10.6          | 10.8          | 11.7        | 11.4         | 12.2       | 12.9       | 10.5      | 11.4      |
| Diabetes            | 15.5          | 23.5          | 15.2        | 24.8         | 16.6       | 26.8       | 13.3      | 23.1      |
| Heart disease       | 29.3          | 32.4          | 29.4        | 33.4         | 30.5       | 32.3       | 25.8      | 29.0      |
| Hypertension        | 51.4          | 65.6          | 52.3        | 65.7         | 52.6       | 70.0       | 46.8      | 62.0      |
| **Smoking status, %** | | | | | | | | |
| Current smoker      | 9.6           | 10.1          | 8.6         | 8.9          | 11.3       | 10.1       | 10.4      | 7.5       |
| Former smoker       | 49.7          | 50.0          | 43.3        | 46.0         | 45.7       | 46.2       | 49.7      | 51.2      |
| Never smoker        | 40.7          | 40.0          | 48.1        | 45.0         | 42.9       | 43.7       | 39.9      | 41.3      |
| **BMI, %**          |               |               |             |              |            |            |           |           |
| <18.5               | 2.3           | 2.0           | 2.9         | 1.4          | 3.7        | 2.4        | 3.5       | 2.2       |
| 18.5-24.9           | 40.6          | 31.2          | 36.2        | 30.8         | 38.9       | 29.9       | 44.8      | 32.2      |
| 25.0-29.9           | 38.8          | 37.2          | 39.9        | 36.2         | 39.5       | 38.1       | 37.2      | 40.7      |
| ≥30.0               | 18.3          | 29.6          | 21.0        | 31.6         | 17.9       | 29.6       | 14.5      | 24.9      |
| **Mean (SD)**       |               |               |             |              |            |            |           |           |
| <12 years           | 4.4           | 3.2           | 4.5         | 3.0          | 4.7        | 2.7        | 3.5       | 2.5       |
| Nursing home resident, % | | | | | | | | |
| Proxy interview, %  | 11.6          | 6.9           | 10.9        | 6.2          | 14.3       | 7.4        | 9.7       | 6.2       |

Estimates weighted for complex sample design and to represent the population. Standard deviations (SD) shown in parentheses.
age and sex. Model 2 added race/ethnicity and nativity. Model 3 added educational attainment and household wealth. Model 4 added health conditions. We applied sample weights to all estimates to account for the complex sampling design in the HRS and make estimates representative of the national and subnational U.S. population. All analyses were conducted using Stata 16.

3. Results

3.1. Sample characteristics

Table 2 presents information on sample characteristics by region and period. The average age of respondents in 2000 and 2012 was about 75 years, with little variation across regions, although the age distribution skewed younger in the South compared to the West in 2012. Most respondents were women across regions and periods. There was statistically significant within-period regional variation in racial/ethnic composition as well as within-region changes over time. For example, in 2000, the Northeast and Midwest had more White older adult residents (88% and 92%, respectively) than the West (84.4%), whereas the South (77.9%) had the fewest White older adult residents. In the Northeast and West there was a decline in the White older adult population from 2000 to 2012, with a concurrent increase in the Latino older adult population.

As expected, there was regional variation in educational attainment and large shifts in the distribution of educational attainment from 2000 to 2012 across all regions. The West had more educated adult residents in both 2000 and 2012 compared to other regions and had a significant decline in the older adult population with 12 years of schooling or less across this time period (22% and 16%, respectively). Conversely, the South had the least educated older adult population compared to other regions - reporting an average of 11 years of education in 2000 and 12 ½ years of education in 2012.

Cardiovascular risk conditions and health behaviors had similar regional patterns. Older adults living in the West were generally healthier than other regions in 2000; however, increasing prevalence of cardiovascular risk conditions and obesity from 2000 to 2012 resulted in smaller regional differences in these conditions and behaviors by 2012. For example, about 46% of older adults in the West were diagnosed with hypertension in 2000. In comparison, hypertension was about 5 points higher in the other regions. By 2012, rates of diagnosed hypertension were about 3 points higher in the Northeast and Midwest than the West; however, the gap had widened to 8 points in the South.

3.2. Sex- and age-adjusted prevalence rates and trends

Dementia prevalence in 2000 and 2012 varied by both census region and division (Fig. 1). The West had the lowest dementia prevalence in 2000 (8.6%), the South had the highest (14.6%). The West South Central division, located in the South, had the highest dementia prevalence of any division at 17.7% in 2000.

We also report the dementia prevalence estimates and 95% confidence intervals as well as absolute and relative changes in dementia prevalence by census region and division in Table 3. Although all regions experienced a decline in dementia prevalence from 2000 to 2012, some regions and divisions experienced larger declines. For instance, while there was an overall decline of 3.3 percentage points in the Northeast, in the New England division of the region there was a decline of 6.0 percentage points, compared to a decline of 2.2 percentage points in the Mid-Atlantic division. In the South, the West South Central division had the highest dementia prevalence of any division at 17.7% in 2000 and one of the largest declines (5.9 percentage points). The smallest changes were observed in the Pacific division, where there was a small absolute (0.6 percentage points) and relative decline (7%) in dementia prevalence between 2000 and 2012.

Table 3 presents odd ratios in Panel A and adjusted marginal effects in Panel B from logistic regression models stratified by region. The estimates weighted for complex sample design and to be representative of the population.

3.3. Multivariable logistic regression

Table 4 presents odd ratios in Panel A and adjusted marginal effects in Panel B from logistic regression models stratified by region. The estimates weighted for complex sample design and to represent the population.
Estimates are weighted for complex sample design and to represent the population. Model 4 adjusts for age, sex, race/ethnicity, nativity, educational attainment, household wealth cardiovascular risk factors, smoking status, and body mass index. Estimates are weighted for complex sample design and to represent the population.

After accounting for race/ethnicity and nativity in Model 2 the West showed statistically significantly lower odds of dementia over time as well, equivalent to a decline of about 2 percentage points. But, as shown in Model 3, the decline in dementia in the West was explained by education and wealth. In addition, education and wealth explained about half of the decline in the South (4%–2%) and about one-third of the decline in the Northwest and Midwest (3%–2%). With further adjustment for differences in health status in Model 4 the dementia trends in the Northwest and Midwest were no longer statistically significant.

Dementia prevalence stratified by census division is presented in Table 5 and follows the same model sequence as the weighted logistic regression models predicting presence of dementia between 2012 and 2000 stratified by region, HRS.

| Panel A. Estimated Odds Ratios (OR) | OR 95% CI | OR 95% CI | OR 95% CI | OR 95% CI | N  N |
|-----------------------------------|-----------|-----------|-----------|-----------|-----|
| Northeast                          | 0.66 (0.51,0.86) | 0.63 (0.48,0.82) | 0.74 (0.56,0.98) | 0.75 (0.55,1.02) | 3,414 | 2,791 |
| Midwest                            | 0.64 (0.52,0.79) | 0.62 (0.50,0.77) | 0.73 (0.59,0.92) | 0.79 (0.62,1.01) | 5,245 | 4,203 |
| South                              | 0.67 (0.58,0.78) | 0.66 (0.57,0.77) | 0.82 (0.70,0.97) | 0.80 (0.68,0.95) | 8,545 | 7,103 |
| West                               | 0.86 (0.66,1.10) | 0.76 (0.58,0.98) | 0.84 (0.64,1.11) | 0.88 (0.66,1.18) | 3,669 | 2,966 |

Panel A. Estimated Average Marginal Effects (AME)

| Panel A. Estimated Average Marginal Effects (AME) | AME 95% CI | AME 95% CI | AME 95% CI | AME 95% CI | N  N |
|-------------------------------------------------|-----------|-----------|-----------|-----------|-----|
| Northeast                                        | 0.00 (-0.02,0.02) | 0.02 (-0.04,0.01) | 0.07 (-0.04,0.01) | 0.03 (-0.03,0.03) | 5,245 | 4,203 |
| Midwest                                          | -0.03 (-0.05,0.0) | -0.03 (-0.05,0.02) | -0.02 (-0.04,0.00) | -0.02 (-0.04,0.00) | 3,669 | 2,966 |
| South                                            | -0.04 (-0.05,0.02) | -0.04 (-0.05,0.02) | -0.02 (-0.03,0.00) | -0.02 (-0.03,0.00) | 5,245 | 4,203 |
| West                                             | -0.01 (-0.03,0.01) | -0.02 (-0.04,0.00) | -0.01 (-0.03,0.01) | -0.01 (-0.03,0.01) | 3,669 | 2,966 |

Table 5

Estimates from logistic regression models predicting presence of dementia between 2012 and 2000 stratified by region, HRS.

| Panel A. Estimated Odds Ratios (OR) | OR 95% CI | OR 95% CI | OR 95% CI | OR 95% CI | N  N |
|-----------------------------------|-----------|-----------|-----------|-----------|-----|
| Northeast                          | 0.47 (0.28,0.80) | 0.49 (0.28,0.83) | 0.55 (0.31,0.96) | 0.58 (0.31,1.10) | 876 | 710 |
| Mid-Atlantic                       | 0.75 (0.56,1.01) | 0.70 (0.52,0.95) | 0.84 (0.61,1.17) | 0.85 (0.60,1.21) | 2,538 | 2,087 |
| West North Central                 | 0.74 (0.57,0.95) | 0.71 (0.55,0.92) | 0.83 (0.64,1.09) | 0.88 (0.66,1.17) | 3,405 | 2,753 |
| West North Central                 | 0.48 (0.33,0.70) | 0.47 (0.32,0.69) | 0.57 (0.38,0.86) | 0.63 (0.40,0.99) | 1,840 | 1,455 |
| South                              | 0.67 (0.55,0.82) | 0.65 (0.53,0.80) | 0.78 (0.63,0.97) | 0.77 (0.61,0.96) | 5,184 | 4,335 |
| East South Central                 | 0.77 (0.53,1.12) | 0.75 (0.51,1.10) | 0.84 (0.55,1.27) | 0.83 (0.54,1.27) | 1,188 | 976 |
| West South Central                 | 0.62 (0.48,0.81) | 0.61 (0.47,0.80) | 0.84 (0.63,1.12) | 0.81 (0.60,1.11) | 2,173 | 1,810 |
| Mountain                           | 0.71 (0.43,1.16) | 0.60 (0.35,1.02) | 0.68 (0.38,1.22) | 0.65 (0.35,1.19) | 1,080 | 896 |
| Pacific                            | 0.92 (0.68,1.23) | 0.82 (0.61,1.12) | 0.95 (0.69,1.30) | 0.98 (0.69,1.38) | 2,588 | 2,090 |

Panel A. Estimated Average Marginal Effects (AME)

| Panel A. Estimated Average Marginal Effects (AME) | AME 95% CI | AME 95% CI | AME 95% CI | AME 95% CI | N  N |
|-------------------------------------------------|-----------|-----------|-----------|-----------|-----|
| Northeast                                        | -0.06 (-0.10,-0.02) | -0.05 (-0.09,-0.02) | -0.04 (-0.08,0.00) | -0.04 (-0.08,0.00) | 876 | 710 |
| Mid-Atlantic                       | -0.02 (-0.04,0.00) | -0.03 (-0.05,0.00) | -0.01 (-0.03,0.01) | -0.01 (-0.03,0.01) | 2,538 | 2,087 |
| West North Central                 | -0.05 (-0.07,0.02) | -0.05 (-0.07,0.02) | -0.03 (-0.06,0.01) | -0.03 (-0.05,0.00) | 1,840 | 1,455 |
| South                              | -0.03 (-0.05,0.02) | -0.03 (-0.05,0.02) | -0.02 (-0.03,0.00) | -0.02 (-0.03,0.00) | 5,184 | 4,335 |
| East South Central                 | -0.03 (-0.07,0.01) | -0.03 (-0.07,0.01) | -0.02 (-0.06,0.02) | -0.02 (-0.06,0.02) | 1,188 | 976 |
| West South Central                 | -0.05 (-0.08,0.02) | -0.05 (-0.08,0.02) | -0.02 (-0.04,0.01) | -0.02 (-0.04,0.01) | 2,173 | 1,810 |
| Mountain                           | -0.02 (-0.05,0.01) | -0.03 (-0.06,0.00) | -0.02 (-0.06,0.01) | -0.02 (-0.06,0.01) | 1,080 | 896 |
| Pacific                            | -0.01 (-0.03,0.01) | -0.01 (-0.03,0.01) | 0.00 (-0.02,0.02) | 0.00 (-0.02,0.02) | 2,588 | 2,090 |
regression models stratified by region. Odds ratios are in Panel A and average marginal effects are in Panel B. The New England division, all census divisions in the Midwest, and two of the census divisions in the South had lower odds of dementia in 2012 compared to 2000 when adjusting for age and sex in Model 1, ranging from a 2–6 percentage point decline. Age and sex-adjusted trends in dementia prevalence in Model 1 were not significant for the Mid-Atlantic division, the East South Central division, or the two census divisions in the West. These trends remained unchanged after accounting for race/ethnicity and nativity in Model 2, except for Mid-Atlantic division, which showed a 3–percentage point decline over time.

The inclusion of education and wealth in Model 3 explained the decline in dementia in the East North Central and West South Central divisions. In the New England, West North Central, and South Atlantic division, education and wealth explained 1–2 percentage points in the decline in dementia between 2000 and 2012. Adjustment for differences in health status in Model 4 fully explained the decline in dementia for the New England division. After the inclusion of health status, there remained a statistically significant decline in dementia over time in the West North Central division (3%), and in the South Atlantic division (2%).

We tested for differences in the dementia trend by Census division after adjusting for age and sex. Compared to the trend for the Pacific division, which had the least decline, the New England (p-value = 0.035), West North Central (p-value = 0.008), West South Central (p-value = 0.051) and South Atlantic (p-value = 0.08) divisions were all at least marginally statistically different in their rates of decline. The difference between the Pacific and South Atlantic divisions was explained with adjustment for race and nativity, whereas the difference between Pacific and West South Central was explained with adjustment for educational attainment and household wealth. All other differences at the division level were explained with adjustment for health status and health behavior.

4. Discussion

This study is the first to evaluate subnational differences in dementia trends among older U.S. adults over a 10-year period. Previous research documented a national decline in dementia prevalence from 11.6% in 2000 to 8.6% in 2012 among those aged 65 and older (Langa et al., 2017). Our findings showed both regional and divisional variation in dementia prevalence in both 2000 and 2012, as well as in change in dementia prevalence during this period. In 2000, dementia prevalence was lowest in the West (8.6%) and highest in the South (14.6%). Dementia prevalence declined over time across all regions of the U.S. from 2000 to 2012 but remained highest in the South (10.7%) compared to the other regions (7.0–7.8%). Despite downward trends in dementia across the U.S., the prevalence of dementia in the South in 2012 approximated levels found in other regions in 2000. There was relatively less change over time in the West compared to other regions, but dementia prevalence was already quite low in this part of the U.S. in 2000. Regional variation in baseline prevalence, as well as differential rates of change, highlight the importance of examining sub-national variation in research on dementia trends.

Dementia trends also varied within region. We found differences between census divisions in both the starting dementia prevalence and change over time within all regions, except the West, where dementia prevalence was relatively low. New England and West North Central divisions experienced such large declines that by 2012 they had among the lowest dementia prevalence, despite having had a relatively high prevalence in 2000. These sub-regional trends suggest there is further geographic variation in dementia prevalence and trends that should be explored with more spatially refined data.

In multivariable models that accounted for changing demographics over time we found statistically significant declines in dementia in all regions and in all census divisions, except for the Pacific and Mountain divisions. Accounting for changing educational attainment across birth cohorts explained the decline observed in the West and much of the decline observed in other regions and census divisions. Education seemed to be a particularly important factor contributing to dementia trends in the South. The South had the lowest levels of educational attainment in 2000, so cohort gains in education during this period may have been particularly consequential for determining dementia prevalence in this region. Gains in education partly explained why the South experienced a large absolute decline in dementia over this period, which is consistent with prior work suggesting that higher educated adults have lower lifetime risk of dementia and older ages of disease onset (Hale et al., 2020). Additionally, studies on national trends in dementia over time indicate that greater educational attainment explains declines in dementia incidence (Farina et al., 2022) and reduces trends in dementia prevalence among older Black and white Americans (Hayward et al., 2021). However, the South also had the lowest relative improvement in education over time compared to other regions, which suggests there may be additional room for declines in dementia as subsequent, more educated birth cohorts enter older adulthood. In comparison, given high levels of education in the West, it seems unlikely that there will be further reductions in dementia prevalence stemming from changes in the distribution of educational attainment in that region of the country.

Recent work points to other aspects of education – including quality and context – as important predictors of cognitive functioning in older adulthood (Moorman et al., 2019; Walsemann & Ailshire, 2020). For instance, a series of studies found that prior success on standardized tests assessing mental ability was associated with better cognitive health in later life and helped explain the relationship between childhood socioeconomic status and later life cognition (Greenfield et al., 2021; Zhang et al., 2020). How well students perform on scholastic tests is often used as an indicator of school quality, is dependent on school context, and varies geographically (Fahle & Reardon, 2018; Lubinski et al., 2008). The U.S. education system also underwent significant changes during the 20th century, including the desegregation of public schools and increased investment in science, mathematics, and special education programs (Costrol et al., 2003; Department of Education, 2003; Fleming, 1960); thus, we might expect that regional variation in educational quality and context will shape future dementia risk.

It is important to note that although increasing educational attainment explained the decline in dementia prevalence in the West and in specific Census divisions, it was only after further accounting for health status and behaviors that we were able to explain declines in dementia in most other regions and divisions. In their examination of national dementia trends, Langa et al. (2017) found a significant decline in heart disease- and diabetes-related risks for dementia, and argued that this is consistent with the hypothesis that improvements in cardiovascular and diabetes treatment and care led to declines in dementia risk in the population, even as disease prevalence has been increasing. However, the factors examined in this paper did not fully explain the decline in dementia in the Southern states.

This is the first study to report on subnational U.S. dementia trends at both census region and division levels. Because we used data from the HRS and replicated analytic decisions from Langa et al. (2017), our study findings on subnational variation can be directly compared with their findings on national dementia trends from 2000 to 2012. As updated estimates on national trends in dementia become available, our study indicates the need to also consider sub-national variation in dementia trends.

One potential limitation of studies such as ours that examine dementia trends using survey data is that dementia status is not based on clinical diagnoses. In the HRS, dementia status is determined from an algorithm that uses survey-based information on respondents’ cognitive and physical functioning. However, the HRS derived dementia status has a 78% concordance with a consensus panel diagnosis of dementia (Crimmins et al., 2011), which suggests the potential for
misclassification is low. Furthermore, the HRS dementia assessment does not depend on whether individuals have a usual source of care, and thus are not subject to bias from differences in healthcare access and diagnoses, an issue that arises when relying on claims data (Chen et al., 2019).

5. Conclusions

A growing body of research shows persistent or widening geographic inequality in the United States (Dwyer-Lindgren et al., 2017; Fenelon, 2013). Our study contributes to research on U.S. dementia trends and geographic inequality in health by showing important subnational variation in dementia levels and trends. It is important to note that the South continues to report the highest rates of dementia prevalence despite having experienced significant declines in dementia between 2000 and 2012, supporting the idea of a “Dementia Belt” that spans the East and West South Central United States. These are parts of the country that may be least prepared to treat and care for large segments of the older adult population with dementia.

Ethical statement

This is an analysis of secondary data that have been de-identified and are publicly available. Ethical approval was not obtained because data was not collected as part of this study.

Author statement

Ailshire and Walsemann conceptualized the paper. Ailshire, Walsemann, and Fisk conducted data management and analysis and literature reviews. All authors contributed to drafting of the manuscript text and revisions.

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Declaration of competing interest

None of the authors have any conflicts of interest to declare.

References

Agüero-Torres, H., von Strauss, E., Viitanen, M., Winblad, B., & Fratiglioni, L. (2001). Geographic diversity in mortality in the United States: Evidence from the Wisconsin longitudinal study. The Journals of Gerontology: Series B, 73 (suppl 1), S48–138. https://doi.org/10.1093/gerona/gba015

Borej, P., Wetzels, R. B., Lucassen, P. L., Pot, A. M., & Koopmans, R. T. (2015). The R01AG055481, P30AG043073, R01AG067536, and T32AG000037).

Borsje, P., Wetzels, R. B., Lucassen, P. L., Pot, A. M., & Koopmans, R. T. (2015). The R01AG055481, P30AG043073, R01AG067536, and T32AG000037).

Bredin, S. D., &卅J. M. (2019). Educational disparities in adult mortality across U.S. States: How do they change over time? A comparison of model- and census-based mortality estimates in U.S. states. Journal of Aging and Health, 31(7), 138. https://doi.org/10.1177/0894197719887354

Chen, Y., Tsinger, R., Crimmins, E., & Zigzimopoulos, J. M. (2019). Analysis of dementia in the US population using Medicare claims: Insights from linked survey and administrative data. Alzheimer’s and Dementia: Translational Research & Clinical Interventions, 5, 197–207. https://doi.org/10.1016/j.trci.2019.04.003

Chen, C., & Zigzimopoulos, J. M. (2018). Racial and ethnic differences in trends in dementia prevalence and risk factors in the United States. Alzheimer’s and Dementia: Translational Research & Clinical Interventions, 4, 510–520. https://doi.org/10.1016/j.trci.2018.08.009

Crabbe, J. C., & Paxson, C. (2009). Early life health and cognitive function in old age. The American Economic Review, 99(2), 104–109. https://doi.org/10.1257/aer.99.2.104

Dwyer-Lindgren, L., Bertozi-Villa, A., Stubbis, R. W., Morozoff, C., Mackenbach, J. P., van Rossum, F. J., & McKee, M. (2019). Inequalities in life expectancy among US counties, 1980 to 2014. JAMA Internal Medicine, 179(7), 1003–1011. https://doi.org/10.1001/jamainternmed.2017.0918

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Fahle, E. M., & Reardon, S. F. (2018). How much do test scores vary among school districts? New estimates using population data, 2009–2015. Educational Researcher, 47(4), 221–234. https://doi.org/10.3102/0013189X18759924

Fennel, A. (2013). Geographic divergence in mortality in the United States. Population and Development Review, 39(4), 611–634. https://doi.org/10.1111/j.1728-4457.2013.00930.x

Fleming, A. S. (1960). The philosophy and objectives of the national defense education act. The Annals of the American Academy of Political and Social Science, 327(1), 132–138. https://doi.org/10.1177/000271626032700116

Freedman, V. A., Kasper, J. D., Spillman, B. C., & Flassman, B. L. (2018). Short-term changes in the prevalence of probable dementia: An analysis of the 2011–2015 national health and aging trends study. The Journals of Gerontology: Series B, 73(1), S48–S56. https://doi.org/10.1093/gerona/gbx144

Friedman, M. D., Zhang, Y. S., Kim, J. K., Hayward, M. D., & Crimmins, E. M. (2022). Trends in dementia prevalence, incidence, and mortality in the United States (2000–2016). Journal of Aging and Health, 34(1), 100–108. https://doi.org/10.1177/0894197719887354

Greenfield, E. A., Moorman, S., & Rieger, A. (2021). Life course pathways from childhood socioeconomic status to later-life cognitive functioning 50 Years later. Alzheimer’s & Dementia, 7(2), 434–441. https://doi.org/10.1002/alz.12011

Hale, J. M., Schneider, D. C., Mehta, N. K., & Myrskey, M. (2020). Cognitive impairment in the U.S.: Lifetime risk, age at onset, and years impaired. SSM - Population Health, 11, Article 100077. https://doi.org/10.1016/j.ssmph.2020.100077

Hayward, M. D., Farina, M. P., Zhang, Y. S., Kim, J. K., & Crimmins, E. M. (2021). The importance of improving educational attainment for dementia prevalence trends from 2000 to 2014, among older non-Hispanic Black and white Americans. Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 76(9), 1870–1879. https://doi.org/10.1093/geronb/gbab015

Koller, D., & Bynum, J. P. W. (2015). Dementia in the USA: State variation in prevalence. Journal of Public Health, 37(4), 597–604. https://doi.org/10.1093/aje/kwv099

Langa, K. M., Larson, E. B., Crimmins, E. M., Faul, J. D., Levine, D. A., Kabeto, M. U., & Flassman, B. L. (2015). The Journals of Gerontology: Series A, 65A(4), 434–441. https://doi.org/10.1093/gerona/glp197

Luppa, M., Luck, T., Weyerer, S., K¨ahler, E., & Riedel-Heller, S. G. (2010). Alzheimer’s and Dementia: Translational Research & Clinical Interventions, 5, 197–207. https://doi.org/10.1016/j.trci.2019.04.003

Moorman, S. M., Greenfield, E. A., Moorman, S., & Rieger, A. (2021). Life course pathways from childhood socioeconomic status to later-life cognitive functioning 50 Years later. Alzheimer’s & Dementia, 7(2), 434–441. https://doi.org/10.1002/alz.12011

Montez, J. R., Zajacova, A., Hayward, M. D., Woolf, S. H., Chapman, D., & Beckfield, J. (2019). Educational disparities in adult mortality across U.S. States: How do they differ, and have they changed since the mid-1980s? Demography, 56(2), 621–644. https://doi.org/10.1007/s13524-018-0750-z

Moorman, S. M., Greenfield, E. A., & Garcia, S. (2019). School context in adolescence and cognitive functioning 50 Years later. Journal of Health and Social Behavior, 60(4), 493–508. https://doi.org/10.1177/0022146519873979

Nowakowski, A. C. H., Shih, J., & Garretta, H. J. (2019). Regional risk: Mapping single and multiple chronic conditions in the United States. Sage Open, 9(1), Article 215824401882385. https://doi.org/10.1177/215824401882385

Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Olfsted, M. B., Burke, J. R., Hard, M. D., Potter, G. G., Rodgers, W. L., Steffens, D. C., McArdle, J. J., Willis, R. J., & Wallace, R. B. (2008). Prevalence of cognitive impairment without
dementia in the United States. *Annals of Internal Medicine, 148*(6), 427–434. https://doi.org/10.7326/0003-4819-148-6-20080318-00005
Prince, M., Ali, G.-C., Guerchet, M., Prina, A. M., Albanese, E., & Wu, Y.-T. (2016). Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer’s Research & Therapy, 8*(1), 23. https://doi.org/10.1186/s13195-016-0188-8
Rajan, K. B., Wexler, J., Barnes, L. L., McAninch, E. A., Wilson, R. S., & Evans, D. A. (2021). Population estimate of people with clinical Alzheimer’s disease and mild cognitive impairment in the United States (2020-2060). *Alzheimers Dement, 17*(12), 1966–1975. https://doi.org/10.1016/j.jalz.2021.100841
Rusanen, M., Kivipelto, M., Quesenberry, C. P., Jr., Zhou, J., & Whitmer, R. A. (2011). Heavy smoking in midlife and long-term risk of Alzheimer disease and vascular dementia. *Archives of Internal Medicine, 171*(4), 333–339. https://doi.org/10.1001/archinternmed.2010.393
Rusanen, M., Rovio, S., Ngandu, T., Nissinen, A., Tuomilehto, J., Soininen, H., & Kivipelto, M. (2010). Midlife smoking, apolipoprotein E and risk of dementia and Alzheimer’s disease: A population-based cardiovascular risk factors, aging and dementia study. *Dementia and Geriatric Cognitive Disorders, 30*(3), 277–284. https://doi.org/10.1159/000320484
Russ, T. C., Batty, G. D., Hearnshaw, G. F., Fenton, C., & Starr, J. M. (2012). Geographical variation in dementia: Systematic review with meta-analysis. *International Journal of Epidemiology, 41*(4), 1012–1032. https://doi.org/10.1093/ije/dys103
Satizabal, C. L., Beiser, A. S., Chouraki, V., Chene, G., Dufoüil, C., & Seshadri, S. (2016). Incidence of dementia over three decades in the framingham heart study. *New England Journal of Medicine, 374*(6), 523–532. https://doi.org/10.1056/NEJMoal1504327
Sonnega, A., Faul, J. D., Ofstedal, M. B., Langa, K. M., Phillips, J. W., & Weir, D. R. (2014). Cohort profile: The health and retirement study (HRS). *International Journal of Epidemiology, 43*(2), 576–585. https://doi.org/10.1093/ije/dyu067
Topping, M., Kim, J., & Fletcher, J. (2021a). Geographic variation in Alzheimer’s disease mortality. *PloS One, 16*(7), Article e0254174. https://doi.org/10.1371/journal.pone.0254174
Topping, M., Kim, J., & Fletcher, J. (2021b). Association and pathways of birth in the stroke belt on old age dementia and stroke Mortality. *SSM - Population Health, 15*, Article 100841. https://doi.org/10.1016/j.ssmph.2021.100841
U.S. Census Bureau. (2015). A half-century of learning: Historical census statistics on educational attainment in the United States, 1940 to 2000: Tables. from https://www.census.gov/data/tables/time-series/demo/educational-attainment/education-al-attainment-1940-2000.html. (Accessed 17 November 2020).
Vega, W. A., Angel, J. L., Gutiérrez Robledo, L. M. F., & Markides, K. S. (2019). Contextualizing health and aging in the americas: Effects of space, time and place. *Springer International Publishing*. https://doi.org/10.1007/978-3-030-00584-9
Walsemann, K. M., & Ailshire, J. A. (2020). Early educational experiences and trajectories of cognitive functioning among US adults in midlife and later. *American Journal of Epidemiology, 189*(5), 403–411. https://doi.org/10.1093/aje/kwz276
Whitmer, R. A., Sidney, S., Selby, J., Johnston, S. C., & Yaffe, K. (2005). Midlife cardiovascular risk factors and risk of dementia in late life. *Neurology, 64*(2), 277–281. https://doi.org/10.1212/01.WNL.0000149519.47454.F2
Wu, Y.-T., Beiser, A. S., Breteler, M. M. B., Fratiglioni, L., Helmer, C., Hendrie, H. C., Honda, H., Iram, M. A., Langa, K. M., Lobo, A., Matthews, F. E., Ohrara, T., Pérez, K., Qiu, C., Seshadri, S., Sjöland, B.-M., Skoog, I., & Brayne, C. (2017). The changing prevalence and incidence of dementia over time—current evidence. *Nature Reviews Neurology, 13*(6), 327–339. https://doi.org/10.1038/nrneurol.2017.63
Zhang, Z., Liu, H., & Choi, S. (2020). Early-life socioeconomic status, adolescent cognitive ability, and cognition in late midlife: Evidence from the Wisconsin Longitudinal Study. *Social Science & Medicine, 244*, Article 112575. https://doi.org/10.1016/j.socscimed.2019.112575