

ARTICLE

The contribution of dementia to the disparity in family wealth between black and non-black Americans

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Abstract

The enormous economic burden of dementia in the United States of America falls disproportionately on families coping with this devastating disease. Black Americans, who are at greater risk of developing dementia than white Americans, hold on average less than one-eighth of the wealth of white Americans. This study explores whether dementia exacerbates this wealth disparity by examining dementia's effect on wealth trajectories of black *versus* non-black Americans over an eight-year period preceding death, using five waves of data (beginning in 2002 or 2004) on decedents in the 2012 and 2014 waves of the Health and Retirement Study (N = 2,429). Dementia is associated with a loss of 97 per cent of wealth among black Americans, compared with 42 per cent among non-black Americans, while wealth loss among black and non-black Americans without dementia did not differ substantially (15% *versus* 19%). Dementia appears to increase the probability of wealth exhaustion among both black and non-black Americans, although the estimate is no longer significant after adjusting for all covariates (for blacks, odds ratio (OR) = 2.04, 95% confidence interval (CI) = 0.83, 5.00; for non-blacks, OR = 1.47, 95% CI = 0.95, 2.27). Dementia has a negative association with home-ownership, and the loss or sale of a home may play a mediating role in the exhaustion of wealth among black Americans with dementia.

Keywords: Alzheimer's disease; dementia cost; racial disparities; wealth disparities; Health and Retirement Study

Introduction

Dementia is a costly health condition for society. Even as age-specific rates of dementia appear to be declining (Langa *et al.*, 2017), annual societal costs in the United States of America (USA), estimated at US \$159 billion to 215 billion in 2010, are expected to soar; without a significant drop in prevalence, those costs could more than double by 2040 as the population ages (Hurd *et al.*, 2013). An estimated 14 per cent of Americans aged 71 years and older have dementia; for

Alzheimer's disease alone, the most prevalent cause of dementia, the number of afflicted older Americans is expected to rise from 5.3 million in 2017 to 13.8 million by 2050 (Alzheimer's Association, 2017). Incremental costs attributable to dementia for all payers are estimated at US \$41,689–56,290 per patient per year, depending on how the value of informal home care is calculated (Hurd *et al.*, 2013), or US \$184,500 from time of diagnosis (mean age 83) to death (Jutkowitz *et al.*, 2017).

Families bear much of the financial burden of dementia. In addition to the implicit value of informal care, discussed below, annual average out-of-pocket health-care spending by individuals with dementia is estimated to be US \$8,216, including US \$5,112 for nursing home care (Delavande *et al.*, 2013). Moreover, a national survey reveals dementia care contributors (family members and friends) spend an average of US \$5,155 out of pocket per year on medical expenses, home health care, groceries and travel (Alzheimer's Association, 2016). These averages mask high costs for some; the mean cost of a semi-private room in a long-term care facility exceeds US \$80,000 a year (MetLife Mature Market Institute, 2012), and 12 per cent of care contributors surveyed had to sell a residence to help pay for care (Alzheimer's Association, 2016). Thus, dementia can have a financial impact on the next generation. Wealth accumulation has been found to be lower among unmarried individuals whose parents developed dementia than among those whose parents did not, regardless of care-giving status (Arora, 2016).

Intergenerational outcomes have relevance in the context of racial wealth disparity. Estimates of the wealth gap vary considerably; the ever-changing value of assets makes it difficult to measure net worth. Before the Great Recession of 2008–2009, median net worth among white Americans was estimated to be 4–12 times greater than among black Americans (Chiteji and Stafford, 1999; Chiteji, 2010; Taylor *et al.*, 2011; Pfeffer *et al.*, 2013; McKernan *et al.*, 2014; Burd-Sharps and Rasch, 2015). Post-recession estimates range from 8–20 times greater (Taylor *et al.*, 2011; Shapiro *et al.*, 2013; Kochhar and Fry, 2014; Herring and Henderson, 2016). While the direct effect of inheritances on the wealth gap is subject to debate (Menchik and Jianakoplos, 1997; Gittleman and Wolff, 2000, 2004; Conley, 2001; Shapiro *et al.*, 2013; McKernan *et al.*, 2014), there is no question that having family wealth to build upon is an advantage. An in-depth discussion of the factors influencing the disparity is outside the scope of this paper, but institutional racism, as demonstrated through policies and practices involving Social Security eligibility, home financing and forced segregation, among others, is a likely contributor (Conley, 2001; Brown, 2016).

Racial differences appear to exist in both the prevalence of dementia and the financial effects of care. Considerable evidence suggests that older black Americans are more likely than their non-Hispanic white counterparts to have Alzheimer's disease or another form of dementia (Gurland *et al.*, 1999; Plassman *et al.*, 2007; Lines *et al.*, 2014; Steenland *et al.*, 2016) – more than twice as likely in one model, even after adjusting for education and several other factors (Langa *et al.*, 2017). Moreover, while the age-specific incidence of dementia appears to be declining among the affluent (Satizabal *et al.*, 2016), there is a seven- to tenfold difference in cognitive limitation or impairment between the top and bottom quartiles of socio-economic status (Choi *et al.*, 2018). In terms of financial effects, given their lower levels of wealth, black Americans with dementia spend a far greater

proportion of that wealth on dementia-related care than do non-black Americans with dementia: researchers found that in the last five years of life, median out-of-pocket health-care spending as a percentage of wealth is almost 84 per cent among black Americans with dementia, compared with 32 per cent among non-black Americans with dementia (Kelley *et al.*, 2015). Among black *versus* non-black Americans without dementia, the comparable rates are 30 and 11 per cent, respectively. As the share of non-white individuals in the older population increases (Vincent and Velkoff, 2010), this disparate financial burden will worsen.

Research also suggests that black American families provide more hours of informal care than do non-black American families (Kelley *et al.*, 2015; Rote and Moon, 2018), which has implications for family wealth. More years of care may be required as well, as black Americans develop cognitive impairment at an earlier age than white Americans and may live three times as many years with dementia (Garcia *et al.*, 2019). The value of informal care specifically for dementia has been estimated at US \$132,850 from time of diagnosis to death, and its value can, on a daily basis, exceed that of long-term care facility costs (Jutkowitz *et al.*, 2017). Furthermore, informal care can result in negative employment consequences, both immediate and long-term; for instance, family members may have to reduce working hours or leave their jobs entirely to care for afflicted parents, leading to lost benefits and reduced Social Security income (Keating *et al.*, 2014). In one analysis, caring for a parent is estimated to cost women, on average, US \$142,693 in lost wages and US \$131,351 in retirement benefits (MetLife Mature Market Institute, 2011).

Finally, as dementia affects an individual's ability to live independently, there are likely to be implications for real-estate assets. For families striving to build wealth that can persist to the next generation, housing is a primary means (Kuebler, 2013). This is especially true among black Americans: the typical share of wealth represented by home equity – rather than stocks, bonds, additional real estate or business ownership – is about 20 percentage points higher for black Americans than for white Americans (Gittleman and Wolff, 2004; Burd-Sharps and Rasch, 2015). Housing equity is an area in which racial disparities are notable from a policy standpoint, because of government agencies' habit of 'redlining' in decades past – shutting neighbourhoods populated by black Americans out of the mortgage market. This was a legal practice until the Fair Housing Act of 1968 (Massey, 2015), and banks persist in such discrimination to the present day (US Department of Housing and Urban Development, 2015). Such practices are blamed for disparities in home-ownership rates as well as the value and growth of home equity (Jackman and Jackman, 1980; Shapiro *et al.*, 2013; Thomas *et al.*, 2018). Differential opportunities to build and retain equity related to home-ownership, involving not only mortgage lending practices but also less-favourable interest rates, are therefore plausible factors in the persistence of black–white wealth disparity (Krivo and Kaufman, 2004; Oliver and Shapiro, 2006; Chiteji, 2010; Shapiro *et al.*, 2013).

Noting dementia's effect on wealth, and acknowledging the contemporary racial wealth disparity, we sought to explore two centrally motivating questions:

- (1) Does dementia contribute to a disproportionate decline in wealth among black Americans compared with non-black Americans?

- (2) If so, what important factors contribute to wealth decline and play a significant role in exacerbating racial wealth disparity? Specifically, what are the roles of out-of-pocket health-care spending and home-ownership?

The study is designed to align with and extend Kelley *et al.* (2015). Kelley *et al.* used the US Health and Retirement Study (HRS) to examine social costs of disease and out-of-pocket spending in the last five years of life, comparing individuals with a high probability of dementia with those whose cause of death was heart disease, cancer or other conditions. While they find that out-of-pocket spending consumed most of the wealth among black Americans in the dementia group, this is largely attributable to the fact that baseline wealth among that group was less than half that of black Americans in the other disease groups. The authors suggest that the baseline wealth disparity might be attributed in part to dementia-related income loss and expenses preceding their five-year study period. Because a dementia diagnosis typically occurs four to eight years before death (Alzheimer's Association, 2017), the current study extends the retrospective period of analysis to a baseline 8–11 years before death, examining wealth trajectories as well as out-of-pocket spending for blacks and non-blacks with and without dementia. Moreover, we investigate the role of housing assets in wealth trajectories, contributing a new policy-relevant focus to the research on racial disparities in wealth loss associated with dementia.

Methods

Study design and population

This study uses six waves of longitudinal data (2002–2012) and 2012 and 2014 exit interviews from the HRS to estimate the effect of a dementia diagnosis on the change in wealth over eight years for black and non-black respondents. The HRS is a panel study of a nationally representative (USA) sample of community-dwelling adults 50 and over, sponsored by the National Institute on Aging (grant number NIA U01AG009740) and conducted by the University of Michigan (Health and Retirement Study, 2014; RAND, 2015). It contains information on family composition, health and cognitive status, government health coverage under Medicare and Medicaid, out-of-pocket health spending, income and assets, and financial transfers between parents and children, among other items. This study uses data from core interview waves conducted every two years from 2002 to 2012 (five waves) and from exit interviews conducted after a respondent's death, with a family member as proxy, in 2012 and 2014.

Extending the work of Kelley *et al.* (2015), the study period captures data from approximately ten years preceding the respondent's death. (The baseline wave, 8–11 years before death, records wealth at the time of interview but includes spending and health information from the previous two years.) The study measures the change in wealth, both including and excluding real-estate assets, over the last five waves before death for four groups: black individuals with dementia, black individuals without dementia, non-black individuals with dementia and non-black individuals without dementia. The study examines dementia as a predictor of wealth exhaustion and the relationship between dementia and change in

home-ownership. It also tests the correlation between out-of-pocket spending and change in wealth for the four groups.

Eligible sample members were identified by the existence of an exit interview in 2012 or 2014 ($N = 2,429$). Those with more than a 36-month gap in information were excluded, namely those for whom death date was uncertain and those who died more than three years after the last core interview or more than three years before the exit interview ($N = 150$). Also excluded were those with missing responses to a diagnosis of Alzheimer's disease or dementia, as defined below ($N = 58$), and those lacking wealth data at baseline ($N = 301$) or after 2008 ($N = 131$). The final sample size is 1,789.

Measurements

For the first explanatory variable, a dummy variable was created to indicate the exit interview response to the question 'Had a doctor ever told [respondent] that he or she had a memory-related disease?', where yes = 1 and no = 0. Where records from the previous wave indicated the respondent had been so diagnosed, the statement was read for confirmation. If the proxy respondent disputed a diagnosis recorded in a past wave, dementia was coded in this analysis as missing. If the proxy did not know, and a diagnosis was recorded in a past wave, dementia was coded as 1. If the exit interview response was unknown and a diagnosis was recorded in the last wave living, dementia was coded as 1. For the second explanatory variable, race was coded dichotomously (black = 1, non-black = 0), whether or not the respondent identified as Hispanic. This decision follows Kelley *et al.* (2015) and was occasioned in part by limitations of the data; breakdown on the race variable beyond white, black and other is masked in the public use file. Hispanic ethnicity is determined by a separate question; 7 per cent of the sample identified as Hispanic (virtually all Hispanic white). Only 38 Hispanic individuals had been diagnosed with dementia, which was judged too small a group for meaningful analysis.

The primary outcome variable is final wealth. Because the majority of exit interviews lack a final account of assets, final wealth consists of the net value of total wealth, including primary residence and any second home, reported in the last core interview before death (0–36 months). For comparison purposes, the amount of final net non-housing assets is also presented. In addition, wealth is reported separately accounting for transfers to and from children: transfers to children over the study period were added back to the parent's wealth, and transfers from children were subtracted. Transfer values were imputed where necessary by RAND for 2002–2010; for 2012, in cases where exact values are missing, the mean of the range was used, or the minimum of the range if it lacked an upper bound. Because of the reliance on imputed values, transfers are omitted in the regression analysis.

The regression analysis controls for baseline net wealth, including housing, and a dummy variable for home-ownership at baseline, specifically the fourth wave preceding the last wave (approximately eight years prior). Other covariates in the regression analysis are as follows: as recorded at the exit interview, age at death, sex, education and marital status; as recorded at the final wave living, average income over the previous ten years, Medicaid status at any time since the previous

wave, and comorbid conditions that have been associated with dementia: stroke, diabetes, heart disease, hypertension, lung disease, cancer, psychiatric problems and arthritis, according to the respondent's report of ever being diagnosed. (Medicaid, the government health coverage for low-income adults and children, is the predominant US payer for long-term services and supports, which have very limited coverage under the Medicare insurance system that covers adults age 65 and over.) Employment status, nursing home residence at final wave and total out-of-pocket spending over ten years are included in the descriptive statistics but not the regression analysis.

Age is treated as a continuous variable, according to HRS assignment of age at time of death. Education is categorised, according to responses, as less than high school, high school degree or equivalent, some college or college graduate. Marital status is categorised as married (including those who defined themselves as 'married', 'married, spouse absent' and 'partnered'); widowed; divorced or separated; and never married.

Household income is averaged on the mean over four or five waves for each individual, then reported as the median per sub-group in descriptive statistics. Home-ownership was coded 0 if total wealth equals non-housing assets and 1 otherwise. Total out-of-pocket spending uses a summary value per wave as determined by RAND, including imputed values (Chien *et al.*, 2015), adjusted for inflation (2012 dollars) based on the Consumer Price Index. Because interviews are conducted mostly around mid-year and respondents report spending over the previous two years, adjustments are based on the year previous to the interview, *e.g.* spending reported in 2012 is converted from 2011 dollars. Natural log transformation is used for household income and baseline wealth variables in the regression analysis, after adding a constant value to eliminate negative and zero values. Finally, to explore the role of housing as a mediator in the relationship between dementia and loss of wealth, a dummy variable was created to indicate respondents who owned a home at baseline but no longer owned one at the last wave living.

Statistical analysis

Sample characteristics are described as percentages, means with standard deviations, or medians. Analysis of variance for age, Kruskal–Wallis for financial variables given on the median and chi-square tests for categorical variables were used in comparisons between black Americans with dementia and black Americans without dementia, and between non-black Americans with dementia and non-black Americans without dementia. Wilcoxon signed rank tests were used to analyse change in median wealth for each sub-group and McNemar tests were used for changes in home-ownership and Medicaid status. Chi-square tests were conducted for associations between dementia and the exhaustion of wealth (defined as no more than US \$1,000 in wealth at the final wave living) for black and non-black sub-groups.

To adjust for baseline wealth and other potential confounders, logistic regression models were fitted for the black and non-black sub-groups, where Y = final wealth equal to or below US \$1,000 and X = dementia status, with explanatory variables introduced in sequential blocks. The first block includes wave set, baseline wealth

and baseline home-ownership; the following blocks include demographic variables, socio-economic variables and health conditions. To investigate the possibility that a cut-off of US \$1,000 would mask important variation, these analyses were also performed with an outcome of final wealth equal to or below US \$10,000. Pearson's correlation explores the relation between total out-of-pocket health spending and dollar change in wealth. A p -value of 0.05 is used as the level for statistical significance. All statistical analyses were performed with SAS version 9.4 (SAS Institute, Cary, NC, USA).

Results

Table 1 summarises descriptive statistics of the sample, by dementia status and by racial sub-group (blacks with dementia, $N = 87$; blacks without dementia, $N = 185$; non-blacks with dementia, $N = 392$; non-blacks without dementia, $N = 1,125$). Individuals with dementia were almost 85 years old on average when they died, compared with 78 years among blacks without dementia and 81 years among non-blacks without dementia.

Differences are numerous across the four groups. Blacks with dementia were almost twice as likely as non-blacks with dementia to lack a high school degree or equivalent (64.4% *versus* 32.4%, $p < 0.001$), and both black and non-black non-dementia groups had more years of education than their respective dementia groups. The non-dementia groups had higher proportions of married individuals; blacks with dementia had the lowest proportion married, at about one-quarter. Black respondents were more likely to have been enrolled in Medicaid regardless of dementia status ($p < 0.001$). Non-black individuals with dementia were more likely than non-blacks without dementia to be enrolled in Medicaid at the final wave ($p < 0.001$); the same pattern among blacks is not statistically significant. Between baseline and final wave, the percentage of individuals with dementia who were enrolled in Medicaid doubled among blacks ($p < 0.001$) and tripled among non-blacks ($p < 0.001$). Unsurprisingly, nursing home residence at the final wave was much higher among all respondents with a diagnosis of dementia; it was also 20 percentage points higher for non-blacks with dementia than for blacks with dementia ($p < 0.001$). Employment rates dropped precipitously for all groups over eight years, as expected for respondents in their sixties and older. Median household income ranged from \$33,602 (all values are US \$) for non-blacks without dementia to \$14,134 for blacks with dementia; the same pattern held for total wealth and non-housing assets at the final wave, to a more extreme degree (\$140,000 *versus* \$1,200 in total wealth, \$38,000 *versus* \$0 in non-housing assets). Total out-of-pocket medical expenditures were \$26,148 for non-blacks with dementia, compared with \$15,228 for non-blacks without dementia and \$9,482 and \$8,759, respectively, for blacks with and without dementia.

Figure 1 shows the trajectory of wealth, including housing, in the last available eight years, ending within three years of death. Median wealth for non-blacks without dementia was \$172,000 in the first wave ($w-4$) and rose in the next wave ($w-3$) before declining to \$140,000 in the final wave, for a decrease of 18.6 per cent. For non-blacks with dementia, there was no gain in the second wave; median wealth was \$141,500 in the first wave and \$82,000 in the final wave, for a decline of

Table 1. Sample characteristics, by sub-group

Characteristic	Black sub-groups			Non-black sub-groups		
	With dementia	Without dementia	Significance	With dementia	Without dementia	Significance
Mean age at death (SD)	84.6 (9.0)	78.2 (9.2)	***	84.6 (8.2)	81.3 (9.4)	***
Female (%)	66.7	55.1		62.0	48.0	***
Education (%):						
Less than high school	64.4	47.6	*	32.4	24.2	**
High school	17.2	31.4	*	36.7	38.2	
Some college	14.9	14.1		17.4	22.8	*
College graduate	3.5	7.0		13.5	14.8	
Marital status at death (%):						
Married	24.1	36.4	*	32.2	48.0	***
Widowed	55.2	38.0	**	54.7	41.6	***
Divorced	19.5	17.4		10.5	8.1	
Never married	1.2	8.2	*	2.6	2.3	
Medicaid (%):						
Eight years before final wave	22.1	20.1		9.3	7.4	
At final wave living	46.2	35.2		28.6	10.8	***
Living in nursing home (%)	26.4	10.8	**	46.2	11.1	***
Health conditions ¹ (%):						
Stroke	38.4	23.8	*	29.8	17.3	***
Diabetes	36.8	40.2		28.6	29.0	
Heart disease	35.6	43.2		48.2	47.8	
Hypertension	77.0	82.6		67.7	69.8	
Lung disease	13.8	14.1		18.2	24.3	*

(Continued)

Table 1. (Continued.)

Characteristic	Black sub-groups			Non-black sub-groups		
	With dementia	Without dementia	Significance	With dementia	Without dementia	Significance
Cancer	17.2	27.2		25.1	32.7	*
Psychiatric problems	18.4	18.0		35.2	17.2	***
Arthritis	77.7	69.7		66.3	69.5	
Employed (%):						
Eight years before final wave	9.2	23.2	**	12.5	24.2	***
At final wave living	0.0	9.7	**	1.3	6.4	***
Household income ² (median, US \$)	14,134	18,608	*	26,065	33,602	***
Home-owner (%):						
Eight years before final wave	59.8	61.6		74.2	81.4	**
At final wave living	41.4	57.8	*	54.9	70.1	***
Household wealth at final wave living:						
Including primary residence (median, US \$)	1,200	26,500	**	82,000	140,000	***
Accounting for transfers (median, US \$)	4,500	28,500	*	82,500	148,300	***
Assets net negative (%)	8.1	10.3		5.4	4.4	
Without real estate (median, US \$)	0	1,000		11,500	38,000	***
Total out-of-pocket health-care expenditures ³ (median, US \$)	9,482	8,759		26,148	15,228	***
Sample size	87	185		392	1,125	

Notes: SD: standard deviation. Sample comprises exit interviews from 2012 (N = 844) and from 2014 (N = 945). Data are also drawn from core interviews. Sample sizes for specific characteristics may vary because of missing values. The Health and Retirement Study over-samples black and Hispanic households and Florida residents, so the characteristics as a whole cannot be generalised to the wider population. No weights have been applied to the statistics in this table. Percentages may not add to 100 because of rounding. 1. Measure reflects percentage of respondents who had ever been diagnosed with a condition as of the final wave living. 2. Household income is calculated as the mean of individual's income over four or five waves, reported as the sub-group median. 3. Expenditures are totalled across the last five waves (approximately ten years). Respondents missing observations in any of the waves are excluded on this variable (blacks with dementia, 10.3%; blacks without dementia, 8.1%; non-blacks with dementia, 8.4%; non-blacks without dementia, 5.2%).

Significance levels: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$ (significant differences between sub-groups were tested with chi-square for categorical variables, analysis of variance for age and two-sided Kruskal–Wallis for financial variables).

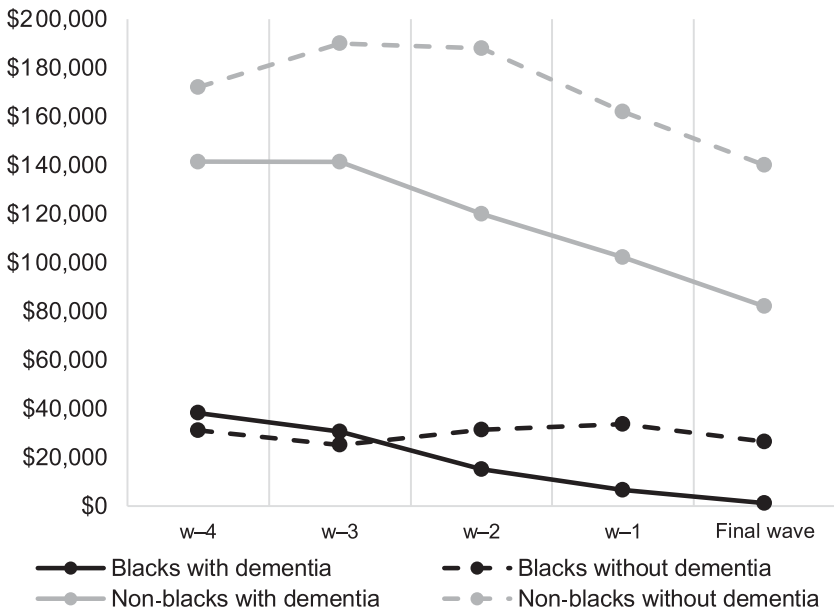


Figure 1. Median total wealth over eight years.

Notes: Wilcoxon signed rank tests were conducted to test for significant changes in median wealth (US \$) from baseline (w-4) to final wave. Blacks with dementia, $p = 0.001$; blacks without dementia, $p = 0.632$; non-blacks with dementia, $p < 0.001$; non-blacks without dementia, $p < 0.001$.

42.0 per cent. Blacks without dementia had a median wealth in the first wave of \$31,000, which fell and then rose before declining again, ending at \$26,500, for a decrease of 14.5 per cent. Finally, blacks with dementia had a median wealth of \$38,205 in the first wave, which dropped steadily to \$1,200 in the final wave – a decline of 96.9 per cent. All median changes in wealth are statistically significant except among blacks without dementia.

Figure 2 shows the same period as Figure 1, considering only non-housing assets. Median assets for non-blacks without dementia declined from \$72,100 to \$38,000; for non-blacks with dementia, assets declined from \$47,500 to \$11,500. Blacks had much lower assets to begin with, with a median between \$1,600 and \$1,800 for the first two waves. These assets were quickly drained to zero for blacks with dementia and reduced to \$1,000 for blacks without dementia, although the last change is non-significant.

Dementia is negatively associated with home-ownership for both blacks ($\chi^2 = 6.4$, $p = 0.011$) and non-blacks ($\chi^2 = 30.4$, $p < 0.001$). The percentage of home-owners for each group over eight years is shown in Figure 3. Both dementia groups show downward trends, with declines of 18.4 percentage points among blacks and 19.3 percentage points among non-blacks; non-blacks without dementia had a decline of 11.3 percentage points, and the decline among blacks without dementia, at 3.8 percentage points, is small and non-significant. Only among blacks with dementia was the final rate of home-ownership below 50 per cent.

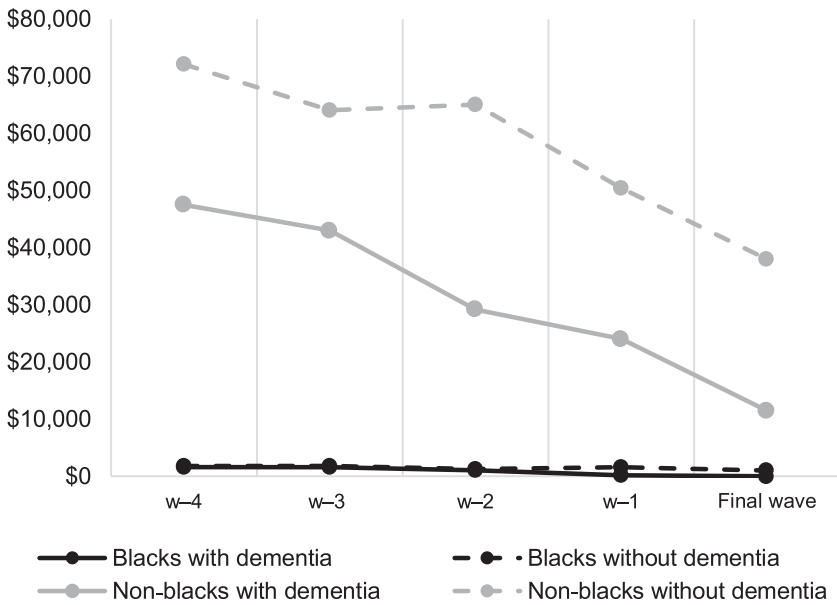


Figure 2. Median non-housing wealth over eight years.

Notes: Wilcoxon signed rank tests were conducted to test for significant changes in median wealth (US \$) from baseline (w-4) to final wave. Blacks with dementia, $p = 0.005$; blacks without dementia, $p = 0.501$; non-blacks with dementia, $p < 0.001$; non-blacks without dementia, $p < 0.001$.

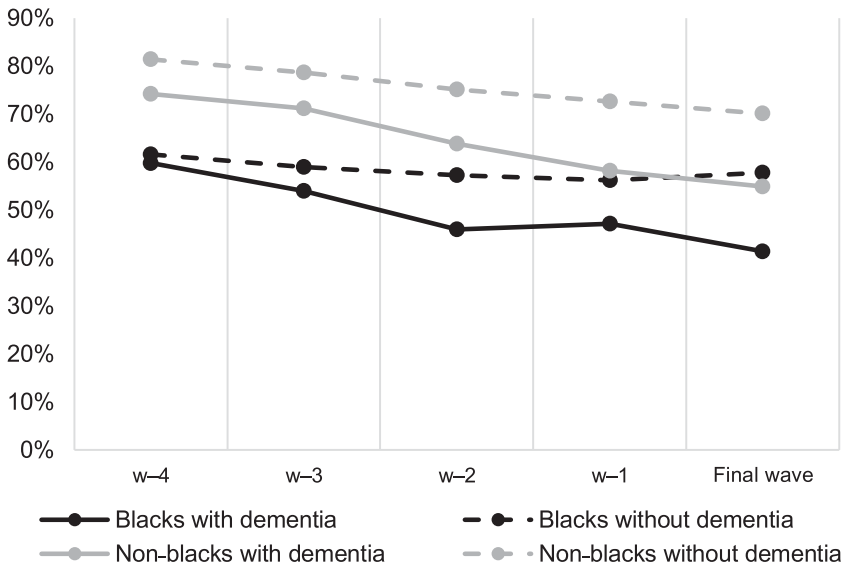


Figure 3. Percentage of home-owners over eight years.

Notes: McNemar tests were conducted to test for significant changes in home-ownership from baseline (w-4) to final wave. Blacks with dementia, $p < 0.001$; blacks without dementia, $p = 0.248$; non-blacks with dementia, $p < 0.001$; non-blacks without dementia, $p < 0.001$.

No meaningful correlation is seen between total out-of-pocket health spending and dollar change in wealth for the full sample ($r = 0.05$, $p = 0.026$) or any of the sub-groups (blacks with dementia, $r = -0.04$, $p = 0.758$; blacks without dementia, $r = -0.00$, $p = 0.951$; non-blacks with dementia, $r = 0.10$, $p = 0.062$; non-blacks without dementia, $r = -0.02$, $p = 0.523$) (not shown).

This study also examines the effect of dementia on the probability of having no more than \$1,000 at the final wave living: for blacks, $\chi^2 = 6.32$, $p = 0.012$; for non-blacks, $\chi^2 = 26.13$, $p < 0.001$. Among blacks, 32 per cent had dementia, 39 per cent had \$1,000 or less and 16 per cent fell in both categories. Among non-blacks, 26 per cent had dementia, 14 per cent had \$1,000 or less and 6 per cent fell in both categories.

Table 2 shows the results of the logistic regression analysis. In the black sub-group, dementia doubles the likelihood of having no more than \$1,000 at the final wave (odds ratio (OR) = 1.94, 95% confidence interval (CI) = 1.15, 3.26); after adjusting for wave set, baseline wealth, baseline home-ownership, demographics, socio-economic characteristics and health conditions, the association is no longer significant (OR = 2.04, 95% CI = 0.83, 5.00). In the non-black group as well, dementia increased the likelihood of having \$1,000 or less at the final wave (OR = 2.18, 95% CI = 1.61, 2.95); the probability drops but remains statistically significant in all models until health covariates are introduced (OR = 1.47, 95% CI = 0.95, 2.27). With the full set of covariates, significant socio-economic and demographic factors among blacks are home-ownership and income. Among the larger sample of non-blacks, baseline wealth, home-ownership and Medicaid status are significant.

As a sensitivity test, chi-square tests and logistic regression analysis were also performed on an outcome of having less than \$10,000; results are similar but OR values are slightly higher, and dementia shows significant effects in all five models for non-blacks (not shown).

Finally, in an exploratory mediation analysis, we fit logistic regression models to investigate whether dementia predicts the loss of a home and whether the loss of a home predicts wealth exhaustion (Table 3). In a bivariate model, dementia is significantly related to home loss for both blacks (OR = 2.23, 95% CI = 1.07, 4.65) and non-blacks (OR = 1.68, 95% CI = 1.26, 2.25). That association is not significant for blacks after controlling age and marital status (OR = 1.54, 95% CI = 0.70, 3.38) but remains significant for the larger sample of non-blacks (OR = 1.42, 95% CI = 1.06, 1.92) and the full sample (OR = 1.42, 95% CI = 1.08, 1.87; not shown). In a bivariate model, home loss predicts wealth exhaustion for blacks (OR = 7.52, 95% CI = 3.13, 18.08) and non-blacks (OR = 2.89, 95% CI = 2.08, 4.02). In the final model, which includes dementia and home loss as predictors of wealth exhaustion as well as controlling age and marital status, dementia almost doubles the odds of wealth exhaustion for both blacks (OR = 1.92, 95% CI = 1.05, 3.48) and non-blacks (OR = 1.96, 95% CI = 1.42, 2.71), with home loss also predicting wealth exhaustion for blacks (OR = 6.43, 95% CI = 2.58, 16.03) and non-blacks (OR = 2.52, 95% CI = 1.78, 3.57).

Table 2. Odds ratios for having US \$1,000 or less in wealth at final wave living, by racial sub-group

Characteristic	Model 1	Model 2	Model 3	Model 4	Model 5
<i>Odds ratios (95% confidence intervals)</i>					
Black sub-group:					
Dementia	1.94* (1.15, 3.26)	2.50** (1.33, 4.71)	2.07* (1.05, 4.10)	1.62 (0.71, 3.66)	2.04 (0.83, 5.00)
Wave set 1 (2002–2010) ¹		1.45 (0.80, 2.64)	1.29 (0.69, 2.40)	1.38 (0.67, 2.87)	1.48 (0.68, 3.22)
Wealth 8 years previous ²		0.43* (0.21, 0.87)	0.44* (0.23, 0.85)	0.72 (0.30, 1.72)	0.64 (0.25, 1.67)
Home-owner 8 years previous		0.13*** (0.06, 0.25)	0.13*** (0.07, 0.26)	0.16*** (0.07, 0.34)	0.13*** (0.06, 0.32)
Age at death			1.01 (0.97, 1.04)	0.99 (0.95, 1.02)	0.97 (0.93, 1.02)
Female			1.87 (0.96, 3.62)	1.27 (0.57, 2.81)	1.12 (0.48, 2.64)
Married at time of death			0.42* (0.20, 0.88)	1.00 (0.39, 2.56)	0.91 (0.34, 2.42)
Level of education ³				0.66 (0.41, 1.07)	0.62 (0.36, 1.06)
Average income over five waves ²				0.17*** (0.07, 0.40)	0.16*** (0.06, 0.42)
Medicaid at final wave				1.13 (0.54, 2.38)	1.11 (0.50, 2.45)
Stroke					1.77 (0.74, 4.20)
Diabetes					1.82 (0.81, 4.07)
Heart disease					1.76 (0.78, 3.97)
Hypertension					1.24 (0.44, 3.45)
Lung disease					0.73 (0.24, 2.23)
Cancer					0.90 (0.33, 2.45)
Psychiatric problems					0.31* (0.10, 0.93)
Arthritis					1.54 (0.64, 3.71)

Non-black sub-group:					
Dementia	2.18*** (1.61, 2.95)	2.10*** (1.48, 2.98)	2.14*** (1.49, 3.07)	1.57* (1.04, 2.36)	1.47 (0.95, 2.27)
Wave set 1 (2002–2010) ¹		0.87 (0.62, 1.22)	0.87 (0.62, 1.22)	0.88 (0.61, 1.27)	1.01 (0.69, 1.47)
Wealth 8 years previous ²		0.18*** (0.12, 0.27)	0.21*** (0.14, 0.31)	0.17*** (0.10, 0.30)	0.18*** (0.10, 0.33)
Home-owner 8 years previous		0.33*** (0.23, 0.48)	0.33*** (0.27, 0.49)	0.41*** (0.27, 0.63)	0.36*** (0.23, 0.56)
Age at death			0.98* (0.96, 1.00)	0.97* (0.95, 0.99)	0.98 (0.96, 1.00)
Female			1.11 (0.77, 1.60)	1.09 (0.73, 1.62)	1.01 (0.67, 1.54)
Married at time of death			0.56** (0.37, 0.85)	0.72 (0.45, 1.16)	0.72 (0.44, 1.17)
Level of education ³				0.88 (0.71, 1.11)	0.85 (0.67, 1.08)
Average income over five waves ²				0.73 (0.50, 1.06)	0.76 (0.52, 1.12)
Medicaid at final wave				3.03*** (2.01, 4.55)	3.04*** (1.99, 4.66)
Stroke					1.37 (0.88, 2.14)
Diabetes					1.12 (0.73, 1.71)
Heart disease					0.91 (0.61, 1.37)
Hypertension					1.42 (0.91, 2.22)
Lung disease					1.40 (0.90, 2.19)
Cancer					0.89 (0.58, 1.37)
Psychiatric problems					1.51 (0.99, 2.31)
Arthritis					1.02 (0.65, 1.59)

Notes: Sample size varies because of missing values. Among the black sub-group, N = 272 in Model 1, N = 242 in Model 5; among the non-black sub-group, N = 1,517 in Model 1, N = 1,416 in Model 5. No weights have been applied to the statistics in this table. 1. Reference is wave set 2 (2004–2012). 2. Wealth and income are log-transformed. 3. Level of education is ordinal: less than high school, high school graduate/GED, some college, college graduate. Significance levels: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 3. Home loss as a mediator of wealth exhaustion

Characteristic	Black sub-group	Non-black sub-group
<i>Odds ratios (95% confidence intervals)</i>		
Odds of home loss:		
Dementia	2.23* (1.07, 4.65)	1.68*** (1.26, 2.25)
Odds of home loss:		
Dementia	1.54 (0.70, 3.38)	1.42* (1.06, 1.92)
Age at death	1.04* (1.00, 1.09)	1.03** (1.01, 1.04)
Married at time of death	0.23* (0.07, 0.78)	0.46*** (0.33, 0.63)
Odds of wealth exhaustion:		
Loss of home	7.52*** (3.13, 18.08)	2.89*** (2.08, 4.02)
Odds of wealth exhaustion:		
Dementia	1.92* (1.05, 3.48)	1.96*** (1.42, 2.71)
Loss of home	6.43*** (2.58, 16.03)	2.52*** (1.78, 3.57)
Age at death	0.97 (0.94, 1.00)	0.96*** (0.95, 0.98)
Married at time of death	0.27*** (0.14, 0.52)	0.31*** (0.21, 0.44)

Notes: Home loss is defined as owning a home at the baseline wave but not at the final wave. Wealth exhaustion is defined as having US \$1,000 or less in wealth at final wave living.

Significance levels: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Discussion

This study uses the HRS, a large, nationally representative study, to examine whether dementia contributes to a disproportionate decline in wealth over an eight-year period preceding death among black Americans compared with non-black Americans. The findings in this study, the first to examine this wealth trajectory, indicate that black Americans with dementia may experience a precipitous drain in assets: their median wealth declined 97 per cent (from \$38,205 to \$1,200), compared with 42 per cent (from \$141,500 to \$82,000) among non-black Americans with dementia. For blacks *versus* non-blacks without dementia, the declines were substantially less, 15 per cent (from \$31,000 to \$26,500) *versus* 19 per cent (from \$172,000 to \$140,000). In a logistic regression stratified by race, dementia increases the probability of having no more than \$1,000 within three years of death for both black and non-black Americans, although the association loses significance after baseline wealth, home-ownership, demographic and socio-economic variables, and health conditions are controlled. Home-ownership eight years previous reduces the probability of wealth exhaustion, as does higher income for black Americans and higher baseline wealth for non-black Americans. Yet dementia is also a predictor of home loss, which appears to play a significant role in wealth exhaustion, especially among black Americans.

In absolute terms, the median amount of wealth lost among individuals with dementia is greater for non-black Americans (\$59,500) than for black Americans (\$37,005). But with lower wealth a decade before death, black Americans are

more likely than non-black Americans to exhaust their assets and have nothing to pass on to the next generation, and such wealth exhaustion is especially likely among blacks with dementia. This difference cannot be definitively attributed to dementia itself. Low income and wealth, as well as a low level of education, predict both dementia incidence (Yaffe *et al.*, 2013; Langa *et al.*, 2017) and low wealth transfer. Yet it is possible that developing dementia has an additive negative effect on the wealth available for transfer, in part through increasing the likelihood of home loss.

The eight-year span of this research confirms and expands on the findings of Kelley *et al.* (2015), who show out-of-pocket spending to be 84 per cent of baseline wealth among black decedents with dementia compared with 30 per cent among black decedents without dementia. Those researchers attribute that disparity not to a difference in spending but to the difference in baseline median wealth between the two groups five years before death (\$25,597 *versus* \$57,971, respectively). The present study finds a similar difference in wealth (\$15,000 *versus* \$31,300) at 4–7 years before death. However, at 8–11 years before death, the two groups of black Americans did not differ significantly in wealth. Kelley *et al.* (2015) speculate that previous care needs may have contributed to the difference they find at five years, and the results presented here are consistent with that. Yet median total out-of-pocket spending is similar for the two black groups over ten years and does not differ greatly in the early period. Thus, it appears that out-of-pocket health-care spending does not account for the difference in wealth trajectory between black Americans with and without dementia, though it is possible that not all types of dementia-related expenditures are captured in the survey out-of-pocket categories. Medicaid probably plays a role in this result, by limiting out-of-pocket spending. Medicaid, which is administered by states and financed jointly by state and federal governments, covers virtually all health-care costs for low-income individuals who qualify under one of its various categories. Income and asset limits differ by state, but in general, individuals are not eligible for coverage of long-term services and supports until they have ‘spent down’ their assets, with the exception of their primary residence (Colello, 2017). It is notable that Medicaid status at the final wave is a significant and substantial predictor of wealth exhaustion among non-black Americans, but not among black Americans, who typically have few non-housing assets. Among those with dementia, the proportion of black Americans with Medicaid doubled from baseline to final wave, while the proportion of non-black Americans with Medicaid tripled.

There are two comparisons to consider when examining differences by both race and dementia status: between black Americans with dementia and black Americans without, and between black and non-black Americans with dementia. In seeking to understand how dementia could affect the family wealth of black Americans, we concentrate on the former. Despite out-of-pocket health spending similar to that of their counterparts with dementia, black Americans without dementia were, at the median, able to keep 85 per cent of their wealth at the final wave, up to three years before their death. If differences in health-care spending do not drive the difference in wealth trajectory, income and home-ownership appear to be prominent factors. Median annual household income over eight years was \$4,500 higher among blacks without dementia than among blacks with dementia, to

some extent due to employment and marital status – which, in turn, are attributable to age, in part. (Black Americans with dementia were more than six years older at the time of death than black Americans without dementia, half as likely to be employed eight years before the final wave and less likely to be married at the time of death.) These findings suggest that for black Americans, an important contributor to final wealth is income still being accumulated in the decade before death.

Owning a home remains an important factor in wealth retention. Yet as the progression of dementia makes it impossible for an individual to live alone, the sale of a home seems all but inevitable in the absence of a full-time co-habiting caretaker, spousal or otherwise. Home-ownership was nearly equal at baseline in the two groups of black Americans. While it barely dropped among blacks without dementia, fewer than three-quarters of baseline home-owners in the dementia group were still home-owners by the final wave. Home loss – having a home a decade before death but selling or losing it to foreclosure – increases the odds of wealth exhaustion sixfold among black Americans. As previously documented, home equity is lower for black Americans than for white Americans (Thomas *et al.*, 2018), yet it constitutes a greater share of their wealth (Gittleman and Wolff, 2004; Burd-Sharps and Rasch, 2015). This combination may leave black Americans with dementia in a financially vulnerable position. If a home sale is forced by circumstance, owners may not be able to avoid selling at a disadvantageous time, *e.g.* after US housing values dropped precipitously in 2008.

When considering intergenerational family wealth, an important question is what happens to the proceeds of a home sale. If the money (or the home) is being transferred to children or other relatives, the change in household wealth does not amount to a decline in family wealth. Investigation of the data in this study found no incidences of deed transfer among black Americans with dementia, although 17 out of 52 baseline home-owners in that group reported adding the names of a child or children to their deeds. Few net financial transfers to children among this group exceeded \$10,000, and only two instances were plausible proceeds from the sale of a house. It seems likely, therefore, that a combination of reduced income and higher needs can quickly drain savings and any profit from a home sale. For individuals receiving long-term care from Medicaid, moreover, final wealth may be deceiving, because Medicaid has the right to claim reimbursement from the estate of the deceased, including the primary residence.

The financial costs of dementia are also potentially severe for non-black Americans, who see greater wealth declines in terms of dollars. In comparing the wealth trajectory of black Americans with dementia and non-black Americans with dementia, we note several differences in associated factors. Income is not a significant predictor of wealth exhaustion among the non-black group, but baseline wealth is significant, suggesting that non-blacks are more likely to draw on assets than current income to cover the expenses of dementia. Also notable is the strong association between Medicaid status and wealth exhaustion among non-blacks and the greater likelihood of living in a nursing home. The picture of ‘spending down to Medicaid’ when care needs exhaust assets appears to be more prominent in this group.

Limitations

This study has several limitations. First, it lacks a direct measure of the inheritance received by the next generation. Estate values are measured at the time of the final interview, which can be up to three years before the respondent's death. Because those with greater wealth at the final wave would have more to spend in the time between the final wave and death, the differences in percentage change in wealth decline are likely somewhat over-estimated, since non-black Americans had more wealth to lose than black Americans. However, the very substantial differences in proportionate wealth loss found in this study are unlikely to be appreciably affected. Second, while transfers to and from children are included in descriptive statistics, it was not possible to account reliably for transfers in the regression analysis, nor to account for transfers to other important people in an individual's life. Third, total out-of-pocket medical expenditures should be interpreted with caution due to missing observations. Fourth, restricting the study to the last living spouse would have resulted in too small a sample size, so where a spouse remains, the eventual amount of any bequest to children is likely to be less. Fifth, dementia is measured by a physician's diagnosis of any memory-related disease, but there have been suggestions that black and non-black individuals are not diagnosed consistently (Alzheimer's Association, 2016). The presence of individuals with dementia in the non-dementia groups would bias estimates towards the mean, although diagnosis itself might influence spending, residential care placement and the likelihood of a home sale. Finally, and fortunately, the cohorts included in this study have dementia risk factors that differ from those of younger cohorts, in particular the large percentage with less than a high school education. If higher levels of education delay dementia onset, the burden found here may therefore lessen in the future. It is also worth noting that the Great Recession of 2008–2009 occurred in the last two or four years of data collection. While research indicates that the racial wealth gap widened in its wake (Pfeffer *et al.* 2013), its effects on the groups involved here are beyond the scope of this paper.

Further research

The study of the effects of dementia on wealth disparities would benefit from a more complete, long-term picture of family finances, including bequests and details of the disposition of real estate. In addition, research into the employment and income trends among Americans with dementia and the consequent effects on family wealth would help determine potential areas of intervention for policy makers interested in reducing racial wealth disparity.

Policy implications

The racial wealth gap tends to grow over the lifecourse (Brown, 2016; Herring and Henderson, 2016), and dementia's greater prevalence among black Americans is likely to exacerbate it. In seeking to reduce this prevalence, policy makers should heed the role of education in delaying the onset of dementia (Crimmins *et al.*, 2018). If one generation's wealth exhaustion reduces the wellbeing and educational opportunities of later generations of black Americans, it could contribute to the

perpetuation of this greater prevalence. Policy makers seeking to address racial disparities associated with ageing should be cognisant of this dynamic.

In the absence of significant investment income, home-ownership is a crucial bulwark against wealth exhaustion, but black Americans still face obstacles in this area. The US Department of Justice filed a lawsuit as recently as 2017 alleging bias in lending, indicating that enforcement of the Fair Housing Act is still needed (US Department of Justice, 2017). Because bias may be entrenched and unintentional, providing clear and consistent guidance to banks may be warranted. Enforcement of laws against predatory lending and unfair foreclosure is also critical, especially in cases where families are struggling to cover long-term care and other expenses related to dementia, or where family members have left their jobs or reduced their work hours to provide care. Low-income families affected by dementia also would be likely to benefit from access to financial counselling.

The unexpected finding that health expenses were not necessarily a main factor in exhausting wealth indicates that Medicaid effectively reduces the burden of health-care spending and makes a substantial difference in the lives of low-income families dealing with dementia. Maintenance of federal and state contributions to Medicaid is important to avoid encumbering families with generations of debt for this care.

It is notable that the share of Medicaid spending on long-term services and supports that goes to institutional care, rather than care in the community, has been declining steadily, from 82 per cent in 1995 to 47 per cent in 2014 (Eiken *et al.*, 2016). The present study found that only 26 per cent of black Americans (46% of non-black Americans) with dementia were living in a nursing home at the time of the final survey wave. A large majority of black Americans with dementia, therefore, are being cared for at home, with consequent demands on family caregivers. In addition to supporting policies that address racial disparities in wealth, a beneficial approach might be to provide Social Security credits to family caregivers, as proposed in bills introduced in the US House of Representatives in 2015 and the US Senate in 2016. Low-income care-givers would receive a scheduled amount of retirement credit in partial compensation for working hours lost. Social Security credits, while rewarding all care-givers for their efforts and time, might also help ease wealth disparities in which dementia plays a role.

Conclusion

This study finds that dementia is associated with a significant loss of wealth, as well as the loss of a home, among both black and non-black Americans. For black Americans especially, all wealth may be exhausted over the course of dementia, leaving nothing for the next generation. The loss or sale of a home may play a mediating role in such wealth exhaustion.

This research suggests that the effects of dementia on family wealth may hinder efforts to level the economic playing field for Americans. Black Americans may be twice as likely to develop dementia as non-black Americans, but at least half of black Americans have insufficient wealth to withstand dementia's financial effects. Because of the importance of home equity in the accumulation of wealth, this circumstance may be, in part, a final legacy of housing discrimination once enshrined

in US policies and practices. If dementia hinders a family's efforts to improve its socio-economic status, and lower status is associated with a higher risk of dementia, not only wealth disparities but dementia itself may be part of a vicious cycle.

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