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Commentary

# Introduction to a Supplement on Population Level Trends in Dementia: Causes, Disparities, and Projections

**Robert F. Schoeni, PhD,[1,2,3] Vicki A. Freedman, PhD,[1] and Kenneth M. Langa, MD, PhD[1,4,5]**

[1]Institute for Social Research, University of Michigan, Ann Arbor. [2]Ford School of Public Policy, University of Michigan, Ann Arbor. [3]Department of Economics, University of Michigan, Ann Arbor. [4]University of Michigan Medical School, Ann Arbor. [5]Veterans Affairs, Ann Arbor Center for Clinical Management Research, Michigan.

Address correspondence to: Robert F. Schoeni, PhD, Institute for Social Research, University of Michigan, 426 Thompson Street, Ann Arbor, MI 48106. E-mail: bschoeni@umich.edu

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Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD; hereafter dementia) are a set of conditions affecting primarily adults in later life that are characterized by impairments in memory and other cognitive processes severe enough to interfere with day to day functioning. These conditions have a large and growing impact on older adults, their families, and societies globally. In 2015, more than 46 million people around the world had dementia (Prince et al., 2015). The economic impact of dementia, including unpaid care provided by families, is estimated to be $818 billion worldwide (Prince et al., 2015). Because the world population is aging and the incidence of dementia increases sharply over the age of 75, some researchers have projected a tripling of the number of people living with dementia by 2050 unless delays in onset or treatment breakthroughs occur in the future (Prince et al., 2015).

Recent studies examining population-level trends in dementia suggest there may be offsetting factors that will temper this projection. Indeed, a growing number of studies of high-income countries report declines in dementia incidence or prevalence (Langa, 2015; Wu et al., 2017). For example, a declining age-specific risk of dementia has been found in Rotterdam (Schrijvers et al., 2012), within several areas in England (Matthews et al., 2013, 2016), and for the United States as a whole (Langa et al., 2008, 2017; Sheffield & Peek, 2011). Researchers have speculated that the reasons for such trends may include rising levels of education and more aggressive treatment of cardio- and cerebrovascular risk factors, such as hypertension, diabetes, and hypercholesterolemia.

Building on these initial findings, the papers in this Supplement are an outgrowth of a workshop held in May 2017 with funding from the National Institute on Aging (NIA) to significantly broaden the evidence base for understanding dementia trends. The workshop was held jointly with the annual meeting of the NIA-supported TRENDS Network, a network of researchers working to accelerate scientific understanding of changes over time in old-age disability and health. Papers in this Supplement provide important new evidence on whether dementia trends, and cognitive health more broadly, have in fact been favorable. They broaden and deepen the empirical evidence on trends by analyzing three national surveys and several studies in large cities. They evaluate trends for older adults and those approaching old age, determine whether favorable trends have been experienced by both more and less advantaged groups, and explore whether estimated trends are robust to using alternative measurement approaches. The studies also investigate reasons for trends, including the potential contributions of education and treatment of cardiovascular risk factors (CRFs). Moreover, one paper develops caseload and prevalence projections that are crucial to planning appropriate public and private sector responses (Zissimopoulos, Tysinger, St. Clair, & Crimmins, 2018). Authors also lay the groundwork for identifying future research questions.

## Articles in this Supplement

### National Studies

Six articles in this Supplement draw upon three national data sources, two from the United States and one from the Netherlands. The U.S. resources are the Health and Retirement Study (HRS) and the National Health and Aging Trends Study (NHATS). The HRS, which is a biennial survey representative of the U.S. population over 50, has been collecting measures of cognitive function in older adults since the study began in 1992. NHATS is a nationally representative survey of U.S. Medicare beneficiaries ages 65 and older designed to study trends in disability and functioning of the older population, including cognitive functioning. Begun in 2011, NHATS carries out in-person annual assessments of cognitive function, allowing for analysis of both dementia prevalence and incidence.

The strength of the U.S. national data sources is that they are drawn from sampling frames in which individuals have a known probability of being selected and participating, and that nonresponse adjusted sampling weights are provided to ensure that estimates reflect the national population. These surveys also include the nursing home population. Both HRS and NHATS use relatively brief cognitive screening protocols, with measures of memory, orientation, and executive functioning, to identify those with cognitive limitations. Both surveys also have protocols for proxy-reported dementia. Study participants are typically classified as having dementia if they score below a given threshold on either protocol. HRS also includes the Aging, Demographics, and Memory Study (ADAMS) substudy, which offers more in-depth evaluations similar to those in clinical studies. ADAMS offers a direct crosswalk to a dementia diagnosis for a subset of the HRS sample and was also used to validate the NHATS dementia classification.

Using the HRS, Hudomiet, Hurd, and Rohwedder (2018) reassess the evidence on national trends in the prevalence of dementia, placing the spotlight on issues of measurement and survey design. Like prior studies, they use cognition measures in the main HRS interview along with clinical assessments in the ADAMS substudy. Unlike prior studies, they estimate trends in cognitive ability using a latent model. They also emphasize the importance of appropriately incorporating sample members whose interview is completed by a proxy respondent. Although only 12.3% of interviews were conducted with a proxy in their baseline year of 2000, about half of the people classified as having dementia had their information provided by a proxy. Therefore, the subsequent decline in the use of proxies to 7.0% in 2012 (the article's end year) may heavily influence estimates of dementia prevalence if proxy-based measures are not as reliable as test-based measures. Hudomiet and colleagues estimate that the prevalence of dementia decreased in the 65 and older population from 12.0% in 2000 to 10.5% in 2012, or about 1% per year. This improvement is smaller than has been found in prior studies using the same data, and the difference is in large part attributable to how they incorporate proxy interviews into the analysis.

Crimmins et al. (2018) provide estimates of life expectancy and aggregate changes in life expectancy (between 2000 and 2010) with dementia at ages 65 and 85, stratified by educational group. They combine estimates of cognitive functioning in HRS with mortality from vital statistics to estimate life expectancy by cognitive state. Consistent with a well-established literature (Berkman, 1986), they find that people with more education have dramatically lower prevalence of dementia relative to their less educated counterparts: at ages 75–79, women and men with less than a high school degree are 4 and 9 times more likely to have dementia than those with 16 or more years of education, respectively. Despite living several years longer than individuals with less than a high school degree, those with 16 or more years of education spend fewer years living with dementia. Between 2000 and 2010, years spent with good cognition increased for most sex-education groups and years spent with dementia decreased for some groups. Improvement in mortality was the most important factor accounting for the increase in years lived with good cognitive function. Furthermore, for women (men), about one-third (one-half) of the increase between 2000 and 2010 in cognitively intact life expectancy at age 65 reflects the compositional shift toward higher education.

Prior research has concluded that some aspects of physical health and functioning of midlife adults ages 45–65 in the United States have been worsening in recent years (Case & Deaton, 2015; Freedman et al., 2013; Martin et al., 2010; Martin & Schoeni, 2014; Weir, 2007). Choi, Schoeni, Martin, and Langa (2018) determine whether cognitive functioning has also been worsening for this population. Using the 1998–2014 waves of the HRS, they find no significant change over time in the overall prevalence of cognitive limitation for 55–69 year olds. Rates of cognitive limitation are 3–4 times higher for blacks relative to whites, and 7–10 times higher in the bottom quartile versus the top quartile of socioeconomic status (SES), whether measured by education, income, or wealth. They find little indication that these large gaps are narrowing and in some cases find evidence consistent with widening disparities.

Zissimopoulos, Tysinger, St. Clair, and Crimmins (2018) use the HRS to make projections of dementia cases for the United States. They use a dynamic simulation model that tracks a cohort of persons ages 51–52 to project dementia onset and mortality. They then use this model to estimate the impact of reducing risk factors associated with dementia and delaying onset of dementia on the number of dementia cases in 2040. They conclude that lowering the incidence of diabetes by 50% would not reduce the number of remaining years people ages 51–52 will live with dementia and would increase slightly the number of people ages 65 and older in 2040 with dementia. Eliminating hypertension at middle and older ages would increase life expectancy at age

65 by about 1 year, but in doing so it would also increase the number of years living with dementia. By far the largest effect on the number of dementia cases in the future would be developing a new treatment that delays the onset of dementia. A delay of 2 years would reduce the number of people ages 65 and older in 2040 with dementia by 2.2 million.

Freedman, Kasper, Spillman, and Plassman (2018) use the first five waves of NHATS to assess short-term trends in the prevalence and 1-year incidence of dementia among the 70 and older population. They find that the prevalence of dementia declined by 1.4–2.6% per year during 2011–2015. Improvements in prevalence were concentrated among women and non-Hispanic whites and blacks. They also detected improvements in prevalence and declines in incidence among those with no vascular conditions or risk factors. Freedman and colleagues attribute the declines in prevalence to changes in the age and education distribution of the population 70 and older, but caution that declines may not continue into the future as education trends level off and the population becomes more ethnically diverse.

The national Longitudinal Aging Study Amsterdam (LASA) sampled adults ages 55–84 from 11 registries in the Netherlands in 1992/93 and interviewed them every 3 years through 2015/16; in 2001/02 a new cohort ages 55–64 was enrolled. At each wave, interviewers administered two validated dementia screening protocols—one for respondents and the other for proxies. Using LASA, van den Kommer, Deeg, van der Flier, and Comijs (2018) examine trends in the incidence of persistent cognitive decline, 1992/93 through 2011/12, for persons ages 65–88. Cognitive tests included the Mini Mental State Examination (MMSE) for sample members responding for themselves and the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) for sample members who were not able to be or refused the interview. They define persistent cognitive decline as a decline of at least two standard deviations (SD) below the mean decline on the MMSE since the last wave or a score of ≥28 points on the IQCODE, and continued cognitive decline up to the next wave, i.e. decline of at least one SD below the sample mean decline on the MMSE or a score of ≥28 points on the IQCODE at the next wave. Additional conditions apply to some cases, as described in detail by van den Kommer et al. (2018). Rather than developing sample weights to adjust for nonresponse, the authors undertook multiple imputation to fill in information on covariates for cases that attired, excluding decedents. They also adjusted their estimates to match age–sex distributions of the Netherlands under different assumptions about missing cases. They find an increase (worsening) in the incidence of cognitive decline from 2.5% in 1995/96 to 3.4% in 2011/12. Multivariate analyses indicate that incidence is elevated for those who are older, have less education, have diabetes, smoke, have lower body-mass index, and are less physically active. However, adjusting for these and other factors does not account for the increase over time in incidence.

## Subnational Studies

Three articles examine trends using subnational data from three different U.S. cities: Framingham, Chicago, and Indianapolis. These non-national studies are based on samples of older individuals initially in a defined geographic area who are followed longitudinally at regular intervals. The Framingham Heart Study systematically sampled individuals living in Framingham, Massachusetts in 1950; their children were enrolled in an offspring cohort in 1971. These individuals have higher than average SES and health and are mostly white. They have been followed every 2 (original) or 4 (offspring) years. The Chicago Health and Aging Project (CHAP) invited all adults ages 65 year or older living in four racially diverse Chicago neighborhoods in the south side of Chicago in 1993 to participate. Beginning in 2000–2002, additional subjects were enrolled as they turned age 65. The cohort has a higher percentage of low SES and minority participants than the national population, and it has been contacted every 3 years. Finally, the Indianapolis site of the Indianapolis-Ibadan Project (IIDP) enrolled an initial random sample of African American adults ages 65 and older in 1992 from a face-to-face listing of household, and a new cohort ages 70 and older in 2001 from a sample drawn from the Medicare enrollment files. Individuals have been contacted every 2–3 years. None of the articles analyzing subnational data sources use survey weights to address potential selective nonresponse, attrition, or differential enrollment across cohorts. That is, the samples may not be representative initially and are at risk for becoming less well-defined as the cohorts age. In terms of measurement, however, the Framingham study and IIDP both have detailed neuropsychological testing to determine dementia status. The CHAP employs interviewer-administered testing, using somewhat more detailed instruments then HRS, but not as in-depth as neuropsychological testing.

Dufouil, Beiser, Chêne, and Seshadri (2018) use the original and offspring cohorts of the Framingham Heart Study data to estimate change between 1977–84 and 2004–08 in age of onset of dementia, age-specific mortality among those with dementia, and years lived with dementia. They find that age of onset increased from 80 to 86 over the roughly 25-year period in their sample. Age-specific mortality of individuals with dementia declined between 1977–83 and 1986–91 but not thereafter. However, presumably because mortality is much higher at age 86 than age 80, the number of years lived with dementia fell over time in their sample.

Weuve, Rajan, Barnes, Wilson, and Evans (2018) investigate racial differences in trends in global cognition, episodic memory, and perceptual speed from 1993 to 2012 using CHAP. They find that adjusting for age and sex, global cognition, and perpetual speed worsened over time

for both blacks and whites. The racial disparity declined somewhat over time, but at the end of the time period gaps remained very large in favor of whites. For both whites and blacks, inequality in cognitive performance increased: global cognition improved in the top quartile and worsened substantially in the bottom quartile.

Hendrie et al. (2018) analyze the incidence of dementia among African Americans ages 70 and older living in Indianapolis, comparing rates for the 1992 cohort (born before 1923) with the 2001 cohort (born before 1932). Members in each cohort were thoroughly evaluated every 2–3 years. They find lower incidence of both dementia in general and Alzheimer's disease (AD) in particular for the more recent cohort. Early life factors are examined, in particular education and urban versus rural residence in childhood. Consistent with all studies of education in this Supplement, dementia risk is significantly lower for those with more education. Controlling for education accounts for about one-third of the improvement between the two cohorts. Interestingly, education was associated with a lower incidence of dementia and AD only for those who grew up in a rural setting. This finding highlights the need to unpack education's role in predicting dementia.

## Cross-Cutting Themes

Each article addresses specific research questions and provides important new findings. Taken together, the articles point towards six cross-cutting themes.

### Dementia is becoming less prevalent in the United States overall, but not for all groups

Three articles report U.S. national estimates of changes in the prevalence of dementia: Hudomiet et al. (2018) and Crimmins et al. (2018) based on the HRS, and Freedman et al. (2018) based on NHATS. The time periods, age groups, and methods differ among these studies, but all three find favorable trends in dementia prevalence. A common metric used in the literature on trends in disability is the average annual percent decline. Calculating such estimates based on data reported in these studies, the range is a favorable 1.0–2.6% per year.

However, declines are not occurring in all places or for younger age groups. Data from Chicago show, if anything, a worsening of cognition for blacks and whites ages 67 and older (Weuve et al., 2018). Furthermore, cognitive functioning is not improving for Americans ages 55–69 (Choi et al., 2018), a trend important to monitor as these cohorts, which includes Baby Boomers, begin to reach ages when rates of dementia accelerate.

Findings are more mixed with respect to trends in dementia incidence. Hendrie et al. (2018) and Dufouil et al. (2018) find declines in incidence, for African Americans in Indianapolis between 1992 and 2001, and for the Framingham samples between 1977–84 and 2004–08, respectively. Freedman et al. (2018) find that incidence is flat overall in the United States during the 2011–2015 period, but declines did occur among those with no vascular conditions or risk factors. Based on data from the Netherlands, however, van den Kommer et al. (2018) find an increase in the incidence of persistent cognitive decline from 1995/96 through 2011/12.

### Some groups of older adults in the United States are living fewer years with dementia

Among older Americans between 2000 and 2010, there was an increase in life expectancy with good cognition by about 1.7 years and a decrease in life expectancy with dementia by about 0.3 years (Crimmins, Saito, & Kim, 2016). Both men and women at nearly all education levels experienced increases in life expectancy with good cognition (Crimmins et al., 2018). Life-years spent with dementia declined for some groups—for instance more highly educated women—but not others (Crimmins et al., 2018). Analysis of the Framingham data by Dufouil et al. (2018) indicates a large increase in the age of onset of dementia and a decrease in adjusted mortality among individuals with dementia (although neither change is statistically significant). These changes were accompanied by a substantial and statistically significant shortening in the number of years lived with dementia.

### Racial and socioeconomic disparities in dementia are large and not diminishing

Racial and socioeconomic disparities in dementia prevalence are very large, in most cases several times higher for less relative to more advantaged populations. Studies in this Supplement examined disparities by race/ethnicity, income, wealth, and, most frequently, education. National estimates for the United States based on the HRS and NHATS indicate that the prevalence of dementia is roughly 3–7 times higher for high school dropouts relative to college graduates, depending on gender and age.

Evidence is mixed on whether trends differed by race/ethnicity. Analysis of NHATS (dementia for the 70+ population) and HRS (cognitive limitation for the 55–69 population) show improvements for non-Hispanic whites but not for those of Hispanic origin (Choi et al., 2018; Freedman et al., 2018). For non-Hispanic blacks, cognitive limitation for the 55–69 population did not change in analyses of HRS, whereas dementia for the 70 and older population declined for this group in analyses of NHATS. The latter finding appears to be linked to shifts in mortality among those without dementia. Data from Chicago suggest a worsening in global cognition and perpetual speed for blacks and whites, with some evidence of a narrowing in the black-white disparity. Evidence for other racial/ethnic groups is not reported because of inadequate sample sizes in available data.

Trends are more consistent across studies by education group. For the older population (65+ in HRS and 70+ in

NHATS), prevalence rates did not change within any education group. For the population 55–69, there was no systematic difference in trends in cognitive limitation by wealth, but disparities by income rose. Monitoring future trends and determining why trends in disparities differ is important, but arguably most important is determining why such large disparities exist at any given time, and what types of interventions have the potential to shrink the clear racial and socioeconomic disparities in dementia risk.

### Rising levels of education partially account for trends, and more research is needed to better understand the role of CRFs

Education levels of the population 65 and older today are much higher than education levels of the population 65 and older in the recent past. Given the strong association between education and dementia, it is therefore not surprising that education is consistently found to account for a substantial share of observed improvements in dementia prevalence. But why might education be so important? The data from Indianapolis suggest that education's influence on occupation is not a prime candidate, but a variety of other pathways should be tested. And what are the "active ingredients" in education? If they can be identified, can interventions be developed targeting these "ingredients" that are effective at all ages and levels of cognitive health?

The role of better control of CRFs has been studied in this Supplement and other recent studies, but more research is needed. Langa et al. (2015, 2017) concluded that trends in treatment and control of CRFs may play some role in the decline in dementia prevalence. Freedman et al.' s decomposition concludes that treatment for CRFs may not be contributing to very recent declines. One possible cause for the different findings regarding the relationship of CRFs to dementia risk may be that the relationship changes over the life-course, with, for instance, hypertension in mid-life causing an increase in late-life dementia risk, but hypertension in late-life not increasing risk, or perhaps even being protective (Li et al., 2007; Corrada et al., 2017). Given the high prevalence of CRFs among middle-aged and older adults, and the known behavioral and medical interventions to prevent or treat CRFs, future research to better understand the likely complex relationship of CRFs across the life-course to dementia risk seems especially important.

### Postponing the onset of dementia directly is the most effective way to reduce the size of the population living with dementia

Conclusions about the future depend on assumptions about effects of CRFs on survival. Norton et al. (2014) conclude reductions in mid-life CRFs (i.e., diabetes, hypertension, obesity, and physical inactivity) will decrease future dementia incidence and prevalence, but do not take into account effects on survival. In this volume, Zissimopoulos et al. (2018) find that reducing diabetes and hypertension incidence leads to an *increase* in dementia cases and life expectancy with dementia because of increased life expectancy. A better understanding of how CRFs and their treatment in both middle-aged and older adults may affect dementia risk will be especially important for determining whether effective treatments lead to additional years of life with good cognitive function or with dementia.

More generally, reducing risk factors for dementia that also substantially increase life expectancy at older ages may increase the number of people with dementia because the added years of life are at ages where dementia incidence is high. Zissimopoulos et al. (2018) find that a treatment that lowers incident dementia directly would reduce the size of the population living with dementia. A delay of 2 years would reduce the number of people ages 65 and older in 2040 with dementia by 2.2 million.

### Close attention to dementia measurement challenges is critical

Studies in this Supplement highlight important decisions researchers must make in estimating dementia trends. The estimated trend may be sensitive to these decisions, and there is currently no broad consensus on the best approach. Three challenges are particularly important: practice effects, proxy-based measures, and the use of uniform versus differential (or adjusted) thresholds for determining dementia classification.

Most trend analyses are based on longitudinal studies, where individuals complete cognitive tests each wave. Practice effects—the improvement in individuals' scores due to repetition of tests—may bias estimates of dementia trends (Rodgers, Ofstedal, & Herzog, 2003), especially between the first and second administration (Vivot et al., 2016). Some articles in this Supplement address this issue by restricting analyses to first-time respondents or requiring the cognitive limitation to be persistent over multiple waves. More research is needed to understand the magnitude of practice effects in a survey setting and whether they differ by the number of times the test has been taken and the length of time between tests (e.g., 6, 12, or 24 months).

Individuals with dementia are more difficult to interview and therefore more likely to have their interview completed by a proxy informant. Hudomiet and colleagues report that while only 7% of responses were provided by informants in the HRS in 2012, the prevalence of dementia is roughly tenfold higher (using the "cutoff" method) among sample members whose interview was completed by an informant. Informant-based methods used to classify individuals with dementia in this Supplement vary and include: validated instruments such as the AD8 (Freedman et al., 2018), reports by the informant that the participant has ever been diagnosed with dementia (Choi et al., 2018), and a composite including performance on instrumental activities of daily living and memory-related reasons for the proxy report (Hudomiet et al., 2018). If the measures collected

do not accurately predict dementia status, then shifts in the percentage of proxies from wave to wave could confound trends (Hudomiet et al., 2018).

Classifying participants as having dementia often involves selection of a threshold based on a given study's protocol. Some research applies the same threshold to all persons while other research uses thresholds that depend on the study participants' characteristics, such as using a higher threshold for more educated individuals (Dufouil et al., 2018). Researchers have disagreed regarding the most appropriate method for addressing this issue (Berkman, 1986). On the one hand, conditional on the same level of cognitive function, more educated individuals may score better on memory testing simply due to their greater comfort and familiarity with test-taking, which argues for adjusting an impairment threshold for education level. However, if one hypothesizes that more education is a causal factor for the prevention of cognitive impairment, then adjusting an impairment threshold based on education level may lead to a biased estimate of the "true" relationship of education to late-life cognitive function.

## Future Directions

The nine articles in this Supplement and the discussion at the workshop where they were presented identify several research areas of high priority.

### Assess additional risk factors and use a more comprehensive approach to understanding reasons for trends

More research is needed on a number of specific factors identified in the literature as associated with dementia (e.g., NIA, 2013). Research is needed to better understand CRFs' impact on the AD amyloid cascade and determine whether AD is, in large part, a vascular disease. Prevalence of hypertension is high, but use of low-cost treatments has been increasing. Survival from stroke has been improving. Diabetes and obesity have been rising. Smoking and alcohol use differ across birth cohorts. Research indicates that depression among adults is on the rise. Workers have been retiring at older ages in recent years; is this because cognitive health improved, or has postponing retirement improved cognitive health?

Additional research is needed to understand how changes in these and other risk factors influence the prevalence of dementia and the number of people with dementia in the population as a whole. Zissomopolous et al. (2018) conclude that improvements in hypertension and dementia *increase* the number of years people live with dementia and/or the number of people with dementia. At the same time, this work demonstrates the large reduction in dementia cases that could be accomplished by discovering a treatment that delays the onset of dementia per se.

The list of factors associated with dementia is long (e.g., NIA, 2013), but studies assessing reasons for trends typically examine only a small subset. For instance, smoking (Whitmer, Sidney, Selby, Johnston, & Yaffe, 2005), physical activity (Laurin, Verreault, Lindsay, MacPherson, & Rockwood, 2001), obesity (Whitmer et al., 2008), and depression (NIA, 2013) are each associated with dementia, but their role in trends has not been assessed. Several of these factors are also associated with educational attainment because they are either causally influenced by or spuriously correlated with education. Including these factors in future studies may help lead to better understanding of education's role in dementia trends.

### Identify the root causes and the consequences of socioeconomic disparities

Several studies in this Supplement document very large disparities in dementia by race/ethnicity, education, income, and wealth, disparities that are generally not narrowing nationally. Significant effort is needed to better understand the reasons for the disparities, whether rates of dementia are associated with other SES factors like neighborhood or geographic region, how disparities along one dimension of SES (e.g., race) are related to disparities in other dimensions (e.g., education), the role of increasing inequality of income and wealth, and the extent to which SES disparities represent causal effects of SES on dementia. If there are substantial causal effects, the pathway leading to the effect needs to be established. With this knowledge, targeted inventions or policies might be designed that would not only reduce disparities but enhance cognitive outcomes for all. Ideally such interventions would be efficacious even when received at older ages.

### Expand and enhance dementia measurement in the survey context

The United States and many other countries have rich repeated cross-sectional and longitudinal surveys of national populations. A few surveys, most importantly the ones analyzed in this Supplement, include measures of dementia, but many do not. These surveys collect for large samples information on potential risk factors for dementia (e.g., health conditions, social and economic experiences, genetics, individual behaviors) and the domains of life influenced by cognitive decline (e.g., caregiving, health care utilization, economic status, well-being). A systematic assessment is needed to determine whether augmenting various ongoing data collection efforts with measures that would allow dementia to be reliably identified would facilitate important research opportunities.

More research is also needed on the measures of dementia currently being used in surveys. All six survey data resources used by the articles in this Supplement measured dementia and cognitive health differently, which may partially account for conflicting findings between some

articles. Proxy measures were especially diverse. Although survey-based cognitive tests appear to have adequate validity in predicting dementia, they are not currently designed to measure the type of changes typically associated with dementia onset. In addition, such measures are generally unavailable for adults approaching later life (e.g., roughly ages 50–64 years old). Improved measures of less severe cognitive impairment (i.e., Mild Cognitive Impairment or Cognitive Impairment without Dementia) that can be used in the survey context would also be beneficial. One recent effort to improve dementia measurement in the survey context is the Harmonized Cognitive Assessment Protocol (HCAP). HCAP is an expanded assessment of cognitive function being implemented in a sub-sample of about 3,400 respondents in the 2016 wave of the HRS and in a number of other aging surveys around the world. The protocol is being administered to both proxy and non-proxy respondents. Items are designed to allow identification of both dementia and cognitive impairment without dementia. Having comparable protocols across a number of studies should help improve understanding of dementia in the future.

**Answer outstanding methodological questions**

A number of factors associated with the survey process may influence scores on cognitive tests and need to be better understood. In some surveys, mode of interview not only differs between respondents but changes from wave-to-wave for the same respondent. A respondent may score higher or lower if the test is completed face-to-face instead of over the phone; in one study no such difference was found (Herzog & Rodgers, 1999), but more research is needed. More generally, the influence of interviewer characteristics in interviewer-administered tests would be valuable to investigate. Interview setting may also matter. For instance, cognitive scores may be lower if interviews are late in the day when respondents are tired, and more generally differences by time/day/month/season of interview, as well as by background noise and lighting where the test is being taken. Characteristics of the interviewer (e.g., verbal clarity), question order (e.g., perhaps test scores are higher/lower if tests are administered just after questions eliciting whether the respondent has been told they have various health conditions including memory loss), and length of interview prior to beginning the tests (i.e., a longer time may cause the respondent to tire and therefore score poorly) should also be examined. If these survey-related factors change from wave-to-wave and they are associated with cognitive performance, trends may be confounded.

## Summary

Drawing upon both national and subnational data resources, the articles in this Supplement provide important new insights into dementia trends. Although dementia is becoming less prevalent in the U.S. overall and some groups are living fewer years with dementia, the number of older adults living with dementia will rise substantially in the future unless ways to postpone onset are identified and implemented. Not all groups have benefited from these trends and substantial racial and SES gaps persist in the United States. Identifying the root causes and the consequences of these disparities is a priority for future research. Rising levels of education partially account for trends, but more research is needed to better understand the role of CRFs and other potentially mediating influences. Given the significant number of measurement and methodological challenges in understanding dementia trends, future research should focus on ways to enhance its measurement in the survey context and address several outstanding methodological questions.

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