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A Secondary Data Analysis of the Prevalence of Reported Dementia and Subjective Cognitive Decline Across U.S. National Surveys

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by

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ABSTRACT OF THE THESIS

A Secondary Data Analysis of the Prevalence of Reported Dementia and Subjective Cognitive Decline Across U.S. National Surveys

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Within the United States, many large-scale, nationally representative studies exist with the goal of tracking and monitoring aspects of health. These studies are often used to establish the prevalence of dementia and subjective cognitive decline (SCD) in the population. The goal of the current study is to examine how different population-based studies probe respondents about conditions related to cognitive impairment, and to assess similarities and differences in point estimates. We reviewed eight studies and identified comparable items related to dementia and SCD. We calculated design-appropriate point prevalence estimates and compared weighted estimates across studies, finding a wide range and statistically significantly different estimates for dementia (estimates ranging from 2.7% - 9.9%) and for SCD (5.6% - 46.6%). Close analysis of item construction revealed meaningful differences in the use of terminologies and timeframes that could account for these differences. Moreover, subtle but consequential sampling differences were also discovered within study documentation that also could be responsible. Given the importance of prevalence estimates for research, practice, and policy, our findings highlight the need for harmonization across methodology in these large studies, even at their most basic level, to establish the true burden of these conditions.

Keywords: prevalence, self-report, dementia, subjective cognitive decline, secondary data analysis

Introduction

Dementia and subjective cognitive decline (SCD) are public health issues that affect many people in later life. Large-scale, nationally representative health surveillance projects, such as the Health and Retirement Study (HRS) and National Health and Nutrition Examination Survey (NHANES), are designed to track the prevalence of cognitive health in the American population, using a combination of objective assessments and self-reports (Clair et al., 2017). Yet prevalence estimates of cognitive impairment within the population vary considerably among these and similar studies (Brookmeyer et al., 2011; Prince et al., 2016). Previous research on the prevalence of other chronic conditions obtained within these national projects also found variability, which investigators attribute to the use of different disease definitions, items, and research methodologies (Fahimi et al., 2008; Hsia et al., 2020). No previous studies have specifically examined estimates regarding the prevalence of self-reported dementia and SCD across these nationally representative studies.

There are a variety of reasons why it is important to understand the prevalence of a disease or condition. First, policy makers use estimates to identify public health priorities, which in turn influence workforce projections and the development of educational and training initiatives (Noordzji et al., 2010). Second, organizations such as the National Institutes of Health, the Centers for Disease Control, and the Alzheimer's Association rely on prevalence estimates to show the burden of a disease on a given population, set research priorities, and allocate research funds (Anderson & Egge, 2014). Finally, at the level of clinical practice, prevalence estimates help clinicians understand the base rate of a condition among their patients, which can inform clinical decision making (Djulbegovic et al., 2014). For these reasons, obtaining reliable and valid prevalence estimates for dementia and SCD is imperative to establish the true burden

of these conditions in the population. Nonetheless, many nationally representative studies use different methods to establish the prevalence of dementia and SCD, which could lead to different estimates, with the implications outlined above for policy and practice.

Methods to Obtain Prevalence Estimates

Neuropsychological Testing

The two most often cited and influential studies that establish dementia prevalence estimates make use of in-depth neuropsychological measures and clinical case consensus (Hebert et al., 2013; Plassman et al., 2007). Using a sample of adults age 65 or older in the Chicago area, Hebert and colleagues (2013) estimated 11.6% of adults reached diagnostic criteria for Alzheimer's disease (AD) through NINCDS-ADRDA Work Group criteria. In comparison, a national study led by Plassman and colleagues (2007) using a subsample of the Health and Retirement Study (HRS) estimated that 13.9% of noninstitutionalized adults over the age of 70 reached diagnostic criteria for a dementia diagnosis based on a comprehensive in-home assessment and criteria based on the DSM-III-R and DSM-IV. Prevalence estimates generated with standardized, objective assessments are arguably the most reliable and valid, yet even between these two much-cited studies prevalence estimates are different, perhaps due to the different age ranges across studies and the focus of Hebert and colleagues (2013) on AD cases only. Moreover, replications of these findings in other nationally representative samples have been lacking.

Brief Cognitive Testing

Other nationally representative studies conducted at a similar time have used simple cognitive tests to ascertain dementia prevalence. These studies often show much higher estimates. For example, using the AD8 within the nationally representative Panel Study of

Income Dynamics (PSID), Freedman and colleagues (2019) estimated that 21.9% of the population over the age of 65 screened positive for dementia. Similarly, high estimates were found within the National Social Health and Aging Project (NSHAP), which adapted the Montreal Cognitive Assessment and found that 25.8% of older adults screened positive for mild cognitive impairment and 15.3% for dementia (Kotwal et al., 2016). However, using the Telephone Interview for Cognitive Status within the HRS, Langa and colleagues (2017) estimated that 8.8% of older adults have dementia. As shown, the method of assessment can yield very different estimates.

Moreover, one must use caution when interpreting estimates obtained with brief cognitive screening tests given that they may overestimate rates for individuals who have lower educational attainment or who are nonnative speakers (Skoog et al., 2017; Spering et al., 2012). Additionally, past research has found that estimates based on brief cognitive tests performed at a single interview may overestimate the burden of the condition, as longitudinal studies have shown that people may qualify for a diagnosis at one wave but not another (Zissimopoulos et al., 2018), further complicated by practice effects, even in people with mild to more severe pathology (Gross et al., 2018).

Medicare Claims Data

One final method for establishing prevalence estimates features Medicare claims data, which is a valuable epidemiologic tool, as they cover virtually all adults over the age of 65 in the US, including those in both institutional and noninstitutional settings. However, these, too, show differences in estimates depending on disease definition. For example, using a 20% random sample of Medicare fee-for-service beneficiaries throughout the country, Koller and Bynum (2015) estimated that 8.5% of adults above the age of 65 have a dementia subtype. More

recently, Goodman and colleagues (2017) looked at all Medicare beneficiaries and found 14.4% have a dementia subtype listed in their record. Here again, variations in methods (i.e., ICD-9 coding) yield substantially different dementia prevalence estimates. Moreover, some past research has found that Medicare claims may undercount the true prevalence of dementia as compared to more in-depth neuropsychological testing. In a study linking Aging, Demographics, and Memory Study participants to their Medicare claims data, 14.5% of individuals were classified as having dementia based upon neuropsychological assessment but did not have a dementia diagnosis code within their Medicare claims record (Taylor et al., 2009).

Estimates of SCD

Estimates of SCD across studies show even wider variability than those for dementia, likely because there is no standardized approach to measuring it. For example, a recent review of 16 international population-based cohort studies found the prevalence of SCD ranged from 6.1% to 52.7% based on self-reports within adults over age 60 (Röhr et al., 2020), with similarly wide estimates in US samples (van Harten et al., 2018). Moreover, an analysis by the Subjective Cognitive Decline Initiative found little consistency in SCD items used across 19 international studies, with 73% of items created uniquely for each individual study (Rabin et al., 2015). There have been recent calls to harmonize measures, and researchers have recently begun to study the impact of individual items used to create estimates, with wide methodology and ways of probing likely causing this range.

While some nationally representative studies make use of cognitive batteries to assess the prevalence of dementia and SCD, more common are self-report items embedded in each study. Estimates garnered from self-report items often complement objective assessment, and they have been shown in past research to produce prevalence estimates that are comparable to more in-

depth case ascertainment (Bernstein & Remsburg, 2007; Griffith et al., 2020; Mulvale, 2015). However, just as objective assessments vary from study to study, so too do self-report items. Next, we review characteristics of these items that could contribute to differences in prevalence estimates.

Variability in Item Construction

Although simple items in national surveys appear to be designed to ask respondents about the same constructs (i.e., the presence of dementia and SCD), inconsistencies in terminology and timeframe could contribute to different prevalence estimates.

Terminology

One source of variability across national studies is their use of different terminology. For example, the Health and Retirement Study (HRS) asks if an individual has ever been diagnosed by their doctor with "dementia, senility, or any other serious memory impairment," while the PSID asks a more general question about a doctor's diagnosis of "[p]ermanent loss of memory or loss of mental ability." Other studies use items that ask about specific conditions, such as the NSHAP, which asks about "Alzheimer's disease" or "vascular dementia," while the BRFSS and NHANES simply discuss "conditions" which cause "problems with remembering." Even greater variation is found across SCD items, which ask respondents, in various ways, about basic cognitive complaints, attention difficulties, difficulties with language, or memory concerns (Abduulrab et al., 2008; Jessen et al., 2014). It is possible that items that use less precise terminology (e.g., "memory loss") may yield higher prevalence estimates than items that use more specific terms (e.g., diagnoses of "Alzheimer disease" or "vascular dementia").

Timeframe

Another facet of items that may lead to variable estimates has to do with the timeframe referenced. An item from the Midlife in the United States Study (MIDUS) study asks participants to rate their memory over the past five years, while one from the HRS uses a 2-year timeframe, and another in the NHATS only uses a single year. Past research on emotional experiences found that when a timeframe of "last week" was used, participants inferred that researchers were more interested in minor, more frequent events (i.e., minor experiences of anger), whereas when the timeframe was "last year," participants inferred that researchers were more interested in major, infrequent events (i.e., episodes of severe anger), leading to different reports of the severity and frequency of symptoms (Winkielman et al., 1998). Extrapolating to items about SCD, when presented with a longer timeframe, respondents might only endorse major changes in cognitive functioning, overlooking minor changes they would identify with a shorter timeframe. The "peak-end rule" suggests that longer timeframes yield higher rates of endorsement, as individuals will have a greater probability of experiencing a significant change over that longer period (Walentynowicz et al., 2018). Conceivably, individuals will have had a greater likelihood of cognitive decline when a longer timeframe is presented, leading them to endorse more frequent and more severe SCD as the timeframe is longer.

Current Study

This review has pointed out several reasons why obtaining estimates of the prevalence of dementia and SCD is difficult in survey studies, and potential reasons why there are disparate findings. Though calls have been made to harmonize items across studies (Rabin et al., 2015), most studies continue to use different items in their most recent waves, which will continue to lead to different estimates. To our knowledge, no previous study has undertaken a systematic

evaluation of methodological variation in dementia and SCD items across national studies and its association with prevalence estimates. Therefore, the purpose of this study is to analyze the dementia and SCD items in eight nationally representative population-based surveys. This study has two specific aims.

First, we will examine the concordance of dementia prevalence estimates for reported dementia and SCD across national studies. Based on previous research on other health conditions, we expect to find significant variability across studies. Second, we will investigate whether differences in prevalence estimates are related to differences in item terminology and timeframe. For dementia, we hypothesize that items that incorporate more broad terminology will receive higher endorsement. For SCD, we hypothesize that items with a longer timeframe will yield higher prevalence estimates.

Methods

Data Sources

We identified eight U.S.-based cross-sectional and longitudinal studies with publicly available datasets that had items related to dementia and SCD (see Table 1). In selecting studies, we followed a similar strategy to Giovanetti and Wolf (2010). Notably, studies needed to employ an observational design, probability-based sampling, and generate nationally representative estimates through weighting. To control for potential time-of-measurement effects, we analyzed data from 2013 – 2014 for most surveys, apart from the NSHAP, whose next closest wave was in 2015-2016. We reviewed each study's fieldwork documentation and questionnaires for dementia- and SCD-related items (see Measures) and extracted those with parallel content in at least one other survey. We analyzed data for all individuals age 65 and above, from both self- and proxy reports when available.

Measures

Prevalence of Reported Dementia

We defined the prevalence of dementia as indicated by an affirmative response regarding a "condition" that impacts "remembering," or through a self or proxy reported diagnosis made by a doctor (see Table 2). Several of the longitudinal studies (i.e., HRS, NHATS, NSHAP, PSID) preload data about whether a respondent reported a dementia diagnosis in a previous wave, which is then verified with the respondent. Both previous and current reporting of dementia indicated a positive case for our analysis. However, if a participant disputed a previous diagnosis, they were treated as a negative case. The HRS was the only study that contained two questions related to dementia, one asking specifically about Alzheimer's disease (AD) and one about other more global indicators of memory loss (such as "senility"). Respondents were first asked about AD, and if a positive response was given, the following question on dementia was not asked. We collapsed these items to form one variable indicating the presence of dementia to allow for overall comparisons across studies.

Prevalence of Self-Reported Subjective cognitive decline

We identified similar self-reported items within four datasets that focused on perceptions of one's own cognitive functioning over time (see Table 3). As discussed in the literature review, there was heterogeneity in SCD items, creating complications for comparisons, though we used items with the most similar content. Since there were several different approaches taken across studies, we broke items into two separate categories, those focusing on changes within memory ability over a longer period, and those focused on frequency of memory problems over a narrower period. Because response scaling options related to the severity of memory loss varied, we collapsed items. Participants who indicated that their memory changed in a negative direction

(e.g., responses including" worse") were considered to have SCD. Items related to frequency were dichotomized, with greater than normal frequency considered an endorsement of SCD (following Taylor et al., 2018).

Demographics

Age, sex, race/ethnicity, and educational level were reported in each dataset. To allow for comparability across each dataset, we grouped respondents into three age categories (65-74, 75-84, 85+). Sex was treated as a binary variable (male, female). We grouped race/ethnicity into three categories (non-Hispanic white, non-Hispanic black, and other races), and education into three levels (less than high school, high school, and some college and above).

Data Analysis

Univariate and descriptive statistics were conducted using analytic weights provided within each dataset to generate estimates for a nationally representative sample. All missing data, including responses such as "Don't know" or "Refused," were excluded from our analyses. We prepared a Complex Sample Analysis Plan and calculated prevalence estimates proportions, standard errors, and 95% confidence intervals in SPSS (Version 27.0). We then ran pairwise comparisons of each survey using a 2-tailed *z*-test, which is consistent with the method used in previous studies that have made comparisons across national surveys (Fahimi et al., 2008; Hsia et al., 2020). *Z*-test analyses were conducted in R (R Core Team, 2019). For prevalence of dementia, we assumed a null hypothesis of equality of proportion estimates across surveys and used a nominal α of 0.05 adjusted for multiple comparisons to determine statistically significant differences across surveys. For SCD, we used a one-tailed *z*-test to determine whether longer time frames were associated with significantly higher estimates.

Results

Reported Prevalence of Dementia

Table 4 shows the weighted point estimates, standard errors, absolute differences, *z*-values, and *p*-values for comparisons of self-reported dementia prevalence across studies. Overall, dementia prevalence within the seven studies ranged considerably from 2.7% - 9.9%. Absolute differences between studies range from 0.04% to 7.18% (mean absolute difference = 3.61%, *SD* = 2.23%). Differences were statistically significant across 17 of the 21 Bonferroni-corrected comparisons. Of note, the prevalence in the BRFSS and NHANES, which used the same item, were comparable ($z = 0.051$, $p = 0.959$), but significantly higher than the prevalence estimates in every other survey. Furthermore, prevalence estimates from the NHIS and NSHAP, the studies with the lowest estimates, did not differ from one another.

Table 5 displays reported dementia prevalence across demographic characteristics (age, sex, race, and education) for persons over age 65 for each study. Because of the limitations associated with conducting multiple statistical tests, we did not calculate differences across studies for these demographic characteristics, but we have included them here as reference for future investigators. Examining trends, here, too, prevalence estimates appear to vary widely, and across all studies, dementia prevalence was higher with later age and lower levels of education. Most studies showed similar trends, with higher rates in females and individuals who did not identity as white.

Reported Prevalence of SCD

Table 6 shows the weighted point estimates, standard errors, absolute differences, *z*-values, and *p*-values for comparisons of reported SCD across studies whose items referenced changes in memory ability over different times frames. Nearly half (46.56%; 95% CI = 42.11 –

51.07%) of the respondents reported SCD in the MIDUS, whose item used a 5-year time window. Nearly one-quarter (24.34%; 95% CI = 23.41 - 25.29%) reported SCD in the HRS, whose item used a 2-year time window. One-seventh (13.01%; 95% CI = 11.83% - 14.29%) reported SCD in the NHATS, with its one-year window. The largest absolute difference was between the MIDUS and the NHATS (31.23%). Consistent with our hypotheses and as evident in Table 6, one-tailed *z*-tests showed higher estimate across the longer time frames.

We further assessed two items that framed self-reported SCD in terms of frequency. On the NHANES measure that asked about SCD experiences only in the past 7 days, 5.64% (95% CI = 4.14 - 7.64%) reported frequent problems with remembering. However, on the NHATS measure that focused on the past month, 8.74% (95% CI = 7.75 – 9.85%) indicated frequent problems with memory. Consistent with our earlier findings, higher rates were evident on the item using a longer time frame, $z = 3.21$, $p < 0.001$.

Discussion

In this study, we compare prevalence rates of reported dementia and SCD across eight prominent national surveys. Prevalence estimates ranged considerably, with a range of 2.7% - 9.9% for dementia and 5.6% - 46.6% for SCD. These prevalence estimates are used for a variety of purposes in research, practice, and policy, and the range we identified across studies has important implications for how the burden of disease is considered. For example, if we extrapolate our dementia percentages based on the 2010 US census, the prevalence across studies would differ by anywhere from 1,080,040 to 3,973,580 cases. Our results point to the need for caution when utilizing survey-based prevalence estimates and the need for consumers of these estimates to be knowledgeable about their source.

Although there might be several explanations for differences across studies, we highlight notably different terminology to assess for the prevalence of dementia and SCD. Among the dementia items analyzed, some studies inquire about specific types of dementia, while others use more global terminology associated with cognition. For example, the PSID asks respondents about "permanent loss of memory or mental ability." This phrase might cover a variety of different pathologies (e.g., stroke, multiple sclerosis, autism spectrum disorder, dementia subtypes), thereby leading to a relatively high estimate because it encompasses several conditions. The BRFSS and NHANES, two of the nation's largest cross-sectional health studies, are similarly broad, with both assessing for a "physical, mental, or emotional condition" that inhibits "thinking, memory, or concentration." Again, considering this kind of broad description, other conditions such as depression or attention-deficit/hyperactivity disorder could lead to higher endorsement rates. And although similarly broad, note the difference in wording from the PSID. These premier studies also use a double-barreled question, which may lead to less valid prevalence estimates (Menold, 2020). Across all our analyses, prevalence rates were significantly higher in studies that used the most general terminology. That fact alone does not necessarily call into the question of the prevalence estimates, but it does highlight the need for readers of these prevalence estimates to pay close attention to how they were obtained.

The NHIS is another study whose question structure and branching logic could have an impact on dementia estimates. The NHIS uses a two-part structure to inquire about dementia. First, participants must affirm that they are limited on an activity of daily living, instrumental activity of daily living, or problems associated with memory. Second, only those who endorse a limitation are presented with a separate, open-ended question about the diseases or conditions that cause the limitation. Conditions associated with age-related memory loss or impairment

(such as Alzheimer's disease) are then coded by the interviewer under the umbrella term "senility." This method has the potential to overlook respondents in the early stages of a neurocognitive disorder in which function is unimpaired. The method also relies on reliable coding by the interviewer, aggregating causes into a very diffuse and technically inaccurate category (i.e., "senility"). The methodological idiosyncrasies of the NHIS argue for ample caution when comparing estimates from this study.

Our item analysis also revealed that many of the studies rely on just one item, and that one item groups many different types of dementia. This stands in contrast to the precision used to establish the prevalence of other health conditions. For example, both the BRFSS and NSHAP inquire about cancer generally and then probe for specific types. A similar method would be recommended for dementia subtypes, to learn more about the burden of these lesser common conditions.

We identified similar methodological variability regarding SCD items, which could explain similar differences in prevalence estimates. Time frames vary widely across studies, with items inquiring about experiences of cognitive impairment in the past week or over as many as the past five years. Consequently, prevalence estimates vary significantly too, from about one in 20 when thinking about only the past week, to just under half of older adults when the time frame is set at five years. As Jessen and colleagues (2014) suggest, the time frame of onset for SCD can have predictive utility for more severe cognitive decline, but only when it is kept short. Longer time frames have the potential to overestimate the burden of SCD and lack clinical utility, as only a small minority will go on to develop dementia. Moreover, response options differ as well. The severity of SCD is rated on a three-point Likert-type scale in the HRS but a five-point Likert-type scale in the MIDUS and NHATS, making comparisons unwieldy.

Another factor that could contribute to variation in prevalence estimates only became apparent as we discovered some of the arcane and obscure details regarding sampling methods across studies. Although all these studies purport to be representative of the community-based US population, in many cases individuals with cognitive impairment are excluded from taking the survey during recruitment, which could itself lead to skewed population prevalence estimates. In the NSHAP, participants were excluded if the interviewer "felt the participant had inadequate cognitive ability to complete the survey questions," (Vasilopoulos et al., 2014, p. S161) which could obviously deflate prevalence estimates. However, these sampling details are not described in study documentation (i.e., field reports, technical files) that we reviewed, but instead were revealed in a 2014 article (Vasilopoulos et al., 2014) that we uncovered after completing our analyses and exploring potential alternative reasons for this low estimate. A similar exclusion strategy is used in the BRFSS, although here again, this information is not available in the publicly available study documentation and was glossed over during a training webinar we attended. The video mentions in one sentence that interviewers are granted the latitude to terminate their telephone conversation should they feel they are obtaining "unreliable data" from someone with a suspected cognitive impairment (Taylor, 2021). Here again, we draw reader's attention to these methodological variations so that prevalence estimates can be placed into appropriate context.

In addition to the factors outlined above, we should also mention the vulnerabilities inherent in self- and proxy-reports of dementia and SCD. Self and proxy reports rely on sufficient insight to identify impairment, yet awareness may be limited, and furthermore, diagnoses of these conditions are lacking. For example, one study looking at 425 community-dwelling older adults admitted to a post-acute care unit found that nearly three-quarters (70.8%)

reached dementia diagnostic criteria but were not diagnosed (Ferretti et al., 2010). More recently, using a subsample of the NHATS, Amjad and colleagues (2018) found that 39.5% of older adults with probable dementia as determined by the study's assessment criteria did not have a diagnosis, and 19.2% had a diagnosis that they were unaware of. Self and proxy reports also rely on a willingness to disclose this information. Stigma and shame may inhibit acknowledging the presence of a dementia diagnosis or memory loss (Milne, 2010), and underdiagnosis and unawareness, especially in community samples, can also play a role (Lang et al., 2017).

Although we identified significant differences in prevalence estimates across national studies and several factors that could contribute to those differences, our own approach has its limitations as well. While we were methodical in reviewing hundreds of pages of study documentation and contacted study investigators to inquire about sampling methods, it is possible that we overlooked sampling details, and we did not get a direct response from every study group. In addition, some studies incorporate proxy reports (HRS, NHATS) but others do not, introducing another source of methodological variability. Previous research has identified discordance between respondent and proxy reports (Howland et al., 2017), though proxies may be able to provide more accurate data than individuals with more severe cognitive impairments. Lastly, estimation of prevalence within survey data is always subject to random error, and the differences we identified between surveys are similarly influenced by this potential error.

In conclusion, while calls have been made to harmonize SCD items across studies (Rabins et al., 2015), large-scale studies continue to use variable methods to ascertain reported prevalence estimates for dementia and SCD. Our study provides additional evidence of the need to establish harmonized terminology and methods. Given that dementia is highly stigmatized, underdiagnosed in some groups, loosely diagnosed in some settings, and vulnerable to reporting

bias, items that inquire about a previous dementia diagnosis may be least useful in establishing prevalence. However, if these items remain on surveys, we recommend unpacking them to learn more about specific subtypes. In addition, we recommend two dichotomous measures on significant changes within memory and thinking that may be useful for future studies. Note that we call for these to be included as separate measures, and for an end to the double-barreled approach to questioning. Lastly, we recommend that studies keep time frames short (past week, past month) to reduce retrospective bias. Harmonizing items across studies may better harness the strengths of national studies identifying the prevalence cognitive limitations and the true burden of disease.

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Tables

Table 1

Population-Based Studies, Funding Agencies, Wave Analyzed and Sample Sizes

Survey	Funding Agency	Wave Analyzed	Total *N* age 65+	Type of Respondent	Study Design Information
Behavioral Risk Factor Surveillance System (BRFSS)	Centers for Disease Control and Prevention	2014	158,990	Self	https://www.cdc.gov/brfss/annual_data/annual_2014.html
Health & Retirement Study (HRS)	National Institute on Aging	2014	10,364	9,553 Self 811 Proxy	https://hrsdata.isr.umich.edu/data-products/2014-hrs-core?_ga=2.215876631.1000590190.1613695753-1049081631.1587072158
Midlife in the United States 3 (MIDUS)	National Institute on Aging	2014	613	Self	https://www.midus.wisc.edu/midus3/index.php
National Health and Nutrition Examination Survey (NHANES)	Centers for Disease Control and Prevention	2013-2014	1,306	1,276 Self 30 Proxy	https://wwwn.cdc.gov/nchs/nhanes/continuousnhanes/default.aspx?BeginYear=2013
National Health and Aging Trends Survey (NHATS)	National Institute on Aging	2014	4,441	3,719 Self 722 Proxy	https://nhats.org/researcher/nhats/methods-documentation?id=data_collection
National Health Interview Survey (NHIS)	Centers for Disease Control and Prevention	2014	15,530	Household Interview	https://www.cdc.gov/nchs/nhis/1997-2018.htm
National Social Health and Aging Project (NSHAP)	National Opinion Research Center	2015-2016	4,377	Self	https://www.norc.org/Research/Projects/Pages/national-social-life-health-and-aging-project.aspx
Panel Study of Income Dynamics (PSID)	National Science Foundation	2013	1,697	Household Interview	https://simba.isr.umich.edu/data/data.aspx

Notes: In household interviews, a single family member from each household answers questions on all individuals living in the same home. Only the MIDUS 3 random digit dial sample used.

Table 2

Items About Dementia

Survey	Variable Name	Item
BRFSS	DECIDE	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
HRS	OC272	Has a doctor ever told you that you have Alzheimer's Disease?
	OC273	Has a doctor ever told you that you have dementia, senility or any other serious memory impairment?
NHANES	DLQ040	Because of a physical, mental, or emotional condition, {do you/does he/does she} have serious difficulty concentrating, remembering, or making decisions?
NHATS	hc4disescn9	Since the time of the last interview, has a doctor told you/SP that you/SP had dementia or Alzheimer's Disease?
NHIS	LAHCA16	What condition or health problem causes you to have difficulty with {names of up to 3 specified activities/these activities}
NSHAP	CONDITNS_83	Has a doctor ever told you that you have dementia, including Alzheimer's disease, vascular dementia, mixed dementia, or Mild Cognitive Impairment?
PSID	ER55293 ER56409	(Has a doctor or other health professional EVER told [you / [HEAD / SP/WIFE]] that [you / he / she] had …) Permanent loss of memory or loss of mental ability?

Notes: Affirmative ("Yes") responses to these items, including if the condition was previously mentioned in earlier years, indicated presence of dementia. For the NHIS item, presence of dementia was indicated through a response of "senility."

BRFSS = Behavioral Risk Factor Surveillance System; HRS = Health and Retirement Study; NHANES = National Health and Nutrition Examination Survey; NHATS = National Health and Aging Trends Survey; NHIS = National Health Interview Survey; NSHAP = National Social Health and Aging Project; PSID = Panel Study of Income Dynamics. SP = Sample Person. Head = Head of household.

Table 3

Items About SCD

Study	Variable Name	Item	Response Options
Severity Point of Reference			
HRS	D102	Compared to [[Previous Month], two years ago], would you say your/SP's memory is better now, about the same, or worse now than it was then?	1. Better 2. Same **3. Worse**
MIDUS	C1SA6E	Compared to five years ago, how would you rate yourself today on	1. Improved a lot 2. Improved a little 3. Stayed the same **4. Gotten a little worse** **5. Gotten a lot worse**
NHATS	cg4memcom1yr	Compared to 1 year ago, would you say your memory is much better now, better now, about the same, worse now, or much worse now than it was then?	1. Much better 2. Better 3. Same **4. Worse** **5. Much worse**
Frequency Point of Reference			
NHANES	MCQ380	Over the past 7 days, how often have you/they? had trouble remembering where you/they put things, like your/their keys or your/their wallet?	1. Never 2. About once **3.** Two or three times **4. Nearly every day** **5. Several times a day**
NHATS	cg4ofmemprob	In the last month, how often did memory problems interfere with your daily activities? Would you say every day, most days, some days, rarely, or never?	1. **Every day (7 days a week)** 2. **Most days (5-6 days a week)** 3. Somedays (2-4 days a week) 4. Rarely (once a week or less) 5. Never

Notes: HRS = Health and Retirement Study; MIDUS = Midlife in the United States Study; NHATS = National Health and Aging Trends Survey; NHANES = National Health and Nutrition Examination Survey. SP = Sample person.

Table 4

Pairwise Comparisons of Proportions of Older Adults with Reported Dementia

Study	BRFSS % (SE)	NHANES % (SE)	NHATS % (SE)	PSID % (SE)	HRS % (SE)	NSHAP % (SE)	NHIS % (SE)
	9.86 (0.17)	9.82 (0.67)	7.27 (0.42)	6.30 (0.74)	4.10 (0.20)	3.26 (0.48)	2.68 (0.15)
NHANES	0.035 0.051 0.959						
NHATS	2.592 5.734 **<0.001**	2.556 3.229 **0.001**					
PSID	3.554 4.665 **<0.001**	3.518 3.513 **<0.001**	0.962 1.127 0.260				
HRS	5.762 21.984 **<0.001**	5.726 8.169 **<0.001**	3.170 6.808 **<0.001**	2.208 2.868 **0.004**			
NSHAP	6.695 13.014 **<0.001**	6.559 7.958 **<0.001**	4.002 6.291 **<0.001**	3.041 3.442 **<0.001**	0.833 1.606 0.108		
NHIS	7.174 31.496 **<0.001**	7.139 10.363 **<0.001**	4.582 10.248 **<0.001**	3.620 4.771 **<0.001**	1.413 5.567 **<0.001**	0.579 1.153 0.249	

Notes: Table figures are rounded to the thousandths place; calculations were not rounded. In order from top to bottom, each cell contains absolute difference, *z*-value, and *p*-value. Bonferroni-corrected significant pairwise differences are indicated with bold text. BRFSS = Behavioral Risk Factor Surveillance System; NHANES = National Health and Nutrition Examination Survey; NHATS = National Health and Aging Trends Survey; PSID = Panel Study of Income Dynamics; HRS = Health and Retirement Study; NSHAP = National Social Health and Aging Project; NHIS = National Health Interview Survey. SE = Standard error.

Table 5

Proportion of Older Adults with Reported Dementia Across Studies

Demographic Variable	BRFSS % (95% CI)	NHANES % (95% CI)	NHATS % (95% CI)	PSID % (95% CI)	HRS % (95% CI)	NSHAP % (95% CI)	NHIS % (95% CI)
Overall	9.9 (9.5, 10.2)	9.8 (8.5, 11.3)	7.3 (6.5, 8.2)	6.3 (5.0, 8.0)	4.1 (3.7, 4.5)	3.3 (2.4, 4.4)	2.7 (2.4, 3.0)
Age 65-74	9.1 (8.7, 9.6)	8.2 (6.6, 10.2)	2.2 (1.6, 3.0)	2.7 (1.6, 4.5)	1.7 (1.4, 2.2)	2.1 (1.3, 3.4)	0.9 (0.6, 1.1)
Age 75-84	10.8 (10.3, 11.4)	12.3 (10.0, 15.0)	7.6 (6.3, 9.1)	5.8 (3.9, 8.5)	5.2 (4.5, 6.0)	4.1 (2.4, 6.9)	3.7 (3.1, 4.5)
Age 85+	NA[a]	NA[a]	18.1 (15.6, 20.9)	22.2 (16.8, 28.6)	12.7 (11.0, 14.6)	8.6 (5.5, 13.3)	8.9 (7.4, 10.7)
Sex							
Male	9.2 (8.8, 9.7)	7.9 (5.5, 11.4)	6.6 (5.5, 7.8)	4.8 (3.5, 6.6)	4.2 (3.7, 4.7)	3.4 (2.1, 5.3)	2.6 (2.1, 3.1)
Female	10.4 (9.9, 10.8)	11.3 (9.5, 13.4)	7.8 (6.8, 9.0)	7.5 (5.6, 10.0)	4.0 (3.5, 4.6)	3.2 (2.2, 4.6)	2.8 (2.4, 3.2)
Race							
White	8.7 (8.4, 8.9)	9.4 (8.0, 11.1)	7.0 (6.1, 8.0)	6.2 (4.8, 8.0)	3.8 (3.4, 4.3)	3.4 (2.5, 4.7)	2.5 (2.2, 2.9)
Black	13.7 (12.4, 15.1)	8.6 (5.3, 13.7)	8.6 (6.9, 10.8)	7.4 (4.4, 12.3)	6.6 (5.1, 8.5)	3.0 (1.4, 6.0)	4.0 (3.1, 5.1)
Other	14.1 (12.5, 15.9)	13.0 (11.2, 15.1)	8.3 (5.8, 11.7)	NA[b]	4.6 (2.7, 7.8)	2.1 (1.0, 4.5)	3.4 (2.3, 5.1)
Education							
Less than HS	18.8 (17.6, 20.1)	15.9 (10.2, 23.9)	12.2 (10.2, 14.6)	10.5 (6.5, 16.4)	6.7 (5.6, 8.0)	4.2 (2.2, 7.6)	4.7 (3.8, 5.7)
HS	10.0 (9.5, 10.5)	9.5 (6.4, 14.0)	7.3 (5.9, 8.9)	7.4 (5.1, 10.7)	3.9 (3.1, 4.8)	2.4 (1.2, 4.8)	2.6 (2.2, 3.1)
College	6.9 (6.5, 7.3)	7.9 (6.1, 10.1)	5.2 (4.2, 6.5)	4.5 (3.2, 6.5)	3.2 (2.9, 3.7)	3.4 (2.5, 4.7)	1.9 (1.6, 2.3)

Notes: Percentages and confidence intervals are weighted.

BRFSS = Behavioral Risk Factor Surveillance System; NHANES = National Health and Nutrition Examination Survey; NHATS = National Health and Aging Trends Survey; PSID = Panel Study of Income Dynamics; HRS = Health and Retirement Study; NSHAP = National Social Health and Aging Project; NHIS = National Health Interview Survey. HS = High school. CI = Confidence Intervals.

[a] Data on ages above 80 are not publicly available for BRFSS or NHANES; for those surveys this category represented age 75 + years.

[b] Due to small sample size of "Other" in PSID, this category represents individuals who do not identify as white.

Table 6

Pairwise Comparisons of Proportions of Older Adults with Reported SCD

Study	**MIDUS** **% (SE)**	**HRS** **% (SE)**	**NHATS** **% (SE)**
	46.56 (2.29)	24.34 (0.47)	13.01 (0.61)
HRS	22.219 9.51 **<0.001**		
NHATS	33.549 14.159 **<0.001**	11.330 14.646 **<0.001**	

Notes: Table figures are rounded to the thousandths place; calculations were not rounded. In order from top to bottom, each cell contains absolute difference, *z*-value, and *p*-value. Bonferroni-corrected significant pairwise differences are indicated with bold text. MIDUS = Midlife in the United States Study; HRS = Health and Retirement Survey; NHATS = National Health and Aging Trends Survey. SE = Standard Error.