

PERSPECTIVE

Population measures of subjective cognitive decline: A means of advancing public health policy to address cognitive health

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Abstract

Subjective cognitive decline (SCD) is receiving increasing attention as studies have suggested that SCD status is associated with risk of future cognitive decline and dementia. Population-based measures of SCD can be extremely useful to the public health community, health-care providers, researchers, and policymakers. A large population-based SCD measure now exists through the state-based Behavioral Risk Factor Surveillance System (BRFSS). All 50 states have included the cognitive decline module, which asks about SCD, to their BRFSS survey one or more times. Population measures of SCD can aid researchers in designing clinical studies by better estimating the populations that may be at risk for more severe cognitive decline based on their SCD status to ensure that the optimal groups are targeted. Population-level estimates of SCD can also help to inform health-care providers' decisions about initiating cognitive assessments, managing other conditions among those with memory problems, and identifying the needs of caregivers.

KEYWORDS

Alzheimer's disease, chronic conditions, cognitive assessments, comorbidities, dementia, population health, public health, survey data

1 | INTRODUCTION

Alzheimer's disease (AD) and other types of dementia do not easily lend themselves to population-based measures and prevalence estimates can be complicated to model accurately.^{1,2} Underdiagnosis of dementia is common, and even among those diagnosed, only about half of persons living with dementia or their caregivers have had the diagnosis disclosed to them.³ Subjective cognitive decline (SCD)—the self-reported worsening of cognitive performance or increasing difficulties with memory and thinking—can be easily measured at a population level and thus provides an alternative option for estimating the extent and burden of cognitive issues in the population as a whole.

SCD is receiving increasing attention from researchers as studies have suggested that SCD is associated with increased risk of future

cognitive decline and dementia.^{4–12} Due to this association between SCD and future risk for dementia, population-based measures of SCD can be extremely useful to the public health community, health planners, and policymakers in planning efforts. Although the presence or absence of SCD alone cannot definitively determine whether someone will go on to develop dementia, it can serve as a good starting point for clinicians, policymakers, and others in prioritization and planning efforts. It can be an important tool for researchers in the course of conducting individual clinical studies; estimating the populations that are at increased or reduced risk for more severe cognitive decline and dementia based on their SCD status can help guide future interventions, study designs, and enrollment in studies to ensure that the optimal groups are targeted. Population-level estimates of SCD can also potentially help to inform health-care providers' decisions about

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initiating cognitive assessments, managing other conditions among those with memory problems, and better identifying the needs of caregivers. In the United States, a population-based SCD measure now exists through the state-based Behavioral Risk Factor Surveillance System (BRFSS), and the data are freely available to researchers for analysis annually.

2 | HISTORY OF THE BRFSS

The BRFSS, begun in 1984, is the largest continuously conducted telephone health survey in the world and is one of the primary sources of public health data in the United States. The BRFSS is conducted annually in all 50 states, the District of Columbia, and US territories with financial and technical support from the Centers for Disease Control and Prevention (CDC). Each state sample collected is weighted at the state level. Measures contained in the BRFSS assess, on a population level, a variety of health-related topics including diet, physical activity, health-care access, preventive health practices, and specific health conditions.¹³ In 2018, the BRFSS collected information from a representative sample of > 400,000 community-dwelling adults aged 18 years and older. The BRFSS is a cross-sectional random-digit-dialed telephone survey and is not inherently linked to other information such as medical records and is dependent upon self-report.¹⁴

On an annual basis, BRFSS includes a set of core questions that are asked in all states. These core questions cover a wide range of health behaviors such as exercise habits, tobacco use, and cancer screening.¹⁴ In addition to the core questions, states may choose to include optional modules or other questions of their own design. One of the optional modules is a set of six questions on SCD, called the cognitive decline module.

3 | THE COGNITIVE DECLINE MODULE

3.1 | Development and use of the module

The cognitive decline module was developed in 2007 following recommendations from a national panel of experts that cognitive impairment be addressed as a public health issue.¹⁵ A literature review identified the need for examining issues related to early diagnosis and care-seeking behavior as well as a better understanding among the public about the impact of cognitive impairment. The review also emphasized the importance of determining any disparities that may exist among diverse social and cultural groups.¹⁶

To develop a set of possible questions for the module, a panel of subject matter experts reviewed questions used on other surveys and adapted existing questions. After four rounds of cognitive testing—a method of testing the questions in focus groups—and field testing in California's BRFSS survey in 2008, the module was finalized. The cognitive decline module was initially administered to all adults aged 18 years and older but was limited beginning in 2015 to include only adults aged 45 years and older.¹⁷

RESEARCH IN CONTEXT

1. **Systematic review:** The authors reviewed the literature using traditional (e.g., PubMed, Ovid, Medline, etc.) sources and cited webpages or DOIs as relevant. There is a strong connection between subjective cognitive decline (SCD) and future dementia but few sources on the usefulness of population-level data on SCD.
2. **Interpretation:** Our article defines the availability of population-level data on SCD, its importance, and its relevance to researchers and others.
3. **Future directions:** The article proposes how population-level data on SCD can be useful to health-care providers, policymakers, and public health professionals in identifying future risk for dementia, planning, and identifying disparities among populations in cognitive decline.

Although the module originally consisted of ten questions, it was shortened to six questions in 2015 based on panel feedback and the experience of the module's use between 2011 and 2013. In the six-question cognitive decline module (see Table 1), participants are asked whether, during the previous 12 months, they have “experienced confusion or memory loss that is happening more often or getting worse.” Those answering in the affirmative are classified as having SCD and are then asked four follow-up questions regarding any difficulties they may have in day-to-day household activities or social activities and whether help is available for these difficulties. The final question of the module asks whether the respondent or anyone else has discussed this increasing confusion or memory loss with a health-care professional.¹⁴

The cognitive decline module—originally named the cognitive impairment module—was first used in 2010 in five states (California, Florida, Iowa, Louisiana, and Mississippi) as a pilot. After that, from 2011 to 2013, 47 states and territories added the 10-question optional module to their state surveys at least once. During 2015 and 2016, 49 states, the District of Columbia, and Puerto Rico added the six-question version of the module. By 2018, all 50 states had used the module at least once.¹⁷

3.2 | Results

The CDC's Alzheimer's Disease and Healthy Aging Program aggregated data across all states that used the module between 2015 and 2017. This included responses on the cognitive decline optional module from 23,483 persons aged 45 years and older. For states using the module in multiple years, the most recent data for those states were used. The data show that 11.1% of people aged 45 and older in the United States reported SCD and more than half of them (54.7%) had not talked to a health-care professional about it.¹⁸⁻²⁰ This and other data are available to the public on the CDC website through the Alzheimer's

TABLE 1 Behavioral Risk Factor Surveillance System (BRFSS) cognitive decline module¹⁴

Question	Response	
1. During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?	1 Yes 2 No [ends module] 7 Don't know 9 Refused [ends module]	
1. During the past 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills?	1 Always 2 Usually 3 Sometimes 4 Rarely	5 Never 7 Don't know 9 Refused
1. As a result of confusion or memory loss, how often do you need assistance with these day-to-day activities?	1 Always 2 Usually 3 Sometimes 4 Rarely [skip to Q5]	5 Never [skip to Q5] 7 Don't know 9 Refused
1. When you need help with these day-to-day activities, how often are you able to get the help that you need?	1 Always 2 Usually 3 Sometimes 4 Rarely	5 Never 7 Don't know 9 Refused
1. During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home?	1 Always 2 Usually 3 Sometimes 4 Rarely	5 Never 7 Don't know 9 Refused
1. Have you or anyone else discussed your confusion or memory loss with a health-care professional?	1 Always 2 Usually 3 Sometimes 4 Rarely	5 Never 7 Don't know 9 Refused

Disease and Healthy Aging Data Portal (<https://www.cdc.gov/aging/agingdata/index.html>), which is updated annually with newly released data.¹⁷

From 2011 to 2014, the National Health and Nutrition Examination Survey (NHANES), which combines household interviews and direct health examinations, used the BRFSS SCD question alongside a series of objective cognitive assessments.¹² These assessments included the Consortium to Establish a Registry for Alzheimer's Disease Word List (CERAD-WL) and Delayed-Recall tasks (CERAD-DR), the Animal Fluency test (AF), and the Digit Symbol Substitution Test (DSST).¹² Compared to those who did not report symptoms of SCD, adults who answered "yes" to the SCD question had lower mean scores and were more likely to score in the lowest 25th percentile on the objective cognitive performance tests.¹² However, the SCD question yielded fairly low sensitivity, as only about one in four respondents who reported SCD scored in the lowest 25th percentile on the objective measures. Alternatively, respondents who did not report SCD were highly unlikely to have low scores on these objective tests of cognition, indicating a high level of specificity.¹² These results linking responses to the SCD question to objective cognitive assessments help to underscore both the validity and some limitations of using SCD as a population-based measure for estimating poor cognitive performance and potentially future cognitive impairment or dementia. It is also important to note that while the BRFSS optional cognitive decline module includes participants aged 45 years and older, the NHANES sample was limited to participants aged 60 years and older.^{12,14}

3.3 | Availability for further research

The raw data from the BRFSS cognitive decline module are available on the CDC website (https://www.cdc.gov/brfss/annual_data/annual_data.htm) to allow researchers to further examine the SCD variables and their relationship to other relevant data contained within the BRFSS.¹⁷ A prime example is the relationship between formal education levels and the prevalence of SCD. An analysis of the 2015–2017 data found a higher prevalence of SCD and related functional limitations in persons with less formal education.^{18,20} These results are consistent with a large body of evidence suggesting that fewer years of formal education is associated with cognitive decline and an increased risk for dementia.^{12,21}

The data can also be analyzed to elucidate other significant associations that may exist with SCD. Because of the breadth of other data available through the BRFSS, researchers can, for example, examine the prevalence of other comorbid chronic conditions; describe possible racial/ethnic and sex disparities; and identify the presence of possible risk factors such as physical inactivity, obesity, and smoking for use in cross-sectional analyses.

3.4 | Limitations

The BRFSS and most other population-based measures of SCD are conducted cross-sectionally and it is therefore impossible to

determine whether the individuals in those surveys who reported SCD symptoms went on later to have mild cognitive impairment, AD, or another type of dementia or neurocognitive disorder.^{8,22} Despite this, there is some evidence that even one or intermittent instances of self-reported memory complaints can be predictive of future cognitive impairment and dementia.²² The cross-sectional nature of these studies also means that researchers cannot ascertain whether and how respondents' answers truly reflect changes in cognition over time.¹²

Subjective measures of memory loss are limited in their predictive value for developing future severe cognitive impairment and dementia.^{4,6,7} SCD can be one of the earliest signs of dementia but less than half of those who report symptoms eventually develop severe cognitive impairment and dementia.^{4,6,7} Moreover, although subjective memory complaints like SCD may appear early in the disease trajectory for the most common dementia types like AD, this is not always true for other types of dementia or for mixed types of dementia. SCD symptoms could appear differently between various types of dementia.^{6,23} Positive predictive value may also decrease in younger respondents, such as those ages 45 to 59 compared to those 60 years and older.^{4,22} But, given the trajectory of certain types of dementia, successful interventions, trial enrollment, and planning may require detection of SCD at younger ages.^{24–26}

Finally, the initial SCD question in the BRFSS optional cognitive decline module is fairly broad and like many other population-based measures of SCD can impart ambiguity.⁸ This may require additional follow-up questions to supplement the first question to improve predictive value. However, the BRFSS is a very long and expensive survey to administer and adding more questions is not always feasible or practical for states. Fortunately, combining results from the first question of the cognitive decline module with results from other questions in the module or the rest of the BRFSS has the potential to increase its usefulness.^{5,8}

4 | THE SIGNIFICANCE OF THE COGNITIVE DECLINE MODULE

4.1 | Policy implications

SCD is one of the earliest potential indicators of future AD or other dementia.⁵ Although the majority of people with SCD do not go on to develop dementia, many do.^{5–7} The subjective report of memory problems from the BRFSS, the first question in the module, can help to identify population-level estimates of memory problems for which formal assessments or diagnoses have not been given. Such estimates have the greatest impact when they are used to drive policy and systems change.

For public health officials, particularly given the difficulty in obtaining comprehensive population-level data on dementia itself, the BRFSS cognitive module data provide a basis for planning, preparing for, and developing public health programs to address the challenges associated with cognitive decline. For example, if the data show a large number of people with SCD live alone, public health officials could initiate tailored programs to help with household activities. If SCD is more

prevalent in certain racial and ethnic communities, public health agencies could develop culturally appropriate cognitive health materials better directed at those diverse communities. These campaigns could ensure that communities are aware of risk factors of cognitive decline and are encouraged to seek out a health-care professional to assist with a formal cognitive assessment.

To stimulate action by public health officials and policymakers, the CDC has produced materials to inform states and other stakeholders about populations experiencing SCD. For example, as part of a funded cooperative agreement with the Alzheimer's Association, the CDC has produced national and state-specific infographics (<https://www.cdc.gov/aging/data/index.htm>).¹⁷ There are also racial- and ethnic-specific infographics on SCD that explore prevalence among African American, American Indian/Alaska Native, and Hispanic populations. The national and Hispanic-specific infographics have been translated into Spanish for use among Spanish-speaking readers. Also using data from BRFSS, CDC and the National Association of Chronic Disease Directors have produced topic-specific data briefs (<https://www.cdc.gov/aging/publications/briefs.htm>) focusing on public health issues related to older adults, including SCD. These analyses provide a more in-depth exploration of responses to other questions in the BRFSS—such as those related to heart disease and other comorbid chronic conditions—and their prevalence among those who did and did not report SCD.^{19,27}

Knowing the prevalence of SCD, public health officials and policymakers could begin to assess future capacity of long-term care and home- and community-based services infrastructure. Additionally, by identifying trends in groups who do not report SCD, certain lifestyle, protective factors, or risk-reduction strategies might be gleaned through the associations among responses to the SCD question and demographic, educational attainment, health status, and other relevant data contained within the BRFSS.

The cognitive module's final question regarding whether a person has discussed his or her worsening memory difficulties with a health-care professional is unique from many previous clinical studies on SCD. Other approaches to SCD have used, as a study population, adults who already have taken the initiative to appear at a memory clinic, a center that specializes in memory tests and evaluations. The cognitive decline module can pinpoint more accurately the extent of the problem in the population by including people who have been experiencing increased memory problems but have not sought out care. The module can be helpful in identifying how widespread the failure to talk to a health-care professional is, and thus guide the public health response to promoting the benefits of such communications and encouraging early detection and diagnosis.

4.2 | Health-care provider implications

Population-level data and trends can provide valuable information for health-care professionals. As an example, primary care physicians could use data on the prevalence of SCD among a specific subpopulation or age group to inform and guide the care they provide to those patients. Similarly, data about SCD and comorbid chronic conditions

could help providers identify which patients they should talk to about possible memory problems and when to provide cognitive assessments and subsequent referral to resources. Given the high specificity of “no” responses to the SCD question, providers may be able to better prioritize limited resources and efficiently rule out patients who may be at lower risk for more severe cognitive impairment and dementia.

Moreover, it is critical that persons experiencing memory loss discuss their symptoms with a health-care provider and that providers account for their patients’ subjective complaints. Sometimes these symptoms result in functional limitations and may impair one’s ability to perform routine activities like cooking, cleaning, or taking medications and/or to work, volunteer, or engage in social activities outside the home. Although there is currently no cure for AD, patients often present with other treatable conditions such as delirium or bleeding in the brain for which there are similar memory loss symptoms. Even for those with non-treatable forms of dementia, discussing any confusion or memory concerns with a health-care professional can improve their chances of an early diagnosis, which allows for the development of a plan regarding safety issues, long-term care, medication and comorbid chronic disease management, caregiving, and advance care planning.²⁰

4.3 | Clinical research implications

Population-level data on SCD can also help inform those engaged in clinical research on SCD. It is often important for clinical researchers to understand the broader population context in which they are conducting their studies to determine aspects such as the relevant special populations, scalability, and generalizability of any findings. For researchers engaged in clinical research on SCD, population-level data can be beneficial in describing trends over time, the different symptoms that might be associated with SCD, including functional limitations and other comorbid chronic conditions, and how people in different subgroups (e.g., age, socioeconomic status, education level) respond. For example, although the presence of SCD alone may have limited predictive value for future dementia, combined with responses from other questions in the cognitive decline module the value can increase. Some evidence suggests that those with both SCD symptoms and associated function limitations are at increased risk for dementia compared to those with SCD without functional limitations.^{9,28} Researchers can then make design decisions about their own studies and study populations to determine the extent to which their samples can be generalized. In the absence of population data over time, SCD researchers have been trying to gather this information by attempting to harmonize multiple SCD cohort studies.

5 | FUTURE CONSIDERATIONS

To be of long-term use to the public health community and to policymakers, data on SCD should continue to be collected both for point-in-time purposes and to observe trends over time. The US Congress recognized the importance of this data collection and analysis by

including it in the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act (Public Law 115-406), an initiative designed to increase the public health response to the AD crisis.²⁹ However, funding for this initiative is subject to the annual congressional appropriations process. States, for their part, can continue to collect data on SCD in the BRFSS survey, as outlined in CDC’s Healthy Brain Initiative *State and Local Public Health Partnerships to Address Dementia: The 2018–2023 Road Map*.³⁰

Using SCD data to drive public health action could be advanced through the federal government’s Healthy People program—a national effort to set measurable health-related goals and objectives each decade. Healthy People 2030 includes a new objective of increasing the proportion of adults with SCD who discuss their confusion or memory loss with a health-care professional (<https://health.gov/healthypeople/objectives-and-data/browse-objectives/dementias/increase-proportion-adults-subjective-cognitive-decline-who-have-discussed-their-symptoms-provider-dia-03>).³ The objective aims to increase the proportion of persons with SCD who have discussed their symptoms with a provider by five percentage points over the next decade.³ Healthy People has become a vital framework for prioritizing health issues in the United States, and it serves as a guiding document for budgetary and programmatic decisions of health agencies at all levels of government. Inclusion of this goal in Healthy People 2030 encourages states both to engage in public health activities and interventions addressing the issue and to collect SCD data measuring progress toward the goal.

Finally, the BRFSS cognitive decline module could serve as a model for other nations. Other surveys primarily conducted in the United States have been used as a model and expanded to other nations. For example, the Harmonized Cognitive Assessment Protocol (HCAP) Project was developed as part of the Health and Retirement Study (HRS) and has been used as the basis for similarly modeled studies in other nations such as Mexico, India, England, China, and South Africa to estimate the prevalence of cognitive impairment and dementia.³¹ The difficulty of gathering population-level data on the prevalence of AD and other dementias is not unique to the United States. But, as the United States is now beginning to demonstrate, SCD is a viable alternative for informing public health and policy decision-making on cognitive health issues. It could serve the same function in nations around the world.

6 | CONCLUSION

With evidence continuing to affirm the relationship between SCD and risk of future cognitive decline and dementia, SCD is receiving increased attention at both the clinical and population levels. As clinical research and health practice increasingly focus on early memory problems and SCD, the need for population-level data is becoming more important. The BRFSS is collecting such data in all U. states and territories, and these data are publicly available for analysis and creation of public health data products. The public health community and policymakers can use these data and products as a planning and programmatic indicator for community-level action, and can improve their

efforts by making data-driven decisions. For researchers and providers, these population-level data can help guide and tailor their efforts. As states continue to collect this data and researchers continue to analyze it, public health professionals, providers, and policymakers can all be better informed and prepared for the challenges associated with cognitive decline.

CONFLICTS OF INTEREST

The authors report no conflicts of interest.

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