Unmet Needs for Assistance related to Subjective Cognitive Decline among Community-Dwelling Middle-Aged and Older Adults in the US: Prevalence and Impact on Health-Related Quality of Life

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Abstract

Objectives—To estimate the prevalence of unmet needs for assistance among middle-aged and older adults with subjective cognitive decline (SCD) in the US and to evaluate whether unmet needs were associated with health-related quality of life (HRQOL).

Design—Cross-sectional study

Setting—United States – 50 states, District of Columbia, and Puerto Rico

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Participants—Community-dwelling adults aged 45 years and older who completed the Cognitive Decline module on the 2015–2018 Behavioral Risk Factor Surveillance System, reported experiencing SCD, and always, usually, or sometimes needed assistance with day-to-day activities because of SCD.

Measurements—We defined SCD as confusion or memory loss that was happening more often or getting worse over the past 12 months. Respondents with SCD were considered to have an unmet need for assistance if they sometimes, rarely, or never got the help they needed with day-to-day activities. We measured three domains of HRQOL: (1) mental (frequent mental distress, 14 days of poor mental health in the past 30 days), (2) physical (frequent physical distress, 14 days of poor physical health in the past 30 days), and (3) social (SCD always, usually, or sometimes interfered with the ability to work, volunteer, or engage in social activities outside the home). We used log-binomial regression models to estimate prevalence ratios (PR). All estimates were weighted.

Results—40.4% of people who needed SCD-related assistance reported an unmet need. Among respondents without depression, an unmet need was associated with a higher prevalence of frequent mental distress (PR=1.60, 95%CI:1.15–2.23, p=0.005). Frequent physical distress and social limitations did not differ between people with met and unmet needs.

Conclusions—Middle-aged and older adults with SCD-related needs for assistance frequently did not have those needs met, which could negatively impact their mental health. Interventions to identify and meet the unmet needs among people with SCD may improve HRQOL.

Introduction

More than 16 million people in the United States live with cognitive impairment,(Family Caregiver Alliance, 2001) and many need assistance with daily activities.(Alzheimer's Association, 2019) Cognitive decline occurs on a continuum from minor changes in thinking or remembering that do not impact a person's daily life to severe declines that cause impairments in communication, daily activities, and memory.(Jessen *et al.*, 2014) Subjective cognitive decline (SCD) is one measure of cognitive function that relies on the individual's assessment of his or her own memory.(Jessen *et al.*, 2014; Rabin *et al.*, 2015) SCD may indicate a disease process or the beginning of a trajectory that culminates in cognitive decline or dementia,(Dufouil, Fuhrer and Alpérovitch, 2005; Mitchell *et al.*, 2014) or it may reflect a person's mood or depressive symptoms rather than — or in addition to — changes in cognitive function.(Hohman, Beason-Held and Resnick, 2011; Yates *et al.*, 2017; Zlatar *et al.*, 2018) Regardless, SCD has been related to a variety of poor health outcomes including falls(Al-Sari *et al.*, 2017), frailty,(Hsieh *et al.*, 2018; Gifford *et al.*, 2019) chronic health conditions,(Taylor *et al.*, 2020) and sleep.(Bubbico *et al.*, 2019) Therefore, SCD may be an important indicator of population health in public health surveillance systems where it may not be feasible to conduct lengthy cognitive assessment batteries or clinical examinations/imaging to evaluate cognitive function.(Jessen *et al.*, 2014)

People who experience functional impairments or activity limitations in cognitive domains may need support or assistance from others in order to carry out daily activities.(DeFries *et al.*, 2009; Heller, Scott and Janicki, 2018; Alzheimer's Association, 2019) Most of the support for people with cognitive impairment living in the community is provided by family, friends, and neighbors, who are called informal caregivers.(Alzheimer's Association, 2019) These informal caregivers are often critical to enabling people with cognitive impairment to participate in their communities.(World Health Organization, 2002; Talley and Crews, 2007; Alzheimer's Association, 2019) Having unmet needs for care is associated with institutionalization, poor health, and lower quality of life in people with dementia.(Gaugler *et al.*, 2005; Black *et al.*, 2012)

Health-related quality of life (HRQOL), a sub-domain of quality of life, is "an individual's or group's perceived physical and mental health over time." (Centers for Disease Control and Prevention, 2000)[, p.8] It is a useful indicator of both individual and population health: HRQOL is associated with both morbidity and mortality, and it can be used to indicate what services or programs a community needs.(Centers for Disease Control and Prevention, 2000) Substantial evidence exists to suggest that people with SCD experience reduced quality of life,(Pusswald *et al.*, 2015; Hill *et al.*, 2017; Roehr *et al.*, 2017) including in domains related to mental health, physical functioning, and social functioning.(Hill *et al.*, 2017) These negative HRQOL impacts may result from SCD's interference with a person's ability to perform activities of daily living (ADLs; e.g., eating, dressing, or bathing)(Montejo *et al.*, 2012) and/or their social disengagement(Rotenberg, Maeir and Dawson, 2019) or isolation. Given that previous studies of older adults demonstrate that unmet needs for care often result in adverse consequences like limited mobility within or outside the home, going without getting dressed, and having to stay in wet or soiled clothes,(Beach *et al.*, 2020) we expected that unmet needs related to SCD would be associated with HRQOL.

Previous studies evaluated the prevalence and correlates of unmet needs for care among community-dwelling older adults with dementia diagnoses.(Gaugler *et al.*, 2005; Black *et al.*, 2013, 2019; Vaingankar *et al.*, 2013; Hughes *et al.*, 2014; Tapia Muñoz *et al.*, 2019; Zwingmann *et al.*, 2019; Beach *et al.*, 2020) However, less is known about the needs for assistance among community-dwelling middle-aged and older adults who experience early signs of cognitive decline, namely SCD. The objectives of this study were to estimate the prevalence of unmet needs for assistance among middle-aged and older community-dwelling adults with subjective cognitive decline in the US, to identify characteristics associated with having an unmet need for assistance, and to evaluate whether having an unmet need for assistance was associated with poorer HRQOL in mental, physical, and social domains. We hypothesized that unmet needs for SCD-related assistance would be associated with a HRQOL in all three domains.

Methods

Data Source

Data for this study came from the Behavioral Risk Factor Surveillance System (BRFSS), a state-based telephone survey of non-institutionalized (community-dwelling) adults aged 18 years and older living in the United States and its territories. The BRFSS is designed

to assess health status and health behaviors along with additional topics of public health importance.(Mokdad, 2009) Data are weighted to represent the adult population on the basis of age, sex, race/ethnicity, home ownership, and geographic region.(Centers for Disease Control and Prevention, 2013) All responses are self-reported.

We included data from 50 states, District of Columbia, and Puerto Rico that administered the Cognitive Decline module at least once as part of their BRFSS between 2015 and 2018. If a state/territory used the module in more than one year, we included only the most recent year of data. The Cognitive Decline module is an optional module designed to measure the prevalence of SCD among adults aged 45 years and older and to assess the impact of cognitive decline on their life and activities.

Subjective Cognitive Decline & Unmet Needs for Assistance

Because our aim was to evaluate the prevalence and impact of unmet needs related to SCD, we focused on people who experienced SCD and needed assistance with daily activities as a result of SCD. The Cognitive Decline module is introduced to respondents as follows:

> The next few questions ask about difficulties in thinking or remembering that can make a big difference in everyday activities. This does not refer to occasionally forgetting your keys or the name of someone you recently met, which is normal. This refers to confusion or memory loss that is happening more often or getting worse, such as forgetting how to do things you've always done or forgetting things that you would normally know. We want to know how these difficulties impact you.

The first question in the module screens for the presence of cognitive decline: "During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?" We classified respondents who said "yes" as experiencing SCD. These respondents were then asked the remaining questions in the module. Respondents who said "no" to the first module question were classified as not having SCD. Respondents who did not know if they had experienced the symptoms were excluded from the analysis.

We used two questions in the module to classify people as having met or unmet needs for assistance related to SCD. These questions ask about day-to-day household activities or chores, which are described as activities such as cooking, cleaning, taking medications, driving, or paying bills.

1. As a result of confusion or memory loss, how often do you need assistance with these day-to-day activities?

2. When you need help with these day-to-day activities, how often are you able to get the help that you need?

Response options for both questions were always, usually, sometimes, rarely, and never. The second question is only asked if respondents said always, usually, or sometimes to the first question; therefore, we classified respondents who said they always, usually, or sometimes needed assistance with day-to-day activities as needing SCD-related assistance. We classified respondents who said they always or usually got the help they needed as having their assistance needs met, while we considered respondents who needed SCD-

related assistance but reported they sometimes, rarely, or never got this help as having unmet needs for assistance.

Health-Related Quality of Life

The BRFSS includes four questions about HRQOL.(Centers for Disease Control and Prevention, 2000; *Healthy Days Core Module: HRQOL-14 Measure | HRQOL | CDC*, 2018) These measures were developed by the Centers for Disease Control and Prevention in collaboration with state and local public health agencies, academic researchers, and survey researchers, and subsequently validated against other measures including the Medical Outcomes Study Short Form 36 and 12 (SF-36 and SF-12).(Newschaffer, Jackson-Thompson and Counte, 1998) The HRQOL questions have been included in the BRFSS every year since 1993.(Centers for Disease Control and Prevention, 2000) We used two of these standard items to assess the mental health and physical health aspects of HRQOL. These questions are described below. In addition, the Cognitive Decline module includes one item about SCD interfering with the respondent's ability to engage socially. We used this item as a measure of HRQOL related to social functioning.

Mental Health: Frequent Mental Distress—Frequent mental distress is defined in our study as experiencing 14 days or more of poor mental health in the past 30 days using the question: "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?"(BRFSS Coordinators, 1998; Centers for Disease Control and Prevention, 2000) This 14-day cut-point was selected when the BRFSS HRQOL measures were developed because it was used as a marker for clinical depression and anxiety disorders.(BRFSS Coordinators, 1998) It has since been used by CDC for tracking population health.(BRFSS Coordinators, 1998; Zhao *et al.*, 2018)

Physical Health: Frequent Physical Distress—Frequent physical distress is defined as experiencing 14 days or more of poor physical health in the past 30 days using the question: "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" (Centers for Disease Control and Prevention, 2000) The physical health days measure has been shown to be associated with medical care utilization,(Centers for Disease Control and Prevention, 2000) and a 14-day cut point has been used in previous studies(Strine *et al.*, 2005; Dwyer-Lindgren *et al.*, 2017) and public health measures.(*Frequent physical distress* | County Health Rankings & Roadmaps*, no date)

Social Functioning: SCD-Related Social Limitations—We used the following question to identify the presence of SCD-related social limitations: "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?" Those who said always, usually, or sometimes were classified as having a limitation while those who said rarely or never were classified as having no limitation in social activities due to SCD.(Anderson *et al.*, 2015)

Other Characteristics

We classified respondents' age in five categories (45–49, 50–59, 60–69, 70–79 and 80 years or older). We used existing categories for race/ethnicity, marital status, income, employment, education, and veteran status but collapsed some categories with sparse responses. Specifically, we created a four-category race and ethnicity variable (white, non-Hispanic; black, non-Hispanic; any race, Hispanic; other race or multiple races, non-Hispanic), a four-category education variable (less than high school, high school equivalent, some college, college graduate), and a six-category annual household income variable (<$15,000, $15,000–24,999, $25,000–49,999, $50,000–74,999, $75,000, and missing).

We created a variable to indicate whether respondents lived alone based on the number of adults and children they reported living in their household. We created dichotomous variables to indicate whether respondents had ever been diagnosed with one of the following chronic health conditions: heart disease (stroke, coronary heart disease, or angina), diabetes (other than gestational diabetes), arthritis (some form of arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia), chronic obstructive pulmonary disease [COPD] (includes emphysema and chronic bronchitis), cancer (other than skin cancer), and current asthma. We also created a variable to indicate whether respondents had at least one of these conditions and required respondents to have answered at least 4 of the 6 questions in order to have a value for this variable. We created a variable to indicate whether respondents had ever been diagnosed with depression and included this variable separately from other chronic health conditions because previous studies have suggested that depression may manifest as SCD and also that SCD may increase the risk of depression.(Hohman, Beason-Held and Resnick, 2011; Balash *et al.*, 2013; Stogmann *et al.*, 2016)

Sample

Among 226,788 respondents in these states/territories during 2015–2018 who were asked the SCD screening question, 23,866 (11.0% weighted) reported SCD (201,320 said they did not have SCD and 1,602 said they did not know)(Figure 1). Among those with SCD, 23,600 responded to the question about needing assistance using the always to never scale, and 7,502 (34.9% weighted) said they always, usually, or sometimes needed assistance. Among these, 7,450 provided a valid response to the frequency of receiving assistance. We further restricted our analyses to people who were not missing responses on any of the covariates or outcomes included in the regression model (i.e., age, sex, race/ethnicity, educational attainment, presence of at least one chronic condition, depression history, presence of frequent mental distress and frequent physical distress, and SCD-related social limitations), leaving us with a final analytic sample of 6,603 respondents age 45 and older who needed SCD-related assistance and could be classified as having or not having unmet needs for that assistance.

Statistical Analysis

We calculated the weighted proportion of respondents with and without unmet needs for SCD-related assistance and describe the demographic and health status characteristics of these two groups. We used chi-square tests to compare respondents with and without unmet needs for SCD-related assistance. We did not report estimates when the unweighted

denominator was <50 or the relative standard error (calculated as the weighted standard error divided by the weighted percentage, multiplied by 100) was >30.0 because we were concerned these estimates may not be reliable.

We estimated the prevalence ratio (PR) for having each outcome associated with an unmet need for care using separate weighted log-binomial regression models (generalized linear models with a log link and binomial family). We selected this modeling approach because the study is cross-sectional and our outcomes were relatively common and therefore the odds ratio is unlikely to provide a good approximation of the relative risk.(Barros and Hirakata, 2003) We tested each model for effect modification by depression history. We adjusted each model for demographic factors associated with unmet needs for SCD assistance and each outcome: age, sex, race/ethnicity, and education.(Centers for Disease Control and Prevention, 2000; Taylor, Bouldin and McGuire, 2018) We did not include household income or employment status because our SCD-related social limitation outcome asks about SCD interfering with work. We expected employment status and income to relate to this outcome and including these measures in the model would detract from our ability to estimate this type of limitation. In addition, both variables related closely to education, which is missing less often in the dataset than income and which has a more consistent distribution across categories than employment. We ran a second set of models adjusting for the covariates listed above plus an indicator of having at least one chronic condition, and third set adding an indicator of lifetime depression diagnosis. As a sensitivity analysis, we generated the same set of models defining respondents who rarely or never received assistance as having an unmet need in order to evaluate whether the definition of an unmet need impacted the results. We were unable to run some models with the covariates classified as described above and were limited to adjusting for race/ethnicity by including indicator variables for white, non-Hispanic and Hispanic only. These models are noted in table footnotes. Respondents from other groups (i.e., black, non-Hispanic and other, non-Hispanic) were not excluded from these analyses, since they were coded as "no" for both race/ethnicity categories included in the model.

We used the appropriate weight variable in the BRFSS public data file based on the survey version(s) on which the Cognitive Decline module appeared in each state and guidance available on the BRFSS website.(Centers for Disease Control and Prevention, 2013) All analyses were conducted in Stata version 13.1 (College Station, TX) using survey (svy) commands with a subpopulation statement to account for the complex sample design and restrict analyses to respondents aged 45 years and older. We considered $p<0.05$ to indicate statistical significance, including when testing for effect modification.

Results

Unmet needs for care related to SCD were present among 40.4% (95% confidence interval [CI]: 37.6–43.4) of respondents with SCD who needed assistance. More than six in ten middle-aged and older adults who needed SCD-related help said they needed this help 'sometimes' (66.7%), about one in ten said they 'usually' needed this help (14.9%), and about two in ten reported that they 'always' needed this help (18.3%). Respondents who always needed assistance were more likely to always receive this help compared to people

who needed assistance less often (Table 1). The frequency of rarely or never receiving assistance was similar regardless of how often one needed assistance. Respondents who said they always needed assistance were less likely to have an unmet need for care than those who usually or sometimes needed assistance.

Compared to people whose SCD-related needs were met, those with unmet needs for assistance were more likely to be younger; be non-white, be out of work or unable to work; live alone; and live in a lower income household (Table 2). Chronic health conditions and depression were both common in this population: nearly nine in ten had at least one chronic condition and more than six in ten had ever been diagnosed with depression. The prevalence of individual chronic conditions generally was similar, though arthritis and depression were both statistically more common among people with unmet needs than among those whose needs for SCD-related assistance were met. People with an unmet need had a significantly higher prevalence of a depression history than those whose needs were met.

The prevalence of frequent mental distress, frequent physical distress, and SCD-related social limitations was high in both groups (Table 3). People with unmet needs were significantly more likely than people whose needs were met to experience frequent mental distress (59% versus 48%, p<0.001). There were no significant differences in physical or social HRQOL: about 60% of both groups reported frequent physical distress, and about 70% of both groups reported social limitations. For all three HRQOL measures, the prevalence was higher among people with a history of depression than among people with no history of depression. The statistical differences between groups were consistent, however. Specifically, people with unmet needs had a significantly higher prevalence of frequent mental distress, regardless of depression history. And there were no significant differences in the prevalence of either frequent physical distress or social limitations, regardless of depression history.

We found evidence of effect modification by depression for the frequent mental distress model only (p for interaction between unmet needs and depression status=0.023). Therefore, we present results for frequent mental distress stratified by depression status, while the other two HRQOL models include all respondents (Table 4). In the crude models, people with unmet needs for SCD-related assistance had a higher prevalence of frequent mental distress regardless of depression history. After accounting for sociodemographic characteristics, the prevalence ratios were attenuated for all three HRQOL outcomes. In the adjusted models, frequent mental distress was more common only among people who had never been diagnosed with depression and had an unmet need for SCD-related care (PR=1.60, 95%CI: 1.15–2.23, p=0.005). Among respondents with depression, unmet needs for SCD-related assistance were not associated with frequent mental distress (PR=1.08, 95%CI: 1.00–1.18, p=0.051). Because of the smaller sample sizes in these models (stratified by depression history), we could only include indicator variables for white, non-Hispanic and Hispanic respondents rather than including the four-category race/ethnicity variable. We found no difference in the prevalence of frequent physical distress or social limitations between people with and without unmet needs for assistance in either the crude or adjusted models.

Using the more restrictive definition (rarely or never receiving assistance), 14.2% of respondents were classified as having an unmet need for care and there was no difference in the prevalence of unmet needs by how often people needed assistance (Table 1). In the sensitivity analyses, the prevalence ratios for the relationship between unmet needs and each HRQOL generally were similar, although for frequent mental distress the PR was farther from the null and statistically significant for both people with and without depression (Supplemental Table 1). Because of the smaller sample sizes in these models (fewer people classified as having an unmet need), we could only include indicator variables for white, non-Hispanic and Hispanic respondents rather than including the four-category race/ethnicity variable.

Discussion

Among community-dwelling middle-aged and older adults who need assistance with daily activities as a result of SCD, unmet needs for assistance were relatively common: four in ten people who needed help said they sometimes, rarely, or never received help. A number of sociodemographic characteristics were associated with having unmet needs. People with lower household income had more unmet needs than those with higher income, which could result from an inability to pay for services like formal caregiving. People living alone had more unmet needs, which could reflect the lack of an in-home person to provide support or lower levels of social support in general.(Roth *et al.*, 2007; Ko *et al.*, 2019) We also found that middle-aged adults more often had unmet needs for assistance than older adults, which could be a result of fewer supports being available for or tailored to middle-aged people or of fewer informal caregivers being available to help (e.g., spouses are still working).(Lima *et al.*, 2008) The difference also might relate to lower levels of social support among middle-aged adults, especially given the high prevalence of depression and other chronic health conditions in the sample.(Fischer and Beresford, 2015; Werner-Seidler *et al.*, 2017)

Having an unmet need appears to be associated only with the mental domain of HRQOL (frequent mental distress) and not physical or social domains. Specifically, unmet needs were associated with a roughly 60% higher prevalence of frequent mental distress among people without depression after accounting for demographic, socioeconomic, and health differences between people with and without unmet needs for assistance. The sensitivity analyses suggest there may be an association between unmet needs and frequent mental distress regardless of depression history, but even if so, the relationship is stronger for people without depression than for those with depression. Given the negative effects of having unmet needs for care identified in other studies,(Beach *et al.*, 2020) it is plausible that experiencing delays or inability to complete ADLs or instrumental activities of daily living (IADLs; e.g., shopping, cooking) or to engage with others outside the home could result in poorer HRQOL. Furthermore, it is reasonable that in the presence of depression, unmet needs for care do not impact frequent mental distress — or do not impact it as strongly — because the depressive symptoms themselves have a strong relationship to frequent mental distress, independent of gaps in care, as illustrated in Table 3. Although we expected unmet needs would also be associated with the physical and social HRQOL domains, we did not find this to be true. These data suggest that the adverse consequences of unmet needs may not directly impact physical or social HRQOL in people with SCD who need assistance.

Strengths of this study include the large sample that is representative at the state level of community-dwelling middle-aged and older adults living in all 50 US states, the District of Columbia, and Puerto Rico. We were able to measure the need for and receipt of assistance related to SCD specifically rather than to ask about health conditions more generally. Also, we related these unmet needs to both SCD-specific limitations and more general HRQOL. Although the frequency of having an unmet need for care was much lower using a more restrictive definition, the association between having an unmet need and HRQOL was similar for both definitions.

The study's limitations include the cross-sectional nature of the data, which impedes our ability to determine the temporal sequence of unmet needs for care and the participation and HRQOL outcomes (i.e., whether poor HRQOL impacts the receipt of care rather than the other way around). Also, SCD is a self-report measure of cognitive decline and we did not have any objective measures of cognitive function to which we could compare it, so we could not determine whether people classified as having SCD had any evidence of objective cognitive decline.(Jessen *et al.*, 2014) The Cognitive Decline module did undergo cognitive testing, and, when compared to objective cognitive performance measures, people with SCD tend to have lower average scores than people without SCD.(Brody *et al.*, 2019) Because the Cognitive Decline Module is used for surveillance purposes, we did not have information about the types of assistance needed or the types of care received (e.g., formal versus informal sources), which would be helpful to fully understand what programs and services could address the care gap.(Black *et al.*, 2013) Additional research in the future is needed to evaluate our findings longitudinally, to identify information about needs that are not being met, and to develop and test interventions and policies to reduce unmet needs related to subjective cognitive decline that will improve participation and HRQOL.

The subset of middle-aged and older adults with SCD-related needs for assistance had substantially poorer HRQOL compared to their peers without SCD or even those with SCD who did not report needing assistance (data not shown). This disparity alone suggests the need for intervention at the population level to improve HRQOL.(Centers for Disease Control and Prevention, 2000) The results of this study suggest a need for expanded or more targeted community-based supports and services for middle-aged and older adults with SCD to meet their needs, reduce participation restrictions, and improve HRQOL. Potential interventions include engaging informal caregivers or care partners from their families or communities(Piette *et al.*, 2015; Gitlin *et al.*, 2019), expanding the availability of and access to community-based support programs for people with cognitive decline,(Stevens *et al.*, 2015; Hale-Gallardo *et al.*, 2017; Valluru *et al.*, 2019) and promoting social engagement and participation for middle-aged and older adults with cognitive impairment.(Turner and Morken, 2016; Lin, 2017)

We expect the relationship between unmet needs for SCD-related care and HRQOL to be similar outside of the United States since we hypothesize that the mechanism for the relationship relates to the adverse consequences associated with having unmet needs. We expect the prevalence of unmet needs themselves likely varies depending on policies as well as the availability and uptake of programs at local and national levels, and also by

cultural practices around caregiving and attitudes toward the use of formal supports for people experiencing cognitive decline.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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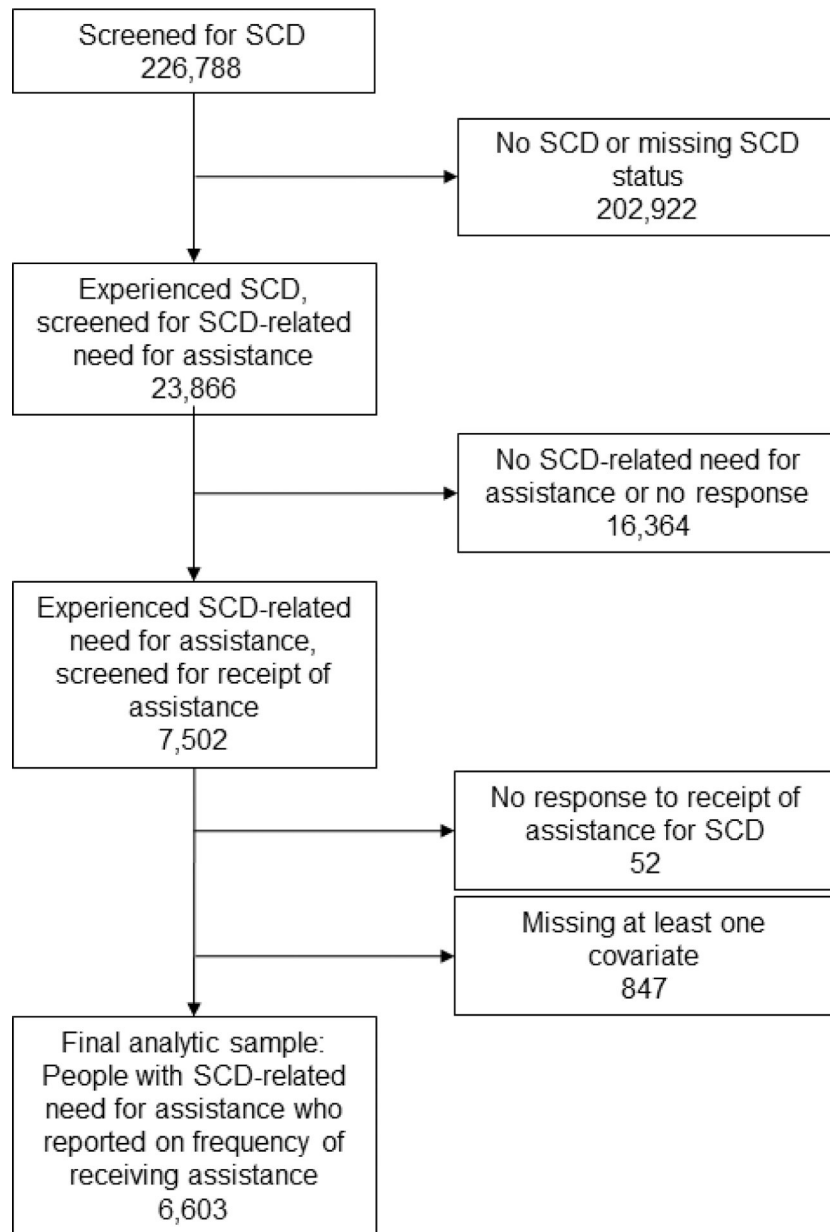
Figure 1.
Flow diagram for Behavioral Risk Factor Surveillance System respondents age 45 years and older included in the analysis.

Table 1.

Frequency of reporting need for assistance with day-to-day activities because of subjective cognitive decline (SCD) and receipt of this assistance among people age 45 years and older with SCD (column percentages, weighted). Data from 50 states, District of Columbia, and Puerto Rico, Behavioral Risk Factor Surveillance System, 2015–2018.

Receive Assistance	Need Assistance			
	Always (n=1,169) Unweighted n Weighted % (95%CI)	Usually (n=1,035) Weighted % (95%CI)	Sometimes (n=4,399) Weighted % (95%CI)	P-value[1]
Always	60.2% (53.9–66.2)	29.7% (24.9–35.0)	38.1% (34.3–42.1)	<0.001
Usually	12.6% (9.4–16.8)	27.3% (22.2–33.1)	18.5% (15.6–21.7)	<0.001
Sometimes	16.5% (12.1–22.1)	26.9% (21.6–32.9)	28.8% (25.6–32.2)	0.001
Rarely	5.2% (3.2–8.1)	6.9% (4.4–10.6)	8.2% (6.6–10.2)	0.18
Never	5.5% (3.8–7.9)	9.3% (4.5–17.9)	6.5% (5.0–8.4)	0.36
Unmet need (primary definition): sometimes, rarely, or never receive assistance	27.2 (22.0–33.1)	43.0 (36.5–49.8)	43.5 (39.7–47.3)	<0.001
Unmet need (sensitivity analysis definition): rarely or never receive assistance	10.6 (7.9–14.2)	16.2 (10.6–23.9)	14.7 (12.4–17.3)	0.23

95%CI: 95% confidence interval for the proportion

[1] p-value based on chi-square test of weighted percentages

Table 2.

Demographic, health, and health-related quality of life characteristics of people age 45 years and older with and without unmet needs for assistance with day-to-day activities related to subjective cognitive decline (SCD) (column totals, weighted). Data from 50 states, District of Columbia, and Puerto Rico, Behavioral Risk Factor Surveillance System, 2015–2018.

Variable	Category	Unmet Need for SCD-related Assistance (n=2,481)	SCD Assistance Needs Met (n=4,122)	P-value[1]
		Weighted % (95%CI)	Weighted % (95%CI)	
Sex	Female	59.8 (55.5–64.0)	59.3 (55.4–63.1)	0.86
Age	45–49	16.9 (13.5–20.9)	12.8 (10.7–15.2)	<0.001
	50–59	41.2 (37.0–45.4)	34.6 (30.7–38.7)	
	60–69	24.3 (20.8–28.2)	23.6 (20.7–26.7)	
	70–79	11.1 (8.3–14.7)	16.4 (13.6–19.5)	
	80+	6.6 (4.8–8.9)	12.7 (9.3–17.0)	
Race/ethnicity	Black only, non-Hispanic	22.4 (19.0–26.2)	13.4 (11.1–15.9)	<0.001
	White only, non-Hispanic	49.5 (45.1–53.9)	67.5 (62.8–71.8)	<0.001
	Other race or multiracial, non-Hispanic	10.2 (7.1–14.6)	4.5 (3.5–5.7)	<0.001
	Any race, Hispanic	17.9 (14.4–22.1)	14.7 (10.6–20.1)	0.32
Education	Less than high school	34.9 (30.7–39.4)	28.1 (23.9–32.8)	0.05
	High school degree or equivalent	30.9 (26.9–35.1)	30.6 (27.5–33.9)	
	Some college	24.0 (20.7–27.6)	29.7 (26.2–33.5)	
	College graduate	10.2 (8.1–12.8)	11.5 (9.1–14.5)	
Veteran status	Ever served on active duty	10.9 (8.8–13.4)	16.8 (14.2–19.8)	0.001
	Missing	0.2	0.2	--
Employment status	Employed	11.9 (9.2–15.3)	9.6 (7.0–13.0)	0.28
	Out of Work	9.0 (6.8–11.9)	5.8 (4.6–7.5)	0.02
	Homemaker	3.1 (2.1–4.5)	--	--
	Student	--	--	--
	Retired	21.0 (17.6–25.0)	30.9 (27.4–34.7)	<0.001

Int Psychogeriatr. Author manuscript; available in PMC 2022 July 01.

Variable	Category	Unmet Need for SCD-related Assistance (n=2,481)	SCD Assistance Needs Met (n=4,122)	P-value[1]
		Weighted % (95%CI)	Weighted % (95%CI)	
	Unable to Work	54.2 (49.8–58.6)	47.3 (43.3–51.4)	0.02
	Missing	0.6	0.2	--
Live alone	Yes	36.3 (32.4–40.3)	23.2 (20.7–26.0)	<0.001
	Missing	1.9	0.8	--
Household annual income	Less than $15,000	33.1 (29.2–37.3)	26.4 (22.5–30.6)	0.001
	$15,000-$24,999	27.1 (23.3–31.2)	23.2 (20.3–26.5)	
	$25,000-$49,999	15.3 (12.5–18.4)	16.9 (14.8–19.3)	
	$50,000 -$74,999	3.9 (2.9–5.2)	8.4 (5.8–12.2)	
	$75,000 or more	5.1 (3.3–7.7)	8.8 (6.5–11.9)	
	Missing	15.6	16.2	
Arthritis	Ever diagnosed with arthritis, gout, lupus, or fibromyalgia	71.0 (66.9–74.8)	64.8 (60.1–69.3)	0.03
	Missing	1.6	0.5	--
Asthma	Current	22.0 (18.9–25.5)	21.5 (19.0–24.2)	0.82
	Missing	0.9	1.1	--
Cancer, Non-skin	Ever diagnosed	16.1 (13.2–19.4)	15.5 (13.4–17.9)	0.80
	Missing	0.4	0.9	--
Cardiovascular Disease (CVD)	Ever diagnosed with myocardial infarction or angina or stroke	33.6 (29.8–37.6)	37.0 (33.4–40.8)	0.25
	Missing	2.9	2.2	--
Diabetes	Ever diagnosed, except during pregnancy	34.6 (30.4–39.2)	33.6 (29.6–37.8)	0.73
	Missing	0.4	0.4	--
COPD	Ever diagnosed with COPD, emphysema or chronic bronchitis	28.1 (24.5–31.9)	29.4 (26.1–32.9)	0.58
	Missing	0.8	1.1	--
Any Chronic Condition	At least one chronic condition above	88.5 (85.3–91.1)	86.6 (82.3–90.0)	0.45
Depression	Ever diagnosed	69.9 (65.6–73.9)	63.2 (59.0–67.2)	0.03

95%CI: 95% confidence interval for the proportion; COPD: chronic obstructive pulmonary disease.

[1] p-value based on chi-square test comparing weighted percentage of people with met and unmet needs for SCD-related assistance

-- Estimate not reported because the relative standard error is >30% or the unweighted denominator is <50.

Table 3.

Prevalence of health-related quality of life outcomes among adults age 45 years and older with and without unmet needs for assistance with day-to-day activities related to subjective cognitive decline (SCD) (column totals, weighted). Data from 50 states, District of Columbia, and Puerto Rico, Behavioral Risk Factor Surveillance System, 2015–2018.

Outcome	Definition	Unmet Need for SCD-related Assistance (n=2,481; 1,754 with depression)	SCD Assistance Needs Met (n=4,122; 2,607 with depression)	P-value[1]
		Weighted % (95%CI)	Weighted % (95%CI)	
Frequent mental distress	14 days of poor mental health in the past 30 days	59.3 (54.9–63.6)	47.6 (43.6–51.7)	<0.001
	Among people with a history of depression	72.3 (67.7–76.5)	65.2 (60.0–70.0)	0.03
	Among people without a history of depression	29.1 (23.1–36.1)	17.6 (13.7–22.3)	0.003
Frequent physical distress	14 days of poor physical health in the past 30 days	62.6 (58.3–66.7)	59.7 (55.2–64.0)	0.34
	Among people with a history of depression	69.8 (65.1–74.1)	66.1 (60.7–71.1)	0.29
	Among people without a history of depression	46.0 (37.7–54.5)	48.6 (41.4–55.9)	0.64
SCD-related social limitations	SCD always, usually or sometimes interfered with ability to work, volunteer, or engage in social activities outside the home	74.6 (70.3–78.5)	69.8 (65.3–73.9)	0.11
	Among people with a history of depression	80.1 (76.0–83.7)	74.8 (69.6–79.3)	0.09
	Among people without a history of depression	61.8 (52.5–70.4)	61.2 (53.1–68.7)	0.92

95%CI: 95% confidence interval for the weighted percentage

[1] p-value based on chi-square test comparing weighted percentage of people with met and unmet needs for assistance related to SCD

Table 4.

Association between having an unmet need for assistance with day-to-day activities because of subjective cognitive decline (SCD) and health related quality of life (HRQOL) outcomes based on log-binomial regression models, Behavioral Risk Factor Surveillance System, 2015–2018.

HRQOL Outcome	Crude PR (95% CI) p-value	Model 1 PR (95% CI) p-value	Model 2 PR (95% CI) p-value	Model 3 PR (95% CI) p-value
Among People with Depression History				
Frequent mental distress	**1.11 (1.01–1.22)** *0.036*	1.09 (1.00–1.18) *0.062*	1.08 (1.00–1.18) *0.051*	N/A
Among People without Depression History				
Frequent mental distress	**1.66 (1.19–2.31)** *0.003*	**1.60 (1.15–2.23)** *0.006*	**1.60 (1.15–2.23)** *0.005*	N/A
Frequent physical distress	1.05 (0.95–1.16) *0.34*	1.02 (0.94–1.11) *0.64*	1.02 (0.94–1.11) *0.63*	1.01 (0.94–1.10) *0.72*
SCD-related social limitations	1.07 (0.98–1.16) *0.11*	1.04 (0.98–1.10) *0.24*	1.04 (0.98–1.10) *0.24*	1.03 (0.97–1.10) *0.29*

N=6,603 unweighted respondents in each model

Model 1: includes age category (45–49, 50–59, 60–69, 70–79, 80+ years), sex, race/ethnicity category (white, non-Hispanic; black, non-Hispanic; any race, Hispanic; other race or multiple races, non-Hispanic), education category (less than high school, high school equivalent, some college, college graduate).

Model 2: includes Model 1 variables plus an indicator for having at least one of the following chronic health conditions: arthritis, asthma (current), cancer (except skin), cardiovascular disease, chronic lung disease including COPD, diabetes

Model 3: includes Model 2 variables plus depression history

Note: frequent mental distress models included white, non-Hispanic and any race, Hispanic indicators only.

Statistically significant estimates (p<0.05) indicated in bold font

PR: Prevalence ratio

95% CI: 95% confidence interval for the prevalence ratio