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Diagnosed Dementia in Adults Age 65 and Older: United States, 2022

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Abstract

Objective—This report presents estimates of diagnosed dementia in the U.S. civilian noninstitutionalized population age 65 and older by selected sociodemographic characteristics.

Methods—Data from the 2022 National Health Interview Survey were used to estimate the percentage of noninstitutionalized older adults with a dementia diagnosis. Information was self-reported unless a knowledgeable proxy responded to questions when the respondent was physically or mentally unable to answer. Prevalence of diagnosed dementia among older adults is presented by age, sex, race and Hispanic origin, veteran status, education, family income as a percentage of the federal poverty level, urbanization, and region. Estimates of dementia reporting by proxy respondent status and interview mode also are presented.

Results—In 2022, 4.0% of adults age 65 and older reported ever having received a dementia diagnosis. The percentage of adults with a dementia diagnosis was similar for men (3.8%) and women (4.2%). The percentage of adults with a dementia diagnosis increased with age, from 1.7% in those ages 65–74 to 13.1% in those age 85 and older, and decreased with rising education level, from 7.9% in adults age 65 and older with less than a high school diploma to 2.2% in those with a college degree or higher. Overall levels of older adults with a dementia diagnosis did not vary significantly by mode of interview (telephone or in person).

Keywords: older adults • Alzheimer’s disease • cognitive impairment • National Health Interview Survey (NHIS)

Introduction

Dementia is a chronic condition that affects cognitive functioning, including memory and reasoning abilities. Alzheimer’s disease is the most common type of dementia; other related dementias, with similar presentation and symptoms, include frontotemporal dementia, Lewy body dementia, and vascular dementia

(1,2). Without extensive clinical testing, it can be difficult to identify the type of dementia a person has, and studies show that many people with dementia have mixed dementias (3–6). Previous research using a variety of data sources and methods estimates that, overall, about 10% of the population age 65 and older

in the United States has dementia, with a higher prevalence found in residents of nursing homes and residential care communities (7–10). The impact of dementia on patients and caregivers is substantial and the financial burden is also high; the costs of dementia care in 2023 in the United States have been estimated to be 345 billion dollars (1,2).

Although many people with dementia live in nursing homes or other long-term care facilities, most older adults with dementia live in community settings. Household survey data can therefore be a key source of information on dementia in those who are noninstitutionalized. Data on dementia can be obtained from population-based surveys in a variety of ways, including by administering questions about cognitive functioning and limitations to survey respondents; by asking respondents if they have received a dementia diagnosis from a health care provider; by administering a cognitive assessment as part of the survey; or, by linking administrative data to the survey, including medical information and insurance claims associated with dementia. In 2019, the National Health Interview Survey (NHIS) added “dementia, including Alzheimer’s disease” to the list of



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questions asking about doctor-diagnosed health conditions. In general, estimates derived from doctor-diagnosed questions may underestimate the true prevalence of a condition (11). Nevertheless, doctor-diagnosed conditions are commonly reported and used for many surveillance and research objectives (12). NHIS now provides ongoing annual data on the prevalence of diagnosed dementia in the noninstitutionalized population.

This report describes the percentage of noninstitutionalized adults age 65 and older with a reported dementia diagnosis by selected sociodemographic characteristics, based on data from the 2022 NHIS. The role of proxy reporting and mode of interview is discussed. NHIS does not include people in long-term care institutions (for example, nursing homes, hospitals for the chronically ill or physically or intellectually disabled); consequently, the estimates presented here represent the community-dwelling population only (11).

Methods

Data source and study population

The estimates of diagnosed dementia in this report are based on data from the Sample Adult file of the 2022 NHIS. NHIS is a nationally representative household survey of the U.S. civilian noninstitutionalized population. It is conducted continuously throughout the year by the National Center for Health Statistics. Interviews are typically conducted in respondents' homes, but follow-ups to complete interviews may be conducted via telephone. Because of the COVID-19 pandemic, interviewing procedures were disrupted, and the level of telephone interviews remains higher than before the pandemic. During 2022, 55.7% of the Sample Adult interviews for all adults age 18 and older and 49.2% for adults age 65 and older were conducted at least partially by telephone (11,13,14). From each household, one sample adult is randomly selected to answer detailed questions about their health status, health-related behaviors, and health care access and use. If the sample adult is physically or mentally incapable of responding to

the survey, a knowledgeable proxy can respond. Proxy respondent status is noted in the Sample Adult file, along with if the proxy is a relative and lives in the same household as the sample adult. Overall, the percentage of proxy respondents in 2022 was about 2% for sample adults age 18 and older and nearly 5% for sample adults age 65 and older. About 95% of proxy respondents were relatives of the sample adult (13). For more information about NHIS, visit <https://www.cdc.gov/nchs/nhis.htm>.

Survey respondents age 65 and older with yes or no responses to the dementia question ($n = 8,757$) were selected for analysis, with less than 1% of respondents age 65 and older being excluded based on their response to the dementia question. Dementia is most common in older adults (1,2), and less than 0.5% of sample adult respondents younger than age 65 reported a dementia diagnosis (13). The NHIS sampling universe excludes people living in long-term care institutions (for example, nursing homes) but includes people living in noninstitutional group quarters where residents do not receive skilled nursing care (15). Consequently, some residents of assisted living communities may be included in the survey.

Measures

Diagnosed dementia

Diagnosed dementia was based on a “yes” response to the question, “Have you ever been told by a doctor or other health professional that you had dementia, including Alzheimer’s disease?”

Selected sociodemographic characteristics

Sociodemographic characteristics presented in this report include age group (65–74, 75–84, and 85 and older), sex (men and women), veteran status, race and Hispanic origin, education level, family income as a percentage of the federal poverty level, urbanization level, and region.

Veteran status—Veterans were defined as adults who had ever served on active duty in the U.S. Armed Forces,

military reserves, or National Guard, and were not currently on full-time active duty with the Armed Forces.

Race and Hispanic origin—Respondents were grouped into three categories: Black non-Hispanic (subsequently, Black), White non-Hispanic (subsequently, White), and Hispanic. These categories were based on responses to two survey questions on race and Hispanic or Latino origin. Those categorized as Black or White indicated one race only. Those characterized as Hispanic or Latino could be of any race or combination of races. People who reported another race, unknown race or ethnicity, or multiple races were not reported separately due to small sample sizes but were included in the overall analysis and other sociodemographic subanalyses.

Education level—Based on years of school completed or the highest degree obtained. The categories shown are less than high school diploma or GED, high school diploma or GED, some college, and college degree or higher.

Family income as a percentage of the federal poverty level (FPL)—Based on the combined income for all people in a household who were related by blood, marriage or cohabitation, or adoption during the past calendar year. For this analysis, family income was categorized based on the ratio of family income to the federal poverty level set by the U.S. Census Bureau for the family’s size (16), and grouped into four categories: less than 100% of FPL, 100% to less than 200% of FPL, 200% to less than 400% of FPL, and 400% of FPL or more. Family income was calculated using NHIS imputed income files (17).

Urbanization level—Based on the 2013 NCHS Urban–Rural Classification Scheme for Counties (18). The National Center for Health Statistics urban–rural classification is based on metropolitan statistical area status, defined by the Office of Management and Budget according to published standards that are applied to U.S. Census Bureau data. The NHIS public-use data file presents the National Center for Health Statistics urban–rural classification in four categories: large central metropolitan (similar to inner cities), large fringe metropolitan (similar to suburbs),

medium and small metropolitan, and nonmetropolitan. Large central and large fringe metropolitan areas have populations of 1 million or more. Metropolitan areas with populations of less than 1 million were classified as medium (250,000–999,999 people) or small (less than 250,000 people). Nonmetropolitan areas are counties in micropolitan statistical areas and noncore counties.

Region—Based on the four regions used by the U.S. Census Bureau. Northeast includes Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont. Midwest includes Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin. South includes Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia. West includes Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming.

Statistical analysis

This report presents percentages and 95% confidence intervals of the prevalence of diagnosed dementia in adults age 65 and older. The 95% confidence intervals were generated using the Korn–Graubard method for complex surveys (19). Estimates were calculated using NHIS survey weights and are representative of the U.S. civilian noninstitutionalized population. Percentages and their corresponding variances were calculated using SAS-callable SUDAAN version 11.0.4 software (RTI International, Research Triangle Park, N.C.) within SAS version 9.4 software (SAS Institute Inc., Cary, N.C.). All procedures accounted for the stratified, complex cluster sampling design of NHIS. Respondents with missing data or unknown information were excluded unless specifically noted. All percentages reported in this analysis meet National Center for Health Statistics standards of reliability

(20). Differences in percentages between sociodemographic subgroup characteristics were evaluated using two-sided significance tests at the $p < 0.05$ level. Trends by age group, education, and family income were evaluated using orthogonal polynomials in logistic regression. Terms such as “more likely,” “less likely,” “higher than,” and “lower than” indicate a statistically significant difference. Lack of comment regarding the difference between any two estimates does not necessarily mean that the difference was tested and not found to be significant.

Because the dementia question was first introduced in NHIS in 2019, only one year of data on this topic was collected before the COVID-19 pandemic. The percentage of NHIS interviews conducted by telephone is currently higher than before the pandemic. To investigate if mode of interview has an effect on the reporting of diagnosed dementia, prevalence estimates were compared for 2019 and 2022. Previous research examined interview mode differences (telephone or in person) in survey-based cognitive testing for dementia and found that mode effects differed by the domain of cognition being tested, but generally were small and more likely to be seen among survey respondents with low levels of cognitive functioning (21). However, it is not known if a change in mode would differentially affect dementia diagnosis reporting, either when reported directly by the sample adult or by a proxy. Information on mode of interview is found in the Paradata file and was merged with the Sample Adult information for 2019 and 2022 for analysis (11,13,14,22–24). A description of these findings is available in Technical Notes.

Results

Diagnosed dementia prevalence

In 2022, 4.0% of adults age 65 and older reported a dementia diagnosis (Table). The percentage of adults with a dementia diagnosis increased with age, from 1.7% for those ages 65–74, 5.7%

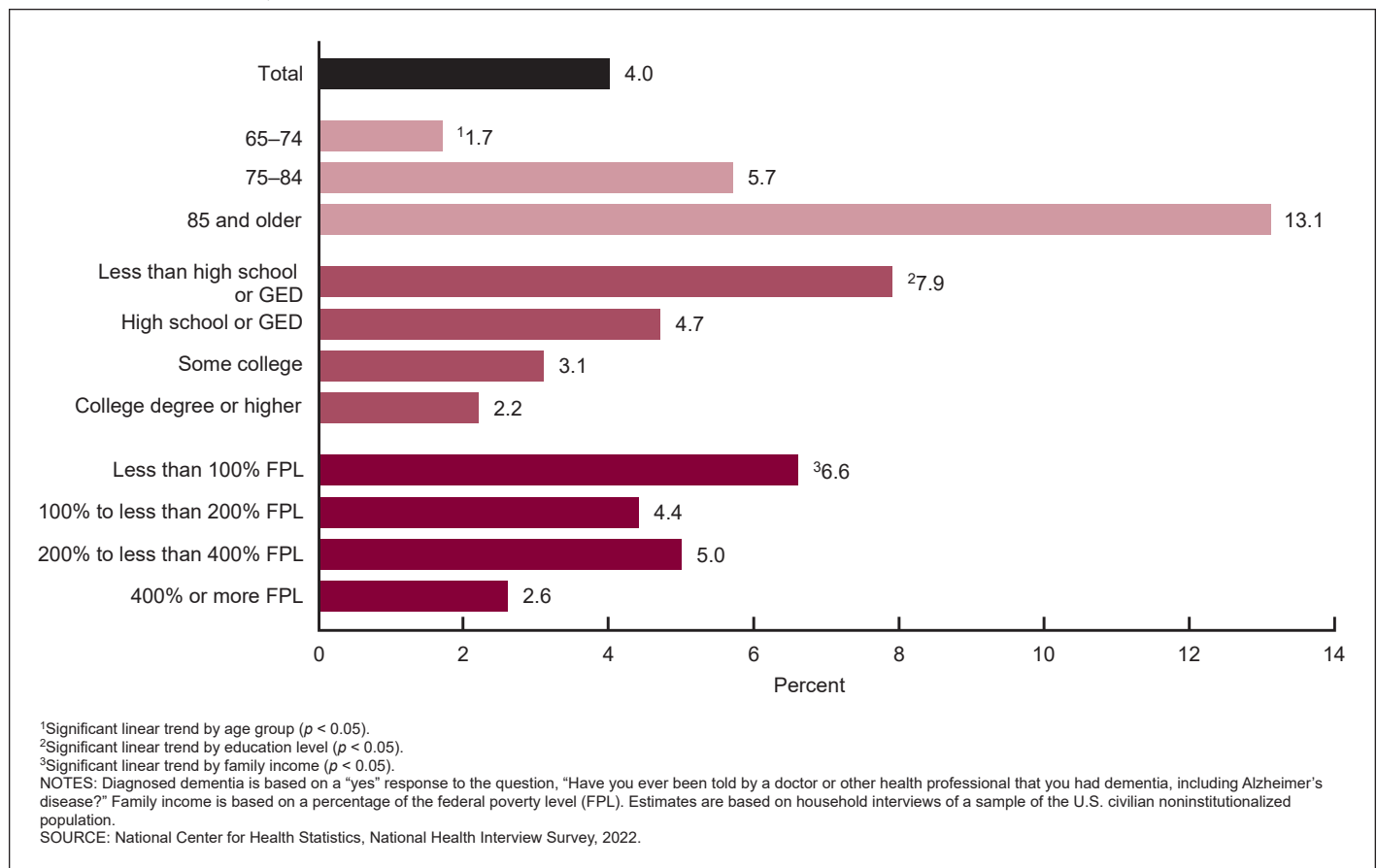
for those ages 75–84, and 13.1% for those age 85 and older. The percentage with a dementia diagnosis decreased with increasing education, from 7.9% for those with less than a high school diploma or GED to 4.7% for those with a high school diploma or GED to 2.2% for those with a college degree or higher. Diagnosed dementia also declined with increasing family income; adults with family incomes of 400% or more of the federal poverty level reported lower levels of dementia (2.6%) than those with lower income levels (Figure). Men and women age 65 and older reported similar levels of diagnosed dementia, and no significant differences by veteran status or race and Hispanic origin were noted. Older adults living in large central metropolitan areas reported lower levels of diagnosed dementia (3.3%) than older adults in medium and small metropolitan areas (4.8%). Other differences by urbanization were not statistically significant. In addition, differences by region were not significant. Among sample adults age 65 and older who responded to the survey questions by proxy, 38.2% reported diagnosed dementia in contrast to 2.3% of those who did not have a proxy. Differences in reported diagnoses of dementia in 2022 by mode of interview were not statistically significant (3.7% for telephone compared with 4.4% for in person) (Table).

Discussion

NHIS added “dementia, including Alzheimer’s disease” to the list of doctor-diagnosed health conditions asked of sample adults beginning with the 2019 survey year. In 2022, 4.0% of adults age 65 and older reported ever having received a dementia diagnosis. The percentage reporting a dementia diagnosis increased with age and decreased with increasing education level. Overall levels of reported dementia diagnosis did not vary significantly by mode of interview.

Estimates of diagnosed dementia from other national surveys are generally similar to the NHIS estimate. Data from the 2021 Medicare Current Beneficiary Survey show that nearly 3% of community-dwelling Medicare beneficiaries reported a diagnosis of

Figure. Percentage of adults age 65 and older with diagnosed dementia, by age group, education level, and family income: United States, 2022



either Alzheimer's disease or any type of dementia other than Alzheimer's disease. This estimate includes Medicare beneficiaries younger than age 65 with a qualifying disability (25,26). Data from the community-dwelling component of the 2015 National Health and Aging Trends Study estimates the percentage of diagnosed dementia in people age 65 and older to be 4.9% (27,28). Among participants age 70 and older in the 2014 Health and Retirement Study, 7.7% reported a doctor's diagnosis of Alzheimer's disease or dementia (29).

Studies show that the prevalence of dementia estimated from reports of diagnoses is lower than the prevalence estimated when cognitive testing is performed or by analysis of Medicare claims. While the methodologies differ between studies, in general only about 40%–60% of those with dementia, documented by cognitive testing or by mention in Medicare claims, reported a dementia diagnosis in various surveys (27–31). Multiple factors likely

contribute to this discrepancy, including that dementia is underdiagnosed in primary care settings, particularly for those with mild dementia (30,32,33). Screening for cognitive impairment as part of the Medicare wellness visit has been a reimbursable cost since the implementation of the Affordable Care Act in 2011 (34); however, the percentage of Medicare beneficiaries who receive a cognitive assessment is low (35). In addition, the United States Preventive Services Task Force, as of 2020, does not recommend screening for community-dwelling people without recognized symptoms of cognitive impairment, having concluded that the current evidence is not sufficient to evaluate the relative benefits and harms (36).

The challenges of reporting a doctor's diagnosis of dementia in surveys compared with other self-reported conditions may also contribute to the gap between reported diagnoses and estimated levels of dementia based on cognitive testing or clinical evaluation.

Respondents with dementia are more likely to have higher levels of missing data compared with respondents without dementia; they also may have cognitive challenges (for example, difficulties with memory or executive functioning) that limit their ability to respond accurately (29,37,38). In addition, respondents may be reluctant to report a dementia diagnosis because of the stigma associated with the condition (39).

The effect of proxy reporting on estimates of dementia diagnosis is multilayered. In general, reporting dementia by a proxy has been shown to have good validity and reliability (40); however, proxy respondents are likely reporting for people who have decreased cognitive function (29). Knowledge of a doctor's diagnosis might vary by the proxy's relationship to the sample adult. Some studies suggest that the stress of caregiving can lead to more negative cognition assessments reported by proxies (41). It is unknown, however, if knowledge and reporting of a doctor's

diagnosis of dementia might also be affected by caregiving stress.

This report has several limitations. The U.S. civilian noninstitutionalized population age 65 and older in NHIS may include some respondents living in residential care communities (for example, assisted living communities). Estimates from surveys of residential care communities show that 42% of residents have a diagnosis of dementia (10). Because it is not possible to definitively identify the number of NHIS survey respondents in those settings, the estimates of diagnosed dementia cannot be disaggregated by residential setting to understand how large a contribution is made by those in supported settings to the overall estimate. Unlike the National Health and Aging Trends Study, the Health and Retirement Study, and the Medicare Current Beneficiary Survey, which have either cognitive tests embedded in the survey, links to Medicare claims, or both, NHIS currently has no other information that could be used to verify diagnoses. Future linkage of NHIS to Medicare data would allow for comparisons of reported diagnoses indicated in claims data. Additionally, the ability to detect significant differences by race that have been documented elsewhere is limited by the relatively small sample size of those who report dementia diagnoses (7,8,42–44).

Dementia is a significant public health concern that impacts large numbers of older adults and their families. Alzheimer's disease was the sixth leading cause of death for adults age 65 and older in the United States in 2022 (45). If other dementia-related causes of death, such as unspecified dementia, vascular dementia, and Lewy body dementia, were included, dementia would have been the third leading cause, behind heart disease and cancer (45,46). Estimates of the population with a known dementia diagnosis can provide useful data for various public health objectives relevant for an aging population. One of the Healthy People 2030 objectives is to increase the proportion of older adults who are aware of their dementia diagnosis (31). Early detection and diagnosis of dementia is an important public health strategy as it allows patients and their families to plan for future needs

(47). Data from NHIS can be used to track progress towards these goals.

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Table. Percentage of adults age 65 and older with diagnosed dementia, by selected characteristics: United States, 2022

Characteristic	Sample size	Percent (95% confidence interval)
Total	8,757	4.0 (3.5–4.6)
Age group		
65–74	5,002	1.7 (1.2–2.2)
75–84	2,754	5.7 (4.6–7.0)
85 and older	1,001	13.1 (10.4–16.1)
Sex		
Men	3,764	3.8 (3.1–4.6)
Women	4,993	4.2 (3.5–5.1)
Veteran status		
Veteran	1,361	4.1 (3.0–5.4)
Nonveteran	7,084	3.9 (3.3–4.6)
Race and Hispanic origin ¹		
Black, non-Hispanic	836	5.5 (3.4–8.2)
White, non-Hispanic	6,911	3.7 (3.1–4.3)
Hispanic	575	5.6 (3.4–8.7)
Education level		
Less than high school diploma or GED	903	7.9 (5.8–10.4)
High school diploma or GED	2,416	4.7 (3.7–5.9)
Some college	2,481	3.1 (2.3–4.0)
College degree or higher	2,909	2.2 (1.6–2.9)
Family income as a percentage of FPL ²		
Less than 100% FPL	768	6.6 (4.4–9.4)
100% to less than 200% FPL	1,831	4.4 (3.2–5.8)
200% to less than 400% FPL	2,783	5.0 (3.9–6.2)
400% or more FPL	3,375	2.6 (1.9–3.4)
Urbanization level ³		
Large central metropolitan	2,177	3.3 (2.4–4.5)
Large fringe metropolitan	1,997	4.2 (3.2–5.5)
Medium and small metropolitan	2,974	4.8 (3.8–5.9)
Nonmetropolitan	1,609	3.5 (2.5–4.7)
Region ⁴		
Northeast	1,504	4.7 (3.4–6.4)
Midwest	2,022	3.7 (2.7–4.9)
South	3,177	4.2 (3.4–5.3)
West	2,054	3.5 (2.5–4.7)
Proxy respondent		
Yes	303	38.2 (31.9–44.8)
No	8,454	2.3 (1.9–2.8)
Mode of interview		
Telephone (all or some)	4,312	3.7 (3.0–4.5)
In person	4,445	4.4 (3.7–5.2)

¹Adults categorized as Hispanic may be of any race or combination of races. Adults categorized as Black non-Hispanic and White non-Hispanic indicated one race only. Total includes other races and multiple races (not shown separately).

²FPL is federal poverty level. Family income as a percentage of the federal poverty level was calculated from the family's income in the previous calendar year and family size using the U.S. Census Bureau's poverty thresholds.

³Urbanization level is measured using metropolitan statistical area status and is defined by the Office of Management and Budget according to published standards that are applied to U.S. Census Bureau data. Metropolitan statistical areas consist of a county or group of counties containing at least one urbanized area with a population of 50,000 or more. Large central metropolitan is a population of 1 million or more (similar to an inner city). Large fringe metropolitan is a population of 1 million or more (similar to a suburb). Medium and small metropolitan is a population of less than 1 million. Nonmetropolitan includes counties or groups of counties not in a metropolitan statistical area.

⁴In the geographic classification of the U.S. population, states are grouped into four regions used by the U.S. Census Bureau. Northeast includes: Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont. Midwest includes: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, Oklahoma, South Dakota, and Wisconsin. South includes: Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, South Carolina, Tennessee, Texas, Virginia, and West Virginia. West includes: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming.

NOTES: Diagnosed dementia is based on a "yes" response to the question, "Have you ever been told by a doctor or other health professional that you had dementia, including Alzheimer's disease?" Sample sizes for individual characteristics may not add up to total because of missing values. Estimates are based on household interviews of a sample of the U.S. civilian noninstitutionalized population.

SOURCE: National Center for Health Statistics, National Health Interview Survey, 2022.

Technical Notes

Reporting diagnosed dementia by interview mode and proxy status

Estimates of diagnosed dementia in adults age 65 and older in 2022 are compared with estimates from data collected before the COVID-19 pandemic in the 2019 NHIS (the first year of data collection for this information). Among NHIS respondents age 65 and older, about 50% had a telephone interview in 2022 compared with about 30% in 2019 (13,14,23,24). Regardless of differences in the percent distribution of respondents

by mode of interview, the overall estimates of diagnosed dementia in adults age 65 and older were similar in 2019 and 2022 (4.0%) (Table). In both years, the estimates of diagnosed dementia by mode of interview were not statistically different (4.0% for both telephone and in-person interviews in 2019, and 3.7% for telephone interviews compared with 4.4% for in-person interviews in 2022).

No statistically significant differences in the estimates of diagnosed dementia in 2019 compared with 2022 were seen by either proxy respondent status or by mode of interview disaggregated by proxy status. In 2022 only, the percentage of older adults with

diagnosed dementia as reported by proxy respondents via an in-person interview (46.4%) was higher than the percentage as reported by proxy respondents via telephone interview (32.5%).

Table. Percentage of adults age 65 and older with diagnosed dementia, by interview mode and proxy respondent status: United States, 2019 and 2022

Characteristic	2019				2022			
	Sample size	Percent	95% confidence interval	Standard error	Sample size	Percent	95% confidence interval	Standard error
Total	9,278	4.0	(3.4–4.6)	0.3	8,757	4.0	(3.5–4.6)	0.3
Mode of interview								
Telephone (all or some)	2,538	4.0	(3.1–5.0)	0.5	4,312	3.7	(3.0–4.5)	0.4
In person	6,740	4.0	(3.3–4.7)	0.4	4,445	4.4	(3.7–5.2)	0.4
Proxy respondent								
Yes	317	34.1	(27.8–40.8)	3.2	303	38.2	(31.9–44.8)	3.2
No	8,961	2.4	(2.0–2.8)	0.2	8,454	2.3	(1.9–2.8)	0.2
Telephone interview (all or some)								
Proxy yes	143	33.7	(24.7–43.6)	4.6	171	32.5	(24.7–41.1)	4.0
Proxy no	2,395	1.8	(1.3–2.5)	0.3	4,141	2.0	(1.5–2.7)	0.3
In-person interview								
Proxy yes	174	34.4	(25.7–43.9)	4.5	132	46.4	(35.8–57.1)	5.2
Proxy no	6,566	2.6	(2.1–3.2)	0.3	4,313	2.6	(2.1–3.3)	0.3

NOTES: Diagnosed dementia is based on a "yes" response to the question, "Have you ever been told by a doctor or other health professional that you had dementia, including Alzheimer's disease?" Estimates are based on household interviews of a sample of the U.S. civilian noninstitutionalized population.

SOURCE: National Center for Health Statistics, National Health Interview Survey, 2019 and 2022.

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