

Classification of Persons by Dementia Status in the National Health and Aging Trends Study

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Cognitive impairment in the older population often reaches the threshold for dementia, and Alzheimer's disease (AD) is widely recognized as the most common underlying cause (Alzheimer's Association 2013; Plassman et al. 2007; Wilson et al. 2011). Identifying persons with dementia or AD in large population-based studies where clinical evaluations are not feasible poses challenges. Dementia and AD prevalence estimates vary across studies that take different approaches to selecting study populations, defining disease, and differentiating among types of dementia (Wilson et al. 2011; Brookmeyer et al. 2011; Seshardri et al 2011). This document describes the types of information that the National Health and Aging Trends Study (NHATS) provides to identify persons with cognitive impairment and our approach to classifying persons as having dementia.

NHATS items for classification of persons with dementia

Three types of information from NHATS can be used to identify persons who are cognitively impaired:

- A report by the sample person or proxy respondent that a doctor told the sample person that he/she had dementia or Alzheimer's disease.
- A score that indicates probable dementia on the AD8 Dementia Screening Interview, which is administered to proxy respondents who are answering the NHATS interview for the sample person. This 8-item instrument assesses memory, temporal orientation, judgment and function (Galvin et al. 2005, 2006).
- Cognitive tests that evaluate the sample person's memory (immediate and delayed 10-word recall), orientation (date, month, year, and day of the week; naming the President and Vice President), and executive function (clock drawing test). For more details on items and administration see Kasper and Freedman (2012); NHATS Data Collection Procedures (2011).

The information available varies by type of respondent (Table 1). For self-respondents, report of a diagnosis and cognitive test items are available. Like self-respondents, proxy respondents were asked whether the sample person had received a diagnosis. In addition the AD8 was administered to all proxies. Proxy respondents also were asked whether the sample person could be asked the cognitive test items and a little over half agreed. For these cases, report of a diagnosis, the AD8 score, and cognitive test items are available. For proxies who said the sample person could not be asked the cognitive items, report of a diagnosis and the AD8 score can be used. Respondents living in nursing homes at baseline were not interviewed directly but will have MDS information available at a later date.

Most NHATS participants were self-respondents (92% of those 65+; 91% of those 71+) (Table 1).

Table 1. Data available for classifying persons as cognitively impaired

	Report of diagnosis	AD8 items	Cognitive test items	Total ¹	Age 71+
Self-respondent	X	NA	X	7,026	5,355
Proxy (said SP could be asked cognitive tests)	X	X	X	299	274
Proxy (said SP could not be asked cognitive tests)	X	X	NA	284	260
Nursing home residents	NA	NA	NA	468	458

¹ All persons 65 and older.

Criteria for dementia classification

NHATS participants are classified into 3 groups—probable dementia, possible dementia, and no dementia—using criteria shown in Table 2. A report by either the NHATS participant or a proxy respondent that a doctor told the sample person that he/she had dementia or Alzheimer’s disease was used to classify persons as probable dementia. Proxy respondents not reporting a diagnosis who gave answers to the AD8 that met criteria for likely dementia (a score of 2 or higher) also were classified as probable dementia. For all others—self-respondents not reporting a diagnosis and a small number (n=79) with proxy respondents who had no diagnosis reported and did not meet AD8 criteria, but had test information—score cutpoints applied to cognitive tests were used.

Factor analysis of the 5 NHATS cognitive tests identified 3 domains of cognitive functioning: memory, orientation, and executive functioning (Appendix Table 1). Impairment was defined as scores at or below 1.5 Standard Deviations (SD) from the mean for self-respondents.¹ We required impairment in at least 2 cognitive domains for probable dementia; a cut-point of ≤ 1.5

¹ As in other studies (e.g. the Health and Retirement (HRS) Study; see Crimmins et al. 2011; Langa, Kabeto, Weir 2009) data from self-respondents were used to develop score cutpoints. In a small number of cases, mean values were imputed— for the clock score if it was missing because it was not received from the interviewer (n = 63) and for the date orientation items if the respondent used an aid such as a calendar (n = 296). When these cases were dropped rather than imputed, score cutpoints were unchanged.

SDs below the mean in 1 domain was used for cognitive impairment indicating possible dementia.

Table 2. Criteria for dementia classification and unweighted Ns by age group

Dementia classification	Probable dementia			Possible dementia	No dementia
Criteria	Diagnosis reported	Met AD8 criteria if no diagnosis reported (proxy only)	≤ 1.5 SDs below mean in at least 2 domains	≤ 1.5 SD below mean in 1 domain	All others
Persons 65+ ¹	457	159	422	996	5,575
Person 71+ ¹	435	140	393	878	4043

¹Total N for 65+ = 7609; Total N for 71+ = 5889. Excludes nursing home residents: 468 persons 65+ and 458 persons 71+. See Table 5 for dementia classification of nursing home residents.

Score cutpoints developed using weighted data are shown in Table 3. Self-respondents who refused a test or answered don't know or were unable to do a test were scored as 0.

Table 3. Score cutpoints for ≤ 1.5 SDs below mean on NHATS cognitive domains

Domain	Orientation	Memory	Executive functioning
Score range	0 to 8	0 to 20	0 to 5
Score cutpoints	≤ 3	≤ 3	≤ 1

Several decisions are involved in developing classification criteria for dementia. Neuropsychological tests, like those administered in NHATS, have been used in many large population-based studies to characterize cognitive function and provide a means of identifying persons with severe impairment and likely dementia. The choice of tests to include varies across studies, but key domains include those assessed in NHATS (memory and orientation). Seshadri et al. (2011) concluded that differences in tests across studies was not a major source of variation in dementia estimates.

The choice of cutpoints and how to apply these (e.g. to a summary score as in Langa, Kabeto, Weir 2009, or to domains) also varies. A cutpoint of ≤ 1.5 SDs below the mean has been commonly used to classify persons as having cognitive impairment (Morris 2012). Following

revised criteria for diagnosing Alzheimer’s disease dementia (Morris 2012; McKhann et al. 2011), we required impairment in at least 2 domains for probable dementia. A cut-point of ≤ 1.5 SDs below the mean in 1 domain (as opposed to multiple) has been used in some studies to designate Cognitive Impairment Not Dementia (CIND) or Mild Cognitive Impairment (MCI) (Seshadri et al. 2011; Morris 2012). There is considerable variation in diagnostic criteria for CIND and MCI, however, and prevalence estimates range from 10% to over 20% of persons 65 or older (Alzheimer’s Association 2013). Morris (2012) states that recently revised criteria for MCI (Albert et al. 2011) have blurred the distinction between MCI and mild or early Alzheimer’s disease.

A final issue is how to classify persons with proxy respondents, many of whom may not have cognitive tests administered. NHATS asked proxy respondents whether the sample person could be asked the cognitive items and about half agreed. In addition, however, the AD8 was included for purposes of providing an additional indicator (aside from reported diagnosis) of likely dementia for persons with proxy respondents. Treating those with proxy respondents as missing cases because they do not have cognitive test information underestimates dementia (Crimmins et al. 2011), since cognitive impairment is one reason an individual may not be able to participate as a self-respondent in a study.

Table 4 provides a comparison of reports of diagnosis and AD8 criteria with cognitive test criteria for classification as having probable or possible dementia. Cognitive test criteria are available for all self-respondents and about half of persons with proxy respondents. We would expect high percentages of persons for whom a diagnosis was reported or who met AD8 criteria to also meet criteria for dementia classification based on cognitive test criteria. This was confirmed. A high percentage of persons who reported a diagnosis, either self-report or by proxy, also met the test criteria for probable (≤ 1.5 SDs below mean in at least 2 domains) or

Table 4. Concordance of cognitive test criteria with reports of diagnosis and AD8 criteria¹

Cognitive test criteria	Diagnosis reported		Met AD8 criteria if no diagnosis reported (89)	Self-respondents not reporting a diagnosis (6838)
	Self-respondent (188)	Proxy respondent (131)		
≤ 1.5 SDs below mean in at least 2 domains (probable)	47.3%	86.2%	59.5%	5.8%
≤ 1.5 SDs below mean in 1 domain (possible)	22.3%	9.9%	22.5%	14.2%
All other (no dementia)	30.3%	3.8%	18.0%	80.0%

¹Unweighted data for all self-respondents and for persons with proxy respondents who reported a diagnosis or met AD8 criteria and for whom cognitive tests were administered (299 out of 583 had cognitive tests; 220 had a diagnosis reported or met AD8 criteria).

possible dementia (≤ 1.5 SDs below mean in 1 domain). Among persons with a proxy respondent who reported a diagnosis, 96.2% met probable or possible dementia criteria, as did 82.0% of those with proxy respondents who did not report a diagnosis but whose answers on the AD8 met criteria. While about two-thirds (69.7%) of self-respondents who reported a diagnosis also met probable or possible criteria, one-third did not.²

There are important limitations to dementia classification based on data obtained in large-scale population surveys. A documented history of decline in cognitive functioning is a key element in a diagnosis of dementia. Prospectively collected information of this kind is not available from NHATS baseline data, but as a longitudinal study NHATS offers the possibility of establishing decline through repeated assessments. The battery of neuropsychological tests in surveys, including NHATS, also is much more limited than would be the case in a standard neurological examination to arrive at a diagnosis. For example, the NHATS cognition battery was about 7 minutes of interview time on average. ADAMS administered 90 to 100 minutes of neuropsychological tests to arrive at diagnoses of dementia and CIND (Langa et al. 2005).

NHATS estimates of dementia

Table 5 provides estimates by dementia classification for persons ages 65 and older and for persons 71 and older (NHATS sample is representative of the Medicare population 65+ which includes 96% of persons 65+ in the US; Montaquila et al. 2012). In all, 4.3 million persons 65 or older have probable dementia and an additional 4.0 million have cognitive impairment indicating possible dementia. Among persons 71 or older, estimates are 3.6 million with probable dementia and 3.1 million with possible dementia. (See Appendix Table 2 for breakouts by 10-year age groups.)

NHATS did not interview persons who were permanent nursing home residents at baseline ($n = 468$). For purposes of producing population estimates in Table 4, we assigned half of these individuals to the probable dementia group and half to the normal group. This is likely a conservative estimate. Magaziner et al. (2000) found 48% to 54% of new admissions to all nursing homes in the state of Maryland met DSM criteria for dementia; this population included persons being admitted for post-acute care. Dementia rates would likely be higher among a long-stay, permanent resident population. Data from the 2004 National Long Term Care Survey (Spillman 2011) indicated that 62% of those in institutional settings, primarily nursing home residents, had cognitive impairment based on staff reports of Alzheimer's Disease, dementia, mental retardation, or any combination.

² Possible explanations include inaccurate reporting of a diagnosis, for example a misunderstanding of what a doctor has said, as well as being in the early stage of dementia, which might not be identified without a more extensive cognitive test battery.

The point estimates in Table 5 are sensitive to how the nursing home population is allocated. If two-thirds of the nursing home population are assigned to the probable dementia group, rather than half, the percentage with probable dementia increases to 4,446,000, or 11.7% of persons 65 or older (for persons 71+ those with probable dementia increases to 3,802,000 million or 15.5% of this age group).

Table 5. Population estimates (to the nearest thousand) by dementia status

	Total % Weighted N	Diagnosis reported	Met AD8 criteria if no diagnosis reported	All others	Nursing Home Residents ¹
Age = 65 or older (38,152,000)²					
Probable dementia	11.2% 4,273,000	4.3%	1.6%	3.8%	1.5%
Possible dementia	10.6% 4,044,000	---	---	10.6%	---
No dementia	78.2% 29,835,000	---	---	76.7%	1.5%
Age = 71 or older (24,567,000)					
Probable dementia	14.8% 3,636,000	5.8%	1.8%	5.1%	2.1%
Possible dementia	12.8% 3,145,000	---	---	12.8%	---
No dementia	72.4% 17,786,000	---	---	70.3%	2.1%

¹ Assigns 50% of nursing home residents to probable dementia and 50% to no impairment.

² 96% of persons ages 65 and older in the United States are Medicare beneficiaries. According to the 2010 US Census, there were 40.3 million individuals ages 65 and older living in the United States (Howden and Meyer, 2011). CMS estimates Medicare enrollment for its aged beneficiaries to be 38.8 million (excluding Puerto Rico and the Virgin Islands, but including if state unknown <https://www.cms.gov/MedicareEnRpts/Downloads/10Aged.pdf>). Dementia status population estimates for the 65+ and 71+ populations use age at the time of drawing the sample (total weighted N = 38,152,000 and 24,567,000 respectively).

Sensitivity and Specificity of NHATS criteria

A recent wave of ADAMS data provides a useful means of assessing the sensitivity and specificity of NHATS dementia criteria. The Aging, Demographics, and Memory Study (ADAMS) Wave E was conducted in 2010 with 121 persons ages 65 and older drawn from the HRS. As in earlier waves of ADAMS, a 3 to 4 hour structured in-home clinical assessment was administered (Langa et al. 2005). A consensus panel assigned a diagnosis in two stages. First, using all data

except medical records a diagnosis was assigned based on clinical judgment that was anchored in DSM-III-R and DSM-IV criteria. Next, the consensus panel used all data including medical records to assign a final research diagnosis (again using clinical judgment that was anchored in DSM-III-R and DSM-IV criteria). Three diagnostic classifications were developed: dementia, CIND (functional impairment that did not meet criteria for dementia or performance ≥ 1.5 SDs below published norms on any one of multiple cognitive tests and performance was below expectation based on educational level, reading level and occupational attainment) and normal. NHATS criteria were developed for the ADAMS Wave E participants as well.³

Table 6 shows sensitivity and specificity of NHATS dementia classifications if dementia is narrowly defined as probable dementia only, and broadly defined, as probable or possible dementia. Sensitivity for the narrow NHATS definition (proportion correctly identified among ADAMS dementia diagnosis cases) is 65.7%. Not surprisingly, sensitivity drops considerably against a diagnosis of dementia or CIND in ADAMS (43.6%). Specificity is high using the NHATS narrow definition (possible or no dementia) against ADAMS-based criteria for normal (87.2%) or normal plus CIND (100%).

If a broader definition of probable or possible dementia is used, sensitivity improves—85.7% against a dementia diagnosis in ADAMS, and 71.8% of those diagnosed as dementia or CIND.

Table 6. Sensitivity and Specificity of NHATS criteria

NHATS criteria	ADAMS research diagnosis criteria			
	Dementia (35)	CIND+ Normal (86)	Dementia+ CIND (78)	Normal (43)
<u>Narrow definition:</u> Probable	65.7% (23)	12.8%(11)	43.6% (34)	---
Possible +No dementia	34.3% (12)	87.2% (75)	56.4% (44)	100.0% (43)
<u>Broad definition:</u> Probable +Possible	85.7% (30)	38.4%(33)	71.8% (56)	16.3% (7)
No dementia	14.3% (5)	61.6% (53)	28.2% (22)	83.7% (36)

³ With support from David Weir PhD, PI of the HRS, and Brenda Plassman PhD, PI and study director for the ADAMS, the clock drawing test, which is a component of the NHATS cognitive test battery was included in the ADAMS Wave E data collection.

Specificity declines against persons classified as normal or CIND by ADAMS (61.6%), but improves (83.7%) for persons classified as normal.

In sum, the NHATS broad definition shows high sensitivity against ADAMS dementia diagnosis and reasonably good sensitivity against diagnoses of dementia or CIND. Sensitivity is lower for the NHATS narrow definition, but specificity is high for the narrow definition and for the broad definition against ADAMS normal classification. Accurate identification of persons with CIND and MCI may require the type of extensive diagnostic data available in ADAMS, which provides a much more robust base from which to assess persons who do not clearly fall into the severely impaired or not impaired groups. Diagnostic criteria also continue to evolve for mild dementia and early Alzheimer’s (Morris, 2012).

Comparison of estimates of dementia in NHATS and other studies

Table 7 shows comparisons between NHATS estimates of dementia and published estimates from the HRS and ADAMS. NHATS finds for the total population 65 and older, 11.2% have probable dementia, rising to 14.8% of those 71 and older. Plassman et al. (2007) using ADAMS data, and more recently Hurd et al. (2013), found about 14% of persons 71 or older have dementia.

Table 7. NHATS percentage estimates of dementia and comparisons with HRS and ADAMS by age

	Total	65-70	71-79	80-89	90+
NHATS¹					
Ages 65+					
Probable dementia	11.2%	3.9%	---	---	---
Possible dementia	10.6%	6.0%	---	---	---
Ages 71+					
Probable dementia	14.8%	---	8.2%	20.3%	38.4%
Possible dementia	12.8%	---	10.8%	15.4%	16.1%
ADAMS² ages 71+					
Dementia	13.9%	---	5.0%	24.2%	37.4%
CIND	22.0%	---	16.0%	29.2%	39.0%
HRS³ ages 71+					
Dementia	---	---	8.1%	19.8%	44.5%
CIND	---	---	20.5%	28.2%	32.3%

Only about 4% of persons ages 65 to 70 have probable dementia. Estimates within age groups vary across studies. NHATS and HRS have similar estimates for the 71-79 and 80-89 year age

groups. NHATS and ADAMS are more similar for those 90+, but estimates range more widely in this age group. The number of persons 90+ in all three studies also is smaller than for other age groups.

In addition to estimates of dementia, both ADAMS and HRS provide estimates of CIND. NHATS provides an estimate of persons with cognitive impairment indicating possible dementia. Not surprisingly, NHATS estimates of probable or possible dementia are generally considerably lower than those from ADAMS and HRS that combine dementia and CIND. As noted earlier, estimates of MCI, CIND and early Alzheimer's disease vary widely across studies due to differing definitions and evolving diagnostic criteria.

Appendix Table1. Cognitive domains based on factor analysis^a of NHATS tests

	Factor 1: Memory	Factor 2: Orientation	Factor 3: Executive Functioning
Delayed word recall	.804	.232	.181
Immediate word recall	.738	.366	.239
President/vice President naming	.254	.640	.198
Date	.242	.633	.226
Clock drawing	.266	.371	.494

^aRotated not correlated.

Appendix Table 2. Population estimates for age groups (to the nearest thousand) by dementia status

Dementia Status	Total % Weighted N ¹	Diagnosis reported	Met AD8 criteria if no diagnosis reported	All others	Nursing Home Residents ²
Age = 65 to 70 (13,584,000)					
Probable dementia	3.9% 530,000	1.2%	1.2%	1.3%	.2%
Possible dementia	6.0% 815,000	---	---	6.0%	---
No dementia	90.1% 12,239,000	---	---	89.9%	.2%
Age = 71 to 79 (13,816,000)					
Probable dementia	8.2% 1,133,000	3.0%	1.1%	3%	1.0%
Possible dementia	10.8% 1,492,000	---	---	10.8%	---
No dementia	81.0% 11,191,000	---	---	80.0%	1.0%
Age = 80 to 89 (8,845,000)					
Probable dementia	20.3% 1,796,000	8.7%	2.3%	6.6%	2.7%
Possible dementia	15.4% 1,362,000	---	---	15.4%	---
No dementia	64.3% 5,687,000	---	---	61.6%	2.7%
Age = 90+ (1,907,000)					
Probable dementia	38.4% 732,000	13.1%	5.0%	12.2%	8.1%
Possible dementia	16.1% 307,000	---	---	16.1%	---
No dementia	45.5% 868,000	---	---	37.4%	8.1%

¹ 96% of persons ages 65 and older in the United States are Medicare beneficiaries. According to the 2010 US Census, there were 40.3 million individuals ages 65 and older living in the United States (Howden and Meyer, 2011). CMS estimates Medicare enrollment for its aged beneficiaries to be 38.8 million (excluding Puerto Rico and the Virgin Islands, but including if state unknown <https://www.cms.gov/MedicareEnRpts/Downloads/10Aged.pdf>). Dementia status population estimates use age at the time of drawing the sample (total weighted 65+ N = 38,152,000 and 71+ N = 24,567,000).

² Assigns 50% of nursing home residents to probable dementia and 50% to no impairment.

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