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The Aging, Demographics, and Memory Study: Study Design and Methods

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Abstract
Objective: We describe the design and methods of the Aging, Demographics, and Memory Study (ADAMS), a new national study that will provide data on the antecedents, prevalence, outcomes, and costs of dementia and 'cognitive impairment, not demented' (CIND) using a unique study design based on the nationally representative Health and Retirement Study (HRS). We also illustrate potential uses of the ADAMS data and provide information to interested researchers on obtaining ADAMS and HRS data. ***Methods:*** The ADAMS is the first population-based study of dementia in the United States to include subjects from all regions of the country, while at the same time using a single standardized diagnostic protocol in a community-based sample. A sample of 856 individuals age 70 or older who were participants in the ongoing HRS received an extensive in-home clinical and neuropsychological assessment to determine a diagnosis of normal, CIND, or dementia. Within the CIND and dementia categories, subcategories (e.g. Alzheimer's disease, vascular dementia) were assigned to denote the etiology of cognitive impairment. ***Conclusion:*** Linking the ADAMS dementia clinical assessment data to the wealth of available longitudinal HRS data on health, health care utilization, informal care, and economic resources and behavior, will provide a unique opportunity to study the onset of CIND and dementia in a nationally representative population-based sample, as well as the risk factors, prevalence, outcomes, and costs of CIND and dementia.

Introduction

Given the growing importance of dementia as a cause for disability among older adults in the next decades [1], and the wide-ranging impact of dementia on individuals, families [2], and government programs [1, 3], accurate estimates of the prevalence, outcomes, and societal costs of dementia are required for informed health care planning and policy-making. Most prior studies of dementia have been based on clinical samples or community-based

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samples from geographically confined areas, thus raising questions about the generalizability of findings.

The Aging, Demographics, and Memory Study (ADAMS) was designed to provide nationally representative data on the antecedents, prevalence, outcomes, and costs of dementia and less advanced cognitive impairment not meeting criteria for dementia (cognitive impairment, not demented; CIND), using a unique study design based on the nationally representative Health and Retirement Study (HRS). The ADAMS is the first population-based study of dementia in the United States to include subjects from all regions of the country, while at the same time using a single standardized diagnostic protocol in a community-based sample. Its linkage with the HRS, which provides detailed longitudinal data on health, health care utilization, informal care, and economic resources and behavior, will allow for in-depth investigations into the risk factors and outcomes of CIND and dementia, as well as the lifetime costs of dementia in the population. The main objectives of this article are to describe the design and methods of the ADAMS, report basic characteristics of the ADAMS sample, illustrate some of the potential uses of the data, and provide information on how to obtain ADAMS and HRS data.

The Aging, Demographics, and Memory Study

Main Goals of the ADAMS

The ADAMS had four main goals all directed toward providing researchers with population-based representative data to support a wide range of studies on the risk factors, prevalence, outcomes, and costs of CIND and dementia in the United States. The first goal of the ADAMS was to conduct in-home clinical assessments leading to a diagnosis of normal, CIND, or dementia, in a subsample of about 850 HRS respondents age 70 years or older. The second goal was to perform 18-month in-home follow-up assessments on all individuals who received an initial diagnosis of CIND, or who were flagged by the consensus diagnosis panel as 'ambiguous' cases for whom a follow-up assessment would help significantly in clarifying the diagnosis. The third goal was to link the information obtained from the ADAMS clinical assessments with the extensive survey data from all waves of the longitudinal HRS. The fourth goal was to use the clinical assessments for the ADAMS subjects as the basis for a statistical model to estimate the likelihood of dementia for all HRS respondents age 70 years or older.

Using the HRS as the Foundation for the ADAMS

Design of the HRS

The HRS is a nationally representative, prospective study of persons born in 1953 or earlier, designed to investigate the health, social, and economic implications of the aging of the American population [4]. The HRS is funded by the National Institute on Aging and conducted by the Institute for Social Research at the University of Michigan. The original HRS sample consisted of individuals born between 1931 and 1941, inclusive. This sample came from a screening of 69,336 households that was conducted in 1992. That sample of households was generated using a multi-stage, clustered area probability frame. The second sample was generated for what began as a separate study: Asset and Health Dynamics among the Oldest Old (AHEAD). This sample consists of individuals born in 1923 or before. Those born between 1914 and 1923, and about half of those born in 1913 or before, were identified through the same household screening used to identify the original HRS sample. The other half of those born in 1913 or before were identified using the Medicare enrollment files maintained by the Health Care Financing Administration (HCFA, since renamed the Centers for Medicare & Medicaid Services, or CMS). In 1998, the HRS and AHEAD studies were merged, with a single interview schedule.

The current HRS combines the original HRS and AHEAD cohorts, as well as three additional national cohorts of study subjects that were enrolled at different times since 1992. Spouses of HRS respondents, regardless of their year of birth, are included in the HRS sample. African-American and Hispanic individuals are oversampled. With these five cohorts, the HRS now represents the entire U.S. population over 50 years of age with a national sample of more than 30,000 individuals (including over 5,000 who have died after their entry into the sample).

Interviews are conducted with all HRS respondents every 2 years, either by telephone or in-person, with the latter mode used preferentially for those age 80 or older. Approximately 10% of the interviews are done with proxy informants for sample members who are unable or unwilling to complete the survey interview themselves, but are willing to have someone else (most often a spouse or daughter) answer for them. The proportion of interviews done with proxy informants increases with age, and thus a higher proportion (about 14%) of the age 70 or older sample who were eligible for the ADAMS was represented by a proxy in the 2002 HRS. Approximately 60% of the age 70 or older respondents who were represented by a proxy had cognitive impairment.

Table 1. Selected HRS and ADAMS variables available for studies of the risk factors and outcomes of CIND and dementia

Measure	HRS question[1]
Demographic variables	
Birthdate	A1
Country/state of birth	A2a, A2b
Year immigrated	A2c
Gender	CS1a
Race/Ethnicity	A7, A8
Socioeconomic variables	
Marital status and marital history	CS4–CS15, A43
Living arrangements	CS11–CS15
Mother/father living	D90/D93
Frequency of contact	D107/D126
Number of children	D0
Ages	D1
Living arrangements	D0
Proximity of residence	D01b
Frequency of contact	D4
Number of grandchildren	D40/D42
Amount of caregiving	D76
Number of siblings	D130
Proximity of siblings	D142
Education	A3
Highest grade	A3
High school diploma/equivalency	A3a
Highest degree obtained	A3c
Parents' level of education	A5/A6
Religious preference	A36/A36a
Importance of religion	A36b
Region/area of residence	A25
Residential history	A26a
Social interaction variables	
Good friends/relatives in neighborhood	D155
Frequency of visiting friends	D156
Enjoyable times with spouse/partner	D158
Spending free time with spouse	D159
Volunteer work for organizations	E172
Assisting friends/family with chores	E173
Employment history variables	
Occupation	G25, G41b, G42
Employment history	Section GG
Military service	A10
Retirement	G1
Pensions	G30, G69
Father's occupation	A4f
Income history	Section H
Assets and debts	Section J
Capital gains	Section J

Measure	HRS question[1]
Health variables	
General health	B1
Change in general health	B1a–B1c
Hypertension	B3
Medications	B3a
Treatment	B3b
Diabetes	B4
Medications	B4a/B4b
Treatments	B4c/B4d
Cancer	B5
Doctor visit in last 2 years	B5a
Treatments	B5b/B5c
Year diagnosed	B5j
Chronic lung disease	B6
Medications	B6b
Treatments	B6c/B6d
Limits on activities	B6f
Heart problems	B7
Medications	B7a
Heart attack	B7d
Congestive heart failure	B7kb
Cardiac catheterization / angioplasty	B7p
Heart surgery	B7q
Stroke	B9
Doctor visit in last 2 years	B9a
Symptoms/remaining problems	B9c–B9f
Physical therapy	B9h
Psychiatric conditions	B10
Medications	B10c
Other treatment	B10b
Emotional health	C5
Cigarette smoking history	B20
Alcohol use history	B21
Physical activity	B19q
Weight (current)	B22
Gain or lose 10 lbs in last 2 years	B22a
Height	B22d
Activities of daily living	E72–E77
Memory variables	
History of 'memory-related disease'	B10d
Self-rating of current memory	RC1
Rating of memory compared to 2 years ago	RC2
Family history of memory-related disease	D91d, D94d
Selected additional ADAMS variables	
APOE genotype	
History of head injury	
Full list of current medications	

[1] Question numbers are from the HRS 2000 survey.

The baseline participation rate for the HRS and AHEAD cohorts was about 80%, and the re-interview participation rates for subsequent waves have been 92–95%. Additional information on sampling strategy, participation rates, and mortality of study subjects is available at the HRS web site.

Informed consent is obtained orally from all respondents prior to each HRS interview, and written informed consent was obtained from ADAMS study subjects after study procedures were fully explained. The HRS was approved by the Institutional Review Board of the University of Michigan, and ADAMS was approved by both the Michigan and Duke University Institutional Review Boards.

Data from the HRS are available free of charge to the research community. As of April 2004, an estimated 2,500 investigators had either used or were registered to use the HRS data, and over 800 publications and reports had been prepared based on the data. (See the HRS web site at http://hrsonline.isr.umich.edu for more information on the organization and design of the HRS and ADAMS, and procedures for downloading data.)

HRS Measures

The HRS collects an extensive set of data on the demographics, health, employment, wealth, family structure, and family transfers (both financial and caregiving) of study subjects [4]. See table 1 for selected HRS variables. Full documentation of all survey measures and variables is available at the HRS web site.

Especially relevant to the ADAMS are the HRS cognitive measures administered at each wave of the survey. This cognitive battery includes an abbreviated version of the Telephone Interview for Cognitive Status (TICS) [5] to assess cognitive function, and two vocabulary tests to measure knowledge or baseline intelligence [6]. The TICS was patterned after the Mini-Mental State Examination [7], and the abbreviated version used in the HRS includes: an immediate and delayed 10-noun free recall test to measure memory; a serial seven subtraction test to measure working memory; a timed counting backwards test to assess attention and mental processing speed; an object naming test to measure knowledge and language, and recall of the date, the president, and the vice-president to measure orientation. A similar version of this instrument (the TICS-m) detects a range of mild to moderate cognitive impairments and is a useful indicator of dementia [8, 9].

In proxy interviews, cognitive decline and dementia are measured using the short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) which asks about change over the last 2 years in the respondent's ability to remember various types of information and to perform typical daily activities [10, 11]. Prior studies have shown that the IQCODE discriminates well between those with and without a diagnosis of dementia [10, 11]. For more detailed information on the self-report and proxy cognitive measures used in the HRS, see documentation [12] at the HRS web site: http://hrsonline.isr.umich.edu/docs/userg/dr-006.pdf.

Longitudinal Follow-Up of HRS/ADAMS Respondents

Tracking respondents from wave to wave is a critical activity in longitudinal surveys. The Survey Research Center at the University of Michigan successfully tracks 98–99% of the HRS sample members at each biennial wave of the survey. The Survey Research Center uses multiple sources for tracking HRS respondents who move or become institutionalized. First, all respondents are asked to provide the name, address, and phone number for two individuals who may be contacted in the event that the respondent cannot be reached. This information is collected in the baseline interview and is updated at each subsequent wave. Social Security numbers are also collected for tracking purposes. If efforts to reach a contact person fail, a combination of national directories/registries, internet resources, and local sources (e.g. voter registration records, motor vehicle registration, local Department of Health and Human Services office) are employed. These HRS tracking methods used for all HRS sample members were supplemented by additional efforts by ADAMS study personnel at Duke University to track relocated or institutionalized ADAMS subjects in order to perform the initial and 18-month follow-up assessments.

The HRS tracking methods described above also provide information on whether a respondent has died between survey waves. A respondent's vital status determined through these follow-up procedures is verified through a linkage to the National Death Index (NDI) maintained by the National Center for Health Statistics. This NDI linkage also provides a verification of the date of the HRS respondent's death, and detailed information on the cause of death. Currently, data on vital status for all HRS respondents are available through the 2002 wave (see the HRS web site for information on obtaining these data). For each HRS respondent who has died, a proxy informant is sought to provide an 'exit interview' regarding important details of the last few months of the respon-

dent's life (e.g. advanced directives, illnesses, health care utilization, hospice use, and family caregiving). Vital status, including NDI verification, and exit interview data will be available for ADAMS subjects.

ADAMS Sample Selection

The nationally representative HRS sample provided the sample frame for the ADAMS. From the larger HRS sample, a random subsample of 1,770 individuals age ≥70 was selected for participation in the ADAMS, with the goal of obtaining clinical assessments on about 850 individuals. In order to ensure a sufficient number of respondents across the full range of cognitive ability, the sample was stratified based on cognitive status. Five cognitive strata (ranging from 'low functioning' to 'high normal') were defined based on respondents' performance on the cognitive measures in the most recent HRS interview (either 2000 or 2002, depending on the timing of recruitment into the ADAMS). Scores on the full set of HRS cognitive tests (ranging from 0 to 35 points) were used to classify self-respondents, and scores on the IQCODE were used to classify proxy respondents. The cognitively normal group was further stratified by age (age 70–79 versus 80 or older) and sex in order to ensure adequate numbers in each of these subgroups. More detailed information on the ADAMS sampling strategy, including the cut-points and sample size for each cognitive stratum will be available with the ADAMS data and documentation at the HRS web site.

Initial ADAMS assessments were completed for 856 subjects (representing a 56% response rate among nondeceased sample members) between August 2001 and December 2003. Eighteen-month follow-up visits were completed for 252 subjects (85% follow-up rate among nondeceased sample members) between November 2002 and March 2005.

ADAMS Diagnostic Evaluation

The ADAMS in-person evaluation was a 3- to 4-hour structured assessment conducted in the subject's residence by a nurse and neuropsychology technician. The following information about the respondent was collected from a knowledgeable informant: (1) a chronological history of cognitive symptoms; (2) medical history; (3) current medications; (4) current neuropsychiatric symptoms; (5) measures of severity of cognitive and functional impairment; (6) family history of memory problems, and (7) a caregiving questionnaire detailing the time and strain associated with providing care. During the assessment, the respondent completed: (1) a battery of neuropsychological measures (table 2); (2) a self-report depression measure; (3) a standardized neurological examination; (4) a blood pressure measure; (5) collection of buccal DNA samples for APOE genotyping, and (6) a 7-min videotaped segment covering portions of the cognitive status and neurological examinations. Medical record releases were also sought to obtain relevant prior neuroimaging and laboratory results from subjects' physicians.

The ADAMS neuropsychology technicians were from Duke University and were trained by a PhD-level clinical neuropsychologist. The supervising neuropsychologist accompanied new staff on initial visits to certify level of performance, conducted reviews of audiotapes for quality assurance, and also reviewed the raw neuropsycholological data from each test visit. All testing was scored by the original technician and scored again by a second technician before final review by the supervising neuropsychologist.

Table 2. ADAMS neuropsychological and other measures

Neuropsychological measures
CERAD Animal Fluency
CERAD Abbreviated Boston Naming Test
Mini-Mental State Exam
CERAD Word List Three Trial Learning, Delayed Recall and Recognition
CERAD Constructional Praxis Copying, Delayed Recall and Recognition
Trail Making Test Part A and B
Wechsler Memory Scale-Revised Logical Memory I (immediate) and Logical Memory II (delayed)
Controlled Oral Word Association
Symbol Digit Modality Test
Digit Span
Fuld Object Memory Test
Shipley Vocabulary Test (Shipley Institute of Living Scale)
WRAT 3 Blue Reading Test (literacy)
HRS self-respondent cognitive measures (modified TICS)
Other measures
Clinical and medical history
Clinical Dementia Rating Scale
Blessed Dementia Scale
Modified Hachinski Ischemic Score
Dementia Severity Rating Scale
Neuropsychiatric Inventory
Composite International Diagnostic Interview (CIDI depression screen)
Memory Impairment Screen
HRS Self-Report of Memory Problem Questions
Buccal DNA sample for APOE genotyping
Standardized Neurological Physical Examination
Current prescription medications
Caregiving Questionnaire

ADAMS Neuropsychological and Other Measures

The full ADAMS neuropsychological test battery administered to the respondent and other measures that are collected during the in-home assessment are shown in table 2. This battery of neuropsychological tests has proven useful in several other research protocols that require differential diagnosis in cohorts at risk for dementia [13–15]. In these other protocols, and in the ADAMS, this battery of tests has been well accepted by elderly subjects, reasonably brief (average time to complete is 90–100 min), reasonably comprehensive, and sensitive to longitudinal changes in performance [16]. In addition, the tests are sensitive to early changes of AD, other dementias, and CIND, and able to assesses the full range of cognitive performance levels, thereby minimizing 'ceiling' and 'floor' effects [17]. The tests are sufficiently structured to allow standardized administration, thereby minimizing variation across examiners, and widely used, so results can be readily interpreted by most dementia researchers. Finally, many components of the test battery, such as those of the CERAD, have been studied in US minority populations [18, 19], as well as cross-culturally [20, 21]. Spanish-language versions of almost all measures were available via publishers or ongoing research studies.

The severity of dementia or cognitive impairment was rated with two separate measures: the informant-completed Dementia Severity Rating Scale [22], and the clinician-completed Clinical Dementia Rating Scale [23]. The Dementia Severity Rating Scale and Clinical Dementia Rating Scale show good correlation [22]. The modified Hachinski Ischemic Score [24], a standard measure of risk for vascular dementia, was completed after the in-home visit at the time of the diagnostic conference (described below).

Additional information gathered to aid with interpretation of neuropsychological test results included: demographic information, developmental and occupational history, handedness information [25], and family history of memory impairment. Also, all ADAMS informants completed a self-administered questionnaire that included items addressing functional limitations in the ADAMS subject, out-of-pocket medical expenditures for the ADAMS subject, and employment and demographic information for the informant. If the informant provided informal care or supervision to the ADAMS subject during the past month, the informant also answered questions regarding caregiving time, caregiver strain [26], depressive symptoms, adjustments to work schedule and leisure activities due to caregiving, and the use of paid caregivers. The informant questionnaire also included the IQCODE to facilitate comparisons of ADAMS informant assessments of cognitive decline to those collected for all respondents (age ≥ 65) in the HRS.

Assigning a Diagnosis

A Duke University geropsychiatrist (D.C.S.), neurologist (J.R.B.), neuropsychologist (G.G.P.), and cognitive neuroscientist (B.L.P.) reviewed all information collected during the in-home assessment, and assigned a preliminary research diagnosis regarding cognitive status. Subsequently, the study geropsychiatrist reviewed available medical records and revised the preliminary research diagnosis when justified by this additional medical information. Diagnoses fell within the three general categories of normal cognitive function, CIND, and dementia. Within the CIND and dementia categories, there were several subcategories to denote etiology of cognitive impairment (table 3). Diagnostic criteria were established prior to the start of the ADAMS and were based on published criteria such as the DSM-III-R [27] and DSM-IV [28]. (See table 3 for the sources of additional diagnostic criteria used in the ADAMS.) To capture the likely range of etiologies and clinical presentations of CIND, we defined CIND broadly as functional impairment reported by the ADAMS subject or informant that did not meet criteria for dementia, or performance on neuropsychological measures that was below expectation and ≥ 1.5 standard deviations below published norms on any test within a cognitive domain (e.g. memory, orientation, language, executive function, praxis). Final diagnoses were assigned by a consensus expert panel made up of neuropsychologists, neurologists, geropsychiatrists, and internists. The Duke University researchers and the consensus diagnosis panel were blind to the HRS cognitive stratum from which the individual was drawn.

Eighteen-Month Follow-Up Assessments

A subset of 333 ADAMS subjects (39%) was selected to undergo a follow-up assessment approximately 18 months after the initial assessment. Follow-up assessments were completed for 252 subjects (76%); 36 subjects (11%) died before a follow-up visit could be completed, and 45 subjects (13%) refused a follow-up visit or did not participate for another reason (e.g. the subject did not have an available informant or the in-home assessment was cancelled due to illness in the subject or informant).

The same in-home assessment protocol was used for both the initial and follow-up assessments. Subjects were selected to receive a follow-up assessment for one of two

Table 3. ADAMS diagnostic categories

Demented
Alzheimer's disease [34]
Probable Alzheimer's disease
Possible Alzheimer's disease
Vascular dementia [35]
Probable vascular dementia
Possible vascular dementia
Subcortical dementias
Parkinson's disease
Huntington's disease
Progressive supranuclear palsy
Normal pressure hydrocephalus
Other dementias
Dementia of undetermined etiology
Frontal lobe dementia [36]
Severe head trauma
Alcoholic dementia
ALS with dementia
Hypoperfusion dementia
Lewy body dementia [37]
Postencephalitic dementia
CIND
Mild-ambiguous
Mild cognitive impairment [38]
Cognitive impairment secondary to vascular disease
Stroke
Other neurological conditions
Other medical conditions
Depression
Psychiatric disorder
Low baseline intellect/mental retardation
Alcohol abuse (past)
Alcohol abuse (current)
Normal cognitive function
Normal/non-case

reasons: (1) they received an initial diagnosis of CIND, or (2) they received an initial diagnosis of normal or demented, but the consensus panel thought the data collected at the initial assessment were ambiguous and a second assessment providing longitudinal data would help to clarify the diagnosis. After the follow-up assessment, the consensus panel reviewed all of the information collected to date and assigned a final diagnosis. At the time of the consensus review of the follow-up assessments, the panel of experts was blind to the diagnosis assigned after the first in-home assessment. However, the panel members were able to examine the clinical and neuropsychological data from the initial assessment as part of their deliberation regarding the diagnosis for the follow-up assessment.

Characteristics of the ADAMS Sample

Table 4 shows the characteristics of all 1,770 individuals in the HRS random subsample drawn for the ADAMS. The first column shows the characteristics of the 856 ADAMS subjects (48%) who were assessed; the second column shows the 227 individuals (13%) who died before they could be contacted or assessed; the third column shows the 687 individuals (39%) who refused participation or who did not participate for other reasons, and the final column shows characteristics for the total sample.

The 856 ADAMS subjects did not differ significantly from study nonparticipants in age, sex, or education, but were more likely to be African-American ($p < 0.05$), to have been a self-respondent at the prior HRS wave ($p < 0.05$), and to have scored in the normal range on the HRS cognitive test in the prior wave ($p < 0.05$). The detailed information on ADAMS nonparticipants that is available from their HRS interviews (e.g. their performance on the HRS cognitive tests from prior survey waves) will allow researchers to identify and possibly adjust for potential biases that might result from differences between ADAMS subjects and study nonparticipants.

Because the ADAMS sample was drawn from the nationally representative HRS sample, researchers will be able to derive national estimates for the age 70 or older US population by using ADAMS survey weights that will be available when the ADAMS is completed. The percentages included in table 4 are unweighted and do not represent population level estimates for these sample characteristics.

Most of the 856 assessed ADAMS subjects were between 75 and 84 years old, but nearly one third of the sample was 85 or older. About 60% of ADAMS subjects were female, 10% were Hispanic, and 19% were Black (Non-Hispanic). Eleven percent of ADAMS subjects lived in a nursing home at the time of their 2000 or 2002 HRS interview. About three fourths of ADAMS subjects provided self-reports in the HRS wave prior to their assessment (either 2000 or 2002), while about one fourth was represented by a proxy respondent. The subjects lived in 42 states distributed throughout all census regions of the US.

Approximately 36% of ADAMS subjects were diagnosed as normal, 28% received a diagnosis of CIND, and 36% were diagnosed with dementia. It should again be noted that this distribution of diagnoses is unweighted and cannot, therefore, be used to estimate national prevalence of dementia until the ADAMS survey weights are available when the study is completed.

Table 4. Characteristics of the ADAMS sample

Characteristic	Assessed (n = 856)	Deceased (n = 227)	Not assessed[1] (n = 687)	Total sample (N = 1,770)
Age (in HRS 2000 or 2002)				
70–74	171 (20)	13 (6)	151 (22)	335 (19)
75–79	188 (22)	33 (15)	160 (23)	381 (22)
80–84	224 (26)	51 (22)	166 (24)	441 (25)
85–89	149 (17)	59 (26)	126 (18)	334 (19)
90+	124 (15)	71 (31)	84 (12)	279 (16)
Sex				
Male	355 (41)	94 (41)	263 (38)	712 (40)
Female	501 (59)	133 (59)	424 (62)	1,059 (60)
Race/ethnicity				
Hispanic	84 (10)	16 (7)	55 (8)	155 (9)
Black, Non-Hispanic	159 (19)	39 (17)	101 (15)	299 (17)
White, Non-Hispanic	613 (72)	170 (76)	530 (77)	1,313 (74)
Education				
<12 years	442 (52)	117 (52)	324 (47)	883 (50)
12 years	196 (23)	54 (24)	200 (29)	450 (25)
>12 years	218 (25)	56 (24)	163 (24)	437 (25)
Residence[2]				
Community	763 (89)	147 (65)	622 (91)	1,532 (87)
Nursing home	93 (11)	80 (35)	65 (9)	238 (13)
Respondent type				
Self-respondent	657 (77)	96 (42)	484 (70)	1,237 (70)
Proxy	199 (23)	131 (58)	203 (30)	533 (30)
US census region				
Northeast	120 (14)	41 (18)	137 (20)	298 (17)
Midwest	167 (19)	61 (27)	165 (24)	393 (22)
South Atlantic	239 (28)	57 (25)	154 (22)	450 (25)
South Central	163 (19)	38 (17)	125 (18)	326 (19)
West	167 (20)	30 (13)	106 (16)	303 (17)
Diagnosis				
Normal	307 (36)	0	0	307 (17)
CIND	241 (28)	0	0	241 (14)
Dementia	308 (36)	0	0	308 (17)
Not assessed	0	227 (100)	687 (100)	914 (52)

Figures in parentheses indicate unweighted percentages.

[1] The 'Not assessed' category includes 500 individuals who refused participation in the study and 186 who did not participate for other reasons.

[2] Residence indicates where the subject was living at the time of the HRS interview prior to the ADAMS assessment. N = 109 (13%) subjects assessed in ADAMS resided in a nursing home at the time the ADAMS assessment was conducted.

Potential Uses of ADAMS Data

Identification of Risk Factors for CIND and Dementia

Linking ADAMS clinical assessment data to the wealth of available longitudinal HRS data will allow a wide range of studies on the natural history of cognitive change in older people. Additionally, the linked HRS-ADAMS data will facilitate studies of the demographic (e.g. age, gender, race), socioeconomic (e.g. education level, net worth), behavioral (e.g. tobacco and alcohol use, level of physical activity), medical (e.g. hypertension, heart disease, diabe-

tes, head trauma), and genetic (APOE genotype) characteristics that are potential protective or risk factors for CIND and dementia. The combination of up to 10 years of prior HRS survey data (including risk factor information that may predate the onset of cognitive impairment) and the full clinical assessment from the ADAMS will provide a unique opportunity to study the onset of CIND and dementia in a nationally representative population-based sample. Table 1 shows selected HRS and ADAMS variables that are available for studies of potential risk factors for CIND and dementia.

Outcomes of CIND and Dementia

In addition to the 18-month in-home follow-up assessment for ADAMS subjects diagnosed with CIND at the initial assessment, all surviving ADAMS subjects (and their spouses) were re-interviewed during the 2004 HRS field period, and future waves of HRS data collection are planned for 2006, 2008, and 2010. The availability of this extensive longitudinal information for ADAMS subjects from both before and after their ADAMS assessments will allow users with varied disciplinary backgrounds to study the impact of CIND and dementia on a wide range of clinical, family, and economic outcomes.

Costs of CIND and Dementia

The HRS and ADAMS will provide an unprecedented opportunity to study the economic and social costs associated with CIND and dementia in a nationally representative sample. Each wave of the HRS collects extensive data on utilization of health care services, including nursing home stays, inpatient hospital stays, physician visits, outpatient procedures, dental visits, and home health care. For services used, respondents are asked whether any of the costs were covered by health insurance, and what their total out-of-pocket expenditures were (if any). The HRS also has a wide range of income, asset, net worth, and insurance data that are important for understanding the distribution of the costs of dementia across private (e.g. out-of-pocket medical expenditures) and public (e.g. the Medicare and Medicaid programs) sources, and the dynamics of spending behaviors that may result from cognitive decline (e.g. nursing home 'spend-down').

Informal (unpaid) caregiving provided by families is a major component of the cost associated with dementia, especially when the affected individual is living in the community rather than in a nursing home [2, 3]. The HRS collects extensive data on informal caregiving and changes in living arrangements that will allow a comprehensive picture of a family's provision of informal care associated with CIND and dementia. In addition, as noted above, the extensive caregiver data from the HRS were supplemented in the ADAMS by additional information on caregiver strain, caregiver depression, and caregiver adjustments to work schedule and leisure activities.

Population Prevalence Estimates of CIND and Dementia

A sampling weight based on the probability of selection into the HRS is available for each HRS respondent. This weight can be used to obtain national population estimates when using the HRS data. Similarly, a sampling weight for each ADAMS subject will be available with the ADAMS data, thereby allowing estimation of the population prevalence of CIND and dementia based on the distribution of diagnoses in the ADAMS. Population prevalence of CIND and dementia can be estimated as the simple weighted average of the CIND and dementia diagnoses that are included in the ADAMS data set. Likewise, the weighted ADAMS data can be used for estimation of many other characteristics and relationships in the full national population. For example, a population model for the relationship of CIND diagnosis to cognition measures, medical history variables, and other covariates can be estimated by fitting a weighted logistic regression applied to the ADAMS data. Small sample sizes for some of the diagnoses within the CIND and dementia categories (e.g. alcoholic dementia, Lewy body dementia, psychiatric disorder) will preclude the possibility of obtaining useful national prevalence estimates for these individual diagnoses, and they will need to be collapsed with other diagnoses within the larger CIND and dementia categories.

Estimation of the Likelihood of CIND and Dementia for All HRS Subjects

Data from the ADAMS clinical evaluation and consensus diagnosis will be combined with longitudinal HRS data for ADAMS subjects to estimate statistical models relating the ADAMS CIND and dementia diagnoses to the cognition, demographic, and health measures collected at each HRS interview. A multinomial logistic model estimated from the ADAMS sample will then be applied to the covariate measures for the full HRS data set to estimate for each case a vector of probabilities indexing the likelihood of being normal, CIND, or demented. These probability indices may be used directly as dependent variables to estimate dementia prevalence or to model risk factors for dementia and CIND [29]. The predicted

probability indices may also be employed as independent variables in models and simulation studies of the effects of CIND and dementia on functional decline, institutionalization, health care costs, caregiver burden, and other outcomes.

International Comparisons

The ADAMS will provide nationally representative data on the prevalence and outcomes of CIND and dementia in the United States, thereby facilitating cross-national comparisons of prevalence, health care utilization, and outcomes related to CIND and dementia in other countries. The Canadian Study of Health and Aging [30] is a population-based study of CIND and dementia in Canada. The CIND criteria and subcategories used in the Canadian Study of Health and Aging and ADAMS are similar, so valid comparisons across the two countries in prevalence, subtypes, and outcomes can be made.

Three other population-based surveys with content patterned after that of the HRS have recently been fielded, including the Mexican Health and Aging Study [31], the English Longitudinal Study of Ageing [32], and the Survey of Health and Aging in Europe [33]. Each of these studies has measures of cognitive impairment, as well as health, wealth, and family information that is comparable to that collected in the HRS. The HRS/ADAMS will provide an excellent opportunity to compare the prevalence and impact of cognitive impairment in the United States with that in the other countries represented by these similar population-based studies of aging.

Strengths and Limitations of the ADAMS

As noted above, the main strengths of the ADAMS are its population-based sample that included participants from all regions of the country, a standardized diagnostic protocol, and the extensive longitudinal data from the HRS that can be linked with the ADAMS clinical assessments. The national sample of the ADAMS provides greater geographic representation than prior epidemiologic studies of dementia in the US, and greater diversity in socioeconomic characteristics compared to studies that are limited to clinical samples.

A number of limitations of the ADAMS will be important for users of the data to consider. While the initial participation rate of 56% (net of mortality) is comparable to prior epidemiologic studies in older adults, it does raise the possibility that generalizability of the findings will be less than ideal. Second, the ADAMS mainly provides data on prevalent, rather than incident, cognitive impairment, thereby making more difficult the identification of the direction of causality between potential risks and outcomes for CIND and dementia. As noted above, the available HRS data on cognitive function from both before and after the ADAMS assessments will allow researchers to partially address this limitation, but it will remain an important issue for users of ADAMS data to consider.

Obtaining ADAMS Data

ADAMS data will be publicly available to all interested researchers. Data files will be available for download from the HRS web site in late 2005. In order to protect the confidentiality of HRS/ADAMS participants, access to some types of data will be restricted. A description of the process for obtaining access to restricted data is available at the HRS web site.

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