ORIGINAL ARTICLE

Asking Family About Memory Loss

Is It Helpful?

Lea C. Watson, MD, MPH,¹ Carmen L. Lewis, MD, MPH,² Gerda G. Fillenbaum, PhD³

¹Department of Psychiatry, Duke University Medical Center, Durham, NC, USA; ²Department of Medicine, Division of General Internal Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; ³Center for the Study of Aging and Human Development, Duke University Medical Center, Durham, NC, USA.

OBJECTIVE: To compare a family informant's report of memory loss in an older family member to standardized clinical diagnoses of cognitive impairment.

SETTING: Duke Established Populations for Epidemiologic Studies of the Elderly (EPESE), a 10-year longitudinal study of community dwellers aged 65 and greater in five counties of North Carolina.

PARTICIPANTS: A stratified random sample of potentially demented participants was selected from the second wave of the Duke EPESE using responses to a brief cognitive screen. A neuropsychological battery was administered to these participants, and their family informants were asked whether they recognized memory loss in the participant. One hundred fifty-seven participants completed the full evaluation and also had an available family informant.

MAIN OUTCOME MEASURES: Family informant's report of memory loss (yes, no, sometimes) compared to expert consensus diagnosis of cognitive impairment or dementia.

RESULTS: There was poor concordance between the clinical diagnoses of cognitive impairment or dementia and the family informant's recognition of memory loss ($\kappa = -0.05$; $P = .74$). When informants reported memory loss, 30% of participants were found not to have a cognitive loss. Among participants in whom family informants reported no memory loss, 75% were diagnosed with dementia or cognitive impairment (sensitivity, 0.70, 95% confidence interval [CI], 0.61 to 0.78; specificity, 0.24, 95% CI, 0.13 to 0.40; positive predictive value, 70%; negative predictive value, 25%).

CONCLUSIONS: Asking family members about memory loss in a patient may be an unreliable strategy to detect dementia.

KEY WORDS: dementia; informants; screening.

DOI: 10.1111/j.1525-1497.2004.40113.x

J GEN INTERN MED 2004; 20:28-32.

Dementia and clinically significant memory impairment are common, and are associated with substantial morbidity.¹⁻⁴ However, detection of dementia in primary care is poor.^{5,6} Among community residents with dementia, dementia is not recognized in 2 out of 3 people who see their physician.^{7,8} If clinicians recognize cognitive impairment, they can

address safety issues before urgent needs arise, and can in some instances prolong quality of life by prescribing medications directed at slowing disease progression.^{1,3,9} They can also prepare patients and family for the realities of a difficult illness.

Recognizing memory loss is central to diagnosing dementia and to defining mild cognitive impairment.¹⁰ Ten percent to 12% of patients diagnosed with mild cognitive impairment go on to develop dementia within 1 year.¹¹⁻¹³ However, people with dementia frequently do not complain of memory loss, nor do they endorse it when questioned.^{5,6} Therefore, clinicians may rely on informants, usually family members, to report signs of dementia in older patients. This is understandable given the time limitations in the primary care setting, particularly when the possibility of dementia is not the occasion for the visit.

The accuracy of informant reporting on persons with dementia has been addressed primarily in the context of performing research. Investigators have raised concerns about the reliability of informant reporting in research studies involving demented participants.^{14,15} In a systematic review that evaluated the validity of informant responses in studies of older adults, results showed that informants performed well on most factual and objective measures, but tended to describe more impairment in functioning and emotional well-being than was seen in the subject, a finding that was particularly marked in subjects with cognitive impairment.¹⁶

Fewer studies specifically address informant recognition of cognitive impairment, and the results are mixed. In outpatient clinic populations, where patients or families have recognized symptoms and initiated dementia-related care, informant reporting of impairment generally agrees with clinical findings.¹⁴ The only study we identified from a primary care population, however, showed that when informants were asked about specific aspects of the patient's cognitive functioning, the corresponding psychometric tests in the patient were concordant only 60% of the time.¹⁷ On the other hand, in several studies of community dwellers, informant's responses to structured questionnaires were concordant with results of participant's cognitive testing,^{18,19} and in a study including hospitalized patients, combining cognitive testing of the participant with results from a structured informant report increased the accuracy of detecting dementia.²⁰

The constraints of primary care often prevent the routine use of structured questionnaires for family members of patients. While clinicians are more likely to ask family members informal questions about memory impairment in their older patients, the accuracy of these responses is unknown. The purpose of this study is to compare a family informant's report

Accepted for publication June 1, 2004

The authors do not have any competing interests to report.

This work was presented in part at the 15th annual meeting of the American Association for Geriatric Psychiatry, Orlando, FL, February 2002 and at the Robert Wood Johnson Clinical Scholars national meeting, Fort Lauderdale, FL, November 2002.

Address correspondence and requests for reprints to Dr. Watson: Department of Psychiatry, Program of Geriatric Psychiatry, Duke University Medical Center, Box 3903, Durham, NC 27710 (e-mail: watso069@mc.duke.edu).

about memory loss with a standardized clinical diagnosis of cognitive impairment or dementia.

METHODS

This work is a cross-sectional analysis of a subsample from the Duke Established Populations for Epidemiologic Studies of the Elderly (EPESE), one of four national sites funded by the National Institute on Aging to investigate prospectively the health and functional status of persons aged 65 years and older in the United States.²¹ To improve statistical precision in racial comparisons, the Duke site oversampled African Americans. Data were collected from the index community-dwelling older adult (hereafter referred to as the “participant”) and from a family member (hereafter referred to as the “informant”) identified as the closest contact. The Institutional Review Board of Duke University Medical Center approved the study.

Our study sample (Fig. 1) was drawn from the Duke EPESE second in-person wave (1989 to 1990; $N=3,337$). Each participant had completed the Short Portable Mental Status Questionnaire (SPMSQ),²² a 10-item screen of cognitive function that when adjusted shows little race or education bias. To select a subsample of participants with a spectrum of cognitive functioning, but enriched with those likely to have dementia, SPMSQ scores were classified as unimpaired, marginally impaired, or cognitively impaired based on race- and education-adjusted cut points. Randomized sampling from each category²³ yielded 343 participants who consented to participate in this study. Because this substudy oversampled for cognitive impairment, participants are not representative of the Duke EPESE population.

All interviews were conducted in participants’ homes. Information was collected from participants (with assistance from informants), about the participants’ demographic characteristics, functional status, and health status. Ability to perform activities of daily living (ADL) was determined by

responses based on the Katz ADL scale²⁴ and the Older Americans Resources and Services instrumental ADL scale.²⁵ Participants then completed the Consortium to Establish a Registry for Alzheimer’s Disease (CERAD) Neuropsychological Battery.²⁶ This battery included 5 measures, tapping areas of cognitive function implicated in Alzheimer’s disease: verbal fluency; confrontational naming; the Mini Mental State Examination (MMSE)²⁷; word list learning, recall, and recognition; and constructional praxis. The clock-drawing test from the CERAD Clinical Battery was added.

Simultaneously at the same interview, structured questionnaires were administered to informants regarding the participants’ behavior, personality, and ability to care for themselves. Additionally, the informant was specifically asked, “Does he/she (participant) have a memory loss?” Possible responses were “yes,” “no,” and “sometimes.”

Participants were selected for a full clinical evaluation if they complained of poor memory or their informant mentioned this, scored less than 24 (if white) or 18 (if African American) on the MMSE,²⁸ had an inadequate drawing of a clock, recalled fewer than 3 items from a 10-item word list recall task, or appeared significantly memory impaired to the interviewer. One hundred eighty-three participants met these criteria and received a clinical evaluation. This included an in-home evaluation by a project-trained clinical research nurse, a review of all available medical records within the last 5 years, and the administration of the CERAD Clinical Battery expanded to include dementias other than Alzheimer’s disease. The CERAD Clinical Battery focuses on health history relevant to dementia, depression, medications, ability to perform instrumental and basic ADLs, and language ability. It includes measures of cognitive function and brief physical and neurological assessments.

Two experienced clinicians (a geriatrician and a neurologist) independently reviewed clinical evaluation data and a consensus diagnosis was reached. These diagnoses were related to a specific etiology when possible, based on criteria defined by the Diagnostic and Statistical Manual of Mental Disorders-IV and the criteria for Alzheimer’s disease from the National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer’s Disease and Related Disorders Association.²⁹ Cognitive impairment was defined as clinically significant memory loss which nevertheless did not affect ability to perform activities of daily living. We used descriptive statistics to characterize the sample of participants and family informants. κ was used to test for agreement beyond chance between family informant responses about participant memory loss and clinical diagnosis of dementia or cognitive impairment.³⁰ Sensitivity, specificity, and likelihood ratios were calculated to determine the accuracy with which the question about memory loss identified dementia.

RESULTS

Of the 343 participants who agreed to the study, 183 completed a full clinical evaluation for dementia. We included only those participants who received this evaluation and also had a family informant, resulting in a final sample of 157. The absence of an available informant accounted for all ineligible participants.

Participants had an average age of 75 years, and half had no education beyond grade school (Table 1). Sixty-five percent of the participants were African-American, and the median

FIGURE 1. Study sample. *Based on DSM-IV, National Institute of Neurological Diseases and Stroke-Alzheimer’s Disease and Related Disorders Association criteria. EPESE, Established Populations for Epidemiologic Studies of the Elderly; SPMSQ, Short Portable Mental Status Questionnaire, a brief 10-item cognitive screen; CERAD, Consortium to Establish a Registry for Alzheimer’s Disease neuropsychological battery, a comprehensive cognitive evaluation by trained interviewers.

Table 1. Patient Characteristics (N=157)*

Mean age, y (range)	75 (65 to 92)
Median years education	7.5
African American	102 (65)
Median MMSE score	18
Female	110 (70)
Married	35 (22)
Widowed	102 (65)
Health conditions†	
Arthritis	91 (58)
Hypertension	70 (45)
Heart disease	47 (30)
Stroke	31 (20)
Diabetes	30 (19)
Lung disease	19 (12)
Cancer	13 (8)
Needs assistance with	
Housework	107 (68)
Transportation	99 (63)
Shopping	97 (62)
Cooking	96 (61)
Handling money	94 (60)
Taking medications	85 (54)
Telephone	79 (50)
Needs assistance with	
Bathing	71 (45)
Dressing	69 (44)
Grooming	63 (40)
Walking	60 (38)
Continence	58 (37)
Transfers	50 (32)
Feeding	31 (20)

*Values expressed as number (percentage) unless otherwise noted.

†Health conditions in the patient were defined by report of the patient/family informant when asked what diagnoses had been given by a physician.

MMSE, Mini Mental State Exam.

MMSE score was 18/30. The majority of participants had multiple medical conditions, and also commonly required assistance with basic and instrumental ADLs.

Family informants had an average age of 60 (range, 26–93); 77% were female, and they had known the participant an average of 43 years. Most were daughters (29%), followed by extended family (22%), spouses (16%), sons (13%), formal caregivers (10%), and friends (10%).

Of the 157 participants undergoing full clinical evaluation for dementia, 112 (71%) had clinically significant memory impairment as determined by clinical consensus diagnosis. Among those with significant impairment, 19 (17%) were cognitively impaired and 93 (83%) met criteria for dementia. Of those classified as demented, 54 (58%) had Alzheimer's disease, 17 (18%) vascular dementia, 8 (9%) a combination of Alzheimer's disease and vascular dementia, 13 (14%) dementia of unknown etiology, and 1 (1%), alcohol dementia.

The agreement between family informant report of memory loss and a clinical diagnosis of cognitive impairment or dementia resulted in a κ of -0.05 , indicating no agreement beyond chance. These findings persisted when we excluded participants with mild cognitive impairment ($n=19$) and when we stratified by participant race.

Among participants whose informants reported memory loss (answering "yes" or "sometimes" when asked whether the participant had memory loss; $n=113$), clinical evaluation revealed significant cognitive impairment or dementia in 79 participants (70%); however, in 34 participants (30%), clinical

Table 2. Family Informant's Report of Memory Loss Versus Clinical Diagnosis of Dementia or Cognitive Impairment

Informant Reports Memory Loss	Clinical Diagnosis		Total
	Yes	No	
Yes/sometimes	79	34	113
No	33	11	44
Total	112	45	157

$\kappa = -0.05$; $P = .74$; sensitivity, 70%; specificity, 24%; positive predictive value, 70%; negative predictive value, 25%.

evaluation did not identify any cognitive loss. Among the 44 participants for whom informants reported no memory loss, clinical evaluation revealed significant cognitive impairment or dementia in 33 participants (75%) (Table 2).

Using the question about memory loss as a diagnostic test for detecting cognitive impairment or dementia, the sensitivity was 0.70 (95% confidence interval [CI], 0.62 to 0.78) and the specificity was 0.24 (95% CI, 0.13 to 0.40). This corresponded to a positive predictive value (PPV) of 70% and a negative predictive value (NPV) of 25%.

DISCUSSION

In a community sample of older adults selected for possible cognitive impairment, we found poor concordance between informant's report about memory loss and the presence or absence of clinically diagnosed dementia or cognitive impairment in the participant. Well-acquainted family informants frequently did not report memory loss in the participant despite a clinical diagnosis of dementia. They also commonly perceived a memory loss when thorough clinical evaluation revealed no cognitive loss. These results suggest that clinicians should not depend on a family member to detect dementia. However, family members who initiate a visit or spontaneously report memory problems in the patient should undoubtedly be taken seriously.

Families may not report memory loss in older adults for several reasons. They may view it as a normal part of aging, or not recognize slow progressive change.^{2,31} Families may also be unwilling to accept that someone on whom they depend is decompensating. Stigma about dementia, often perceived as "losing your mind," is also a challenge in older adults and their spouses fearful about loss of independence.^{32,33} Consistent with the reviews on proxy reporting,^{16,34} informants may be able to report accurately on observable signs, but be less accurate when reporting on subjective signs such as memory loss. Finally, some informants may be impaired themselves, and thus unable to recognize memory loss in others.

In contrast, informants in our study who reported memory loss in the absence of a clinical diagnosis of impairment may have been recognizing benign forgetfulness. Because informants were free to interpret the meaning of "memory loss," we cannot draw conclusions about what threshold of severity they deemed important. These results suggest that there likely is variation in the definition and interpretation of memory loss.

We acknowledge several limitations. Our study selected for cognitively impaired individuals and, therefore, does not reflect the community at large. We also examined only one

target question in reference to memory impairment. There is no specific evidence to support that this question mimics clinical practice, but our collective experiences in primary care and with our colleagues suggest that clinicians commonly ask older patients and their family about memory loss (likely because it is the key feature of dementia) without any further inquiry. Finally, small cell sizes limited our ability to perform subgroup analyses among those categorized as demented, which may have revealed improved concordance with increasing severity. It should be noted, however, that this sample was enriched for impairment (median MMSE, 18).

Participants included both African Americans (65% of our sample) and whites; cultural differences in accepting, recognizing, and reporting memory impairment may be present.^{35,36} It has been shown that African-American caregivers may choose not to seek care for dementia outside of the family system, and that they often "normalize" demented behaviors to fit their cultural values.³⁶ Similarly, in one study of Yoruba Nigerian and African-American elderly, caregivers recognized personality change, not memory loss, as the initial sign of dementia.³⁵ These and other potential cultural perspectives may have influenced the responses to our study questions.

These findings support the use of valid and reliable measures to screen for dementia in vulnerable older adults. Fortunately, several brief cognitive screens have been shown to be accurate and easily administered. For instance, Borson et al. have developed the "mini-cog," which includes 3 recall questions and a clock-drawing test.³⁷ Callahan et al. have developed a 6-item screen, which evaluates recall and orientation, and shows good discriminate ability for varying levels of cognitive impairment; the absence of clock drawing in this instrument allows for an even briefer administration time.³⁸ These and similar measures can also be administered in the waiting room by trained personnel, allowing the physician to focus on patients with positive screens.

Our results show poor concordance between family recognition of memory loss and clinical diagnoses of cognitive impairment or dementia. As clinicians, we must not rely on family members to detect dementia in our patients. Although informant input is crucial to the definitive diagnosis and management of dementia, families may not be consistent in recognizing the onset of memory loss and initiating treatment. Routine, structured screening, reinforced with family education about normal versus abnormal aging, may help overcome the complex barriers to identifying dementia.

Dr. Watson was supported by the Robert Wood Johnson Clinical Scholars Program at the University of North Carolina at Chapel Hill, and the study was funded by NIA grant AG08937. Participants in this study were selected from the Duke Established Populations for Epidemiologic Studies of the Elderly, which was performed pursuant to NIA contract N01-AG12102.

REFERENCES

- Cummings JL, Cole G. Alzheimer disease. *JAMA*. 2002;287:2335-8.
- Small GW, Rabins PV, Barry PP, et al. Diagnosis and treatment of Alzheimer disease and related disorders Consensus statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society. *JAMA*. 1997;278:1363-71.
- Tariot PN. Maintaining cognitive function in Alzheimer disease: how effective are current treatments? *Alzheimer Dis Assoc Disord*. 2001;15(suppl 1):S26-S33.
- Petersen RC. Aging, mild cognitive impairment, and Alzheimer's disease. *Neurol Clin*. 2000;18:789-806.
- Callahan CM, Hendrie HC, Tierney WM. Documentation and evaluation of cognitive impairment in elderly primary care patients. *Ann Intern Med*. 1995;122:422-9.
- Valcour VG, Masaki KH, Curb JD, Blanchette PL. The detection of dementia in the primary care setting. *Arch Intern Med*. 2000;160:2964-8.
- Lagaay AM, van der Meij JC, Hijmans W. Validation of medical history taking as part of a population based survey in subjects aged 85 and over. *BMJ*. 1992;304:1091-2.
- Sternberg SA, Wolfson C, Baumgarten M. Undetected dementia in community-dwelling older people: the Canadian Study of Health and Aging. *J Am Geriatr Soc*. 2000;48:1430-4.
- Winblad B, Brodaty H, Gauthier S, et al. Pharmacotherapy of Alzheimer's disease: is there a need to redefine treatment success? *Int J Geriatr Psychiatry*. 2001;16:653-66.
- Petersen RC, Stevens JC, Ganguli M, Tangalos EG, Cummings JL, DeKosky ST. Practice parameter: early detection of dementia: mild cognitive impairment (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2001;56:1133-42.
- Tierney MC, Szalai JP, Snow WG, Fisher RH. The prediction of Alzheimer disease: The role of patient and informant perceptions of cognitive deficits. *Arch Neurol*. 1996;53:423-7.
- Ritchie K, Artero S, Touchon J. Classification criteria for mild cognitive impairment: a population-based validation study. *Neurology*. 2001;56:37-42.
- Petersen RC, Doody R, Kurz A, et al. Current concepts in mild cognitive impairment. *Arch Neurol*. 2001;58:1985-92.
- Magaziner J. Use of proxies to measure health and functional outcomes in effectiveness research in persons with Alzheimer disease and related disorders. *Alzheimer Dis Assoc Disord*. 1997;11(Suppl 6):168-74.
- Nelson LM, Longstreth WT Jr, Koepsell TD, van Belle G. Proxy respondents in epidemiologic research. *Epidemiol Rev*. 1990;12:71-86.
- Neumann PJ, Araki SS, Gutterman EM. The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. *J Am Geriatr Soc*. 2000;48:1646-54.
- Kemp NM, Brodaty H, Pond D, Luscombe G. Diagnosing dementia in primary care: the accuracy of informant reports. *Alzheimer Dis Assoc Disord*. 2002;16:171-6.
- Jorm AF, Christensen H, Henderson AS, Korten AE, Mackinnon AJ, Scott R. Complaints of cognitive decline in the elderly: a comparison of reports by subjects and informants in a community survey. *Psychol Med*. 1994;24:365-74.
- Jorm AF. Methods of screening for dementia: a meta-analysis of studies comparing an informant questionnaire with a brief cognitive test. *Alzheimer Dis Assoc Disord*. 1997;11:158-62.
- Mackinnon A, Mulligan R. Combining cognitive testing and informant report to increase accuracy in screening for dementia. *Am J Psychiatry*. 1998;155:1529-35.
- Cornoni-Huntley J, Blazer DG, Lafferty M, Everett D, Brock D, Farmer M. Established Populations for Epidemiologic Studies of the Elderly. Volume II. Resource Data Book. Bethesda, MD: National Institute on Aging, U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health; 1990.
- Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *J Am Geriatr Soc*. 1975;23:433-41.
- Fillenbaum GG, Heyman A, Huber MS, et al. The prevalence and 3-year incidence of dementia in older black and white community residents. *J Clin Epidemiol*. 1998;51:587-95.
- Katz S, Akpom CA. A measure of primary sociobiological functions. *Int J Health Serv*. 1976;6:493-508.
- Fillenbaum G. Multidimensional Functional Assessment of Older Adults: The Duke Older Americans Resources and Services Procedures. Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.; 1988.
- Morris JC, Heyman A, Mohs RC, et al. The Consortium to Establish a Registry for Alzheimer's Disease (CERAD). Part I. Clinical and neuropsychological assessment of Alzheimer's disease. *Neurology*. 1989;39:1159-65.
- Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12:189-98.

28. **Murden RA, McRae TD, Kaner S, Bucknam ME.** Mini-Mental State exam scores vary with education in blacks and whites. *J Am Geriatr Soc.* 1991;39:149-55.
29. **McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM.** Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology.* 1984;34:939-44.
30. **Fleiss JL.** The Design and Analysis of Clinical Experiments. Wiley Series in Probability and Mathematical Statistics. Applied Probability and Statistics. New York, NY: Wiley; 1986.
31. **Goldman WP, Morris JC.** Evidence that age-associated memory impairment is not a normal variant of aging. *Alzheimer Dis Assoc Disord.* 2001;15:72-9.
32. **Benbow SM, Reynolds D.** Challenging the stigma of Alzheimer's disease. *Hosp Med.* 2000;61:174-7.
33. **Jolley DJ, Benbow SM.** Stigma and Alzheimer's disease: causes, consequences and a constructive approach. *Int J Clin Pract.* 2000;54:117-9.
34. **Magaziner J, Bassett SS, Hebel JR, Gruber-Baldini A.** Use of proxies to measure health and functional status in epidemiologic studies of community-dwelling women aged 65 years and older. *Am J Epidemiol.* 1996;143:283-92.
35. **Smith-Gamble V, Baiyewu O, Perkins AJ, et al.** Informant reports of changes in personality predict dementia in a population-based study of elderly African Americans and Yoruba. *Am J Geriatr Psychiatry.* 2002;10:724-32.
36. **Dilworth-Anderson P, Gibson BE.** The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Dis Assoc Disord.* 2002;16(Suppl 2):S56-S63.
37. **Borson S, Scanlan J, Brush M, Vitaliano P, Dokmak A.** The mini-cog: a cognitive 'vital signs' measure for dementia screening in multi-lingual elderly. *Int J Geriatr Psychiatry.* 2000;15:1021-7.
38. **Callahan C, Unverzagt F, Hui S, Perkins A, Hendrie HC.** A six-item screener to identify cognitive impairment among potential subjects for clinical research. *Med Care.* 2002;40:771-81.