

The Detection of Dementia in the Primary Care Setting

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Background: Recognition and medical record documentation of dementia in the primary care setting are thought to be poor. To our knowledge, previous studies have not examined these issues in private practice office settings within the United States.

Objective: To determine the rate of unrecognized and undocumented dementia in a primary care internal medicine private practice.

Methods: This was a cross-sectional study of 297 ambulatory persons aged 65 years and older attending an internal medicine private group practice within an Asian American community of Honolulu, Hawaii. Of the subjects, 95% had been with their current primary care physician for at least 1 year. Each subject's primary care physician noted the presence or absence of dementia by questionnaire at the time of an office visit. An investigating physician (V.G.V.) subsequently assessed cognitive function using the Cognitive Abilities Screening Instrument, and confirmed the presence of dementia and

its severity, if present, using Benson and Cummings' criteria and the Clinical Dementia Rating Scale, respectively. A trained research assistant completed telephone interviews to proxy informants for collateral information concerning cognition, behavior, and occupational or social function. Subjects' outpatient medical records were reviewed for documentation of problems with cognition.

Results: Twenty-six cases of dementia were identified. Of these 26, 17 (65%) (95% confidence interval, 44.3-82.8) were not documented in outpatient medical records; of 18 patients, 12 (67%) (95% confidence interval, 40.9-86.7) were not thought to have dementia by their physicians at the time of the office visit. Recognition and documentation rates increased with advancing stage of disease.

Conclusion: Dementia is often unrecognized and undocumented in private practice settings.

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THE RECOGNITION of dementia by primary care physicians is thought to be poor. Reported rates of overlooked dementia are between 35% and more than 90%.¹⁻⁵ Nevertheless, standards of care suggest physicians should initiate an early search for reversible causes of dementia, and some research^{6,7} suggests that there is a benefit to early intervention with cholinesterase inhibitors. Most research concerning the recognition of dementia within the United States has been done in academic centers, yet most patients receive their care in a private practice setting.

With the exception of geriatric medicine, most clinical practice guidelines do not recommend routine screening for dementia.⁸ Some suggest that situations or "triggers" should prompt an assessment in patients who are not in a high-risk group.⁹ Many of these triggers relate to subjective data from third-party informants.

These third parties, who are often not present during the examination, are frequently not aware of the dementia, particularly when it is mild.¹⁰

Our study was designed to determine the rates of unrecognized dementia within a primary care internal medicine private practice setting. We identified recognition rates by the primary care physician at the time of a patient visit and documentation rates in the outpatient medical record.

RESULTS

One thousand thirty-eight patients aged 65 years or older were seen in the physicians' offices during the study period. Sixty subjects were ineligible for the study because of known enrollment in the Honolulu-Asia Aging Study, a longitudinal study that includes regular cognitive testing that

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SUBJECTS AND METHODS

SUBJECTS

The study took place in a 6-physician internal medicine outpatient practice within a predominantly Asian American community of Honolulu, Hawaii. Consecutive patients, aged 65 years or older and seen between August 17, 1998, and September 26, 1998, were invited to participate in a 1-hour interview of cognitive testing. Subjects identified a person (proxy) who could provide collateral history regarding memory and thinking. This was usually a family member (89%) who was often interviewed by telephone.

All patients in the study lived in the United States; ethnicity was self-reported.

MEASUREMENTS

Cognitive testing was offered in English or Japanese by trained examiners. Cognition was assessed by the Cognitive Abilities Screening Instrument, a test designed for cross-cultural and cross-national comparisons and previously validated in Japan, Hawaii, Los Angeles, Calif, and Seattle, Wash.¹¹ The Cognitive Abilities Screening Instrument tests 9 domains of cognitive function. Ninety-six percent of men ultimately diagnosed as having dementia in the Honolulu-Asia Aging Study had a score of 74 or less on the Cognitive Abilities Screening Instrument, the cutoff used for our study.¹² Further cognitive testing included a past memory inventory and a clock-drawing task.¹³ The degree of impairment was rated by the Clinical Dementia Rating Scale.¹⁴

Depression screening included the Geriatric Depression Scale 15-item version and a physician assessment using the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, criteria for major depression.¹⁵⁻¹⁷

Proxy interview tools included the Jorm and Korten Informant Interview, the Blessed Activities of Daily Living assessment tool, the Behavioral Pathology in Alzheimer's Disease Rating Scale, and a questionnaire concerning decline in occupational or social function.¹⁸⁻²¹

A single geriatrician (V.G.V.), involved in all testing, provided a diagnosis of *dementia* using Benson and

Cummings' criteria, defined as acquired impairment in at least 3 of 5 domains, including memory, language, visuospatial ability, higher cognition, and mood or personality.²²

PHYSICIANS' RECOGNITION OF DEMENTIA

Immediately after primary care physicians saw patients in their offices for a routine visit, they completed a form, which asked the following: "Based on this encounter and my previous experience with this patient, in my best opinion, does this patient have dementia?" Response options were "yes," "no," and "unsure." Investigators were blinded to these responses until data analysis. Clinicians were aware that this question would be asked and had no study-imposed restrictions regarding what tests they could perform during the office visits.

REVIEW OF OUTPATIENT RECORDS

An investigating physician (V.G.V.) completed a review of outpatient medical records for the previous 2 years or the maximum number of months seen within this practice, whichever was longer (mean number of months reviewed, 22.6). The start date from which notes were retroactively reviewed corresponded to the date when the clinicians were first made aware of the study (July 17, 1998). All portions of the medical record were reviewed, probing for any evidence of concern regarding memory and cognition using a broad list of key words. Problem lists were included in the medical record review regardless of date, unless an entry was clearly made and dated after the primary care physician received written results of the subject's cognitive testing from this study.

STATISTICAL ANALYSIS

Commercially available statistical software (SAS Institute Inc, Cary, NC) was used. Continuous data were analyzed by a 2-tailed *t* test. Dichotomous data were analyzed by χ^2 analysis or the Fisher exact test if the category size was small. Univariate logistic regression models were used to search for predictors of early detection. A local institutional review board approved the protocol.

is subsequently reported to subjects' primary care physicians.²³ Forty-six subjects were ineligible because of lack of a home telephone or our inability to contact them by telephone despite multiple attempts.

Nine hundred thirty subjects were contacted. Five hundred thirty-three subjects (57.3%) reported that they were too busy or not interested in participating. An additional 10.1% refused for numerous reasons (felt too ill, were caregivers, had died, or had no transportation). The final participation rate was 32.6%, resulting in 303 subjects. Ninety-five percent of these subjects reported being with their current primary care physician for at least 1 year. Six participants were not included in the final analysis due to the presence of factors thought to affect cognitive testing (depression [n=2], severe aphasia [n=1], severe hearing loss [n=1], and the use of a medication that could affect cognition [n=2]).

Clinicians completed forms indicating their opinion regarding the presence of dementia in 73% of patient encounters. There were no significant differences between patients for whom judgment forms had or had not been completed (**Table 1**). Most subjects were Asian American and more than half were women. A total of 26 subjects were found to have dementia (8.8% of the group); 18 of these 26 had opinion forms regarding the presence of dementia completed by their physicians at the time of office visit (**Table 2**). In 66.7% of the subjects, primary care physicians did not recognize the presence of dementia (Table 2). Physicians were uncertain regarding the diagnosis (responded unsure) in about half of these missed cases and believed that dementia was not present (responded no) in the other half. When dementia was mild, 90.9% of the cases were overlooked. When dementia was severe (Clinical Dementia Rating Scale score of >2), no cases were missed.

Table 1. Baseline Demographic Data*

Variable	All Patients (N = 297)	Patients With Judgment Forms		P
		(n = 218)	Patients Without Judgment Forms (n = 79)	
Age, mean ± SD, y	74.6 ± 6.18	74.7 ± 6.04	74.5 ± 6.59	.83
Education, mean ± SD, y	12.0 ± 3.07	11.9 ± 3.17	12.4 ± 2.79	.22
Asian American†	96	95	97	.49
Female sex	63	65	58	.31
≥1 y With current physician†	95	96	92	.23
CASI score, mean ± SD	83.3 ± 14.2	83.5 ± 13.0	82.6 ± 17.0	.66

*Data are given as the percentage of patients unless otherwise indicated. The 2-tailed t test was used for continuous variables, and the χ^2 test was used for dichotomous variables. CASI indicates Cognitive Abilities Screening Instrument.

†The Fisher exact test was used.

Table 2. Recognition of Dementia by Physicians at the Time of the Office Visit*

CDR Stage (Score)	Total No. of Cases	Cases		Cases Not Recognized, % (95% CI)†
		Recognized	Unrecognized	
Mild (0.5 or 1)	11	1	10	90.9 (58.7–99.8)
Moderate (2)	4	2	2	50.0 (6.7–93.3)
Severe (>2)	3	3	0	0 (0–70.8)
All stages	18	6	12	66.7 (40.9–86.7)

*CDR indicates Clinical Dementia Rating Scale; CI, confidence interval.

†Confidence intervals are based on exact methods for a binomial distribution.

Table 3. Documentation of Dementia at Medical Record Review Searching for Key Words*

CDR Stage (Score)	Total No. of Cases	Cases		Cases Not Documented, % (95% CI)†
		Documented	Undocumented	
Mild (0.5 or 1)	14	3	11	78.6 (49.2–95.4)
Moderate (2)	7	2	5	71.4 (29.0–96.4)
Severe (>2)	5	4	1	20.0 (0.5–71.7)
All stages	26	9	17	65.4 (44.3–85.0)

*CDR indicates Clinical Dementia Rating Scale; CI, confidence interval.

†Confidence intervals are based on exact methods for a binomial distribution.

The rate with which dementia was documented mirrored the rate of recognition with an important exception (**Table 3**). For moderate to severe dementia, the rate of documentation was less than the rate of recognition at the time of clinic office visit.

Many subjects had low scores on cognitive testing and evidence of functional decline due to cognition but fell short of our strict criteria for dementia. Thus, we defined all subjects with low Cognitive Abilities Screening Instrument scores (<74) and a Clinical Dementia Rating Scale score of greater than 0 as being *cognitively impaired*. Thirty-three cases of cognitive impairment were identified by these criteria. In 69.7% of these cases, there

Table 4. Predictors of Medical Record Documentation of Cognitive Impairment: Univariate Logistic Regression Models*

Variable	Not Documented (n = 23)	Documented (n = 10)	P
Age, y	81.70 ± 8.89	80.80 ± 5.39	.71
Education, y	8.70 ± 3.01	9.89 ± 4.73	.39
CASI score	60.73 ± 14.78	38.38 ± 31.43	.02†
CDR score‡	1.13 ± 0.69	1.95 ± 1.01	.02†
ADL score§	2.87 ± 2.62	8.45 ± 5.12	.01†
BEHAVE-AD score	2.22 ± 2.84	9.00 ± 5.68	.004†
GDS score¶	2.59 ± 2.38	3.33 ± 1.86	.48
No. of office visits/2 y	10.48 ± 6.93	11.10 ± 3.14	.78
JORMS score#	3.77 ± 0.54	4.50 ± 0.47	.007†
Decline in social or occupational function, No. (%)	15/21 (71)	8/9 (89)	.25

*Data are given as the mean ± SD unless otherwise indicated. CASI indicates Cognitive Abilities Screening Instrument; CDR, Clinical Dementia Rating Scale; ADL, Blessed Activities of Daily Living; BEHAVE-AD, Behavioral Pathology in Alzheimer's Disease Rating Scale; GDS, Geriatric Depression Scale; and JORMS, Jorm and Korten Informant Questionnaire on Cognitive Decline in the Elderly.

†There was a significant ($P < .05$) difference.

‡The possible scores are 0.5, 1, 2, 3, 4, and 5; a higher score indicates increased severity.

§The range of possible scores is from 0 to 17; a higher score indicates an increase in functional dependence.

||The range of possible scores is from 0 to 75; a higher score indicates increased behavior problems.

¶The range of possible scores is from 0 to 15; a higher score indicates increased depressive symptoms.

#The range of possible scores is from 0 to 5; a higher score indicates an increase in cognition-associated findings by proxy.

was no medical record documentation of any problem with memory or thinking.

As expected, more cases were documented when cognitive impairment was advanced (a higher Clinical Dementia Rating Scale score) (**Table 4**). Other predictors of documentation included more behavioral symptoms or more dependence in activities of daily living. Higher scores on the Jorm and Korten Informant Interview predicted documentation as well. These scores represent subjective impressions from proxy informants, suggesting that family members are concerned about memory and thinking.

COMMENT

Dementia was not recognized nor documented by primary care physicians in two thirds of our subjects. This rate is comparable to that seen in a study looking at an academic setting within the United States by Callahan et al.² This rate is also similar to several community-based trials outside the United States.^{3,5}

Poor recognition of dementia can have significant consequences for patients and family members. Lack of recognition delays the search for reversible causes.² Patient safety issues cannot be addressed in a timely manner, such as risk for financial exploitation, wandering and getting lost, or self-injury from unsafe cooking practices (forgetting to turn off the stove). Caregiver stress cannot be effectively alleviated through education and

outreach.⁶ Although few options are available, poor recognition can affect our ability to treat mild and early disease.

Subjects with mild disease were more often overlooked, yet this is the stage in which recognition is most important, particularly if we want to alter the course toward advanced dementia.²⁴ Even when we include situations in which physicians were unsure if dementia was present (all responses except no), rates of detection remained less than 50%. Better means are necessary to identify these patients in the future. This may involve reevaluating the usefulness of regular screening with simple cognitive tests such as the Mini-Mental State Examination.²⁵

Several reasons have been postulated for lack of dementia recognition, including lack of awareness of the disease process by patients themselves and family members.¹⁰ Family members may consider changes in cognition as an accepted aspect of normal aging. As such, primary care physicians may not be told of memory problems until severe behavioral problems manifest in later stages of the disease.⁶ Cultural factors could affect family members' perception and reporting of dementia as well.²⁶

Other possible explanations for lack of recognition include physicians' concerns about the futility of making a diagnosis of dementia because of a perceived lack of treatment options.²⁷ Physicians may not be aware of increased caregiver stress and increased use of medical resources by the caregiver and the patient when dementia is present.^{2,28-30} They may not be aware of the benefits associated with early intervention using cholinesterase inhibitors.⁷ In addition, physicians may be concerned about the time required to effectively diagnose the disease and educate patients and their families.²⁷

To our knowledge, there are no previously published studies looking at the private practice outpatient setting within the United States. To our knowledge, there are also no studies looking at predominantly Asian-American populations. Our initiative adds to the study by Callahan et al² by showing a deficit in recognition and documentation outside of an academic setting and within a different minority population. This is particularly important since most patients receive primary medical care outside of academic centers.

For logistical reasons, we worked with one group practice. The rate at which dementia was detected in this group might be better than that at an average private practice for several reasons. First, these physicians admit patients to a hospital with an internal medicine residency program and an active geriatric medicine fellowship program, increasing attending physician exposure to training in dementia. In addition, many of their patients are involved in the Honolulu-Asia Aging Study, providing the physicians with ongoing results of cognitive testing for that subset of patients.²³ Such an exposure might increase awareness of the disease in other patients.

There could be unrecognized factors that decrease physicians' ability to recognize dementia in this group practice, limiting our ability to generalize these data to

other settings. Comparisons with other practice and cultural settings might be an interesting area of future research.

Low rates of depressive symptoms were seen in these subjects. This may be a manifestation of a selection bias, as patients were recruited by telephone. Patients with depression might simply have refused. Little is known about the subjects who did not agree to participate. We used several assessment tools for depression. Nevertheless, these tests may have less than optimal sensitivity, particularly for occult or masked depression resulting in lower rates detected. This difficulty exists with most screening instruments for depression and is a probable limitation to this endeavor.

Study evaluations were completed on average 5.25 months after the clinician office visit. It is conceivable that cognition had declined in the interim period. This would give scores that were lower than they would have been at the time of the clinician office visit. Given the natural course of dementia, however, with a slow decline over a period of years, it is doubtful that this would have had a significant effect.

A larger study could be designed to better define the barriers toward early diagnosis of dementia and cognitive impairment. Further research is also needed to identify methods that increase recognition of cognitive impairment, particularly when it is mild.

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