

Implementing a Screening and Diagnosis Program for Dementia in Primary Care

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BACKGROUND: Primary care physicians are positioned to provide early recognition and treatment of dementia. We evaluated the feasibility and utility of a comprehensive screening and diagnosis program for dementia in primary care.

METHODS: We screened individuals aged 65 and older attending 7 urban and racially diverse primary care practices in Indianapolis. Dementia was diagnosed according to International Classification of Diseases (ICD)-10 criteria by an expert panel using the results of neuropsychologic testing and information collected from patients, caregivers, and medical records.

RESULTS: Among 3,340 patients screened, 434 scored positive but only 227 would agree to a formal diagnostic assessment. Among those who completed the diagnostic assessment, 47% were diagnosed with dementia, 33% had cognitive impairment—no dementia (CIND), and 20% were considered to have no cognitive deficit. The overall estimated prevalence of dementia was 6.0% (95% confidence interval (CI) 5.5% to 6.6%) and the overall estimate of the program cost was \$128 per patient screened for dementia and \$3,983 per patient diagnosed with dementia. Only 19% of patients with confirmed dementia diagnosis had documentation of dementia in their medical record.

CONCLUSIONS: Dementia is common and undiagnosed in primary care. Screening instruments alone have insufficient specificity to establish a valid diagnosis of dementia when used in a comprehensive screening program; these results may not be generalized to older adults presenting with cognitive complaints. Multiple health system and patient-level factors present barriers to this formal assessment and thus render the current standard of care for dementia diagnosis impractical in primary care settings.

KEY WORDS: dementia; cognitive impairment; primary care; vulnerable adult; screening.

DOI: 10.1111/j.1525-1497.2005.0126.x
J GEN INTERN MED 2005; 20:572-577.

Dementia is a growing public health problem, with the prevalence ranging from 3% to 11% among people aged 65 and over.¹⁻¹² There were an estimated 7 million cases of dementia in the U.S. in 2000 and this number may grow to 18.5 million by the year 2050.¹³ Dementia leads to a high burden of suffering for patients, families, and society, with an annual estimated cost of \$100 billion.¹⁴ Alzheimer's disease (AD) is the primary diagnosis in 60% of all cases.^{3,6-12} In an effort to reduce the societal burden of AD, researchers have been focusing on the discovery of drugs and other therapies that might prevent or slow the rate of progression of this disease. Early diagnosis of dementia and thus, AD, would be fundamental to any treatment effort.

Several guidelines have been published on diagnosis and management of dementia.^{15,16} The American Academy of Neurology published quality standards for the diagnosis of dementia and recommended that standardized diagnostic criteria be routinely used for the dementia diagnosis.¹⁷ Unfortunately, two thirds of dementia cases may remain undetected.¹⁸⁻²⁰ These low detection rates, the availability of therapy, and having the opportunity to elucidate patients' preferences for future health planning drive interest in dementia screening programs in primary care. Implementation of such programs would require screening of asymptomatic elders, the capacity to conduct an accurate diagnostic assessment, and the resources to provide education and management for patients with a confirmed diagnosis. Such resources are not available in the typical primary care practice. Some physicians rely on clinical judgment in making dementia diagnosis, while others overestimate the specificity of routine screening tests.^{18,20}

In a systematic evidence review for dementia screening, the U.S. Preventive Services Task Force (USPSTF) concluded that a brief interview test can detect the syndrome with reasonable accuracy and that various interventions are available to decrease dementia burden.¹⁹ However, the USPSTF was not able to identify any study that demonstrated the practical applicability of a dementia screening and diagnosis program in primary care.²¹ As part of a trial to test the efficacy of collaborative care program as compared with usual care in improving the outcomes of AD patients, we were able to examine the feasibility and utility of a dementia screening and diagnosis program among patients presenting to a routine primary care visit with no cognitive symptoms.

METHODS

The study was approved by the Indiana University Purdue University Indianapolis Institutional Review Board (IRB). All screened subjects gave verbal consent, and all subjects completing the diagnostic assessment provided written informed consent (Fig. 1).

Population

The sample included all patients aged 65 and older receiving their primary care services within Wishard Health Services (WHS) from January 1, 2002 through October 31, 2003. WHS includes a 450-bed, urban public hospital and 7 primary care centers in Indianapolis. These centers are staffed by 35 general Internists and 118 Internal Medicine residents.¹⁸ We excluded prisoners, nursing home patients, and patients unable to speak English, not having access to telephone, or not been seen by a WHS primary care physician within 2 years. We

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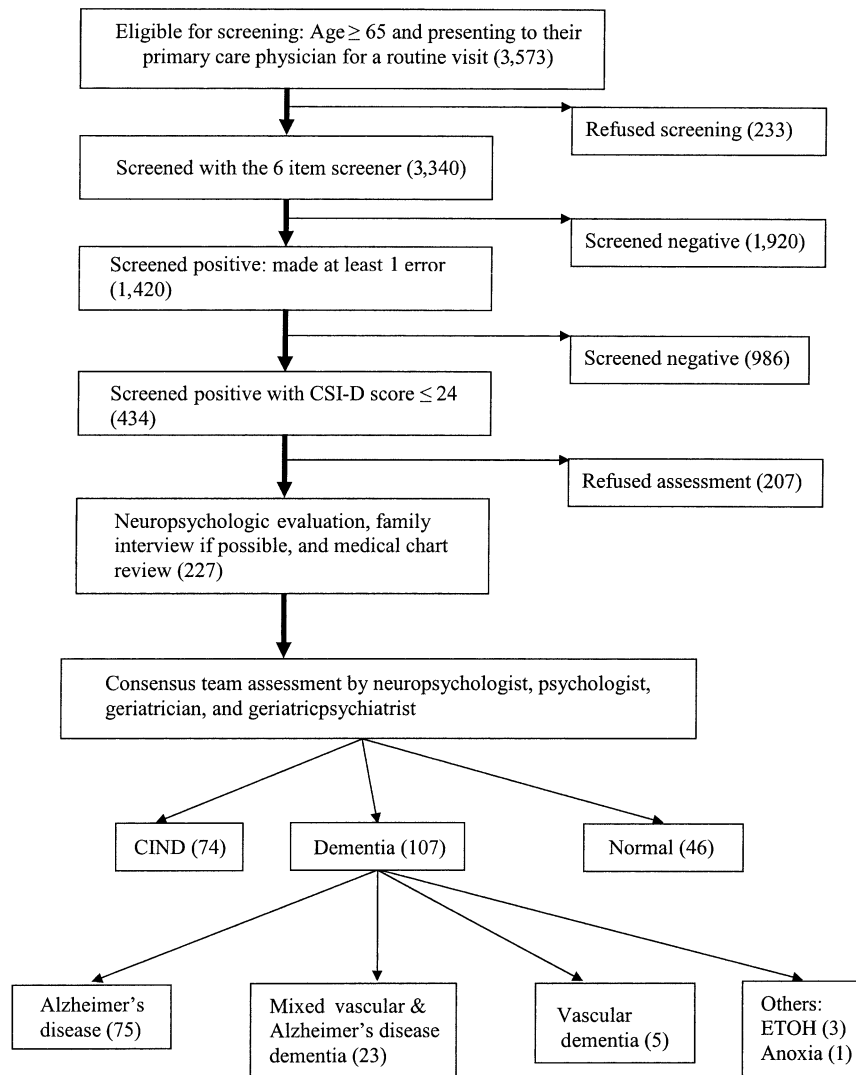


FIGURE 1. Sampling method.

screened 3,340 out of 3,573 eligible participants for dementia. Those who refused screening were similar in age, gender, and race to those who accepted screening.

Screening Procedure

The first phase of screening included the 6-item screener.²² This instrument consists of 3-item query of temporal orientation and a 1-item recall of 3 words. Any patient who made at least 1 mistake was asked to complete the second stage of screening. This cut score has a sensitivity of 97.7 and a specificity of 49.2.²² Those who made no errors on this instrument were excluded from further evaluation. The second stage of the screening included an abbreviated version of the Community Screening Interview for Dementia (CSI-D).^{23,24} The CSI-D evaluates cognition across multiple domains with no requirement for reading ability. It includes 28 items with a score range of 0–34. A cut-off score of ≤ 24 points has a sensitivity of 87%, and specificity of 83.1%.⁶

Patients who made at least 1 error on the 6-item screener and subsequently scored ≤ 24 on the CSI-D were considered

to have positive dementia screening results and were eligible for the diagnostic assessment.

Diagnosis Procedure

We used several incentives to encourage patients who screened positive to undergo the diagnostic assessment. First, the patient's physician recommended the assessment. Second, the study personnel provided information on the importance of the assessment. Third, the assessment was offered free of charge within the primary care clinic. If transportation was a barrier, the patient was offered free transportation or home-based assessment (2 assessments were conducted in patients' homes). Fourth, patients and caregivers were reimbursed for their time with a \$10 gift for each.

The diagnostic assessment included (1) a modified version of the Consortium to Establish a Registry for Alzheimer's Disease neuropsychologic battery (CERAD),²⁵ (2) the Geriatric Depression Scale,²⁶ and (3) a semi-structured interview with an informant.⁶

The CERAD battery includes Animal fluency, Boston naming, Mini-Mental State Examination, Constructional praxis, Delayed recall of constructional praxis, Word list learning, and Delayed recall of word list learning. The informant interview included a review of the patient's (a) memory, language, judgment, and reasoning, and (b) performance of the activities of daily living (ADL). Professional research assistants underwent a detailed training by the study neurophysiologist and were certified in conducting both the CERAD battery and the informant interview.

In addition, we reviewed the patient's medical records for the presence of comorbid conditions, medications, vitamin B₁₂ (Vit B₁₂) level, thyroid test, syphilis tests, and brain imaging. When relevant to making a diagnosis and unavailable in the patient's record, laboratory tests or brain imaging were requested. A panel constituting a psychologist, neuropsychologist, geriatrician, and geriatric psychiatrist reviewed the previous data and used the ICD-10 criteria²⁷ to diagnose dementia and its subtypes. The diagnosis of cognitive impairment-no dementia (CIND) was made if the (1) informant reported or clinician detected clinically significant decline in cognition or (2) cognitive test score(s) below the seventh percentile, and (3) the patient had no clinically significant impairment in ADL.²⁸ The normative values of the CERAD were determined based on previously published similar samples.^{29–31}

Other Data Collection

Subject's age, gender, race, and education level were obtained through the informant. We used prescription medications to structure (1) a variable that included all psychotropics (neuroleptics, antidepressants, anxiolytics, or hypnotics) and (2) the Chronic Disease Score (CDS). The CDS excludes medications used for treatment of acute problems or common symptoms. Individual medications are assigned to pharmacy classes, which are then mapped to the chronic diseases that class of medication would treat. Each CDS class was assigned a weight by the original developers to calculate the total CDS (range 0 to 24). The CDS has been validated, and its scores are correlated with future resource utilization.^{32,33} Chart-based dementia diagnosis was considered present if the patient's medical records included any ICD-9 diagnostic codes for dementia or AD.

We estimated the program cost by including the cost of the screening interviews (\$40 per patient), the Medicare reimbursement for the neuropsychologic assessments (\$250), the laboratory testing (TSH level=\$80.67 and Vit B₁₂ level=\$25.00 per test) and brain imaging (Head CT Scan=\$786 per scan),^{15–17} and the overall program administration (\$10 per patient). Customary charges for neuropsychologic testing vary based on the setting and the clinical complexity (\$64 to \$185 per hour), and the assessment length (2 to 6 hours). We used a mean hourly charge of \$125 and a 2-hour assessment to estimate a mean charge for neuropsychologic assessment of \$250. It is important to state that our cost analysis used charge estimates rather than actual reimbursements.

Analysis

We used χ^2 tests (dichotomous variable) or two-sample *t*-tests and analysis of variance (ANOVA) models (continuous variable)

to test for group differences. We used a logistic regression model to predict the probability of dementia in the patients receiving the diagnostic assessment. The model included age, CSI-D score, and a previous chart diagnosis of dementia. No other variables were significantly associated with dementia diagnosis. The model fit well with an area under the receiver operating characteristic (ROC) of 0.84. We used this model to calculate the number of predicted dementia cases in the group who screened positive but refused diagnostic assessment. Prevalence was defined as the number of dementia cases plus the number of predicted dementia patients of the testing refusals divided by the number of patients screened. All 2-tailed tests were considered significant at a level of .05.

RESULTS

Based on the patient's performance on the 6-item screener and subsequently the CSI-D, 434 individuals screened positive for possible dementia (see Fig. 1). In comparison with patients who screened negative, those with a positive screen were older and more likely to be African American. However, there were no group differences in terms of gender, comorbidity, or the use of psychotropics. Dementia was diagnosed by the primary care physicians in 7.8% of the patients with a positive screen and in 1% of those with a negative screen (see Table 1).

Among the 434 patients who screened positive, 227 accepted the diagnostic assessment (see Fig. 1). In comparison with the decliners, those who accepted were younger (73.8 vs 75.4; *P*=.01) and had poorer CSI-D performance (18.3 vs 19.2; *P*=.07). We found no group differences in terms of race, gender, comorbid conditions, psychotropics, or chart documentation of dementia or depression.

Among the 227 patients who screened positive and accepted the diagnostic assessment, 107 had dementia, 74 had CIND, and 46 were considered to be cognitively normal. Dementia was diagnosed in 84% of patients with a CSI-D score < 15 points, 58% of those with 15 to 19 points, and 28% of those with 20 to 24 points.

After adjusting for patients who refused the diagnostic assessment, 6.0% (95% confidence interval (CI) 5.5% to 6.6%) of the overall primary care older population had dementia. This prevalence was 2.2% (95% CI 1.5% to 2.9%) among pa-

Table 1. Characteristics of the Patients with Positive Screening for Possible Dementia and those with Negative Screening

Variable	Subjects with Positive Screening (N=434)	Subjects with Negative Screening (N=2,906)	<i>P</i> Value*
Mean age (SD)	74.6 (6.9)	71.1 (5.6)	<.001
African American (%)	67.9	59.7	.001
Female (%)	67.1	70.6	.135
Mean CDS (SD)	6.3 (4.2)	6.2 (4.2)	.549
Chart diagnosis of dementia (%)	7.8	1.0	<.001
Chart diagnosis of depression (%)	6.7	6.3	.759
Receiving any psychotropic medications (%)	22.1	24.9	.218

*Based on bivariate analysis, using *t* test and Pearson χ^2 test. N, number of subjects; SD, standard deviation; CDS, chronic disease score.

Table 2. The Differences Between Screened Positive Subjects with Dementia, CIND, or no Cognitive Impairment*

Variable	Dementia (N=107)	CIND (N=74)	No Cognitive Impairment (N=46)	P Value
Mean age (SD)	75.6 (6.2)	72.0 (6.2)	72.4 (5.8)	<.001
African American (%)	69.2	68.9	71.7	.939
Female (%)	62.6	67.6	71.7	.521
Mean years of education (SD)	7.3 (3.7)	7.7 (4.0)	7.5 (3.4)	.836
Mean MMSE score (SD)	17.7 (5.3)	22.2 (3.7)	24.6 (2.9)	<.001
Mean CDS (SD)	5.8 (4.0)	7.2 (4.3)	7.0 (4.0)	.054
Chart diagnosis of dementia (%)	18.7	1.4	0.0	<.001
Chart diagnosis of depression (%)	5.6	2.7	6.5	.562
Receiving any psychotropic medication (%)	19.6	23.0	23.9	.789
Receiving ChEI (%)	7.5	1.4	0.0	.035

*Based on analysis of variance (ANOVA) or Pearson χ^2 test comparing the 3 groups.

N, total number of subjects; CIND, cognitive impairment no dementia; MMSE, mini mental status examination; CDS, chronic disease score; ChEI, cholinesterase inhibitors.

tients aged 65 to 69 years, 7.2% (95% CI 6.3% to 8.1%) among those aged 70 to 79 years, and 17% (95% CI 13.6% to 20.8%) among those aged 80 and older.

In comparison with patients with CIND or those with positive screening but normal cognition, dementia patients were older, had less comorbidity, and were more likely to receive cholinesterase inhibitors. There were no group differences in terms of gender, race, education, or the use of psychotropics (see Table 2).

Physicians recognized only 18.7% of all dementia patients identified by our program. This recognition varied with patients' age: the physicians recognized 21.1% of dementia patients aged 65 to 69 years, 20.9% of those aged 70 to 79 years, and 11.5% of dementia patients aged 80 and older.

Among the 107 patients with dementia, 75 (70.1%) had probable or possible AD, 5 (4.6%) had probable vascular dementia, and 23 (21.5%) had mixed AD and vascular dementia. There were no group differences in terms of age, gender, race, education, comorbidity, or the use of cholinesterase inhibitors. However, patients with mixed dementia were more likely to receive psychotropics (see Table 3).

The cost of the program among patients aged 65 and older was \$128 per patient screened and \$3,983 per patient diagnosed with dementia. This cost decreased among patients aged ≥ 70 (\$3,126 per dementia case) and those aged ≥ 80 years (\$2,581 per dementia case). These estimates did not include the cost of the diagnostic panel or the patient incentives. The

estimates did not account for the possible cases of dementia that might exist among patients who screened positive but refused diagnostic assessment.

DISCUSSION

To our knowledge, this is the first study that describes the feasibility and utility of dementia screening and diagnosis program in a racially diverse and low-income primary care setting. We found that 13% of patients aged 65 and older screened positive for possible dementia and only 47% of the screened positive patients were demented. Thus, clinicians must rely on detailed diagnostic assessments before making a dementia diagnosis.¹⁷ Furthermore, 33% of the screened positive patients were diagnosed with CIND. This group has a 10% probability of converting to dementia every year and 25% probability of returning to normal.²⁸ There are no guidelines on the appropriate care and counseling needed for this group.

We identified several barriers to implementing a screening and diagnosis program for dementia in primary care. First, *the program requires substantial financial and human resources*. The program cost \$128 per patient screened and \$3,983 per patient diagnosed with dementia. Administering the screening tests requires approximately 20 minutes per patient. Importantly, a positive screen does not signal a diagnosis of dementia but rather the need for a detailed evaluation by the primary care physician, a neuropsychologist, or other clinicians. Including an interview with an informant, the minimum additional time of this evaluation is approximately 30 minutes. Furthermore, some primary care practices may not have referral access to neuropsychology or similar services, which itself represents a barrier for program implementation. Because of the effect of age on the prevalence of both recognized and unrecognized dementia, targeting an older cohort group to initiate screening might be more cost effective. We found that the program costs \$3,126 per patient diagnosed with dementia among individuals aged ≥ 70 and \$2,581 among those aged ≥ 80 . Moreover, the program's cost would also be reduced to \$2,315 if the diagnostic interview did not include brain imaging, and to \$3,452 if the diagnostic work-up did not include neuropsychologic testing. However, eliminating either of the above 2 steps will affect the specificity of the diagnosis. The second barrier to widespread implementation is patient acceptance. The refusal rate for the screening was low (6.5%). Half of the older adults with positive screening results, however, refused further diagnostic assessment. This refusal rate

Table 3. Comparison Between Subjects with Probable or Possible AD, Vascular Dementia, and those with Mixed Possible AD and Vascular Dementia*

Variable	Vascular or Mixed Dementia (N=28)	Probable or Possible AD (N=75)	P Value
Mean age (SD)	75.5 (6.1)	75.9 (6.2)	.817
African American (%)	67.9	69.3	.886
Female (%)	71.4	61.3	.342
Mean years of education (SD)	7.4 (3.3)	7.4 (3.9)	.991
Mean MMSE score (SD)	17.6 (5.5)	17.8 (5.2)	.831
Mean CDS (SD)	6.2 (4.5)	5.6 (3.9)	.512
Receiving any psychotropic (%)	35.7	14.7	.018
Receiving ChEI (%)	10.7	6.7	.495

*Based on bivariate analysis using t test and Pearson χ^2 test.

N, total number of subjects; SD, standard deviation; MMSE, mini mental status examination; CDS, chronic disease score; ChEI, cholinesterase inhibitors.

was similar to that reported among affluent residents of continuous care retirement communities (51% of residents would not agree to routine memory screening).³⁴ The findings suggest that patients believe that dementia is a devastating condition with no available treatment or that dementia diagnosis would lead to potential harms such as depression and anxiety, social stigma, loss of insurance coverage, or loss of independence. Unfortunately, our program was not designed to measure potential harms and public acceptance of dementia screening. However, we are hypothesizing that the low acceptance rate of the diagnostic assessment suggests that patients perceive dementia screening as a source of stigma that might lead to potential harms.

Our findings may not be generalizable to case-finding activities directed toward older adults presenting with cognitive complaints as compared with the unselected patients screened in this study. Thus, the refusal rate in our study might have changed if the patients had perceived themselves to be symptomatic or if they were seeking medical help for their cognitive complaints. In addition, any future advancement in dementia management that is perceived by the public to be effective, such as the discovery of a pharmacologic intervention that may stop dementia progression, could change patient refusal and increase the success of implementing a dementia screening and diagnosis program. Consistent with the conclusions of the USPSTF,²¹ the refusal of dementia diagnostic assessment calls for further study of whether dementia screening is perceived more negatively than other screening maneuvers.

The third barrier is the operating characteristics of the screening tests. The false-positive rate of the current screening tests is substantial (20% of those with positive screening had normal cognition and another 33% had CIND). Using the sensitivity of the 2 screening instruments used in our program, we anticipate that our program missed 172 (5.9% of all patients screened negative) patients with dementia. Because the harms of false-positive screening results as opposed to false-negative results are uncertain, it is difficult to recommend an optimal cut-off score on the screening test. Practicing physicians must understand the operating characteristics of these screening tests with the same familiarity as diagnostic tests for other common medical conditions. A positive screening test is only one step in making the diagnosis. Access to an informant who could document a fall from a prior level of cognition and impaired social functioning would improve the accuracy of the diagnosis, but such informants are frequently unavailable. In our previous community studies, 19% of subjects had no such informant.²⁴ In our current primary care study, we had access to informants in 95% of the patients who screened positive. However, only 87% of the informants were patients' relatives (spouse, child, sibling, or other relative). We found a trend indicating that patients who did not have informants scored higher on the CSI-D than those with informants ($P=.07$).

The fourth barrier is a consequence of improved dementia recognition: the need for a counseling program for those patients diagnosed with dementia. In our experience, revealing this diagnosis to patients and family typically requires 1 hour of professional time. Although this communication does not have to come from the physicians, many primary care physicians will be the only persons available to have the conversation. Local Alzheimer's Associations may offer assistance to patient and families in coordination with the physician.

Our study had some limitations. Although the USPSTF found insufficient evidence to recommend a routine screening for dementia in primary care, their decision was influenced by the absence of a screening trial that evaluated the direct evidence that links screening to health outcomes.²¹ Thus, our study provides important data to fill this gap in the literature. Our study was not designed as a typical clinical epidemiologic study. We did not sample patients who screened negative to assess for false negatives that our program missed (approximately 5.9% of all patients with negative screening results), and therefore our prevalence estimate is conservative. We screened all patients aged 65 and older attending primary care clinics for a routine visit. Our study did not collect data related to the reasons for the clinic visit. Thus, we do not know with certainty whether the patients presented with cognitive or functional decline. However, less than 2% of all screened patients had a chart-based diagnosis of dementia. We believe that the majority of the screened patients were not seeking medical help for cognitive or functional problems. Therefore, the results of our study cannot be extrapolated into screening and diagnosing dementia among patients attending primary care clinics for work-up of their cognitive complaints. Our screening program used a cross-sectional approach to screen for dementia. It is possible that using multiple screening series over time would improve the effectiveness of dementia screening and reduce its cost and potential harms. However, we are not aware of any study that confirms the benefit of this approach. Our findings, focused on a population of vulnerable urban older adults, may not generalize to other patient populations.

In summary, most primary care practices are ill prepared to engage in a screening and diagnosis program for dementia. Some of the shortcomings may be a result of negative attitudes toward the importance of a dementia diagnosis, but at least some of the problems lie in the human and financial resources needed to implement such a program. The paradox lies in the reality that a growing population of underdiagnosed or misdiagnosed patients with dementia also results in substantial societal expenditures as well as significant patient and family burden. We not only need additional research to improve current practice, we need national discussion about where to best allocate resources to improve the care of older adults with dementia.

Supported by grant R01 HS10884-01 from the Agency for Healthcare Research and Quality.

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