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## Acceptability and results of dementia screening among older adults in the United States

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### Abstract

**Objectives**—To measure older adults acceptability of dementia screening and assess screening test results of a racially diverse sample of older primary care patients in the United States.**DESIGN**—Cross-sectional study of primary care patients aged 65 and older.**SETTING**—Urban and suburban primary care clinics in Indianapolis, Indiana, in 2008 to 2009.**PARTICIPANTS**—Nine hundred fifty-four primary care patients without a documented diagnosis of dementia.**MEASUREMENTS**—Community Screening Instrument for Dementia, the Mini-Mental State Examination, and the Telephone Instrument for Cognitive Screening.**RESULTS**—Of the 954 study participants who consented to participate, 748 agreed to be screened for dementia and 206 refused screening. The overall response rate was 78.4%. The positive screen rate of the sample who agreed to screening was 10.2%. After adjusting for demographic differences the following characteristics were still associated with increased likelihood of screening positive for dementia: age, male sex, and lower education. Patients who believed that they had more memory problems than other people of their age were also more likely to screen positive for dementia.**CONCLUSION**—Age and perceived problems with memory are associated with screening positive for dementia in primary care

### Keywords

dementia screening; Alzheimer's disease; primary care; diagnostic assessment

## INTRODUCTION

Most primary care physicians (PCPs) are hesitant to screen for dementia and PCPs may not be aware of cognitive impairment in 50% of their patients [5]. As a result, the diagnosis of dementia often occurs late in the disease process [16]. Late identification may be attributable to patient, provider, and system barriers. Some of these barriers include patient fear of stigmatization or loss of independence, limited PCP knowledge about clinical assessment procedures, and lack of belief by the PCP in the value of making diagnosis, and time constraints in the primary care encounter [17]. While population dementia screening is often perceived negatively [37], studies have shown patients' attitudes about dementia screening show many people can have positive attitudes about screening. In one study, 65% to 90% of older adults felt that dementia screening would provide them with the opportunity to plan their future financial and health care, create advance directive, participate in research, and possibly motivate them to have a healthier life style [27–28]. Few older adults perceive a negative impact of dementia screening on their emotional health and their independence [27–28]. Other studies based on small surveys of genetic screening and the disclosure of a dementia diagnosis [17,18] find that while some patients report distress from receiving a diagnosis of dementia, among those who reported symptoms, the majority wanted to know the results of diagnostic testing [19]. One study has reported on patient refusals of diagnostic work-up following a positive screen [20]. In this study, older primary care patients who perceived themselves as having no cognitive symptoms were more likely to refuse a diagnostic assessment, but the study did not investigate the processes driving patients' beliefs and behaviors about the benefits and risks of dementia screening. These findings suggest that the process of dementia screening may provide benefit not only for patients with unrecognized dementia but also for older adults with screen negative results, including, at minimum, the assurance of the absence of significant cognitive impairment.

In an effort to reduce the burden of dementia, various clinicians, researchers and advocates have recommended routine screening for dementia in primary care [21,23]. However, in 2003 and 2013, the United States Preventive Services Task Force (USPSTF) reviewed the evidence regarding the benefits and harms of dementia screening in primary care and “The task force could not determine whether the benefits of screening for dementia outweigh the harms” [5,24,25]. Over the past decade our team at Indiana University conducted a series of studies that looked at the receptivity and feasibility of screening in older adults for dementia in primary care [27,28]. In this paper, we present the acceptability of screening and screening test results of a racially diverse sample of older patients receiving primary care within urban and suburban settings in Indianapolis.

## METHODS

### Study Population

Patients were eligible to participate in our study if they were 65 years or older, did not have a documented diagnosis of Alzheimer's disease or related dementia, and received their primary care at Eskenazi Health (EH), St. Vincent Health (STV), or Community Health Network (CHN) in Indianapolis, Indiana. EH is an urban health care system with ten community-based primary care practice centers staffed by faculty and residents of Indiana

University School of Medicine. STV is large Indiana based Catholic health system with a large medical campus in Indianapolis. CHN is an integrated health system with three hospital locations and multiple community-based health pavilions with access to primary care and other health services. Both STV and CHN serve the urban and suburban population of the greater Indianapolis, IN area. This study was approved by the Indiana University Purdue University-Indianapolis, St. Vincent Health, and Community Health Network Institutional Review Boards.

Recruitment for this study took place from January 2008 to June 2009. Research assistants from Indiana University Practice Based Research Network (IU-PBRN) approached all potential participants at the EH community-based primary care clinics who met the eligibility requirements and invited them to participate in the study. All EH recruiting was conducted in-person through the IU-PBRN, a research network that facilitates recruitment of primary care patients into clinical studies. Eligible patients from the STV and CHN primary care were obtained from primary care office staff and appointment scheduling records. Eligible patients at these two sites were approached by telephone and offered the opportunity to participate in the study by research assistants from the Indiana University Center for Aging Research. All recruitment procedures complied with the U.S. Health Insurance Portability and Accountability Act and institutional review board regulations. Informed consent was obtained from all patients who agreed to participate in the study.

### Study Procedures and Instruments

The study used the Community Screening Instrument for Dementia (CSI-D) [29] the Mini-Mental State Examination (MMSE), [30] or the Telephone Instrument for Cognitive Screening (TICS) [31] for dementia screening. Eskenazi Health Patients completed the MMSE or the CSI-D. CHN and STV participants completed the TICS. The CSI-D is a dementia screening instrument comprised of two components, a cognitive test for non-literate and literate populations and an informant interview. This study utilized the abbreviated version which omits the informant interview. No data was collected from informants as a part of this study. The MMSE is a well validated cognitive test that is often used in both in clinical evaluation and dementia research [30]. The TICS is a validated phone based screening instrument that uses a cut off scores of 30 as a positive screen. The variation in test instrument was a result of a change in protocol for a concurrent study enrolling patients from the same clinics. These instruments were selected for their psychometric properties and validation with the populations who would be approached for this study.

Participants whose results were positive on the screening instrument (24 on the CSI-D[29] or the MMSE[30] or 30 on the TICS [31]) were referred to the local memory clinic at Eskenazi Health [36] or a specialist at either St. Vincent Health or Community Health Network for an evaluation and diagnostic assessment.

Research assistants approached all eligible subjects either in the clinics or by phone and explained to them the nature of the study and obtained informed consent. During the informed consent process patients were informed that being diagnosed with dementia was a potential risk. Once consented, patients were asked to complete a survey about their beliefs

and perceptions of screening [35] and to undergo a dementia screening test. Results of the surveys regarding perceptions and beliefs have been published elsewhere. [27,28,35]

### Statistical Analysis

Data included for analysis included demographics (age, race, gender, education level, and marital status), recruitment site, and three questions related to their experience with dementia (Do you have a relative or friend with Alzheimer's disease?; Do you believe that you are at higher risk of Alzheimer's disease than others of your same age?; Do you think you have more memory problems than others of your same age?). We used Chi-square tests to test for differences in demographics and prior dementia experience across the three recruiting locations as well as testing for positive screening results across demographics. We constructed a multivariate logistic regression model to test the association of recruitment site with positive screening adjusting for demographics and prior dementia experience. Specifically, we adjusted for age, race, gender, and variables found to be significantly associated with positive screening. All analyses were performed using SAS v9.3.

### Results

A total of 1,737 older adults were approached for participant in the study, of which 954 older adults were recruited and signed consent. Of these 554 (58.1%) were from EH, 278 (29.1%) were from STV and 122 (12.8%) were from CHN. Of the 954, 748 (78.4%) agreed to be screened for dementia after completing the consent and survey. The overall response rate was 7.48%. Among the 206 who refused screening, 57 (10.3%) were from EH, 105 (37.8%) from STV, and 44 (36.1%) from CHN [27,28]. Participants at the CHN and STV sites without a friend or relative with Alzheimer's disease were found to be significantly more likely to refuse screening [28]. At EH, participants ages 70–79 were more likely to refuse screening compared to both the 65–69 and 80 and older age groups [27].

Demographic characteristics of the 748 participants who agreed to be screened are presented in Table 1. There are significant differences across the three sites with regard to demographic features. Patients from EH are more likely to be African-American, are younger, and less likely to be married. Patients from STV have the highest amount of education with 70% of having more than a high school education. Patients from STV and CHN were significantly more likely to know a relative or friend with AD while patients from EH were more likely to report they have more memory problems compared to other people of their age.

Among the 748 who agreed to be screened, 76 (10.2%) screened positive and were referred to a specialty memory care program or a specialist physician for a confirmatory diagnostic assessment.

The associations of demographic features with positive screening results are presented in Table 2. Patients with lower education, male patients, older patients, and patients from the EH site were more likely to screen positive for cognitive impairment. Patients who knew a close relative or friend with AD were less likely to screen positive while patients who

responded that they believe they had more memory problems were more likely to screen positive for cognitive impairment.

The multivariate logistic regression results assessing the association of site with positive screening after adjusting for age, race, gender, and significant variables from Table 2 are presented in Table 3. After adjusting for demographic characteristics, there is no longer a difference in positive screening results between the three study sites. Age, being male, and having a lower education are still associated with a higher likelihood of screening positive. In addition, patients who believed they had more memory problems than others of their age were more likely to screen positive for cognitive impairment.

## Discussion

Our study shows that an overwhelming majority (>78%) of older adults who receive primary care in the greater Indianapolis, IN area and agreed to participate in this study are willing to be screened for dementia as part of routine primary care and that on average, 10% screen positive. The positive screen rate for those who completed the screen via telephone at STV (4.0%) and CHN (7.7%) was lower than those who screened in person at EH (12.2%). It is possible that these differences could be explained by demographic characteristics across sites or that different screening instruments were used. The EH population Further exploration of the differences in methods when screening via telephone versus in clinic settings could be beneficial.

This refusal rate and prevalence rate is significantly lower than what others have found in rural primary care clinics [17] but similar to what The Alzheimer's Foundation of America found. In 2014, as part of the National Memory Screening Day, The Alzheimer's Foundation of America screened 3,064 adults aged 18 and older for dementia with an 11.7% positive screen rate. This study also found that there were no differences based on sex and that older age was associated with increased likelihood of positive screen [35].

Similar to this prior study, we found that increasing age was associated with increased likelihood of positive screen. In contrast to that study, we found the females were less like to screen positive. In addition, we found that patients endorsing a subjective belief about more memory problems than peers are associated with increased likelihood of screening positive for cognitive impairment. Having lower educational status was found to have an association with screening positive, which is consistent with other literature which suggests that educational bias exists in screening instruments and lower education is a risk factor for dementia [38]. Further research is needed about the harms and benefits of dementia screening in order to support and improve dementia screening programs and policy.

The limitations of our study include an inherent selection bias as a result of the recruitment process, sample size and its generalizability to other populations of primary care patients. We recognize that inferences about perceptions and behavior are more difficult with a small sample and without follow-up interview data about the reason for refusing participation in the study, reasons for refusing screening or more detailed information from those who screened positive. Although our sample was restricted to one US state, it was drawn from

suburban and urban across the age range of people over 65 years and therefore provides data that fill some important gaps regarding acceptance and results of screening for dementia [32,33]. Additionally, while the individuals who refused to participate in the study did not differ by age, sex, or race as compared with those who agreed, they may have declined participation directly because of their lack of willingness to be screened or suspicions about cognitive impairment, introducing bias in our sample.

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Comparison of Demographics By Site for Participants who underwent dementia screening, n(%)

Table 1

	Community Health Network (n=78)	St. Vincent Health (n=173)	Eskenazi Health (n=497)	Overall (n=748)	P-value
<b>Female</b>	60 (76.9)	115 (66.5)	351 (70.6)	526 (70.3)	0.237
<b>African-American</b>	2 (2.6)	35 (20.2)	280 (56.3)	317 (42.4)	<0.001
Age					0.001
<b>65-69</b>	19 (24.4)	55 (31.8)	185 (37.2)	259 (34.6)	
<b>70-74</b>	18 (23.1)	39 (22.5)	148 (29.8)	205 (27.4)	
<b>75-79</b>	16 (20.5)	34 (19.7)	91 (18.3)	141 (18.9)	
<b>80+</b>	25 (32.0)	45 (26.0)	73 (14.7)	143 (19.1)	
Education	<0.001				
<b>0-11 Years</b>	10 (12.8)	3 (1.7)	203 (41.0)	216 (28.9)	
<b>High School Grad</b>	39 (50.0)	48 (27.8)	168 (33.9)	255 (34.2)	
<b>&gt; High School</b>	29 (37.2)	122 (70.5)	124 (25.1)	275 (36.9)	
Marital Status					<0.001
<b>Married</b>	37 (47.4)	98 (57.0)	133 (26.8)	268 (35.9)	
<b>Widowed</b>	33 (42.3)	48 (27.9)	196 (39.5)	277 (37.1)	
<b>Divorced</b>	6 (7.7)	17 (9.9)	131 (26.4)	154 (20.6)	
<b>Never married</b>	2 (2.6)	9 (5.2)	36 (7.3)	47 (6.3)	
<b>Live Alone</b>	29 (37.2)	57 (33.0)	203 (40.9)	289 (38.7)	0.172
<b>Know relative or friend with AD</b>	34 (43.6)	89 (51.7)	160 (32.2)	283 (37.8)	<0.001
<b>Believe I am at higher risk for AD</b>	8 (10.4)	27 (15.8)	91 (18.4)	126 (17.0)	0.198
<b>Believe I have more memory problems</b>	4 (5.2)	14 (8.1)	72 (14.6)	90 (12.1)	0.012

**Table 2**

Proportion of patients screening positive by site, demographics, and survey responses

	Screen Positive N (%)	P-value
<b>Overall (n=748)</b>	76 (10.2)	
Site		0.004
<b>Community (n=78)</b>	6 (7.7)	
<b>St. Vincent (n=173)</b>	7 (4.0)	
<b>Eskenazi (n=497)</b>	63 (12.7)	
Age		0.023
<b>% 65–74 years (n=464)</b>	38 (8.2)	
<b>% 75+ years (n=284)</b>	38 (13.4)	
Education		<0.001
<b>% 0–11 Years (n=216)</b>	49 (22.7)	
<b>% High School Grad (n=255)</b>	22 (8.6)	
<b>% &gt; High School (n=275)</b>	5 (1.8)	
Sex		0.049
<b>Male (n=222)</b>	30 (13.5)	
<b>Female (n=526)</b>	46 (8.8)	
Race		0.241
<b>African-American (n=317)</b>	37 (11.7)	
<b>White; Other (n=431)</b>	39 (9.0)	
<b>Know a friend or relative with AD</b>		0.007
<b>No (n=464)</b>	58 (12.5)	
<b>Yes (n=283)</b>	18 (6.4)	
<b>Believe you are at higher risk for AD</b>		0.720
<b>No (n=617)</b>	62 (10.0)	
<b>Yes (n=126)</b>	14 (11.1)	
<b>Think you have more memory problems than others your age</b>		0.014
<b>No (n=652)</b>	58 (8.9)	
<b>Yes (n=90)</b>	16 (17.8)	

**Table 3**

Factors Related to Screening Positive for Alzheimer's disease and related dementia

	<b>OR (95% CI)</b>	<b>P-value</b>
Site		0.676
<b>Community Health Network</b>	0.62 (0.21, 1.80)	
<b>St. Vincent Health</b>	0.88 (0.34, 2.30)	
<b>Eskenazi Health (reference)</b>	1.00	
<b>Age 75+</b>	2.55 (1.49, 4.36)	0.001
<b>Female vs. Male</b>	0.48 (0.28, 0.82)	0.008
<b>African-American</b>	0.83 (0.48, 1.45)	0.517
Education		<0.001
<b>0–11 Years</b>	15.60 (5.48, 44.38)	
<b>High School Grad</b>	6.47 (2.30, 18.24)	
<b>&gt;High School (reference)</b>	1.00	
<b>Know close relative or friend with AD</b>	2.04 (1.04, 3.97)	0.068
<b>Think have more memory problems than others</b>	0.58 (0.32, 1.04)	0.037

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