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Alzheimers Dement (Amst). 2015 June ; 1(2): 236–241. doi:10.1016/j.dadm.2015.01.002.**Traits of patients who screen positive for dementia and refuse diagnostic assessment****Nicole R. Fowler^{a,b,c,*}, Amie Frame^{a,b}, Anthony J. Perkins^{a,b}, Sujuan Gao^d, Dennis P. Watson^e, Patrick Monahan^d, and Malaz A. Boustani^{a,b,c}**Nicole R. Fowler: nfowler@iupui.edu^aIndiana University Center for Aging Research, Indianapolis, IN, USA^bRegenstrief Institute, Inc., Indianapolis, IN, USA^cDepartment of Medicine, Indiana University School of Medicine, Indianapolis, IN, USA^dDepartment of Biostatistics, Indiana University School of Medicine, Indianapolis, IN, USA^eDepartment of Health Policy and Management, Indiana University Richard M. Fairbanks, School of Public Health, Indianapolis, IN, USA**Abstract**

Background—As part of the debate about screening for dementia, it is critical to understand why patients agree or disagree to diagnostic assessment after a positive screening test. We used the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) questionnaire to measure the characteristics of patients who screened positive for dementia but refused further diagnostic assessment.

Methods—Survey of patients 65 years old without a diagnosis of dementia attending primary care clinics in Indianapolis, IN, in 2008 and 2009.

Results—Five hundred and fifty-four individuals completed the PRISM-PC and 63 screened positive. Of those, 21 (33%) accepted and 42 (67%) refused diagnostic assessment. In adjusted models, having larger stigma domain scores and living alone were significantly associated with increased odds of refusing the diagnostic assessment.

Conclusion—Despite screening positive, many patients refused a diagnostic assessment. Living alone and the perceived stigmas of dementia are associated with the refusal of diagnostic assessment for dementia.

Keywords

Dementia screening; Alzheimer's disease; Primary care; Diagnostic assessment

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1. Introduction

Dementia poses a major challenge to public health and can have devastating emotional and economic impacts on patients and their families. It is currently estimated that 5.3 million Americans have dementia and that as many as 50% of patients with dementia are never diagnosed [1–3]. Among patients aged 70 years and more with cognitive problems, only 45% have a history of a cognitive evaluation [4], suggesting that as many as 1.8 million Americans with dementia have not seen a physician about their cognitive problems.

The driving forces for the under detection of dementia are unclear. Patients may delay or decline a diagnostic assessment for dementia because of concerns that others might learn about their cognitive status, the belief that dementia cannot be treated, or a general negative attitude toward medical assessment [5,6]. Patient caregivers also influence the decision to obtain a cognitive evaluation. Previous work has found that despite caregivers acknowledging the benefits of a cognitive evaluation, 70.3% had a hard time accepting their family member's cognitive decline, and 67.7% were concerned with how a diagnosis of dementia would impact their own lives [5].

Physicians' attitudes about dementia and their confidence in performing cognitive evaluations may also contribute to the under detection of dementia [5]. Primary care physicians (PCPs) sometimes question the clinical usefulness of an early diagnosis because of limited treatment options and the need to prioritize other “treatable” health problems [7].

Those in favor of the earlier identification of dementia argue that population-based screening will increase the likelihood that dementia will be diagnosed [5]. It is also argued that early diagnosis has a variety of potential benefits including the following: earlier evaluation and treatment of reversible causes of cognitive symptoms [5]; improvements in care processes and long-term outcomes by providing opportunities for physicians to discuss prognosis, learn about patient's goals, and tailor prevention and disease-management targets [6,8,9]; and improvements in patient and family outcomes such as knowledge about dementia, preparedness for future medical decisions, and confidence in medical decision making [10]. Despite these potential benefits, it is unclear if routine screening for dementia in primary care would increase the likelihood that patients would receive a diagnostic assessment or result in improvements in patient and caregiver outcomes. There is no evidence that screening for dementia delays or alters disease progression [11,12], and relatively few studies have evaluated patient, caregiver, and physician perceptions about the value of early identification of dementia as a result of screening in primary care [13–17].

In an effort to design patient-centered interventions that will improve earlier recognition, diagnoses and patient outcomes, it is important to understand and enumerate the relationship between attitudes and behaviors of older primary care patients regarding dementia screening and diagnosis. Almost half (47.7%) of primary care patients in one recent study refused a cognitive evaluation after a positive screening test for dementia [18]. Patients who self-identified as African American, were 70 to 79 years old, and who do not perceive themselves as having any decline in their cognitive abilities were most likely to refuse diagnostic assessment; however, this study did not investigate the effect of patients'

perceptions regarding dementia and screening on their willingness to undergo diagnostic assessment.

The purpose of this study is to measure older primary care patients' perceptions of dementia screening and compare those perceptions between those who screened positive for dementia and accepted a diagnostic assessment versus those who screened positive and refused a diagnostic assessment. Based on our previous work investigating older adults' perceptions and beliefs about screening, we hypothesized that patients in the mid-range of our sample, ages 70 to 80 years, would be more likely to refuse diagnostic assessment. In addition, patients who acknowledged the benefits of early detection of dementia would be more likely to accept a follow-up cognitive evaluation after a positive screening test [6,14].

2. Methods

2.1. Study population

Patients were eligible to participate in our study if they were 65 years or older, did not have a documented diagnosis of dementia, and received their primary care at Eskenazi Health in Indianapolis, IN. Eskenazi Health is an urban health care system with 11 community-based primary care practice centers staffed by faculty and residents of Indiana University School of Medicine. In 2007, approximately 11,000 patients 65 years and older received care at Eskenazi Health, with most of these patients visiting a PCP an average of four times a year.

All study recruitment was conducted through the Indiana University Practice Based Research Network (IU-PBRN). The IU-PBRN is a research network that uses informatics tools to coordinate the recruitment of primary care patients into local research studies. The IU-PBRN research assistants, who are trained in the protection of patient privacy and institutional review board (IRB) policies and procedures for conducting research with human subjects, approached eligible patients within the primary care clinics and obtained informed consent from those who agreed to participate in the study. This study was approved by the Indiana University, Purdue University-Indianapolis's IRB.

2.2. Study procedures and instruments

Patients' perceptions about dementia and screening for dementia were obtained through face-to-face encounters and measured with the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) questionnaire. The PRISM-PC questionnaire consists of 50 items, including 12 items on the sociodemographic characteristics of the participants and their experiences with Alzheimer's disease. The remaining 38 items measure patients' experiences with dementia, their perceptions of the benefits and harms of screening for dementia, and their perceptions regarding the acceptability of dementia screening with different methods. These 38 items are scored on a 5-point Likert scale ("strongly agree" to "strongly disagree") (Supplementary Material). The psychometric properties of the PRISM-PC questionnaire have been previously published [13].

At the time of enrollment, patients were asked to complete the PRISM-PC questionnaire first and then asked if they would be willing to be screened for memory problems using one of two paper-and-pencil screening instruments: (1) Community Screening Instrument for

Dementia (CSI-D) [19] or (2) Mini-Mental State Examination (MMSE) [20]. If they agreed, the research assistant would administer the cognitive screen and follow a script based on the patient's score. Two screening instruments were used because of a change in protocol from a concurrent study that was enrolling patients from the same clinics.

For patients who screened ≥ 24 on MMSE and CSI-D, they were reassured that the screening test was not a diagnostic test and asked if they would like to be contacted by the Healthy Aging Brain Center (HABC) at Eskenazi Health for a complete cognitive evaluation and diagnostic assessment. Program coordinators from the HABC attempted to contact participants who screened positive on multiple occasions over a 6-month period after the positive screening test. The HABC program has two phases: an initial assessment phase and a follow-up phase. An individualized care plan is developed in the first phase of the program after a full cognitive evaluation that includes a structured neurological and physical examination, neuropsychological testing, blood work, brain imaging, and a diagnostic conference with the patient and their family. The follow-up phase focuses on monitoring and the modification of the collaborative care plan based on continued interaction with the patient and caregiver and input from the HABC team and the patient's PCP [17]. In the study presented here, we examined responses on the PRISM-PC questionnaire for only the patients who screened positive for dementia and we compared responses between those who agreed and refused a cognitive evaluation and diagnostic assessment.

3. Statistical analyses

Before conducting the analyses, we reverse-coded responses on the PRISM-PC questionnaire so that a higher score indicated stronger agreement with the items. To facilitate the interpretation of the domain scores, we converted all domains to the same metric by taking the sum of the reverse-coded responses and then transformed the sum to a 0 to 100 scale by subtracting the minimum possible score and dividing it by the possible range. For a given domain, this meant that 0 represented “strongly disagree” on all items, 100 represented “strongly agree” on all items, and 50 represented neutral scores on all items.

We used the Fisher exact test for categorical variables and the two-sample *t* test for continuous variables to compare demographics and PRISM-PC domain scores across diagnostic assessment status. To model the association of the PRISM-PC domains and demographics with the refusal of diagnostic assessment, we used logistic regression using the variables with *P*-values $< .10$ from the univariate analyses. The final model retained only variables significant at the .05 level. For all statistical analyses, we used SAS statistical software version 9.3 (SAS Institute Inc., Cary, NC).

4. Results

Of the 1065 patients asked to participate in this study, 554 agreed and provided informed consent. The 511 nonparticipants did not vary significantly from the participants in terms of age ($P = .07$), sex ($P = .19$), or race or ethnicity ($P = .62$). Among the 554 who completed the PRISM-PC questionnaire, 497 (89.7%) agreed to dementia screening and details about this sample have been previously reported [14]. Of the 497, 63 (12.7%) patients screened positive and were referred for the HABC for diagnostic assessment. Among the 63 referred

for a full cognitive evaluation, 21 (33.3%) accepted and completed the cognitive evaluation and diagnostic assessment and 42 (66.7%) refused. A participant was counted as a refusal if they reported to the HABC program coordinator that they did not want to be evaluated or if they were unable to be reached or scheduled for an appointment in the 6 months after the positive screening test.

Most respondents who screened positive and were referred for diagnostic assessment were female (61.9%), African Americans (55.6%), and had an annual income less than \$20,000 (88.9%). Approximately half of the respondents were widowed, 71% had less than a high school education, and 48% lived alone. Comparisons of diagnostic assessment refusal rates by sociodemographic characteristics are presented in Table 1. Respondents who lived alone were significantly more likely to refuse the diagnostic assessment than those living with someone. Respondents with an annual income of \$10,000 or more were more likely to refuse the diagnostic assessment compared with those with an annual income less than \$10,000, although only marginally significantly different likely because of the sample size and that 28.6% of the sample had missing income data.

Tables 2 and 3 present comparisons of PRISM-PC domains and items by diagnostic assessment. Patients who refused diagnostic assessment had significantly higher stigma domain scores on the PRISM-PC questionnaire compared with those who agreed and completed the diagnostic assessment. Respondents who refused the diagnostic assessment generally had higher scores on each item in the stigma domain. No other domains were significantly different between the two groups. Respondents who agreed to a diagnostic assessment were significantly more likely to agree to yearly colorectal cancer screening. Two other items were marginally significant ($.05 < P < .10$) and were considered for evaluation. Respondents who refused the diagnostic assessment tended to have higher incomes and be more likely to agree that a treatment for Alzheimer's disease (AD) is not currently available.

In a final adjusted logistic model for refusing diagnostic assessment, three variables were statistically significant. Larger stigma domain scores (adjusted odds ratio [AOR] for 5-point increase 1.43; 95% confidence interval [CI] 1.04, 1.98) and living alone (AOR 7.28; 95% CI 1.81, 29.29) were significantly associated with increased odds of refusing the diagnostic assessment. In addition, higher agreement with colorectal cancer screening was associated with the decreased odds of refusing diagnostic assessment for dementia (AOR 0.25; 95% CI 0.07, 0.90).

5. Discussion

This is the first study to examine the relationship between older primary care patients' attitudes about dementia screening and their behavior regarding cognitive evaluations following a positive dementia screening test. More than half of the 63 (66.7%) study participants who screened positive refused a follow-up cognitive evaluation and diagnostic assessment. Patients' perceptions of the stigmas surrounding dementia and dementia screening were associated with the refusal of diagnostic assessment.

The findings from our study are important given the low rates of detection of dementia and the high percentage older adults with dementia who never receive a cognitive evaluation. Early intervention and education of patients and their caregivers on dementia and dementia screening could increase the number of patients seeking diagnostic assessment, specifically those that address the perceived stigmas associated with dementia screening.

Living alone was the only demographic characteristic associated with the refusal of a diagnostic assessment. This finding is comparable with other studies that have found a relationship between marital status and higher rates of cognitive evaluations and diagnoses [4]. Approximately half of the participants eligible for a diagnostic assessment were widowed. Although not statistically significant, patients who were not married had higher refusal rates for the diagnostic assessment than those who were married. This complements earlier work that has shown patients with an identified caregiver and the caregivers themselves overwhelmingly want information about a dementia diagnosis [21]. Taken together, this suggests that patients without a potential caregiver may be less likely to agree to a cognitive evaluation and diagnostic assessment and more likely to perceive stigma associated with a diagnosis. This may be associated with a belief that formally identifying cognitive impairments may lead to loss of activities such as driving and the independence they have been accustomed to. For most patients with dementia, the person living with the patient assumes the role of the caregiver [22]. In the absence of a caregiver, the patient is challenged to find physical and social support, which are important mediators for a variety of health outcomes [23,24].

Patients who accepted a cognitive evaluation and diagnostic assessment were more likely to agree to the item on the PRISM-PC regarding a desire for an examination for colorectal cancer by their physician. This may be because of a patient's overall feeling that screening and testing is a good health behavior or because of an acknowledgment that both dementia and colorectal diseases are associated with age and should be addressed as a person gets older. Previous studies show that a general lack of knowledge about dementia and its etiology and symptomatology are strong barriers to receiving a diagnosis. Interestingly, our previous work has shown that patients' beliefs about cognitive decline as a normal aging process may prevent patients from seeking a diagnosis and getting more information [10].

Limitations to the study include a small sample size and generalizability. Nevertheless, despite lower power from a small sample, several relationships were statistically significant. A very small percentage of participants screened positive (12.7%) with an even smaller sample completing the diagnostic assessment. Given the findings discussed previously, it is interesting that the relationship between patients' perceptions of dementia screening's effect on independence and their decision to refuse the assessment was not significant. This may be because of the small sample size, and future work should further investigate the relationship between these two variables. Although the study cohort consisted primarily of minority and low socioeconomic individuals, inferences can be made that are useful in developing educational programs and interventions, specifically for older primary care patients. Another limitation was our lack of ability to track if the patients who screened positive and refused a cognitive evaluation and diagnostic assessment sought further evaluation from their own physician or program outside the HABC.

6. Conclusion

Most patients, despite screening positive for dementia, refused a diagnostic assessment. Patients who completed the diagnostic assessment were less likely to believe there are stigmas associated with dementia screening and diagnosis and were less reluctant to accept other examinations and screenings by their PCP. The only significant difference in sociodemographics between the diagnostic assessment refusal and acceptance groups was living alone. Intervening on patients' perceptions about dementia diagnosis, misconceptions about stigmas, and providing information about benefits of early identification could potentially increase the number of patients seeking diagnostic assessment of dementia.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Research in Context

1. Systematic review: Patients' willingness to be screened for dementia and willingness to follow-up with diagnostic assessment after a positive screen has been shown to be related to their perceptions about their own cognitive health and about the harms of receiving a dementia diagnosis especially in the face of limited of treatment or preventive methods for dementia.
2. Interpretation: Our study shows that in a sample of community dwelling older adults who screened positive for dementia, more than half (67%), refused diagnostic assessment after the positive screen. Based on survey responses of those who refused a diagnostic assessment, patients who refused diagnostic assessment were more likely to live alone and agree with statements associated with stigmas related to dementia.
3. Future directions: Intervening on patients' perceptions about dementia in general, and about diagnosis and treatment, could potentially increase the number of patients seeking or accepting the diagnostic assessment of dementia.

Table 1
Comparison of the sociodemographic characteristics of study participants who accepted and refused diagnostic assessment for dementia

Variable	No. (%) of pts. (accepted diagnostic assessment; n = 21)	No. (%) of pts. (refused diagnostic assessment; n = 42)	P value
Age groups (yr)			.448
65–69	4 (19.1)	15 (35.7)	
70–74	7 (33.3)	8 (19.1)	
75–79	6 (28.6)	10 (23.8)	
80	4 (19.1)	9 (21.4)	
Gender, female	14 (66.7)	25 (59.5)	.784
Race, nonwhite	13 (61.9)	23 (54.8)	.788
Years of education, 0–11 yrs	18 (85.7)	27 (63.3)	.138
Lives alone	5 (23.8)	25 (59.5)	.008
Marital status, married	7 (33.3)	8 (19.0)	.227
Annual income			.072
<\$10,000	7 (33.3)	10 (23.8)	
\$10,000–\$19,999	4 (19.1)	24 (57.1)	
Missing	10 (47.6)	8 (19.1)	

Table 2
Comparison of responses to questions on the PRISM-PC of study participants who accepted and refused diagnostic assessment for dementia

Items on the PRISM-PC	No. (%) who accepted diagnostic assessment (n = 21)	No. (%) who refused diagnostic assessment (n = 42)	P value
Do you have a relative or friend with Alzheimer's disease [*] ? Yes	5 (23.8)	9 (21.4)	1.000
Do you believe that you are at a higher risk of Alzheimer's disease than others of your same age? Yes	3 (14.3)	8 (19.0)	.738
Do you think you have more memory problems than others of your same age? Yes	6 (28.6)	8 (19.0)	.349
Has a doctor told you that you have memory problems? Yes	1 (4.8)	1 (2.4)	1.000
Are you taking medication to help with memory? Yes	1 (4.8)	1 (2.4)	1.000

Abbreviation: PRISM-PC, Perceptions Regarding Investigational Screening for Memory in Primary Care.

* Because our early work indicated that patients more readily understood the term "Alzheimer's disease" than the term "dementia," we used "Alzheimer's disease" as a proxy for dementia for this study.

Table 3
Comparison of PRISM-PC scales between participants who screened positive and accepted diagnostic assessment (DA) for dementia and those who refused diagnostic assessment

PRISM-PC domains	Accepted DA, mean (SD) (n = 21)	Refused DA, mean (SD) (n = 42)	P value
Acceptance of dementia screening	67.6 (13.3)	60.9 (17.6)	.128
Stigma of dementia screening	35.2 (10.7)	42.0 (13.1)	.045
Negative impact of dementia screening on independence	47.7 (14.2)	51.8 (16.2)	.318
Suffering related to dementia screening	50.9 (19.2)	51.3 (13.3)	.921
Individual questions not included in a domain score			
Acceptance with colorectal cancer screening	4.0 (0.5)	3.5 (0.9)	.047
Acceptance with depression screening	3.8 (0.8)	3.5 (0.9)	.361
Belief that a treatment for Alzheimer's disease is not currently available	2.5 (0.9)	2.9 (0.9)	.059

Abbreviations: PRISM-PC, Perceptions Regarding Investigational Screening for Memory in Primary Care; SD, standard deviation.