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Impact of Patients' Perceptions on Dementia Screening in Primary Care

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Abstract

Objectives—To determine patients' perceptions concerning dementia screening and to evaluate the possibility of an association between their perceptions and willingness to undergo screening.

Design—Cross-sectional study of primary care patients who are ≥65 years old.

Setting—Urban primary care clinics in Indianapolis, Indiana, in 2008–2009.

Participants—A sample of 554 primary care patients without a documented diagnosis of dementia.

Measurements—The Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) Questionnaire and agreement or refusal to undergo dementia screening.

Results—Of the 554 study participants, who completed the PRISM-PC, 65.5% were ≥70 years old, 70.0% were female, and 56.5% were African American. A total of 57 (10.3%) refused screening for dementia. Among the 497 (89.7%) who agreed to screening, 63 (12.7%) screened positive. After adjusting for age, perception of depression screening, perception of colon cancer screening, and belief that no treatment is currently available for Alzheimer's disease, the odds of refusing screening were significantly lower in participants who had higher PRISM-PC domain scores for benefits of dementia screening (OR, 0.85; 95%CI, 0.75–0.97; P=.02). In the same regression model, the odds of refusing screening were significantly higher in patients aged 70–74

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All authors were responsible for the study concept, design, acquisition of data, analysis and interpretation of data and preparation of the manuscript.

Conflict of Interest
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years (OR, 5.65; 95%CI, 2.27–14.09; $P<.001$) and patients aged 75–79 years (OR, 3.63; 95%CI, 1.32–9.99; $P=.01$) than in the reference group of patients aged 65–69 years old.

Conclusion—Patients' age and their perceived benefit of screening are associated with acceptance of dementia screening in primary care.

Keywords

dementia screening; patient perception; dementia; older adults

INTRODUCTION

Dementia is a debilitating and degenerative neurologic condition that affects about 4.5 million people in the United States.[1] There is no cure for dementia and the latest recommendation by the United States Preventive Services Task Force[2] concluded that the evidence to systematically screen for dementia in primary care (PC) is insufficient due to a lack of studies evaluating the efficacy, benefits and harms of dementia screening in primary care.[3] Beginning in January 2011, in compliance with the Patient Protection and Affordable Care Act, the Centers for Medicare and Medicaid Services will cover the costs of an annual wellness visit for Medicare beneficiaries. The visit will emphasize preventive care, and the goal will be for primary care physicians (PCPs) to work with Medicare beneficiaries to create personalized disease prevention plans for patients. To meet the requirements of the annual wellness visits, PCPs must cover nine elements during the visit, one of which is detecting any cognitive impairment.[4] The success of the new government policy to promote prevention will depend on patients' perceptions of the benefits and harms of screening as will the success of other interventions designed to reduce the effects of dementia.[2,5,6]

An understanding of patients' perceptions of the benefits and harms of dementia screening may shed light on the barriers and possible facilitators to implementing dementia screening programs in primary care.[7,8] In addition, it may facilitate the development of patient-oriented decision aids and educational programs that could reduce the negative impact of early dementia detection on patients and their family members.[9,10] With this in mind, researchers at the Indiana University Center for Aging Research developed the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) Questionnaire. This instrument has been used in both the US and the UK to capture the attitudes of older adults receiving primary care services in the community as well as the attitudes of family members who care for patients with Alzheimer's disease detected by a dementia screening and diagnosis program.[11–13]

The purpose of this cross-sectional study was to use the PRISM-PC to determine primary care patients' perceptions of dementia screening and to evaluate the possibility of an association between their perceptions and their willingness to undergo screening. We hypothesized that patients with concerns that dementia screening would be harmful will have higher refusal rates for screening as compared with those who believe that the early detection of dementia via screening would be beneficial.

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 dementia, and received their primary care at Wishard Health Services (WHS) in Indianapolis, Indiana. WHS is an urban health care system with seven community-based primary care practice centers staffed by faculty and residents of Indiana

University School of Medicine, and the study was approved by the Indiana University Purdue University-Indianapolis Institutional Review Board.

From January 2008 to June 2009, research assistants from Indiana University Practice Based Research Network (IU-PBRN) approached all potential participants at the community based primary care clinics who met the eligibility requirements and invited them to participate in the study. All recruiting was conducted through IU-PBRN, a research network that facilitates recruitment of primary care patients into clinical studies. IU-PBRN operating procedures are compliant with all HIPAA and IRB regulations, and all research assistants have certification of training for research involving human subjects. It is the only method by which the primary care practices allow patients to be recruited into research projects. The purpose of IU-PBRN is to maximize the efficient enrollment of patients into clinical studies with minimal perturbation of the delivery of primary care and close attention to human subjects concerns. Those who agreed to participate in the study provided informed consent.

Study Procedures and Instruments

The study used the PRISM-PC,[14] the Community Screening Instrument for Dementia (CSI-D),[15] and the Mini-Mental State Examination (MMSE).[16] We developed the PRISM-PC to examine the perceived harms and benefits of screening for dementia. Because our early work indicated that patients more readily understood the term “Alzheimer’s disease” than the term “dementia,” the PRISM-PC refers to Alzheimer’s disease as a proxy for dementia. The instrument’s face and content validity were established by researchers who were guided by the health belief model and had expertise in dementia care in the United States and United Kingdom.[13,14]

The PRISM-PC has a total of 50 items. It includes 12 items that capture sociodemographic data and information about a study participant’s experience with Alzheimer’s disease. In addition, it includes 38 items that measure the participant’s perceptions of and attitudes about the acceptability, benefits, and harms of dementia screening, and is scored on a 1–5-point Likert scale, with responses ranging from “strongly agree” to “strongly disagree.” Most of these Likert-scale items concern the following domains (see appendix): benefits of dementia screening (8 items), stigma of dementia screening (10 items), negative impact of dementia screening on independence (6 items), and suffering related to dementia screening (4 items). However, 6 items measure perceived acceptance of different types of dementia screening, 2 of the Likert-scale items concern screening for other conditions (colon cancer and depression), and 2 concern the belief that a treatment for Alzheimer’s disease is not currently available.

For the PRISM-PC, the internal consistency of the benefits and harms subdomains have a Cronbach’s alpha range of 0.73 to 0.85.[14] In the study reported here, we focused on participants’ scores concerning these subdomains. This focus was driven by our interest in investigating the association between perceptions about screening and actual behavior related to screening (i.e., agreeing or refusing to be screened), rather than the association between perceptions about screening and acceptance of the idea of screening.

IU-PBRN research assistants approached eligible subjects at the local clinic, explained to them the nature of the study, and administered the PRISM-PC in a face-to-face interview to those who consented for study participation. The research assistants then asked the participant to undergo dementia screening with a written test, either the CSI-D or the MMSE. The variation in test instrument was a result of a change in protocol for a concurrent study enrolling patients from the same clinics. Participants whose results were positive on the screening instrument (24 on the CSI-D[15] or the MMSE[16]) were referred to the local memory clinic at WHS for a diagnostic assessment.

Statistical Analyses

Prior to conducting the analyses, responses on the PRISM-PC were reverse-coded so that a higher score indicated stronger agreement with the items. To facilitate interpretation of the domain scores, we used a similar approach that is used to analyze scale scores on the SF-36.[17] We converted all domains to the same metric by taking the sum of the reverse-coded responses and then transforming the sum to a 0 to 100 scale by subtracting the minimum possible score and dividing 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.

For comparisons of groups of participants, we used t tests if the variables were continuous and Fisher's exact tests if the variables were categorical. To model the association of the PRISM-PC domains with the dependent variable (acceptance versus refusal of screening), we used logistic regression and adjusted for covariates found to be significant ($P<.05$) in bivariate analyses. We reported the results in terms of odds ratios (ORs) and confidence intervals (CIs).

For all statistical analyses, we used SAS statistical software version 9.2 (SAS Institute Inc., Cary, North Carolina).

RESULTS

Of the 1065 individuals approached at the primary care clinics, 201 declined participation at that visit but agreed to be approached at a follow-up visit. Among the 864 patients who discussed participation in the study on the day that they were approached, 554 (64.0%) signed informed consent, 110 (13%) refused participation for any research study, and 200 (23%) refused participation in this study. The 310 nonparticipants did not vary significantly from the participants in terms of age ($P=.07$), sex ($P=.19$), or race/ethnicity ($P=.62$). Unfortunately, due to insufficient resources, we were not able to follow-up the 310 to assess their reasons for not wanting to participate.

Of the 554 participants, 363 (65.5%) were ≥70 years old, 388 (70.0%) were female, 313 (56.5%) were African American, 232 (42.1%) had less than a high school education, 360 (77.4%) had an annual income of less than $20,000, and 327 (59.0%) lived alone. When asked to undergo screening for dementia, 57 (10.3%) refused.

Of the 497 (89.7%) who underwent screening, 63 (12.7%) screened positive and were referred for a confirmatory diagnostic assessment.

A bivariate analysis of the participants' sociodemographic characteristics and experience with Alzheimer's disease (Table 1) showed that the only significant difference between the participants who accepted screening and those who refused screening was in age ($P<.001$).

A bivariate comparison of the mean PRISM-PC scores of participants who accepted screening for dementia and participants who refused it (Table 2) showed that there was a significant difference in the average domain score for benefits of dementia screening (73.0 vs. 67.3; $P=.001$), but not in the average domain scores for the stigma of dementia screening, the negative impact of dementia screening on independence, and the suffering related to dementia screening. There were also significant differences regarding the following individual items: agreement about planning for future health care as a benefit (4.0 vs. 3.8; $P=.03$), agreement with screening for colon cancer (3.5 vs. 3.1; $P=.02$), agreement with screening for depression (3.4 vs. 3.1; $P=.008$), and belief that a treatment for Alzheimer's disease is not currently available (2.7 vs. 3.0; $P=.02$).

The logistic regression model adjusted for items found to be significant in Tables 1 and 2. The results of regression analysis (Table 3) indicated that the odds of refusing screening were significantly lower in participants who had higher domain scores for benefits of dementia screening (OR, 0.85; 95%CI, 0.75–0.97; *P*=.02). The odds of refusing screening were significantly higher in patients aged 70–74 years (OR, 5.65; 95%CI, 2.27–14.09; *P*<.001) and patients aged 75–79 years (OR, 3.63; 95%CI, 1.32–9.99; *P*=.01) than in the reference group of patients aged 65–69 years old. The odds of refusing screening among patients aged ≥80 years were higher (OR, 2.44; 95%CI, 0.78–7.66; *P*=.13) than in the reference group, but these results were not significant.

A bivariate comparison of the mean PRISM-PC scores of participants who screened positive for dementia and those who screened negative for dementia (Table 4) showed that participants in the positive result group had a significantly higher score on the stigma domain (39.8 vs. 32.1; *P*<.001) and on the item regarding agreement with screening for colon cancer (3.7 vs. 3.4; *P*=.03).

DISCUSSION

In our sample of older patients from an urban primary care setting, an overwhelming majority (89.7%) agreed to be screened for dementia following completion of the PRISM-PC questionnaire. Study participants' perceptions about the benefits of dementia screening were associated with their willingness to accept screening. Participants who had stronger agreement with the statements regarding the benefits of knowing about dementia earlier (e.g., ability to plan for the future) were more likely to accept screening.

Of the various sociodemographic data that were gathered for our study, only age was highly predictive of acceptance. The middle age range of the sample (participants aged 70–79) were less likely to accept screening for dementia than the younger participants (aged 65–69) and older participants (aged ≥80). While it is somewhat disconcerting to find that individuals in the age range of 70 to 79 years—arguably the ones most likely to benefit from screening for dementia due to prevalence—are also the ones most likely to refuse screening, we suspect this phenomenon may be linked to their increasing experience with dementia, either because of friends or family, as well as their own recognition that developing dementia is a real possibility for them as well.

Among the participants who accepted screening, 12.7% screened positive. These participants with positive results had higher scores on the stigma domain of the PRISM-PC. This suggests that individuals who may already be experiencing some cognitive difficulties are more likely to perceive stigma related to the recognized cognitive decline.

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 following completion of the PRISM-PC questionnaire or more detailed information from those who screened positive. Although our sample was relatively small, it was drawn from urban clinics serving a predominantly African American population and therefore provides data that fill some important gaps regarding perceptions held by a vulnerable segment of the primary care population.[18,19] Additionally, while the individuals who refused to participate in the study did not differ by age, gender, or race as compared with those who agreed, they may have declined participation directly because of their lack of willingness to be screened, introducing bias in our sample.

To our knowledge, our study is the first to include data on primary care patients' attitudes, their behaviors of accepting or refusing screening, and their cognitive performance on screening tests. We believe that our findings provide the kind of information that will help primary care physicians and the United States Preventive Services Task Force in evaluating the benefits and harms of dementia screening by including the voice and perceptions of the patients attending primary care.

Our findings are consistent with studies that have reported high levels of acceptance of screening as part of routine primary care and research that has used willingness-to-pay models to show that even in the absence of direct treatment options, people value diagnostic information for a host of health-related and other reasons, such as planning for the future and prioritizing important relationships and life events.[20,21] On the other hand, our findings stand in contrast to those of previous studies on health care providers' attitudes. These studies demonstrated that health care providers have complex beliefs, and that some do not think that making the diagnosis of dementia has great value.[22,2325,26] Moreover, providers do not always believe that patients want to know if they are at risk of developing dementia.[24–26]

Important next steps for this line of inquiry include further testing of instruments such as the PRISM-PC to help determine whether patients who have already begun to experience cognitive impairment perceive screening differently. For example, do patients with self-recognized cognitive deficits have different attitudes and beliefs regarding screening for dementia, and, if so, to what extent do they perceive screening to be important for preparing for future medical decisions?

We recognize that participation in this study is not directly analogous to accepting a physician's offer to screen for cognitive impairment. Yet, to fully achieve the benefits of detecting cognitive impairment as part of the Medicare annual wellness examination, our study shows that further work needs to be conducted to understand what motivates older patients to accept and undergo screening.

CONCLUSIONS

The vast majority of participants in this study agreed to undergo screening for dementia. Refusal rates did not vary with race/ethnicity, education level, or other sociodemographic characteristics. However, the odds of refusal were higher in patients aged 70–79 years than in younger Medicare beneficiaries and for those who felt that screening may be harmful.

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Table 1

Bivariate Comparison of the Sociodemographic Characteristics and Experience with Alzheimer's Disease of Study Participants Who Accepted and Refused Screening for Dementia[a]

	No. (%)		
Variable	**Accepted Screening (n = 497)**	**Refused Screening (n = 57)**	***P* Value**
Age, y			
65–69	185 (96.9)	6 (3.1)	<.001
70–74	148 (83.2)	30 (16.8)	
75–79	91 (86.7)	14 (13.3)	
≥80	73 (91.2)	7 (8.8)	
Gender			
Female	351 (90.5)	37 (9.5)	.36
Male	146 (88.0)	20 (12.0)	
Race/ethnicity[b]			
White	208 (90.4)	22 (9.6)	.91
African American	280 (89.5)	33 (10.5)	
Other	7 (87.5)	1 (12.5)	
Education, y			
0–11	203 (87.5)	29 (12.5)	.15
≥12	292 (91.5)	27 (8.5)	
Housing status			
Living alone	293 (89.6)	34 (10.4)	.89
Living with someone	203 (90.2)	22 (9.8)	
Marital status			
Married	133 (91.1)	13 (8.9)	.52
Widowed	196 (89.5)	23 (10.5)	
Divorced	131 (91.0)	13 (9.0)	
Never married	36 (83.7)	7 (16.3)	
Income (N = 465)			
<$10,000	115 (89.2)	14 (10.8)	.18
$10,000–$19,999	212 (91.8)	19 (8.2)	
$20,000–$39,999	64 (87.7)	9 (12.3)	
≥$40,000	32 (100.0)	0 (0.0)	
Do you have a relative or friend with Alzheimer's disease?			
No	337 (88.9)	42 (11.1)	.45
Yes	160 (91.4)	15 (8.6)	
Do you believe that you are at higher risk of Alzheimer's disease than others of your same age?			
No	404 (89.6)	47 (10.4)	.86
Yes	91 (91.0)	9 (9.0)	

Variable	**No. (%)**		***P* Value**
	Accepted Screening (n = 497)	**Refused Screening (n = 57)**	
Do you think you have more memory problems than others of your same age?			
No	421 (89.4)	50 (10.6)	.55
Yes	72 (92.3)	6 (7.7)	
Has a doctor told you that you have memory problems?			
No	481 (89.7)	55 (10.3)	.69
Yes	15 (88.2)	2 (11.8)	
Are you taking medication to help with memory?			
No	488 (89.7)	56 (10.3)	0.99
Yes	6 (100.0)	0 (0.0)	

[a] Because our early work indicated that patients more readily understood the term “Alzheimer’s disease” than the term “dementia,” in this study we used Alzheimer’s disease as a proxy for dementia.

[b] Race/ethnicity was self-reported.

Table 2

Bivariate Comparison of the Mean PRISM-PC Scores of Study Participants Who Accepted and Refused Screening for Dementia

Domains and Individual Items[a]	**Mean Score (SD)**		***P* Value**
	Accepted Screening (n = 497)	**Refused Screening (n = 57)**	
Domain: benefits of dementia screening	73.0 (10.5)	67.3 (12.4)	.001
Domain: stigma of dementia screening	33.1 (12.2)	33.0 (11.5)	.95
Domain: negative impact of dementia screening on independence	50.3 (13.9)	48.4 (13.8)	.33
Domain: suffering related to dementia screening	52.9 (15.2)	52.7 (14.3)	.88
Item in no domain: agreement with screening for colon cancer	3.5 (1.0)	3.1 (1.1)	.02
Item in no domain: agreement with screening for depression	3.4 (1.0)	3.1 (1.1)	.008
Item in no domain: belief that a treatment for Alzheimer's disease is not currently available	2.7 (0.9)	3.0 (0.8)	.02

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

[a] For each domain, the table includes the individual item that was most relevant to our study objectives. The table also includes the 3 individual items that are not covered under any domain. Because our early work indicated that patients more readily understood the term "Alzheimer's disease" than the term "dementia," the PRISM-PC refers to Alzheimer's disease as a proxy for dementia.

Table 3

Logistic Regression Analysis of the Odds of Refusing to Undergo Screening for Dementia[a]

Variable	Odds Ratio (95% Confidence Interval)	*P* Value
PRISM-PC responses		
High domain score: perception that dementia screening is beneficial[b]	0.85 (0.75–0.97)	.02
Perception that colon cancer screening is beneficial	0.87 (0.65–1.18)	.37
Perception that depression screening is beneficial	0.86 (0.63–1.18)	.35
Belief that no treatment is currently available for Alzheimer’s disease	1.29 (0.93–1.78)	.13
Age, y		
65–69 (reference group)	1 [Reference]	
70–74	5.65 (2.27–14.09)	<.001
75–79	3.63 (1.32–9.99)	.01
≥80	2.44 (0.78–7.66)	.13

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

[a] The logistic regression analysis adjusted for age, perception of depression screening, perception of colon cancer screening, and belief that no treatment is currently available for Alzheimer’s disease. Because our early work indicated that patients more readily understood the term “Alzheimer’s disease” than the term “dementia,” the PRISM-PC refers to Alzheimer’s disease as a proxy for dementia.

[b] This measure was based on a 5-point difference in domain scores between those who agreed to undergo screening and those who refused. The area under the receiver operating characteristic (ROC) curve for this difference was 0.744.

Table 4

Bivariate Comparison of the Mean PRISM-PC Scores of Study Participants Who Screened Positive and Screened Negative for Dementia

	Mean Score (SD)		
Domains and Individual Items[a]	**Screened Positive (n = 63)**	**Screened Negative (n = 434)**	***P* Value**
Domain: benefits of dementia screening	71.7 (10.7)	73.1 (10.4)	.30
Domain: stigma of dementia screening	39.8 (12.7)	32.1 (11.8)	<.001
Domain: negative impact of dementia screening on independence	50.4 (15.6)	50.3 (13.7)	.96
Domain: suffering related to dementia screening	51.2 (16.6)	53.1 (15.0)	.35
Item in no domain: agreement with screening for colon cancer	3.7 (0.9)	3.4 (1.1)	.03
Item in no domain: agreement with screening for depression	3.6 (0.9)	3.4 (1.0)	.09
Item in no domain: belief that a treatment for Alzheimer’s disease is not currently available	2.8 (0.9)	2.7 (0.9)	.43

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

[a] Because our early work indicated that patients more readily understood the term “Alzheimer’s disease” than the term “dementia,” the PRISM-PC refers to Alzheimer’s disease as a proxy for dementia.

APPENDIX

Perceived Harms and Benefits Domains and Items in the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) Questionnaire[a]

Acceptance of dementia screening	
1	I would like to know if I am at higher risk for Alzheimer’s disease
2	I would like to know if I have Alzheimer’s disease
3	I would like to be tested for Alzheimer’s disease with a short questionnaire
4	I would like to be tested for Alzheimer’s disease with a blood sample
5	I would like to be tested for Alzheimer’s disease with a CT scan or MRI
6	I would like a doctor to examine me for Alzheimer’s disease
Benefits of dementia screening	
1	It would increase the chance to treat the disease better
2	It would give my family a better chance of caring for me
3	It would give me more time to plan my future
4	It would give me more time to talk with my family about my health care
5	It would give me more time to talk with my family about my finances
6	It would motivate me to sign my advance directive or my living will
7	It would motivate me to have a healthier lifestyle
8	It would make me more willing to participate in research about this disease
Stigma of dementia screening	
1	I would not want my family to know
2	I would feel humiliated by my family members or others who would treat me poorly or laugh at me
3	I would no longer be taken seriously
4	I would be considered stupid and unable to do things
5	I would feel ashamed or embarrassed
6	I would give up on life
7	My doctor would not provide the best care for my other medical problems
8	My doctor and other health professionals would not listen to me
9	I would be concerned that my health insurance company would find out
10	I would be concerned that my employer would find out
Negative impact of dementia screening on independence	
1	I would not be able to get health insurance
2	I would not be able to get life insurance
3	I would not be able to get long-term care insurance
4	I would lose my home
5	I would be living in a nursing home
6	I would lose my driver’s license and other privileges
Suffering related to dementia screening	
1	My family would suffer financially
2	My family would suffer emotionally

3	I would be depressed
4	I would be anxious
Screening for other conditions	
1	I would like a doctor to examine me yearly for colon cancer
2	I would like a doctor to examine me yearly for depression
Beliefs related to treatment for Alzheimer's disease	
1	I believe that a treatment for Alzheimer's disease is currently available
2	I believe that early detection of Alzheimer's disease increases treatment chances

Abbreviations: CT, computed tomography; MRI, magnetic resonance imaging.

[a] Because our early work indicated that patients more readily understood the term "Alzheimer's disease" than the term "dementia," the PRISM-PC refers to Alzheimer's disease as a proxy for dementia.