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## MEASURING PRIMARY CARE PATIENTS' ATTITUDES ABOUT DEMENTIA SCREENING

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### Abstract

**Objectives**—To develop a questionnaire that will capture patients' attitudes about dementia screening in primary care.

**Methods**—Cross-sectional study of 315 patients aged 65 and older attending urban and rural primary care clinics in Indianapolis and North Carolina. The Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) questionnaire was administered via face-to-face or phone interview.

**Results**—The PRISM-PC questionnaire consists of two separate scales: the patient's acceptance of dementia screening scale and the patient's perceived harms and benefits of dementia screening scale. The face validity of the PRISM-PC questionnaire was based on a systematic literature review and the opinions of 16 clinician-investigators with experience in screening for dementia. Exploratory factor analyses for the acceptance scale revealed the presence of two dimensions: knowledge about dementia risk and testing for dementia. For the benefits and harms scale, exploratory factor analyses identified four dimensions: perceived benefits of screening, stigma of screening, suffering from screening, and impact of screening on patients' independence. The internal consistency of each of the above subscales was good with Cronbach's alpha ranging from 0.58–0.85.

**Conclusion**—The PRISM-PC questionnaire captures primary care patients' acceptance, perceived harms, and perceived benefits of dementia screening.

### Keywords

Dementia; Screening; Attitudes; Harms

## INTRODUCTION

A global consensus of dementia epidemiologists estimated that every 7 seconds, there is a new patient diagnosed with dementia across the globe (Ferri, 2005). It is anticipated that if no scientific advances alter the incidence and progression of these dementing disorders, between 8 and 13 million people in the U.S. will be suffering from the syndrome by the year 2050 (Sloane, 2002). Dementia causes a high burden of suffering for patients and their families (Boustani, 2003).

Screening for dementia has been suggested as a method to decrease dementia burden. However, the United States Preventive Services Task Force (USPSTF) concluded that there is insufficient data to recommend for or against routine dementia screening (Boustani, 2003; USPSTF, 2003). The USPSTF found no study that evaluated the patients' attitudes as potential patient-based barriers for dementia screening (Boustani, 2003). Most of the current available data on patients' attitudes about dementia screening are based on scattered small surveys of genetic screening and the disclosure of dementia diagnosis (Boise, 1999; Jha, 2001; Holroyd, 1996; Holroyd, 2002; Macguire, 1996; Welkenhuysen, 1997; Neumann, 2001; Barak, 2002; Green, 1997; Husband, 2000; Roberts, 2000; Tibben, 1997; Draper, 1998). None of the previous studies evaluated the patients' perceptions of loss of independence, such as placement in institutional settings, loss of driving privileges, or loss of insurance. As a first step in filling this gap in the literature, we developed a questionnaire, the Perceptions Regarding Investigational Screening for Memory in Primary Care questionnaire (PRISM-PC questionnaire) to capture primary care patients' attitudes about dementia screening. This paper describes the early process of developing the PRISM-PC questionnaire and reports its psychometric properties.

## METHODS

### **The PRISM- PC questionnaire was administered to 3 different convenience samples**

The first sample consisted of sampling consecutive patients age 65 years and older from seven outpatient clinics within the Indiana University Medical Group (IUMG) system. To be eligible for the study, patients had no documented history of dementia, depression, schizophrenia, or bipolar disorder and spoke English. Of the 187 eligible patients contacted, 125 (66.8%) completed the questionnaire in person with a trained interviewer. The second sample consisted of caregivers enrolled in a randomized trial of collaborative care for Alzheimer's disease (Callahan, 2006). Patients enrolled in the study received their primary care either in the IUMG system or at the Roudeboush Veterans Affairs Medical Center in Indianapolis. Trained interviewers were able to administer the questionnaire to 81 (90%) of 90 eligible caregivers over the phone. The third sample used the North Carolina Family Practice Research Network, an established stratified random sample of 16 practices equally representing urban and rural settings in North Carolina. This sample included 109 adults  $\geq 65$  out of 245 eligible participants who had seen their primary care doctor at least once in the last year and met the same inclusion criteria as the Indiana samples. The questionnaire in this sample was administered over the phone by a trained interviewer. Both of the Indiana studies were approved by the Indiana University Purdue University Indianapolis Institutional Review Board and the North Carolina study was approved by the University of North Carolina at Chapel Hill Institutional Review Board. All of the participants provided consent to be enrolled in the study.

### **The content of the PRISM-PC questionnaire**

was based on (1) health belief model, (2) review of the literature of previous attitudinal surveys of AD genetic screening and dementia diagnosis disclosure, (3) two prior studies of acceptance of dementia screening in primary care clinics and continuous care retirement communities, and (4) our clinical experience in managing patients with dementia (Boustani, 2003 (A, B));

Boustani, 2006). We used the Health Belief Model as the theoretical framework for the development of the PRISM-PC questionnaire. The Health Belief Model has been used to understand a person's reluctance to engage in preventive health behavior. The components of the Health Belief Model are based upon four main concepts: the perceptions of disease susceptibility and severity, and the perceived benefits of and barriers/costs to taking a specific health action (Becker, 1974; Becker, 1975).

The PRISM-PC items aim to capture both the patient's acceptance of dementia screening and the patient's perception of potential harms and benefits of such a screening. A preliminary draft of the PRISM-PC questionnaire was tested for face validity by 16 clinical researchers with expertise in survey design and dementia care. These experts were asked to evaluate the content and the language of each suggested question, decide to accept or modify the question accordingly, and suggest any additional relevant questions. Based on the experts' feedback, we modified the questionnaire's content and language prior to initial patient pilot testing. This version (see appendix) included 46 items. Excluding respondents' prior experience with AD and respondents' comments, each item was rated on a 5-point Likert scale (strongly agree, agree, don't know, disagree, and strongly disagree). All of the respondents had the opportunity, via answering section E and a direct conversation with the study interviewers, to discuss and provide any additional perceptions related to the potential harms or benefits of dementia screening. Although we were interested in patients' attitudes about dementia screening, we used the term Alzheimer's disease as an alternative to dementia because our early work showed that "Alzheimer's disease" is a more readily understood term than dementia.

### **The construct validity was assessed via factorial validity**

The factor structure of the questionnaire was studied by using factor analysis with the principal axis method of factor extraction. The adjusted squared multiple correlations were specified as prior communalities. Factor patterns were rotated using varimax rotation. The number of factors was determined by a combination of the screen plot and clinical judgment. Cronbach's alpha was calculated to assess internal consistency of scale scores. For all analyses, items were recoded such that 5 was equivalent to strongly agree and 1 was equivalent to strongly disagree.

## **RESULTS**

The mean age of the study participants was 72.8 (SD, 9.1); 70% of the patients were female, 44% were African-American, 39% had at least a high school education, 33% were living alone, and 40% were married. The mean administration time for PRISM-PC ranged from 20 to 26 minutes. The item language, mean score and the percentage of missing data are presented in Table 1. No new additional items were identified by the participants and approximately 95% of the participants felt comfortable answering the questions.

The VARIMAX-rotated factor loadings for the 8 screening acceptance items are presented in Table 2. The screen plot suggested the existence of one or two factors. Specifically, the eigenvalues of the first four factors were: 5.10, 1.03, 0.64, and 0.47, showing that the eigenvalues leveled off after two factors. Clinical judgment suggested that the two-factor solution was sensible. Specifically, we found that the 8 items on acceptance of screening loaded on two dimensions, accepting the screening to know the risk and accepting the actual testing for AD screening. We also found that two pairs of items were redundant with a high correlation of 0.81 for items 7 and 8 and correlation of 0.97 for items 12 and 13. Thus, we recommend selecting only items 7 and 13 in the final PRISM-PC questionnaire. These two factors explained 76.6% of the total variance and 90.7% of the shared variance in the eight items. Although the data suggest that scores from the acceptance scale be reported as two factors by summing the items from each subscale, it would also be appropriate to report a total score on this scale in

addition to the two subscale scores given that the one-factor solution revealed loadings above .60 for all eight items.

The VARIMAX-rotated factor loadings for the 29 perceived benefits and harms items are presented in Table 3. Based on the scree plot (first four eigenvalues were 5.41, 4.42, 1.42, and 1.34) and clinical judgment, we obtained 4 major factors (see table 3). The first factor consisted of items related to benefits of dementia screening, while the second factor consisted of items related to the stigma of being diagnosed with AD. The third factor consisted of items related to insurance and loss of independence. The final factor consisted of items related to negative effects on family and emotion. One item did not load on any factor, item 16. In Table 3, the loading for each item is bolded under the factor loaded most highly. The exception was that item 39 was lumped under the Stigma factor (based on clinical judgment), despite the fact that this item loaded slightly higher (.38) on Benefits than Stigma (.37). These four factors explained 43.4% of the total variance and 78.8% of the shared variance in the eight items.

We report the internal consistency of all subscale scores and of the total acceptance score, using Cronbach's alpha coefficient, in Table 4. The screening acceptance scales show good internal consistency with values of 0.77 or higher. All of the benefits and harms scales showed good internal consistency (values > 0.70) except the suffering/emotional scale.

## DISCUSSION

We have developed, pilot tested, and validated, for the first time, a survey questionnaire which captures the attitudes of primary care patients about dementia screening. The PRISM-PC questionnaire is composed of the acceptance scale and the perceived harms and benefits scale. The acceptance scale has two underlying constructs (knowledge of dementia screening and being tested for dementia). The perceived harms and benefits scale has four constructs (benefits, stigma, suffering, and negative impact of screening on independence). The questionnaire has good face and internal validity and it is easy to administer (less than 30 minutes) via face-to-face and phone based interviews.

There are multiple barriers for dementia screening. Chief among these barriers is the patient's refusal to proceed with a diagnostic evaluation following a positive screening test. Nearly half of the patients who screened positive for cognitive impairment refused a diagnostic evaluation (Boustani, 2005). One reason for these refusals may be the patient's perception of the harm of dementia screening (Boustani, 2005). This hypothesis is somewhat supported by the findings from the development of our PRISM-PC questionnaire. It appears that patients have concerns about dementia screening such as losing their health insurance coverage, their driver privileges, and / or their employment positions. At the same time, the data collected via the PRISM-PC questionnaire suggests the presence of potential positive non-medical consequences of dementia screening, such as having more time for future planning for an individual's health, financial, and housing needs and more time for an overall family discussion and planning. Both of these perceived benefits and harms are influencing the patient's decision of accepting dementia screening. This decision in the current data is perceived favorably for the general screening method.

Our study has some limitations. It was based on a selective population with lower educational level and a higher representation of minority participants attending primary care clinics in urban Indianapolis and rural North Carolina. The sample also included patients who were caregivers and thus the generalizability of our data is limited. Our study did not conduct a confirmatory factor analysis because we did not have prior hypothesized factors to be confirmed. Instead, we reviewed the literature, used our clinical expertise, and depended on the 16 experts to identify possible items that reflected the overall benefits and harms of dementia screening.

Future studies should perform confirmatory factor analyses on the factors that we have suggested here. Also, our study did not conduct test-retest reliability. We are planning to assess the day-to-day stability of the patients' attitudes about dementia screening in a future validation study.

Capturing data via the PRISM-PC questionnaire might help clinical providers, policy makers, and health services researchers in dementia understand the patients' perspectives related to the risks and benefits of dementia screening. Such understanding could facilitate the development of an individualized counseling program that could modify any patient-based barriers for dementia screening and lead to the successful implementation of prevention methods, in order to decrease the current and future burden of dementia.

### Key Points

- 1)- We have developed the PRISM-PC questionnaire, which captures the attitudes of primary care patients about dementia screening.
- 2)- The PRISM-PC questionnaire is composed of the acceptance scale and the perceived harms and benefits scale. The acceptance scale has two underlying constructs (knowledge of dementia screening and being tested for dementia), and the perceived harms and benefits scale has four constructs (benefits, stigma, suffering, and negative impact of screening on independence).
- 3)- The PRISM-PC questionnaire has good face and internal validity and it is easy to administer (less than 30 minutes) via face-to-face and phone based interviews.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1**

Item score, SD, and percentage of missing data

Item	Mean score	SD	% Missing data
<b>Screening Acceptance for Dementia</b>			
6. I would like to know if I am at higher risk than others for developing AD	3.4	1.1	0.3
7. I would like to know if I have AD	3.6	1.0	0.3
8. I would like to know if I have a problem with memory	3.6	1.0	0.3
9. I would like to be tested for AD with a short questionnaire	3.3	1.1	0.0
10. I would like to be tested for AD with a blood sample	3.1	1.1	0.0
11. I would like to be tested for AD with pictures of my head or brain	2.9	1.1	0.0
12. I would like a doctor to examine me every year to know if I have developed memory problems	3.4	1.0	0.3
13. I would like a doctor to examine me every year to know if I have developed AD	3.3	1.1	0.0
<b>Benefits and Harms of Dementia Screening</b>			
16. I do not believe treatment for AD is currently available	2.9	1.0	0.0
17. Early detection of AD increases the chance to treat the disease better	4.0	0.6	0.3
18. If AD, my family would suffer financially	3.2	1.1	0.3
19. If AD, my family would suffer emotionally	3.9	0.8	0.3
20. If knew AD earlier, my family would have a better chance to take care of me	3.9	0.6	1.0
21. If AD, would not want my family to know	2.0	0.7	1.0
22. If AD, would feel humiliated by family members, etc.	2.2	0.8	0.0
23. If AD, no longer taken seriously.	2.8	1.0	0.3
24. If AD, would be considered stupid and unable to do things	2.3	0.9	0.0
25. If knew AD, would be ashamed or embarrassed	2.3	0.8	0.0
26. If knew AD, I would be depressed	3.3	1.0	0.0
27. If knew AD, I would be anxious	3.2	0.9	0.3
28. If knew AD, would give up on life	2.0	0.7	0.0
29. Found out early AD, have more time to plan future	3.8	0.8	0.0
30. Found out early AD, have more time to talk with family about my health care	3.9	0.7	0.3
31. Found out early AD, have more time to talk with family about my finances	3.9	0.7	0.6
32. Found out early AD, would sign my advance directive or living-will	3.8	0.8	1.0
33. If AD, my doctor would not provide best care for my medical problems	2.2	0.7	0.0
34. If knew had AD earlier, would be motivated to have healthier lifestyle	3.5	0.9	0.3
35. If AD, my doctor and other health professionals would not listen to me	2.3	0.8	0.0
36. If knew had AD earlier, be more willing to participate in research about this disease	3.8	0.8	0.0
37. If AD, would not be able to get health insurance	3.1	0.9	0.0
38. If AD, concerned that my health insurance company would find out	2.9	1.0	0.0
39. If AD, concerned my employer would find out	3.1	1.0	2.2
40. If AD, would not be able to get life insurance	3.2	0.9	0.0

Item	Mean score	SD	% Missing data
41. If AD, would not be able to get long-term care insurance	3.4	0.9	0.0
42. If AD, would lose my home	2.5	0.9	0.3
43. If AD, would be living in a nursing home	2.9	1.0	0.0
44. If AD, would lose driver's license and other privileges	3.8	0.7	0.3



**Table 2**

Factor loadings for screening acceptance

Item	2 Factor Model	
	Testing	Knowledge
<b>Screening Acceptance for Dementia</b>		
6. I would like to know if I am at higher risk than others for developing AD	0.38 (0.31)	<b>0.49 (0.54)</b>
7. I would like to know if I have AD	0.26 (0.26)	<b>0.84 (0.84)</b>
8. I would like to know if I have a problem with memory	0.30 (0.28)	<b>0.86 (0.83)</b>
9. I would like to be tested for AD with a short questionnaire	<b>0.77 (0.74)</b>	0.41 (0.43)
10. I would like to be tested for AD with a blood sample	<b>0.80 (0.81)</b>	0.21 (0.18)
11. I would like to be tested for AD with pictures of my head or brain	<b>0.67 (0.66)</b>	0.26 (0.32)
12. I would like a doctor to examine me every year to know if I have developed memory problems.	<b>0.87 (0.82)</b>	0.36 (0.35)
13. I would like a doctor to examine me every year to know if I have developed AD.	<b>0.88 (0.88)</b>	0.36 (0.35)

\* Number between parentheses is based on a sample that excluded the 81 caregivers.

\*\* The loading for each item is bolded under the factor loaded most highly

**Table 3**  
Factor loadings for benefits and harms of dementia screening

Item	Benefits	Stigma	Independence	Suffering
16. I do not believe treatment for AD is currently available	-0.03 (-0.06)	0.14 (0.03)	0.14 (0.01)	0.06 (0.15)
17. Early detection of AD increases chance to treat better.	<b>0.47 (0.49)</b>	-0.29 (-0.18)	0.07 (0.10)	-0.05 (-0.14)
18. If AD, my family would suffer financially	0.09 (-0.02)	0.06 (0.09)	0.01 (0.04)	<b>0.46 (0.35)</b>
19. If AD, my family would suffer emotionally	0.22 (0.26)	-0.21 (-0.25)	0.10 (0.18)	<b>0.64 (0.51)</b>
20. If knew AD earlier, family would have a better chance to take care of me	<b>0.52 (0.72)</b>	-0.13 (-0.09)	0.13 (0.01)	0.03 (0.04)
21. If AD, would not want my family to know	-0.23 (-0.31)	<b>0.68 (0.64)</b>	-0.05 (-0.08)	-0.11 (-0.01)
22. If AD, would feel humiliated by family members, etc.	-0.19 (-0.21)	<b>0.74 (0.69)</b>	0.07 (-0.08)	-0.13 (0.06)
23. If AD, no longer taken seriously.	-0.06(-0.03)	<b>0.46(0.49)</b>	0.11 (0.04)	0.16 (0.26)
24. If AD, would be considered stupid and unable to do things	-0.22 (-0.15)	<b>0.60 (0.59)</b>	0.12 (-0.12)	-0.01 (0.20)
25. If knew AD, would be ashamed or embarrassed	-0.16 (-0.13)	<b>0.63 (0.55)</b>	0.01 (-0.16)	0.39 (0.43)
26. If knew AD, would be depressed	0.18 (0.20)	0.13 (0.18)	0.14 (0.16)	<b>0.64 (0.63)</b>
27. If knew AD, would be anxious	0.20 (0.29)	0.11 (0.08)	0.28 (0.15)	<b>0.45 (0.46)</b>
28. If knew AD, would give up on life	-0.11 (-0.05)	<b>0.49 (0.48)</b>	0.20 (0.11)	0.17 (0.33)
29. Found out early AD, have more time to plan future	<b>0.78 (0.74)</b>	-0.06 (0.09)	-0.03 (0.12)	0.18 (0.02)
30. Found out early AD, have more time to talk with family about health care	<b>0.78 (0.79)</b>	-0.14 (-0.15)	-0.04 (0.09)	0.40 (0.24)
31. Found out early AD, have more time to talk with family about my finances	<b>0.82 (0.83)</b>	-0.14 (-0.12)	-0.02 (0.18)	0.41 (0.36)
32. Found out early AD, would sign my advance directive or living-will	<b>0.57 (0.47)</b>	-0.26 (-0.27)	0.13 (0.34)	0.26 (0.16)
33. If AD, my doctor would not provide best care for my medical problems	0.01 (0.07)	<b>0.51 (0.56)</b>	0.19 (0.12)	-0.07 (-0.01)
34. If knew had AD earlier, would be motivated to have healthier lifestyle	<b>0.54 (0.47)</b>	0.10 (0.14)	-0.08 (-0.03)	0.07 (-0.02)
35. If AD, my doctor and other health professionals would not listen to me	0.07 (0.13)	<b>0.49 (0.59)</b>	0.28 (0.20)	0.01 (-0.03)
36. If knew had AD earlier, be more willing to participate in research about this disease	<b>0.79 (0.74)</b>	-0.13 (-0.05)	-0.01 (0.03)	-0.03 (-0.12)
37. If AD, would not be able to get health insurance	0.09 (0.12)	0.21 (0.21)	<b>0.64 (0.60)</b>	-0.10 (0.01)
38. If AD, concerned that my health insurance company would find out	0.23 (0.16)	<b>0.46 (0.47)</b>	0.29 (0.23)	-0.20 (-0.23)
39. If AD, concerned my employer would find out	0.38 (0.29)	<b>0.37(0.39)</b>	0.36 (0.37)	0.05 (-0.05)
40. If AD, would not be able to get life insurance	0.00 (-0.04)	0.12 (0.09)	<b>0.71 (0.77)</b>	0.07 (0.14)
41. If AD, would not be able to get long-term care insurance	0.05 (-0.03)	0.07 (0.00)	<b>0.71 (0.76)</b>	0.08 (0.18)
42. If AD, would lose my home	-0.15 (-0.12)	0.48 ( <b>0.60</b> )	<b>0.49 (0.20)</b>	0.11 (0.11)

Item	Benefits	Stigma	Independence	Suffering
43. If AD, would be living in a nursing home	-0.12 (0.02)	0.26 ( <b>0.40</b> )	<b>0.41</b> (0.18)	0.13 (0.05)
44. If AD, would lose driver's license and other privileges	0.10 (0.12)	0.03 (0.09)	<b>0.41 (0.43)</b>	0.23 (0.07)

\* Number between parentheses is based on a sample that excluded the 81 caregivers.

\*\* The loading for each item is bolded under the factor loaded most highly

**Table 4**

Internal Consistency for the various scales of the PRISM-PC Questionnaire

Scale	Items	Cronbach's Alfa
Overall acceptance	6, 7, 8, 9, 10, 11, 12, 13	0.88
Overall acceptance	6, 7, 9, 10, 11, 13	0.89
Knowledge	6, 7, 8	0.77
Knowledge *	6, 7	0.66
Testing	9, 10, 11, 12, 13	0.89
Testing *	9, 10, 11, 13	0.85
Benefit	17, 20, 29, 30, 31, 32, 34, 36	0.79
Stigma	21, 22, 23, 24, 25, 28, 33, 35, 38, 39	0.74
Insurance/Independence	37, 40, 41, 42, 43, 44	0.72
Suffering/Emotional	18, 19, 26, 27	0.58

\* After excluding highly correlated items (item 8 and Item 12).