

Traits of patients who screen positive for dementia and refuse diagnostic assessment

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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.

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Keywords:

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

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 Amer-

icans 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].

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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

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