


Patient, Family Caregiver, and Provider Perceptions on Self-Assessment Screening for Cognitive Impairment in Primary Care: Findings From a Qualitative Study

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Abstract

The purpose of this study was to evaluate patient, family, and provider perspectives on routine cognitive screening of older adults in primary care using a novel self-assessment tool for detection of early cognitive impairment (CI). We conducted four virtual focus groups with patients aged 65 and older with no CI ($n = 18$) and family caregivers of patients with CI ($n = 5$) and interviews with primary care providers ($n = 11$). Patient and family caregiver participants felt that early detection of CI was important in primary care and may facilitate planning for the future including finances, living arrangements, and advance care planning. Providers reported that they do not use a standardized tool to routinely screen patients for CI yet endorsed the use of a self-assessment CI screening tool. These results suggest that routine screening of older adults using a brief, self-assessment screening tool for CI in primary care may be acceptable to patients, family caregivers, and providers. The findings from this study will inform the development of a brief self-assessment CI screening tool for use in primary care.

Keywords

cognitive impairment, screening, qualitative, primary care, self-assessment

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Introduction

An estimated 15% to 20% of individuals aged 65 and older have mild cognitive impairment, an early stage of cognitive impairment (CI; CDC, 2019; Roberts & Knopman, 2013). CI is characterized by a decline in cognition greater than expected for an individual's age and education level but without significant interference in everyday activities (Mitchell & Shiri-Feshki, 2009; Panegyres et al., 2016). CI is considered a risk factor for dementia (Moyer, 2014), and roughly one third of individuals with mild CI will develop Alzheimer's dementia (Langa & Levine, 2014; Mitchell & Shiri-Feshki, 2009; Ward et al., 2013).

Early detection of CI among patients aged 65 and older through routine screening can be useful in identifying individuals early in their disease trajectory and who may be at risk for developing dementia, which can

lead to early intervention that may slow disease progression with lifestyle changes and improve quality of life (Dubois et al., 2016; Hogan et al., 2008; Livingston et al., 2020). Early diagnosis may give patients the opportunity to enroll in clinical trials or receive more

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coordinated care early in the disease process, as many patients with dementia experience avoidable hospitalizations related to comorbid conditions (“Alzheimer’s Disease Facts and Figures Special Report: Financial and Personal Benefits of Early Diagnosis,” 2018; Dubois et al., 2016; Hogan et al., 2008; J. S. Lin et al., 2013; P. J. Lin et al., 2013). Furthermore, studies have suggested that earlier diagnosis of CI is associated with reduced out-of-pocket costs for patients and lower costs to Medicare and Medicaid (Barnett et al., 2014; Long et al., 2014).

Prior research suggests mixed evidence on the acceptability of screening for cognitive impairment among patients and providers, including comfort level and perceived importance (Bond et al., 2010; Borson et al., 2007; Bush et al., 1997; Judge et al., 2019; Martin et al., 2015). In addition, there is a lack of conclusive evidence on the outcomes of screening (Fowler et al., 2020; Patnode et al., 2020). Additionally, there are also several barriers to screening for CI in primary care including limited time during patient visits, lack of provider follow-up, complexity of diagnosis, and hesitancy to make a diagnosis that may cause distress for patients and families (Aminzadeh et al., 2012; Barnes et al., 2014; Chodosh et al., 2004; Sabbagh et al., 2020). Innovative ways of increasing and improving early detection of CI are needed to mitigate some of these challenges (Galvin, 2020).

These prior studies on acceptability and outcomes of screening for CI in primary care, however, have focused largely on existing performance-based cognitive assessments such as the Mini-Mental Status Exam (MMSE; Creavin et al., 2016), the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005), and the St. Louis University Mental Status (SLUMS) Exam (Tariq et al., 2006). These existing cognitive assessments have limitations, including the time to administer the assessment, possibility of administrator error, and the potential for practice effects with repeated administration (Howland et al., 2017; Patnode et al., 2020). For example, the MMSE requires administration time (10–15 minutes) and cost (PAR, 2022). Patient-reported measures of cognitive function, however, allow for increased flexibility in timing and mode of administration and center on the patient’s experience, (Howland et al., 2017; Lai et al., 2009, 2014; Morley et al., 2015) which may facilitate earlier detection of cognitive decline. The use of a brief self-assessment tool for screening for CI may mitigate some of the barriers to screening in primary care, and preliminary evidence suggests that self-reported cognitive assessments may have utility as a prescreening tool to identify patients with cognitive decline (Howland et al., 2017; author blinded citation). However little is known about the acceptability of this type of CI screener for use in primary care.

As a first step in developing a brief self-assessment tool, the purpose of this study was to understand the

acceptability of screening for CI in primary care specialties (general internal medicine, family medicine, and geriatrics) among patients, family caregivers, and providers. We focused specifically on the acceptability of a brief, self-assessment screening tool (i.e., two to four items) for CI that can be taken in preparation for or during a primary care visit. This tool is designed to be patient-centered and minimally burdensome while providing useful data that can alert the clinician to subtle changes in cognitive function that may imply a need for follow-up. The tool is also designed to be easily implemented into primary care because of its brevity, non-propriety nature, and ease to score. We conducted virtual focus groups with patients aged 65 and older with no known CI and family caregivers of patients with diagnosed dementia to understand comfort level, acceptability, and perceived importance of screening for CI with a self-assessment screening tool. We also conducted semi-structured interviews with primary care providers to gain insight into current processes of screening and perspectives on a self-assessment screening tool for CI in primary care. This qualitative study is part of a larger project to develop and validate a standardized self-administered screening tool for detection of CI in primary care and is the first step in understanding acceptability and preferences for the screening tool.

Methods

This study uses the standards for reporting qualitative research (SRQR; O’Brien et al., 2014).

Focus Groups

Patient and family caregiver recruitment. We recruited patients and family caregivers in Pittsburgh, Pennsylvania through the Clinical and Translational Science Institute (CTSI) at the University of Pittsburgh Medical Center (UPMC). Patient participants were eligible to participate if they were age 65 or older, self-reported that they did not have a diagnosis of CI, and received primary care at UPMC. Family caregivers were eligible to participate if they had a family member with a diagnosis of dementia because of the association of CI and subsequent development of dementia. Patients and family caregivers were notified of the study through the CTSI’s website. Those who expressed interest in the focus groups were sent an information sheet about the research study via email, and three researchers conducted follow-up screening calls with interested participants to confirm eligibility and to obtain verbal consent for participation in the focus group. We made a concerted effort to identify participants of diverse racial and ethnic backgrounds and worked with the CTSI to reach participants who identified as racial and/or ethnic minorities. This study was approved by the Human Subjects Protection Committee at the RAND Corporation and UPMC.

Interviews With Primary Care Providers

Provider recruitment. We recruited primary care providers including physicians, physician assistants, and nurse practitioners in primary care, family medicine, and geriatric medicine to participate in semi-structured interviews about their current practices for screening patients for CI. We recruited providers through the CTSI at UPMC and through a recruitment email sent to members of a national general internal medicine professional society throughout the US to capture a variety of perspectives.

Process and Procedures

Focus group and interview protocols (e.g., scripts) were developed by the study team to understand patient, caregiver, and provider perspectives on screening for CI using a self-assessment screening tool. We chose focus groups for patients and family caregivers to facilitate group discussion; because of providers' limited time and clinic schedules, we conducted one-on-one interviews for ease of scheduling and to elicit specific information about their own clinic processes that were more conducive to an interview format. The patient focus group protocol included questions to elicit patient perceptions of their comfort level with being asked about memory issues by their primary care provider using a self-assessment screening tool, prior experiences with screening for CI, and patient preferences for next steps if a provider were to identify possible CI. The family caregiver focus group protocol included questions around early signs of CI in their family member and their experiences of the diagnosis of CI. Patient focus groups were conducted separately from family caregiver focus groups. The provider interview protocol focused on questions around current CI screening processes and on the potential utility and impact of a brief self-administered screening tool for CI in their clinical practice.

Focus groups and interviews were conducted concurrently in the spring of 2021 by three researchers trained in qualitative methods including a sociologist, health services researcher, and physician policy researcher. All focus groups and interviews were conducted via video-conference and were audio recorded. Focus group size ranged from three to six participants and were 75 minutes in duration. Interviews with providers ranged from 32 to 76 minutes. Patient participants, family caregivers, and provider participants received a \$75 gift card for their participation in the study.

Focus groups and interviews were transcribed by a member of the research team, and all were analyzed using a rigorous directed content analysis (Hsieh & Shannon, 2005). Data were coded initially by question using a deductive approach, and new and modified themes were developed throughout the analysis to identify patterns in the data. This process was conducted by two researchers with extensive experience with qualitative

research, who discussed emerging findings throughout the data collection and analysis process and discussed discrepancies and questions on a weekly basis as part of the data validation process. Data were analyzed concurrently with data collection to identify areas for additional probing in the focus groups and interviews and to identify when data saturation was reached (e.g., when no new themes emerged).

Results

Eighteen patient participants and five family caregivers participated in the virtual focus groups. Eleven primary care providers, including nine physicians and two nurse practitioners, practicing throughout the US participated in a semi-structured interview. Table 1 presents demographic information from the patient, family caregiver, and provider participants. Most patients and caregiver participants were White, non-Hispanic, and female. The mean age of patient and caregiver participants was 68.3 and 54.0 years, respectively. Most providers were attending physicians, White, non-Hispanic, and male.

Findings from the focus groups and interviews are presented below with the following structure: (1) patient participant perceptions and experiences with screening for CI; (2) family caregiver experiences with a family member's diagnosis of CI; and (3) primary care provider perspectives on screening for CI.

Patient Experiences With Screening for CI

Most patient participants reported that they had never been formally screened for CI by a physician. Six patient participants stated that their primary care physician (PCP) had asked them questions about their memory, but they reported variability in this process ranging from some being asked informal questions about their memory while others were asked to complete evaluative tasks such as word recall or a clock drawing exercise. One patient participant, who had been asked by her PCP to complete a self-assessment of her cognition, shared that she did not respond candidly about changes she noticed in her memory due to a lack of a long-standing relationship with her new provider and because she was more focused on her physical concerns. This patient stated:

“Although the truth is that I'm starting to have trouble remembering things. . . Realizing that I was not fully honest in my response to the one question, I am thinking that I would appreciate if the physician would push me on this with specific examples of issues.”

While the majority of patient participants did not have prior experiences with screening for CI, most expressed that they would be comfortable and would even “welcome” their provider asking them questions about their memory or completing a self-assessment about their memory. As one patient stated:

Table 1. Demographics of Patient, Family Caregiver, and Provider Participants ($N=34$).

Characteristics	No. (%) or mean
Patients/caregiver focus group participants (N=23)	
Role	
Patient	18 (78.3)
Caregiver	5 (21.7)
Gender	
Female	15 (65.2)
Male	8 (34.8)
Race	
Non-Hispanic White	17 (73.9)
Non-Hispanic Black or African American	4 (14.4)
Asian	2 (8.7)
Age	
Mean age of patients	68.3 years ($SD=3.2$)
Mean age of caregivers	54.0 years ($SD=10.4$)
Provider participants (N=11)	
Role	
Attending physician	9 (81.8)
Nurse practitioner	2 (18.2)
Specialty	
Internal medicine	5 (45.4)
Family medicine	2 (18.2)
Geriatrics	4 (36.4)
Gender	
Female	4 (36.4)
Male	7 (64.6)
Race	
Non-Hispanic White	7 (63.6)
Asian	3 (27.3)
Other	1 (9.1)
Gender	
Female	4 (36.4)
Male	7 (64.6)
Average years since completing training (missing data for one provider)	12.1 years ($SD=10.7$)

“I would have no problem with the doctor asking me about my memory and also following up with me via some short test to expand what it is that they were asking. As opposed to just asking the problem.”

We presented patient participants with a list of types of questions that may be included on a self-assessment for CI. While participants were generally comfortable with the questions, they overwhelmingly expressed a preference for those with a positive framing that focused on abilities rather than deficits (e.g., “My ability to remember things that I need to do has been as good as usual.”). Lastly, we asked patients to consider the mode of administration for a self-assessment screener for CI, and many patients stated that they would prefer options that would allow them to complete the questionnaire prior to their visit because they could think about their responses and

would be less anxious (e.g., via a patient portal). As one patient stated,

“I’m sure it [screening] has to be done in a clever way because if it’s just performative, if it’s the medical assistant is asking performative questions, you’re going to just glaze over it and say no, doctor has to be skillful about it.”

Patients emphasized that regardless of the mode of administration, they would want their provider to follow up with them about their results even prior to a definitive diagnosis being made.

Most patient participants felt that screening for memory issues was particularly critical to prevent dangerous situations that could put the patient at risk (e.g., forgetting to turn off the stove) and often cited their own experiences as a caregiver for a family member with dementia. One participant noted that one barrier to screening may be providers themselves; she felt that providers are “afraid” to ask patients about their memory because they worry about insulting patients: “I just want the honest truth and I’ve seen physicians who’ve done this, they don’t want to be the ones to give the bad news.” Some patient participants were particularly concerned about their memory because of a family history of dementia.

Patient participants stated that they would want to be informed immediately if the results of early screening for CI were to show any potential abnormalities, even if the diagnosis was not definitive:

“I think it’s important that they address this right away, because if they suspect an issue, it’s better to follow up with it immediately instead of delaying.”

“I think I would be more relieved that they’re trying to prepare me or set me up so that I don’t run into that issue later on or extend my mental capacities right now.”

“I would like some assurance that I don’t have any serious issues or problems. But we don’t talk about it [memory issues] enough to get to that level of understanding or agreement on it.”

Patient participants seemed hopeful that earlier diagnosis of CI may slow progression of the disease. They also expressed that knowing about any potential CI would enable them to communicate with their family members and friends and to help plan for their future, not only in the medical sense of advanced care planning (ACP) but also for their personal lives including living arrangements and financial planning.

Family Caregiver Experiences With Patient Diagnosis of CI

Family caregivers reported that their family members were not screened early for CI, with the exception of one caregiver who noted that her mother had previously

been screened as part of her routine care but had screened negative. Three family caregivers reported that the diagnosis of CI was prompted by an acute medical event (e.g., fall leading to a hospitalization). One family caregiver explained that her husband's PCP dismissed her concerns about his memory, so she took her husband to a specialist who diagnosed him with CI. Two family caregivers noted that the patient was diagnosed by a PCP but at a late stage in their illness.

Family caregivers felt that early diagnosis of CI would be beneficial, and that the patient's PCP plays an important role in facilitating an early diagnosis and treatment by making a referral to specialists and making recommendations for the patient and family. Family caregivers stressed that clear communication among the PCP, patient, and family are critical in these situations. In other words, family caregivers emphasized that early detection would be helpful in planning for patient's future care: "The benefit [of early screening] would be to identify the memory strain and the thought process to continue in a productive fashion, opens the door to other issues before they become a problem." Furthermore, family caregivers felt that early screening and diagnosis would help with planning: "What I would have done differently is that I wouldn't have let her live alone by herself, maybe if the doctor recommended something else she would've listened."

Provider Perspectives on Screening for CI

Many providers reported that they do not routinely screen patients for CI outside of the Medicare annual wellness visit but felt that certain clinical situations may warrant screening. Such scenarios included patients' concerns about their memory, family concerns, as well as conversational cues that may arise in providers' interactions and discussions with patients. In addition, some providers noted signs of potential CI in patients who struggled with medication adherence, had difficulty managing their chronic conditions, had multiple readmissions, or frequently missed appointments. Providers also reported using a variety of tools, noting the absence of one standardized method of screening. Many providers initiated their evaluation process with the Mini Cog (Borson et al., 2000) or MMSE (Creavin et al., 2016) and used the MoCA (Nasreddine et al., 2005) for patients with certain concerns or complaints. However, their processes varied not only in terms of the tools used but also in who administered the test (e.g., medical assistant vs. physician/nurse practitioner) and what types of patients they would consider screening.

Some providers noted issues around routinely screening for CI given the absence of effective pharmacologic treatments in curing or slowing the progression of many causes of CI. One provider stated:

"[Aricept] has a lot of side effects, very minimal improvement in memory. So a lot of times I'll describe, 'I could give it to you, it's not needed, it's not going to improve your memory that much.'"

Others also worried about the impact of adding another screening tool to an already-too short primary care visit. As one provider noted,

"It does get frustrating for primary care doctors to have these tools, because then it becomes a metric. Then if you're not doing it. . . All of a sudden all of your time with a patient is gobbled up ticking boxes and no time for free conversation."

Some providers also noted that in their patient population, screening was particularly difficult due to high levels of limited English proficiency (LEP) or low educational attainment among their patients.

Providers described their follow-up actions if a patient were to screen positive for CI. Most providers stated that they would refer patients to specialists (e.g., neuropsychologists, neurologists, or psychiatrists) for additional testing and evaluation or to social workers for resources to support patients and family members. However, a few providers raised concerns about the potential of "overwhelming the system" with referrals because of a limited number of available specialists. Some providers stated that they would start patients on medications but also would consider risks and benefits of the side effects of these medications as well as patient preference. In addition to lab work and imaging to look for modifiable risk factors or to identify reversible causes of CI, many providers also noted they would initiate non-pharmacological interventions including providing patients with community health resources and referrals to local support groups for practical support and ensuring that patients were safe in their living environments.

In contrast to existing tools that providers found time intensive, most providers strongly supported a brief, self-administered screener for CI in primary care because such a tool would allow them to screen for CI in an efficient, standardized way that the patient would complete as part of a self-assessment. One provider described the need for a brief, standardized self-administered screener:

"This is exactly what's needed. . . And I think the screening tool would take a burden off spending the time and doing a MoCa. Sometimes that is the biggest thing in our job where we can't spend an hour with someone, we want to, but we can't. And I think if we had some way to screen for this, it would be wonderful."

Discussion

This study highlights the acceptability of a brief self-assessment screening tool for CI in primary care and serves as a first step in gathering data from to develop this patient-centered tool. Patient participants, family

caregivers, and providers recognized the importance of screening for CI in primary care using a self-administered measure of cognitive function. In contrast to other research that focuses on the acceptability to patients of performance-based measures (Martin et al., 2015), we asked patients to comment on a brief self-assessment screener that asks patients to respond to questions about their memory. Patient participants expressed a preference for questions around their memory framed in a positive way (i.e., focusing on their abilities), which is a novel finding and has important implications for the development of a standardized self-assessment tool for CI. This finding around patient preferences for wording of questions about memory will be used to inform the development of the screener by including items framed in a positive way.

Providers described a range of processes for screening for CI, highlighting a lack of standardization around screening for CI. Providers generally supported a brief, standardized self-assessment for CI as a screening tool because it would be self-administered and would require less provider training than a provider-administered tool, which would mitigate some of the concerns around screening that they described around existing tools. Their comments around the implications of such a screening tool including steps they may take if a patient screened positive and considerations around the need for referrals have important implications for the use and implementation of this screener in primary care.

Despite the benefits of early detection and identification of CI, the United States Preventive Services Task Force (USPSTF) concludes that the current evidence is not sufficient to support screening for asymptomatic older adults (Patnode et al., 2020). However, Petersen and Yaffe (2020) have argued that the USPSTF recommendation is based on a limited number of negative randomized clinical trials, yet there are key challenges to conducting randomized control trials for screening for CI, and there may be benefits to screening that are not easily measurable. In fact, there may be several important potential clinical impacts of implementing such a screener in primary care. In our study patients, family caregivers, and even providers viewed screening as an opportunity for patients to engage in not only early ACP for their future medical care but also for planning for future financial and living arrangements, which is supported by the ACP literature (Sudore & Fried, 2010). Screening also identifies individuals earlier in their disease course when certain lifestyle interventions—such as diet and exercise—may slow the course of illness (Livingston et al., 2020). Identification of CI may also help clinicians understand why patients are struggling to manage other chronic diseases (Petersen & Yaffe, 2020). Such an endpoint—the ability to plan *early* for the future—is not one that can be easily measured in a clinical trial—yet was of importance to patients and providers and may be a compelling reason to screen for CI.

Limitations

We recruited patient and family caregiver participants from a single institution in the Northeast United States, and their experiences may not be generalizable to other geographic settings. By contrast, providers represented multiple geographic regions, clinical institutions, and professional training. However, providers self-selected to participate and may have had an interest in CI screening.

Conclusion

In conclusion, patients, family caregivers, and primary care providers expressed strong support for routine screening of older adults for CI in primary care using a self-administered screener. The findings from this study will inform the development of this screener to ensure that the tool is designed in a patient-centered way for use in primary care.

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Ethical Approval

This study was approved by the Human Subjects Protection Committee at the RAND Corporation IRB # 2020-N0691.

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