Feasibility and Acceptability of the "About Me" Care Card as a Tool for Engaging Older Adults in Conversations About Cognitive Impairment

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ABSTRACT

PURPOSE We aimed to address fears and lived experiences of cognitive decline among adults via whole-person conversations that elicit problems and goals that matter most to patients. Currently, 6.7 million Americans have Alzheimer disease or related dementias, with an additional 28 million people reporting subjective cognitive decline—a possible indicator of Alzheimer disease and related dementias. A review of tools for older adults with cognitive impairment showed strong clinical specificity, with insufficient whole-person support for patients. We developed and tested the feasibility and acceptability of a tool to enhance conversations for adults with cognitive impairment at the point of care.

METHODS We conducted a feasibility study to build a conversation tool, guided by principles of shared decision making, called the "About Me" Care Card. Informed by an environmental scan, we created and pilot-tested prototypes at implementation sites. All phases were overseen by a multidisciplinary steering committee.

RESULTS Fourteen diverse clinicians consisting of 7 clinician types across 7 institutions piloted the card during in-person visits or by telephone. Observations showed that the card (1) allowed time to elicit what matters most to patients, (2) created space for personalized care conversations, (3) opened an examination of social care needs, and (4) moderated emotional relationships between families and individuals.

CONCLUSION A community-based codesign process led to a feasible tool for primary care teams to facilitate whole-person conversations with aging adults. The About Me Care Card appeared to broaden conversations compared with routine care. More work is needed to determine scalability and effects on outcomes.

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INTRODUCTION

Onversations with aging adults about cognitive decline are not happening. In 2011, the Centers for Medicare and Medicaid Services (CMS) recommended yearly screening of cognitive function as part of its annual wellness visit, yet capacity and aptitude limits in primary care make monitoring brain health challenging.¹ According to the World Health Organization, by 2030, 1 in every 6 people will be >60 years of age.² One major concern as the world's population ages is the number of people living longer with chronic illness including some form of cognitive impairment. Experts contend that primary care is ideally placed to meet this challenge via the provision of health education and promotion and enabling cost-effective care.³⁻⁵

High-quality evidence showing a clear causal link between primary care and improved cognitive health is limited,^{6,7} yet several recent reviews^{8,9} have identified the benefits of early detection and decreasing health-risk behaviors. Another reason primary care is an appropriate setting to address cognitive challenges is the link between blood pressure management (routinely performed by a primary care clinician) and cognition.¹⁰ Trial evidence also shows a decreased risk of mild cognitive impairment among people aged \geq 50 years who maintained lower systolic blood pressure.¹¹ A notable finding suggests that the practice of detailed history taking, unique to primary care, can detect cognitive impairment without additional clinical burden.^{9,12}



Monitoring the cognitive health of aging adults by providing the appropriate care at the appropriate time is one of health care's most serious challenges. Citing proximity to communities served and the value inherent in relationships built and maintained over time, policy makers argue that primary care is in an ideal position to provide primary and secondary prevention.¹³ One compelling reason posits that primary care is where clinicians are anchored to their patients in ways that help link the ordinary to the extraordinary via diagnosis and treatment.¹⁴ Leading medical organizations, such as the US Preventive Services Task Force, argue that cognitive screening and early detection of illnesses in primary care are necessary and needed.¹⁵ In a 2021 analysis of data from the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study, the authors found that not only was primary care physician supply positively associated with cognitive health, having a routine source of primary care lowered the odds of cognitive impairment.¹⁶ Despite this growing evidence base, primary care conversations about whole-person care that supports cognitive health are not occurring as hoped.

Experts agree that it is critical for health systems to establish methods that support the types of dialog required to adequately address the complex care of aging adults.¹⁷⁻¹⁹ Recent attention to gaps in current health system infrastructure has called for improving systems to address workforce preparation and new approaches to care delivery.²⁰ Decades of evidence call attention to the importance of respecting the values, preferences, and objectives of the individual, which is why any efforts to address this concern should be guided by shared decision making (SDM).²¹

As a model of care, SDM provides a communication process to engage patients in what Montori and colleagues call an "antidote to medical paternalism."²² A collaborative process involving patients, their families, and health care clinicians, SDM is aimed at making informed decisions anchored in the best available evidence and tailored to the patient's values and aspirations.²³ Purposeful SDM is a problem-based approach that situates SDM within the context of care for aging adults by centering on patient and family fears or concerns as well as evolving beliefs and/or perceptions relative to their cognitive health.²⁴

Patient engagement tools (decision aids or encounter tools) that have been designed with SDM as a guiding framework have shown their capacity to enhance clinical conversations and thereby improve the overall quality of patient care.²⁵⁻²⁷ We report on a project to assess the feasibility and acceptability of one such intervention, the "About Me" Care Card. The intervention was designed to promote dialog regarding cognitive impairment between patients, their families, and health care clinicians. Given the absence of dialog in care broadly and in primary care specifically, the aim of this intervention was to examine how the About Me Care Card might promote dialog regarding care for older adults with potential cognitive impairment.

METHODS

We conducted a feasibility study using a community- and user-centered design approach to develop a theory-based communication card to support care conversations. The purpose was to assess how the card was used to promote dialog between patients, caregivers, families, and clinicians on care related to dementia, cognitive impairment, and aging. A protocol was reviewed by the University of Minnesota Institutional Review Board, which determined it not human research.

Design and Approach

The About Me Care Card was informed by a new problembased approach that expands on the classic model of SDM²⁸ to focus on patient concerns, nonmedical needs, and hard-toquantify problems.²⁴ The idea for an About Me Care Card was born from early work of one of the authors (G.K.) and his experience implementing an About Me Card for a health system in North Carolina, which has now collected more than 100,000 of the original About Me Cards across primary care, specialty care, and inpatient settings. The present project assessed the use of the About Me Care Card in multiple care settings among individuals with various levels of cognitive function.

Global Steering Committee

A global steering committee composed of health care professionals, patient advocacy groups, caregivers/family members, and individuals with dementia (<u>Supplemental Appendix</u>) oversaw the project. Committee meetings provided iterative feedback at each phase. Meetings were recorded via Zoom (Zoom Communications, Inc), and Google Jamboard (Google Inc) facilitated discussions and interactions to iterate changes and feedback.

Site and Participant Recruitment

Sites were purposefully selected on the basis of professional relationships and associations among steering committee members and the research team. Patient recruitment was tailored around site-specific practice habits. Clinical site leaders were asked to recruit patients according to local needs and existing relationships with patients.

Data Collection

Data collected included paper-based About Me Care Cards with patient feedback, postuse surveys, researcher notes from interviews with clinicians, patients, and caregivers, and steering committee meeting/workshop outputs. A 5-item investigator-developed postuse survey was distributed to patients after completing the About Me Care Card and collected independently by each testing location. Surveys collected data on usability among patients, asking whether completing the card improved conversations with clinicians, understanding if patients valued telling their clinician what was important to them, if the card helped cocreate a whole-person care plan



based on patient goals and concerns, and if the patient would recommend the card to other patients. Sites interviewed patients about their experience with the card and asked them to provide feedback about those interactions. An investigatorcreated interview guide framed conversations with clinicians regarding their use and experience with the card, their perception of the card's effect on the patient-clinician interaction, and their observations regarding using the card within usual care workflows.

Data Analysis

We assessed and characterized 4 sources of data including patient feedback, clinician interviews/feedback, postuse surveys, and steering committee guidance. The analysis of these data was guided by Bowen et al's rationale for document analysis,²⁹ which details the examination of text, interviews, and narratives for the express purpose of interpreting and relating the context of observations within a document. In addition, we used Hsieh and Shannon's conventional content analysis to assess the phenomena of using the card with patients.³⁰

The 2-phase study design (Figure 1) incorporated an environmental scan to characterize current research and practice and was overseen by the expert steering committee.³¹ Scan findings led us to create a new, simple tool that elicited care conversations extending into the realm of social care needs (preprototype). This preprototype helped engage phase 1 sites to refinement and style of the preprototype and next test prototype 1.

Phase 1: Feasibility

We elicited feedback from the steering committee and clinic partners on the core design features and permitted local tailoring and testing of the tool (preprototype). Clinicians at 7 clinic sites (care teams) were interviewed after testing, and improvement strategies were characterized. Variations in the card design across clinical sites, clinician interviews, and patient feedback guided feasibility assessment.

Phase 2: Acceptability

A second global steering committee meeting was held to synthesize phase 1 findings and design and strategize prototype 2 acceptability. Based on feedback from sites and the steering committee, we collaborated with an artist to modify the tool design to a trifold format. Phase 2 applied the same engagement, testing, and evaluation approach with 5 clinical sites (care teams, 1 site from phase 1), capturing an additional 94 About Me Care Cards during patient care encounters at the 6 sites. Phase 1 and phase 2 insights were synthesized (phase 2 synthesis) and presented to the steering committee, and key lessons were noted.

RESULTS

Below is a summary of findings on the design, validation, and implementation processes that occurred from summer 2022 to spring 2023. This includes the postuse survey, steering committee output, and observations from 12 clinical sites (care teams) (<u>Table 1</u>). Qualitative findings are organized by phase and assessment type (feasibility and acceptability).

Phase 1: Feasibility (Prototype 1)

In the summer of 2022, we approached the steering committee with the following primary question: What are your recommendations for modifying the original About Me Card into a new care card that can be used at the point of care to coproduce care pathways that matter most to people living with Alzheimer disease and related dementias and their carer(s)/care partner(s)? Two key themes emerged from the insights shared by the steering committee. They wanted to see the card designed in a way that leveraged patient autonomy and what matters most for individuals living with dementia. Among members who had clinical experiences, there was a desire to keep the design simple and relevant to key care-based issues (<u>Table 2</u>).

Interviews and card feedback provided design and intervention responses from clinicians, patients, and care managers. We present the findings extracted from phase 1 and 2 testing below. These key insights led to the first version of the card. During the first test in a clinical setting, a discharge planner on an inpatient neurology unit suggested that a greeting card format would present the card in a welcoming manner, allowing the patient to open the card as if they were receiving a gift. We used the card shown in <u>Figure 2</u> for the remainder of phase 2.

Postuse Survey

We distributed a total of 50 postuse surveys across sites, and 44 were completed. Survey responses ranged from 1 to 5, where lower numbers indicated low agreement and higher

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Clinician (n)	Care team/clinical site	Delivery setting	Setting	Implementation timing	Patients (n)
Phase 1					
Social worker (1)	Midsize (<\$1 billion), not- for-profit US health sys- tem home health team	Telephone	Southeast United States, rural	Independent of home visit with social worker to discuss social needs only	10
Senior PCP (1)	Private, independent phy- sician (single provider practice)	In-person, in assisted living setting	Midwest United States, rural	During medical visit with physician	8
Palliative care physician (1)	Midsize (< \$1 billion), not- for-profit US health sys- tem palliative care team	In-person, palliative care clinic room	Southeast United States, rural	During medical visit with physician	4
Employed neuro- hospitalist (1)	Midsize (<\$1 billion), not- for-profit US neurohospi- talist team	Hospital room	Southeast United States, rural	During medical visit with physician, discharge planner, and researcher	3
Social worker (1)	Not-for-profit independent area on aging agency	Telephone	Midwest United States, rural	Independent of home visit to ensure understanding of patient's social needs	10
PACE PCP (1; identical to phase 2)	Program of all-inclusive care for elderly	PACE care facility	Midwest United States, rural	Patients completed About Me Care Card with administrator before visit with PCP, then discussed card with PCP during medical encounter	10
Employed PCP (1)	Large (≥\$1 billion), not-for- profit US health system	Skilled nursing facility	Midwest United States, small city	During medical visit with PCP	6
				Phase 1 total	51
Phase 2					
PACE PCP (1; identical to phase 1)	Program of all-inclusive care for elderly	PACE care facility	Midwest United States, rural	Patients completed About Me Care Card with administrator before visit with PCP, then discussed card with PCP during medical encounter	7
Social worker (1)	Midsize (<\$1 billion), not- for-profit US social care team, inpatient visit	Part of Hospital Elder Life program	Southeast United States, rural	Social worker conversation with inpatient	5
Nurse practitio- ner (1)	Private, independent mem- ory clinic	Telehealth and in- person visits with patients in nursing homes	Midwest United States, rural	During visit with patients via tele- health or in person to specifically assess for cognitive, memory care	10
Employed PCP (1)	Midsize (<\$1 billion), not- for-profit US primary care team	Primary care clinic	Southeast United States, rural	Patient asked to complete About Me Care Card when arriving at clinic, immediately before visiting with PCP; PCP discussed card with patient during medical encounter	51
Employed PCPs and nurse prac- titioners (3)	Midsize (< \$1 billion), not- for-profit US primary care team	Primary care clinic	Southeast United States, rural	Patient asked to complete About Me Care Card when arriving at clinic, immediately before visiting with PCP; PCP discussed card with patient during medical encounter	16
Employed neu- rologist (1)	Memory clinic/institute	Academic tertiary hospital	Madrid, Spain (large city)	Patient asked to complete About Me Care Card when arriving at clinic, immediately before visiting with neurologist; neurologist discussed card with patient during medical encounter	5
				Phase 2 total	94
				Overall total	145

Table 1. Implementation Settings and Patients Engaged (Phases 1 and 2)

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Table 2. Qualitative Findings, Phase 1: Feasibility

Key design recommendations

Simplify content: decrease options in "My Life" section

Make relevant to user: what is important to you?

Ensure content is easy to review and elicits questions

Feasibility

Conversation preparation: "does not waste time on trying to determine goals...clinician can focus on guiding conversation around goals or concerns"

Flexibility of use: "face-to-face worked well, phone was a little difficult"

Adaptability: "can be used in a variety of clinical settings, assisted living, social care, primary care, home care"

Adoption: "simply need to practice to know how it impacts efficacy"

numbers indicated high agreement. Overall, 41% of patients found the card easy to use, 43% found that the card helped them talk about things that matters most, 59% felt it was important to tell the provider what they found meaningful in life, 32% said the card helped identify a plan to address what was most important, and 65% would recommend the card for people >65 years of age.

Phase 1: Summary

Phase 1 included 51 About Me Care Card encounters at 7 US clinical sites (care teams) across a variety of settings (<u>Table</u> <u>1</u>). The feasibility study of the About Me Care Card can be characterized by the following 3 global themes: conversation preparation and content validity, clinical setting adaptability, and target population.

Front of card		Left inside of card		
ABOUT I	ME CARD	My Care Plan		
		Complete the sections below during the conversation with your care provider .		
		WHAT MATTERS MOST	WHAT COMES NEXT	
Please complete the fi ("MY LIFE" and "LIVING M upcoming conversation	r st two sections below IY BEST LIFE") before your with your care provider.	What matters most to you when thinking about living your best life?	What are the next steps that can help you live your best life (a life with purpose)?	
The purpose is to help y what you can do together to	your provider understand help you live your best life .			
Right inside of card	LIEE	Back of card	IV DECT LIEE	
Right inside of card MY find purpose (meaning) in life b	LIFE y (through)	Back of card LIVING M What worries (concerns) you the mos life (a life with purpose)? Check one worry (concern) next to "Other."	IY BEST LIFE st when you think about living your be or more of the options below or write	
Right inside of card MY find purpose (meaning) in life b Please complete the sentence abo the options below or writing your	LIFE y (through) ove by checking one or more of r answer next to "Other."	Back of card LIVING M What worries (concerns) you the mos life (a life with purpose)? Check one worry (concern) next to "Other." Getting the help I need to take care of the things I used to do by myself	IY BEST LIFE st when you think about living your be- or more of the options below or write My sleep The amount of alcohol I drink or tobacco I use	
Right inside of card MY find purpose (meaning) in life b Please complete the sentence abo the options below or writing your Spending time with people 1	LIFE y (through) ove by checking one or more of r answer next to "Other." Working	Back of card LIVING M What worries (concerns) you the mos life (a life with purpose)? Check one worry (concern) next to "Other." Getting the help I need to take care of the things I used to do by myself My ability to live on my own	IY BEST LIFE st when you think about living your be or more of the options below or write My sleep The amount of alcohol I drink or tobacco I use My balance, falling	
Right inside of card MY find purpose (meaning) in life b Please complete the sentence above the options below or writing your Spending time with people I care about Roing independent	LIFE y (through) we by checking one or more of answer next to "Other." Working Volunteering	Back of card LIVING M What worries (concerns) you the mos life (a life with purpose)? Check one worry (concern) next to "Other." Getting the help I need to take care of the things I used to do by myself My ability to live on my own My safety My finances	IY BEST LIFE st when you think about living your be or more of the options below or write My sleep The amount of alcohol I drink or tobacco I use My balance, falling My hearing or vision	
Right inside of card MY find purpose (meaning) in life b Please complete the sentence above Please complete the sentence above Spending time with people I care about Being independent Taking care of my daily	LIFE y (through) ove by checking one or more of r answer next to "Other." Working Volunteering Caring for/being with my pets	Back of card LIVING M What worries (concerns) you the mos life (a life with purpose)? Check one worry (concern) next to "Other." Getting the help I need to take care of the things I used to do by myself My ability to live on my own My safety My finances My anxiety	IY BEST LIFE st when you think about living your be or more of the options below or write My sleep The amount of alcohol I drink o tobacco I use My balance, falling My hearing or vision Being alone Being a burden to my family or	
Right inside of card MY find purpose (meaning) in life b Please complete the sentence abo the options below or writing your Spending time with people I care about Being independent Taking care of my daily needs (eg, bathing, paying bills, cooking)	LIFE y (through) ove by checking one or more of answer next to "Other." Working Volunteering Caring for/being with my pets Other:	Back of card LIVING M What worries (concerns) you the mos life (a life with purpose)? Check one worry (concern) next to "Other." Getting the help I need to take care of the things I used to do by myself My ability to live on my own My safety My finances My anxiety Losing interest in my preferred hobbies	IY BEST LIFE st when you think about living your be or more of the options below or write My sleep The amount of alcohol I drink or tobacco I use My balance, falling My hearing or vision Being alone Being a burden to my family or carers Other:	
Right inside of card MY find purpose (meaning) in life b P Please complete the sentence abore P Please complete the sentence abore P Spending time with people I care about Being independent Taking care of my daily needs (eg, bathing, paying bills, cooking) Exercising or playing games regularly	LIFE y (through) ove by checking one or more of r answer next to "Other." Working Volunteering Caring for/being with my pets Other:	Back of card LIVING M What worries (concerns) you the mos life (a life with purpose)? Check one worry (concern) next to "Other." Getting the help I need to take care of the things I used to do by myself My ability to live on my own My safety My finances My anxiety Losing interest in my preferred hobbies My diet (what I eat) How confident are you that you can	IY BEST LIFE st when you think about living your be or more of the options below or write My sleep The amount of alcohol I drink o tobacco I use My balance, falling My hearing or vision Being alone Being a burden to my family or carers Other: address the worries (concerns) you	



A central idea across settings was that the card helped move past mundane details and focus immediately on patient goals and concerns. The challenge for clinical teams is the effort to integrate the card into usual care. To be feasible, a team member must be available to share the card with patients shortly before the care conversation with the clinician, or for some aging individuals with cognitive impairment, help the patient complete the card. Notably, patients with more advanced cognitive challenges found the card hard to answer on their own and asked for help.

The overall feedback across sites was positive, yet how the tool worked and how it engaged patients appeared to vary in noticeable ways. Despite this variation, the core purpose remained, with a purpose to engage and promote bidirectional exchange of information. Clinician feedback showed how the card promoted out-of-the-box thinking, a way of practicing that many of the clinicians interviewed embraced. One primary care clinician noted that much of their current practice (ie, usual care) keeps them from having focused, personal conversations with their patients. The tool gave them permission to go beyond the standard talking points. Another primary care clinician pointed out how the presence of the tool, by itself, changed the context of the conversation.

Determining appropriate patients who should receive the card within the busyness of the daily workflow was a challenge. This might prevent clinicians from adopting the card.

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SECTION 1: MY LIFE	SECTION 2: LIVING MY BEST LIFE	SECTION 3: NEXT STEPS TO LIVING MY BEST LIFE					
I am living my best life when I	What concerns you the most when you think about living your best life?	What are the next steps that can help you live					
Please complete the sentence above by checking one or more of the options below or writing your answer next to "Other."	Please check one or more of the options below or write a concern next to "Other." Getting the help I need to take care of the things I used to do by myself	Please answer the question above in partner- ship with your care provider and write your response in the space below.					
Take care of my daily needs (eg, bathing, paying bills, cooking)	 My ability to live on my own My safety 						
Exercise or play games regularly	My finances						
 Participate in my favorite hobby/hobbies (eg, reading, music, art, gardening) Spend time outdoors or travel 	My anxiety Losing interest in my preferred hobbies My dist (what heat)						
Work, volunteer, or help others	Being lost or feeling lost (disoriented)						
Spend time with my pets	□ My sleep						
Other:	The amount of alcohol I drink or tobacco I use						
	☐ My balance, falling						
	My hearing or vision						
	Being aburden to my family or carers						
	☐ The quality of care I receive						
	Other:						
	How confident are you that you can address the concerns you selected above?						
	Please check one of the options below.						
	Very confident Somewhat confident						
	Not very confident						

Figure 3b. The Inside Pages of Version 2 of the About Me Care Card for Aging Adults With Alzheimer Disease and Related Dementias

Note: A participating health system with experience using the original About Me Care Card also tested a slightly different version of the About Me Care Card.

Doing so might take too much time, given the burden of trying to determine how appropriate the card would be for a specific patient based on their known or estimated level of cognitive burden. As a result, phase 1 care teams and the steering committee recommended that clinical practices use the card for all aging adults, regardless of their diagnosis. On this point, one primary care group of a large US health system decided to use the card for all patients \geq 55 years of age.

We learned from patients that it is important to avoid assuming who would or would not respond to the card. One patient in a neurology unit of a US hospital system completed the card with comments such as, "I want to get up knowing there is something to do" and "I want to keep going, keep living, and to put energy into life." She did not want people telling her "what I can't do."

Phase 2: Acceptability (Prototype 2)

The card design shown in Figure 3 was used for phase 2, which included 94 About Me Care Card encounters at 5 clinical sites (care teams) (Table 1). Phase 2 also included an at-home, family led test with an 85-year-old male patient with moderate to severe dementia in Sweden. Design insights

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Table 3. Qualitative Findings, Phase 2: Acceptability

Key design insights

Personalization: [living my best life] "gave me a chance to reflect on my life" (patient)

Elicited new information: "new [patient] information [they] found enlightening, which doctor never knew" (clinician)

Acceptability

Focused on right care: "guided the discussion, permitting a palliative care mindset" (clinician)

Slowed down time: "provided time and space for people to think about what they want and how they want to express it" (clinician)

Expanded conversation: "I found out a patient was lonely...made a referral to social care" (clinician)

(<u>Table 3</u>) and themes reflected patient and family acceptance and clinician acceptance.

Patient and Family Acceptance

When patients and families were asked to reflect on the value and utility of the tool, the most salient feedback expressed by patients included the following: (1) "It gives me time to reflect and to appreciate the time I have left to spend with my family," (2) "It provided a chance to reflect," and (3) "The card helps me be heard." When the card was completed before the visit, those who independently completed the card appreciated the time to think about their goals and concerns before the conversation—that it "removed the pressure of the faceto-face moment."

Clinician Acceptance

One of the structural features noted by clinicians was the value of the card as an artifact to disrupt usual care. In this way, the card was found to slow time, directing more energy from clinicians to support engaging conversations with patients. The card also provided an opening for clinicians and patients to talk about ideas, concerns, and fears not typically discussed in routine practice. When clinicians introduced the card, they also noticed that the act of providing the card "changed the context of the conversation" for the better. This type of personalization gave patients a chance to call attention to their needs rather than the clinical needs of the clinician or protocol.

DISCUSSION

A simple paper-based intervention to promote conversations on aging and cognitive health provided space for clinicians to expand on patients' values and goals beyond the routine elicitation and collection of acute symptoms. The findings presented here, which examine the About Me Care Card for feasibility and acceptability across various levels of cognitive function and clinician department affiliation, appeared to promote use and needed conversations, especially when the level of cognitive impairment/burden was unknown. The design features of the card appeared to elicit patient questions and focus clinician time and attention on patient goals and concerns. Clinicians noted how the card supported "slowing down time" to provide space for patients by eliciting new information sometimes missed in routine visits. When applied to primary care settings, these features appeared to grant permission to clinicians to engage patients beyond routine communication patterns, giving way to novel insights regarding patient goals, fears, and values.

Our present findings directly address an Alzheimer's Association report that less than one-half (47%) of adults ≥ 65 years of age have ever discussed their thinking or memory abilities with a health care clinician, with less than one-third (28%) having ever been assessed for cognitive problems.³² One review shows reluctance among primary care clinicians as one factor.33 Another study among adults identified fear of receiving unnecessary treatment and a belief that symptoms might go away on their own.³⁴ These barriers leave little chance for adults to engage cognitive health in a meaningful way with their physician. Under these circumstances, our findings indicate the value of short and simple tools within primary care settings to promote difficult conversations and to directly address established barriers to implementation including clinician time, relevance to patient group, institutional inertia or bureaucracy, clinician training, patient awareness, and limited involvement of clinicians during the design and development phases.³⁵⁻³⁷ Acknowledging that implementation barriers are also systemic and that many clinicians view new tools with skepticism,³⁸ our findings indicate that the About Me Care Card can easily fit into established workflows via its adaptability to complexity and helping guide conversations with patients to what matters most to them.

In context, these findings describe a potential and meaningful solution to an overburdened primary care environment.³⁹ This is even more important when we consider how workflows and technology are reshaping expectations for primary care to do more with less.⁴⁰ A simple tool to elicit conversations on patient perceptions on aging and cognitive health is supported by health services research identifying primary care as an ideal context for managing patients with dementia.⁴¹ Others suggest that early conversations can guide and support appropriate intervention,⁴² an argument underscoring the inherent value of primary care for having meaningful conversations on aging and cognitive health.

The importance and value of using patient-engagement tools to promote patient care for cognitive health has been detailed by Wolff and colleagues.⁴³ Even though findings such as these highlight communication support for medical management and cognitive health, gaps on how to promote conversations on aging and cognitive decline remain.⁴⁴ The About Me Care Card shows that simple tools designed to foster intentional conversations at the point of care offer an accessible and effective approach to improve care for older adults.

Limitations

Our approach to this feasibility and acceptability study has some limitations; therefore, our findings should be reviewed with some caution. The lack of standardization across the various implementation sites was part of the design as well as a reflection of differences between clinics. Additional work is needed to test the effect of the tool on patient outcomes as well as treatment choice alignment with patient expectations. Because most of the findings related to patient feedback were taken directly from comments on the card or relayed by clinicians, additional work is needed to capture patient-reported data more effectively to enhance reliability. Future research and implementation and evaluation work will need to include a robust plan for collecting and reporting diverse patient and caregiver feedback to enhance contextual understanding.

CONCLUSIONS

The About Me Care Card has immediate application in primary care to guide meaningful conversations with older adults as they manage complexities and uncertainties associated with the aging process. The card has shown that it has the potential to help primary care and other clinical or social care settings support early, whole-person conversations with aging adults that could mitigate avoidable suffering among patients and their carers. Moving forward, it will be necessary to identify the mechanisms by which behavior change and treatment adaptation over time are facilitated by the card. The authors can be contacted for the most up-to-date version of the card.

Read or post commentaries in response to this article.

Key words: dementia; Alzheimer disease; cognitive health; shared decision making; decision support

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Supplemental materials

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