Patient and caregiver perspectives on a tool to identify undiagnosed dementia: A qualitative study

Lorella Palazzo (Lorella.G.Palazzo@kp.org)
Kaiser Permanente Washington Health Research Institute
Clarissa Hsu
Kaiser Permanente Washington Health Research Institute
Deborah Barnes
University of California, San Francisco
Marlaine Figueroa-Gray
Kaiser Permanente Washington Health Research Institute
Mikael Anne Greenwood-Hickman
Kaiser Permanente Washington Health Research Institute
Eric Larson
Kaiser Permanente Washington Health Research Institute
Sascha Dublin
Kaiser Permanente Washington Health Research Institute

Research Article

Keywords: Dementia, focus groups, risk assessment, early diagnosis, electronic health records

Posted Date: May 13th, 2021

DOI: https://doi.org/10.21203/rs.3.rs-513568/v1

Patient and caregiver perspectives on a tool to identify undiagnosed dementia: A qualitative study

Running title: **Patient perspectives on dementia diagnosis tool**

Lorella Palazzo, PhD;[1] Clarissa Hsu, PhD;[1] Deborah E. Barnes, PhD, MPH;[2,3] Marlaine Figueroa Gray, PhD;[1] Mikael Anne Greenwood-Hickman, MPH;[1] Eric Larson, MD;[1] Sascha Dublin, MD, PhD[1]

[1]Kaiser Permanente Washington Health Research Institute, Seattle, WA

[2]Departments of Psychiatry and Behavioral Sciences and Epidemiology & Biostatistics, University of California, San Francisco

[3]San Francisco Veterans Affairs Health Care System

Corresponding author: Lorella.G.Palazzo@kp.org

Kaiser Permanente Washington Health Research Institute

1730 Minor Avenue Suite 1600, Seattle, WA 98101

206-220-2173 (phone)

206-287-4071 (fax)

Number of references: 35

Number of tables: 5

Main text word count: 2863

Abstract word count: 250

Keywords: Dementia, focus groups, risk assessment, early diagnosis, electronic health records

Abstract

BACKGROUND

Early detection of dementia may improve patient care and quality of life, yet as many as half of patients are undiagnosed. Electronic health record (EHR) data could potentially be used to help

identify patients at risk of having undiagnosed dementia who could be targeted for outreach and assessment, but acceptability to patients and caregivers is unknown.

METHOD

We conducted five focus groups at Kaiser Permanente Washington, an integrated healthcare system in Washington State, to explore feelings about timing of dementia diagnosis, use of EHR-based tools to predict risk of undiagnosed dementia, and communication about risk. Two team members analyzed transcripts using inductive thematic coding.

RESULTS

Participant groups included: patients with dementia or mild cognitive impairment, patients with neither diagnosis, and caregivers. People who were non-white or Hispanic were oversampled. Forty patients and caregivers (63% women; 59% non-white/Hispanic) participated in focus groups. Participants supported early diagnosis, describing benefits such as time to adjust to the disease, plan, involve caregivers, and identify resources. They also acknowledged the possible psychosocial toll of receiving the diagnosis. Participants also supported use of an EHR-based tool, but some worried about accuracy and privacy. Participants emphasized that information about dementia risk should be communicated thoughtfully by a trusted provider and should include advice about prognosis, treatment options and other resources.

CONCLUSION

Overall, patients and caregivers supported using EHR-based tools to help identify patients at risk of having undiagnosed dementia. Such tools must be implemented carefully to address concerns and ensure patients and caregivers are adequately supported.

BACKGROUND

In the United States, about 5.8 million people currently have dementia,(1) yet a large proportion of people with dementia are undiagnosed.(2-4) Routine screening of older adults for dementia remains controversial. There are many differing opinions among patients, care givers and health care providers about the benefits and harms of routine screening. Boustani et al found differences between patients and their care givers in the perceived benefits and receptivity to routine screening.(5) Physicians are also divided, with some worrying about the harms of dementia screening,(6) while others argue that screening may improve patients' lives overall.(7, 8)

The U.S. Preventive Services Task Force does not recommend for or against routine screening for dementia in older adults due to lack of evidence on benefits and harms.(9)However, several organizations, such as the Alzheimer's Association and the Gerontological Society of America advocate for early diagnosis to maximize time for planning and support for patients and caregivers.(10-12)

There are many barriers to dementia diagnosis in primary care. Dementia onset can be insidious,(13) and patients and caregivers often fail to recognize and seek care for mild cognitive changes.(14, 15) Clinicians may have difficulty recognizing symptoms during brief clinical encounters, particularly early in the disease process, or may focus on physical symptoms more than cognitive problems and concerns.(3, 16-19) System-level barriers also exist such as competing priorities during clinical encounters.(3) To overcome these barriers, several studies have called for standardized tools and information technology resources to support earlier recognition of dementia in primary care.(2, 3, 18)

Our team has developed a tool called the electronic health record Risk of Alzheimer's and Dementia Assessment Rule (eRADAR) that uses electronic health record (EHR) data (such as dementia-related symptoms, healthcare utilization patterns, and dementia risk factors) to identify

patients who may have undiagnosed dementia, which could address some barriers to diagnosis.(19) Use of this tool could provide an alternative to routine screening for dementia by supporting further evaluation of those patients identified as being at particularly high risk for undiagnosed dementia.

In this paper we report results of focus groups with patients and caregivers held while eRADAR was in the early stages of development. The focus groups explored feelings about diagnosis timing, use of EHR-based tools to predict risk of undiagnosed dementia, and communication about risk. We discuss implications of our findings for improving dementia care.

METHODS

DESIGN AND PARTICIPANTS

Study design

We held five focus groups with members of Kaiser Permanente Washington (KPWA), an integrated healthcare system in the Pacific Northwest, and their caregivers. Participants provided written informed consent. All study protocols were approved by the Kaiser Permanente Washington Institutional Review Board. All procedures were carried out in accordance with approved protocols and all relevant local, state, and national research guidelines and regulations.

Sampling and recruitment

The five focus groups included four types of participants: 1) KPWA patients diagnosed with dementia (1 group); 2) KPWA patients diagnosed with mild cognitive impairment (MCI) (1 group); 3) KPWA patients with no diagnosis of dementia or MCI (2 groups) and 4) caregivers of KPWA patients with dementia (1 group). We used purposive sampling(20) to recruit participants

and oversampled non-white and Hispanic patients. See Table 1 for inclusion and exclusion criteria.

Table 1.

Potential patient participants were sent a recruitment letter, and then called to assess interest and eligibility. The Short Portable Mental Status Questionnaire(21) was administered to patients with MCI or dementia diagnoses to exclude those with more severe cognitive impairment who we thought would not be able to meaningfully participate. Participants received a $100 incentive and were offered transportation.

Data collection

Three qualitative researchers, two of whom had extensive experience conducting focus group (CH, LP, MG) co-facilitated 90-minute focus groups at two Seattle/Tacoma-area clinics. At least two of the three facilitators were at each of the focus groups and while one researcher served the primary facilitator, the co-facilitator also helped guide the discussion and asked follow questions. Facilitators' backgrounds and roles on the research team were shared with participants.

Group discussions were audio recorded and transcribed by a court reporter. Semi-structured guides were developed and customized as needed for the different focus groups. For example, all the guides asked about experience with diagnosis but for patients and caregivers they were asked to recount their actual experiences, while the group with no dementia or MCI diagnosis were asked about any experiences they might have had with loved ones and/or what they would like if they were to be diagnosed. We included a role-playing exercise into the first groups that was not used in subsequent groups due to time considerations. All the guides addressed experiences with and preferences for timing of diagnosis; feelings and perceptions about memory loss and

dementia; and acceptability and practical aspects of an EHR-based tool to assess undiagnosed dementia risk. The tool was described to participants as a potential resource that would not prove someone had dementia but could help identify people who might need more evaluation for dementia. All facilitators used these guides to ensure consistency in the topics raised during the focus groups. However, since qualitative data collection is open-ended and driven by participant experiences there were expected differences in some of the specific topics and issues that emerged in each group.

Data analysis

Two authors (CH, LP) carried out qualitative coding using an iteratively developed code list. An initial coding list based on focus group questions was expanded and refined inductively through repeated reading of transcripts. All transcripts were then coded independently by each coder, compared and reconciled through discussion.(22, 23) Data were reviewed by specific codes to confirm key themes and surface subthemes and connections. Key themes were documented in a coding memo. This manuscript focuses on preferences for timing of diagnosis and feelings about an EHR-based risk assessment tool. Analysis used Atlas.ti (version 7.5.2). Quotations have been edited for clarity.

RESULTS

The five focus groups included 40 people: patients with diagnoses of dementia (n=4) or MCI (n=9), patients with no such diagnosis (two groups: n=10, n=11), and caregivers (n=6). Table 2 shows participant characteristics. When looking across all participants, there were slightly more women than men and a large percentage of participants were college graduates. We over recruited for ethnic and racial diversity and as a result had a higher proportion of non-white or Hispanic participants than in the general population.

Table 2.

This manuscript reports findings under three domains: 1) preferences about dementia diagnosis timing, 2) perspectives on risk assessment for undiagnosed dementia, and 3) perspectives on communication about dementia risk. Quotes are attributed to participants based on their assigned number in the focus groups.

Preferences about dementia diagnosis timing

Table 3 summarizes the pros and cons of early dementia diagnosis described by participants. Patients and caregivers stated that earlier diagnosis could allow the patient to participate in planning for future needs, while their cognitive capacities were still intact, and improve the patient and family's ability to deal with new challenges. This could mean implementing lifestyle changes to enhance the patient's health and wellbeing and ensure safety as their cognitive status declined. Participants also felt that early diagnosis could enable families to prepare for future caregiving responsibilities.

> [O]ne of the pro[s] would be preparation for the family for facilities, costs, end-of-life sort of things that need to be decided by family, and also will give family an opportunity to adapt and…know…heart breaking as it is, this is what's [ahead]. – *Participant 4*, *No Diagnosis group 1*

Further, knowing the cause of behavior changes brought on by dementia could help family members understand and adjust their interactions with the patient and improve social support.

Table 3.

Along with many positives, participants also recognized potential drawbacks of earlier diagnosis. Those primarily included patient stress, anxiety, and social isolation.

> A con for early diagnosis would be for the person themselves: depression, stress, anxiety. – *Participant 5, No Diagnosis group 1*

For some participants, knowing that those diagnosed with dementia had a poor prognosis and few therapeutic options was a cause for distress. In addition, others' perceptions or beliefs about dementia could damage social interactions, contributing to the hardship of an early diagnosis.

Perspectives on risk assessment for undiagnosed dementia

Overall, participants liked the idea of an EHR-based tool for undiagnosed dementia risk assessment, saying they would choose it for themselves or loved ones. Despite initial anxiety, they would want to know their risk of having undiagnosed dementia so they and their families could plan.

> I think it would be a wonderful thing. If there's some problems, I want to know about it so I can -- I don't know what I can do, but it would just help me realize how things are going in my head. - *Participant 7, Dementia group*

Another perceived benefit was possible early intervention to slow disease progression or improve prognosis.

> I want to know what tests are available to determine where we are with this. I want to know what treatments are available so that we perhaps can slow it down. And then we do family planning…. including expenses. –*Participant 11, No Diagnosis group 1*

Dementia risk assessment made sense to participants who wanted to be engaged in their care and was seen as similar to routine medical testing.

> I get regular blood work. I can even get on my phone and see my baseline on my blood. Now, if you come up with a tool like that for the probability or possibility of dementia or Alzheimer's, great. *–Participant 6, No Diagnosis group 2*

Some participants expressed mixed feelings or worried about psychological harm, and several participants who favored risk assessment acknowledged that others may hold different views.

> Some people don't want to believe it, you know, "No. No. No this is not happening to me." And there's people that want to know, like me…. But most people are somewhere in the middle. *–Participant 7, Dementia group*

Most questions and concerns focused on practical aspects of a risk-assessment tool, including how it was developed, whether there would be continued evaluation of its effectiveness, how providers would know how to use it, and who would have access to the risk scores. Worries about "false-positive" results were also expressed, which highlights how patients may conflate obtaining a risk assessment score with receiving a diagnosis (Table 4).

Table 4.

Perspectives on risk communication

We asked participants how they would want to hear that they or their loved ones had elevated risk for undiagnosed dementia. One group of patients with no diagnosis of dementia or MCI did a role-playing exercise of patient-doctor conversations. Table 5 provides participants' preferences about approach, language, and topics for providers talking with patients about risk of undiagnosed dementia.

Participants recommended that conversations occur in the context of established care relationships, ideally primary care, and were concerned that some providers may not know how to talk about memory issues effectively without additional training. They also agreed that a skillful approach and the ready availability of additional resources could help reduce emotional and psychological distress possibly aroused by such conversations. Participants expressed the importance of clear messages around what the test can and cannot determine – if the provider is communicating risk rather than diagnosis, they must ensure this difference is understood by the patient.

Considering family involvement, participants generally wanted loved ones to be involved in the conversation early to discuss risk assessment results.

Table 5.

DISCUSSION

This qualitative study examined patients' and caregivers' perspectives on timing of dementia diagnosis and an EHR-based tool to assess risk of undiagnosed dementia. While previous work has explored patient and caregiver experiences of receiving and adjusting to dementia diagnosis,(24-26) our study is the first to focus on a risk-assessment tool to support earlier recognition of dementia in the clinical setting.

We found that patients and caregivers favored early diagnosis for practical and social reasons, while raising concerns about the stress it might cause. Participants endorsed use of EHR information to assess risk of undiagnosed dementia and mentioned several benefits of risk assessment. Participants also voiced clear preferences for how risk should be communicated,

including that communication occur in the context of an established relationship with a health care provider. These preferences may reflect the sensitivity of discussing risk assessment for undiagnosed dementia and subsequent results with patients and caregivers who may fear the disease and be apprehensive about available treatments. Participants expressed the importance of having providers offer information about prognosis, therapeutic options and other resources.

Few studies have explored both advantages and risks of early diagnosis(8) from the patient and caregiver perspective. Our approach asked patients and caregivers to assess the full implications of receiving a diagnosis. Robinson et al.(27) found that many in their sample were initially in favor of early diagnosis of Alzheimer's disease (the most common cause of dementia(28)) but reconsidered when prospects of potential loss of autonomy were raised. Those who valued confronting bad news continued to choose early diagnosis. Our participants had analogous concerns about the effect of diagnosis on social interactions, while generally preferring timely knowledge of dementia. van den Dungen et al.'s systematic review found ability to plan was a key benefit and psychological distress an important drawback of disclosing a dementia diagnosis.(29) In this study, patients and caregivers voiced similar pros and cons of early diagnosis, contributing valuable insights into the attitudes and motivations underlying individuals' desire to understand the cause of memory loss symptoms.

Many focus group participants supported using EHR data to assess risk of undiagnosed dementia. They recognized advantages that included knowledge of one's disease status, engagement of family members, planning, and receiving treatments that might improve prognosis. While holding mostly favorable attitudes, participants were also apprehensive about accuracy, disclosure of risk scores, and psychosocial stress. Worries about negative labeling from risk assessment, particularly in the case of "false positive" results, serve as a reminder that

dementia carries significant social stigma.(30) Our findings suggest that patients need and want to learn how risk score and diagnosis differ, thus a clear understanding of each could help alleviate some of the concerns expressed about a potential risk assessment tool. Another implication is that any assessment for undiagnosed dementia during routine care should be designed and implemented with safeguards to allay patients' and caregivers' concerns about privacy and unintended disclosure. Further, efforts to detect early dementia should be accompanied by education or counseling to help individuals cope with potential consequences like perceived stigma.

Reflecting on clinician-patient communication, patients and caregivers in our sample stressed a need for clear, direct messages delivered thoughtfully and containing helpful information and resources to deal with the condition. These views are aligned with practice recommendations that emphasize the value of plain, honest, patient-centered conversations at every stage of diagnosing and treating dementia.(31, 32)

Given the communication concerns raised by participants, specialized training may be needed for providers to help them have conversations with patients about their risk for undiagnosed dementia. Existing resources like a communication toolkit(12) for primary care conversations about memory loss provide guidance. However, targeted instruction may be needed to facilitate patient-centered conversations that involve family members, explain a complex tool and process for risk detection of undiagnosed dementia, and offer concrete information and resources. In general, implementing new programs is challenging in busy practices. Structural interventions, such as longer or consecutive visits, that support ongoing care with a trusted provider could ease difficult conversations while addressing symptoms and concerns.

This study had limitations. Focus group participants formed a small, self-selected sample that may not reflect all perspectives.(33) They were highly educated and drawn from a single geographic region. Patients and some caregivers were members of an integrated health system with a focus on primary care, thus their experiences may differ from those of individuals receiving care in other contexts. In the focus groups it was sometimes difficult to engage participants in discussions of abstract notions of risk and a potential risk detection tool, though participants were very engaged and willing to share their perspectives on other topics, some of which were sensitive and/or emotionally charged. Because the tool was under development at the time the focus groups were held, we could only explore general acceptability of using EHR-based data to assess risk of undiagnosed dementia. With further development of the tool, we plan to investigate patient and caregiver perspectives on different cut off points for the model's positive predictive value (PPV)(34).

This study also had strengths. Within our geographic region, we solicited diverse perspectives, including input from patients with and without memory loss and caregivers. We also included robust representation from non-white participants across a major metropolitan area, providing an opportunity for cultural differences in attitudes regarding dementia to surface.

CONCLUSIONS

We found that patients attribute many benefits to earlier dementia diagnosis and that implementing EHR-based risk detection tools for undiagnosed dementia may be broadly acceptable. However, implementing such a tool will require a thoughtful approach and responsive health systems to ensure that new processes improve experiences for patients and caregivers by providing support and resources to those diagnosed with dementia.

LIST OF ABBREVIATIONS

EHR - Electronic Health Record

eRADAR - Risk of Alzheimer's and Dementia Assessment Rule

KPWA - Kaiser Permanente Washington

MCI - Mild Cognitive Impairment

DECLARATIONS

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

All study protocols were approved by the Kaiser Permanente Washington Institutional Review Board. All procedures were carried out in accordance with approved protocols and all relevant local, state and national research guidelines and regulations. Participants provided written informed consent.

CONSENT FOR PUBLICATION

Not Applicable.

AVAILABILITY OF DATA AND MATERIALS

Inquiries about the use of the data presented in this manuscript should be directed to the corresponding author.

COMPETING INTERESTS

There are no potential conflicts of interest to report.

FUNDING

The study received support from the National Institute on Aging (Grant # R56 AG056417).

Preliminary results of this study were presented at the 2019 Annual Meeting of the Society for Applied Anthropology in Portland, OR, March 19-23

AUTHORS' CONTRIBUTIONS

SD and DB conceived of and designed the study and provided vision and direction for the manuscript. MAGH managed study activities. CH, SD, DB, and MAGH designed the data collection protocol and instruments. CH, LP and MG contributed to data collection and analysis. LP led data analysis and manuscript writing. LP, CH, DB, MG, MAGH, EL and SD contributed to results interpretation and provided ongoing scientific input. All authors reviewed and edited manuscript drafts. All authors read and approved the final manuscript.

ACKNOWLEDGEMENTS

The authors wish to thank Chris Tachibana for scientific manuscript editing. The authors are grateful to all study participants for contributing their experiences and insights.

REFERENCES

1. Alzheimer's Association. Alzheimer's Disease Facts and Figures 2018 https://www.alz.org/media/Documents/alzheimers-facts-and-figures-infographic.pdf. Accessed 10 February 2020.
2. Aminzadeh F, Molnar FJ, Dalziel WB, Ayotte D. A review of barriers and enablers to diagnosis and management of persons with dementia in primary care. Can Geriatr J. 2012;15(3):85-94.
3. Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. Alzheimer Dis Assoc Disord. 2009;23(4):306-14.
4. Eichler T, Thyrian JR, Hertel J, Kohler L, Wucherer D, Dreier A, et al. Rates of formal diagnosis in people screened positive for dementia in primary care: Results of the DelpHi-Trial. J Alzheimers Dis. 2014;42(2):451-8.
5. Boustani MA, Justiss MD, Frame A, Austrom MG, Perkins AJ, Cai X, et al. Caregiver and noncaregiver attitudes toward dementia screening. J Am Geriatr Soc. 2011;59(4):681-6.
6. Brunet MD, McCartney M, Heath I, Tomlinson J, Gordon P, Cosgrove J, et al. There is no evidence base for proposed dementia screening. BMJ (Clinical research ed). 2012;345:e8588.
7. Borson S, Frank L, Bayley PJ, Boustani M, Dean M, Lin PJ, et al. Improving dementia care: the role of screening and detection of cognitive impairment. Alzheimers Dement. 2013;9(2):151-9.
8. Dubois B, Padovani A, Scheltens P, Rossi A, Dell'Agnello G. Timely diagnosis for Alzheimer's disease: a literature review on benefits and challenges. J Alzheimers Dis. 2016;49(3):617-31.

9. U.S. Preventitive Services Task Force. Recommendation Statement - Cognitive Impairment in Older Adults: Screening 2014 https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/cognitive-impairment-in-older-adults-screening. Accessed 10 February 2020.
10. The Gerontological Society of America. Workgroup on Cognitive Impairment Detection and Earlier Diagnosis: Report and recommendations 2015 https://www.geron.org/images/gsa/documents/gsaciworkgroup2015report.pdf. Accessed 10 February 2020.
11. Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, et al. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. Alzheimers Dement. 2013;9(2):141-50.
12. Gerontological Society of America. KAER Model Cognitive Impairment Toolkit 2015 https://www.giaging.org/resources/kaer-model-cognitive-impairment-toolkit. Accessed 10 February 2020.
13. Larson EB, Kukull WA, Katzman RL. Cognitive impairment: dementia and Alzheimer's disease. Annu Rev Public Health. 1992;13:431-49.
14. Chrisp TAC, Tabberer S, Thomas BD, Goddard WA. Dementia early diagnosis: triggers, supports and constraints affecting the decision to engage with the health care system. Aging & Mental Health. 2012;16(5):559-65.
15. Spectrum Health Study Finds Delay in Initial Demensia Diagnosis: Spectrum Health Newsroom; 2018 https://newsroom.spectrumhealth.org/spectrum-health-study-finds-delay-initial-dementia-diagnosis/. Accessed 10 February 2020.
16. Hansen EC, Hughes C, Routley G, Robinson AL. General practitioners' experiences and understandings of diagnosing dementia: factors impacting on early diagnosis. Soc Sci Med. 2008;67(11):1776-83.
17. Hinton L, Franz CE, Reddy G, Flores Y, Kravitz RL, Barker JC. Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. J Gen Intern Med. 2007;22(11):1487-92.
18. Iliffe S, Manthorpe J, Eden A. Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study. Fam Pract. 2003;20(4):376-81.
19. Barnes DE, Zhou J, Walker RL, Larson EB, Lee SJ, Boscardin WJ, et al. Development and validation of eRADAR: a tool using ehr data to detect unrecognized dementia. J Am Geriatr Soc. 2020;68(1):103-11.
20. Bernard HR. Research Methods in anthropology: qualitative and quantitative approaches. Rowman & Littlefield; 2017.
21. Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. J Am Geriatr Soc. 1975;23(10):433-41.
22. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. Health Serv Res. 2007;42(4):1758-72.
23. Miles MB, Huberman AM. Qualitative Data Analysis: a sourcebook of new methods. SAGE Publications; 1984.
24. Bunn F, Goodman C, Sworn K, Rait G, Brayne C, Robinson L, et al. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. PLoS medicine. 2012;9(10):e1001331.
25. Read ST, Toye C, Wynaden D. Experiences and expectations of living with dementia: a qualitative study. Collegian. 2017;24(5):427-32.
26. Walker R, Ratcliffe J, White A, Visvanathan R. Dementia assessment services: what are the perceptions of older people? Australas J Ageing. 2018;37(1):43-7.

27. Robinson SM, Canavan M, O'Keeffe ST. Preferences of older people for early diagnosis and disclosure of Alzheimer's disease (AD) before and after considering potential risks and benefits. Arch Gerontol Geriatr. 2014;59(3):607-12.
28. Alzheimer's Association. What is Alzheimer's Disease? 2019 https://www.alz.org/alzheimers-dementia/what-is-alzheimers. Accessed 10 February 2020.
29. van den Dungen P, van Kuijk L, van Marwijk H, van der Wouden J, Moll van Charante E, van der Horst H, et al. Preferences regarding disclosure of a diagnosis of dementia: a systematic review. Int Psychogeriatr. 2014;26(10):1603-18.
30. Alzheimer's Association. Overcoming Stigma 2019 https://www.alz.org/help-support/i-have-alz/overcoming-stigma. Accessed 10 February 2020.
31. Chmelik E, Emtman R, Borisovskaya A, Borson S. Communication in dementia care. Neurodegener Dis Manag. 2016;6(6):479-90.
32. Zaleta AK, Carpenter BD. Patient-centered communication during the disclosure of a dementia diagnosis. Am J Alzheimers Dis Other Demen. 2010;25(6):513-20.
33. Stewart DW, Shamdasani PN. Focus Groups: Theory and practice. SAGE Publications; 2014.
34. Fletcher RH, Fletcher, Suzanne W., Fletcher, Grant S. Clinical Epidemiology: The Essentials. 5th Edition. Fifth Edition ed. Boston, Massachusetts: Wolters Kluwer/Lippincott Williams & Wilkins Health; 2005. 253 pages p.

428 **Table 1.** Inclusion and exclusion criteria by participant group.

Patient Groups	
All patients were required to meet the following criteria:	
· Enrolled in KPWA · Aged 70-85 · At least one healthcare visit at KPWA in the last 12 months · Not living in a nursing home or special care facility · Comfortable speaking English without a translator	
The following additional criteria were applied to specific patient groups:	
Dementia diagnosis	· EHR-documented diagnosis of Alzheimer's or any other dementia in the past 24 months · No evidence in EHR of a low score on a cognitive screening test* · On phone interview, aware of being diagnosed with Alzheimer's disease or dementia · SPMSQ(21) score with ≤ 4 errors at time of phone screening
MCI diagnosis	· EHR-documented diagnosis of MCI in the past 24 months · No evidence in EHR of a low score on a cognitive screening test* · On phone interview, aware of being diagnosed with MCI · SPMSQ(21) score with ≤ 4 errors at time of phone screening**
No dementia/MCI diagnosis* **	· No evidence in the EHR of a diagnosis of MCI or dementia · No prescription fills for a dementia medication
Caregiver Group	
All caregivers were required to meet the following criteria:	
· Identified by a patient in the dementia group as a caregiver OR individual from the sample without evidence of cognitive impairment who reported being a current caregiver of someone with dementia. · Aged 18-85 · Not living in a nursing home or special care facility · Comfortable speaking English without a translator · On phone interview, no self-reported problems with memory or thinking	

Abbreviations: **MCI**, mild cognitive impairment; **SPMSQ**, Short Portable Mental Status Questionnaire; **EHR**, electronic health record; **KPWA**, Kaiser Permanente Washington; **MMSE**, Mini-Mental State Examination.
***** Most patients did not have any cognitive test results recorded. If they did have results from a MMSE or Montreal Cognitive Assessment, the score had to be above 20.
****** SPMSQ score with > 4 errors indicates more severe cognitive impairment. These patients were excluded to help ensure that focus group participants would be able to meaningfully participate.
******* Due to ethics concerns, we were not able to screen this group for cognitive impairment as part of recruitment.

429

Table 2. Participant characteristics.

Characteristic	N=40 n (%)
Female Gender	25 (63)
Age	
55-64	1 (3)
65-74	9 (23)
75-84	26 (65)
85+	4 (10)
Race/Ethnicity*	
Non-Hispanic White	16 (41)
Black/African American	8 (21)
Asian-American	6 (15)
Hispanic/Latino	2 (5)
Other race or multiple races	7 (19)
Highest education completed*	
Some high school or GED	5 (13)
Some college or other school after high school	7 (18)
4-year degree	6 (15)
More than 4-year degree	21 (54)
Focus group composition	
Patients with dementia diagnosis	4 (10)
Patients with MCI diagnosis	9 (23)
Patients without MCI or dementia diagnosis	21 (53)
Caregivers	6 (15)

Abbreviations: **MCI**, mild cognitive impairment; **GED**, General Educational Diploma
*N=39, information missing for 1 participant

Table 3. Pros and cons of early dementia diagnosis noted by participants.

Pros	
Time/ability to adjust to the disease, plan and prepare	You can plan…We can know what we should be doing, for instance, physical, social, eating carefully. The earlier you know, the more you can gear your life that way. *Participant 5, MCI group* You can start working through and being very careful with your time, with people, working with machinery and stuff like that…You know, being aware, slowing down because your brain is slowing down anyway. *Participant 7, Dementia group*
Opportunity to gather information and resources	In terms of my own physical health and others, I always want to know as much as possible at the front end. I think you do go through potentially a fatalistic, "Oh, my God, I have such and such." And then it helps you also figure out how to get access to things to help you. *Participant 2, Caregiver group* You can have timely and/or early referrals to things, like physical therapy rehab for safety and walking, and that type of a thing. *Participant 6, MCI group*
Timely knowledge for caregivers	A spouse would love to be able to be a better support system, but that does involve early knowledge. When you have the best time to learn, to figure out what it is the best things that you can do, and to get some real assistance in carrying them out. *Participant 6, MCI group* The early diagnosis [for my loved one] was helpful for me because it put me on alert that I now have a greater responsibility to stay healthy. *Participant 2, Caregiver group*
Understanding and accommodating cognitive and behavioral changes	If the person is diagnosed early and the family knows of the diagnosis, then they are considered having the dementia rather than being considered a normal person with terrible behavior. *Participant 1, No Diagnosis group 1* For me, an early diagnosis would have been helpful because I thought [the change] was all in my head. *Participant 5, Caregiver group*
Cons	
Emotional/psychological distress about prognosis	Do I really want to know that? If there's nothing that can be helped, I don't want to worry about…it's really bad, but there's nothing that anybody can do for me. So why live like that? *Participant 7, No Diagnosis group 2* I guess the con would be, if it were for me, just knowing what was going to happen. *Participant 10, MCI group*
Negative/uncomfortable interactions	One of the disadvantages [of being diagnosed] is contacts with ill-informed people who without intention can be deeply hurtful to you. *Participant 6, MCI group* It's still…a taboo type thing when you talk about short term memory loss. And people don't like to hear it. *Participant 10, MCI group*

435 **Table 4.** Questions and concerns about a potential dementia risk-assessment tool.

Concern	
Risk calculation	I have an analytical mind, so the first thing I will want to say is, "well, how did he determine this risk?" You know, what tests did he use so I know from what certainty there is. *Participant 5, No Diagnosis group 1*
Proper evaluation and use of a risk-assessment tool	[The tool] sounds intriguing… I assume there would be some ongoing evaluation of its efficacy. We're not blinded by, oh, this is a new computer thing. But I appreciate it's the result of human thought, labor and it deserves to be fairly evaluated as to whether it's efficacious or not. *Participant 3, MCI group* [Primary care doctors] have got to be educated strongly in the tool and how it works and how to use it. *Participant 8, No Diagnosis group 2*
Privacy of risk data and potential labeling	If they put a risk label on you, how is that going to affect your care, and how many other unscrupulous people would get a hold of this and try to do something with this data? Because, man, if they think you're demented or even at risk, they're going to go after you and target you as a victim somewhere. *Participant 5, No Diagnosis group 1* I would want [risk data] in my records. But other people, you know, might have that option of whether or not they wanted it to be. Because there's some families with people with dementia, they're really secretive. They keep it closed. *Participant 11, No Diagnosis group 1*
"False-positive" results	I think [the tool] would [be] good as long as they worked it out so there wouldn't be false positives…Because that could just tear your life up too if you're false diagnosis or indication. *Participant 4, No Diagnosis group 1*

436

437 **Table 5.** Preferred approach and content of patient-provider conversations about dementia risk
438 assessment**.**

Conversation approach	
Direct and thoughtful communication	You might have to stretch it out and take a long time…You just can't say "You are having this problem, end of story." You know, "We don't know what to do to help you out, but this is it." You have a responsibility to get the information out to them. Be kind and loving, have a nice smile on your face…I think most people will accept what you have to say. Unless you get somebody just [saying] "No, no, no, no, no," and you have a different approach. *Participant 7, Dementia group* I think that [the first wording used] shouldn't be possible dementia. But maybe [terms] like cognitive functioning evaluation or something like that, cognitive evaluation. Something so that when it's first presented to you, it isn't already pushing you in the "you can't even hear what's being said because you're already thinking of dementia." *Participant 6, MCI group*.
Provider skills and training	[Doctors] need to be able to speak about dementia so that it doesn't set off all the fire alarms. And so, for doctors to talk about dementia, because most of us are in that age group where we're all thinking about it, you know, they need training…They need words. *Participant 5*, *No Diagnosis group 1*
Communication in the context of	I think [risk assessment] should be at the primary care provider level. Because they're your baseline physician. And they're supposed to be responsible for your overall health. *Participant 8, No Diagnosis group 2*

an established care relationship	Your primary care physician [should talk to you] because that's the one, hopefully, that you have a relationship with. You want [someone] who knows who you are. I don't want psychology, somebody who only speaks medical-ese. I don't want that. I want someone who knows who I am. *Participant 5*, *No Diagnosis group 2*
Clear distinction between risk assessment and diagnosis	[In the role-playing exercise] I was the doctor, and I kept trying to say that you may be at risk, because this was not a definitive test. And that we would have to do more follow-up and testing. *Participant 5, No Diagnosis group 1*
Involving family members	I did ask [my partner acting as patient in role-playing] how close her family was. Because …that would impact how personally I would proceed if I were the doctor…I might say, "Well, would you mind if I gave them a call" or…something like that. *Participant 10, No Diagnosis group 1* [What was comforting was] the doctor [other participant acting as doctor in role-playing] explaining to me that I might be developing dementia, and we're going to make an appointment with my son to come in and we will talk about this. *Participant 9, No Diagnosis group 1*
Topics important to cover in a clinician-patient risk-assessment conversation	
Information on dementia, treatment, and prognosis	It would be nice to have a human being in front of me talking about how this impacts me, and what can be done, and how things will end up and so forth. *Participant 7, Dementia group* [I will want to know] was there any treatment for it. And given this risk, how fast is it going to proceed? *Participant 5, No Diagnosis group 1*
Concrete support and resources	[My partner acting as a patient in role playing] was real clear that she wanted more specific information…She wanted literature, support groups for herself and possibly for family at a time when they could get there, like weekends or after work, that kind of stuff. *Participant 10, No Diagnosis group 1*

439