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Title

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Journal

Alzheimer's & Dementia Diagnosis Assessment & Disease Monitoring, 13(1)

ISSN

2352-8729

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Publication Date

2021

DOI

10.1002/dad2.12157

Peer reviewed

RESEARCH ARTICLE

Pilot study of an Alzheimer's disease risk assessment program in a primary care setting

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Funding information

Anchor Medical Associates of Rhode Island

Abstract

Introduction: The goal of this study was to pilot a referral-based cognitive screening and genetic testing program for Alzheimer's disease (AD) risk assessment in a primary care setting.

Methods: Primary care providers (PCPs; $N = 6$) referred patients ($N = 94$; $M = 63$ years) to the Rhode Island Alzheimer's Disease Prevention Registry for apolipoprotein E (APOE) genotyping and cognitive screening. PCPs disclosed test results to patients and counseled them about risk factor modification.

Results: Compared to the Registry as a whole, participants were younger, more likely to be non-White, and had lower cognitive screening scores. Mild cognitive impairment participants correctly reported a higher perceived risk of developing AD. Patients who recalled being counseled about modifiable risk factors were more likely to report positive health behavior changes.

Discussion: A referral-based program for cognitive and genetic AD risk assessment in a primary care setting is feasible, acceptable to patients, and yielded a more demographically diverse sample than an AD prevention registry.

KEYWORDS

Alzheimer's disease, prevention registry, primary care, risk screening

1 | INTRODUCTION

Early detection of mild cognitive impairment (MCI) and dementia due to Alzheimer's disease (AD) is critical for medical management; initiation of healthy behaviors that may delay disease progression; long-term planning; and entry into clinical research, including participation in clinical trials of potential disease-modifying therapies. Primary care providers (PCPs) are ideally positioned to improve early detection of AD, as adults over age 65 make an average of 2.8 primary care visits annually.¹ Although detecting cognitive impairment is a component of

the Medicare Annual Wellness Visit², structured cognitive assessment is not mandated, and only 16% of older adults receive regular cognitive screening in the primary care setting.³ Barriers to routine screening in primary care include time constraints, limited PCP knowledge of or comfort with AD risk assessment, lack of perceived benefit in making a diagnosis, and patient concerns about stigmatization.⁴ In addition to low rates of cognitive screening, few patients receive counseling about genetic risk for AD or testing for apolipoprotein E (APOE) genotype, the most established genetic risk factor for AD.⁵ With the rise in direct-to-consumer (DTC) genetic testing, PCPs are increasingly

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confronted with patients' genetic information, though many lack knowledge or have low comfort with counseling patients about genetic test results.⁶

Willingness to undergo dementia screening among primary care patients is high, especially among those who know someone with AD.⁷⁻⁹ Disclosure of APOE genotype is also well tolerated, though most prior studies have carefully screened patients for depression or anxiety that may increase risk of adverse outcomes.^{10,11} A randomized clinical trial (REVEAL) showed that cognitively normal (CN) participants who were told their APOE status did not differ from controls in short-term psychological distress, although lower risk (non- ϵ 4) individuals had less test-related distress than higher risk (ϵ 4+) individuals.¹⁰ Older adults cite a desire to use information from dementia risk assessment to inform long-term care planning and engage in preventative health behaviors.^{9,12-14} For example, our group previously reported that among participants in an AD prevention registry who were unaware of their APOE status, 80% desired to know this information, with the most commonly cited reasons being to participate in AD research (76%), arrange personal affairs (74%), and move plans closer in the future (66%).¹⁴

The goal of this study was to determine feasibility, acceptability, and design appropriateness of a referral-based AD risk assessment screening program in a primary care setting in partnership with the Rhode Island Alzheimer's Disease Prevention Registry. Specific objectives included to (1) compare demographics of patients from this program to the AD Prevention Registry as a whole, (2) evaluate patients' understanding of their cognitive screening and genetic test results, and (3) assess patient reactions to screening disclosure. We also describe health behavior changes reported by the participants after AD risk disclosure.

2 | METHODS

2.1 | Participants and study design

Patients ($N = 572$) from an urban primary care practice were pre-selected for eligibility based on an automated chart review of their electronic health records (criteria were age ≥ 45 years and family history of dementia or active memory complaint). PCPs ($N = 6$) saw an automated flag in eligible patients' charts and referred 127 patients to the Rhode Island Alzheimer's Disease Prevention Registry based at Rhode Island Hospital in Providence, Rhode Island, USA, where they were further screened for eligibility (Figure 1). Fliers were also placed in exam rooms advertising the program, so patients who met the above criteria could self-initiate referral if their PCP did not bring up the program to them. We did not capture reasons for non-referral of the 445 patients pre-selected but not referred to the program. For pre-selected patients referred to the program, inclusion/exclusion criteria for the general Registry were applied. Specifically, participants were included if they were 45 to 85 years of age, fluent in English, and had memory complaints or a family history of AD. Exclusion criteria included prior diagnosis of (1) dementia or a major neurological disorder (e.g., Parkin-

RESEARCH IN CONTEXT

- 1. Systematic review:** The authors reviewed the literature using traditional (e.g., PubMed) sources and meeting abstracts and presentations. There have been several recent studies of dementia screening in primary care populations. Relevant citations are appropriately cited.
- 2. Interpretation:** Our findings provide a model for cognitive screening and genetic Alzheimer's disease (AD) risk assessment for use by primary care providers (PCPs). Results also support partnerships with primary care to increase the demographic diversity of AD prevention registries.
- 3. Future directions:** The article offers preliminary data demonstrating the value of an AD risk screening program for patients and PCPs, including the impact on positive behavior changes. Larger scale implementation studies are needed to demonstrate whether PCP disclosure of patient risk factors is a motivator for health behavior change.

son's disease, stroke, multiple sclerosis), (2) major psychiatric disorder, or (3) learning disorder or intellectual disability. As part of the Registry protocol, all participants signed a document of informed consent approved by the Rhode Island Hospital Institutional Review Board. Participants underwent cognitive screening with the Minnesota Cognitive Acuity Screen (MCAS), a telephone-administered screening instrument that is sensitive and specific for discriminating normal cognition, MCI, and dementia (maximum score = 65; score > 52 = CN; score of 43-52 = MCI; score < 43 = dementia¹⁵). Patients provided a DNA sample via cheek swab, which was used to perform rapid polymerase chain reaction-based APOE genotyping using the Spartan Cube® (Spartan Bioscience; small validation study of 72 samples showed 100% concordance with Clinical Laboratory Improvement Amendments [CLIA]-certified testing¹⁶). Recruitment occurred over a 10-month period from September 2018 to June 2019.

Results of the cognitive and genetic testing were faxed to the primary care practice on a single page that included the MCAS score, MCAS score interpretation (CN, MCI, or dementia range based on normative cutoffs), and APOE genotype. The fax sheet also included reminders that the APOE genotype was not performed by a CLIA-approved laboratory and that MCAS scores are intended for screening, rather than diagnostic purposes. Physician assistants (PAs), in concert with patients' respective PCPs, called patients to disclose their screening results and provide counseling about brain health and risk factor modification (e.g., management of chronic medical conditions; recommending health behavior changes such as diet, exercise, or smoking cessation), ordering additional tests or referrals, or prescribing medication. These recommendations and care management decisions were documented at the time of the telephone call.

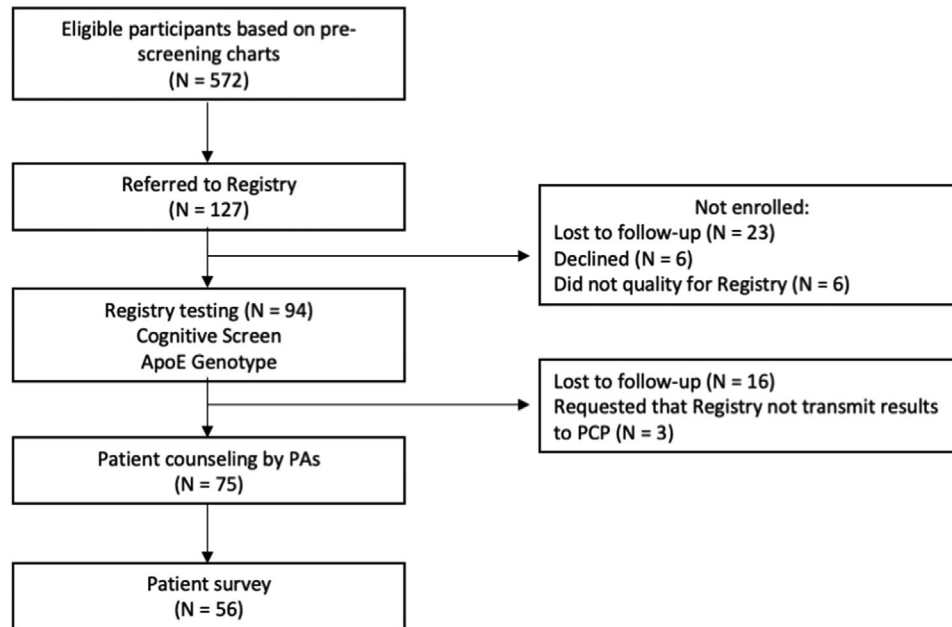


FIGURE 1 Flow diagram of the progress through phases of recruitment for the study

Prior to the start of the study, PCPs and PAs received the study protocol and reference materials about MCI, risk factor modification, cognitive screening, and APOE genotyping. These materials were reviewed in an in-service presentation in which they were given the opportunity to ask questions and discuss implications for their patients. PCP education included general guidelines and suggestions for disclosing results, but they were not asked to follow a prescriptive protocol for telephone disclosure or use results to make specific patient management decisions. PCPs were educated about (1) the limitations of non-CLIA-certified lab testing for APOE results and the need for clinical validation; (2) lifestyle interventions for AD, including benefits of the Mediterranean/MIND diet, aerobic and strength-training exercise, and mental activity; and (3) other modifiable risk factors for AD (i.e., obesity, diabetes, smoking, hypertension, depression, sleep apnea). Providers documented risk disclosure on a response sheet that captured (1) which test results were disclosed, if any; (2) brain health lifestyle recommendations (e.g., diet, exercise, cognitive training); (3) recommended risk factor modification (e.g., lose weight, treat sleep apnea); (4) referrals made (e.g., memory center, genetic counseling, psychological counselor, neuropsychological testing); (5) tests ordered (e.g., repeat APOE test at a CLIA-certified laboratory, vitamin B12, thyroid-stimulating hormone); and (6) treatment initiated (e.g., cholinesterase inhibitor, memantine, vitamins/supplements).

Approximately 3 months ($M = 109$ days; $SD = 60$ days) after receiving their screening results, participants were invited to complete a survey in one of two available modalities: electronically or via a hard copy sent to their home. The survey included 21 items assessing knowledge of screening results, understanding of the meaning of screening results, emotional reactions or mood changes after the results, recall of recommended risk factor modification, and implementation of any risk factor modification strategies (see supporting information). Participants were

also asked their perceived risk of developing AD on a 0 to 100% scale. PCPs ($N = 6$) completed a paper survey with fourteen 5-point Likert items evaluating the value of the pilot screening program and its impact on their practice and patient management decisions. PCPs were also asked to report any adverse events.

2.2 | Statistical analysis

We used two-sided t -tests or χ^2 tests to compare groups based on cognitive status (CN vs. MCI) and genetic status (APOE $\epsilon 4$ vs. non- $\epsilon 4$), with $\alpha = .05$. Statistical analyses were performed using SPSS v26 (IBM). Groups were compared on PA-reported recommendations and on patient-reported survey responses. Given the small number of PCPs who participated in the study, their survey responses are summarized descriptively.

3 | RESULTS

Of 127 patients referred from their PCPs, 94 participants were enrolled in the study and completed cognitive screening and APOE genotyping (Table 1). Twenty-three participants (24%) scored in the MCI range on the MCAS. None scored in the dementia range. APOE genotyping revealed 24 participants (28%) with one $\epsilon 4$ allele and 6 (7%) $\epsilon 4/\epsilon 4$ carriers; cognitive screening diagnosis did not differ between these groups ($\chi^2 = .59$, $P = .39$). Fifty-six participants (60%) completed the follow-up survey (52 electronically, 4 via hard copy). There was no difference in survey response rate between CN (65% responded) and MCI participants (58%), $\chi^2 = .44$, $P = .51$. MCI participants had lower educational attainment than CN, $t(92) = 2.81$, $P = .006$, but the groups did not significantly differ in age, sex, or ethnicity.

TABLE 1 Demographic characteristics

	Primary care referrals (N = 94)	Rhode Island AD Prevention Registry (N = 613)	Difference	P
Age (years); M(SD)	63.3 (8.0)	67.9 (9.1)	$t = 4.6$	<.0001
Sex; count (%)			$\chi^2 = 3.6$.06
Male	15 (16%)	153 (25%)		
Female	79 (84%)	460 (75%)		
Ethnicity; count (%)			$\chi^2 = 20.0$	<.0001
Non-Hispanic White	72 (77%)	542 (92%)		
Non-Hispanic Black	17 (18%)	22 (4%)		
American Indian/Alaska Native	2 (2%)	0 (0%)		
Asian/Pacific Islander	0 (0%)	4 (1%)		
Hispanic	3 (3%)	9 (2%)		
Education (years); M(SD)	15.7 (2.5)	15.9 (2.6)	$t = 0.7$.49
MCAS cognitive status; count (%)			$\chi^2 = 1.7$.19
Cognitively normal	52 (69%)	516 (84%)		
MCI	23 (31%)	98 (16%)		
Dementia	0 (0%)	0 (0%)		
APOE genotype; count (%)			$\chi^2 = 0.8$.67
non- $\epsilon 4$ ($\epsilon 2/\epsilon 2$, $\epsilon 2/\epsilon 3$, $\epsilon 3/\epsilon 3$)	57 (66%)	262 (63%)		
one $\epsilon 4$ ($\epsilon 2/\epsilon 4$, $\epsilon 3/\epsilon 4$)	24 (28%)	132 (32%)		
$\epsilon 4/\epsilon 4$	6 (7%)	22 (5%)		

Abbreviations: APOE, apolipoprotein E; MCAS, Minnesota Cognitive Acuity Screen.

Compared to the RI Alzheimer's Disease Prevention Registry as a whole, participants recruited for this project were younger, ($M = 63.7$ years for this sample, $M = 68.3$ for the general registry, $t[706] = 4.61$, $P < .001$), more likely to be a racial/ethnic minority group member (23% of this sample vs. 8% in the general registry, $\chi^2 = 20.01$, $P < .001$), and had lower MCAS scores ($t[715] = 2.45$, $P = .01$). Although substantially more women (84%) than men participated in the study, this is broadly consistent with the Registry as a whole (76% women; $\chi^2 = 3.59$, $P = .06$). Educational attainment and likelihood of having a non-normal cognitive screening diagnosis did not differ between the samples (P 's $> .05$). There was no difference in age, sex, ethnicity, or years of education between survey respondents and nonrespondents (all P 's $> .05$).

3.1 | Patient knowledge and understanding of screening results

Regarding cognitive screening results, about one in four participants (26% of CN and 27% of MCI participants) reported that they were not informed of their cognitive screening results, despite PA documentation that those results were disclosed (Table 2). Of those who remembered being told their results, significantly more CN than MCI participants correctly identified their cognitive screening diagnosis, $\chi^2 = 11.73$, $P = .02$. CN participants reported that the testing results

indicated that they did not have AD (52%) or had lower than average AD risk (29%). Only 29% of MCI participants reported that their results indicated higher than average risk for AD. However, when rating their perceived likelihood of developing AD on a scale from 0 to 100%, MCI participants reported a higher likelihood than did CN participants, $t(36) = 4.22$, $P < .001$ (Figure 2).

Regarding genetic testing results, 30% of APOE non- $\epsilon 4$ carriers and 53% of $\epsilon 4$ carriers did not recall their test results or said they were not informed. Of those who recalled their results, all $\epsilon 4$ non-carriers and 80% of $\epsilon 4$ carriers correctly reported their APOE status, $\chi^2 = 24.3$, $P < .001$. All APOE $\epsilon 4$ carriers and 95% of $\epsilon 4$ non-carriers correctly reported that the $\epsilon 4$ allele confers greater risk for AD. However, $\epsilon 4$ carriers and non-carriers did not differ in their perceived likelihood of developing AD, $t(31) = .90$, $P = .37$.

3.2 | Patient-reported lifestyle modification

PAs reported that they recommended health behavior modification to 98% of patients, including exercising more regularly, dietary changes, or cognitive training. However, only 29% of patients reported that a PA or PCP had recommended any type of lifestyle modification. Recall of the recommendations did not differ by diagnostic group ($P = .40$) or APOE status ($P = .51$). Patients who recalled being told to modify their lifestyle were significantly more likely to report having done so (12% of

TABLE 2 Patient recall and reaction to screening results

	CN (N = 39)	MCI (N = 15)	non-ε4 (N = 33)	ε4 (N = 21)
Perceived cognitive screening results				
CN	26 (67%)	5 (33%)		
MCI	2 (5%)	5 (33%)		
I was not informed	10 (26%)	4 (27%)		
I was informed, but I do not recall	0 (0%)	1 (7%)		
I do not recall if I was informed	1 (3%)	0 (0%)		
If recalled, meaning of screening diagnosis				
Definitely do not have AD	16 (52%)	2 (29%)		
Somewhat lower risk for AD	9 (29%)	2 (29%)		
Possibly have AD; the test cannot say for sure	1 (3%)	0 (0%)		
Somewhat higher risk for AD	0 (0%)	2 (29%)		
Did not discuss/do not recall	2 (6%)	1 (14%)		
Immediate reaction after cognitive screening disclosure				
Any negative emotion (e.g., anxious, angry, hopeless)	1 (3%)	0 (0%)		
Any positive emotion (e.g., happy, relieved)	20 (51%)	7 (47%)		
Perceived APOE status				
non-ε4			23 (70%)	2 (10%)
ε4			0 (0%)	8 (38%)
I was not informed			5 (15%)	6 (29%)
I was informed, but I do not recall			1 (3%)	0 (0%)
I do not recall if I was informed			4 (12%)	5 (24%)
If recalled, meaning of APOE genotype				
APOE is not an established AD risk factor			1 (5%)	0 (0%)
e4 allele means a person is more likely to develop AD			20 (95%)	9 (100%)
e4 allele means a person will definitely develop AD			0 (0%)	0 (0%)
Immediate reaction after cognitive screening disclosure				
Any negative emotion (e.g., anxious, angry, hopeless)			0 (0%)	3 (14%)
Any positive emotion (e.g., happy, relieved)			19 (58%)	2 (10%)

Abbreviations: AD, Alzheimer's disease; APOE, apolipoprotein E; CN, cognitively normal; MCI, mild cognitive impairment.

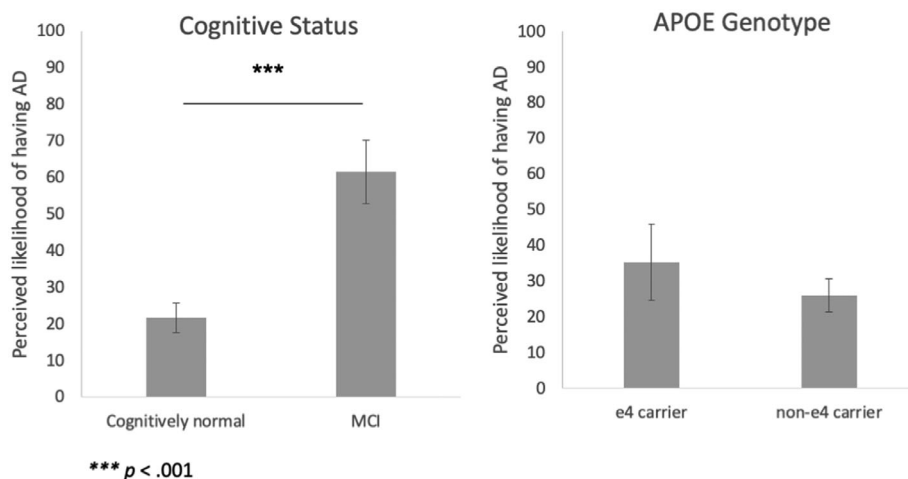


FIGURE 2 Perceived likelihood of developing Alzheimer's disease (AD) after receiving screening results. Patients told they were in the mild cognitive impairment (MCI) range on screening reported greater perceived likelihood of developing AD than cognitively normal individuals. There was no difference between groups based on apolipoprotein E genotype

TABLE 3 Likelihood of patient making a lifestyle change after provider recommendation

Patient made lifestyle change	Provider recommended lifestyle change, per patient		
	No	Yes	Total
No	33	8	41
Yes	4	7	11
Total	37	15	52

those who did not recall a lifestyle recommendation vs. 47% who did; $\chi^2 = 8.23$, $P = .004$; Table 3). The most common participant-reported health behavior changes were aerobic exercise (17% of all respondents), greater mental activity (11%), diet changes (8%), strength training (6%), and a mind-body practice (6%).

3.3 | Patient reactions to screening disclosure and adverse events

Participants were asked to recall their immediate emotional responses to disclosure of results (e.g., happiness, relief, depression, anger) as well as to report longer-lasting changes in mood or anxiety over the follow-up interval (Table 2). After learning their cognitive screening results, 51% of CN participants and 47% of MCI participants reported an immediate positive emotional response (i.e., happiness or relief). One CN participant reported a negative emotional reaction (anxiety). Of those participants who recalled being told their APOE genotype, 58% of non- $\epsilon 4$ carriers and 10% of $\epsilon 4$ carriers reported feeling happy or relieved. Fourteen percent of $\epsilon 4$ carriers (three individuals) reported an immediate negative emotional response. One $\epsilon 3/\epsilon 4$ carrier reported feeling confused by the results but no longer-lasting changes in depression or anxiety. Two $\epsilon 4/\epsilon 4$ carriers reported immediately experiencing multiple negative emotions (i.e., depression, anxiety, anger, hopelessness) and longer-lasting increases in depression and anxiety. Two other $\epsilon 4$ carriers also reported longer-lasting increases in anxiety. Chart review for patients reporting a negative emotional response showed no changes in psychiatric medications or referrals for psychiatric treatment. There were no PCP-reported adverse events.

3.4 | PCP reactions to screening program

All of the PCPs reported that the screening program was “always” or “often” a valuable addition to their practice and valuable to patients, and none reported that the program was burdensome. All of the PCPs reported that knowing their patients’ cognitive status was “always” or “often” helpful to them counseling patients about risk for AD and making management decisions. Regarding APOE status, four (67%) PCPs reported that this was helpful for counseling patients about risk for AD, while five (83%) said it was helpful for making management decisions. All providers said they were comfortable counseling patients regarding

their cognitive status, and five (83%) said they were comfortable counseling patients about their genetic status. All PCPs reported that they would be interested in continuing the program if it were available.

4 | DISCUSSION

This pilot study demonstrates the feasibility and acceptability of a cognitive screening and genetic risk assessment program as a resource for PCPs. The program was well received by both patients and their providers and yielded a more demographically diverse sample compared to a larger AD prevention registry. Patients demonstrated generally good understanding of their cognitive and genetic screening results. Further, providing healthy lifestyle recommendations was associated with patient-reported increases in healthy behaviors (i.e., exercise, mental activity, diet changes) among some patients and more frequently among those who recalled such recommendations being made.

A key objective of the study was to determine whether PCP disclosure of cognitive and genetic test results facilitated patients’ understanding of their risk of developing AD. Studies have shown a significant discordance between providers’ and patients’ recall of relevant health information, with patients often recalling less than half of what was disclosed.¹⁷⁻¹⁹ In our study, approximately one in four participants did not recall their cognitive screening results, and 71% did not recall being given health behavior recommendations. However, patients who did recall their risk screening results demonstrated generally good understanding of the implications of the results for their AD risk. Although MCI participants were less likely to correctly identify their cognitive screening diagnosis, they reported a higher perceived likelihood of developing AD than did CN participants, indicating that they correctly understood the meaning of the screening results.

The majority of participants correctly reported their APOE status and identified the $\epsilon 4$ allele as conferring greater risk for AD. Interestingly, there was no difference between $\epsilon 4$ and non- $\epsilon 4$ carriers in self-perceived risk for AD. This is consistent with prior research showing dissonance between genetic test results and perceived risk. For example, in the REVEAL trial, 48% of participants believed that their risk of AD was higher or lower than what they were told, despite accurately recalling their APOE genotype and associated AD risk estimate.²⁰ The reasons for this are not entirely clear, but possible explanations may include poor layperson understanding of genetic information, inadequate explanation by providers, psychological coping mechanisms to deal with threatening health information, or subtle cognitive deficits affecting understanding of complex personal health information. This is an important area for future investigation.

Another objective of the study was to determine the acceptability of this AD risk screening program for patients and providers. Many patients, particularly those who were non- $\epsilon 4$ carriers, reported positive emotions such as happiness or relief after risk factor disclosure. Importantly, several $\epsilon 4$ carriers (and particularly two $\epsilon 4/\epsilon 4$ carriers) reported immediate negative responses (e.g., depression, anxiety, anger, and

hopelessness) as well as increased mood and anxiety symptoms after risk factor disclosure. Although it is difficult to draw conclusions given the low overall number of $\epsilon 4$ carriers, these negative responses are greater than those reported by the REVEAL trial.¹⁰ Although PCPs did not report any adverse events or need for psychiatric or psychotherapeutic intervention for mood or anxiety, this raises important concerns about the tolerability of genetic risk factor disclosure for AD by non-specialists. Unlike the REVEAL protocol, which used a gold standard disclosure process that involved multiple visits, this program included disclosure via a single telephone call by a non-specialist. Longer follow-up intervals will be useful to determine the duration of any negative impact of APOE disclosure on mental health. Importantly, PCPs reported very positive experiences with the risk screening program and found it helpful to their clinical practice. This provides further evidence supporting the feasibility of this approach, as PCPs are key stakeholders for population-level AD risk screening efforts.

This study also describes self-reported health behavior changes after telephonic education about modifiable risk factors in the context of an individualized AD risk assessment. A recent study found that older adults believe that cognitive disorders are strongly heritable and lack knowledge about primary prevention of AD.²¹ Prevention efforts may include regular aerobic exercise, following a healthy diet such as the Mediterranean/MIND diet, and staying mentally active, all of which may reduce AD risk (see Crous-Bou et al.²² for review). However, a large body of evidence shows a discrepancy between patients' knowledge about healthy behaviors and their adherence to those behaviors.^{23–26} Failure to engage in positive health behaviors may be driven by low self-efficacy, lack of knowledge about benefits, or perceived environmental barriers (e.g., finances, time; see Hardcastle et al.²⁷ for review). Educating patients about the link between a healthy lifestyle and reduced risk of AD may be a potent motivator, particularly when health behavior recommendations are delivered by a trusted PCP. Although the main objectives of this study were to establish feasibility and acceptability of the risk screening program, we report preliminary data showing that patients who recalled receiving diet and exercise recommendations in the context of their AD risk assessment results were significantly more likely to report positive health behaviors than those who did not recall those recommendations. Given the limited number of people who recalled providers' recommendations, additional research with a larger sample is needed to stratify patients by AD risk level and investigate risk factor disclosure as a motivator of behavioral change.

Use of an Alzheimer's disease prevention registry to provide screening information to PCPs was a particularly novel aspect of this pilot program. Few data in this area are available to guide investigators overseeing registries.²⁸ Our results suggest that registries may serve an important and effective role in providing risk factor information in a valid, ethical, and cost-effective way that helps to minimize the time burden for the busy PCP. A potentially critical secondary benefit of such a partnership is that it may enhance minority outreach, an important challenge for current early AD intervention and prevention trial recruitment.²⁹ In this study, participants recruited through the PCP practice were significantly more likely to be racial/ethnic minor-

ity group members than the prevention registry as a whole. This more diverse recruitment occurred within the same geographic catchment area, as Rhode Island Hospital (headquarters of the Registry) and the primary care practice are located within several blocks of one another. One possible explanation for this is that participants from minority backgrounds may have greater trust in and access to their PCPs than a specialty research setting.

This study had several limitations. The program was delivered in a single primary care practice with a small number of physicians, and there was no control group or randomized design. This limits our ability to make causal inferences about the impact of the cognitive and genetic testing program. Additionally, a significant minority of patients (17%) were lost to follow-up after completing testing procedures and many patients (78% of those pre-selected based on chart review) were never referred to the study. Future work should examine the barriers and facilitators to delivering this type of program in a busy PCP practice. Another limitation is that although providers documented telephone calls in which they disclosed patients' cognitive and genetic risk assessment results, we did not record these calls for later review. Thus, we cannot determine whether some patients' inability to recall their results was due to patient-level factors (e.g., memory impairment, poor health literacy) versus unclear communication of results by providers. Although this method minimized administrative burden within the busy private practice setting, future studies measuring fidelity to a structured risk disclosure protocol are necessary to understand the discordance between patient and provider reports. Poor patient recall of cognitive and genetic screening results raises concern that telephonic PCP risk factor disclosure may present significant barriers to patients' understanding and retention of important health information. This study is also limited by reliance on patients' self-report of behavior modification at a single time point after risk factor disclosure, using a generic self-report inventory. Future work using objective, empirically validated assessments of diet, exercise, and other health behaviors will be important to understand whether AD risk factor disclosure results in longer-lasting lifestyle change.

In conclusion, we report that a pilot program delivering cognitive screening and genetic AD risk assessment for use by PCPs is feasible and acceptable to patients and providers. Participants demonstrated good understanding of their AD risk. Disclosure of AD risk factors, including APOE genotype, was generally well tolerated, although several $\epsilon 4/\epsilon 4$ carriers reported psychological distress related to the results. Notably, partnering with a primary care practice yielded a more racially and ethnically diverse sample than the general AD prevention registry, offering a potential strategy to diversify brain health registries and enrollment into clinical trials. Together, these findings provide a framework for assessing at-risk older adults in a primary care setting, facilitating early detection and prevention efforts.

ACKNOWLEDGMENTS

We wish to thank Anchor Medical Associates of Rhode Island for their kind support and essential participation in this project. Data from this study were presented in abstract form at the Alzheimer's Association International Conference virtual meeting (July 2020).

CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

How to cite this article: Korthauer LE, Denby C, Molina D, et al. Pilot study of an Alzheimer's disease risk assessment program in a primary care setting. *Alzheimer's Dement*. 2021;13:e12157. <https://doi.org/10.1002/dad2.12157>