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Public perspective on medications to delay Alzheimer's disease symptoms

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Abstract

Disease-modifying treatments for Alzheimer's disease are emerging. Our research examined how personal risk for AD may influence intentions to ask for medications to delay symptoms of AD, and how the availability of such medications impacts interest in AD-related genetic testing. Invitations to a web-based survey were posted on social media sites. Respondents were sequentially assigned to imagine that they had a 5%, 15%, or 35% chance of developing AD. They were then provided a hypothetical scenario describing a medication that delayed AD symptoms. After reporting intentions to ask for the medication, respondents were asked about their interest in genetic testing to predict AD risk. Data from 310 individuals were analyzed. Intentions to ask for a preventative medication were greater for respondents presented AD risks of 35% compared to risks of 15% and 5% (86% vs. 66% vs. 62%, respectively, $p < 0.001$). The proportion who would ask for genetic susceptibility testing increased from 58% to 79% when respondents were told to imagine that a medication that delayed AD symptoms existed ($p < 0.001$). Findings suggest that individuals who know they have an increased risk for AD are more likely pursue medications to delay onset of disease symptoms, and the availability of AD-delaying treatments will increase interest in associated genetic testing. Findings provide insight about who will pursue emerging preventative medications, including individuals for whom the medications may be inappropriate, and the impact on genetic test utilization.

KEYWORDS
Alzheimer's disease, attitudes, genetic susceptibility, genetic testing, risk assessment, survey

1 | INTRODUCTION

Alzheimer's disease (AD) has been historically known for its lack of effective treatments, despite decades of research. However, the FDA's approval of aducanumab as the first AD—modifying treatment in 2021, followed by approval of lecanemab in 2023, created significant hope among patients and speculation among providers (Abbott, 2022; Budd Haeberlein et al., 2022; Fernandez & Silva, 2021; Mahase, 2023). While most disease-modifying treatments are perceived positively by the public and highly sought after, which individuals would seek a preventative treatment prior to a diagnosis is less widely understood. At present, few studies provide insight about who would seek preventative treatments and how they may vary by key factors, such as perceived susceptibility to disease and potential side effects (Gooblar et al., 2015; Rosenberg et al., 2020).

The availability of options to prevent or delay the onset of AD symptoms may also affect interest in associated tests, including

genetic risk assessment. Genetic testing of the Presenilin 1 and 2 genes (*PSEN1/PSEN2*) and the Amyloid Precursor Protein gene (*APP*) can identify individuals that are nearly certain to develop early-onset AD, although the prevalence of pathogenic variants in these genes is lower than 0.5% (Lane et al., 2018). Genetic testing can also provide insight about individuals with an increased risk for developing AD. About 25% of the population has a copy of the *ε4* allele of *APOE*, for instance, which is associated with a threefold increase in odds for developing AD in the future (Huang & Mahley, 2014). Presently, a number of commentators, professional organizations, and payers have discouraged AD susceptibility testing in healthy individuals primarily because of the lack of preventative options (Arias et al., 2021; Goldman et al., 2011; Post et al., 1997). Yet, some companies such as direct-to-consumer laboratories provide accessible ways for patients to obtain this information and market it as a benefit of their service, potentially manipulating consumers into feeling that they need the information. Nonetheless, availability and interest in such tests may increase if treatment options emerge (Christensen et al., 2011; Salmon et al., 2013).

Additionally, pharmacogenomic (PGx) tests have emerged that can help physicians tailor medication choices according to patients' genomic information by identifying individuals who are more or less likely to respond to specific medications as well as by identifying individuals who are more or less likely to experience adverse drug responses (Gupta, 2015; Roden et al., 2019; Valgus et al., 2019). Recent studies have attempted to identify biomarkers for AD that predict short-term memory loss, with the hope of revealing targets for existing drugs and new drug candidates and developing methods for personalized treatment selection (Niculescu et al., 2020; Veitch et al., 2019). PGx testing currently has a limited role for informing decisions regarding AD prevention or treatment, but is likely to play a larger role in the future (Cacabelos, 2020).

Few studies have examined interest in preventative medications for AD or how the availability of such medications may influence attitudes toward AD-associated genetic tests (Sheffrin et al., 2016). We addressed these gaps in knowledge by administering a web-based survey to assess interest in a hypothetical treatment that would delay the onset of AD symptoms by 5 years. We hypothesized that respondents would report stronger intentions to ask for a preventative medication if they are told they have a greater risk of developing disease. We also examined how the availability of such a treatment might impact interest in genetic testing for disease susceptibility, treatment, and potential side effects. We hypothesized that respondents would report stronger intentions to pursue genetic testing for disease susceptibility if told preventative options exist.

2 | MATERIALS AND METHODS

2.1 | Design

This study presented hypothetical scenarios to individuals recruited through social media in late 2020, prior to the FDA's approval of aducanumab. To address the primary research question about how

> **What is known about this topic**
>
> Medications to delay the onset of Alzheimer's disease are emerging. Interest in such preventive medications may be affected by genetic risk estimates, and the availability of such medications may affect interest in genetic susceptibility testing and associated pharmacogenomic testing.
>
> **What the paper adds to the topic**
>
> In a population-based survey, we show that interest in preventive medications to delay Alzheimer's disease is likely to be greatest among individuals who know they have an increased for disease, and that the availability of such medications would increase interest in associated genetic testing.

personalized risk estimates may affect interest in a hypothetical medication, individuals were assigned to one of three arms based on order of survey entry. (1) The first, fourth, seventh, etc. survey entrants were assigned to an increased risk arm where individuals were told they have a significant increased risk (35%, which is approximately equal to the risk for individuals who are heterozygous for the *APOE ε4* variant). (2) The second, fifth, eighth, etc. survey entrants were assigned to a general population risk arm where individuals were told they have the same lifetime risk (15%) as the general population. (3) The third, sixth, ninth, etc. survey entrants were assigned to a decreased risk arm where individuals were told they have a decreased risk (5%, which is approximately equal to the risk for individuals who are homozygous for the risk-reducing *APOE ε2* variant) compared to the general population (Bird, 2021; Christensen et al., 2016; van der Lee et al., 2018).

An overview of the survey flow is presented in Figure 1, and the survey instrument is presented in Data S1. All individuals were told their risk scenario (5%, 15%, or 35% chance of developing AD) with language that compared their risk to an average person's chance of developing AD of 15%. Individuals were then asked about their intentions to ask their doctor for a medication that could delay the onset of AD symptoms. This was done twice: first after receiving their risk scenario, and once again after reading clarifying information that the medication would delay onset of AD symptoms by 5 years, that it had a 75% chance of working for them, and that there was a 45% chance that it would cause side effects. Stated side effects included headaches, dizziness, and upper respiratory infections.

Next, individuals were reminded that the average person has a 15% chance of developing AD. Individuals were then asked about their interest in pursuing genetic testing to learn their personal susceptibility to AD, genetic testing to learn the likelihood that a medication to delay the onset of AD symptoms would work for them, and genetic testing to learn the likelihood that they would experience side effects from the medication. To ensure the utility of the findings
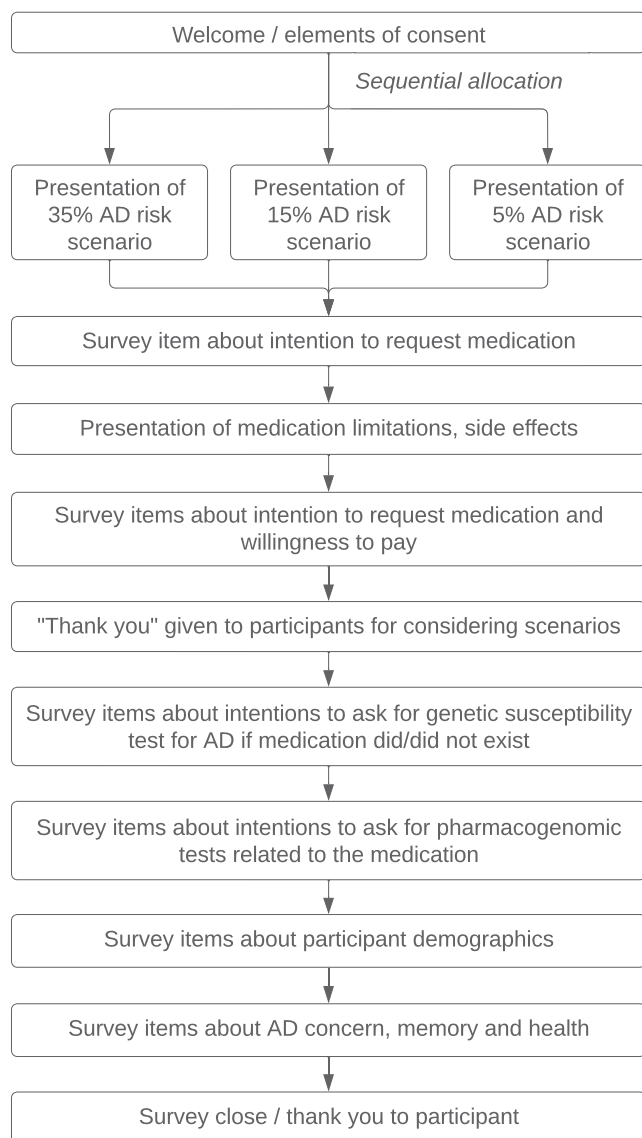
FIGURE 1 Flow of survey participation. After an introduction to the study, participants were assigned to review one of three hypothetical scenarios about their personal risk for Alzheimer's disease.

to those involved in drug development, percentages of disease susceptibility and treatment response are modeled after data from *APOE* genotyping studies and current clinical trials. The potential side effects are also modeled after past and current clinical trials but were specifically kept in the mild range so that the results would be more widely applicable to the large variety of side effects possible in medication use (Lopez Lopez et al., 2019).

Individuals were recruited from popular social media sites, including Facebook, Twitter, LinkedIn, and Reddit. Seven separate surveys that were identical in design were implemented for each social media site and for AD-specific pages within each site (e.g., Facebook pages for AD advocacy groups). Respondents were assigned sequentially to study arms as noted previously in each separate survey (e.g., the first participant to each survey was assigned to the increased

risk arm). Data were collected with REDCap web-administered questionnaires. Individuals remained anonymous and were only asked to provide demographic information (age, sex, ethnicity, race, marital status, education, income, personal history of AD and mild cognitive impairment, self-rated health using a single item from the SF-12v2 (Ware et al., 1996), subjective memory (self-rated memory compared to other people of the same age), and family history of first-degree relatives with AD) using items with prespecified response options. Respondents were also asked to provide open-ended responses to the question, "do you have any health conditions that you feel put you at a higher risk to develop Alzheimer's Disease?" The survey remained open from September 2020 to January 2021.

Intentions to ask for the medication to delay the onset of AD symptoms and having a genetic test were assessed in two ways. Individuals were first asked how likely they would be to ask their doctor for the medication or genetic tests. Response options included "definitely would not," "probably would not," "probably would," and "definitely would" ask for the medication or genetic test. Individuals who expressed any intentions to ask for the medication or genetic tests were also asked to type the maximum amount they would be willing to pay out of pocket for them.

Individual demographics, experiences, and concerns about AD were collected via self-report at the end of the survey. Concerns were assessed using a scale (Cronbach $\alpha = 0.68$) where respondents rated their agreement to four statements, such as "I am concerned that I will develop AD" and "I believe that I will someday develop AD." Higher scores on the 0–16 scale signified greater AD concern (Christensen et al., 2015).

2.2 | Data analysis

Respondents were included in analyses if they answered at least one item in the survey. Responses to the open-ended question about respondents with health conditions that increased their AD risk were classified as "yes," "no," or "unsure" by M.B.R. Many responses were classified as "yes" even if the evidence supporting a condition's association with AD risk was limited. The rationale for this coding approach was because we were most interested in whether respondents perceived an increased risk for AD regardless of whether they had a true increased risk for AD.

We compared individual characteristics by arm using *t*-tests, Wilcoxon rank sum, and Chi-squared tests for continuous, ordinal, and categorical data, respectively. To test the first hypothesis that intentions to ask for preventative medications would vary by susceptibility to AD, we used Kruskal–Wallis tests on our measure of intention to ask about preventative treatments. If differences across the three arms were observed, we then used Wilcoxon rank sum tests to compare any two study arms. We used Wilcoxon signed rank tests to test the second hypothesis that intentions to ask for genetic susceptibility tests would be greater if preventative medications existed. In secondary analyses, we used Wilcoxon signed rank tests to compare interest in genetic susceptibility testing against interest in

PGx tests, as well as to compare interest in PGx testing about medication efficacy against interest in PGx testing about adverse drug responses. We also used Kruskal–Wallis tests to examine whether intentions to ask for genetic tests varied by study arm and followed up with Wilcoxon rank sum tests to compare any two arms if differences were observed. The same nonparametric tests were used in analyses of willingness to pay for preventative medications and genetic tests, given highly skewed data. In instances where respondents had reported they would "definitely not" ask their doctor for the medication or tests, willingness to pay was imputed as $0.

We also conducted exploratory analyses to examine whether associations between study arms and intentions to ask for preventative medications varied by individual characteristics and source of recruitment, including comparisons of individuals who were recruited from social media sites for AD support groups and individuals who were not. These analyses used logistic regression models where responses were dichotomized to "definitely/probably would ask" and "definitely/probably would not ask," and statistical models included individual characteristics as independent factors and as factors in interaction with assigned arm.

Statistical significance was set at $\alpha = 0.05$. Available-case analyses were conducted using R version 4.1.2. Data from four individuals who clearly provided nonsensical responses (e.g., ages of 109,990 years) were omitted. The study was deemed exempt from human subject's research by the Mass General Brigham Institutional Review Board.

3 | RESULTS

3.1 | Individual characteristics

Three hundred and ten individuals responded to invitations posted on social media, including 266 individuals (85.5%) from Facebook, 26 from LinkedIn (8.4%), 11 (3.5%) from Reddit, and 7 (2.3%) from Twitter. Only 13 individuals (4.2%) responded to links posted on social media sites for AD support groups, including 11 (3.5%) from a support group hosted on Facebook and 2 (0.6%) from a support group hosted on Reddit. Two hundred and thirty-three individuals completed the full survey (75.2% of respondents who initiated the survey). See Table 1. The majority of individuals who provided personal characteristics were female (82.1%), white (93.7%), and of non-Hispanic ethnicity (95.7%). Individuals were more likely to rate their memory as better than average versus worse (27.0% vs. 18.0%, respectively, $p = 0.040$) and 19.1% reported having a health condition that increases their risk of AD. Responses included health conditions such as diabetes, high blood pressure, and anxiety. No differences were observed by arm on any respondent characteristics (all $p > 0.05$). Compared to respondents who were not recruited from AD support groups, respondents who were recruited through AD support groups were more likely to report having an AD-affected first-degree relative (83.2% vs. 100.0%, respectively, $p < 0.001$). They were also less likely to respond "no" about whether they were

TABLE 1 Participant characteristics.

Characteristic	N (%), unless noted	p-Value
Mean age ($n = 230$)	45 (sd = 16)	0.607
Female ($n = 234$)	192 (82.1%)	0.051
White ($n = 234$)	224 (95.7%)	0.848
Hispanic ($n = 234$)	10 (4.3%)	0.678
Living with a Partner ($n = 223$)	131 (58.7%)	0.821
Married ($n = 232$)	129 (55.6%)	0.555
College degree or higher ($n = 218$)	160 (69.0%)	0.417
Household income > $90,000 ($n = 218$)	129 (59.2%)	0.393
Has an AD-affected first-degree relative ($n = 232$)	44 (19.0%)	0.709
Diagnosed with mild cognitive impairment ($n = 233$)	3 (1.3%)	>0.999
Diagnosed with Alzheimer's Disease ($n = 234$)	2 (0.9%)	0.756
Self-reported health ($n = 234$)		0.436
Poor–Fair	29 (12.4%)	
Good	115 (49.4%)	
Very good–Excellent	89 (38.2%)	
Reported a health condition that increases Alzheimer's disease risk ($n = 183$)[a]		
Yes	35 (19.1%)	
Unsure	13 (7.1%)	
Subjective memory ($n = 233$)		0.178
Much worse–Little worse	42 (18.0%)	
Same	128 (54.9%)	
Little better–Much better	63 (27.0%)	
Mean AD concern score ($n = 232$)	7.7 (sd = 3.2)	0.968

Note: Data were unavailable for 76 of 310 individuals who did not provide data to any items in the demographics section at the end of the survey.

[a]Only data from respondents who provided a response to this open-ended question were analyzed.

Hispanic or Latino/a (94.7% vs. 66.7%, respectively, $p = 0.044$) and more likely to report "do not know" about their ethnicity (0.9% vs. 33.3%, respectively, $p = 0.003$).

3.2 | Intentions to ask for AD prevention medication

As hypothesized, respondents' intentions to ask their doctor for a preventative medication differed between the three study arms according to the AD risk they were presented, regardless of whether respondents were informed about limitations in the medication's efficacy and side effects ($p < 0.001$ in both analyses). See Figure 2. Secondary analyses confirmed that respondents who were presented a 35% risk for AD were more likely to report intentions to ask for the preventative medication than

respondents who were presented a 5% or 15% risk for AD (all $p < 0.001$). However, presenting AD risks of 15% versus 5% did not affect intentions to ask for the preventative medication (all $p > 0.79$). Respondents were also less likely to report intentions to ask for the medication when they were informed that it would not work for some patients and may have side effects ($p < 0.001$). On average, respondents were willing to pay an average of $27 per month for the preventative medication, with no differences observed between study arms ($p = 0.77$).

Associations between intentions to ask for the AD preventative medication and respondent characteristics were not observed, with two exceptions. After controlling for the risk estimates that were communicated and only in the scenario that described efficacy limitations and adverse drug responses, individuals who reported a family history of AD were more likely to report intentions to ask for the medication than individuals who did not report a family history (OR = 2.48, 95% CI [1.22 to 5.18], $p = 0.013$). In addition, individuals with higher AD concern scores were more likely than those with lower AD concern scores to report intentions to ask for the medication both when they were informed about the limitations of the medication (OR = 1.20 per 1-point increase on the scale, 95% CI [1.09 to 1.32], $p < 0.001$) and when they were not informed about the limitations (OR = 1.27 per 1-point increase on the scale, 95% CI [1.15 to 1.42], $p < 0.001$). No interactions were observed between the risk information that individuals received and respondent characteristics on intentions to ask for the preventative medication (all $p > 0.05$).

3.3 | Interest in genetic testing

When told that no proven prevention options existed, 58% of individuals reported that they would ask their doctor for a test that estimated their susceptibility for AD. This proportion increased to 79% when individuals were told to imagine that a medication that delayed symptom onset existed ($p < 0.001$).

Of the three types of genetic tests presented, respondents' intentions were highest for AD susceptibility information, followed by PGx testing about medication effectiveness and then adverse drug responses (all $p < 0.002$). See Figure 3. The maximum amount individuals would be willing to pay out of pocket for genetic tests averaged $337 for AD susceptibility information, $318 for PGx information about medication efficacy, and $312 for PGx information about adverse drug responses. Differences in willingness to pay for genetic tests were not statistically significant (all $p > 0.07$).

Notably, intentions to ask for genetic tests appeared to vary according to the initial AD risk information individuals were presented. Respondents who were initially presented a 15% risk for AD reported weaker intentions to ask for PGx information about medication effectiveness than respondents initially presented a 5% or 35% risk for AD (60% would ask for the test vs. 74% and 75%, respectively, both p-values < 0.006). In addition, respondents who were initially presented a 15% risk for AD reported weaker intentions to ask for PGx information about adverse drug responses than respondents who were initially presented a 35% risk for AD (62% would ask for the test vs. 69%, $p < 0.001$).

FIGURE 2 Intention of respondents to pursue preventative medication, stratified by assigned Alzheimer's disease risk. Percentages summarize the proportion of respondents in each arm who said they would probably or definitely ask their doctor for the medication to delay Alzheimer's disease.
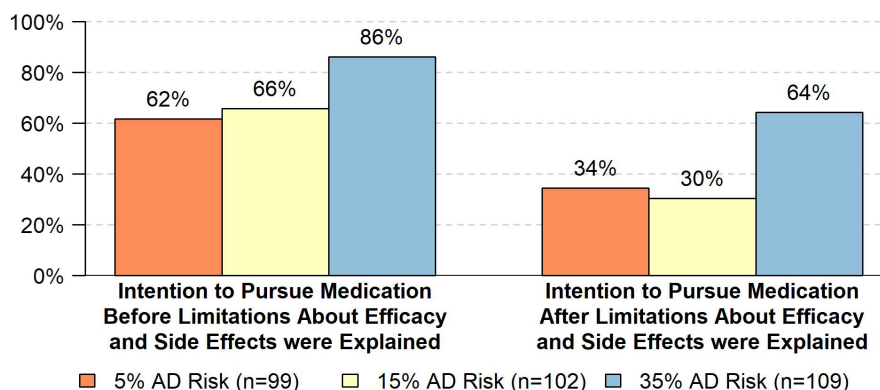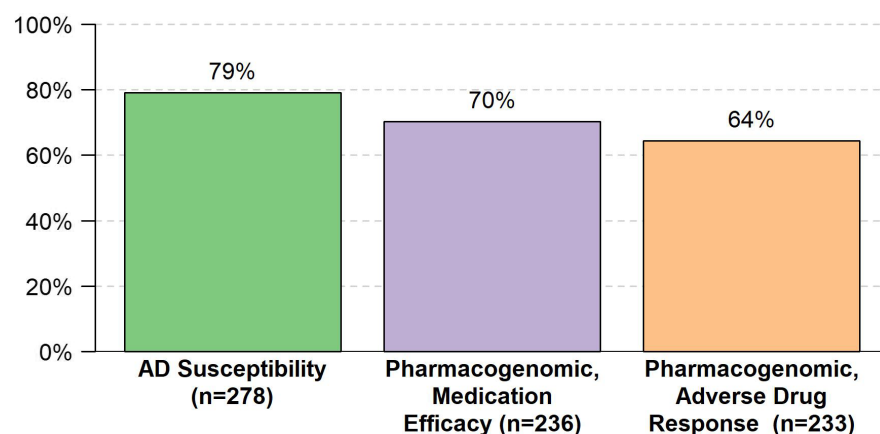
Legend: ■ 5% AD Risk (n=99) □ 15% AD Risk (n=102) ■ 35% AD Risk (n=109)

FIGURE 3 Intention of all respondents to pursue varying types of genetic testing. Percentages represent the proportion of respondents who responded that they would probably or definitely ask their doctor for the tests.

4 | DISCUSSION

This is one of the first studies to examine the public's intentions about pursuing preventative AD medications. Findings showed a strong interest in AD preventative medications. Moreover, findings confirmed the hypothesis that individuals presented with higher AD risk estimates would be more likely to pursue medications to delay AD than individuals presented with moderate or low AD risk estimates. In addition, findings showed intentions were lower when individuals were informed of the limited efficacy and potential side effects of the medication. Our results are particularly timely, given the FDA's approvals of aducanumab and lecanemab, and the possibility of additional disease-modifying options or even prevention options in the future. Findings highlight the demand these and other emerging medications may generate as they come to market, as well as the influence that personalized risk estimates, such as with *APOE* genotype, may have. Results also demonstrate how important communication of medication limitations and risks will be on demand.

Interestingly, no differences were observed in intentions to ask for the preventative medication between individuals presented an average risk for AD and those presented with a below average risk. Limitations in the ability of people to make sense of quantitative risk information is well-known (Fischhoff et al., 2011; Lautenbach et al., 2013), and individuals often simplify risk information for themselves into categories such as high risk and low risk (Lautenbach et al., 2013). It is possible that the difference between a 5% and 15% risk for AD was not large enough to make a qualitative difference to our survey respondents, while the difference between a 15% and 35% risk for AD was. Findings raise questions how AD risk assessments may be communicated in the future and how communication strategies will impact people's interest in pursuing preventative medications.

This is also one of the first studies to provide insight about how interest in AD genetic tests may increase as preventative medications emerge. Our findings confirmed our hypothesis and showed that individuals were about 21% more likely to express intentions to pursue AD susceptibility testing if preventative options existed. Even without preventative options, many individuals have already pursued *APOE* genotyping through direct-to-consumer testing and research opportunities (Doostparast Torshizi & Wang, 2018; Zallen, 2018). Our data suggest we should expect an increase in requests for such tests as AD prevention medications continue to emerge.

Our findings highlight the need for healthcare providers to be prepared to discuss how approved and emerging AD-delaying medications are only indicated for individuals with diagnosed memory problems and not for those that are asymptomatic. Moreover, the FDA's expedited review of aducanumab and lecanemab has raised concerns that even for symptomatic patients, benefits may be overstated while risks for adverse drug responses may be high (Mahase, 2023). Healthcare providers, including genetic counselors, may need to be prepared to address the appropriateness and limitations of AD preventive medications to help patients make informed choices about pursuing AD-related genetic tests.

While exploratory analyses did show an interest in PGx testing, it was a weaker interest than AD susceptibility testing. Moreover, interest in PGx testing was greater for predicting medication efficacy than medication side effects. These findings raise some concerns about differing expectations that may exist between patients and health care providers, where interest in pharmacogenomic information about adverse drug responses may be highest (Haga et al., 2012; Pereira et al., 2019). Admittedly, fears surrounding AD may be stronger than fears for other more medically actionable conditions (Tang et al., 2017), and findings from other research contexts may not be applicable for AD. In addition, differences we observed in interest between all three types of genetic testing could have been influenced by survey ordering effects (Schwarz, 1994), as interest was shown to decrease as additional tests were presented.

An unanticipated finding from our study was the impact of study arm assignment on intentions to ask for PGx tests. Even after we thanked individuals for imagining that they received a customed AD risk estimate and reminded them about population risk for AD, respondents' preferences for PGx tests varied according to assigned arm. Moreover, the differences we observed were that respondents who were initially told to imagine that they were at population risk reported weaker intentions to ask for PGx tests than respondents initially told to imagine that they had higher and lower risks than the general population. It is possible that the initial presentation of 15% as population risk may have primed these individuals to think that genetic testing is not very informative. If so, findings suggest that uninformative findings from genetic testing for disease risks may decrease the perceived utility of other types of genetic testing.

Responses also provided insight into the public's value of preventative medications and genetic services. Willingness to pay amounts for the preventative medication were about $30 per month, similar to a medication co-pay. However, it remains unlikely that a much sought after newly approved preventative medication would cost only $30/month (Dusetzina et al., 2019). For example, newly approved disease-modifying treatments, aducanumab and lecanemab, were priced at over $4000 and $26,000 per month, respectively (Mahase, 2023; Tampi et al., 2021). The Centers for Medicare & Medicaid Services recently announced that Medicare would cover these types of AD prevention medications for the purposes of evidence generation in symptomatic patients with confirmed presence of plaque on the brain (Centers for Medicare and Medicaid Services, 2022), and large payers are likely to omit the medication in their formularies. This large out-of-pocket price most patients would incur would likely greatly decrease the number of individuals who would be interested in a preventative medication compared to what our research showed. The average willingness to pay amounts for the genetic tests were between $300 and $350, which corresponds to the amount many companies charge for PGx panels (Invitae, 2021; OneOme, 2021). It is possible that the amounts that were reported

in our web-administered study were based on information that respondents learned while they were completing the survey.

No associations were observed between interest in preventative medications or genetic testing and individual risk factors, such as current health conditions. Nineteen percent of respondents reported that they had a health condition that increased their risk of AD. However, in review of the conditions they felt increased their risk, many of these indicated conditions or factors are not currently known to pose a significant risk for AD. For example, mental health concerns were reported by multiple individuals as an AD risk factor while there is weak evidence to link these two conditions (Baumgart et al., 2015), suggesting an overall lack of knowledge surrounding AD risk factors.

These findings should be interpreted in the context of several limitations. As stated earlier, the descriptions of our testing scenarios did not address how the emerging array of AD-delaying medications is appropriate only for patients with diagnosed memory problems or in the early stages of dementia. The external validity of results is unclear: our respondents were self-selected and were likely to have an interest in AD, as well as being a largely white population. Individuals were recruited from social media sites, where users tend to be younger with a higher level of education compared to the general public (Pew Center Research, 2021). Results may not generalize to more diverse populations or to interest in preventive medications for other conditions. Preplanned exploratory analyses to compare response rate from AD support group members were omitted due to low response rates, potentially because members utilize these sites for communal support rather than education and research. It is probable that members of these groups have greater interest in AD prevention medications and associated genetic testing. Once beginning the survey, individuals were sequentially assigned to study arms rather than randomized. The content of the hypothetical scenarios was also limited in scope and may not have included all the factors that individuals would need to make informed decisions about requesting the preventative medication or genetic tests. For instance, scenarios did not address whether medications would be appropriate for preclinical patients or only patients with evidence for an increased risk of AD (e.g., β-amyloid or tau accumulation) who would likely have the greatest interest in AD-delaying medications. It is possible that such evidence would be required before health care providers would prescribe AD-delaying medications, and that patients may encounter important barriers that were unaddressed by the current study (e.g., limited coverage for the medication by payers) for individuals who we would expect to have greater interest in the medication. Scenarios also omitted information about side effects specific to aducanumab, such as brain micro-bleeds, cerebral edema, and reduced brain volume, which were unknown to our study team at the time the survey was developed. In addition, hypothetical responses are often different from actual actions (Genetti et al., 2019), although intentions are among the strongest predictors of behaviors (Fishbein & Ajzen, 1975). More

research is needed to validate our study's findings in populations that are more likely to be appropriate recipients of these medications and tests.

5 | PRACTICE IMPLICATIONS

Medications that prevent or delay AD are emerging. Given the increasing availability of genetic risk assessments for AD, genetic counselors need to be prepared to field questions about and address the appropriateness and limitations of these medications, particularly with patients with the greatest risk estimates. In addition, the emergence of such medications is likely to increase interest and demand for AD-related genetic tests, including genetic risk assessments and related pharmacogenomic tests.

6 | CONCLUSION

Our study provides novel insight about who may seek preventative medications and how such medications may affect interest in genetic services. Findings are particularly important, given the FDA controversial approval of aducanumab. The possible emergence of additional preventative medications for AD may be slow, given the heterogenous nature of AD and the need for medications to intervene on other disease mechanisms. Still, we can expect demand for aducanumab and other medications, if they emerge, to be strong, particularly among individuals who are told that they have an increased risk for disease.

DATA AVAILABILITY STATEMENT

Data and materials are available upon request.

ETHICS DECLARATION

The Massachusetts General Hospital IRB reviewed this study and granted it exempt status, as individuals were only asked to provide deidentified information. Therefore, informed consent was not required.

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