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Original Research

US Adults' Likelihood to Participate in Dementia Prevention Drug Trials: Results from the National Poll on Healthy Aging

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Abstract

BACKGROUND: Recruitment to dementia prevention clinical trials is challenging, and participants are not representative of US adults at risk. A better understanding of the general public's interest in dementia prevention research participation is needed to inform future recruitment strategies.

OBJECTIVE: To examine US adults' characteristics associated with self-reported likelihood to participate in dementia prevention clinical trials.

DESIGN: We conducted a cross-sectional survey using the October 2018 wave of the University of Michigan National Poll on Healthy Aging.

SETTING: The National Poll on Healthy Aging is a nationally representative survey of adults using KnowledgePanel (Ipsos Public Affairs LLC), a probability-based panel of the civilian, noninstitutionalized US population.

PARTICIPANTS: We analyzed data from 1,028 respondents, ages 50 to 64 years, who completed a web survey module on brain health.

MEASUREMENTS: We used logistic regression models to examine associations between sociodemographic and dementia-related factors (e.g., family history) and self-reported likelihood to participate in a dementia prevention clinical trial of a new medicine ("very" or "somewhat likely" vs. "not likely" survey responses). Among respondents not likely to participate, we examined frequency of reasons endorsed for this decision, stratified by age, sex, and race and ethnicity.

RESULTS: Of the 1,028 respondents, half were female, 68% Non-Hispanic White, 13% Hispanic, and 12% Non-Hispanic Black. Twelve percent of respondents reported being very likely to participate in a dementia prevention trial, 32% somewhat likely, and 56% not likely. Factors associated with higher likelihood to participate were higher perceived risk of dementia [OR, 2.17 (95% CI, 1.61, 2.93)], a positive family history of dementia [OR, 1.75 (95% CI, 1.27, 2.43)], and having discussed dementia prevention with a doctor [OR, 2.20 (95% CI, 1.10, 4.42)]. There were no differences in likelihood to participate by sociodemographic characteristics. Among 570 respondents not likely to participate, 39% said they did not want to be a guinea pig, 23% thought dementia would not affect them, 22% thought there would be too high a chance for harm, 15% indicated study participation would take too much time, and 5% reported fear of learning information about oneself. There were no differences across age, sex, and racial and ethnic groups.

CONCLUSIONS: In this study, perceived risk of dementia, family history, and discussion of prevention with a doctor were associated with likelihood to participate in a dementia prevention clinical trial, whereas sociodemographic factors including race and ethnicity were not. Findings suggest that recruitment interventions focused on increasing knowledge of dementia risk and prevention trials and involving healthcare providers may be effective tools to improve enrollment rates, regardless of target community.

Key words: Prevention, clinical trials, recruitment.

Introduction

The current US National Plan to Address Alzheimer's Disease sets an ambitious goal to prevent and effectively treat Alzheimer's disease and related dementias (AD/ADRD) by 2025 (1). To achieve this goal, clinical trials are recruiting tens of thousands of older adults to test promising preventative and disease-delaying interventions (2-4). Inadequate and slow recruitment of volunteer participants to dementia prevention clinical trials, however, is delaying progress and requires urgent intervention (4-9). Critically, under-representation of racial and ethnic groups in prevention trials limits the generalizability of results to sub-populations at greatest risk for AD (6, 10-13). Black and Hispanic adults are at 2 and 1.5 times greater risk to develop AD compared to their Non-Hispanic White counterparts, respectively, but make up just 10% of AD research participants (10, 11) compared to 32% of the general population (14). Additionally, a recent meta-analysis found that the proportion of women in AD clinical trials was significantly lower than that of women with AD in the general population (15).

Recruitment of cognitively healthy older adults to AD prevention clinical trials is challenging. By design, these trials are burdensome on participants and their family members, often requiring large screening efforts to meet stringent eligibility criteria, testing of new drugs with potential side effects, and performing procedures to assess biomarker and genetic risk information. A recent systematic analysis found that eligibility criteria, specifically, may lead to disproportionate exclusion of racially and ethnically diverse individuals in AD clinical trials (13). Additionally, previous research on barriers to

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recruitment to dementia prevention clinical trials suggests that logistical constraints (e.g., time commitment, lack of transportation), concerns related to medications and procedures, and general lack of interest in participation are important challenges for enrollment and may vary by sociodemographic factors (16-21). Conversely, positive attitudes toward research in general (22) and higher perceived risk for AD (16, 23) may facilitate enrollment in prevention trials.

Older adults who do participate in dementia prevention clinical trials are typically Non-Hispanic White, have higher income and education level, are retired or not working, and are married or partnered (20, 23). To inform future recruitment interventions to diversify enrollment in dementia prevention clinical trials, the field needs a better understanding of the general public's interest in dementia prevention research participation, reasons for disinterest, and how interest may vary across sociodemographic factors. This cross-sectional secondary data analysis explored characteristics of US adults, ages 50 to 64 years, that are associated with likelihood to participate in a dementia prevention clinical trial of a new medication. The study further examined reasons for not wanting to participate, stratified by age, sex, and race and ethnicity.

Methods

Data source

The University of Michigan National Poll on Healthy Aging (NPHA), sponsored by the American Association of Retired Persons (AARP) and Michigan Medicine, is a regularly recurring, nationally representative web-based survey of adults ages 50 to 80 years. The NPHA is administered by KnowledgePanel (Ipsos Public Affairs, LLC), a probability-based online panel of the civilian, noninstitutionalized US population. Panel members are randomly recruited using address-based sampling methods. Specific survey samples for the NPHA are selected using stratified random sampling based on study design and panel member geodemographic data. Once survey data are collected and processed, design weights are adjusted to account for any differential nonresponse that may have occurred.

The NPHA survey that was fielded in October 2018 sampled 3,202 panel members ages 50 to 80 years (main survey completion rate=64%). This secondary analysis examined data from a subset of respondents ages 50 to 64 years who completed a supplementary module on brain health (n=1,028; completion rate=62%). The supplementary module consisted of 10 additional survey questions related to dementia that can be retrieved at www.healthyagingpoll.org. The University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board deemed this study exempt from human subjects review as it involved the analysis of only deidentified data.

Respondent characteristics

Independent variables included respondent characteristics that were categorized as either sociodemographic factors or dementia-related factors (Table 1). Sociodemographic variables included age (collapsed into categories 50 to 54 years, 55 to 59 years, 60 to 64 years); sex (male vs. female); race and ethnicity (collapsed into Non-Hispanic White; Non-Hispanic Black; Hispanic; Other Non-Hispanic race or more than one race); educational attainment (collapsed into high school or less; some college; bachelor's degree or higher); annual household income (collapsed into less than $30,000; $30,000 to $59,999; $60,000 or greater), employment status (collapsed into working vs. retired/not working), and marital status (collapsed into married/partnered vs. not married/partnered). Dementia-related variables from the supplementary brain health module included the following: 1) a subjective memory rating (How would you rate your memory compared to when you were younger?) collapsed into "as good as when I was younger" vs. "slightly/much worse than when I was younger"; 2) perceived risk for dementia (How likely are you to develop dementia during your lifetime?) collapsed into "very/somewhat likely" vs. "not likely"; 3) family history of dementia (Do/did any of your family members have dementia?) collapsed into "yes" vs. "no/don't know"; 4) caregiver experience (Have you ever been a caregiver for a person with dementia?) "yes" vs. "no"; and 5) interaction with a doctor (Have you ever discussed ways to prevent dementia with your doctor?) "yes" vs. "no".

Likelihood to participate in a dementia prevention trial

The dependent variable was self-reported likelihood to participate in a dementia prevention clinical trial. Respondents read the following primer: T*hink about the types of research described below. For each type of research, all costs of health care directly related to the research would be covered. You would pay nothing for the research or for related medical care*. Respondents were then asked to rate how likely they would be to take part in the following types of health research related to dementia, indicating "very likely, "somewhat likely" or "not likely" for each item separately: testing a new medicine to prevent dementia; testing a new treatment for dementia; and giving a DNA sample to let researchers study genetic patterns of dementia. The primary outcome of interest for this analysis was responses to testing a new medicine to prevent dementia. If respondents indicated "not likely" to participate, they were asked to complete a follow-up question: Why are you not likely to take part in testing a new medicine to prevent dementia? Respondents could select all reasons that applied, including "fear of finding out information about myself"; "I don't think

Table 1. Characteristics of Survey Respondents (n=1,028*)

Sociodemographic Characteristics	Sample Size No.	Weighted %
Age category, years		
50 to 54	305	33.3
55 to 59	393	34.6
60 to 64	330	32.1
Sex		
Male	506	48.2
Female	522	51.8
Race and ethnicity		
Non-Hispanic White	762	68.4
Non-Hispanic Black	93	11.7
Hispanic	101	12.9
Other†	72	7.0
Educational status		
High school or less	342	40.4
Some college	340	27.0
Bachelor's degree or higher	346	32.6
Household income		
Less than $30,000	151	17.9
$30,000 to $59,999	194	19.7
$60,000 or greater	683	62.4
Employment status		
Working	732	69.1
Retired or not working	296	30.9
Marital status		
Married or partnered	740	69.8
Not married or partnered	288	30.2
Dementia-Related Characteristics		
Subjective memory rating		
Slightly or much worse than when I was younger	681	65.9
As good as when I was younger	344	34.1
Perceived likelihood to develop dementia		
Very or somewhat likely	497	48.5
Not likely	522	51.5
Family history of dementia		
Yes	364	33.9
No or don't know	662	66.1
Dementia caregiving experience		
Yes	191	18.0
No	837	82.0
Discussed dementia prevention with doctor		
Yes	55	5.2
No	969	94.8

* Missing data on individual survey items ranged from n=0 to n=9; † Respondents self-reported "Other, Non-Hispanic" or "2+ Races, Non-Hispanic"

dementia will affect me"; "I don't want to be a 'guinea pig' for researchers"; "participation would take too much time"; "there is too high a chance for harm"; and "other." Response options were chosen by the NPHA research team based on previous surveys of attitudes toward genetic testing and research participation.

Statistical analyses

All analyses applied post-stratification survey weights to reflect the population of US adults ages 50 to 64 years. Chi-square tests were used to examine potential differences based on likelihood to participate in a dementia prevention clinical trial. Unadjusted and multivariable logistic regression models were used to examine associations between respondent characteristics and being "very/somewhat likely" vs. "not likely" to participate in a dementia prevention clinical trial (Table 2). Among respondents "not likely" to participate in a dementia prevention clinical trial, we performed a sub-analysis to examine frequency of reasons endorsed, stratified by age, sex, and race and ethnicity (Figure 1). Analyses were performed using Stata version 17.0 (StataCorps LLC). A two-tailed P-value < 0.05 was considered statistically significant and all analyses were based on complete case analysis.

Results

Respondent characteristics

Among the 1,028 respondents ages 50 to 64 years, half were female, 68% were Non-Hispanic White, 13% were Hispanic, and 12% were Non-Hispanic Black based on estimates of population characteristics (Table 1). Most respondents were married (70%) and employed (69%) with an annual income of $60,000 or more (62%). Nearly half of respondents reported they were at least somewhat likely to develop dementia (49%) and 66% felt their memory was slightly or much worse than when they were younger. A third of respondents reported a family history of dementia, and 18% had previous or current experience caring for someone with dementia. Very few respondents (5%) reported having ever discussed dementia prevention with a doctor.

Likelihood to participate in a dementia prevention trial

Twelve percent of respondents reported being very likely to participate in a dementia prevention trial of a new medication, 32% somewhat likely, and 56% not likely. Sociodemographic characteristics, including age, sex, race and ethnicity, educational status, household income, employment status, and marital status, were not associated with likelihood to participate in a prevention trial (Table 2). Among dementia-related characteristics, factors associated with higher likelihood to participate in a dementia prevention clinical trial were 1) perceived likelihood of developing dementia [adjusted OR, 2.17 (95% CI, 1.61, 2.93)], 2) family history of dementia [adjusted OR, 1.75 (95% CI, 1.27, 2.43)], and 3) having discussed dementia prevention with a doctor [adjusted OR, 2.20 (95% CI, 1.10, 4.42)].

Figure 1. Reasons "Not Likely" to Participate in a Dementia Prevention Trial by (A) Age, (B) Sex, and (C) Race and Ethnicity (n=570)

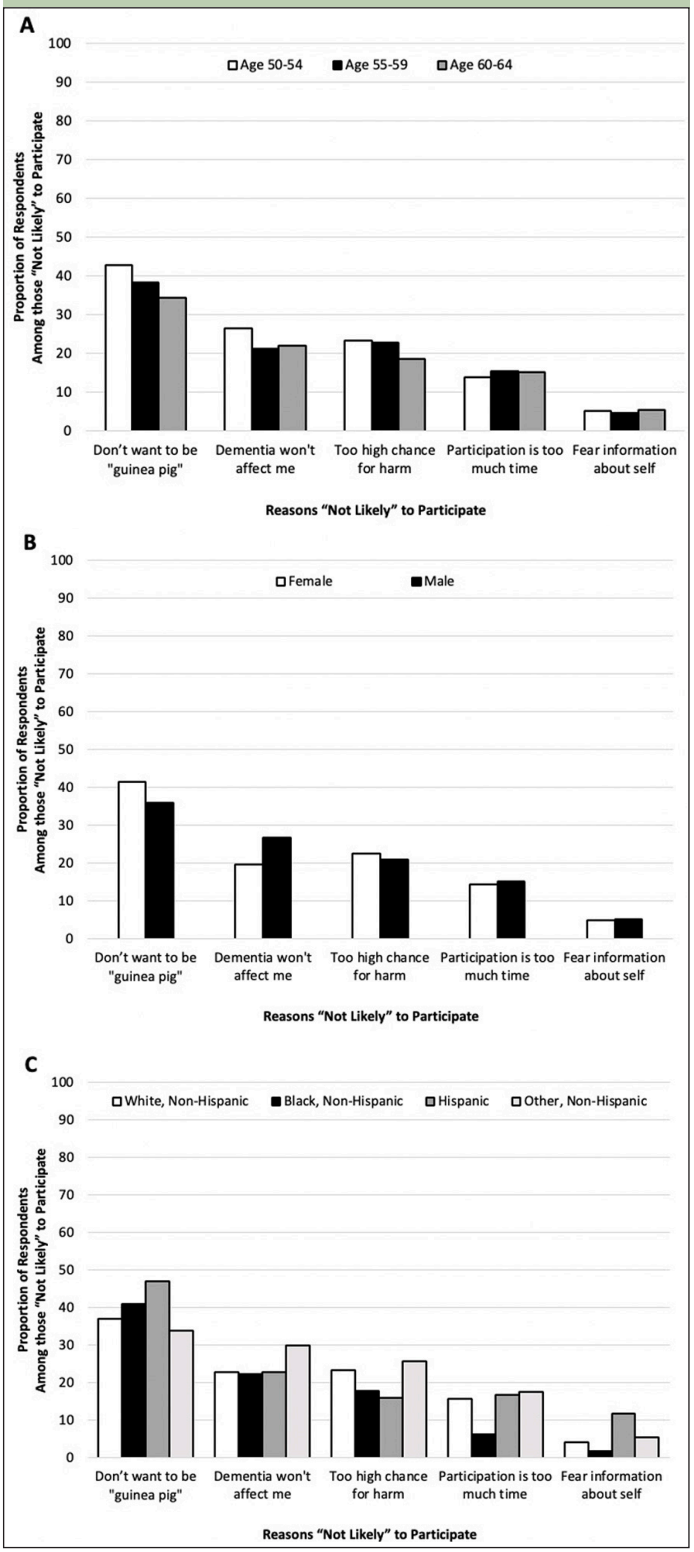

Table 2. Associations with Being "Very/Somewhat Likely" to Participate in a Dementia Prevention Trial

Sociodemographic Characteristics	Odds Ratios (95% CI†)	
	Unadjusted	Adjusted‡
Age category, years		
50 to 54	1.00 (reference)	1.00 (reference)
55 to 59	1.05 (0.77, 1.44)	0.92 (0.65, 1.28)
60 to 64	1.19 (0.86, 1.66)	0.96 (0.67, 1.39)
Sex		
Male	1.00 (reference)	1.00 (reference)
Female	1.25 (0.96, 1.62)	1.09 (0.82, 1.44)
Race and ethnicity		
Non-Hispanic White	1.00 (reference)	1.00 (reference)
Non-Hispanic Black	0.63 (0.40, 1.01)	0.71 (0.43, 1.17)
Hispanic	0.75 (0.48, 1.16)	0.77 (0.48, 1.24)
Other	0.89 (0.50, 1.58)	1.06 (0.59, 1.92)
Educational status		
High school or less	1.00 (reference)	1.00 (reference)
Some college	1.09 (0.79, 1.48)	1.06 (0.75, 1.50)
Bachelor's degree or higher	0.89 (0.65, 1.22)	0.89 (0.62, 1.29)
Household income		
Less than $30,000	1.00 (reference)	1.00 (reference)
$30,000 to $59,999	0.88 (0.56, 1.37)	0.85 (0.52, 1.41)
$60,000 or greater	0.76 (0.52, 1.10)	0.73 (0.45, 1.17)
Employment status		
Working	0.87 (0.65, 1.16)	1.02 (0.74, 1.42)
Retired or not working	1.00 (reference)	1.00 (reference)
Marital status		
Married or partnered	1.07 (0.80, 1.42)	1.18 (0.83, 1.67)
Not married or partnered	1.00 (reference)	1.00 (reference)
Dementia-Related Characteristics		
Subjective memory rating		
Slightly or much worse than when I was younger	1.68 (1.27, 2.22)**	1.32 (0.97, 1.78)
As good as when I was younger	1.00 (reference)	1.00 (reference)
Perceived likelihood to develop dementia		
Very or somewhat likely	3.03 (2.31, 3.96)**	2.17 (1.61, 2.93)**
Not likely	1.00 (reference)	1.00 (reference)
Family history of dementia		
Yes	2.65 (2.01, 3.48)**	1.75 (1.27, 2.43)*
No or don't know	1.00 (reference)	1.00 (reference)
Dementia caregiving experience		
Yes	2.49 (1.77, 3.50)**	1.37 (0.92, 2.06)
No	1.00 (reference)	1.00 (reference)
Discussed dementia prevention with doctor		
Yes	3.22 (1.68, 6.18)**	2.20 (1.10, 4.42)*
No	1.00 (reference)	1.00 (reference)

* p-value < 0.05; ** p-value < 0.001; † Abbreviation: Confidence Interval; ‡ Adjusted for all factors in table

Reasons to not participate in a dementia prevention trial

Fifty-six percent (n=570) of respondents in this sample reported they would not be likely to participate in a dementia prevention clinical trial of a new medication. The most frequently endorsed reason to not participate was not wanting to be a "guinea pig" for research (39%). Twenty-three percent of respondents thought dementia would not affect them, 22% thought there would be too high a chance for harm, 15% indicated it would take too much time, and 5% reported fear of learning information

about oneself. There were no statistically significant differences in reasons for not wanting to participate across age, sex, and racial and ethnic groups (Figure 1).

Discussion

This study explored characteristics associated with US adults' likelihood to participate in dementia prevention clinical trials. Based on data from the NPHA, nearly half of respondents ages 50 to 64 reported they would be at least somewhat likely to participate in a trial of a new medication to prevent dementia. Inconsistent with actual enrollment behaviors, no differences were observed in likelihood to participate by sociodemographic characteristics, including race and ethnicity. This finding suggests that overall interest in dementia prevention research participation may be consistent across different sexes, racial and ethnic backgrounds, and socioeconomic statuses. On the other hand, structural and logistical components of AD prevention clinical trials, such as recruitment methods, eligibility criteria, and access to trial sites, pose significant barriers to participation and disproportionately impact communities of color (13). Previous research on recruitment of under-represented groups to AD clinical trials suggests community outreach may be the most effective tool to address these disparities. Specific strategies may focus on involving community members in the planning of trial protocols and recruitment plans, management of trials in the community rather than academic settings, and hiring trial staff who are representative of the target populations (25-27).

Consistent with previous studies and actual enrollment behaviors, higher perceived risk of dementia among respondents was associated with a two-fold increase in likelihood to participate in dementia prevention trials (16, 20, 23). Given that adults are generally interested in learning their risk for AD (28-30), risk assessment (e.g., subjective cognitive complaint screening, genetic testing, biomarker testing) either as a recruitment strategy or trial criterion may aid enrollment. In fact, some recruitment registries have incorporated risk assessment to identify participants most likely to be eligible for trials (31, 32). A common variant in the apolipoprotein E (APOE) gene is the strongest known genetic risk factor for late-onset AD, and direct-to-consumer (DTC) genetic testing is accessible for a fee to anyone age 18 and older. A community-based registry examined local utilization of DTC APOE testing and whether registrants would be willing to share this information for AD trial recruitment. Though few registrants had used DTC testing, over 90% reported willingness to share APOE information for study ecruitment (33). Given that Black and Hispanic adults are at increased risk for dementia, improving access to risk information for these groups may facilitate greater interest in prevention research. For example, a recent pilot study of an AD risk assessment program in a primary care setting found the intervention yielded a more demographically diverse sample than an AD prevention registry (34), suggesting this approach may be a potential method to improve recruitment.

Though very few respondents reported having discussed dementia prevention with a doctor, those who had were more than two times as likely to report willingness to participate in a trial compared to those who never had the conversation with their doctor. Clinical referral to AD trials has been studied mainly in the context of recruitment of symptomatic patients and has found mixed results (8). Previous studies suggest physicians have low general awareness of AD clinical trials but are willing to refer patients if awareness is increased and barriers are overcome, such as time constraints (35, 36). Efforts to improve physician knowledge of referral resources (e.g., AD research recruitment registries, National Institute on Aging AD Research Centers), particularly in the context of Medicare Annual Wellness Visits that require cognitive impairment screening, may be another potential avenue to improve AD prevention clinical trial enrollment.

This study has several limitations. The survey measured general interest to participate in a hypothetical dementia prevention clinical trial of a new medication, which cannot be translated to actual participation behaviors of respondents where practical barriers exist. The survey provided no context on what a clinical trial of a new medication to prevent dementia may involve, such as potential drug side effects and medical procedures. For example, previous research suggests racial and ethnic minority groups may be less willing to engage in research protocols typical of AD prevention clinical trials, involving procedures such as blood draws, brain imaging, and investigational medications (21). The absence of descriptive information may have resulted in more frequent endorsement of being very or somewhat likely to participate in a prevention trial. Though the data were collected relatively recently, the COVID-19 pandemic, large national social movements, and FDA approval of the first AD drug in more than 15 years all occurred in the interim and could affect current interest in dementia prevention research.

Recruitment to AD prevention clinical trials poses persistent challenges that require urgent intervention. The struggle to enroll participants in AD research has been a decades-long challenge for the field. The slow and inadequate enrollment of cognitively unimpaired older adults into clinical trials is delaying the development of preventative and disease-modifying treatments for AD. This is the first study to explore interest in dementia prevention clinical trial participation within a nationally representative sample of middle-to-older aged adults. The findings suggest that recruitment interventions focused on increasing knowledge of dementia risk and prevention trials, and involving healthcare providers, may be effective tools to improve enrollment rates, regardless of target community.

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Ethical standards: The University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board deemed this study exempt from human subjects review as it involved the analysis of only deidentified data.

Conflict of interest: The authors report no conflicts of interest.

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