Development and validation of the Alzheimer's prevention beliefs measure in a multi-ethnic cohort—a behavioral theory approach

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ABSTRACT

Background Understanding health beliefs and how they influence willingness will enable the development of targeted curricula that maximize public engagement in Alzheimer's disease (AD) risk reduction behaviors.

Methods Literature on behavioral theory and community input was used to develop and validate a health beliefs survey about AD risk reduction among 428 community-dwelling adults. Principal component analysis was performed to assess internal consistency. Linear regression was performed to identify key predictors of Willingness to engage in AD risk reduction behaviors.

Results The measure as well as the individual scales (Benefits, Barriers, Severity, Susceptibility and Social Norm) were found to be internally consistent. Overall, as Benefits and Barriers scores increased, Willingness scores also increased. Those without prior AD experience or family history had lower willingness scores. Finally, we observed an interaction between age and norms, suggesting that social factors related to AD prevention may differentially affect people of different ages.

Conclusions The Alzheimer Prevention Beliefs Measure provides assessment of several health belief factors related to AD prevention. Age, Family History, Logistical Barriers and total Benefits are significant determinants of willingness to engage in AD risk reduction behaviors, such as seeing a doctor or making a lifestyle change.

Keywords beliefs, health promotion, measurement

Introduction

Educational interventions aimed at raising public awareness have the potential to reduce the global burden of Alzheimer's Disease (AD).[1] AD poses a substantial threat to public health worldwide, with a 2010 prevalence of approximately 4.7 million older adults affected in the United States (US), a number expected to triple by 2050.[2] AD begins with a progressive, prodromal period ('Preclinical AD'), which occurs at least 10 years prior to the emergence of cognitive decline.[3] During this time, amyloidosis and other potentially reversible risk factors converge to influence the timing, nature and progression of the disease.[4] For example, during midlife, even the presence of a mild metabolic disorder such as insulin resistance or benign

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vitamin B12 deficiency has been shown to increase the risk of brain degeneration in later life.[5,6] Better detection of these and other reversible risk factors, at critical stages of the lifespan, is paramount in persons with genetic risk for late-onset AD.[7] In fact, several national public health initiatives are targeting 'brain health', based on the scientific evidence showing the importance of reducing modifiable risk factors such as cardiovascular disease and diabetes.[8] Of particular importance are on-going clinical trials, such as the Anti-Amyloid Treatment in Asymptomatic Alzheimer's study ('A4 trial'). Preliminary Phase 3 findings suggest that treatment with the investigational drug solanezumab, an antiamyloid-beta monoclonal antibody, is safe and effective in lowering amyloid burden if delivered prior to the onset of later protein changes of AD.[9]

Despite the availability of interventions proven to reduce risk during midlife, and even with the widespread concern of this disease, public engagement in AD risk reduction remains low,[10] especially for underrepresented minorities and those with learning disability (LD) or low health literacy. As a result, individuals carrying genetic or socioeconomic risk for AD continue throughout life with unaddressed risk, while Alzheimer's research studies routinely fail to meet recruitment goals.

Gender and race-based differences in pre-existing beliefs about AD are particular important.[11–15] However, prior studies exploring the relationship between pre-existing health beliefs and willingness to engage in AD risk reduction have yielded mixed results, with few measures incorporating behavioral theory.[10–16] Prior studies have not assessed health literacy levels or presence of LD. As a result, the health beliefs that most influence willingness, in specific, underrepresented groups, remain to be identified. This is a critical research gap because the future of AD prevention depends upon early detection and treatment of risk factors in minimally symptomatic, susceptible adults.

In this study, our objectives were (i) to develop and validate a self-report questionnaire of AD health beliefs using a community-based, participatory approach; (ii) to describe AD health beliefs in an urban-based sample with varying levels of health literacy; and (iii) to examine whether self-reported beliefs are associated with self-reported willingness. We hypothesized that demographic factors such as gender, race and level of health literacy would influence health beliefs, and that health beliefs would be directly related to willingness to engage in AD risk reduction behaviors such as making a lifestyle change, seeing a doctor, taking a medication or participating in an AD prevention trial. These hypotheses were based on the Health Belief Model (HBM) and other behavioral theory models, which posit that health beliefs such as personal susceptibility, perceived severity of the disease, perceived benefits or barriers, and social norms are a key mediator of willingness to engage in a wide variety of health-related behaviors.[17,18]

A better understanding of health beliefs and how they influence willingness will enable the development of targeted curricula that maximize public engagement in AD risk reduction behaviors during midlife.[10] In 2014, The U.S. Department of Health and Human Services (HHS) updated 'The National Plan to Address Alzheimer's Disease', addressing the need to develop measures of quality care to ensure that people with Alzheimer's receive culturally competent, high-quality services. This objective can be achieved through the development of validated survey questions that can be used at the national, state and local levels to track awareness and perceptions about cognitive health, thereby improving access to clinical services and research trials and potentially influencing patient outcomes.[19]

Methods

Questionnaire development

The questionnaire was informed by: (i) a systematic review of the literature on behavioral theory; and (ii) extended discussion with content experts including two board-certified neurologists, a stroke prevention educator, a survey developer, a nurse educator, a social worker and a caregiver of dementia patients. The purpose of this process was to ensure content validity of the new measure. The measure included both original items and items adapted from prior validated scales, including the Fear of Alzheimer's Disease Scale[20] and the Motivation to Change Lifestyle and Health Behaviors for Dementia Risk Reduction Scale.[21] Semi-structured interviews were then conducted with a representative sample of persons for whom the measure would be used. The purpose of that process was to maximize face and construct validity. The questionnaire was revised based on the feedback of these interviews.

Primary predictor—health beliefs

To assess the primary predictor, Health Beliefs, we used a 5-point Likert scale (Strongly disagree, value of 1; Strongly agree, value of 5) using a set of questions specifically addressing the following domains; Perceived Severity, Perceived Susceptibility, Perceived Benefits, Perceived Barriers and Social Norms. Beliefs can be favorably or unfavorably associated with action.[22,23] In our study, we propose that someone who thinks AD is severe, knows they have high risk, recognizes the benefits of acting and expects few barriers to

action would be expected to have high willingness to prevent AD. Therefore a high total score on the beliefs questions was considered an indication that a person's health beliefs were 'favorable' to engagement.

Primary outcome measure—willingness to engage in AD risk reduction

To assess the primary outcome, Willingness, individuals were asked to rate their willingness to engage in four specific behaviors related to AD prevention (e.g. seeing a doctor, registering for an online course, signing up to be notified about AD prevention studies and determining personal risk). These items were presented using a Stages of Change scale,[24] ranging from pre-contemplation ('won't do', value of 1) to maintenance ('already did', value of 5). Participants then rated themselves using a 5-point Likert scale ('Very unlikely', value of 1; 'Very likely', value of 5) regarding the likelihood of engaging in eight behaviors varying in degree of action (e.g. taking an online survey, talking to a nurse, seeing a primary care doctor, seeing a neurologist, memory testing, getting a blood test, getting a brain scan and getting a genetic blood test). A high total score on the Stages of Change question was considered an indication of high total Willingness. Stages of change models have been used in a wide variety of conditions ranging from tobacco cessation to cancer prevention.[22–24]

Age, gender, ethnicity and educational attainment were obtained by self-report. Health literacy was measured using the Brief Health Literacy Screening measure.[25] To assess for childhood LD, we included a battery of nine questions about prior evaluation, prior diagnosis, perceived diagnosis, childhood learning difficulty and family history of LD. The sum of affirmative answers was calculated, and individuals answering affirmatively to at least 3/9 questions were classified as having Possible LD. We were limited to these questions because self-report measures to assess childhood LD have not been developed and validated in a memory loss prevention population. Personal Experience with AD was measured using three questions about family history, caregiving status, and working in a medical profession. Individuals endorsing at least one of these factors were classified as having some Prior Experience with AD. The Alzheimer's Disease Knowledge Scale (ADKS), a comprehensive measure of AD knowledge with good psychometric properties, was used to assess basic knowledge of AD.[26]

Study population and procedure

Participants were recruited from a variety of community-based sources to maximize heterogeneity of sample. Programs included health fairs and educational talks and community events including soup kitchens, food pantries, adult day cares, churches and social services organizations. Events were sponsored by the Weill Cornell Medical College Clinical and Translational Science Center (CTSC) and the Heart to Heart Community Outreach Program Partnership, a free diabetes/heart disease screening and intervention program. Events were held primarily in minority and underserved communities of New York City. All Questionnaires were delivered in person, were paper and pencil, and returned immediately to study team. Participants were offered a $10 voucher for completing the survey. This study was approved by the Weill Cornell Institutional Review Board.

Statistical analysis

Internal consistency of the predefined constructs (Willingness, Benefits, Barriers, Susceptibility, Severity, and Norms) was assessed using Cronbach's alpha. Each construct consisted of 4–14 items. For each construct, the 'Cronbach's alpha if item is deleted' was also calculated. If the overall Cronbach's alpha was <0.7, and deletion of a single item resulted in a Cronbach's alpha >0.7, then the item was deleted.

After using this criterion to determine which items should remain in the predefined constructs, factor analysis using the principal axis factoring extraction method and direct oblimin with Kaiser Normalization rotation method was applied on each construct. The direct oblimin rotation allowed for the factors to be correlated. Factors with eigenvalues >1 and factor loading of 0.50 or greater were retained. Once we performed factor analysis on the predefined constructs, and removed items as necessary, we repeated factor analysis again on the entire set of items. We also performed further analyses to assess concurrent validity and generalizability.

Once reliable factors were identified, we performed descriptive comparisons of belief factor scores across subgroups. Summary statistics were provided as counts and percentages for categorical variables and as means, standard deviations (SD), ranges and medians for continuous variables. In additional to the summary statistics, analysis of each potential factor was completed one at a time in univariate analysis. Finally, using all statistically significant predictors, along with all interactions, a multivariable, regression model was built. The model included four fixed covariates: age, gender, college education and ethnicity. P-values < 0.05 were considered to be statistically significant. Statistical analysis was performed using SAS V9.4.[27]

Table 1 Univariate analysis, willingness score, demographics and health beliefs

Characteristic	Statistic/category	N = 428	P-value
WILLINGNESS_SCORE	N	428	
	Mean ± SD	43.0 ± 8.57	—
	Range	12.0–60.0	
	Median	44	
AGE	N	421	
	Mean ± SD	42.8 ± 16.63	0.31
	Range	18.0–94.0	
	Median	43	
GENDER	Female	308 (72.0%)	0.95
	Male	109 (25.5%)	
	Missing values	11 (2.6%)	
RACE	Black	192 (44.9%)	0.87
	White	97 (22.7%)	
	Other	79 (18.5%)	
	Missing values	60 (14.0%)	
ETHNICITY	Hispanic or Latino	98 (22.9%)	0.21
	Not Hispanic or Latino	246 (57.5%)	
	Missing values	84 (19.6%)	
EDUCATIONAL_ATTAINMENT	Graduate degree	81 (18.9%)	0.04
	Bachelor's degree	122 (28.5%)	
	High school degree	168 (39.3%)	
	Less than high school	52 (12.1%)	
	Missing values	5 (1.2%)	
COLLEGE	No	220 (51.4%)	0.08
	Yes	203 (47.4%)	
	Missing values	5 (1.2%)	
COUNTRY_OF_BIRTH	Other country	145 (33.9%)	0.44
	USA	280 (65.4%)	
	Missing values	3 (0.7%)	
COHORT	Community	11 (2.6%)	0.64
	Live present	387 (90.4%)	
	Office	30 (7.0%)	
PRIOREXPERIENCE_CAREGIVER	No	382 (89.3%)	0.006
	Yes	41 (9.6%)	
	Missing values	5 (1.2%)	
PRIOREXPERIENCE_FAMHISTORY	No	361 (84.3%)	<0.001
	Yes	63 (14.7%)	
	Missing values	4 (0.9%)	
LOW HEALTH LITERACY	No	323 (75.5%)	0.74
	Yes	94 (22.0%)	
	Missing values	11 (2.6%)	
LEARNING DISABILITY	No	409 (95.6%)	0.47
	Yes	19 (4.4%)	
SUSCEPTIBILITY_SYMPTOMS	N	424	0.27
	Mean ± SD	17.0 ± 7.15	
	Range	8.0–40.0	
	Median	16	

Continued

Table 1 Continued

Characteristic	Statistic/category	N = 428	P-value
BENEFITS_EMPOWERMENT	N	428	<0.001
	Mean ± SD	24.8 ± 4.26	
	Range	6.0–30.0	
	Median	24	
BARRIERS_LOGISTICS	N	422	<0.001
	Mean ± SD	29.3 ± 6.68	
	Range	8.0–40.0	
	Median	30	
BARRIERS_STIGMA	N	428	0.08
	Mean ± SD	20.5 ± 5.47	
	Range	2.0–30.0	
	Median	20	
PERCEIVED_SEVERITY	N	422	0.007
	Mean ± SD	12.6 ± 3.45	
	Range	4.0–20.0	
	Median	13	
BENEFITS_GENERAL	N	422	<0.001
	Mean ± SD	15.8 ± 3.27	
	Range	4.0–20.0	
	Median	16	
BENEFITS_EARLYDETECTION	N	428	<0.001
	Mean ± SD	11.5 ± 2.44	
	Range	3.0–15.0	
	Median	12	
SUSCEPTIBILITY_HEALTHVIGILANCE	N	422	0.26
	Mean ± SD	6.7 ± 2.28	
	Range	3.0–15.0	
	Median	6	
SUSCEPTIBILITY_CONCERN	N	424	<0.001
	Mean ± SD	11.0 ± 2.77	
	Range	3.0–15.0	
	Median	11	
SUSCEPTIBILITY_SCORE	N	424	0.58
	Mean ± SD	23.7 ± 8.30	
	Range	8.0–55.0	
	Median	23	
SEVERITY_SCORE	N	422	0.05
	Mean ± SD	14.6 ± 3.71	
	Range	5.0–25.0	
	Median	15	
NORMS_SCORE	N	424	0.003
	Mean ± SD	9.9 ± 3.75	
	Range	1.0–20.0	
	Median	11	
BENEFITS_SCORE	N	428	<0.001
	Mean ± SD	51.8 ± 8.20	
	Range	13.0–65.0	
	Median	52	

Continued

Table 1 Continued

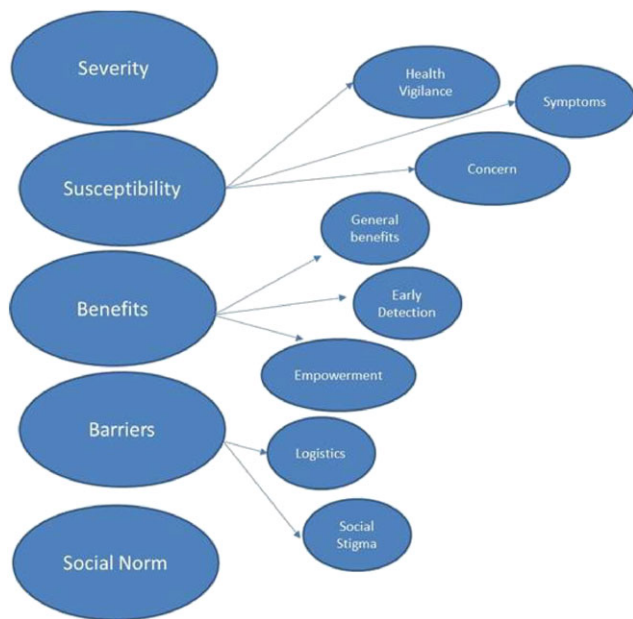| Characteristic	Statistic/category	N = 428	P-value
BARRIERS_SCORE	N	428	<0.001
	Mean ± SD	49.4 ± 10.52	
	Range	10.0–70.0	
	Median	49	
TOTAL_ADKS	N	426	0.37
	Mean ± SD	19.8 ± 4.52	
	Range	8.0–30.0	
	Median	20	
TOTAL_BELIEF_SCORE	N	428	<0.001
	Mean ± SD	148.9 ± 17.94	
	Range	49.0–193.0	
	Median	150	

Fig. 1 Sub-factors of health beliefs regarding AD risk reduction.

Results

A total of 428 community-dwelling adults completed the survey. Most of the surveys were completed at community health fairs ($n = 387$, 90.4%), with the remainder completed after a live presentation ($n = 20$), or during a clinic visit for an affected family member ($n = 30$). The sample was relatively young, with a mean age of 42 years ($SD = 16.63$), range of 18–94. A large proportion of the group were women (72%) and self-reported as Non-Hispanic/Latino ($n = 246$, 57.5%). The sample also comprised a significant representation of persons with low education ($n = 220$, 51.4% high school or less), who were first-generation immigrants ($n = 145$, 33.9% foreign-born), low health literacy ($n = 94$, 22%) and a self-reported history of LD ($n = 19$, 4.4%). A considerable number of participants reported that they had both prior experience as a caregiver ($n = 382$, 89.3%) and a familial history of AD ($n = 361$, 84.3%). See Table 1 for the demographic characteristics.

Internal consistency, construct validity and generalizability

Overall, each predefined factor structure (Willingness, Benefits, Barriers, Susceptibility, Severity and Social Norm) was found to be internally consistent. Two items were removed (both from the Perceived Severity construct) in order to increase the internal consistency of that particular scale. For four of the factors, several additional subconstructs were identified, yielding a total of 10 Health Belief factors, shown in Fig. 1. Perceived susceptibility consisted of Health Vigilance, Concern and Symptom subconstructs. Perceived benefits consisted of General, Early Detection and Empowerment sub-constructs. Perceived barriers were either related to Social Stigma or Logistics. Social Norm and Severity did not show evidence of subconstructs. The setting in which the measure was taken (in a clinic by a caregiver, at a presentation or at a community health fair) did not influence any of these results.

Health beliefs and willingness

The total Willingness score for the whole sample ranged from 12 to 60, ($M = 43$, $SD = 8.6$). About 30–40% reported 'Ready, will do' to make an appointment with a doctor to discuss ways to prevent AD, register for an online

Table 2 Final multivariable model

Factor	Parameter estimate	Standard error	Test statistic	P-value
Intercept	−1.40564	3.99047	−0.35	0.7249
Age	0.18223	0.06825	2.67	0.0080
Gender	0.18389	0.89150	0.21	0.8367
College education or higher	0.18330	0.79135	0.23	0.8170
Ethnicity	1.07113	0.89920	1.19	0.2344
Prior experience with family history of Alzheimer's	3.64468	1.12439	3.24	0.0013
Barriers logistics	0.23827	0.06280	3.79	0.0002
Total norms score	1.01189	0.28578	3.54	0.0005
Total benefits score	0.51970	0.05334	9.74	<0.0001
Age × norms interaction	−0.01952	0.00647	−3.02	0.0028

Table 3 Summary of initial factor analysis and reliability measure scores

Factor name	# of items	# of items removed	# of items with $\lambda > 1$	Cumulative variance explained (%)	Initial Cronbach's alpha	Final Cronbach's alpha
Willingness	12	0	2	51.7	0.885	0.885
Benefits	13	0	3	69.5	0.913	0.913
Barriers	14	0	2	52.0	0.874	0.874
Susceptibility	14	0	3	66.8	0.849	0.849
Severity	6	2	1	46.9	0.665	0.774
Norms	4	0	1	62.6	0.865	0.865

λ = Eigenvalue.

course to learn about AD prevention, sign up to be notified about trials or know their personal AD risk. Table 2 shows a summary of willingness and likelihood of engaging in behaviors and tests to reduce AD risk.

In univariate analyses, the following factors were significantly related to the total Willingness score: Educational attainment, Prior experience as caregiver, Prior experience with family history, Benefits (empowerment), Barriers (logistics), Perceived severity, Benefits (general), Benefits (early detection), Susceptibility (concern), Norms, Benefits (total), Barriers (total), Beliefs (total). Willingness increased as education increased. Those with prior experience as a caregiver and those with family history of AD had higher Willingness than those without. The remaining univariate statistically significant factors (continuous variables) increased as Willingness increased (Tables 3 and 4).

In multivariable analyses, after adjusting for age, gender, education, and ethnicity, the following factors were identified as independent factors for inclusion in the final model: Prior experience with family history, Barriers (logistics), Benefits (total) and Interaction between Norms score and Age. The other univariate significant factors fell out of the final model as they did not provide enough independent information to warrant their inclusion. Table 5 shows the final model.

Discussion

Main finding of the study

In this study, we used the literature on behavioral theory, in addition to community input, to develop and validate a health beliefs survey about AD risk reduction which could enable assessment of key health beliefs known to influence health behavior. The measure, as a whole, as well as the individual scales (Benefits, Barriers, Severity, Susceptibility and Social Norm), were found to be internally consistent. In addition, the data demonstrated additional, more specific aspects of general health beliefs. Overall, as the Benefits and Barriers scores increased, the Willingness score also increased. Those without prior experience or family history had lower willingness scores than those with prior experience or family history. Finally, we observed an interaction between age and norms, suggesting that social factors related to AD prevention may differentially affect people of different ages.

Table 4 Pattern matrix for final included items

	Factor									
	1	2	3	4	5	6	7	8	9	10
To what extent do you agree with these statements?										
AD is one of the worst diseases someone could have	0.039	−0.025	0.078	−0.013	0.011	0.755	−0.034	0.053	−0.004	0.048
I would rather have a painful physical illness (e.g. cancer or AIDS) than AD	−0.001	−0.030	−0.036	0.075	−0.001	0.566	0.052	−0.035	−0.044	−0.024
The thought of AD scares me	−0.041	0.113	−0.010	−0.072	0.009	0.698	−0.031	−0.021	0.010	0.028
AD is more serious than other diseases	0.030	−0.002	−0.071	0.013	−0.054	0.654	−0.034	0.047	−0.006	−0.015
In my opinion, compared to other people my age:										
My chances of developing AD are higher	−0.036	−0.019	0.037	0.008	−0.047	0.106	0.038	0.034	−0.518	0.183
My overall body health is worse	−0.051	0.055	−0.129	−0.035	0.026	−0.040	−0.084	−0.046	−0.700	−0.160
My overall brain health is worse	−0.021	−0.028	0.003	0.024	−0.011	0.014	0.015	−0.012	−0.897	−0.019
Next are some questions about how healthy you think your brain is. Over the last seven days:										
I have had trouble forming thoughts	−0.844	−0.029	0.027	0.020	−0.049	−0.044	−0.028	0.086	−0.014	−0.014
My thinking has been slow	−0.853	−0.075	−0.031	0.030	−0.024	−0.005	−0.053	0.040	−0.011	0.002
I have had trouble concentrating	−0.801	0.070	−0.023	−0.055	0.000	0.074	−0.034	−0.089	0.008	−0.026
I have had to work really hard to pay attention or I would make a mistake	−0.877	−0.001	0.019	−0.020	0.043	0.063	0.013	−0.052	−0.031	−0.015
My brain was not working as well as usual	−0.872	0.020	−0.016	0.025	0.013	−0.005	0.021	−0.005	0.043	0.033
I have worked harder to keep track of what I am doing	−0.800	0.004	−0.032	−0.057	−0.016	−0.005	−0.013	−0.041	0.005	0.041
I have had trouble shifting back and forth between different activities that require thinking	−0.849	0.057	−0.016	0.023	−0.029	−0.071	0.047	0.003	−0.030	−0.008
Problems with memory interfered with my daily life	−0.825	−0.061	0.024	0.037	0.014	−0.050	0.048	0.057	−0.037	0.024
How important is your brain health?										
I have to pay attention to my brain health	−0.030	0.104	−0.052	0.041	0.008	0.014	−0.133	−0.005	0.116	0.699
I am concerned about my brain health	−0.033	0.059	−0.044	0.025	−0.016	0.016	−0.101	0.020	−0.131	0.674
I often think about my brain health	−0.024	0.059	0.030	0.031	0.049	0.049	−0.129	−0.006	0.023	0.658
Seeing a doctor to discuss brain health would help me to:										
Know my personal risk for developing AD	0.007	0.079	−0.003	−0.069	0.062	0.057	−0.096	0.631	0.039	0.037
Detect AD before I ever get symptoms	0.024	−0.006	−0.004	−0.029	−0.006	0.011	−0.035	0.957	0.050	−0.052
Reduce my chances of developing AD	−0.012	0.092	0.020	0.000	0.008	−0.013	−0.006	0.603	−0.045	−0.012
Knowing my personal risk for AD would help me to:										
Set my personal affairs in order	0.052	0.744	0.017	0.020	−0.058	−0.049	−0.013	0.121	−0.021	0.010
Make plans for long-term care	0.020	0.864	0.004	−0.019	−0.018	−0.052	−0.028	0.009	−0.076	0.044
Prepare my family	−0.005	0.808	−0.006	0.035	0.033	−0.028	−0.110	0.001	−0.016	−0.023
Do important things sooner	−0.040	0.883	0.025	0.056	0.043	0.028	0.030	−0.011	0.011	−0.011
Identify things I can change about my behavior	−0.016	0.752	−0.010	0.007	−0.001	0.058	−0.018	0.012	0.023	0.048
Identify things I can change about my health	0.018	0.804	0.017	−0.029	−0.018	0.089	0.076	0.081	0.071	0.048
Overall how beneficial is:										
Seeing a doctor to discuss brain health	−0.055	−0.004	−0.015	0.045	0.091	0.063	−0.677	0.120	0.009	0.105
Learning about AD	−0.004	0.006	−0.011	0.014	−0.022	0.020	−0.890	0.003	0.054	0.024
Signing up to be notified about AD prevention studies	−0.014	−0.005	0.100	0.058	−0.064	0.000	−0.741	0.025	−0.089	0.119
Knowing my personal risk for future AD	0.054	0.055	−0.032	−0.026	0.011	−0.017	−0.845	0.042	−0.019	−0.002
I do not want to know my personal risk for AD because:										
It would cause me more worry than good	0.088	0.021	−0.013	0.028	0.600	−0.019	0.018	0.062	0.018	0.105
My health insurance might change	0.006	−0.048	0.090	−0.091	0.657	0.019	0.031	−0.052	0.026	0.090
My friends or family might treat me differently	−0.006	0.047	−0.024	0.039	0.872	−0.004	0.034	0.026	−0.001	−0.066
My employer might treat me differently	−0.042	−0.004	0.030	−0.045	0.805	0.014	0.031	−0.003	−0.043	−0.057

Table 4 Continued

| | Factor | | | | | | | | | |
	1	2	3	4	5	6	7	8	9	10
My feelings about myself might change	−0.012	−0.073	−0.027	0.080	0.756	−0.046	−0.031	0.070	0.009	−0.027
AD risk should be kept a secret	0.083	0.111	0.045	−0.110	0.458	−0.012	−0.186	−0.115	0.052	−0.020
What are some practical barriers to doing things to prevent AD?										
I do not have access to medical care when I need it	0.003	−0.041	0.720	0.011	0.033	0.093	−0.048	−0.064	0.034	−0.117
My doctor would not know about brain health	0.031	−0.032	0.683	0.039	0.034	0.021	0.004	0.022	−0.009	−0.057
I do not know which doctor to see about my brain health	0.044	−0.008	0.730	0.030	−0.044	−0.082	0.027	0.005	−0.012	−0.062
The test would be inconvenient	0.063	0.123	0.673	−0.040	−0.002	−0.025	0.013	0.002	−0.021	0.048
I do not have enough time	−0.005	0.047	0.673	0.051	0.076	−0.100	0.018	0.012	−0.048	0.149
I do not have enough money	0.000	−0.067	0.764	0.058	0.063	−0.001	−0.006	0.099	−0.005	0.039
It is hard to get information about AD	0.017	0.030	0.725	−0.095	−0.075	0.034	−0.020	−0.048	0.099	0.054
It is hard to understand information about AD	−0.055	0.029	0.714	−0.066	0.004	−0.031	−0.020	0.001	0.060	−0.040
How many of your friends are doing the following:										
Seeing doctors to discuss brain health?	0.011	−0.070	−0.023	0.634	−0.044	−0.068	0.057	0.059	−0.062	0.118
Taking supplements/vitamin to improve brain health?	−0.040	0.051	−0.021	0.886	0.018	0.052	−0.025	−0.056	0.053	−0.070
Making lifestyle changes (diet, sleep, exercise) specifically to improve brain health?	0.002	0.064	0.069	0.823	0.006	0.041	−0.071	−0.027	−0.008	−0.059
Signing up for brain games programs such as Lumosity®?	0.027	0.016	−0.021	0.784	−0.004	0.003	−0.013	−0.046	0.022	0.055

Table 5 Results from overall sample on The Willingness to Prevent AD Scale

	Will not do (%)	Have not considered (%)	Considered but have not decided (%)	Ready, will do (%)	Already did (%)
If these options were available to you, would you do any of the following things?					
Make an appointment with a doctor to discuss ways to prevent AD	5	31	22	37	4
Register for an online course to learn about AD	8	35	19	30	8
Sign up to be notified about AD prevention research studies	8	33	19	36	4
Know my personal risk for AD	4	27	22	40	7
What would you be willing to do to measure your brain health?					
Take an online survey about health and lifestyle	5	5	17	46	27
See a nurse	5	15	20	38	23
See a primary care doctor	4	7	11	41	37
See a neurologist / memory expert	4	10	17	37	32
Take tests on memory and thinking	4	4	12	44	36
Get a blood test	3	5	12	42	38
Get a brain scan	5	12	18	34	31
Get a genetic test (a blood test that looks at your DNA)	5	8	14	40	33

What is already known on this topic

In general, our results were consistent with prior studies showing that age, prior experience with AD, and Perceived Benefits are key factors when it comes to willingness to undergo susceptibility testing.[10,28,29] In the Risk Evaluation and Education for AD study, 47/196 participants (24%) who

were systematically contacted through AD research registries subsequently underwent susceptibility testing. This number may be inflated due to the fact that the sampling frame consisted of people who were part of AD research registries and were therefore more likely to be interested in undergoing testing.[15] We did not have direct data about behavioral decisions, but approximately 40% of our sample reported willingness to know their own risk. These numbers corroborate the idea that a significant number of individuals are already interested in susceptibility testing, and also demonstrate the significant amount of work left to be done by educators in creating curricula to convey the benefits of susceptibility testing.

Curiously, we found no race or ethnicity-related differences in health beliefs, despite several prior studies demonstrating these differences. Researchers have found African Americans to be significantly more likely to associate memory loss with normal aging, less knowledgeable about genetics and AD risk, and different from non-Hispanic Whites with respect to beliefs about causes and effectiveness of various options for risk reduction or treatment.[12–14,15] Dementia symptoms are also likely to be considered a normal part of the aging process among Asian American immigrants.[13] Our study raises the important question whether prior race-related differences in health beliefs were actually attributable to health literacy levels, which were not measured robustly in those studies.

Limitations of the study

Our study had several limitations. Participants in this study were recruited from a convenience sample of community-dwelling adults and therefore the group is not necessarily representative of the overall U.S. population. We did not measure test-retest reliability. Importantly, our question items were not delivered in random order, so our data could have been subject to the Halo effect, whereby subjects' overall impression of the construct influenced most of the responses. Also, since we delivered different numbers of questions for each construct (based on the availability of good questions in the literature), our total Beliefs score weights certain factors higher than others. Regarding LD, the study may have some classification bias because validated measures for diagnosing LD in the adult are not validated for these types of populations. Finally, the ADKS scale we used to measure AD knowledge does not directly address prevention-specific facts which have may have more implications with respect to perceived control.

Key strengths of this study were the incorporation of behavioral theory into the measure, the involvement of the community in drafting the questionnaire, the diversity of the sample population, the greater attention to health literacy levels, and also the inclusion of a Willingness scale that takes into account a comprehensive approach to AD risk reduction. The population was relatively young (mean age 42), which is a strength because risk reduction for AD must begin in midlife or sooner.

Future research is required to examine the test-retest reliability of this measure, to incorporate better assessment of AD prevention knowledge, and to further explore how health literacy and LD influence beliefs and willingness. This is particularly important because the tool could ultimately be used to measure the effectiveness of educational interventions to increase engagement for underrepresented groups.

What this study adds

It is well established that an individual's health behaviors are influenced by multiple factors, including personal beliefs and the perceived value or benefit of the behavior.[30,31] To our knowledge, this is one of the first studies that used Behavioral Theory to construct a self-report measure for the assessment of AD risk reduction beliefs. The Alzheimer Prevention Beliefs Measure provides an assessment of several health belief factors related to AD prevention. Age, Family History (or lack thereof), Logistical Barriers and total Benefits are significant determinants of willingness to engage in AD risk reduction behaviors, such as seeing a doctor, making a lifestyle change or participating in prevention research trials.

Development of theory-based measures of AD beliefs could enable more accurate public health surveillance of AD prevention attitudes. This could lead to the development of targeted, hypothesis-driven educational messaging aimed at reducing barriers to earlier diagnosis and prevention, especially for underrepresented groups. A tool such as this may also play a role in better defining strategies to increase recruitment into Alzheimer's prevention research trials.[32]

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