



Published in final edited form as:

Alzheimers Dement. 2014 October ; 10(0): S381–S389. doi:10.1016/j.jalz.2013.07.001.

Public beliefs and knowledge about risk and protective factors for Alzheimer's disease

J. Scott Roberts^{*}, Sara J. McLaughlin, and Cathleen M. Connell

Department of Health Behavior and Health Education, University of Michigan School of Public Health, Ann Arbor, MI, USA

Abstract

Background—The purpose of this study was to assess public beliefs and knowledge about risk and protective factors for Alzheimer's disease (AD).

Methods—A brief survey module was added to the Health and Retirement Study, a longstanding national panel study of the U.S. population over the age of 50.

Results—Respondents were 1641 adults (mean age = 64.4 years, 53.6% female, 81.7% White). Most (60.1%) indicated interest in learning their AD risk, with 29.4% expressing active worry. Many failed to recognize that medications to prevent AD are not available (39.1%) or that having an affected first-degree relative is associated with increased disease risk (32%). Many respondents believed that various actions (e.g., mental activity, eating a healthy diet) would be effective in reducing AD risk.

Conclusion—Older and middle-aged adults are interested in their AD risk status and believe that steps can be taken to reduce disease risk. Tailored education efforts are needed to address potential misconceptions about risk and protective factors.

Keywords

Illness perceptions; Public understanding; Health education; National survey; Attitudes and beliefs

1. Introduction

Alzheimer's disease (AD) affects approximately 5.4 million people in the United States, with its prevalence expected to increase dramatically over the next 20 years [1]. The financial and emotional costs of the disease have been well documented in the scientific literature and high-profile media coverage [2,3]. Although there are no proven strategies to prevent the disease, much has been learned in recent years about possible risk and protective factors for AD beyond genetics and age, including physical activity, diet, social connections, and environmental exposures [4]. The identification of potentially modifiable risk factors has encouraged public initiatives promoting “brain health,” including the National Alzheimer's

Association's "Maintain Your Brain" campaign [5] and the Centers for Disease Control and Prevention's (CDC) Healthy Brain Study [6].

In addition, new diagnostic categories and techniques for preclinical detection of disease have emerged. For example, mild cognitive impairment (MCI) has become a formal diagnostic category and billing code that many neurologists now use in practice [7]. Several biomarkers are also under investigation that may one day be used to detect the disease process before clinical manifestations can be observed [8]. Given this increased attention to early detection and cognitive health promotion among older adults, it is important to examine public understanding of risk and protective factors for AD. Such an assessment provides an opportunity to gauge public awareness of scientific advances in AD and to identify potential misconceptions to address via health education initiatives.

Illness perceptions have long been recognized as an important factor in response to symptom recognition, seeking a diagnosis, and disease self-management. For example, perceived threat of disease (i.e., beliefs about personal susceptibility to and concern about a given disorder) predicts willingness to seek out preventive and screening options [9] whereas beliefs about causes, course, and severity can influence coping with illness and disease self-management [10]. In the case of AD, illness perceptions and misconceptions may hamper efforts in the areas of risk reduction and early diagnosis, making an increased understanding of public views about the disease a priority.

Several studies have examined public attitudes, beliefs, and knowledge about AD [11–16]. However, much of this work is based on convenience samples or specific at-risk populations (e.g., first-degree relatives of people with AD), making findings difficult to generalize to the general public. Another criticism of this work is the limited racial and ethnic diversity in study samples and a lack of information on sampling frames and sample weighting techniques used for national estimates [17]. These limitations make it difficult to assess the representativeness of reported results. Given these gaps in the literature, it is not surprising that a prominent report issued by the CDC and the Alzheimer's Association [5] made a first-priority recommendation to "determine how diverse audiences think about cognitive health and its association with lifestyle factors." The present study addresses this recommendation by examining knowledge and beliefs about AD risk and protective factors among a nationally representative sample of U.S. adults over the age of 50 [18].

2. Methods

2.1. Participants and procedures

Data for this investigation are from the Health and Retirement Study (HRS), a longstanding panel study of the community-dwelling U.S. population over the age of 50 [5]. To supplement its biannual core assessment of labor and health issues, the HRS uses various brief modules that are administered in-person or over the telephone to a subsample of participants. Given the lengthy nature of the core HRS survey, these modules are limited to a brief set of questions that can be administered in approximately 3 minutes. In this study, a random subsample ($n = 2213$) of those who participated in the 2010 HRS survey ($n = 22,037$) was invited to complete a module that focused on knowledge and beliefs about AD.

Of the 2213 sampled participants, 200 had sampling weights of zero, meaning that they were not eligible for participation for reasons such as nursing home residency. An additional 120 individuals were ruled ineligible for this study because they required proxy respondents. Of the remaining 1893 individuals, 1840 individuals were of Hispanic, non-Hispanic Black, or non-Hispanic White race/ethnicity. Of those, 1641 (89.2%) completed the AD module and constitute the analytic sample for this study. Of note, we compared the characteristics of the analytic sample to the larger HRS sample from which it was drawn (excluding those of “other” race and those with sampling weights of zero) and found no significant differences by age category, gender, educational level, or race/ethnicity ($P = .19$ in all cases).

2.2. Survey items

All investigators who conduct supplementary survey modules via HRS are asked to limit the time of completion to approximately 3 minutes. Given these constraints, we chose survey items that had been administered via telephone in previous published work, with an emphasis on risk and protective factors. Doing so allowed us to compare our results with previously published studies and to respond to the aforementioned recommendation from CDC to examine public perceptions of how lifestyle factors affect cognitive health. Thirteen close-ended questions were selected that covered the following domains:

2.2.1. Personal experience with AD—Respondents were asked if they knew anyone who had AD and if they had an affected spouse/partner, parent, sibling, or adult child.

2.2.2. Perceived threat of AD—Three items taken from our previous work assessed perceived concern about, and susceptibility to, AD [19]. Participants indicated their level of agreement (i.e., strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, strongly disagree) with three statements about the possibility of getting AD: (1) “You would like to know your chances of someday getting Alzheimer’s,” (2) “You believe you will get Alzheimer’s someday,” and (3) “You worry about getting Alzheimer’s someday”. Responses of “somewhat” or “strongly agree” were classified as agreeing with each statement. All other responses, including don’t know responses (between 19 and 26 respondents across the three items), were classified as not agreeing.

2.2.3. Knowledge about selected AD risk and protective factors—Two true-false items from the validated Alzheimer’s Disease Knowledge Scale [20] assessed understanding of certain risk and protective factors for AD. Items were (1) “Prescription drugs that prevent Alzheimer’s disease are available” (correct answer = false), and (2) “Having a parent or sibling with Alzheimer’s disease increases the chance of developing it” (correct answer = true). Don’t know responses were classified as incorrect.

2.2.4. Beliefs about risk and protective factors—On the basis of our previous work on AD illness representations [19], respondents were asked how important (i.e., very, somewhat, or not at all) stress and genetics are “in increasing a person’s chances of getting Alzheimer’s.” To assess beliefs about protective factors, respondents indicated how effective (i.e., very, somewhat, or not at all) four health behaviors are “in lowering a person’s chances of getting Alzheimer’s.” Behaviors included (1) keeping physically active, (2) keeping

mentally active, (3) eating a healthy diet, and (4) taking vitamins or dietary supplements. Responses were classified according to whether or not they indicated a behavior was “very important” or “very effective” in increasing or lowering AD risk. Don't know responses (between 21 and 50 individuals across items) were classified as not endorsing the behavior.

2.3. Data analyses

To assess AD knowledge and beliefs, we first calculated the percentage of adults who agreed with each statement about perceived threat and who correctly answered each AD knowledge item. We also examined the distribution of ratings of the importance and effectiveness of each potential AD risk and protective factor. We then used multiple logistic regression analyses to examine potential demographic correlates of knowledge and beliefs. Specifically, we regressed each item on variables that were core demographic characteristics and/or had been shown in prior research to be associated with perceptions and knowledge about AD. These variables included age category (50–64 years, 65–74 years, 75 years [referent]), gender, race/ethnicity (Hispanic, non-Hispanic Black, non-Hispanic White [referent]), education (no degree, General Educational Development [GED] or high-school diploma, 2-year college degree [referent]), and personal experience with AD (does not know anyone with AD; knows someone with AD; has a spouse/partner, parent, sibling, or adult child with AD [referent]). Variables were categorized based on conceptual and/or statistical rationales (e.g., ensuring sufficient cell sizes for multivariate analyses). All variables of interest were simultaneously entered into logistic regression models.

HRS participants were selected using a complex sampling design that involved clustering, stratification, and over-sampling of certain segments of the population (e.g., Hispanic adults) [21]. Data are weighted to correct for over-sampling and nonresponse. Reported standard errors account for clustering and stratification. All analyses were conducted using SAS statistical software, version 9.2.

3. Results

3.1. Sample characteristics

Table 1 summarizes the demographic characteristics and AD experience of the weighted sample. The mean age was 64.4 years (SE = 0.4), with most of the sample (81.9%) under the age of 75. Almost one fifth of the sample is non-White; 10.3% of respondents identified as non-Hispanic Black and 8.0% identified as Hispanic. Most respondents (87.4%) completed high school. Nearly two thirds (63.8%) reported having known someone with AD, and 13.3% reported having had a close relative affected with the disease.

3.2. Perceived threat of AD

Table 2 summarizes responses to items in this domain. Over half of adults (60.1%) said they would like to know their chances of developing AD. Nearly one fourth of respondents (22.9%) reported a belief that they would one day have AD, and over one fourth (29.4%) noted some worry about the disease.

3.3. Knowledge about risk and protective factors

Table 2 summarizes responses to items in this domain. Over half of respondents (60.9%) correctly answered the item regarding availability of prescription drugs to prevent AD. More than two thirds (68.0%) correctly answered that having an affected parent or sibling increases one's chance of AD.

3.4. Beliefs about risk and protective factors

As shown in Table 3, over one half (51.3%) of respondents endorsed genetics as a very important risk factor for AD. Approximately one fifth (20.5%) believed stress to be very important in increasing AD risk. Several strategies for reducing AD risk were endorsed: keeping mentally active (61.4% reporting as very important), eating a healthy diet (44.3%), keeping physically active (40.6%), and taking vitamins/herbal supplements (20.5%).

3.5. Demographic differences in beliefs about AD

Table 4 reports on regression analyses with AD knowledge and perceived threat items as dependent variables. The odds of wanting to know one's chances of developing AD were significantly higher for both of the younger age groups compared with those 75 years and over (odds ratio [OR] = 1.4 for those aged 65–74; OR = 2.0 for those aged 50–64). Those in the youngest age group (i.e., those aged 50–64) also had significantly greater odds of reporting worry about AD (OR = 1.4) than those aged 75 and over. Individuals who either (1) did not know someone with AD or (2) knew someone, but did not have a relative with AD, had less than half the odds of (1) believing that they would get AD one day and (2) worrying about developing the condition. Those who did not know anyone with AD also had significantly lower odds of wanting to know their own chances of getting AD. Educational and ethnic differences were also evident for perceived susceptibility to AD. The odds of Hispanic adults believing they will ultimately develop AD were 60% higher than for non-Hispanic White adults. Educational differences were notable, with those without a high-school degree having approximately 3 times the odds of believing they will develop AD someday as the college-educated population. Although the difference was smaller (OR = 1.54), the odds of endorsing this belief were also significantly higher for those with a high-school diploma relative to those with a college education.

Sizable educational differences were also evident in knowledge about the lack of availability of prescription drugs to prevent AD. Relative to those with at least a 2-year college degree, those without a high-school diploma had one quarter of the odds (OR = 0.24) of correctly answering this item. Those with a high-school diploma had less than one half of the odds of answering this item correctly relative to those with a college degree.

For the item assessing respondents' knowledge about the effect of having an affected first-degree relative on disease risk, differences were evident by age, education, gender, and race. Compared with adults aged 75 years and over, adults aged 50 to 64 years and those aged 65 to 74 years had approximately 2 times the odds of correctly answering this item. Correct responses to this item were also higher among women than men (OR = 1.7). The odds of Black adults correctly answering this item were nearly two thirds lower compared with non-Hispanic White adults. No significant difference was evident for Hispanic and non-Hispanic

White adults. Compared with their more educated counterparts, the odds of those with and without a high-school diploma correctly answering this item were approximately 40% lower.

ORs for beliefs about risk and protective factors by demographic criteria are shown in Table 5. The odds of women reporting that stress increased the risk of AD were one third lower than for men. Racial and ethnic differences were pronounced for this item, with Hispanic and Black adults having 2.5 and 4.2 times the odds, respectively, of believing that stress is very important in increasing the risk of AD as compared with non-Hispanic Whites. Marked educational differences were also evident. Compared with those with a college degree, those without a high-school diploma had over 3 times the odds of endorsing stress as very important in increasing AD risk. High-school graduates also had significantly greater odds of believing that stress increases AD risk as compared with those who were college educated (OR = 1.95). Differences by exposure to AD were also evident, with both subgroups with less direct personal experience with AD having approximately half of the odds of reporting that stress increases one's chances of AD relative to those with an affected family member.

Demographic differences were also evident for beliefs about the role of genetics in AD. The odds of reporting that genetics increases AD risk were over 2 times greater for both of the younger age categories as compared with those aged 75 years or more. In addition, the odds of women endorsing genetics as an important risk factor were nearly 40% higher than for men.

For three of the four beliefs about possible protective factors—keeping physically active, eating a healthy diet, and taking vitamins—the odds of Black adults endorsing the behavior as very effective in lowering one's chances of AD were no less than 1.5 times greater than for White adults. Compared with Whites, Hispanic adults had 1.56 times the odds of reporting that taking vitamins or supplements lowered one's chances of developing AD. Educational differences were also evident. Compared with those with a college degree, those with and without a high-school diploma had greater odds of reporting that taking vitamins or supplements lowered one's chances of AD. The former also had significantly greater odds of reporting that eating a healthy diet reduced the chance of AD. Differences were also observed by AD exposure, with the odds of reporting that vitamins or dietary supplements lower one's chances of AD nearly 2 times greater for those who either did not know someone with AD or knew someone but did not have a close relative with AD than for those with a close family member with AD.

Overall, few differences were evident for other demographic factors. Compared with men, women had 1.3 times the odds of reporting that eating a healthy diet lowered the risk of AD. Two differences were evident by age: (1) compared with those aged 75 and over, the odds of reporting that keeping physically active lowers risk of AD were lower among those aged 50 to 64 years (OR = 0.61), and (2) those aged 65 to 74 had an increased odds of reporting that taking vitamins or dietary supplements reduces one's risk of AD (OR = 1.51).

4. Discussion

Results of this survey of a nationally representative sample of U.S. adults age 50 and over provide an up-to-date snapshot of the public's knowledge and beliefs about selected risk and protective factors for AD. Such illness perceptions likely shape responses to current and emerging public health campaigns regarding awareness, prevention, early diagnosis, and treatment. A recent review suggests that up to half of all AD cases in the United States may be attributable to modifiable risk factors (e.g., smoking, hypertension, obesity, cognitive inactivity, physical inactivity), and that even a 10% reduction in these risk factors could prevent over 1 million future cases of AD [22]. This new evidence provides a strong rationale for focusing on risk factor reduction for AD, in which the success of such efforts may depend, in part, on the public's evolving knowledge, attitudes, and beliefs on the topic.

Approximately one fifth of our sample believes that they will one day develop AD, and a slightly greater proportion expressed worry about this possibility. This finding is consistent with other survey data [14,23] and demonstrates the generally high level of public concern about AD. Although AD is a fatal and incurable disorder, and the medical community discourages susceptibility testing for the disorder [24,25], most (60%) respondents would be interested in learning their personal risk of AD. This finding is consistent with results from other surveys showing significant public interest in hypothetical predictive testing scenarios for AD [26,27]. Among those who have actually undergone predictive testing for AD in research protocols, primary motivations include advance planning (e.g., long-term care insurance) and the belief that “knowledge is power” [15,28,29]. Respondents in the youngest age category (those between 50 and 64 years of age) reported the highest level of interest in, and worry about, their AD risk. This finding is consistent with our previous predictive testing studies, in which interest is highest in midlife [30,31]. Possible explanations for this finding include cohort differences (e.g., Baby Boomers may be especially health information-seeking) and developmental factors (e.g., using risk information for advance planning may be more salient in midlife rather than older adulthood).

As expected, genetics was viewed as a key risk factor for AD and was viewed as very important by over one half of the sample. Stress was endorsed as a very important risk factor by one fifth of respondents, with higher levels of endorsement among racial and ethnic minority participants and those with lower educational levels. It is interesting to note that these groups were also more likely to endorse beliefs that they themselves would one day develop AD. Such findings are actually consistent with the epidemiological literature suggesting higher dementia risk in ethnic minority and less formally educated populations, although these beliefs may also reflect a more generally fatalistic attitude toward health among less privileged groups.

Overall, the sample endorsed a wide range of protective factors, including keeping mentally healthy, eating a healthy diet, keeping physically active, and taking vitamins or supplements to help lower the chances of developing AD. Qualitative interviews with individuals with a family history of AD have suggested that a “blended inheritance” perspective on AD is common [32], in which genetics is viewed as important in causing AD, but other factors are also believed to be contributory or protective (e.g., diet, physical exercise, cognitive

activity). According to the blended inheritance view, the occurrence of AD is thought to be potentially avoidable even for those at increased risk. On the positive side, such representations of AD suggest an openness to public health messages that encourage risk reduction. On the other hand, these beliefs may increase vulnerability to marketing of unproven “anti-aging” products (e.g., dietary supplements, cognitive training regimens) that capitalize on public anxieties about dementia [33]. In a recent trial of a genetic susceptibility testing protocol for AD, a notable subset of participants who learned they were at elevated risk reported taking vitamins or supplements (e.g., vitamin E) after risk disclosure although the efficacy of these strategies in reducing AD risk is unproven [34]. The limits of public knowledge about AD risk and protective factors were also demonstrated by the finding that nearly 40% of respondents seemingly did not know that medications to prevent AD are not available, and approximately one third were unaware that having an affected first-degree relative is associated with elevated risk for the disease. To the extent that these findings represent true misconceptions (some respondents may have merely confused already available medications to treat AD with currently unavailable preventive pharmacotherapy), they may have implications for patient and family expectations regarding the efficacy of current treatment options as well as for understanding of the relevance of family history for risk of AD. Given these findings, we echo the recent suggestion by the CDC and the Alzheimer's Association (2007) to “establish and maintain a Web-based cognitive health clearinghouse, in partnership with stakeholder organizations that would be recognized as a centralized site for scientifically validated and recognized information.”

Several demographic differences in our findings were particularly notable. As is the case for a wide array of illness perceptions, educational level and race and ethnicity matter. Our results confirm that lower educational levels are associated with significantly higher perceived risk of AD and less objective knowledge about certain established risk and protective factors. For example, those with lower educational levels were more likely to hold the erroneous belief that medications are available to prevent AD. Consistent with previous research [12], Black respondents were significantly more likely than Whites to endorse the benefits of health behaviors in terms of AD risk reduction, including keeping physically active, eating a healthy diet, and taking vitamins. Compared with Whites, Hispanic respondents endorsed just one of these behaviors to a significantly higher level—taking vitamins or supplements. Although full understanding of these differences is difficult given the limited information about how respondents interpreted broad survey concepts such as “healthy diet,” they might reflect the success of targeted public health efforts to increase awareness of the role of diet and lifestyle in reducing overall risk of chronic illness, particularly cardiovascular disease and diabetes, both of which are prevalent in Black and Hispanic communities.

In contrast to previous work in this area, these findings are based on a recent data collection with a large, nationally representative sample that includes sizeable numbers of Black and Hispanic respondents. However, several study limitations should be kept in mind. For example, it is not known how individuals of varying levels of health literacy interpreted the AD knowledge questions, thus making it difficult to determine the extent to which incorrect answers on these items represented true misconceptions about the disease and its treatment options. The necessarily brief survey, limited to just 3 minutes as part of an HRS

supplementary module, precluded extensive measurement of our domains of interest. A recommendation for future research is to conduct an in-depth survey that includes validated instruments such as the highly regarded Illness Perception Questionnaire [35] and the full version of the Alzheimer's Disease Knowledge Scale [20]. In addition, a repeated measures design (e.g., annual national survey) would be ideal to track trends in public AD knowledge and beliefs over time. Of course, the benefits of designing better measures and methods to assess AD knowledge and beliefs will be compromised unless studies are conducted with a diverse and nationally representative sample similar to that available via HRS. Qualitative approaches to data collection are also recommended as a supplement to large-scale surveys. For example, in-depth personal interviews have illuminated health-related beliefs for various diseases and can provide family and life history context that is helpful in interpreting the origin, meaning, and function of particular illness perceptions [14,36]. In a recent study, focus group interviews conducted with ethnically diverse older adults identified key factors believed to contribute to cognitive health: having a positive attitude, keeping mentally active, and staying socially engaged [37]. Such qualitative approaches are particularly well suited to exploring attitudes and beliefs that will necessarily affect response to educational outreach related to prevention and encouragement to seek early diagnosis.

Given the prominent national attention to the prevalence and consequences of AD and related dementias, ongoing assessment of the public's knowledge and beliefs about cognitive health and AD is critical. Results from this nationally representative study confirm that most adults would like to know more about their chances of developing AD. This willingness to confront personal risk, in combination with the high level of endorsement of the benefits of behavioral strategies for risk reduction (i.e., diet, physical and cognitive activity), provides new avenues for expanding the public discourse about disease prevention.

Acknowledgments

This analysis uses data from the HRS, the HRS 2010 Core (Final V3.0), and Cross-Wave Tracker (Final 2010 V1.0) files. The content of this manuscript is solely the responsibility of the authors and does not necessarily represent the official views of the Eunice Kennedy Shriver National Institute of Child Health & Human Development or the National Institutes of Health. The authors wish to thank Dr. Kenneth Langa for facilitating the addition of our survey module to the core HRS battery and Lan Quynh Le for her assistance with manuscript preparation.

The HRS is sponsored by the National Institute on Aging (U01AG009740) and is conducted by the University of Michigan. S.J.M. was supported by Award Number T32HD007422 from the Eunice Kennedy Shriver National Institute of Child Health & Human Development.

References

1. Alzheimer's Association. 2012 Alzheimer's disease facts and figures. *Alzheimers Dement.* 2012; 8:131–68. [PubMed: 22404854]
2. Hagan, C. [Accessed May 11, 2012] Report: Yearly cost of Alzheimer's tops \$200 billion [Internet]. CNN. 2012. Available at: <http://thechart.blogs.cnn.com/2012/03/08/report-yearly-cost-of-alzheimers-tops-200-billion/>
3. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med.* 2013; 368:1326–34. [PubMed: 23550670]
4. Hendrie HC, Albert MS, Butters MA, Gao S, Knopman DS, Launer LJ, et al. The NIH Cognitive and Emotional Health Project. Report of the Critical Evaluation Study Committee. *Alzheimers Dement.* 2006; 2:12–32. [PubMed: 19595852]

5. Alzheimer's Association. [Accessed May 11, 2012] Brain Health [Internet]. Available at: http://www.alz.org/we_can_help_brain_health_maintain_your_brain.asp
6. Centers for Disease Control and Prevention and the Alzheimer's Association. The Healthy Brain Initiative: A national public health road map to maintaining cognitive health. Chicago, IL: Alzheimer's Association; 2007.
7. Roberts JS, Karlawish JH, Uhlmann WR, Petersen RC, Green RC. Mild cognitive impairment in clinical care: a survey of American Academy of Neurology members. *Neurology*. 2010; 75:425–31. [PubMed: 20679636]
8. Roberts JS, Terseegno SM. Estimating and disclosing the risk of developing Alzheimer's disease: challenges, controversies and future directions. *Future Neurol*. 2010; 5:501–17. [PubMed: 20856693]
9. Janz NK, Becker MH. The Health Belief Model: A decade later. *Health Educ Q*. 1984; 11:1–47. [PubMed: 6392204]
10. Leventhal, H.; Benyamini, Y.; Brownlee, S., et al. Illness perception: Theoretical foundations. In: Petrie, K.; Weinman, J., editors. *Perception of health and illness: Current research and applications*. Amsterdam: The Netherlands: Hardwood Academic; 1997. p. 19-45.
11. Ayalon L, Areal PA. Knowledge of Alzheimer's disease in four ethnic groups of older adults. *Int J Geriatr Psychiatry*. 2004; 19:51–7. [PubMed: 14716699]
12. Connell CM, Roberts JS, McLaughlin SJ. Public opinion about Alzheimer disease among blacks, Hispanics, and whites: results from a national survey. *Alzheimer Dis Assoc Disord*. 2007; 21:232–40. [PubMed: 17804956]
13. Connell CM, Roberts JS, McLaughlin SJ, Akinleye D. Racial differences in knowledge and beliefs about Alzheimer disease. *Alzheimer Dis Assoc Disord*. 2009; 23:110–6. [PubMed: 19474569]
14. Cutler, N.; Whitelaw, NW.; Beattie, BL., editors. *American perception on aging in the 21st century*. Washington, DC: National Council on Aging; 2002.
15. Roberts JS, LaRusse SA, Katzen H, Whitehouse PJ, Barber M, Post SG, et al. Reasons for seeking genetic susceptibility testing among first-degree relatives of people with Alzheimer disease. *Alzheimer Dis Assoc Disord*. 2003; 17:86–93. [PubMed: 12794385]
16. Streckenrider J. What people know about Alzheimer's disease: A study of public knowledge. *Am J Alzheimers Dis Other Dement*. 1993; 8:6–14.
17. Anderson LA, Day KL, Beard RL, Reed PS, Wu B. The public's perceptions about cognitive health and Alzheimer's disease among the U.S. population: A national review. *Gerontologist*. 2009; 49(Suppl 1):S3–11. [PubMed: 19525214]
18. Juster FT, Suzman R. An overview of the Health and Retirement Study. *J Hum Resour*. 1995; 30:S7–56.
19. Roberts JS, Connell CM. Illness representations among first-degree relatives of people with Alzheimer disease. *Alzheimer Dis Assoc Disord*. 2000; 14:129–36. discussion 7–8. [PubMed: 10994653]
20. Carpenter BD, Balsis S, Otilingam PG, Hanson PK, Gatz M. The Alzheimer's Disease Knowledge Scale: development and psychometric properties. *Gerontologist*. 2009; 49:236–47. [PubMed: 19363018]
21. Heeringa, SG.; Connor, JH. Technical description of the Health and Retirement Survey sample design. Ann Arbor, MI: Institute for Social Research; 1995.
22. Barnes DE, Yaffe K. The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurol*. 2011; 10:819–28. [PubMed: 21775213]
23. Cutler SJ, Hodgson LG. Anticipatory dementia: A link between memory appraisals and concerns about developing Alzheimer's disease. *Gerontologist*. 1996; 36:657–64. [PubMed: 8942109]
24. Goldman JS, Hahn SE, Catania JW, LaRusse-Eckert S, Butson MB, Rumbaugh M, et al. Genetic counseling and testing for Alzheimer disease: Joint practice guidelines of the American College of Medical Genetics and the National Society of Genetic Counselors. *Genet Med*. 2011; 13:597–605. [PubMed: 21577118]
25. Post SG, Whitehouse PJ, Binstock RH, Bird TD, Eckert SK, Farrer LA, et al. The clinical introduction of genetic testing for Alzheimer disease. An ethical perspective. *J Am Med Assoc*. 1997; 277:832–6.

26. Neumann PJ, Cohen JT, Hammitt JK, Concannon TW, Auerbach HR, Fang C, et al. Willingness-to-pay for predictive tests with no immediate treatment implications: a survey of US residents. *Health Econ.* 2012; 21:238–51. [PubMed: 22271512]
27. Neumann PJ, Hammitt JK, Mueller C, Fillit HM, Hill J, Tetteh NA, et al. Public attitudes about genetic testing for Alzheimer's disease. *Health Aff (Millwood).* 2001; 20:252–64. [PubMed: 11558711]
28. Chao S, Roberts JS, Marteau TM, Sillman R, Cupples LA, Green RC. Health behavior changes after genetic risk assessment for Alzheimer disease: The REVEAL Study. *Alzheimer Dis Assoc Disord.* 2008; 22:94–7. [PubMed: 18317253]
29. Roberts JS, Cupples LA, Relkin NR, Whitehouse PJ, Green RC. REVEAL (Risk Evaluation and Education for Alzheimer's Disease) Study Group. Genetic risk assessment for adult children of people with Alzheimer's disease: The Risk Evaluation and Education for Alzheimer's Disease (REVEAL) study. *J Geriatr Psychiatry Neurol.* 2005; 18:250–5. [PubMed: 16306249]
30. Roberts JS, Barber M, Brown TM, Cupples LA, Farrer LA, LaRusse SA, et al. Who seeks genetic susceptibility testing for Alzheimer's disease? Findings from a multisite, randomized clinical trial. *Genet Med.* 2004; 6:197–203. [PubMed: 15266207]
31. Roberts JS, Christensen KD, Green RC. Using Alzheimer's disease as a model for genetic risk disclosure: Implications for personal genomics. *Clin Genet.* 2011; 80:407–14. [PubMed: 21696382]
32. Lock M, Freeman J, Sharpies R, Lloyd S. When it runs in the family: Putting susceptibility genes in perspective. *Public Underst Sci.* 2006; 15:277–300.
33. Perls TT. Anti-aging quackery: Human growth hormone and tricks of the trade—more dangerous than ever. *J Gerontol A Biol.* 2004; 59:682–91.
34. Vernarelli JA, Roberts JS, Hiraki S, Chen CA, Cupples LA, Green RC. Effect of Alzheimer disease genetic risk disclosure on dietary supplement use. *Am J Clin Nutr.* 2010; 91:1402–7. [PubMed: 20219963]
35. Weinman J, Petrie KJ, Moss-Morris R. The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychol Health.* 1996; 11:43–5.
36. Suhr JA, Kinkela JH. Perceived threat of Alzheimer disease (AD): The role of personal experience with AD. *Alzheimer Dis Assoc Disord.* 2007; 21:225–31. [PubMed: 17804955]
37. Friedman DB, Laditka SB, Laditka JN, Wu B, Liu R, Price AE, et al. Ethnically diverse older adults' beliefs about staying mentally sharp. *Int J Aging Hum Dev.* 2011; 73:27–52. [PubMed: 21922798]

Reserach in Context

1. Systematic review: The authors used their knowledge of the literature based on prior related work as well as PubMed searches using relevant keywords. Survey items were selected from published scales on the basis of their relevance to beliefs/knowledge about risk and protective factors for AD.
2. Interpretation: Findings demonstrate how older adults view potential risk and protective factors for AD and identify commonly held misconceptions (e.g., lack of awareness about treatment/prevention options and the association of family history with increased risk). Such issues have been examined in prior work but not in a large, nationally representative sample of older adults.
3. Future directions: Additional work should examine how older adults' beliefs and knowledge about AD affect their health behaviors, including efforts to reduce risk of dementia and decisions to seek out diagnosis and treatment options. Examining a broader range of illness perceptions would also be useful.

Table 1
Sample demographics and experience with AD (N = 1641)

	% (<i>n</i>) or mean (SE)
Age (years)	64.4 (0.4)
Female	53.6 (917)
Race and ethnicity	
Hispanic	8.0 (212)
Non-Hispanic Black	10.3 (312)
Non-Hispanic White	81.7 (1117)
Highest educational degree	
No degree	12.6 (311)
GED or high-school diploma	53.4 (889)
2-year college degree	34.0 (441)
Knows someone with AD	
No	36.2 (622)
Yes, but not a spouse/partner, parent, sibling, or adult child	50.5 (807)
Yes, a spouse/partner, parent, sibling, or adult child has AD	13.3 (212)

Abbreviations: AD, Alzheimer's disease; GED, General Educational Development.
 Note. Percentages are weighted; sample numbers (*n*) are not weighted.

Table 2
Responses to perceived threat of AD and AD knowledge items (N = 1641)

Items	Response
Perceived threat	Somewhat or strongly agree, % (<i>n</i>)
You would like to know your chances of someday getting Alzheimer's.	60.1 (983)
You believe you will get Alzheimer's someday.	22.9 (401)
You worry about getting Alzheimer's someday.	29.4 (491)
Knowledge (correct answer)	Correct answer, % (<i>n</i>)
Prescription drugs that prevent AD are available (false).	60.9 (917)
Having a parent or sibling with AD increases the chance of developing it (true).	68.0 (1037)

Abbreviation: AD, Alzheimer's disease.

Note. Percentages are weighted; sample numbers (*n*) are not weighted. Four or five data points are missing for all items.

Table 3
Perceptions of risk and protective factors for Alzheimer's disease

Risk factors	Don't know % (n)	Not at all important % (n)	Somewhat important % (n)	Very important % (n)
Genetics	1.8 (44)	9.3 (173)	37.6 (632)	51.3 (786)
Stress	3.4 (50)	41.3 (599)	34.8 (575)	20.5 (410)
Protective factors	Don't know % (n)	Not at all effective % (n)	Somewhat effective % (n)	Very effective % (n)
Keeping mentally active	0.9 (21)	6.2 (115)	31.5 (472)	61.4 (1027)
Eating a healthy diet	1.3 (27)	11.4 (218)	43.0 (612)	44.3 (778)
Keeping physically active	1.1 (26)	11.1 (198)	47.2 (675)	40.6 (735)
Taking vitamins/dietary supplements	1.6 (37)	27.7 (451)	50.2 (769)	20.5 (378)

Note. Percentages are weighted; sample numbers (*n*) are not weighted. Six or seven data points are missing for all items.

Table 4
Adjusted OR for likelihood of endorsing AD perceived threat and AD knowledge items

Participant characteristic	Perceived threat items			Knowledge items		
	You'd like to know your chances of getting AD	You believe you will get AD someday	You worry about getting AD someday	Prescription drugs to prevent AD are available	Having a parent or sibling with AD increases risk	
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Age, years						
50–64	2.04 (1.53–2.72)	1.29 (0.92–1.82)	1.43 (1.01–2.04)	1.05 (0.74–1.50)	2.30 (1.70–3.12)	
65–74	1.41 (1.05–1.91)	1.04 (0.71–1.53)	1.24 (0.88–1.77)	1.05 (0.76–1.46)	2.08 (1.55–2.79)	
75	1.00	1.00	1.00	1.00	1.00	
Female	1.01 (0.75–1.36)	0.83 (0.59–1.18)	1.32 (0.99–1.76)	0.77 (0.60–1.00)	1.70 (1.27–2.28)	
Race/ethnicity						
Hispanic	1.12 (0.68–1.83)	1.60 (1.05–2.44)	1.19 (0.72–1.95)	0.80 (0.54–1.18)	0.84 (0.56–1.26)	
Black	1.16 (0.74–1.82)	1.26 (0.81–1.95)	0.81 (0.57–1.16)	0.74 (0.48–1.14)	0.36 (0.24–0.52)	
White						
Education						
No degree	1.10 (0.70–1.74)	3.17 (2.05–4.91)	1.55 (0.92–2.63)	0.24 (0.16–0.36)	0.63 (0.40–0.98)	
High school/GED	1.13 (0.78–1.62)	1.54 (1.07–2.21)	1.01 (0.70–1.47)	0.37 (0.26–0.52)	0.58 (0.40–0.84)	
2-year college degree	1.00	1.00	1.00	1.00	1.00	
Know anyone with AD?						
No	0.60 (0.39–0.92)	0.26 (0.17–0.41)	0.29 (0.19–0.44)	0.84 (0.55–1.28)	0.70 (0.44–1.09)	
Yes, but not a spouse or first-degree relative	0.67 (0.42–1.06)	0.31 (0.20–0.50)	0.41 (0.26–0.66)	0.93 (0.58–1.49)	0.94 (0.64–1.38)	
Yes, a spouse or first-degree relative	1.00	1.00	1.00	1.00	1.00	

Abbreviations: AD, Alzheimer's disease; CI, confidence interval; GED, General Educational Development; OR, odds ratio. Note. All data are weighted, and there were between 4 and 5 missing data points across items. Statistically significant results are noted in bold.

Table 5
Adjusted OR for likelihood of endorsing perceived risk and protective factors for AD

Participant characteristic	Perceived risk factors			Perceived protective factors		
	Stress	Genetics		Keeping physically active	Keeping mentally active	Eating a healthy diet
	OR (95% CI)	OR (95% CI)		OR (95% CI)	OR (95% CI)	OR (95% CI)
Age, years						
50-64	0.95 (0.69-1.31)	2.56 (1.89-3.48)	0.61 (0.46-0.79)	0.89 (0.67-1.19)	0.98 (0.73-1.31)	1.07 (0.69-1.66)
65-74	1.22 (0.82-1.80)	2.08 (1.58-2.73)	0.85 (0.60-1.20)	1.09 (0.83-1.43)	1.06 (0.79-1.42)	1.51 (1.10-2.09)
75	1.00	1.00	1.00	1.00	1.00	1.00
Female	0.66 (0.46-0.95)	1.38 (1.09-1.76)	1.02 (0.79-1.31)	1.02 (0.80-1.30)	1.31 (1.05-1.65)	1.17 (0.88-1.55)
Race/ethnicity						
Hispanic	2.51 (1.46-4.31)	1.03 (0.70-1.53)	1.13 (0.77-1.66)	0.91 (0.53-1.53)	1.49 (0.90-2.45)	1.56 (1.03-2.36)
Black	4.17 (2.78-6.24)	0.76 (0.47-1.23)	1.51 (1.11-2.06)	1.11 (0.79-1.54)	1.71 (1.31-2.24)	2.05 (1.35-3.12)
White	1.00	1.00	1.00	1.00	1.00	1.00
Education						
No degree	3.67 (2.13-6.32)	0.81 (0.52-1.27)	1.13 (0.78-1.65)	0.80 (0.53-1.21)	1.51 (0.98-2.33)	2.15 (1.28-3.60)
High school/GED	1.95 (1.24-3.07)	0.96 (0.69-1.35)	1.21 (0.88-1.66)	1.27 (0.93-1.72)	1.49 (1.12-1.98)	1.55 (1.11-2.17)
2-year college degree	1.00	1.00	1.00	1.00	1.00	1.00
Know anyone with AD?						
No	0.54 (0.33-0.88)	0.81 (0.53-1.23)	1.28 (0.85-1.93)	1.29 (0.87-1.91)	1.07 (0.69-1.66)	1.93 (1.12-3.32)
Yes, but not a spouse or first-degree relative	0.55 (0.34-0.88)	1.13 (0.72-1.76)	1.29 (0.81-2.04)	1.47 (0.87-2.48)	1.05 (0.66-1.66)	1.82 (1.03-3.22)
Yes, a spouse or first-degree relative	1.00	1.00	1.00	1.00	1.00	1.00

Abbreviations: AD, Alzheimer's disease; CI, confidence interval; GED, General Educational Development; OR, odds ratio. Note. All data are weighted; 6 or 7 missing values across items. Statistically significant results are noted in bold.