



Research Article

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

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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.

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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

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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 ($P \geq .19$ in all cases).

2.2. Survey items

All investigators who conduct supplementary survey modules via HRS are asked to limit the time of comple-

tion 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 the 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

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