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Featured Article

What features of stigma do the public most commonly attribute to Alzheimer's disease dementia? Results of a survey of the U.S. general public

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Abstract

Introduction: Understanding the prevalence of beliefs, attitudes, and expectations about Alzheimer's disease dementia in the public could inform strategies to mitigate stigma.

Methods: Random sample of 317 adults from the U.S. public was analyzed to understand reactions toward a man with mild-stage Alzheimer's disease dementia.

Results: In adjusted analyses, over half of respondents expected the person to be discriminated against by employers (55.3%; 95% confidence interval [CI] = 47.0–65.2) and be excluded from medical decision-making (55.3%; 95% CI = 46.9–65.4). Almost half expected his health insurance would be limited based on data in the medical record (46.6%; 95% CI = 38.0–57.2), a brain imaging result (45.6%, 95% CI = 37.0–56.3), or genetic test result (44.7%; 95% CI = 36.0–55.4).

Discussion: Public education and policies are needed to address concerns about employment and insurance discrimination. Studies are needed to discover how advances in diagnosis and treatment may change Alzheimer's disease stigma.

Keywords: Alzheimer's disease; Stigma; General public; Policy; Program development

1. Background

Alzheimer's disease (AD) presents a unique challenge. It is the only top 10 cause of disability that does not have a therapy to slow its progression [1]. Several large clinical trials are actively studying individuals to discover potential therapies by 2025 [1]. The success of these trials, however, depends upon individuals being willing to undergo gene and biomarker testing and learn the related risk of AD dementia. AD stigma presents an obstacle to them doing this [1,2].

Stigma of AD dementia can take the form of one or more of a collection of beliefs, behaviors, and attitudes. The assumptions made about AD and people with the disease often reflect those that confirm stereotypes about symptoms or functional abilities. These stereotypes often depict the later stages of disease when a person is most impaired and fully dependent upon others for care [3–6]. As a result of these negative expectations, stigma can discourage a person from seeking diagnosis, educating themselves about the disease, and participating in research [2,7–9]. It can also lead people to react poorly such as patronizing, isolating, and discriminating against a person with the disease [10–12].

Stigma of AD dementia can differ based on one's personal characteristics and beliefs about a disease. As

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compared to no diagnosis, a diagnosis of AD dementia can mitigate against some forms of stigma, such as harsh judgments about a person's poor hygiene or esthetics stage [13]. But its prognosis—that symptoms are expected to worsen over time—can exacerbate discrimination, pity, and social distance. Belief that AD dementia is a mental illness exacerbates how individuals judge the severity of a person's symptoms [14]. Other personal characteristics of a person, such as age and gender, can also affect how they judge or react to someone with AD dementia [14].

Understanding the composition of beliefs, attitudes, and expectations about AD dementia held by the general public could help inform specific strategies to mitigate stigma and its consequences. If, for example, members of the general public do not only worry that a person with AD dementia faces discrimination [14] but also worry specifically that a confirmatory genetic test for AD could make a person vulnerable to being discriminated against by health insurance purveyors, this knowledge would be valuable for informing how to direct public education about certain policies, such as the Genetic Information Nondiscrimination Act of 2008 (GINA) [15] that offers protections against gene-based health care insurance discrimination. Alternatively, such information could help identify gaps in current policy protections, whereby concerns among the public are common, but policy protections are lacking or insufficient. Together, this information could be useful for understanding factors that deter individuals from seeking care or enrolling in AD research.

The purpose of this study was to understand what features or attributes are most commonly paired with AD dementia by the public. Based on prior studies [13,14], we hypothesized that concerns about discrimination and the propensity to overattribute the severity to symptoms would be among the most prevalent. Among those most common, we sought to determine whether their prevalence differed based on characteristics of population subgroups. We expected that older respondents would be more likely to expect a person with AD would encounter employment discrimination and that African American respondents would be less likely than white respondents to expect a person with AD would be excluded from medical decision-making. Understanding which attributes are most often associated with AD dementia by the public may help identify the most overt and wide-reaching concerns related to the disease, which may help inform interventional programs and policy changes to reduce AD stigma.

2. Methods

2.1. Study design

This is a secondary analysis of how a random sample of adults from the general U.S. public reacted to a fictional description of a person with mild-stage AD dementia. The data analyzed in the present study are a subset of those used in studies [13] and [14].

2.2. Data source

Data were obtained from an experimental study that examined whether the cause and prognosis of mild dementia were related to how adults in the general population judged a person with mild AD dementia. The study asked respondents to read a vignette and then complete a survey. Respondents were recruited from September 5 through 13, 2013, by an online panel provider. The demographic profiles of online panels have been shown to be representative of the U.S. general population [16].

The survey was distributed to a random sample likely to be adults in the United States who were able to provide informed consent and read English. The survey completion rate was 58%. Respondents were asked to provide standard demographic information. The collection of race and ethnicity information was informed by the Census Alternative Questionnaire Experiment [17]. Respondents were asked to self-identify by race or ethnicity or by multiple races.

The original study used a 3×3 factorial design whereby consenting adults ($N = 1025$) were assigned to one of nine conditions using unrestricted simple randomization [18]. In the present study, we analyzed data from 317 of those respondents randomized to three of the nine conditions. All of these respondents were told the cause of the mild-stage dementia was AD. The three conditions differed based on whether they were told the person's condition would (1) worsen, (2) improve, or (3) remain unchanged. A fuller description of the design and randomization is available elsewhere [14].

2.3. Vignette design

The original study used vignettes to examine how diagnostic label and prognosis contributed to attitudes, emotions, and expectations expressed by the general public. The study was described to participants as being about "health beliefs" and did not mention AD during recruitment or consent.

The vignette described a man suffering from impairments typical of the mild stage of AD dementia. The symptoms described were consistent with observable impairments in six domains of the Clinical Dementia Rating scale [19]: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care.

To personalize the vignette, the character was given a name, Mr. Andrews, and referred to as "he." Pilot versions of the survey included male and female versions of the vignette, but restrictions in sample size required reducing the number of vignettes. Interest in being consistent with previous research in which vignettes relied on male characters [11] favored retaining the male version of the vignette. Studies of AD dementia that have experimentally varied