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.

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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
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 person with AD dementia could help inform general population subgroups. 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 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].

2.2. 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
the gender of nonfamilial vignette characters have not found appreciable differences in reactions among the general public [20,21]. No other demographic characteristics of the vignette character were given.

After reading the vignette, respondents were given a comprehension test to confirm that they accurately understood the salient details. They had two opportunities to answer correctly. Those who failed on the second attempt were excluded (Supplementary Fig. A). After this exclusion, the final sample in the present study included data from 317 respondents.

2.4. Study measures

A modified version of the Family Stigma in Alzheimer’s Disease Scale (FS-ADS [22]) was used to assess the beliefs, feelings, and expectations of respondents. Some items on the original instrument were adapted for understandability and relevance in the context of the present study (see Supplementary Materials in the study by Johnson et al. [13]). The modified FS-ADS asked respondents how likely they believed the person (described in the vignette) would be to have his health care insurance limited due to documentation in his medical record, due to a result from a brain scan, or due to a result from a genetic test. Respondents were also asked the extent to which they expected the person would be discriminated against by employers, excluded from voting or medical decision-making, or exhibit certain symptoms such as not remembering recent events, failing at simple tasks, or suffering incontinence. In addition, respondents were asked about their expectations for the person’s esthetics—like whether they expected the person to have poor hygiene or neglect self-care—and the extent to which they expected people would be disgusted or repulsed by the person. Respondents were asked the extent to which they expected others to feel concern, compassion, sadness, pity, or to behave in ways that ignored, isolated, or helped the person. Responses were on a scale from 1 to 5 with higher scores indicating stronger endorsement.

A shortened Alzheimer’s Disease Knowledge Scale (ADKS [23]) was used to evaluate general knowledge of Alzheimer’s disease. The abbreviated instrument omitted eight items on the original assessment because they could have been answered using information in the vignette [13]. Respondents were also asked to rate the degree that they felt the person’s condition (i.e., AD) was a mental illness from “not at all” (1) to “a very great extent” (5). A fuller description of the study’s methods is available elsewhere [13].

2.5. Statistical analysis

Responses of four and five on the FS-ADS were considered a positive result in the present study. This cut point was consistent with the 50th percentile or above on all items and the 75th percentile or above on 21 of 44 items. Adjusted generalized linear models with a log link were used to estimate the percentage of the respondents who strongly endorsed each item on the modified FS-ADS. These models adjusted for study prognostic condition (i.e., static, improve, and worsen). To mitigate family-wise errors of the first kind, a limited number of items were carried forward for further analysis [24]; those endorsed by 60% or more of respondents in the condition where the person’s prognosis was expected to worsen.

In separate bivariate analyses, we used generalized linear models with a log link to estimate the percentages of respondents strongly endorsing each outcome when they were told the person’s condition would worsen, improve, or remain unchanged over time. In these analyses, estimates with 95% confidence intervals (CIs) that do not overlap are statistically significant at \( P < .05 \). To build a multivariate model, we used forward step-wise selection in multivariable generalized linear models to construct statistical models that adjusted for interrelationships among respondent characteristics (Alpha-to-Keep \( \leq .20 \)). Candidate covariates were all assessed demographic characteristics, general knowledge about AD, and strength of belief that this disease was a mental illness. We then entered the retained covariates together into a multivariate analysis that statistically adjusted for variance shared among the outcomes. We report differences in percentages of respondent endorsement for each outcome and their respective 95% CIs. In these

| Table 1 Characteristics of random sample of adult general public (N = 317) |
|------------------|------------------|
| Respondent characteristic | Alzheimer’s disease (N = 317) |
| Age, median (IQR) | 49 (29) |
| 65+ years, % (n) | 19.1 (61) |
| Females, % (n) | 49.0 (156) |
| Race/ethnicity, % (n) | |
| White, non-Latino | 80.4 (255) |
| African American, non-Latino | 7.3 (23) |
| Other* | 12.3 (39) |
| Education, % (n) | |
| High school/GED or less | 23.7 (75) |
| Some college or 2-year degree | 41.6 (132) |
| 4-year college degree or beyond | 34.7 (100) |
| Caregiver (past or present), % (n) | 6.0 (19) |
| Urban/metro setting, % (n) | 78.5 (249) |
| Mental Illness Rating, median (IQR) | 3 (3) |
| Alzheimer’s Disease Knowledge Scale (ADKS), median (IQR) | 15 (5) |

Abbreviations: GED, General Education Diploma; IQR, interquartile ratio.

NOTE. Column percentages may not total 100 due to rounding.

*Category includes those who identified as Asian, Native American, multiple races, Hispanic or Latino only, other, or did not respond (n = 4).

1Reported past or current primary caregiver of a person with Alzheimer’s disease.

2Resides in urban rather than rural area based on Rural Urban Commuting Area (RUCA) classifications. Urban areas included RUCA classes 1 to 3 and rural included classes 4 to 10.

Respondents were also asked to rate the degree that the condition described in the vignette was a mental illness from “not at all” (1) to “a very great extent” (5).
analyses, estimates with 95% CIs that do not include zero are statistically different from zero \((P < .05)\). The multivariable analyses have at least 89% power to detect a difference of 8% or more.

Respondents’ caregiver status was excluded from analysis because small group size prohibited comparisons \((n = 19)\) and its inclusion did not substantively alter the main results [25]. All independent variables were screened for multicollinearity (correlation coefficient \(r > 0.7\)). In analyses that adjusted for multiple comparisons, all independent variables were screened for interactions with the study prognostic category \((P > 5.0)\). All statistical tests were two sided. \(P\) values \(\leq .05\) were considered statistically significant. All statistical analyses were performed using Stata 14 (College Station, TX).

3. Results

3.1. Respondent characteristics

In a sample of 317 adults in the general public, respondents’ median age was 49 years (interquartile ratio 29),
Table 4

<table>
<thead>
<tr>
<th>Disease attribute</th>
<th>Exclusion from medical decision-making</th>
<th>Employment discrimination</th>
<th>Insurance limited due to data in medical record</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female vs. male</td>
<td>7.9 (2.2-17.7)</td>
<td>11.5* (1.5–21.5)</td>
<td>17.4** (6.6–28.1)</td>
</tr>
<tr>
<td>Age 50+ vs. under 50 yrs</td>
<td>11.5* (1.5–21.5)</td>
<td>20.6** (4.4–36.9)</td>
<td>36.9–56.3)</td>
</tr>
<tr>
<td>Black vs. white</td>
<td>0.2 (0.04 to 2.1)</td>
<td>3.3 (1.0–10.3)</td>
<td>12.0–31.1)</td>
</tr>
<tr>
<td>College vs. HS</td>
<td>2.1 (0.5–9.4)</td>
<td>7.4 (2.1–26.4)</td>
<td>26.4–72.4)</td>
</tr>
<tr>
<td>Strong belief AD is a mental illness</td>
<td>17.6*** (7.5–27.7)</td>
<td>8.1 (2.8–19.0)</td>
<td>12.0–31.1)</td>
</tr>
</tbody>
</table>

Abbreviations: AD, Alzheimer's disease; HS, high school or less; 95% CI, 95% confidence interval.

NOTE. Results from multivariate analysis of variance that adjust for covariates and variance shared among outcomes. Estimates that do not include zero are statistically significant at \( P < .05 \).

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In a multivariate analysis, African American respondents were 20.6% (95% CI = -40.6 to -0.6) less likely than white respondents to expect the person with AD dementia would encounter employment discrimination (Table 4). They were also less likely than white respondents to expect about half (49%) were female, most (80%) self-identified as white (non-Latino), and over half (65%) had less than a 4-year college degree (Table 1).

In analyses that adjusted statistically for study prognostic condition, about three-quarters of respondents expected that a person with mild-stage AD dementia would not remember most recent events (73.8%; 95% CI = 65.8–82.7). In adjusted analyses, over half of respondents expected a person with AD dementia would be discriminated against by employers (55.3%; 95% CI = 47.0–65.2) and would be excluded from medical decision-making (55.3%; 95% CI = 46.9–65.4; Table 2). Similarly, high percentages expected the person would have his health care insurance limited due to data in the medical record (46.6%; 95% CI = 38.0–57.2) or have his health care insurance limited due to a brain imaging result (45.6%; 95% CI = 37.0–56.3).

3.2. Effects of AD prognosis

When explicitly informed that the condition of the person with AD dementia would worsen over time, most respondents expected the person would encounter employment discrimination (78.4%; 95% CI = 70.4–86.5; Table 3). This percentage was substantially higher than when respondents were told that the person’s condition either would improve (63.4%; 95% CI = 54.4–72.4) or would remain unchanged (55.3%; 95% CI = 45.7–65.0).

When informed that the condition of the person with AD dementia would worsen over time, most respondents expected the person would have his health care insurance limited due to data in the medical record (65.7%; 95% CI = 56.4–75.0) or due to a brain imaging result (62.7%; 95% CI = 53.3–72.2). Both estimates were substantially higher than when respondents were told the person’s condition would improve or remain unchanged over time, 46.6% (95% CI = 36.9–56.3) and 45.6% (95% CI = 35.9–55.3), respectively.

About three-quarters of those told the condition of the person with AD dementia would worsen over time expected that the person would be excluded from medical decision-making (73.5%; 95% CI = 64.9–82.2). This percentage was about 33% higher than that for respondents told the person’s condition would improve over time (55.3%; 95% CI = 45.7–65.0). No statistically discernible difference was observed between respondents who were told the person’s condition would worsen and those who were told the person’s condition would remain unchanged (\( P > .05 \)).

3.3. Effects of personal characteristics, knowledge about AD dementia, and belief that AD is a mental illness

In a multivariate analysis, African American respondents were 20.6% (95% CI = -40.6 to -0.6) less likely than white respondents to expect the person with AD dementia would encounter employment discrimination (Table 4). They were also less likely than white respondents to expect...
the person would have his health care insurance limited due to information in the medical record (−30.8%; 95% CI = −51.8 to −9.9) or have his health care insurance limited due to a brain imaging result (−33.2%; 95% CI = −54.3 to −12.1). In addition, they were 26.4% (95% CI = −46.8 to −5.9) less likely than white respondents to expect the person would be excluded from medical decision-making.

Respondents aged 50 years and older were 17.4% (95% CI = 6.6–28.1) more likely than younger adults to expect that the person with AD dementia would encounter employment discrimination. They were also more likely than those under age 50 to expect the person with AD dementia would have his health care insurance limited due to data in the medical record (13.7%; 95% CI = 2.5–25.0) and to expect that he would not remember most recent events (11.5%; 95% CI = 1.5–21.5).

Compared to those with weaker beliefs, respondents believing strongly that AD was a mental illness were more likely to expect a person with mild-stage AD dementia would not remember most recent events (17.6%; 95% CI = 7.5–27.7). They were also more likely to expect that the person would have his health care insurance limited due to a brain imaging result (17.4%; 95% CI = 5.9–28.9).

4. Discussion

Analyses of a sample of 317 adults in the U.S. general population showed that the most common features attributed to a person with mild-stage AD dementia were expecting the person would not remember most recent events (73.8%), would be discriminated against by employers (55.3%), and would be excluded from medical decision-making (55.3%). The least common attributes included expecting the person would be unkempt (11.7%), neglect self-care (6.8%), and have a bad odor (5.8%). These findings were consistent with our earlier study that found the diagnosis of AD dementia mitigates against negative judgments about a person’s esthetic characteristics [13].

We found that almost half of respondents expected that, as a result of having an AD diagnosis, a person would have his health care insurance limited because of data in the medical record (46.6%) or due to a brain imaging result (45.6%) or due to a genetic test result (44.7%). Our findings have implications for the success of the national Alzheimer’s plan’s goal of developing an effective therapy by 2025 [1,2]. To achieve the ambitious goal, individuals with mild or even no symptoms of AD dementia are currently being asked to enroll in prevention trials. These candidates are being identified and enrolled into prevention trials based on results of gene and biomarker testing that places them at elevated risk for developing the disease. Our findings suggest, however, that many people expect that gene and biomarker testing could result in health care insurance capitations. These expectations may affect a person’s willingness to learn AD gene and biomarker test results. This could substantially impede the success of prevention trials, which are dependent, for purposes of recruitment and the underlying science, on persons undergoing gene and biomarker testing and learning those results.

Educating the public about GINA [15], which offers protections against gene-based health care insurance discrimination, may help address some of the public’s concerns. However, our findings suggest the public’s concerns also include issues unaddressed by GINA [26,27]. For example, while GINA offers protections for genetic test results, it does not extend to all types of testing, such as brain imaging results [28]. Moreover, it does not offer protections for long-term care insurance, which is often a key factor for persons undergoing AD gene and biomarker testing [29,30].

Reducing public stigma of AD is important for facilitating the success of Alzheimer’s prevention research [1,2]. Reciprocally, research advances may help to mitigate AD stigma. In randomized comparisons, we found that when told the person’s prognosis would improve over time, 24% to 41% fewer respondents expected that the person would encounter discrimination or exclusion than when told the person’s prognosis would worsen (Table 3). Thus, advances in therapies that improve the prognosis of AD could help reduce stigma.

Current efforts to discover therapies for AD contrast that of “improving” impaired functioning. These innovations focus on discovering interventions—behavioral and pharmaceutical—that interrupt the underlying neuropathophysiology in persons with no or mild symptoms [31]. In turn, this would slow or prevent cognitive and physical declines. In our study, with one exception, the fact that the person’s condition would remain unchanged showed no differences compared to the current status quo, whereby the person’s condition worsened over time. Our findings suggest that how advances in the science of AD therapies are communicated—as offering improved longevity versus retaining functioning or preventing declines—could radically affect the social and psychological experience of the disease. Studies are needed to understand how advances in diagnosis, testing, and treatment may shift AD stigma and to help position these advances as opportunities to reduce AD stigma.

We assessed whether respondents reacted differently to a person with AD dementia based on whether they self-identified as white, African American, or another race. Given that as a social group, African Americans do not hold the majority’s social power, which is essential for being able to create stigma [9,32], and that they have a higher probability of direct contact with persons with AD dementia, which aids in mitigating stigma [33], we expected AD stigma would be less common among this group than white respondents. In a multivariate analysis, we found support for our hypothesis; African American respondents were less likely than white respondents to endorse all but one of the five attributions. Our findings provide pilot data that suggest further research in this area is warranted. Understanding whether these findings are replicable with larger samples and, if so, how other factors like beliefs about prognosis,
Our results are consistent with prior studies that have found members of the general public can react differently toward a person with AD dementia based on their ages [14,34]. In the present study, we found that older age and stronger belief that AD dementia was a mental illness were related to how respondents reacted to the person with AD dementia. These findings suggest that, in addition to ensuring appropriate policy protections exist, it may be necessary to focus on distributing information about these policies within certain population subgroups.

A strength of this study is that the sample was drawn randomly from a large national panel. This type of panel has been found to be representative of the general population [16]. Moreover, respondents were randomized to the diagnosis and prognosis categories. Selection of a random sample and the random assignment of that sample to the study categories lends to the robustness of our findings. However, our sample of 317 is small to adequately reflect the diversity of the large U.S. general population. We acknowledge that our sample approximates the age, gender, and race composition of the general population. It also approximates the distribution for educational attainment when adjusted for race-based disparities. But, particularly given its size, it cannot be fully representative of the nation. Further research with large random samples of the general population is needed to derive more precise estimates and to understand how stigma of AD may differ across divergent racial, ethnic, and socioeconomic groups [34–37]. In addition, our vignette described a specific patient with symptoms of mild-stage dementia. Results to date from similar studies—particularly those that have experimentally varied the gender of the vignette character—have not found appreciable differences in reactions among the general public–based gender of the vignette character. However, they have found evidence that suggests a person’s judgments about social roles, such as the vignette character’s identification as a “mother” or “father” can affect how that person judge’s someone with AD [20,21,38]. It is an area that warrants further investigation. Moreover, although we did not find statistically significant differences based on respondent gender, our analyses may not have had sufficient statistical power to detect these differences, which ranged from 1% to 10.7% (Table 4).

4.1. Implications

Public education and policies are needed to address expectations of employment and insurance discrimination related to gene and biomarker risk data. In addition, it is unlikely that advances in therapies will serendipitously reduce AD stigma. Studies are needed to understand how advances in diagnosis, testing, and treatment may shift AD stigma and to help position these advances as opportunities to reduce AD stigma.

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Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.jalz.2018.01.006.

RESEARCH IN CONTEXT

1. Systematic review: We surveyed a random sample of the general population to learn what beliefs, attitudes, and expectations are most often associated with Alzheimer’s disease (AD) dementia. This information may help inform strategies to mitigate stigma.

2. Interpretation: People expected a person with AD would be discriminated against by employers, excluded from medical decision-making, and have his health insurance limited due to documentation in the medical record, a brain imaging result, or a genetic test result. Our results suggest that the general public may need education about existing policy protections. In cases where clearly no protections exist, our results support the need for policy development.

3. Future directions: Our findings call for research to understand how advances in diagnosis, testing, and treatment may shift AD stigma and to help position these advances as opportunities to reduce AD stigma.

References