Effects of Advances in Biomarker-Based Diagnosis and Disease-Modifying Treatment on Alzheimer’s Disease Stigma

Shana D. Stites, PsyD1, Jeanine Gill, BS2, Emily A. Largent, JD, PhD, RN2, Kristin Harkins, MPH1, Cara Fallon, PhD, MPH2, Abba Krieger, PhD3, Pamela Sankar, PhD2 & Jason Karlawish MD1

1Perelman School of Medicine at the University of Pennsylvania

Background

- Alzheimer’s disease (AD) causes progressive disability and, ultimately, death. Currently no therapy can delay or slow cognitive and functional decline. Poor prognosis contributes to the general public’s negative reactions toward individuals with AD.1,2
- The purpose of this study is to discover how diagnosis and treatment of AD before the onset of cognitive impairment (i.e., in a preclinical phase) would change public stigma.

Methods

- A random sample of 1,817 adults was drawn from a nationally representative survey panel.
- Respondents read about AD and answered a comprehension question. Those who answered correctly were randomized to read a vignette about a fictional character. Each vignette varied the character’s biomarker test result (positive vs negative), treatment (available vs not available), level of cognitive impairment (Clinical Dementia Rating (CDR) categories 0 (none), 1 (mild), and 2 (moderate)). Vignettes were balanced for the character’s sex (female or male) and age (60, 70, or 80 years old).
- The modified Family Stigma in Alzheimer’s Disease Scale (FS-ADS) measured 7 empirically-derived domains:
  - Structural Discrimination - worrying about institutional discrimination
  - Negative Severity Attributions - expecting symptoms like speaking repetitively or suffering incontinence
  - Negative Aesthetic Attributions - expecting traits like poor hygiene or neglected self-care
  - Antipathy - endorsing feelings of disgust or repulsion
  - Support - expecting others would feel concern, compassion, or be willing to help
  - Pity - expecting others would feel sympathy, sadness, or pity
  - Social Distance - expecting limited social contact
- Ordered logistic regressions were used to examine differences in the probability of higher responses on the FS-ADS.

Table 1

<table>
<thead>
<tr>
<th>Ref. (1)</th>
<th>Structural Discrimination</th>
<th>Negative Severity Attributions</th>
<th>Negative Aesthetic Attributions</th>
<th>Antipathy</th>
<th>Support</th>
<th>Pity</th>
<th>Social Distance</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.12</td>
<td>10</td>
<td>8</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>0.12</td>
</tr>
</tbody>
</table>

Randomized Comparisons:

- Alzheimer’s disease knowledge scale. Maximum possible score = 30.
- Respondents were asked how much time they personally spent with a person with AD dementia; response options ranged in frequency and intensity from “rarely or never” to “every day for many hours.”

Conclusions

References


Acknowledgements: This study was funded grants from the Alzheimer’s Association (AARF-17-528934) and the Alzheimer’s Foundation of America and by the Penn Neurodegenerative Disease Ethics and Policy Program and the Healthy Brain Research Center, supported in part by NIA P01 AG010124 and cooperative agreement from CDC’s Prevention Research Centers Program (U48 DP 005053). Thank you to all study participants.