

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

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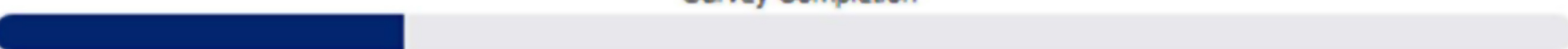
Background

- 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).

Survey Completion

0% 

Mr. Andrews is 60 years old. Mr. Andrews comes with his daughter to a memory center for a new patient visit because he is having memory problems and is worried that he might have Alzheimer's disease. Before beginning the examination, the doctor tells Mr. Andrews that a brain scan test could determine whether his memory problems are being caused by Alzheimer's disease. If the problems are caused by Alzheimer's disease, there is treatment available that could slow the progression of the disease. Mr. Andrews decides that it would be helpful to have the brain scan.

- 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.

Results

Table 1

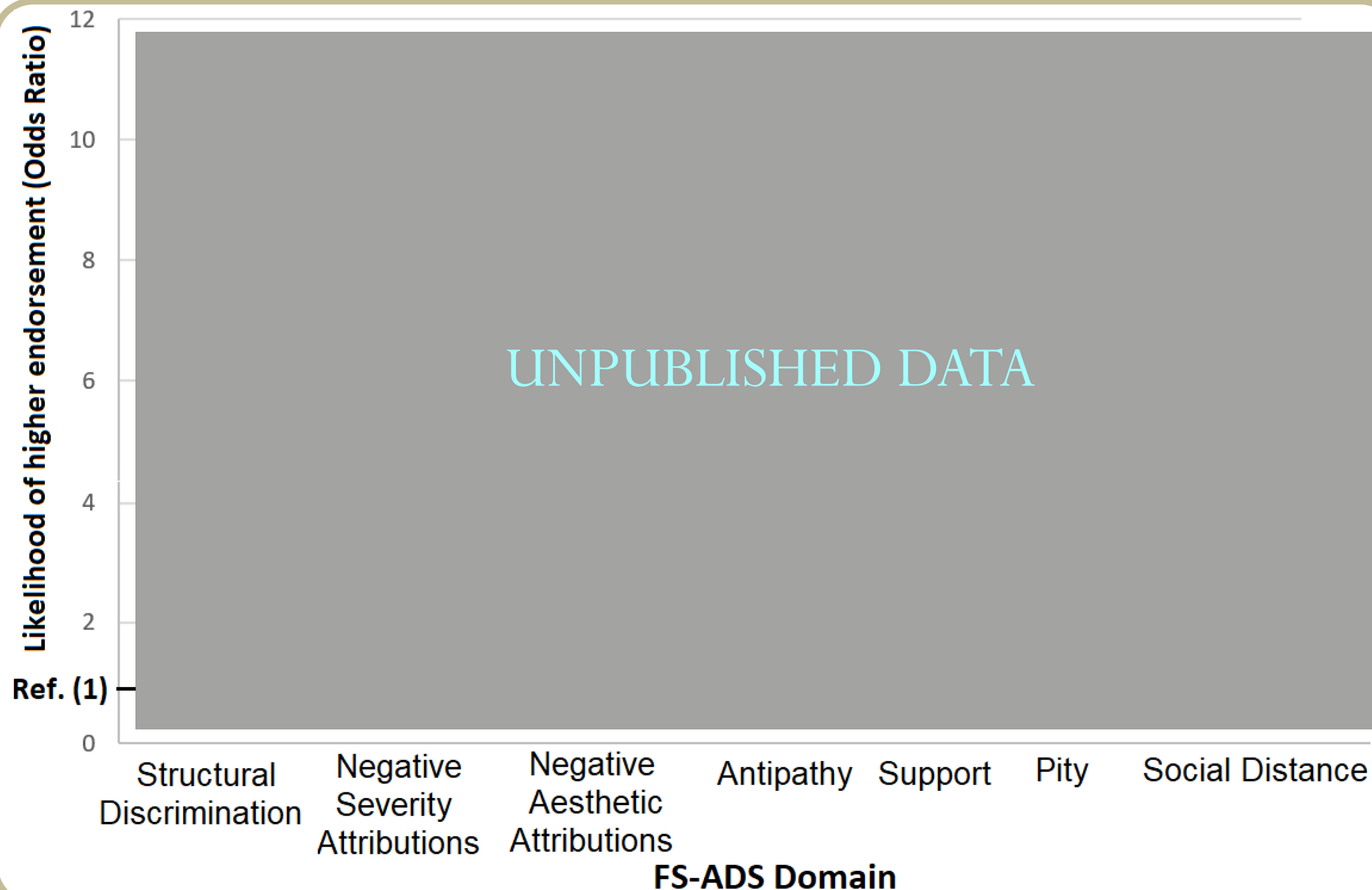
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^a Alzheimer's disease knowledge scale. Maximum possible score = 30.

^b 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."

Randomized Comparisons:

UNPUBLISHED DATA



Conclusions

UNPUBLISHED DATA

References

1. Johnson, R., Harkins, K., Cary, M., Sankar, P., & Karlawish J. (2015). The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment. *Social Science & Medicine*, 143, 117-127. doi:10.1016/j.socscimed.2015.08.031
2. U.S. Department of Health and Human Services. National plan to address Alzheimer's disease: 2014 update.