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The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment

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ABSTRACT

Background: The classification of Alzheimer's disease is undergoing a significant transformation. Researchers have created the category of "preclinical Alzheimer's," characterized by biomarker pathology rather than observable symptoms. Diagnosis and treatment at this stage could allow preventing Alzheimer's cognitive decline. While many commentators have worried that persons given a preclinical Alzheimer's label will be subject to stigma, little research exists to inform whether the stigma attached to the label of clinical Alzheimer's will extend to a preclinical disorder that has the label of "Alzheimer's" but lacks the symptoms or expected prognosis of the clinical form.

Research questions: The present study sought to correct this gap by examining the foundations of stigma directed at Alzheimer's. It asked: do people form stigmatizing reactions to the label "Alzheimer's disease" itself or to the condition's observable impairments? How does the condition's prognosis modify these reactions?

Methods: Data were collected through a web-based experiment with $N = 789$ adult members of the U.S. general population (median age = 49, interquartile range, 32–60, range = 18–90). Participants were randomized through a 3×3 design to read one of 9 vignettes depicting signs and symptoms of mild stage dementia that varied the disease label ("Alzheimer's" vs. "traumatic brain injury" vs. no label) and prognosis (improve vs. static vs. worsen symptoms). Four stigma outcomes were assessed: discrimination, negative cognitive attributions, negative emotions, and social distance.

Results: The study found that the Alzheimer's disease label was generally *not* associated with more stigmatizing reactions. In contrast, expecting the symptoms to get worse, regardless of which disease label those symptoms received, resulted in higher levels of perceived structural discrimination, higher pity, and greater social distance.

Conclusion: These findings suggest that stigma surrounding pre-clinical Alzheimer's categories will depend highly on the expected prognosis attached to the label. They also highlight the need for models of Alzheimer's-directed stigma that incorporate attributions about the condition's mutability.

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1. Introduction

The classification of Alzheimer's disease (AD) has undergone several transformations. Changes in the 1970s eliminated the distinction between senile dementia, which referred to persons over 60 with memory problems, and Alzheimer's disease, which, at the time, referred to persons whose problems began at an earlier age. Alzheimer's thus shifted from a rare diagnosis that garnered little public attention, to a leading cause of death and therefore a pressing public health issue (Fox, 1989; Chaufan et al., 2012). This first transformation contributed to our current associations between Alzheimer's disease, old age, and severe cognitive impairment (Chaufan et al., 2012). These associations often focus on Alzheimer's disease in its most severe form, depicting persons with Alzheimer's as "empty shells" who experience a "death of the mind" (Van Gorp and Vercruysse, 2012), or Alzheimer's as a "death sentence"(Beard and Neary, 2013).

The classification of Alzheimer's disease is changing again. A

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work group from the National Institute on Aging and Alzheimer's Association has created the category of "preclinical Alzheimer's," characterized by biomarker pathology rather than observable symptoms (Sperling et al., 2011). Similarly, a work group composed primarily of European researchers has proposed a category of "asymptomatic at risk for Alzheimer's disease" based on similar criteria (Dubois et al., 2014). Preclinical Alzheimer's begins with the accumulation of amyloid beta in the brain and ends with the presence of neuro-degeneration and subtle signs of cognitive decline. In this new model, Alzheimer's disease spans from a stage where there is a complete absence of observable cognitive or behavioral symptoms, to later stages marked by behavioral changes, loss of awareness, and difficulty with activities of daily living.

While Alzheimer's first transformation contributed to its image as a severe form of cognitive impairment prevalent among the elderly, preclinical Alzheimer's may undo the cultural association between Alzheimer's and severe cognitive impairment. This may create a new cultural understanding of how to react to persons diagnosed with Alzheimer's. Each research group has recommended that preclinical Alzheimer's should be used only in research settings (Sperling et al., 2011; Dubois et al., 2014). But as policymakers place an increased emphasis on early detection and prevention of dementia through efforts such as the U.S. National Alzheimer's Plan (U.S. Department of Health and Human Services, 2014), the likely migration of preclinical AD categories to a broader range of settings raises questions about how expanding the "AD spectrum" will affect persons and their families.

The expansion of the AD spectrum can help research to prevent the disabling, symptomatic form of the condition (Sperling et al., 2014). Yet this strategy, designed to reduce the burden of disability, may create *spillover stigma*, where public fear, social distance, and negative reactions directed towards persons with symptomatic AD (see Werner, 2014 for a review) could spill over to persons given a preclinical AD diagnosis. Some argue that preclinical AD diagnoses will subject persons to "stigma and discrimination"(Gauthier et al., p.110); others worry that the diagnosis may be "distressing, alarming, and stigmatizing"(Le Couteur et al., 2013, p. 17); still others are concerned that persons testing positive for biomarker-based AD risk will face "stigmatization" (Luck et al., 2012, p. e50792).

Unfortunately, little research exists to inform whether the stigma attached to the label of clinical Alzheimer's will extend to the preclinical label (Gauthier et al., 2013; Le Couteur et al., 2013). Similarly, while there is much speculation that clinical stigma will spillover to at-risk labels for conditions like schizophrenia (Corcoran et al., 2005) or cancer (Lerman and Shields, 2004), the few empirical studies of spillover stigma for these conditions focus on patients' experiences of stigmatization rather than attitudes among members of the general public (e.g., DiMillo et al., 2015; Vodermaier et al., 2010).

Should spillover stigma occur for Alzheimer's, the stigma of Alzheimer's clinical form will encompass a constituency of people who are seemingly well, many of them employed and otherwise engaged in social, cultural and political spaces. Should it not, the experience of stigma might divide the Alzheimer's patient community into factions: those with clinical AD who experience both worse symptoms and greater stigma and those with preclinical AD. These scenarios suggest very different approaches to decisions such as diagnostic disclosure of preclinical AD and public health messaging.

The present study pursues these questions by examining the foundations of stigma directed at Alzheimer's clinical stage. Using a vignette-based experiment with a U.S. general population sample, we randomized participants to read about the same set of behavioral symptoms associated with Alzheimer's but assigned different disease labels and different prognoses. The experimental design allows us to examine *which* aspects of Alzheimer's provoke negative reactions: its behavioral symptoms? The Alzheimer's label? Or, the perceived prognosis?

Disentangling the contributors to Alzheimer's stigma lays the groundwork for understanding if preclinical AD categories will be accompanied by *spillover stigma* from the condition's clinical form. If the *Alzheimer's label* itself is the primary contributor to stigma, then those with preclinical Alzheimer's may be subject to stigma even in the absence of symptoms. In contrast, if symptoms are the primary contributor to stigma, then persons who are labeled but asymptomatic may not experience stigma. Furthermore, if stigma is linked to beliefs that the person's cognitive problems will get worse, communication that the course of preclinical AD varies among patients will be important. Understanding contributors to the stigmatization of persons with Alzheimer's thus helps us anticipate the consequences of transforming the condition to include a "preclinical" stage.

1.1. General framework for stigma

The present study draws on a social-cognitive model of stigma that identifies four components of stigmatization (Fig. 1). First, a signal marks someone as a potential target of negative reactions, such as a mental illness label or a person's appearance; 2) the signal prompts others to apply negative *stereotypes*, cognitive frameworks that give meaning to signals; 3) these *stereotypes* contribute to *affective* responses such as pity or fear; 4) these *affective* responses may escalate into *discrimination* against members of the stigmatized group such as social avoidance (Corrigan, 2000, 2007). Below, we also show how the study's findings can be interpreted through other frameworks such as the approach outlined in Link and Phelan (2001). The present study aims to make two main contributions to empirical research inspired by each framework.

The first contribution is to better understand how mild symptoms of cognitive impairment serve as *signals* triggering a chain of negative reactions. Most research on the *signal* step of stigma has examined disorders associated with fear or dangerousness, presenting vignettes of aberrant behaviors such as delusions, paranoia, or impulsivity in the absence or presence of a disease label and asking respondents to report their and others' expected reactions to the person so depicted (e.g., Angermeyer and Matschinger, 2003; Edens et al., 2004; Murrie et al., 2005). A recent systematic review found that labeling behaviors as schizophrenia or as a mental illness led respondents to view the condition as more serious and the person's social skills as more impaired than when the same symptoms were presented without a disease label (Angermeyer and Matschinger, 1996; Arkar and Eker, 1996; Cormack and Furnham, 1998; Sarbin and Mancuso, 1970; for a review, see Read et al., 2006). Less clear is the relative importance of disease labels versus observable behaviors for memory disorders such as Alzheimer's.

The second contribution the present study aims to make is a better understanding of how a disease's perceived *course* contributes to stigma. Jones (1984) highlights course as one of six underlying dimensions of stigma, defining course as the "pattern of change over time" persons associate with a condition (p. 24). Yet subsequent research has primarily studied disease course as a *dependent* variable, asking: how does manipulating the perceived cause or controllability of a stigmatized condition *affect* persons' perceptions of that condition's course? For instance, Weiner et al. (1988), depicting conditions as having a controllable versus non-controllable onset, found no effect on persons' perceptions of the condition's course as more or less reversible. In contrast, research