



SPECIAL SECTION: State of the Field: Advances in Neuroimaging from the 2017 Alzheimer's Imaging Consortium

Advances in Alzheimer's imaging are changing the experience of Alzheimer's disease

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Abstract

Neuroimaging is advancing a new definition of Alzheimer's disease (AD). Using imaging biomarkers, clinicians may begin to diagnose the disease by identifying pathology and neurodegeneration in either cognitively impaired or unimpaired adults. This "biomarker-based" diagnosis may allow clinicians novel opportunities to use interventions that either delay the onset or slow the progression of cognitive decline, but it will also bring novel challenges. How will changing the definition of AD from a clinical to a biomarker construct change the experience of living with the disease? Knowledge of AD biomarker status can affect how individuals feel about themselves (internalized stigma) and how others judge them (public stigma). Following a review of AD stigma, we appraise how advances in diagnosis may enable or interrupt its transfer from clinical to preclinical stages and then explore conceptual and pragmatic challenges to addressing stigma in routine care.

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Keywords:

Stigma; Alzheimer's disease; Early diagnosis

1. Introduction

In medicine, stigma describes how, after a person is labeled with a disease that has negative social connotations, their social status and sense of self may be tainted and devalued [1–3]. In persons with Alzheimer's disease (AD), stigma can affect how they perceive themselves, such as feeling they have little worth or are incompetent and how others treat them, such as acting in ways that discriminate, patronize, or isolate [4–7]. This stigma can lead to problems such as economic hardships, loneliness, and depression [8]. To date, the experience of stigma has been grounded in a disease label that is based on diagnosis of disabling cognitive and behavioral impairments, that is, dementia caused by AD. Advances in neuroimaging and other biomarker assays are changing our understanding of AD from a disease defined

clinically to one defined biologically, and, in this article, we argue that a biological definition will change the experience of stigma.

A biomarker-based definition—using, for example, structural magnetic resonance imaging that measures neurodegeneration and positron emission tomography studies that measure brain metabolism or the presence of pathologic markers—is a departure from the historic, and still quite common, understanding of AD as a clinicopathologic state, defined by observable signs and symptoms. This definition is often referred to as “dementia due to Alzheimer's disease” or “Alzheimer's disease dementia.”

Researchers are using a biomarker-based definition to test in biomarker positive persons interventions to prevent or slow cognitive and functional declines [9]. Should these trials succeed, clinicians will use biomarker tests and these interventions to diagnose and treat patients before the onset of clinical signs and symptoms. This “preclinical” diagnosis is a novel opportunity to slow cognitive decline, but, it will also bring challenges. The stigma experience of the clinical

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stages of the disease may spillover to individuals diagnosed in preclinical stages.

A biomarker-based definition of the disease will also change the experience of living with the diagnosis. Persons who have dementia that fits the clinical criteria of AD but a biomarker result that excludes AD will have doubt cast on their personal narratives of a symptom experience and their families' caregiving narratives. Persons in the "preclinical stages" and their families will have to interpret what symptoms mark the transition from asymptomatic to symptomatic AD. In short, biomarkers will change what it means for a person to live with AD.

We report a narrative review of what is known about AD stigma and its effects on persons living with dementia and their caregivers. This literature was derived from a search of PubMed and Google Scholar with the key terms of "stigma" and "Alzheimer's disease." We then discuss how advances in diagnosis and their translation into clinical practice may change stigma and thereby the experience of the disease. We offer research recommendations and considerations for practice and public policy.

2. Alzheimer's disease stigma defined, its context and its effects

Stigma is a complex social experience, referring to the reaction of others when a person was thought to deviate from "normal" [2]. Stigma is often described as a process in which a label, such as a diagnosis, links the person to discrediting characteristics associated with that label [10]. This process has three features [10,11]. First, there is an authority who has the power to apply a label to others. In medicine, this is typically a physician or other clinician who makes a diagnosis. Second, the label must relate to negative or deviant qualities, such as a disease marked by physiologic pathology, functional impairments, and symptoms outside of normal functioning. Third, the person receiving the label must have less social power than the individual assigning the label, which is typically the case in the patient-clinician relationship.

When a clinician diagnoses a person with AD, the person is transformed into a patient with the disease. The person is a member of a patient group associated with behaviors, abilities, and experiences related both formally and informally to the diagnosis [10]. The diagnostic label implies what signs and symptoms the person may have and may be expected to develop [2]. It is also linked to predictions about the patient's future, such as prognosis and life expectancy.

The connection between observable characteristics of a disease and its diagnosis reflects the medical convention of using a symptom-based system of classification to define and diagnose disease. This approach can contribute to reifying stereotypes and biases about the disease. It can lend to presumptions that, even in the absence of a diagnosis, individuals fit stereotypes of the disease because they are seen to have symptoms that are strongly associated with the disease.

Stereotypes about AD center on it being a chronic and debilitating neurodegenerative disease. The diagnosis is strongly associated with the loss of capacity, suffering, disability, economic losses, and other undesirable features [8]. These associations inform widely held ideas about the characteristics of a person who has AD. These ideas lead to stereotypes that focus on the later stages of disease when a person is most impaired and fully dependent for care [12–15]. These ideas lead people to act in ways that undermine a person's competency, identity, sense of normality, self-control, and social capital. This may include pressuring an individual to retire prematurely or habitually interrupting to finish the individual's sentences. This can have deleterious effects on how persons living with dementia and caregivers feel about themselves and what they choose to do or not do [6].

2.1. Types of stigma

Many models have been put forward to conceptually describe the AD stigma experience [3]. Three models that describe the patient, caregiver, and public experience of AD stigma are public stigma, self-stigma, and spillover stigma.

Public stigma, also referred to as "enacted" stigma, describes how the general population may carry negative or pejorative beliefs that cause them to act in discriminatory, exclusionary, or patronizing ways toward persons who either have or are closely associated with persons with AD [7,16].

Self-stigma, also referred to as "felt" or "internalized" stigma, describes when a person cognitively or emotionally absorbs negative beliefs, attitudes, assumptions, and stereotypes related to the disease, such as feeling ashamed and inferior because of being closely linked to the disease [4]. Self-stigma is associated with depression, avoidant coping, social avoidance, low self-esteem, hopelessness, relatively worse psychiatric symptoms, and decreased help-seeking behaviors [5].

Spillover stigma, also referred to as "stigma by association," describes how people who do not have AD are nonetheless affected by the stigma related to the disease [5]. Spillover stigma often affects individuals who share close social proximity to those who have the disease, such as family members and caregivers [17,18]. It can also affect individuals who have a different but similar condition, such as mild cognitive impairment (MCI) [19].

2.2. Cultural context

Stigma associated with the clinical form of the disease—that is, AD dementia—has been well documented across many cultures, but its presentation varies by cultural context [20,21]. In this section, we describe how disease characteristics together with culturally influenced aspects of social identity—such as age, race, and gender—can interact (Fig. 1). When they do, they can make AD stigma more frequent and intense.

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