

# The Framing of “Alzheimer’s Disease”: Differences Between Scientific and Lay Literature and Their Ethical Implication

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## **Abstract:**

**Background and Objectives:** The meaning of Alzheimer’s disease (AD) is changing in research. It now refers to a pathophysiological process, regardless of whether clinical symptoms are present. In the lay literature, on the other hand, AD is understood as a form of dementia. This raises the question of whether researchers and the lay audience are still talking about the same thing. If not, how will these different understandings of AD shape perspectives on (societal) needs for people with AD?

**Research Design and Methods:** We use framing analysis to retrieve the understandings of the term AD that are upheld in the research literature and in national Dutch newspaper articles. We make explicit how the framings of AD steer our normative attitudes toward the disease.

**Results:** In the analyzed research articles, AD is framed as a pathological cascade, reflected by biomarkers, starting in cognitively healthy people and ending, inevitably, in dementia. In the lay literature, AD is used as a synonym for dementia, and an AD diagnosis is understood as an incentive to enjoy “the time that is left.”

**Discussion and Implications:** The two different uses of the term AD in research and in the lay literature may result in misunderstandings, especially those research framings that falsely imply that people with AD biomarkers will inevitably develop dementia. Adoption of the research understanding of AD in clinical practice will have normative implications for our view on priority setting in health care. For example, it legitimizes biomarker testing in people without dementia as improving “diagnostic” certainty

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