



HHS Public Access

Author manuscript

Lancet Psychiatry. Author manuscript; available in PMC 2018 April 13.

Published in final edited form as:

Lancet Psychiatry. 2017 April ; 4(4): e6–e7. doi:10.1016/S2215-0366(17)30089-5.

Expanding our engagement with the ethical implications of changing definitions of Alzheimer’s disease

Richard Milne, PhD and

Department of Public Health and Primary Care, Institute of Public Health, University of Cambridge School of Clinical Medicine, Cambridge, United Kingdom

Jason Karlawish, MD

Professor of Medicine, Medical Ethics and Health Policy, and Neurology, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania United States

The Alzheimer’s disease (AD) research landscape is changing rapidly. What was once a clinical construct identified by a history of stereotypical signs and symptoms is being redefined as a biological continuum described by biomarkers. This changing focus raises ethical and social challenges which need to be addressed before diagnostic criteria for asymptomatic persons move from research to the clinic¹. Clinicians do not routinely diagnose patients with ‘preclinical AD’, but a series of clinical trials now are testing drugs in cognitively normal persons with gene or biomarker-defined risk². Should these demonstrate effective drug interventions, then preclinical AD will transform from a research label to a diagnosis.

Concerns have been raised about the potential psychological harm caused by learning information about Alzheimer’s disease risk. Studies of genetic susceptibility testing suggest that such information can enable individuals and families to plan and that – in controlled settings – psychological harm is uncommon³. However, other potential consequences need to be considered, including for life and health insurance coverage, employment and driving¹. We suggest this discussion should be extended to consider the implications for an individual’s social position and identity. A focus on disease stigma may be a useful starting point for this discussion. Stigma helps to understand how people identified as belonging to a ‘preclinical’ group see themselves, how they expect people to relate to them and consequently how they are socially integrated or excluded.

Stigma contributes to marginalisation and discrimination against people with AD dementia, their caregivers and families⁴. Studies have yet to examine whether stigma exists in the preclinical stage of AD. However, evidence that shows a major driver of stigma in persons with mild stage AD dementia is the threat of future cognitive decline⁵ suggests that stigma

Author contribution

Both authors contributed equally to writing this correspondence

Conflicts of interest

None

Ethics committee approval

N/A

may also be experienced by persons in the preclinical stage. If this is the case, then it further emphasizes the importance of broader social and cultural framings which shape people's fears and expectations related to a 'preclinical diagnosis.'

Assessments of the psychological impact of AD risk information on the individual, such as depression and anxiety, may consequently be overly narrow. Research is needed to understand the experience of stigma by individuals and families, how it is felt and enacted and how people adapt to and manage information they have been given about their possible future health.

Acknowledgments

Funding source

RM is funded by the Ethical Legal and Social Implications work package of the European Prevention of Alzheimer's Dementia (EPAD) study EPAD receives support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115736, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007-2013) and EFPIA companies' in kind contribution.

References

1. Karlawish J. Addressing the ethical, policy, and social challenges of preclinical Alzheimer disease. *Neurology*. 2011; 77:1487–93. [PubMed: 21917767]
2. Carrillo MC, Brashear HR, Logovinsky V, Ryan JM, Feldman HH, Siemers ER, et al. Can we prevent Alzheimer's disease? Secondary "prevention" trials in Alzheimer's disease. *Alzheimer's Dement*. 2013; 9:123–131e1. [PubMed: 23411394]
3. Bemelmans S, Tromp K, Bunnik E, Milne R, Badger S, Brayne C, et al. Psychological, behavioral and social effects of disclosing Alzheimer's Disease biomarkers to research participants - a systematic review. *Alzheimers Res Ther*. 2016; 8:46. [PubMed: 27832826]
4. Milne A. The "D" word: Reflections on the relationship between stigma, discrimination and dementia. *J Ment Heal Taylor & Francis*. 2010; 19:227–233.
5. Johnson R, Harkins K, Cary M, Sankar P, Karlawish J. The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment. *Soc Sci Med*. 2015; 143:117–127. [PubMed: 26356823]