



Psychological, behavioral and social effects of disclosing Alzheimer's disease biomarkers to research participants: a systematic review

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Background: Current Alzheimer's disease (AD) research initiatives focus on cognitively healthy individuals with biomarkers that are associated with the development of AD. It is unclear whether biomarker results should be returned to research participants and what the psychological, behavioral and social effects of disclosure are. This systematic review therefore examines the psychological, behavioral and social effects of disclosing genetic and nongenetic AD-related biomarkers to cognitively healthy research participants.

Methods: We performed a systematic literature search in eight scientific databases. Three independent reviewers screened the identified records and selected relevant articles. Results extracted from the included articles were aggregated and presented per effect group.

Results: Fourteen studies met the inclusion criteria and were included in the data synthesis. None of the identified studies examined the effects of disclosing nongenetic biomarkers. All studies but one concerned the disclosure of APOE genotype and were conducted in the USA. Study populations consisted largely of cognitively healthy first-degree relatives of AD patients. In this group, disclosure of an increased risk was not associated with anxiety, depression or changes in perceived risk in relation to family history. Disclosure of an increased risk did lead to an increase in specific test-related distress levels, health-related behavior changes and long-term care insurance uptake and possibly diminished memory functioning.

Conclusion: In cognitively healthy research participants with a first-degree relative with AD, disclosure of APOE $\epsilon 4$ -positivity does not lead to elevated anxiety and depression levels, but does increase test-related distress and results in behavior changes concerning insurance and health. We did not find studies reporting the effects of disclosing nongenetic biomarkers and only one study included people without a family history of AD. Empirical studies on the effects of disclosing nongenetic biomarkers and of disclosure to persons without a family history of AD are urgently needed.

Alzheimer's Research & Therapy 2016

Published **Online**

November 10, 2016

<http://dx.doi.org/10.1186/s13195-016-0212-z>

