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DEMENTIA CARE RESEARCH (RESEARCH PROJECTS; NONPHARMACOLOGICAL)

Interest in and perceived benefits and risks of Alzheimer's disease clinical and biomarker results disclosure among diverse participants and care partners

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Abstract

Background: Alzheimer's disease (AD) biomarker disclosure is a potential avenue for tailoring person-centered care for patients and families and targeting known health disparities. However, disclosure cannot take a one-size-fits-all approach. It is critical to understand whether older adults with and without cognitive impairment (i.e., mild cognitive impairment (MCI)) and their care partners are interested in engaging in biomarker disclosure, and what perceived benefits and risks exist, as a function of race, social determinants, and clinical status.

Method: 57 participant-care partner dyads [*participants*: 56.1% female; 36.8% Black, 74.3±5.98 years, 42.1% with MCI; *partners*: 79.0% female; 33.3% Black, 66.9±10.9 years] completed a semi-structured interview assessing demographic factors, healthcare access, economic stability, social support, and perspectives on AD biomarker disclosure. Fisher's exact tests were used to assess participant and partner characteristics associated with interest in, and perceived benefits and risks of the participant engaging in results disclosure. Differences in participant and care partner responses were evaluated using two-sample *t*-tests.

Result: When asked to select the main benefit and disadvantage of knowing AD risk (out of 9 benefits and 10 disadvantages), participants and partners described varied benefits. Participants and partners both endorsed having the opportunity to engage in Alzheimer's disease treatments and/or clinical trials (23.2% v. 29.8%), followed by having the opportunity to inform long-term care plans (14.3% v. 17.5%) and learning more about the participants' health (12.5% v. 15.8%) as primary motivators for engaging in biomarker disclosure. In contrast, the majority of participants (80.8%) and partners (82.1%) endorsed no perceived disadvantages of learning the participants' biomarker information for risk of dementia-Alzheimer's Type. Nearly all dyads endorsed moderate to strong interest in cognitive test results (96.5% participants; 93.0% partners), structural neuroimaging (94.8%; 89.4%), genotyping (94.8%; 87.7%)

and protein biomarker disclosure (98.3%; 87.7%). Interest was not associated with diagnosis, race, or social determinants of health.

Conclusion: Participants and care partners endorse almost universal interest, varied benefits and few disadvantages of learning the participant's AD biomarker results. Pre-disclosure education and decisional-capacity assessment are needed to ensure informed decision-making. Further data on how social determinants may influence motivations for, reactions to, and risks of AD biomarker disclosure are needed.