

Psychosocial factors and environmental design / Living with dementia and quality of life

Study partner perspectives on disclosure of amyloid PET scan results

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Abstract

Background: Alzheimer's disease (AD) secondary prevention trials typically require cognitively unimpaired individuals to learn the results of an amyloid PET scan. Additionally, they are required to enroll with a study partner who serves as a knowledgeable informant and often learns the participant's amyloid PET scan result. The purpose of this study is to understand how study partners understand and experience the disclosure of another person's amyloid PET scan result.

Method: Participants in this qualitative study are study partners of cognitively unimpaired adults aged 60–75 years who learned their amyloid PET scan result as part of Risk Evaluation and Education of Alzheimer's Disease: The Study of Communicating Amyloid Neuroimaging (REVEAL-SCAN; NCT02959489). The sample was recruited to be balanced on the REVEAL-SCAN participants' amyloid PET scan results (i.e., "elevated" or "not elevated") and the nature of participant-study partner relationships (i.e., spousal or non-spousal). We have interviewed 80 study partners. All interviews were recorded, transcribed, and coded in NVivo 12.0. The University of Pennsylvania IRB approved this study.

Result: Most study partners knew their REVEAL-SCAN participant's amyloid PET scan result and were able to explain what the result meant. For example, they generally understood that an "elevated" result indicates an increased but uncertain risk of developing dementia caused by AD. Study partners most often described feeling relief after learning a "not elevated" result, while emotions after learning an "elevated" result included sadness, concern, and resignation. Study partners felt the amyloid PET scan result gave them additional insight into the REVEAL-SCAN participant's memory. Nearly all study partners denied that learning the amyloid PET scan result changed their relationship with the REVEAL-SCAN participant, but they reported changing future plans (e.g., about leisure, caregiving) in light of the result.

Conclusion: Study partners' understanding of and reactions to another person's amyloid PET scan result mirror those of the person. This suggests that disclosure of AD biomarkers in clinical practice will have implications not only for patients but also for their families. Looking forward, clinicians will need guidelines for how best to disclose biomarker results, including engaging and supporting patients' family members.