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DEMENTIA CARE RESEARCH (RESEARCH PROJECTS; NONPHARMACOLOGICAL)

Assessment of decisional capacity for Alzheimer's disease PET disclosure among cognitively symptomatic individuals

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Abstract

Background: Older adults are highly interested in learning their Alzheimer's disease (AD) positron emission tomography (PET) amyloid-beta (Aβ) and tau results. However, knowledge about the meaning, uses, and risks of learning personal biomarker results is variable. Tools are needed to assess decisional capacity prior to biomarker disclosure, particularly for individuals with cognitive impairment.

Methods: 30 participants (46.7% female; 93.3% white, age = 71.9±7.14 years) diagnosed with either mild cognitive impairment (MCI; 60.0%) or dementia-Alzheimer's type (DAT; 40.0%) completed Aβ and tau PET, an interactive education session and results disclosure decision-making assessment. When available, cognitively unimpaired care partners ($n = 27$) attended these sessions and their ability to demonstrate decisional capacity for participant biomarker disclosure was assessed. Decisional elements evaluated included *understanding* of the meaning of biomarker results, *appreciation* of risks and benefits of engaging in disclosure, communication of a *choice* to learn the participant's biomarker results, and demonstration of a *rationale* for engaging (or not) in disclosure. Chi-squared tests were used to assess whether successful demonstration of each element differed by diagnosis.

Result: More participants with MCI (77.8%) than participants with DAT (25.0%) demonstrated disclosure decisional capacity ($\chi^2 = 8.17$, $p = .008$). Across the full sample, participants had the most difficulty understanding the difference between AD and DAT (34.6% incorrect), the meaning of elevated amyloid (19.0% incorrect) or tau (10.0% incorrect), and biomarker disclosure risks (19.0% incorrect). Compared to participants with DAT, those with MCI were more likely to demonstrate understanding of biomarker results (33.3% DAT v. 77.8% MCI; $\chi^2 = 5.93$, $p = .024$) and appreciation of personal benefits and risks of biomarker disclosure (33.3% DAT v. 83.3% MCI; $\chi^2 = 7.75$, $p = .009$). There were no differences in demonstration of rationale or communication of choice by diagnosis. All care partners demonstrated adequate decisional capacity for disclosure of the participant's PET results.

Conclusion: Appreciation and understanding, two elements rarely evaluated in clinical or research settings, are more challenging than rationale or choice for cognitively

impaired participants to demonstrate. Prior to disclosure, education should emphasize the possible meaning, usefulness, and risks of PET amyloid and tau information. Family or care partner disclosure decision-making assessment should be a standard part of disclosure protocols.