Analysis of Psychological Symptoms Following Disclosure of Amyloid–Positron Emission Tomography Imaging Results to Adults With Subjective Cognitive Decline

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Importance: Individuals who are amyloid-positive with subjective cognitive decline and clinical features increasing the likelihood of preclinical Alzheimer disease (SCD+) are at higher risk of developing dementia. Some individuals with SCD+ undergo amyloid-positron emission tomography (PET) as part of research studies and frequently wish to know their amyloid status; however, the disclosure of a positive amyloid-PET result might have psychological risks.

Objective: To assess the psychological outcomes of the amyloid-PET result disclosure in individuals with SCD+ and explore which variables are associated with a safer disclosure in individuals who are amyloid positive.

Design, Setting, and Participants: This prospective, multicenter study was conducted as part of The Amyloid Imaging to Prevent Alzheimer Disease Diagnostic and Patient Management Study (AMYPAD-DPMS) (recruitment period: from April 2018 to October 2020). The setting was 5 European memory clinics, and participants included patients with SCD+ who underwent amyloid-PET. Statistical analysis was performed from July to October 2022.

Exposures: Disclosure of amyloid-PET result.

Main Outcomes and Measures: Psychological outcomes were defined as (1) disclosure related distress, assessed using the Impact of Event Scale–Revised (IES-R; scores of at least 33 indicate probable presence of posttraumatic stress disorder [PTSD]); and (2) anxiety and depression, assessed using the Hospital Anxiety and Depression scale (HADS; scores of at least 15 indicate probable presence of severe mood disorder symptoms).

Results: After disclosure, 27 patients with amyloid-positive SCD+ (median [IQR] age, 70 [66-74] years; gender: 14 men [52%]; median [IQR] education: 15 [13 to 17] years, median [IQR] Mini-Mental State Examination [MMSE] score, 29 [28 to 30]) had higher median (IQR) IES-R total score (10 [2 to 14] vs 0 [0 to 2]; P < .001), IES-R avoidance (0.00 [0.00 to 0.69] vs 0.00 [0.00 to 0.00]; P < .001), IES-R intrusions (0.50 [0.13 to 0.75] vs 0.00 [0.00 to 0.25]; P < .001), and IES-R hyperarousal (0.33 [0.00 to 0.67] vs 0.00 [0.00 to 0.00]; P < .001) scores than the 78 patients who were amyloid-negative (median [IQR], age, 67 [64 to 74] years, 45 men [58%], median [IQR] education: 15 [12 to 17] years, median [IQR] MMSE score: 29 [28 to 30]). There were no observed differences between amyloid-positive and amyloid-negative patients in the median (IQR) HADS Anxiety (–1.0 [–3.0 to 1.8] vs –2.0 [–4.8 to 1.0]; P = .06) and Depression (–1.0 [–2.0 to 0.0] vs –1.0 [–3.0 to 0.0]; P = .46) deltas (score after disclosure – scores at baseline). In patients with amyloid-positive SCD+, despite the small sample size, higher education was associated with lower disclosure-related distress (ρ = –0.43; P = .02) whereas the presence of study partner was associated with higher disclosure-related distress (W = 7.5; P = .03). No participants with amyloid-positive SCD+ showed probable presence of PTSD or severe anxiety or depression symptoms at follow-up.

Conclusions and Relevance: The disclosure of a positive amyloid-PET result to patients with SCD+ was associated with a bigger psychological change, yet such change did not reach the threshold for clinical concern.

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