

# Exploring Characteristics of Individuals Who Decline Genetic Testing and Alzheimer's Disease Risk Assessment After Education: The REVEAL Study

Diana Toledo, Denise M. Lautenbach, Brenda Barry, MaryAnn W. Campion  
Boston University School of Medicine, Boston, Massachusetts

**Purpose:** Alzheimer's disease (AD) is the most common form of dementia, characterized by progressive decline in cognition and behavior. Carriers of the *APOE*  $\epsilon$ 4 susceptibility allele have an increased risk over the general population of developing AD. Due to the lack of preventive treatments, low sensitivity/specificity of testing, and the anticipated risk of psychological distress, *APOE* genetic susceptibility testing has not been indicated in a clinical setting. The goal of this present study was to examine characteristics of individuals who received education regarding risk assessment and *APOE* testing for AD and then declined to proceed either with testing or with results disclosure.

**Methods:** The REVEAL Study is the first multi-site randomized clinical trial to explore the psychological and behavioral impact of Alzheimer's disease risk assessment and disclosure of *APOE* genotype. We examined characteristics of decliners and hypothesized that these individuals would be more likely to report a lower perceived ability to cope with an adverse genetic test result than those who continued. Additionally, we examined demographics and reasons for study withdrawal cited by decliners.

**Results:** Decliners were more likely to be female, younger, non-Caucasian, single, and less educated. Decliners reported a significantly lower perceived ability to cope with an adverse outcome than continuers (79.1% vs. 87.2%). Concern about emotional well-being was cited as the primary reason for not moving forward with results disclosure by 27.1% of decliners.

**Discussion:** This study contributes to gaps in literature by illustrating characteristics of individuals who decline genetic susceptibility testing or results disclosure following education. The findings suggest that individuals who perceive themselves as less able to cope with learning an adverse genetic testing result or express concern about their emotional well-being surrounding risk information may remove themselves from a situation where there is the potential to learn distressing genetic and risk information.