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Communicating risk status to at-risk Alzheimer's patients

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How would you feel, as a cognitively healthy person, if a doctor said you had high odds of developing Alzheimer's disease within two to five years? Thousands of older adults who volunteer for new Alzheimer's prevention trials face that revelation. These trials select cognitively normal people in their 60s and 70s who are at high risk for the disease because they have inherited the genetic risk factor ApoE4, or because PET scans reveal their brains are accumulating amyloid. Such people are the most likely to benefit from experimental drugs designed to slow disease onset, but in order to participate in these trials, they have to learn about their heightened risk. Will this information cause depression, anxiety, or despair? How can clinicians best communicate risk status in a way that minimizes psychological ill effects?

Researchers conducting these new prevention studies are drawing on lessons learned from the cancer field. They will first teach trial volunteers about the limits of genetic or amyloid testing, emphasizing that the results do not equate to a diagnosis of Alzheimer's, and that a negative result does not mean that a person will never develop the disease. Then researchers will ask volunteers to consent to the procedure. After testing, a genetic counselor or clinician skilled in delivering serious medical news will discuss the results with the volunteers. Researchers will then follow up over time to see how the participants are doing, and whether the knowledge has affected their mood or life decisions.

Alzforum's two-part series describes how the ongoing Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease (A4) trial discloses amyloid status (part 1), and how the upcoming Alzheimer's Prevention Initiative's ApoE4 trial will incorporate technology such as computers and videoconferencing to inform thousands of people of their genetic test results (part 2). Although no data is yet available from these trials, preliminary results from smaller studies suggest that most people take this type of news in stride, perhaps paving the way for a future where communicating Alzheimer's risk could become part of standard medical practice.

Source:
Alzforum
