

Alzheimer's risk: Would you want to know?

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When people learn they are predisposed to Alzheimer's disease, any depression or anxiety is not long lasting, a new study indicates.

These findings help address a longstanding debate about whether learning such information might cause lasting psychological harm, at least among those with a [family history](#) of Alzheimer's disease, says Scott Roberts, a University of Michigan researcher at the School of Public Health and co-author of the study findings, which appear today in the [New England Journal of Medicine](#).

People with a family history are already at higher risk, which is further increased if they also carry a certain version of the gene called Apolipoprotein E (APOE).

Roberts and colleagues at Boston University, Case Western Reserve University, and Cornell Medical College tested 162 people with a parent with Alzheimer's, which means their risk for developing the disease by age 85 is about 30-35 percent, compared with the general population risk of about 10-15 percent.

After an educational session about Alzheimer's and genetic testing, researchers tested people for their APOE genotype to learn if they carried the genetic variant. The presence of the gene increases the risk for those with a family history of Alzheimer's to more than 50 percent. For subjects who did agree to the test, specially trained genetic counselors then disclosed results and researchers followed participants over one year to determine the impact of risk information.

The researchers measured anxiety, depression and test-related distress after six weeks, six months, and one year. Test-related distress did increase slightly at six weeks for people with the risk-increasing form of the gene, but not at 6 months or one year, Roberts said. Anxiety and depression levels remained stable.

"Some people might say, 'I'm thinking about this a lot,' but it didn't translate into long-term [depression](#) or [anxiety](#)," Roberts said. "The findings show if you do (disclose this genetic information) genetic counseling may be an important component to ensure that most people do not respond with significant distress.

"Genetic counselors help put the test results in context so that people understand the meaning and limits of the results," Roberts said. For example, for participants with a 55 percent lifetime risk, counselors explained that there was a 45 percent chance that they would never develop the disease.

The APOE link to Alzheimer's was identified in the 1990s, and traditionally, the medical community doesn't favor disclosure of the APOE genotype---or other genetic markers---unless telling patients directly impacts clinical treatment, Roberts says. However, now that private companies offer genetic testing for a variety of conditions, the debate over clinical utility versus personal utility is growing.

Some argue it's paternalistic to tell people what information they can or cannot know about their own genome, he says. After the initial educational session, 20 percent of the subjects opted out of the actual test, which means the majority wanted to know.

"I think most adult children of Alzheimer's patients would favor the right to at least have the choice," he said.

Roberts conducted this research while at Boston University. He came to the U-M in 2006.

Roberts is second author on the paper, called "Disclosure of APOE Genotype for Risk of Alzheimer's Disease," and co-principal investigator on the Risk Evaluation and Education for Alzheimer's Disease (REVEAL), a series of randomized clinical trials examining the impact of a genetic susceptibility testing program for adult children of people with Alzheimer's.

Source: University of Michigan ([news](#) : [web](#))

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