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With genetic testing results, more may be better

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By Kathryn Doyle

(Reuters Health) - When people undergo genetic testing to find out whether they're at risk for a specific disease, doctors often wonder how much information to give them. What if the genetic testing results reveal a risk for a disease the patient hadn't been wondering about?

Geneticists are "grappling with what to do with all the information that could be disclosed, but wasn't why the study was ordered in the first place," Kurt D. Christensen of Brigham and Women's Hospital in Boston told Reuters Health.

Though in theory, giving people more risk information than they were expecting might increase anxiety or depression, that didn't turn out to be the case in a study Christensen recently led.

He and his colleagues studied a group of volunteers who were having tests to see if they're genetically at risk for Alzheimer's disease. It turned out these people weren't more distressed when they received additional results about their risk for coronary artery disease.

In some cases, those who got extra information were actually less distressed one year later.

“It was the opposite of what we were expecting,” Christensen said in a phone interview.

That might be because patients can do little about their risk for Alzheimer’s disease, but lifestyle changes can help prevent future coronary artery disease, the authors wrote in the *Annals of Internal Medicine*.

These results might help researchers and doctors decide how much information to give patients based on genetic testing results, Christensen said.

The researchers included 257 adults without symptoms, more than half of whom had a close relative with Alzheimer’s disease, to be tested for a variant of the apolipoprotein E (APOE) gene, which has a strong association with Alzheimer’s disease risk.

All participants received information about their APOE genotype, cumulative lifetime risk of Alzheimer’s - which ranged from six percent to 73 percent - and risk up to age 85. Half the group was also told that the same gene variant that

increases Alzheimer's risk may also increase coronary artery disease risk, and that this risk can be reduced by quitting smoking, having a healthy diet, losing weight, and treating high cholesterol.

The researchers assessed each subject's anxiety, depression, distress and health behavior changes like diet and exercise activities at six weeks, six months and 12 months after they received the genetic results.

At the one-year point, anxiety and depression scores were similar in both groups. Among those who were carriers of the high-risk APOE allele, those who were also told about their coronary artery disease risk had lower distress levels and more healthy behavior changes than those who only got Alzheimer's information.

In the past, experts have been concerned about how much genetic information to share with patients who are otherwise healthy, based on the potential for misunderstanding or making serious health choices based on their genes, senior author Dr. Robert C. Green of Brigham and Women's Hospital and Harvard Medical School in Boston told Reuters Health by phone.

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“There’s an inaccurate stereotype that DNA is destiny,” Green said.

Genetic sequencing, which used to cost three billion dollars, now costs about \$1,000, he said, or about 923 euros.

“People who choose to get (Alzheimer’s risk) information actually do very well, even though there’s no treatment or prevention,” he said. “But if you start off wanting to know Alzheimer’s risk information, and get surprised with information you completely didn’t expect, how will you react?”

“This mimics the way a lot of genetic testing is going,” Green said. “You might get tested for a heart problem and might find out you have a risk for cancer. Is it ethical to surprise people with that?”

It would be risky to generalize the results of this study to every kind of genetic risk, he said.

“If we’re talking about setting up approaches for the general population, I think emphasizing the results that we are confident about and that we

can do something about should (be) put at the top of the list,” said Dr. Michael F. Murray of the Geisinger Health System in Forty Fort, Pennsylvania.

“If the question is, ‘Should we go in and find that some people might be at risk for Alzheimer’s disease but they can’t do anything about it, or should we look at breast cancer risk, which they can do something about,’” most people would choose to learn about their breast cancer risk, Murray, who wrote an editorial accompanying the new results, told Reuters Health by phone.

A healthy person who is very motivated and has the resources may still want to know their genetic risk for Alzheimer’s, and should be able to find out, but until a treatment or way to prevent the disease is developed, it’s not a test that should be done for the general population, Murray said.

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