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Patients get mixed reactions from docs over mail-ordered genetic tests

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(Reuters Health) - Patients who order direct-to-consumer genetic tests report mixed experiences when they take the results to their doctors, a new study found.

About a quarter of people who ordered direct-to-consumer genetic testing from companies like 23andMe reported discussing the results with their primary care doctors. But nearly one in five were not at all satisfied with the conversations, researchers report.

How doctors react to patients' direct-to-consumer genetic test results matters, said senior author Dr. Robert Green, director of the Genomes2People Research Program at Brigham and Women's Hospital in Boston.

"Even if doctors want to make intellectual points, which is their prerogative, I think they can do it in ways that A) respects their patient and B) finds a teachable moment around health issues that dovetails with the patient's interests," he told Reuters Health.

Direct-to-consumer genetic testing allows people to order tests from the comfort of their own homes without a doctor's permission. The results can provide information about ancestry, non-medical traits like tongue curling, health risks like diabetes as well as how a person might respond to certain drugs, write the researchers in the *Annals of Internal Medicine*.

In 2013, the U.S. Food and Drug Administration halted health analyses from the popular direct-to-consumer genetic testing company 23andMe. But those kinds of tests are available in other countries and will likely be available in the U.S. again, Green said.

In the meantime, companies in the U.S. can still run the tests and provide consumers with raw genetic data. But it's difficult for patients to obtain an analysis of that data.

To see how patients felt about discussing their results with their doctors, the researchers surveyed new 23andMe and Pathway Genomics customers between March and July 2012. Overall, they had data from 1,026 customers.

Of those, 63 percent said they planned to share their results with their primary care doctors - and six months later, 27 percent had done so. Another 8 percent reported sharing the results with other healthcare providers.

The majority of customers didn't ultimately share their findings said the results either weren't important enough or they didn't have time.

Thirty-five percent of those who shared the results with their primary doctors were very satisfied with the encounter, but 18 percent said they were not at all satisfied.

Those who had satisfying experiences frequently reported that their doctors understood genetics, willingly discussed the results and didn't differ in the interpretation of the results.

On the other hand, people who were not satisfied with their experience had doctors that were most likely to disagree with the results.

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For example, one customer's doctor said she doesn't believe in direct-to-consumer genetic testing. "I sent the results from (23andMe) to her and she never looked," said the customer. "She told me it wasn't needed and not to believe the results."

Dr. Wylie Burke, of the Department of Bioethics and Humanities at the University of Washington in Seattle, said professional societies for doctors could help the situation by appointing committees to evaluate evidence related to different kinds of direct-to-consumer tests.

Burke told Reuters Health by email that there is no evidence the information from these tests improves health outcomes.

And with common diseases, such as heart disease and diabetes, "even though genetic risk plays a role, other factors such as diet, activity level, whether or not one smokes, etc. are simply more important in determining risk," wrote Burke, who co-authored an editorial accompanying the new study.

Green said patients should be prepared for a range of reactions from their doctors when they bring up direct-to-consumer genetic test results.

“I think it’s a good thing that patients want to bring this to their doctors,” he said. “I think doctors ought to be open to the conversations that could be stimulated by the information received.”

SOURCE: bit.ly/1TizpvK and bit.ly/1TizoYV Annals of Internal Medicine, online February 29, 2016.