Future Shock

If a test could tell whether you'd develop a disease later in life, would you take it?

June 6, 2016 By Kate Ferguson

In February 2014, Kristen Powers, an 18-year-old college student at the time, debuted a documentary titled Twitch at Stanford University. The film chronicled Powers's life as she prepared for and finally took a genetic test for Huntington's disease. The illness is a hereditary degenerative disease that destroys a person's ability to walk, talk, think and reason—and eventually leads to death. Huntington's killed Powers's mother in 2011, and Powers knew she and her two brothers had a 50 percent chance of the same fate.

Today, according to the American Medical Association, there are more than 2,000 genetic tests that doctors can use to diagnose diseases and determine treatment for more than 1,000 illnesses. These tests identify changes in chromosomes, genes or proteins in the body and can confirm or rule out suspicions about a genetic illness. What's more, they can help determine an individual's chance of developing or transmitting a genetic disorder.

In general, there are several different ways doctors can identify genetic disorders: They can screen newborns or conduct diagnostic, carrier, prenatal, preimplantation, predictive and presymptomatic tests. These genetic tests screen for diseases caused by a defect affecting a single gene, such as sickle cell disease, cystic fibrosis and Huntington's disease. Usually, they are extremely accurate in determining whether someone will be affected by or is a carrier of the illness.

But there are also genetic tests people can buy to assess their risk of developing certain diseases. These DTC, or direct-to-consumer, genetic tests are easy to take. They can be conveniently purchased online and mailed directly to your home.

Typically, you take the test by either swabbing the inside of your cheek for a DNA sample to mail back to a lab, or you can also visit a clinic to have your blood drawn. Most of the DTC genetic tests are based on genome-wide association studies, which look for genetic sequences in DNA that are associated with diseases caused by multiple genes.

DTC genetic tests range from a few hundred dollars to more than $1,000, depending on the test. But, despite their affordability, many are concerned about these largely unregulated health awareness tools.

In 2010, the U.S. Food and Drug Administration (FDA) issued an initial round of warning letters to

several DTC genetic testing companies saying the tests are medical devices that require regulatory clearance or approval.

Since then, the FDA has sent warning letters to more DTC genetic test makers because of concerns that patients might make decisions without a doctor's guidance, "such as stopping or changing the dose of a medication or continuing an unhealthy lifestyle," says Jeffrey Shuren, MD, director of the FDA's Center for Devices and Radiological Health. "The risk points out the importance of ensuring that consumers are also provided accurate, complete and understandable information about the limitations of test results they are obtaining."

Powers consulted with doctors before undergoing genetic testing to learn whether she carries the gene for Huntington's. For her test results, check out Twitch online, or view, rent or download the film on Vimeo OnDemand, iTunes, Kanopy, Amazon and Google Play.

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