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Genetic counseling is rare among BRCA-tested women

Andrew M. Seaman

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(Reuters Health) - Although counseling is widely recommended before gene testing, most U.S. women who were sent by doctors to be tested for BRCA1 and BRCA2, two genes that increase the risk of breast and ovarian cancer, never met with a counselor beforehand.

The main reason, researchers found, is that the women's doctors didn't recommend seeing a genetic counselor.

"There are very clear and consistent guidelines that people should receive genetic counseling before genetic testing for cancer susceptibility," said Dr. Rebecca Sutphen, the study's senior author from the University of South Florida Morsani College of Medicine in Tampa.

Although women who received counseling before gene testing were more knowledgeable about the test and the meaning of its results, as well as more satisfied overall, some experts say traditional genetic counseling may no longer be the only or best option – especially as gene tests become cheaper and more accessible.

BRCA 1 and BRCA 2 gene mutations are linked to about 5 to 10 percent of all breast cancers, and about 15 percent of ovarian cancers, according to the U.S. National Cancer Institute (NCI).

Genetic counselors typically explain the test's appropriateness, medical implications, psychological risks and the possibility the results won't be informative. They may also discuss the risk of passing on the gene mutation to children.

The new study involved Aetna-insured women whose doctors ordered BRCA testing in 2012. Several Aetna employees were on the research team.

The insurer sent questionnaires to 11,159 women, but just 35 percent returned them. The final analysis focused on 3,628 women.

Only about 37 percent said they'd received counseling from a trained genetics professional in person or on the phone before the gene test, the researchers report in JAMA Oncology.

Sutphen told Reuters Health that doesn't mean the vast majority of women didn't receive some level of counseling, but it wasn't from someone trained to counsel people about genetics.

Women most commonly said they didn't see a genetic counselor because their doctors didn't recommend the service.

Those who did receive counseling were more knowledgeable about BRCA and reported better understanding and satisfaction, compared to women who didn't receive counseling.

The study shows patients and providers that there are benefits to counseling by trained genetic counselors, Sutphen said.

"Many progressive providers like Aetna provide those services by telephone," she said. "And, under the Affordable Care Act, genetic counseling is a preventive service that is to be covered without out of pocket cost to the patient."

In an editorial, Dr. Steven Narod of the Women's College Research Institute in Toronto writes that more women will likely be tested for BRCA mutations with the cost of genetic testing now ranging from $200 to $300. Whether traditional one-on-one genetic counseling would benefit all of them, or is even feasible, is unclear, he writes.

In the current study, one woman with genetic mutations was identified for every 20 women counseled, but if testing becomes more common, "we cannot expect to counsel 100 women for the sake of one positive test result, so other forms of knowledge transfer (e.g., print or electronic media) need to be explored," Narod said.

Those sentiments were echoed by Robert Green, a medical geneticist and physician-scientist at Brigham and Women's Hospital in Boston.

Green, who was not involved in the new study, said his research among people being tested for gene mutations tied to Alzheimer's disease found no greater distress or depression in those receiving a condensed genetic counseling session that included

mailed brochures, compared to those who met with counselors.

"I think as we imagine a world in which genomics is a daily practice of medicine, traditional models of genetic counseling are probably not feasible," he said. "We need to understand where genetic counseling would be maintained and where new models of counseling and testing should be incorporated."

SOURCE: bit.ly/1KPGGg4 and bit.ly/1KPGKMK JAMA Oncology, online October 1, 2015.