Women getting BRCA testing not receiving counseling by trained genetics professionals

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Most women who underwent BRCA genetic testing did not receive genetic counseling by trained genetics professionals and the lack of clinician recommendation was the most commonly reported reason in a study of commercially insured women, according to an article published online by *JAMA Oncology*.

Women with susceptibility to hereditary breast and ovarian cancer (HBOC) face high lifetime risks of 24 percent to 86 percent for breast cancer and 16 percent to 67 percent for ovarian cancer. Professional guidelines delineate clinical criteria based on personal and family history and recommend, for women who meet the criteria, consultation with a professionally trained, board-certified genetics clinician for genetic counseling.

Rebecca Sutphen, M.D., of the University of South Florida Morsani College of Medicine, Tampa, and coauthors examined the factors associated with use of BRCA testing, assessed whether delivery of genetic counseling and testing services adheres to professional guidelines, and measured the impact on patient reported outcomes.

In collaboration with the commercial health insurer Aetna, the American BRCA Outcomes and Utilization of Testing (ABOUT) study analyzed data from 11,159 women whose clinicians ordered BRCA testing between December 2011 and December 2012. Aetna mailed study packet questionnaires to women and 34.7 percent of them completed it. Aetna's commercial health plans cover genetic counseling services by a

professional genetics clinician either in person or by telephone, according to the study background.

The majority of women (an estimated 53.3 percent) undergoing BRCA testing did not have a personal history of breast or ovarian cancer; an estimated 43.3 percent had a personal history of breast cancer; 2.9 percent had a personal history of ovarian cancer; and 0.5 percent had a personal history of breast and ovarian cancer.

Among 3,628 women whose physicians ordered comprehensive BRCA testing, most were white non-Hispanic (69 percent), college-educated (81.4 percent) and married (75.8 percent) with higher incomes (55.4 percent). Of these women, authors report 16.4 percent (596) did not meet testing criteria. Mutations were identified in 161 (5.3 percent) women who had comprehensive testing. About 36.8 percent (1,334) of the 3,628 women reported receiving genetic counseling from a genetics professional, and the lowest rates (130[12.3 percent]) were among patients of obstetricians/gynecologists. The most common reason reported by women for not receiving this service was the lack of a clinician recommendation.

The women who did receive genetic counseling by a trained genetics professional displayed greater knowledge of BRCA and expressed greater understanding and satisfaction, according to the results.

Limitations to the study include that the authors were unable to directly obtain additional information from ordering providers about the potential underlying causes for the suboptimal genetic counseling referral patterns and relatively high rate of inappropriate test requests.

"These findings demonstrate important gaps in clinical genetic services. Recently mandated coverage of genetic counseling services as a preventive service without patient cost sharing should contribute to

improving clinical genetics services and associated outcomes in the future," the study concludes.

In a related editorial, Steven Narod, M.D., of the Women's College Research Institute, Toronto, writes: "The article by Armstrong et al tells an interesting story, but it is a story of the recent past told from a particular point of view, and given the rapid pace of change, it is a story that may not be a relevant guide for the future. It is disingenuous to think that we can maintain the status quo in terms of universal 1-on-1 pretest counseling if we are to fully realize the technical advances in genetic sequencing and apply these to the practice of personalized medicine. We should test as widely as possible to find as many carriers as we can. To do this, we need to find adequate alternatives to 1-on-1 counseling and focus our attention on those with positive test results. We need to expand our research programs to gain a better understanding of the meaning of each test result."

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