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Genetic counseling linked to increased use of preventive ovary removal in women at high risk for ovarian cancer

SAN ANTONIO – Genetic counseling is a preferred method for informing women with BRCA1 or BRCA2 genetic mutations and/or a family history of breast or ovarian cancer about their risks for getting such cancers, but little has been known about the impact of genetic counseling on efforts to reduce the risk of ovarian cancer.

A randomized clinical trial conducted by researchers at Fred Hutchinson Cancer Research Center has found, for the first time, that proactively offering genetic counseling to women at high risk of ovarian cancer can increase the use of prophylactic oophorectomy, or preventive ovary removal.

M. Robyn Andersen, PhD, MPH, a member of the Public Health Sciences Division at Fred Hutchinson Cancer Research Center in Seattle, led the study, which was funded by the National Cancer Institute of the National Institutes of Health.

Many women with a family history of breast cancer who carry a BRCA mutation know they are at increased risk of breast cancer but may not realize they are also at an increased risk for ovarian cancer, Andersen said.

“Most high-risk women with BRCA mutations have a family history of breast cancer and know about their relatives who died of breast cancer. Fewer have had relatives with ovarian cancer. ... It isn’t an intuitively obvious jump to go from, ‘My mom and her sisters had breast cancer’ to ‘I’m at high risk for ovarian cancer,’” Andersen said. “Many women, even those who know a lot about their elevated risk for breast cancer, haven’t heard much or anything, really, about their ovarian cancer and their elevated risk for it.”

According to the National Cancer Institute, women with a BRCA1 or BRCA2 mutation are at highly elevated risk for both breast and ovarian cancer. It is estimated that 55 to 65 percent of women with a BRCA1 mutation and about 45 percent of women with a BRCA2 mutation will develop breast cancer by age 70. Estimates of lifetime risk of ovarian cancer among BRCA1/2 carriers range from 16 to 45 percent. Unfortunately ovarian cancer is often diagnosed at a late stage and has a poor prognosis.

Preventive surgery, known as prophylactic risk-reducing bilateral salpingo-oophorectomy, or RRSO, greatly reduces the risk of ovarian cancer among women with genetic risk factors. However, a lack of knowledge that a family history of breast cancer confers a risk for carrying a genetic mutation that also increases ovarian cancer risk, coupled with a lack of genetic testing to identify such mutations, can be a significant barrier to informed decision-making.

Andersen and colleagues aimed to determine whether non-directive genetic counseling could increase women’s knowledge of their ovarian cancer risk and their use of preventive surgery. She also sought to determine the impact of genetic counseling on perceived levels of worry about ovarian cancer risk.

The study involved 458 Seattle-area women who reported a BRCA1/2 mutation and/or a personal or family history of breast cancer, no prior ovarian cancer diagnosis and no prior preventive ovary-removal surgery. Half of the study participants were randomized to receive genetic counseling and half to receive standard care. The study participants were then followed over four years and surveyed about their use of genetic counseling, genetic testing and pelvic surgery, including RRSO.

Women offered genetic counseling were more likely than the standard-care group to undergo genetic testing (32.5 percent versus 8.6 percent) and ovary-removal surgery in the two-year period of study follow up (10 women in the intervention group versus three in the usual care group). There was, however, some concern that these positive changes could be associated with potentially distressing elevations in women's levels of worry about and perceived risk of ovarian cancer.

"We found that genetic counseling can provide women with what they need to pursue risk-reduction activities that could save their lives," Andersen said. "We also found that it appears to be possible without causing women undo concern about their risk for ovarian cancer."

Andersen will present these study results at 8:45 a.m. CT on April 25 during the Society of Behavioral Medicine's 2015 Annual Meeting & Scientific Sessions in San Antonio. Her presentation is titled: "Changes in Ovarian Cancer Worry and Risk among High-Risk Women after Genetic Counseling." Other study authors are Jason Thorpe, Kate Watabayashi and Nicole Urban, of Fred Hutchinson, and J. David Beatty, Robert Resta and Charles Drescher, of Swedish Hospital in Seattle. The authors report no financial or other conflicts of interests.

The Society of Behavioral Medicine (SBM) is a 2,200-member organization of scientific researchers, clinicians and educators. They study interactions among behavior, biology and the environment, and translate findings into interventions that improve the health and well-being of individuals, families and communities (www.sbm.org).

At Fred Hutchinson Cancer Research Center, home to three Nobel laureates, interdisciplinary teams of world-renowned scientists seek new and innovative ways to prevent, diagnose and treat cancer, HIV/AIDS and other life-threatening diseases. Fred Hutch's pioneering work in bone marrow transplantation led to the development of immunotherapy, which harnesses the power of the immune system to treat cancer with minimal side effects. An independent, nonprofit research institute based in Seattle, Fred Hutch houses the nation's first and largest cancer prevention research program, as well as the clinical coordinating center of the Women's Health Initiative and the international headquarters of the HIV Vaccine Trials Network. Private contributions are essential for enabling Fred Hutch scientists to explore novel research opportunities that lead to important medical breakthroughs (www.fredhutch.org).

This study will be presented during the SBM 2015 Annual Meeting & Scientific Sessions, held April 22-25 in San Antonio. However, it does not reflect the policies or the opinion of SBM. This presentation will be held on April 25. Given that this study was presented at a scientific meeting, the data and conclusions reached should be regarded as preliminary, until they are published in a peer-reviewed journal. Funding agencies played no role in this study. There are no conflicts of interest for the investigators.

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