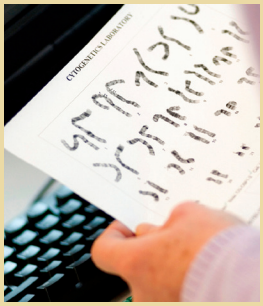
■ Online Exclusive Article

Decision Making After *BRCA* Genetic Testing: Down the Road of Transition

Laurie M. Connors, DNP, FNP-BC, Nicoleta Voian, MD, MPH, Yi Shi, MS, Robin M. Lally, PhD, RN, AOCN®, and Stephen Edge, MD, FACS



© Ingram Publishing/Thinkstock

The purpose of this study was to evaluate women who have completed hereditary cancer risk assessment and *BRCA* genetic testing to determine if they considered themselves prepared to proceed with decision making regarding cancer screening and prevention options. Levels of decisional conflict were explored, as was their preference for information delivery. The prospective, descriptive survey was conducted at a breast and clinical genetics clinic at a comprehensive cancer center in the northeastern United States. Twenty-seven female participants completed the Preparation for Decision Making scale, Decisional Conflict Scale, and a demographic questionnaire. Scores were consistent with high levels of preparation for decision making and low decisional conflict. The face-to-face approach was the preferred method for information delivery. Subgroup analysis demonstrated a difference in the measured objectives based on cancer status but not based on *BRCA* status. The current information delivery approach is meeting the decision-making needs of women considered to be at increased risk for hereditary breast and ovarian cancer.

Laurie M. Connors, DNP, FNP-BC, is a clinical assistant professor in the School of Nursing at the State University of New York in Buffalo; Nicoleta Voian, MD, MPH, is the director of the Clinical Genetics Service in the Department of Medicine at Roswell Park Cancer Institute in Buffalo; Yi Shi, MS, is a predoctoral trainee in the Department of Biostatistics and Robin M. Lally, PhD, RN, AOCN®, is an assistant professor in the School of Nursing, both at the State University of New York; and Stephen Edge, MD, FACS, is the Alfiero Foundation Endowed Chair in Breast Oncology in the Department of Surgical Oncology at Roswell Park Cancer Institute. The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the authors, planners, independent peer reviewers, or editorial staff. Connors can be reached at lconnors@buffalo.edu, with copy to editor at CJONEditor@ons.org. (Submitted June 2013. Revision submitted September 2013. Accepted for publication September 7, 2013.)

Key words: breast cancer; cancer program development/evaluation; communication; genetics/genomics; gynecologic malignancies

Digital Object Identifier: 10.1188/14.CJON.E58-E63

Five to ten percent of all breast and ovarian cancers have an identifiable genetic component (Nelson, Huffman, Fu, & Harris, 2005). To date, the most commonly identified genetic cause of hereditary breast and ovarian cancer (HBOC) are mutations in either the breast cancer–susceptibility gene 1 (*BRCA1*), located on chromosome 17 (Hall et al., 1990; Miki et al., 1994), or breast cancer–susceptibility gene 2 (*BRCA2*), located on chromosome 13 (Wooster et al., 1994). These function as tumor suppressor genes, and a mutation in one of the *BRCA* genes puts the carrier at increased risk for developing certain cancers, including breast and ovarian. *BRCA* mutations are inherited in an autosomal dominant manner through either parent. Women considered at risk for HBOC, because of a personal or family history of disease, often complete hereditary cancer risk assessment and *BRCA1* and *BRCA2* genetic testing to clarify their risk of developing certain cancers and better inform subsequent decisions.

The lifetime risk of breast cancer for the general population is 12%, and the risk of ovarian cancer is 1.4% for women in the United States (Howlader et al., 2013). The risk of breast cancer increases to 45%–65% in women with a deleterious *BRCA* mutation, and the risk of ovarian cancer increases to 11%–39% for those women by age 70 years (Chen & Parmigiani, 2007). To date, no available genetic tests guarantee the identification of all cancer-predisposing *BRCA* mutations; therefore, a certain percentage of mutations may be missed (Petrucelli, Daly, & Feldman, 2011). Women who complete *BRCA* genetic testing (with no family history of a *BRCA* mutation) and receive negative test results are advised that the *BRCA* genetic test results are "uninformative." They are still at an elevated risk of breast and ovarian cancer based on their personal and/or family history of disease. Given the uncertainties still present in genetic test results, healthcare providers face a challenge in giving women accurate and useful information and advice on which