

Message from AMWA

AMWA Position Statement: Genetic Testing

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OVER 200,000 AMERICAN WOMEN will be newly diagnosed with breast or ovarian cancer in 2008, 90% with breast cancer. Over 40,000 of these women will die from their disease.¹ Given these overwhelming statistics, early diagnosis and treatment of these cancers are imperative, as is prevention, particularly in those women who are at high risk. Approximately 5%–10% of breast and ovarian cancers are related to an inherited gene mutation. Through the advances of cancer research, it has been discovered that most of the hereditary cancers (84% of hereditary breast cancer and >90% of hereditary ovarian cancer) are attributable to mutations in the *BRCA1* or *BRCA2* genes, tumor-suppressor genes that code for proteins involved in cellular growth and differentiation. Therefore, genetic testing for *BRCA* mutations is becoming used more frequently in clinical practices to test for cancer susceptibility. By identifying any genetic alterations that may predispose individuals to breast and ovarian cancer, the American Medical Women's Association (AMWA) firmly believes that genetic testing is a necessary measure for maintaining the health and well-being of anyone at a potential cancer risk.

Various methodologies have been developed to identify mutations in *BRCA1* and *BRCA2* genes. A well-documented personal and family medical history is part of the initial assessment for determining a hereditary predisposition to breast cancer. Any family history of early-onset breast cancer, ovarian cancer, bilateral breast cancer, breast and ovarian cancer in one patient, or male breast cancer should increase suspicion of inherited cancer.² As women with known *BRCA* mutations are managed differently from the general population, genetic testing allows for more tailored care of the patient. Women who have the mutation are offered intensified surveillance for early detection, chemoprevention, and risk-reducing surgeries as compared with women without increased risk.³

Potential disadvantages of genetic testing include technological limitations. Some results are of unknown clinical significance and cannot be used in clinical decision making.

Women may experience survivor guilt when their test results are negative while their siblings or other family members carry the mutation. Patients testing negative may not understand that they still have the odds of general risk to the population at large and may experience a false sense of security. Finally, for some patients, identification of a mutation may cause psychological distress.⁴

AMWA makes certain recommendations in order to ensure the ethical and responsible use of genetic testing. AMWA believes that legislation should be enacted that requires counseling for any patients submitting to genetic testing. Currently, the American Society of Clinical Oncology (ASCO) has set forth specific recommendations regarding genetic testing. ASCO strongly recommends that genetic testing be done only when paired with pretest and posttest counseling to ensure that patients are aware of the potential implications of their test results and to ensure that patients make informed medical decisions on receipt of test results.⁵ AMWA supports complete confidentiality of any information obtained from genetic testing as well as legislation that prohibits health and life insurers from denying or limiting coverage and from establishing different rates for individuals based on genetic testing information. AMWA is very much in favor of legislation that prohibits employers from discriminating against an individual because of genetic testing results.

Disclosure Statement

There are no conflicts of interest to report.

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