Position Statement

Hereditary Breast and Ovarian Cancer Risk Assessment

The National Association of Nurse Practitioners in Women’s Health (NPWH) supports the role of women’s health nurse practitioners (WHNPs) in providing hereditary breast and ovarian cancer (HBOC) risk assessment. At a minimum, HBOC risk assessment should include the woman’s personal cancer history; her maternal and paternal first-, second-, and third-degree relative cancer histories, with descriptions of the types of primary cancers and the ages of onset; any Ashkenazi Jewish ancestry; and the results of any cancer predisposition testing in any relative. This assessment should be reviewed and updated regularly. The goal of HBOC risk assessment is to identify women who may benefit from genetic counseling, genetic testing, enhanced surveillance, or other risk management strategies.

WHNPs should be knowledgeable about indicators of an increased risk for HBOC, as put forth by the National Comprehensive Cancer Network (NCCN). Women assessed as being at increased risk should have access to genetic counseling by clinicians with training and expertise in cancer genetics. These specialists can provide genetic testing if indicated and desired, psychosocial support, and evidence-based management that depends on identified risk and genetic testing results—if such testing is done. Resources for locating cancer genetics specialists include the National Society of Genetic Counselors website and the National Cancer Institute’s NCI Cancer Genetics Services Directory.

Primary care providers with appropriate training and skills, including WHNPs, may provide HBOC genetic counseling and testing. Obtaining such knowledge and skills, as well as keeping up to date with evolving cancer genetics knowledge and testing technology, requires additional training beyond that received in a WHNP program. An evidence-based protocol established according to guidelines provided by nationally recognized organizations such as NCCN must be followed to ensure that all recommended components of assessment, counseling, informed consent, appropriate testing, and follow-up are provided. State and federal regulations and laws for informed consent with regard to genetic testing and reimbursement must also be followed. WHNPs should consult with or refer women to a specialist in cancer genetics when their history or test results present a complex situation or when they request such a referral.

A system should be established within WHNPs’ practice settings for referral, consultation, and/or collaboration to ensure that women have timely access to genetic counseling services and subspecialty follow-up. Access barriers to a specialist in cancer genetics may be addressed through avenues such as telegenetic counseling and collaborative models that support WHNPs in providing in-depth risk assessment, counseling, and genetic testing. Therefore, NPWH opposes reimbursement requirements mandating that pre-test counseling be provided only by an individual certified in genetic counseling before genetic testing can be ordered. Such requirements can unduly limit access to timely care.

NPWH will provide leadership and collaborate with other organizations and agencies to deliver education that prepares WHNPs with the knowledge and skills to provide HBOC risk assessment, counseling, and genetic testing in collaboration with specialists in cancer genetics. WHNPs can help ensure that women receive timely, evidence-based care when identified as being at risk for HBOC. In addition, NPWH will provide leadership in monitoring and developing reimbursement and other policies ensuring that qualified WHNPs are able to counsel women regarding HBOC risks and to order and interpret genetic tests. Furthermore, NPWH will collaborate with other organizations and agencies to support research to better inform providers and women on best practice for identifying individuals at risk for HBOC and for counseling, testing, and risk management.

Background

The American Cancer Society (ACS) projects that in 2017, a total of 252,710 new cases of breast cancer will be diagnosed in women in the United States and that 40,610 women will die of breast cancer. In addition, the ACS projects that in 2017, a total of 22,440 new cases of ovarian cancer will be diagnosed, with 14,080 deaths caused by ovarian cancer.

Most breast and ovarian cancers are not related to unique identifiable risk factors, although certain individual, familial, reproductive, and lifestyle factors have been associated with increased risk. About 5%-10%...
of breast cancers and 20%-25% of ovarian cancers are associated with a predisposition from an inherited pathogenic variant (previously called a mutation). The comprehensive genetic counseling process should include a review of personal and family history; a detailed risk assessment; psychosocial assessment and support; individualized risk counseling and education; a discussion of genetic testing, including ethical and legal implications; and informed consent.

When genetic testing is indicated, choices include single-gene testing and multi-gene panel testing. Compared with single-gene testing, multi-gene panel testing with next-generation sequencing technology increases the rate of detection of pathogenic variants and is a more time- and cost-effective approach. NCCN provides management guidelines for the care of women found to have certain pathogenic variants that can be identified by multi-gene panel testing. However, standard management guidelines are not yet available with regard to all of them. In addition, multi-gene panel testing can result in a higher likelihood of detecting one or more variants of uncertain clinical significance (VUS). Women need to be informed of the benefits and limitations of multi-gene panel testing and the meaning of VUS before testing is performed.

Individualized cancer risk-reducing strategies and enhanced surveillance schedules should be established for women who test positive for pathogenic variants that place them at risk for HBOC. Risk-reducing strategies and enhanced surveillance schedules are also indicated for women with a personal or family history concerning for HBOC syndrome even when no pathogenic variant is detected or if only a VUS is identified. Implications for family members regarding testing and risk modification should be addressed if a pathogenic variant is identified.

**Implications for women’s healthcare and WHNP practice**

Identifying women who may benefit from HBOC genetic counseling, genetic testing, enhanced surveillance, and other cancer risk management strategies is essential to improve health outcomes. WHNPs are ideally positioned to conduct HBOC risk assessment during well-woman and other visits. HBOC risk assessment can be completed as part of the routine health history or using HBOC risk-assessment questionnaires completed by the patient prior to or during the visit. WHNPs with appropriate knowledge and skills regarding HBOC risk assessment and genetic testing indications, implications, and limitations can provide counseling, order and interpret genetic tests if indicated and desired by the woman, and discuss individualized enhanced surveillance recommendations and risk-management strategies. NPWH recognizes that
WHNPs who have appropriate training can fill an unmet need to increase availability and accessibility to timely counseling and testing of women who are identified as being at risk for HBOC.

**Recommendations**

**WHNPs should:**

- Conduct preliminary HBOC risk assessment with all women for whom they provide healthcare and update the assessment regularly.
- In a preliminary risk assessment, know the indicators for an increased risk for HBOC.
- Establish resources for referral, consultation, and/or collaboration when an increased risk for HBOC is identified.
- If planning to provide HBOC counseling and genetic testing, obtain additional training and skills, follow evidence-based guidelines, and adhere to state and federal regulations and laws for informed consent and reimbursement.

**NPWH will provide leadership and resources to ensure that:**

- Educational programs for WHNP students impart evidence-based knowledge and skill building for development of competencies to conduct preliminary HBOC risk assessment.
- CE programs are available for WHNPs to obtain evidence-based knowledge and competencies to provide HBOC counseling and genetic testing.

**References**


**Web resources**

A. nsge.org/page/find-a-gc-search

B. cancer.gov/cancertopics/genetics/directory

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