Attitudes and Psychological Impact of Genetic Testing, Genetic Counseling, and Breast Cancer Risk Assessment Among Women at Increased Risk

Sadie Pauline Hutson, MSN, RN, CRNP

Purpose/Objectives: To review research related to the psychological functioning of women with family histories of breast cancer, the impact of genetic counseling on women at increased risk, and their participation in and description of breast cancer risk evaluation programs.

Data Sources: Published articles and material from the World Wide Web.

Data Synthesis: Findings from these sources suggest an underlying level of psychological distress in women with family histories of breast cancer. This may either increase or decrease their surveillance practices. With the onset of commercial genetic testing for BRCA1 and BRCA2, researchers have studied some of the initial psychosocial effects of genetic information on women at high risk.

Conclusions: Women with family histories of breast cancer have a very high interest in genetic testing for BRCA1 and BRCA2 mutations. They have an underlying level of psychological distress that is not relieved by genetic counseling. They tend to state reasons for wanting and not wanting testing that are not polar opposites. Women who attend breast cancer risk assessment programs tend to be self-referred. Caucasian, well-educated, and of middle or upper income status. Large gaps exist in the research on women of color and those who are less educated and of lower socioeconomic status.

Implications for Nursing: Nurses and other healthcare professionals should tailor care given to women at increased risk for hereditary breast cancer by using the current information related to their emotional and medical needs. Decisions regarding genetic testing, genetic counseling, and breast cancer risk assessment are highly individualized. Thus, healthcare professionals should be cautious regarding any generalizations about women at risk for breast cancer.

Key Points . . .

➤ Although knowing whether one is hereditarily predisposed to breast cancer may have benefits, the extent of individual benefit still is unclear. Although knowing mutation status may provide a sense of control in life plans, it may alternatively create high levels of anxiety.

➤ Women at increased risk for breast cancer need comprehensive information about the benefits and limitations of genetic testing, in addition to alternatives, to ensure that choices about genetic testing are informed decisions.

➤ To tailor care to women who have undergone genetic testing for hereditary breast cancer or those who plan to undergo testing, nurses should actively listen to patient concerns and ask questions that probe into their feelings and expectations.

In 2002, an estimated 203,500 new cases of breast cancer developed in the United States, taking the lives of 39,600 women (American Cancer Society, 2003). The disease’s etiology is multifactorial; genetics, environmental factors, and the use of hormones all participate in the ultimate expression of breast cancer. Although no measures can guarantee prevention of breast cancer, steps can be taken to promote early detection. Early detection saves lives, improves quality of life, and reduces healthcare costs.

The average American woman has a 1 in 8 chance of developing breast cancer in her lifetime. Several factors increase a woman’s chances of developing breast cancer, including age older than 40, a personal history of breast cancer or benign breast disease, a mother or sister who has had breast cancer, never giving birth or giving birth after age 30, a long menstrual history, environmental factors, and diet. The most significant risk factors for developing breast cancer are female gender and age older than 40 years.

In addition, having a first-degree relative with breast cancer places a woman at increased risk for developing the disease (Runowicz, Petrek, & Gansler, 1999). A first-degree relative is defined as a biologic parent, sibling, or child. If a woman has a first-degree relative with the disease, her risk increases threefold. This risk increases two to five times the usual risk if the first-degree relative dies of breast cancer at an age younger than 50 years (Runowicz et al.). Risk increases as the age at diagnosis of the first-degree relative decreases.

Sadie Pauline Hutson, MSN, RN, CRNP, is a doctoral candidate in the School of Nursing at the University of Pennsylvania in Philadelphia and the recipient of a predoctoral fellowship at the Clinical Genetics Branch, National Cancer Institute, National Institutes of Health. At the time this article was written, Hutson was a predoctoral fellow in psychosocial oncology, funded by the National Institute of Nursing Research, National Institutes of Health (5-T32-NR-07036), and the American Cancer Society Doctoral Degree Scholarship (DSCN-102702), in the School of Nursing at the University of Pennsylvania. (Submitted January 2000. Accepted for publication May 30, 2002.)

Sadie Pauline Hutson, MSN, RN, CRNP, is a doctoral candidate in the School of Nursing at the University of Pennsylvania in Philadelphia and the recipient of a predoctoral fellowship at the Clinical Genetics Branch, National Cancer Institute, National Institutes of Health. At the time this article was written, Hutson was a predoctoral fellow in psychosocial oncology, funded by the National Institute of Nursing Research, National Institutes of Health (5-T32-NR-07036), and the American Cancer Society Doctoral Degree Scholarship (DSCN-102702), in the School of Nursing at the University of Pennsylvania. (Submitted January 2000. Accepted for publication May 30, 2002.)