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Engaging in Medical Vigilance: Understanding the Personal Meaning of Breast Surveillance

Meghan L. Underhill, PhD, RN, AOCNS®, and Suzanne S. Dickerson, RN, DNS

Purpose/Objectives: To explore how women with a hereditary risk of breast cancer experience living with and managing that risk through surveillance.

Research Approach: Hermeneutic phenomenology guided the qualitative research design.

Setting: The Facing Our Risk of Cancer Empowered online organization.

Participants: 9 women undergoing breast surveillance for hereditary breast cancer risk recruited through purposive sampling.

Methodologic Approach: Data were collected through semistructured interviews lasting about an hour. A team approach guided data analysis of transcribed interview text based on a modified Diekelman, Allen, and Tanner method.

Main Research Variables: Lived experience and personal meaning of hereditary breast cancer risk and surveillance.

Findings: Hereditary risk of breast cancer involves a change in one's view of life and necessitates engaging in medical vigilance, often making these women feel ill when they are otherwise healthy. Most have personal family experiences of cancer and value surveillance, although they live with the "what if" of a cancer diagnosis when waiting for surveillance results. All women discussed a need for accurate information, support, and guidance from healthcare providers.

Conclusions: Women became their own experts at living with and managing hereditary breast cancer risk. Experiences and interactions within the healthcare system influenced the meaning of breast surveillance.

Interpretation: Nurses should be aware of the high level of knowledge among women living with hereditary risk and respect their knowledge by providing accurate and informed care. That can occur only through proper education of nurses and all healthcare professionals working with women at risk for hereditary breast cancer so that they understand current standards of care and how hereditary breast cancer risk is defined and managed.

Mutations in the *BRCA1* or *BRCA2* genes account for 80% of hereditary breast cancers. Women with those mutations have a 36%–85% lifetime chance of developing breast cancer (National Comprehensive Cancer Network [NCCN], 2011). High-risk women hold a substantially elevated lifetime cancer risk burden compared to the average 12% risk of breast cancer in American women (National Cancer Institute, 2010).

Criteria suggesting hereditary breast cancer risk include a personal or close familial history of early-onset breast cancer (i.e., prior to age 50), ovarian cancer, or male breast cancer, or being of Eastern European descent (NCCN, 2011). Women are identified as high risk through evaluation of personal and familial risk factors and may undergo genetic counseling or testing based on that evaluation. Women identified as high risk for hereditary breast cancer through either evaluation mechanism are encouraged to practice surveillance through breast awareness or breast self-examinations, mammography, breast magnetic resonance imaging (MRI), and clinical breast examinations, as well as to consider chemoprevention or prophylactic surgery if indicated (NCCN, 2011). Breast surveillance begins at a younger age than general population breast screening, often at 25 years or based on clinical recommendations and the age at onset of cancer occurring within the family (NCCN, 2011).

Women with knowledge of a potential hereditary breast cancer risk often seek opportunities to enhance their health and control their cancer risk (Hamilton, Williams, Skirton, & Bowers, 2009). Therefore, women may choose to follow surveillance recommendations, thus interacting with the healthcare system about every six months for evaluation