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Learning About a Twist in the Road: Perspectives of At-Risk Relatives Learning of Potential for Cancer

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The following statement illustrates the complexity of communicating newly discovered inherited breast and ovarian cancer risk in families.

We aren't really that close . . . and she basically sent out an e-mail to the family . . . and she said, "The good news is that I am done with chemo and everything is fine, . . . the bad news is I got my genetic test back and I have this mutation, and you probably have it too, so go get tested." . . . It came out of the blue.

More than 200,000 American women are diagnosed with in situ or invasive breast cancer every year. About 5%–10% of breast cancers are caused by inherited mutations in genes such as *BRCA1* or *BRCA2* (American Cancer Society, 2009). Each first-degree relative of a mutation carrier has a 50% chance of inheriting the same mutation. Women with a *BRCA* mutation have a 14%–87% chance of a breast cancer diagnosis by age 70 and a 10%–68% chance of ovarian cancer (National Cancer Institute, 2010). Individuals can benefit from knowing their *BRCA* status because the knowledge can assist them with decision making for screening and surveillance, chemoprevention, lifestyle changes, and risk-reducing surgery. In secondary prevention, the information is used for definitive treatment decisions (Schwartz, Peshkin, Tercyak, Taylor, & Valdimarsdottir, 2005) because women with *BRCA* mutations are at significantly increased risk of future contralateral breast cancer (Smith & Issacs, 2006–2007).

Genetic testing is not without limitations, including the potential for inconclusive results and a lack of certainty because of the variable penetrance and expressivity of *BRCA* mutations. Additionally, risk-reducing procedures such as prophylactic mastectomy and oophorectomy do not guarantee a future without breast or ovarian cancer. The psychosocial consequences of breast cancer genetic testing are unfolding as researchers study the impact of genetic testing on worries, depression, anxiety, emotions, and family and social relation-

Purpose/Objectives: To describe the experiences of women who accessed the Facing Our Risk of Cancer Empowered (FORCE) Web site after learning of a family *BRCA1* or *BRCA2* mutation.

Research Approach: Interpretive phenomenology based on Heideggerian hermeneutics.

Setting: Telephone interviews of women living in the United States who accessed FORCE.

Participants: A purposive sample of eight women aged 19–47 years.

Methodologic Approach: Team interpretation using Diekmann, Allen, and Tanner's seven-step process.

Main Research Variables: Experience of family communication of *BRCA* results.

Findings: Women described (a) finding out, (b) unexpected feelings, (c) mulling it over, (d) finding support, (e) seeking direction from healthcare professionals, (f) redefining future possibilities, and (g) navigating a twist in the road.

Conclusions: Many healthcare professionals are not prepared to address genetic risk. Some women who learned of potential risk experienced turmoil as potential risk for cancer unfolded. They felt isolated and unsupported by healthcare providers. They desired assistance in navigating the healthcare system to protect their future health.

Interpretation: Healthcare professionals have important roles in (a) assessing support networks of individuals seeking *BRCA* testing, (b) providing anticipatory guidance on risk communication, (c) remaining sensitive to the impact of seeing cancer as a future possibility, (d) allowing time for individuals to process such news, (e) assessing the psychosocial impact of news of a family *BRCA* mutation, and (f) providing referrals for support and health needs. Women desire decision support from healthcare providers. Future research should examine cancer risk communication in diverse groups of women.

ships. Studies exploring the psychosocial consequences of genetic testing for hereditary breast and ovarian cancer (HBOC) syndrome found that most women do not experience clinically significant levels of distress, depression, and anxiety (Crotser & Boehmke, 2009).