

Five Families Living With Hereditary Breast and Ovarian Cancer Risk

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This qualitative study explores the communication and decision-making strategies of five families with hereditary breast and ovarian cancer (HBOC) risk. Investigators asked female carriers of *BRCA1* and *BRCA2* genetic mutations to recall early knowledge and experiences concerning cancer risk. Husbands and children (aged 15–25 years) of women with HBOC risk also were interviewed on knowledge, experiences, and expectations for future decisions regarding their risk. Themes derived from the interviews suggested a need for additional studies of families with HBOC risk to address how family history and other factors influence decision making. Nurses should assess patients and their families for issues with body image and adjustment after cancer treatment and offer appropriate support. In addition, parents should be advised on when and how to tell children about their potential risk and support their testing and health-promotion decisions.

Much has been learned about the identification of *BRCA1* and *BRCA2* genetic mutations and related risks for families with hereditary breast and ovarian cancer (HBOC). Specific information about surveillance and preventive interventions for risk reduction and early detection is available for family members who have been tested and have received their results. Although genetic counseling is available, research and informal evidence show that many at risk do not seek genetic testing and counseling; those who do often fail to follow recommendations for surveillance or prevention (Tinley et al., 2004).

Women with a *BRCA* mutation have a 41%–90% lifetime risk for breast cancer and a 8%–24% risk for ovarian cancer (Risch et al., 2006). Children of a parent with a *BRCA* mutation have a 50% chance of inheriting the mutation because *BRCA* genes are autosomal dominant genes (i.e., males and females are equally likely to carry a mutation and have a 50% chance of passing it on to a child, regardless of gender) (Nussbaum, McInnes, & Huntingdon, 2004). The literature shows no consensus about responses to awareness of risk on psychological morbidity; some investigators reported no differences from the general population (Coyne, Kruus, Kagee, Thompson, & Palmer, 2002; Schwartz et al., 2002), but Van Oostrom et al. (2003) found increased anxiety and depression in carriers of HBOC one to five years after disclosure. Women with a history of breast cancer reported increased anger and worry after receiving genetic test results that confirmed their high risk for disease (Bonadona et al., 2002; Dorval et al., 2000; Robertson, 2000). Many at-risk women have even greater concern for their children (Kenen, Arden-Jones, & Eeles, 2004). Men and women who were carriers and believed that their spouses were anxious and unsupportive, experienced clinical distress for two years after testing (Wylie, Smith, & Botkin, 2003). In addition, husbands of

At a Glance

- ◆ Parents thoughtfully and informally communicate hereditary breast and ovarian cancer risk to their children; however, many parents do not talk about the risk.
- ◆ Breast cancer is viewed as a women's issue, so men often are overlooked in discovering risk status.
- ◆ Discussing risk status can be threatening to parents and their children.

carriers wanted counseling for themselves and believed that their wives had received inadequate support at the time of disclosure (Metcalfé, Liede, Trinkaus, Hanna, & Narod, 2002).

The studies provided information on responses to being a carrier or a spouse but did not discuss how families experience intergenerational vulnerability. Although HBOC clearly is a family matter, families rarely have been asked to provide a group perspective on their experiences in living with the risk.

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