

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

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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.

nificant 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.

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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 sig-

Family history encompasses both a shared genetic component and a shared environmental component. This may include, but is not limited to, occupational and chemical exposures, region of residence, or lifestyle factors. A more exact role of genetics in the expression of breast cancer currently is under investigation. The major focus is on molecular genetics, specifically, identifying genes for breast cancer susceptibility.

The locus for hereditary breast and ovarian cancer (*BRCA1*) first was mapped in 1990 to chromosome 17q (Hall et al., 1990). In 1994, *BRCA1* was cloned and a second locus was mapped to chromosome 13q (*BRCA2*) and subsequently cloned. *BRCA1* is classified as a tumor suppressor gene that is inherited in an autosomal dominant fashion. Mutations in this gene greatly increase a woman's risk of developing both breast and ovarian cancer. *BRCA1* is highly penetrant, producing an 80%–90% risk of breast cancer and a 40%–65% risk of ovarian cancer by age 70 (Carter & Hailey, 1999). The inheritance of *BRCA1* mutation, however, does not guarantee that a particular patient will get breast or ovarian cancer. Some evidence suggests that risks of breast and ovarian cancer are related to the position of the mutation. For example, mutations toward the five prime end of the *BRCA1* gene confer a higher risk for ovarian cancer (Ford et al., 1998). Other factors, either genetic or environmental, play an important role and most likely prompt the ultimate occurrence of the disease. *BRCA2* seems to have a similar age-specific breast cancer penetrance to *BRCA1* but is not implicated as highly in the development of ovarian cancer.

About 1 in 200–400 women may carry germline mutations of breast cancer susceptibility genes (Claus, Risch, & Thompson, 1991; King, Rowell, & Love, 1993). Jewish women of Eastern European descent are at higher risk for inheriting a mutation (about 1 in 40) (Runowicz et al., 1999). Commercial testing for mutations in *BRCA1* and *BRCA2* became available in the United States in 1996; however, much testing still is being performed in highly structured and funded research programs.

Varying attitudes and psychological effects are associated with testing for the presence of *BRCA1* and *BRCA2* mutations. Women with a first-degree relative with breast cancer have an underlying level of psychological distress that must be addressed. Moreover, the desire for genetic counseling and genetic testing in women at risk is associated with different motivations and styles of coping, including motivation to participate in breast cancer risk evaluation programs. Nurses in clinical practice and research should be aware of what is known about the experiences of women at increased risk for breast cancer. This article summarizes the current literature related to the psychological functioning of women with family histories of breast cancer, the impact of genetic testing and counseling in women at increased risk, and their participation in breast cancer risk evaluation programs.

Psychological Functioning

Very little is known about the multiple psychosocial sequelae associated with increased breast cancer risk status, especially in women who are considering genetic testing for *BRCA1* and *BRCA2* mutations. A diagnosis of hereditary breast or ovarian cancer can evoke powerful emotions such as anxiety, depression, anger, and guilt for passing on the mutation to offspring (Decruyenaere et al., 1999). Individuals may

react not only emotionally but also cognitively to a threatening genetic condition. For example, a cognitive representation of the causes, symptoms, and risk perception of the disease may be constructed solely on the basis of ongoing and previous experiences with the disease.

The threat of a genetic condition can elicit feelings and reactions that change family and intimate relationships, decisions concerning childbearing and prophylactic surgery, perception of body image, self-esteem, and quality of life. Furthermore, genetic conditions affect entire families, not just individuals. For this reason, family members are likely to develop different ways of coping with genetic susceptibility and disclosure of risk status to other blood relatives. Many of these factors influence whether patients decide to have genetic testing for *BRCA1* and *BRCA2* mutations. Figure 1 summarizes the reactions to genetic testing results most commonly cited in the literature.

Many researchers have studied the baseline psychological functioning of women with family histories of breast cancer. Wellisch, Gritz, Schain, Wang, and Siau (1991) systematically compared daughters of patients with breast cancer with a well-matched comparison group to assess differences in knowledge and attitudes about breast cancer, health behaviors, sexuality, body image, symptomatology, and coping behaviors. The sample was 60 daughters of patients with breast cancer (30 with mothers who were deceased and 30 with mothers still living) and a comparison group of 60 subjects at average risk for breast cancer. The daughters were recruited via a newspaper advertisement and asked to provide the names of four acquaintances, from whom the control group was selected. With regard to knowledge and attitudes about breast cancer, the daughter and comparison groups essentially were equal, with one exception: The daughter group perceived their chances of getting breast cancer to be much higher than the comparison group ($p < 0.0001$). During evaluation of screening practices, however, no significant differences emerged between the groups on mammography, Papanicolaou tests, blood pressure checks, or breast self-examination (BSE). Polednak, Lane, and Burg (1991) reported that increasing age appeared to influence the association between family history of breast cancer and subsequent lack of breast cancer screening utilization. Wellisch et al. (1991) also explored sexual satisfaction; the comparison group (women with average risk) had a significantly higher score ($p < 0.05$) and significantly more frequent sexual intercourse ($p < 0.0035$). No significant differences were found

Anxiety
Depression
Fear
Anger
Guilt
Decreased body image
Decreased self-esteem
Questions concerning childbearing
Altered family relationships
Altered sexual satisfaction

Figure 1. Common Reactions to the Threat of Hereditary Breast Cancer
Note. Based on information from Decruyenaere et al., 1999; Wellisch et al., 1991, 1992.

between the two groups with regard to psychological symptomatology or coping behaviors. The latter study was limited by demographic homogeneity and thus generalizability, as well as the fact that subjects were actively seeking help in a clinic setting.

Wellisch et al. (1992) conducted a second study to characterize the distressed daughters of patients with breast cancer. Using the same sample, they administered a structured interview along with self-administered psychological tests including the Brief Symptom Inventory, the Global Symptom Index, and the Derogatis Sexual Functioning Inventory. Overall, daughters reported that their life courses were altered by their mothers' illness, which had ongoing emotional effects, in particular, integration of the image of a dying mother into a sense of self. Emotional reactions were even more serious for adolescents. Daughters who perceived their mothers' reactions to mastectomy as more distressing (71%) also were more uncomfortable about involvement in their mothers' illness (66%). These findings suggest that daughters were more distressed than the first part of the study implied.

In a study by Kash, Holland, Halper, and Miller (1992), women with family histories of breast cancer scored above the mean on all measures of psychological distress, among them somatization, obsessive compulsive disorder, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. Figure 2 summarizes the study's results. Subjects also had lower scores on social desirability and more distress ($p < 0.0001$). In general, women who perceived susceptibility as "very high" or "extremely high" were sufficiently immobilized by their anxiety to engage in fewer preventive healthcare behaviors, whether for breast cancer or general health care. These findings suggest that high risk for disease may not lead to screening behaviors, but may have exactly the opposite effect as women's fears increase, thereby acting as a deterrent to further screening. More research is needed to uncover the deterrents to screening behavior. In the study by Kash et al., only 40% of subjects performed BSE monthly and only 69% had regular clinical breast examinations (CBEs), a finding also supported by Alagna, Morokoff, and Bevet (1987) and Lerman, Rimer, Trock, Balshem, and Engstrom (1990). In contrast, Hailey, Carter, and Burnett (2000) found that women with family histories of breast cancer ($n = 25$) engaged in more BSE and mammography than women in the comparison group who were at average risk ($n = 26$). The study by Hailey et al. differed from the aforementioned studies in that the sample was not comprised of participants from a breast cancer research program, but rather was made up of university faculty and staff or community members. This

Somatization
Obsessive compulsive disorder
Depression
Anxiety
Phobic anxiety
Paranoid ideation
Psychoticism

Figure 2. Potential Psychological Comorbidities Identified in Women With Family Histories of Breast Cancer

Note. Based on information from Kash et al., 1992.

particular sample was highly educated and may have had more information about the guidelines for breast health surveillance. Moreover, the results may be difficult to generalize because of the small sample size.

According to these studies, some women report less activity in surveillance behaviors and less distress in comparison to others, all with positive family histories. This contradictory information suggests that practitioners should tailor preventive health care to individuals using the most current evidence concerning response to breast cancer risk. Although this area is not clearly understood, it remains an important topic for research. The matter of genetic testing enters into this equation in complex ways.

Genetic Testing

Some advocacy groups propose that genetic testing should be confined to research protocols where comprehensive genetic counseling and support services are offered. Testing for *BRCA1* and *BRCA2* mutations is a highly technical and time-consuming process that can take as long as a year in a research setting. Commercial testing may be very costly; researchers have speculated that new technologies will be available that result in decreased costs (Carter & Hailey, 1999). The ultimate goal of genetic predisposition testing is to reduce mortality in women who have genetic mutations by increasing screening and diagnostic interventions. However, the nature of the psychological impact of high risk for breast cancer still is not clear. This holds true for genetic counseling as well as genetic testing.

Several studies indicate that interest in genetic testing for *BRCA1* and *BRCA2* mutations is very high among women with family histories of breast cancer (Lerman, Daly, Masny, & Balshem, 1994; Lerman, Seay, Balshem, & Audrain, 1995; Shiloh, Petel, Papa, & Goldman, 1998). Lerman et al. (1995) found that 91% of first-degree relatives said they would want testing. This compares with Shiloh et al., who found a lower but still significant number of first-degree relatives interested in genetic testing (70%). They speculated that the differences were the result of the level of detail provided to subjects about the actual testing. Nevertheless, interest in genetic testing remained high among the women polled. All three studies were limited by the hypothetical nature of genetic testing; testing was not presented as an actual option. Thus, results of most studies may be inflated because patients were not confronted with matters of cost, such as insurance coverage or having to pay out-of-pocket. Figure 3 summarizes the reasons found in the literature why women at increased risk for breast cancer would desire or decline genetic predisposition testing.

The psychosocial implications for women who have undergone genetic testing for *BRCA1* and *BRCA2* mutations are being studied. The research, however, is in early stages and limited, specifically to the long-term consequences of predisposition testing. Psychosocial distress appears to be a common response to genetic testing, no matter what the results (Carter & Hailey, 1999). Lerman et al. (1995) found that most women anticipated a negative psychological impact of positive results involving increased anxiety (83%), depression (80%), and decreased quality of life (46%). Seventy-two percent of women indicated that they still would worry, even if test results were negative. Moreover, 32%

Reasons for wanting genetic predisposition testing

- Increase use of cancer screening tests.
- Prepare psychologically for being ill.
- Relieve doubts about whether a diagnosis of breast cancer is or is not likely.
- Learn about offspring's risk.
- Prevent transferring risk to future generations.
- Have an early diagnosis and more effective treatment.

Reasons for not wanting genetic predisposition testing

- Lack of control over progress or severity of disease
 - Potentially decreased quality of life
 - Inability to cope with fear of being diagnosed
 - Worry about insurance coverage
 - Partner and family reactions to test results
 - Worry about test accuracy
-

Figure 3. Reasons Cited for Wanting or Not Wanting Genetic Predisposition Testing

Note. Based on information from Lerman et al., 1995; Matthews et al., 2000; Shiloh et al., 1998.

said they would feel guilty if results were negative because they had survived family members now deceased from breast cancer.

Genetic Counseling

Knowledge of carrier or noncarrier status is important in any assessment of women's breast health surveillance practices, emotional adjustment, and medical decision making (e.g., prophylactic mastectomy or oophorectomy). Studies of genetic counseling suggest that women with first-degree relatives with breast cancer tend to either over- or underestimate their individual risk for disease expression (Evans, Blair, Greenhalgh, Hopwood, & Howell, 1994; Lloyd et al., 1996; Watson et al., 1999). Lloyd et al. evaluated perceptions of risk, psychological morbidity, and health behaviors in women with family histories of breast cancer who participated in genetic counseling. The sample consisted of 88 clinic patients with family histories of breast cancer and a control group of age-matched women without family histories of breast cancer who were accrued from a local general practitioner's office. In the study, 58% of women overestimated their risk for breast cancer before the counseling session and 10% underestimated their risk. One year postcounseling, 66% of women with family histories of breast cancer still continued to either over- or underestimate their lifetime risk. Many genetic counselors advise individuals and present genetic risk based on statistical information. This study may suggest that women fail to translate numerical risk accurately with regard to likelihood of getting the disease. Moreover, numeric or statistical risk may not be as important as other factors to women at high risk for breast cancer.

Watson et al. (1999) found that women who consistently overestimated their lifetime risk were more vulnerable to cancer-specific worry. Thus, caution must be taken in correcting an overestimated risk perception, as women may subsequently have a false sense of security and become less diligent in participating in breast health surveillance practices. However, women who underestimate their risk for developing the disease may be subject to increased anxiety after counseling that their risk is higher than their original perception.

After genetic counseling, women with family histories of breast cancer had a significantly increased level of cancer-

specific distress when compared to a control group, suggesting that women at high risk have breast cancer worries that are not alleviated by genetic counseling (Lloyd et al., 1996). The study may have been biased because a pretest/post-test design was not used. Watson et al. (1999), who also found that levels of cancer-specific distress were unchanged after counseling, did employ a pretest/post-test design. Kash et al. (1992) reported a reduction in cancer anxiety months after genetic counseling, possibly because of better follow-up throughout the year after counseling.

The emergence of genes linked to breast cancer susceptibility has created demands on the skills and resources of health-care professionals caring for women with increased risk for breast cancer. Nurses working in the field of cancer genetics play a critical role in communicating information about genetic susceptibility, prevention, screening, and the implications and limitations of genetic testing. Increased knowledge about the psychosocial processes involved in genetic testing for hereditary breast and ovarian cancer could result in interventions that increase emotional support, provide psychological well-being, and enhance adherence to cancer screening among women with family histories of breast cancer. Health-care providers who offer genetic testing need preparation for the increased number of self-referring individuals who perceive risk, regardless of whether such perceptions are accurate. Providers must recognize these anxieties to better educate and counsel such women, especially if their expectations are not met or requests for screening are denied.

Breast Cancer Risk Assessment Programs

Few studies describe the characteristics of women who participate in breast cancer risk assessment programs. Participation in such programs is increasing, as is media support of and referral to the programs. Breast cancer risk assessment programs aim to (Hoskins et al., 1995)

- Assess patients' ideas about cancer etiology and risk perception.
- Discuss individual factors contributing to elevated risk (genetic and nongenetic).
- Review family histories and construct pedigrees.
- Assess lifetime risk of developing breast cancer based on statistical risk tables or the chance of inheriting an autosomal dominant predisposition gene.
- Help instruct families about appropriate surveillance.
- Identify families eligible for genetic testing and refer them to a specialized cancer genetics center offering testing as indicated.
- Provide referrals to individuals who could benefit from psychological counseling.

Predictors of participation in a risk-counseling trial for first-degree relatives of patients with breast cancer have been identified (Bowen et al., 1999; Rimer, Schildkraut, Lerman, Lin, & Audrain, 1996). In one study, five predictors of participation were education, CBE, estimated breast cancer risk (Gail Model Score), perceived breast cancer risk, and alcohol intake (Bowen et al.). Rimer et al. found that 59% of participants had an education beyond high school, 57% performed CBE monthly, their average Gail Model Score was 15.6%, most had a significantly higher perceived risk for breast cancer, and 54% consumed alcohol. When invited to participate in risk counseling, 47% agreed. The participants all were relatives of recently diagnosed patients with breast cancer. This

may account for either a decrease or increase in interest. Having family members with a recent diagnosis may have inflated participants' perception of individual risk. A relative's diagnosis of cancer may represent a teachable moment, as well as a situational life event that could influence change in a woman at risk (Rimer et al.). Fewer resources may be needed to recruit those who are more advantaged, more educated, Caucasian, and nonsmokers. To reach minority populations, those with less education, and those of low socioeconomic status, more resources and incentives may be needed for study participation. Use of the Gail Model Score has certain limitations for risk assessment because it does not factor in second-degree relatives with breast cancer or the age at diagnosis of the closest relative. In 2000, a study from the United Kingdom explored reasons why women attend familial breast cancer clinics (Brain et al., 2000). The sample included 833 women with family histories of breast cancer who were referred to a randomized control trial. Using the Manchester Family History Clinic Questionnaire, subjects listed reasons for attending the clinic: to learn about risk for breast cancer, obtain knowledge related to family history, ascertain risk to other family members, reduce worry, learn about genetic testing, have a breast check, and find out about prevention methods. The reasons certainly fall within the aims of breast cancer risk assessment programs, although participating subjects may have additional motivations for participation.

Lerman et al. (1996) explored the impact of individualized breast cancer risk counseling on cancer-specific distress. Among women with less formal education, breast cancer risk counseling produced significant reductions in breast cancer-specific distress by the three-month follow-up, a finding with important implications for adherence to breast health surveillance practices. Although breast cancer risk counseling led to reductions in cancer-related distress in this study, it did not affect general mood. This could be attributed to a program more geared toward the reduction of cancer-specific worry. Breast cancer risk counseling is not synonymous with genetic counseling, although calculation of breast cancer risk often is incorporated into genetic counseling sessions.

Overall, breast cancer risk assessment programs have become more popular with the use of tamoxifen for the prevention of breast cancer in high-risk women. Many clinicians are uncertain about whether referral to breast cancer risk assessment programs is useful to all patients at increased risk. Breast cancer risk assessment programs generally are guided by multidisciplinary teams trained in educating patients about factors other than chemopreventive medications. Patients may or may not want to participate in such programs; therefore, referral must be discussed in greater detail. In contrast, many patients who participate in the programs are self-referred. More research should be done to describe the characteristics of high-risk individuals who participate in counseling about breast cancer risk.

Most clinicians will encounter patients with family histories of breast cancer. Therefore, clinicians must understand deter-

minants of risk, recommendations for surveillance, counseling for individuals at risk, and education regarding community resources where patients can access well-established breast cancer risk evaluation programs. In general, women are becoming more aware of risk and the role of genetics in cancer.

Summary

Overall, women with family histories of breast cancer have different levels of psychological distress and functioning. The existing evidence suggests that women at risk may be either more or less likely to use breast health surveillance measures. Decisions appear to be highly individualized, although women at risk for breast cancer generally have great interest in genetic testing. Whether the demand for testing will increase or decrease as better information about testing becomes more widely known is unclear. Individual coping styles are important factors when assessing for possible negative effects from the results of testing. Many legal, emotional, financial, and ethical issues related to genetic testing need to be considered, especially in the early stage of knowledge development concerning risks and benefits of testing.

Information from recent research studies must be used in developing protocols for psychological interventions. Genetic testing can change decisions related to family and intimate relationships, childbearing, body image, and quality of life. Whether results are negative or positive in testing for mutations in *BRCA1* and *BRCA2*, they can have a highly negative impact on women's lives. Clearly, more study of these issues is warranted. Because of the current pace of technology, gathering sufficient data about the psychological outcomes of testing before such testing is widely used is challenging. In particular, women with high levels of cancer-related worry must be targeted, as this may be more useful than genetic testing in increasing screening behaviors and enhancing satisfaction with outcomes. Although the current research is valuable, healthcare professionals should be careful regarding any generalizations about women at risk for breast cancer.

Throughout the studies reviewed in this article, study participants displayed considerable demographic homogeneity, decreasing generalizability of the findings. More information is needed about women from larger sample sizes with varying socioeconomic and educational backgrounds, especially women of color. A much broader understanding is needed about levels of distress related to breast cancer (both acute and chronic), interest in genetic testing, and participation in breast cancer risk assessment programs. Furthermore, more research is needed about the best ways to deliver cancer risk information to the general population.

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