Relationships Between Perceived Risk, Objective Risk and Adherence to Screening Measures in Women at High-Risk for Breast Cancer

by
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Abstract

Breast cancer is a significant public health problem since it affects 1 out of every 8 women in the United States (Jemal, Thomas, Murray, & Thun, 2002). Many risk factors for breast cancer have been extensively studied in the past 25 years and the presence of these risk factors can greatly increase a woman's chance of developing breast cancer. A family history of breast cancer can increase an individual's risk by 1.5 to 3.0 times (Ottman, King, Pike, et al., 1983). The presence of a BRCA1 mutation is associated with an 87% cumulative risk by the age of 70 and BRCA2 mutations are associated with an 84% cumulative risk of breast cancer by age 80 (Ford, Easton, Stratton, et al., 1998). Breast cancer risk assessment models have been developed as a result of the knowledge gained from epidemiological studies. These models can provide more accurate estimates of lifetime risks for the development of breast cancer. Oftentimes, a woman's perceived risk of breast cancer is significantly different than her objective risk and this can impact on the adherence to breast cancer screening measures. A brief review of the literature on breast cancer risk perception and adherence to screening measures is provided in this paper. Additionally, a small pilot study addressing risk perception, objective risk and adherence to screening measures is described. The women in this study were attending a high-risk cancer clinic because of family histories of breast cancer. Finally, some
Suggestions are made about strategies that may be effective for improving women’s breast cancer risk perception.
ACKNOWLEDGEMENTS

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<td>Description</td>
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<tr>
<td>--------------</td>
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</tr>
<tr>
<td>BRCA1</td>
<td>breast cancer gene associated with hereditary breast/ovarian cancer</td>
<td></td>
</tr>
<tr>
<td>BRCA2</td>
<td>breast cancer gene associated with hereditary breast/ovarian cancer</td>
<td></td>
</tr>
<tr>
<td>BRCAPRO</td>
<td>breast cancer computer software program used for hereditary breast/ovarian cancer syndromes</td>
<td></td>
</tr>
<tr>
<td>BSE</td>
<td>breast self-examination</td>
<td></td>
</tr>
<tr>
<td>CBE</td>
<td>clinical breast examination</td>
<td></td>
</tr>
<tr>
<td>FCCC</td>
<td>Fox Chase Cancer Center</td>
<td></td>
</tr>
<tr>
<td>FDR</td>
<td>first-degree relative</td>
<td></td>
</tr>
<tr>
<td>JHOC</td>
<td>Johns Hopkins Oncology Center</td>
<td></td>
</tr>
<tr>
<td>SCPC</td>
<td>Strang Cancer Prevention Center</td>
<td></td>
</tr>
<tr>
<td>TPC</td>
<td>tailored print communication</td>
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</table>
Introduction

In the year 2002, breast cancer will remain the number one cause of cancer in women (excluding non-melanoma skin cancers) within the United States. Breast cancer is expected to account for 31% of new cases of cancer this year (Jemal, Thomas, Murray, & Thun, 2002). Estimated deaths from breast cancer this year are 15% of all cancer deaths, making it the second leading cause of cancer death in women. Only lung cancer deaths are expected to surpass breast cancer deaths in women this year. Approximately 25% of all cancer deaths are expected to be due to lung cancer. What can be derived from the statistics is that breast cancer is not an uncommon disease and in fact, breast cancer affects 1 out of every 8 women in the United States (Jemal, et al., 2002). This is based on a woman’s lifetime probability, from birth to death. For many women this risk is even higher and it is based on a multitude of factors. Over the past twenty-five years, epidemiological studies of breast cancer have yielded crucial information about the factors that may predispose women to this disease. These risk factors include age, and family history of breast, ovarian, or prostate cancer, prior radiation to the chest, an abnormal breast biopsy, personal history of breast, ovarian and/or endometrial cancer, reproductive history, and the presence of BRCA1 or BRCA2 genetic mutations. Epidemiological studies are also contributing knowledge on other possible risk factors, such as diet, alcohol consumption, cigarette smoking, and physical activity.
Results of large epidemiological studies focused on many of the above risk factors and have provided researchers and clinicians with a framework for assessing breast cancer risk. There are now four different risk models that clinicians can use to predict breast cancer risk (Armstrong, Eisen, & Weber, 2000). Two of the risk models are specific for women who have either a mother or sister with breast cancer and are used primarily for genetic counseling purposes. It is important to know which women may be at higher risk for the development of breast cancer because prevention and screening measures may be different for them than for women at average risk. For example, clinicians, along with their patients, can devise individualized management strategies based on the patient’s personal risk of developing breast cancer. This could include mammography starting at an earlier age, more frequent mammograms and clinical breast exams, prophylactic mastectomy and/or oophorectomy, chemoprevention, and, possibly, lifestyle changes.

A person’s perception of the risk, or susceptibility to developing a disease, has been found to be a strong predictor of preventive health behaviors (Strecher & Rosenstock, 1997). Additionally, perception of risk may alter psychological adjustment. For many women, the thought of developing breast cancer can evoke fear and grave concern. This is especially true for women who are at high risk for developing breast cancer based on a positive family history of the disease. A review by Lerman and Schwartz (1993) revealed two findings across studies of high-
risk women: first, these women had high levels of psychological distress due to worries about developing breast cancer, and second, despite their elevated risk and worries about breast cancer, they often did not adhere to cancer screening guidelines. In contrast to the above, several other studies found a positive association between psychological distress and adherence to screening measures. Another study has shown that women at high risk overestimated their actual risk, which led to higher anxiety and a low performance of breast self-examination (Gagnon, et al., 1996).

The purpose of this paper is threefold. The first is to provide an overview of risk factors for breast cancer and risk factor assessment models, as well as provide a review of the literature on breast cancer risk perception. The third is to describe a small pilot-study focused on personal breast cancer risk perception, objective risk and screening behaviors. As part of the study, qualitative data on personal risk perceptions were compared to quantitative data derived from breast cancer risk models.

Breast Cancer Risk Factors

Age and Family History

There are many factors associated with an increased risk of breast cancer. One uncontrollable risk factor is age. In the general population, the lifetime probability of developing breast cancer in a female is approximately 12% (Jemal, et al., 2002). From birth to age 39, the probability of developing breast cancer is only 0.44%; from ages 40 to 49, the probability increases to 4.17%; and in the age group 60 to 79, the
probability rises to 7.14% (Jemal, et al., 2002). Next to age, family history is the most significant risk factor. We currently know of two different types of breast cancer risk related to family history. For the majority of women with a family history of breast cancer, the disease in the family member is probably not related to a germline mutation in a tumor-suppressor gene. The risk of developing breast cancer in women who do not have a germline mutation in a tumor-suppressor gene, but do have a first-degree relative (mother or sister) with a history of breast cancer, is increased by 1.5 to 3.0 times (Ottman, Pike, King, & Henderson, 1983). Anderson and Badzioch (1993) found that breast cancer risks were 2.7-fold higher in families with prostate, endometrial, or ovarian cancers, than in families without these diseases. Interestingly, these risks increased 6- to 8-fold when there were two or more cases of prostate cancer in the family. True inherited breast cancer, which is a result of a germline mutation, accounts for approximately 7% of breast cancer cases (Claus, Schildkraut, Thompson, & Risch, 1996). The majority of these hereditary breast cancers are associated with two high-penetrance breast cancer susceptibility genes, BRCA1 and BRCA2 (Ford, Easton, Stratton, et. al, 1998). The frequency of these two genes may be higher in certain populations, such as in Ashkenazi Jews (Easton, Ford, & Bishop, 1995). It has been estimated that BRCA1 mutations are associated with an 87% cumulative risk of breast cancer by age 70 and BRCA2 mutations are
associated with an 84% cumulative risk of breast cancer by age 80 (Ford, et al. 1998). These mutations are also associated with earlier age of breast cancer onset, a high risk of contralateral breast cancer, high risk of ovarian cancer, and a higher than average risk of prostate cancer in men and pancreatic cancer in men and women (American Medical Association, 2001).

**Hormonal Factors**

Hormones are related to breast cancer occurrence with many studies showing associations with early age of menarche, late age of menopause, and nulliparity. In a review by MacMahon, Cole, and Brown (1973), it appears that there is a 20% decrease in breast cancer risk for each year that menarche is delayed. For women who begin menopause before age 45, there is a 50% reduction in risk for breast cancer compared to women whose menopause occurs after age 55 (Trichopoulos, MacMahon, & Cole, 1972). Nulliparous women have a higher risk of breast cancer than do parous women. Also, women who have their first full-term pregnancy after age 30 are at higher risk for breast cancer (2- to 5-fold increase) than women who have had a first full-term pregnancy by age 19 (Trichopoulos, Hsieh, & MacMahon, 1983). To date, there is no clear evidence of a relationship between use of exogenous hormones (hormone replacement therapy or oral contraceptives) and breast cancer. However in one meta-analysis of estrogen replacement therapy, there was a small but
statistically significant increase in the risk (RR, 1.3) of breast cancer (Steinberg, Thacker, Smith, et al., 1991).

**Benign Breast Disease**

Premalignant histologic changes in breast tissue can place a woman at higher risk for developing breast cancer. In fact, Dupont and Page (1985) showed that atypical hyperplasia on biopsy leads to a relative risk of 4 to 5 for the development of breast cancer. This risk was found to be even greater if a woman had at least one first degree relative (i.e., mother or sister) with breast cancer.

**Environmental and Dietary Factors**

Although these risk factors are not accounted for in the risk models, they may still be important to consider when evaluating a woman’s risk for breast cancer. The most important environmental factor that places a woman at high risk is exposure to ionizing radiation to the chest. Women, who have received mantle irradiation for Hodgkin’s Lymphoma before the age of 15, have a markedly increased risk for breast cancer (Hancock, Tucker, & Hoppe, 1993). Studies on fat intake and breast cancer have been inconclusive thus far, but many studies of alcohol intake have suggested an association between breast cancer and moderate alcohol consumption (Greenwald & Hunter, 1999; Ellison, Zhang, McLennan, & Rothman, 2001).

Breast Cancer Risk Assessment Models
Various breast cancer risk models have been developed in order to assist clinicians in evaluating an individual's personal risk for breast cancer. Many of these risk factors for breast cancer were described above and many of them may interact to increase breast cancer risk. An epidemiological and clinical challenge has been how to determine risk based on a combination of risk factors. Several prediction models have been devised to address this issue. These prediction models are based on the risk factors that are most consistently associated with breast cancer. Thus, they do not include dietary and environmental risk factors that currently have shown inconclusive results in epidemiological studies. Although it is known that prior irradiation exposure to the chest is strongly associated with breast cancer, it is not included in the models because it is relatively rare in the general population. The three different risk models that will be described are The Gail Model, The Claus Model, and the BRCAPRO model.

The Gail Model

The Gail Model is the most widely used prediction model for women in the general population. It is a model of relative risks for various combinations of risk factors that was developed from the Breast Cancer Detection Demonstration Project, a large mammographic-screening program in the 1970's (Gail, et al., 1989). Of particular note, this study involved only Caucasian women. After evaluating a number of risk factors, Gail, et al. (1989) included the following risk factors in the model:
age at menarche, age at first live birth, number of previous breast biopsies, and number of first-degree relatives with breast cancer. Calculations of five-year and lifetime risks for breast cancer can be derived from this model. A software program, available from the National Cancer Institute, can be used for easy calculations of breast cancer risk (National Cancer Institute, n.d.).

The Claus Model

Another commonly used risk prediction model was developed by Claus, Risch, and Thompson (1994). It is based on data from the Cancer and Steroid Hormone Study, which was a population-based, case-control study conducted by the Centers for Disease Control. This model is mostly based on family history of breast cancer and on assumptions of the prevalence of high-penetration genes for susceptibility of breast cancer. Information on family history, such as age at diagnosis in first- and second-degree (grandmothers or aunts) relatives breast cancer is incorporated into the model. Only a small number of non-Caucasian women were included in the study. Therefore, just as with the Gail Model, one must use caution when using these models for non-Caucasian women.

The BRCAPRO Model

A more recent model, by Parmigiani, Berry, and Aguilar (1998) computes the probability that an individual carries a germ-line mutation at BRCA1 or BRCA2, on the basis of family history of breast cancer and
ovarian cancers. It is now well known that carriers of these inherited mutations are at a much higher risk for the development of breast and ovarian cancer. Some of the family-history risk factors for carrying a BRCA1 or BRCA2 mutation are outlined in Table 1.

Table 1

<table>
<thead>
<tr>
<th>Risk Factors for Carrying a BRCA1 or BRCA2 Mutation</th>
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<tbody>
<tr>
<td>Known BRCA1 or BRCA2 mutation in a family member</td>
</tr>
<tr>
<td>Breast and ovarian cancer in the same individual</td>
</tr>
<tr>
<td>Two or more family members with ovarian cancer or breast cancer before the age of 50</td>
</tr>
<tr>
<td>Presence of bilateral breast cancer</td>
</tr>
<tr>
<td>Any male breast cancer in the family</td>
</tr>
<tr>
<td>Early-onset breast cancer and Ashkenazi Jewish ancestry</td>
</tr>
<tr>
<td>Ovarian cancer at any age and Ashkenazi Jewish ancestry</td>
</tr>
</tbody>
</table>


The BRCAPRO model is used as a tool by clinicians who offer genetic counseling, to determine whether an individual should pursue genetic testing. It is not designed to assess breast cancer risk in general, but instead is specific for women with family history risk factors.

Prediction models: limitations

The Gail and Claus models are both limited based on the variables that were chosen as risk factors. Both models excluded some well-established breast cancer risk factors such as family history of ovarian cancer and a family history of bilateral breast cancer. Furthermore, Gail and colleagues only included first-degree relatives with a history of breast cancer. Therefore, when an individual has a significant family history of breast cancer, it may be preferable to use the Claus model. The disadvantage of
both the Gail and Claus models in hereditary breast cancer is that they underestimate breast cancer risk in BRCA1 and BRCA2 mutation carriers, and over-estimate risk for a woman from the same family who does not carry either of these mutations (Costantino, et al., 1999). The BRCAPRO model can be used as a supplement when an individual’s family history suggests that there may be an autosomal dominant inheritance. Typically it is only used if an individual has a strong family history of breast cancer and is interested in genetic susceptibility testing for the presence of BRCA1 and/or BRCA2.

Perceived Risk of Breast Cancer and Adherence to Screening Measures – A Review

Results from previous studies have found both positive and negative associations between family history of breast cancer, high perceived risk and compliance with screening measures such as mammography, clinical breast exam (CBE), and breast self examination (BSE). In Rosenstock’s article (1974), he states, “A person’s perception of the risk of, or susceptibility to, developing a disease is believed to be an important determinant of his or her health-related behaviors” (p. 354). This is based on the Health Belief Model that is often used to guide research on the use of screening measures to detect illness. Researchers have used this model to examine factors associated with the use of mammography, CBE, and BSE. A recent study by Finney and Iannotti (2001) expanded the use of the Health Belief Model to include issue involvement with breast cancer
(i.e., the level of involvement with breast cancer fundraisers or other educational forums, degree of reading about breast cancer, etc.) and salience of breast cancer family history. Lipkus, Rimer, and Strigo (1996) have used the Transtheoretical Model to examine relationships among objective and subjective risk for breast cancer and mammography use. Other researchers have merely studied risk perception of breast cancer without applying the concept to any specific behavioral model. Several breast cancer risk perception studies will be reviewed more closely in the following sections. These particular studies were chosen because they addressed both perceived risk of breast cancer and adherence to screening measures.

*Psychological Distress and Surveillance Behaviors of Women with a Family History of Breast Cancer*

Kash, Holland, Halper, and Miller (1992) used the Health Belief Model to examine their hypothesis that women who perceived themselves as vulnerable to breast cancer, and who thought that the efficacy of early-detection measures outweighed the barriers, would adhere to early-detection measures more often than women who did not hold these same beliefs. Additionally, they used Fear Arousing Communication Theory to help determine whether women with a moderate level of anxiety would engage in screening measures more often than women with either low or high levels of anxiety related to breast cancer. Subjects were selected from an early detection program for women at high risk for breast cancer.
seen at the Strang Cancer Prevention Center between January 1989 and September 1990. The program included a CBE, mammography, and instructions for BSE and follow-up visits scheduled every 6 months. Women had to have either two or more first-degree relatives with breast cancer, a first-degree relative with premenopausal breast cancer, or a mother and maternal grandmother with breast cancer to be eligible for the program. A total of 217 (69%) women were included in the final study sample. The mean age of the women was 44 years, and the majority of them were white, college educated, and in professional or managerial positions. While these women were waiting for their medical visits, they were asked to complete a self-administered questionnaire that took between 30-45 minutes. The questions based on the Health Belief Model assessed perceived susceptibility to breast cancer, severity of disease, benefits and risks of interventions and obstacles to interventions. Preventive health behaviors were also assessed and the items ranged from general behaviors such as vitamin usage and dental visits to specific behaviors such as the practice of BSE. In addition, several psychological scales were included that measured psychological symptoms, social support, and social desirability.

Results from the questions about health beliefs revealed that 76% of these women felt they were at moderate to extreme risk for developing breast cancer. Interestingly, only 24% felt their chances of developing breast cancer were low to none at all, despite the fact that they chose to
attend the high-risk breast cancer program. Most of the women adhered to scheduled mammograms and CBE, but slightly less than half performed monthly BSE (see Table 2). Multiple regression analysis was used to reveal predictors for engaging in preventive health behaviors. Women who did not come for their mammograms as scheduled were found to be significantly more anxious (P<0.007). Lower cancer anxiety also resulted in better adherence to clinical breast exams and performance of breast self-examinations. Women who never performed BSE perceived themselves to be at higher risk for breast cancer in contrast to women who performed monthly BSE perceiving themselves as being at moderate risk (P<0.05). The three significant predictors of preventive health behaviors were lower psychological distress (P<0.0004), lower perceived susceptibility (P<0.01), and greater perceived personal efficacy in preventing breast cancer (P<0.04).
Table 2

Percentages of Health Beliefs and Early Detection Methods Used by Women

<table>
<thead>
<tr>
<th>Health Beliefs and Early Detection Methods</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer is a serious disease</td>
<td>&gt;95</td>
</tr>
<tr>
<td>Ability to personally do something</td>
<td>&gt;70</td>
</tr>
<tr>
<td>Perceived Susceptibility to Breast Cancer</td>
<td></td>
</tr>
<tr>
<td>Very to extremely likely</td>
<td>41</td>
</tr>
<tr>
<td>Moderately likely</td>
<td>35</td>
</tr>
<tr>
<td>Low to none at all</td>
<td>24</td>
</tr>
<tr>
<td>Scheduled mammograms</td>
<td>94</td>
</tr>
<tr>
<td>Regular breast examinations</td>
<td>69</td>
</tr>
<tr>
<td>Perform breast self-examination</td>
<td></td>
</tr>
<tr>
<td>Monthly</td>
<td>40</td>
</tr>
<tr>
<td>Not regularly</td>
<td>50</td>
</tr>
<tr>
<td>Not at all</td>
<td>10</td>
</tr>
</tbody>
</table>


Increased perceived susceptibility and personal efficacy predicted fewer general health care behaviors than would be supported by the Health Belief Model. The women who rated themselves as high on perceived risk and had high psychological distress were the least likely to use preventive behaviors as they relate to breast health. The authors conclude that being at high risk for breast cancer may not be a cue to action to initiate breast cancer screening. In fact, it may increase a woman’s level of fear to the point where it may act as a deterrent. Educational and psychological interventions should aim at reducing a woman’s level of anxiety before they can be expected to engage in routine breast cancer surveillance. The authors also cautioned that the findings of this study should not be generalized beyond the study population because it included mostly white, well-educated, urban women.
The Impact of Family History of Breast Cancer on Women's Health

Beliefs

Finney and Iannotti (2001) incorporated components of the Health Belief Model into their investigation of differences in health beliefs between women with and without positive family histories of breast cancer. The researchers also expanded on the model to include issue involvement (defined previously) and salience of breast cancer family history as they relate to the use of mammography screening. The study population included primarily white women, over the age of forty, who were attending mammography screenings at a women's health clinic in Ohio. The sample size was 395 after excluding women under forty and women who did not complete the questionnaire. Women who reported having a least one first or second degree relative with breast cancer were classified as having a positive family history (n=159) and those who reported no family history were classified as having a negative family history (n=219). Women who were unaware of their family history (n=17) were excluded from part of the analysis. The relative’s age at breast cancer diagnosis was not addressed. The survey included questions about demographic characteristics, family history of breast cancer, and breast health behavior (i.e. BSE, CBE, and mammography). Questions assessing health belief variables focused on benefits and barriers to mammography screening, perceived susceptibility to developing breast cancer, perceived severity of breast cancer, and cues to action. Two scales
were developed to assess (1) the extent to which women’s concerns about breast cancer were related to a personal family history of the disease and (2) issue involvement; which included things such as, frequency of worrying about the development of breast cancer, reading articles about breast cancer, and participation in fund- or awareness-raising activities.

Bivariate analyses examined whether there were differences in responses based upon whether a woman had a negative or positive family history of breast cancer. Demographic variables were controlled for in a logistic regression model. Results showed that there were no significant differences between women with positive and negative family histories of breast cancer based on socio-demographic variables and breast health behaviors. However, some significant differences were obtained between women with and without a positive history for breast cancer (see Table 3). Women with a positive family history were more likely to perceive themselves as susceptible to developing breast cancer, had higher responses to cues to action regarding mammography, had higher levels of salience of family history, and showed greater levels of breast cancer issue involvement.
Table 3

Differences in Mean and Standard Deviation (S.D.) of Health Beliefs for Women with Positive and Negative Family Histories of Breast Cancer

<table>
<thead>
<tr>
<th>Health Belief Component</th>
<th>Positive Mean (S.D.)</th>
<th>Negative Mean (S.D.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barrier</td>
<td>2.71 (.89)</td>
<td>2.63 (.89)</td>
</tr>
<tr>
<td>Benefit</td>
<td>6.11 (.88)</td>
<td>6.11 (.91)</td>
</tr>
<tr>
<td>Susceptibility</td>
<td>4.29 (1.26)</td>
<td>3.21 (1.13)*</td>
</tr>
<tr>
<td>Severity</td>
<td>5.05 (.96)</td>
<td>4.98 (1.04)</td>
</tr>
<tr>
<td>Cue to Act</td>
<td>4.08 (1.17)</td>
<td>3.33 (1.02)*</td>
</tr>
<tr>
<td>Salience of Family History</td>
<td>4.85 (1.96)</td>
<td>2.28 (1.19)*</td>
</tr>
<tr>
<td>Issue Involvement</td>
<td>4.02 (1.09)</td>
<td>3.60 (1.08)*</td>
</tr>
</tbody>
</table>

Note. *Means significantly different, P<0.001.

The findings from this study indicate that women with a family history of breast cancer view themselves as being much more susceptible to breast cancer than those with a negative history and they also are more responsive to cues to action. Both of these issues have important implications for health care providers. First, health care providers should be more sensitive to the idea that women with a positive family history of breast cancer may view themselves as being at higher risk for breast cancer. Secondly, these women may have a better response to reminder letters about mammography screening.

The authors identified a few limitations of the study, however. The sample included a small number of minority women and included only women being screened by mammography. It would be important to
include other women in the population, since women already receiving mammograms may be more health conscious.

_Lipkus, Rimer, and Strigo (1996) examined perceived risk in relation to stages of change. Their study had three objectives. The first was to examine the relationship between objective and subjective risk indices and screening patterns among women age 50 and older in a health maintenance organization. The second objective was to test whether objective and subjective risk predicted stages of change as defined by the Transtheoretical Model. Past studies have shown that higher pro and lower con decisional balance scores have been associated with the use of mammography screening (Rakowski, Fulton, & Feldman, 1993). Therefore, their third objective was to determine whether objective and subjective risk predicted stages of change in addition to decisional balance (i.e. the overall weighing of pros and cons).

The study population was from the Kaiser Foundation Health Plan of North Carolina in the Research Triangle area. Medical records were reviewed and only women age 50 and above who had received two or fewer mammograms in a 36-month period were eligible. Of the 1913 eligible women, 638 provided consent. From the 638 women, 486 (87% response rate) completed the baseline interview. These women were
contacted 3 months later to update information about mammography screening and psychosocial variables related to mammography.

Some of these women were dropped from the study due to death or illness, change in health insurance, and the lack of response to the 3-month survey. Analyses were based on the remaining 364 women with an average age of 58.4 years. Most were white (83%), married (83.2%), and had some college education (60.4%). None of these demographic variables affected the results significantly. Objective measures of risk were based on the Gail Model and the mean lifetime risk was 11.2%.

Subjective risk was measured by asking the women what they thought their chances were of developing breast cancer in the next 10 years compared to other women their age. Next, stages of change for mammography were assessed and women were placed in the following categories; 1) precontemplation (n=8), never had a mammogram and do not intend to, 2) relapse (n=33), have not had a mammogram in the past year and do not intend to in the next year, 3) relapse risk (n=29), have had a mammogram in the past year, but do not intend to have one the next year, 4) contemplators (n=86), have not had a mammogram in the past year, but intend to have one, 5) action (n=103), have had a mammogram in the past year and plan to have one the next year, and 6) maintenance (n=105), have had at least one mammogram each year and plan to have another next year.
Overall, the majority of women assessed their comparative risk as less than average (40.1%), or as average (43.4%), with fewer women reporting higher than average risk (16.5%). Women reporting higher subjective risk were more likely to have a higher objective risk and women with family members who had breast cancer also were more likely to perceive subjective risk as being high. Table 4 provides an analysis of the subjective risk as a function of objective risk.

Table 4

Proportional Odds Regression Analyses Predicting Subjective Risk From Objective Risk Indices

<table>
<thead>
<tr>
<th>Model interval</th>
<th>Odds Ratio</th>
<th>95% confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall objective risk</td>
<td>2.74*</td>
<td>1.65-4.56</td>
</tr>
<tr>
<td>Components of objective risk</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of relatives with breast cancer</td>
<td>5.94*</td>
<td>2.91-12.11</td>
</tr>
<tr>
<td>Number of breast biopsies</td>
<td>1.28</td>
<td>0.86-1.91</td>
</tr>
<tr>
<td>Age at menarche</td>
<td>0.85</td>
<td>0.60-1.23</td>
</tr>
<tr>
<td>Age at first live birth</td>
<td>0.88</td>
<td>0.71-1.09</td>
</tr>
</tbody>
</table>

Note. *Means significantly different, P<0.001.

The authors had predicted that women with higher subjective and objective risk would be more likely to be in the later stages of change for mammography screenings (e.g. action and maintenance). These predictions were supported. Women reporting a higher subjective risk were more likely to be in a later stage of change (OR 1.47, CI 1.13-1.91) and women who reported having family members with breast cancer, as a measure of objective risk, were also more likely to be in a later stage of change (OR 1.93, CI 1.01-3.70).
Study findings show that a family history of breast cancer is the most salient feature among the objective components of risk. Also, both a higher subjective risk and family history of breast cancer were related to the later stages of change in regards to mammography use. Although the results showed a relationship between subjective and objective risk (women reporting high subjective risk also had high objective risk), it was only modest and the correlation was only 0.21. The authors suggest that improvements should be made in risk communications, so that risk is more accurately perceived. Other physiological risk factors included in the objective risk did not predict subjective risk. Therefore, health care providers must educate women about these important risk factors, as well as the risk factor of family history of breast cancer. Since risk perceptions seem to have a great impact on screening behaviors, modifying them early may influence women in the precomtemplation and contemplation stages of mammography adoption (Lipkus, Rimer, & Strigo, 1996).

The main limitation of this study is generalizability, given that the population was from an HMO. Women in this study were also mostly white, married and had college educations. Again, caution must be used when applying results to other groups of women.

Younger Women at Increased Risk for Breast Cancer: Perceived Risk, Psychological Well-being, and Surveillance Behavior

In 1994, Lerman, Kash, and Stefanek explored the relationship between psychological characteristics and surveillance behaviors of women under
the age of 50 who are at increased risk for breast cancer based on family history. To more fully evaluate these variables, the author's main objective was to compare risk perception, psychological symptoms, and surveillance patterns of women in different age groups. Study participants came from three major east coast cancer centers and analyses were provided for each site.

The Fox Chase Cancer Center (FCCC) enrolled 179 females between the ages of 30-75, who reported a history of breast cancer in at least one first degree relative. There was a 98% response rate for a 15-minute telephone interview. The majority of the respondents were white (92%), and 37% had an education beyond the high school level. There was a fairly equal proportion of women in the various age groups: ages 30-34 [23%], ages 35-39 [26%], ages 40-49 [25%], and ages 50 and over [26%]. About 9% of the women had more than one first-degree (FDR) relative with breast cancer, while 91% had only one FDR affected. The sample from the Johns Hopkins Oncology Center (JHOC) included 238 females between the ages of 20-75, with a family history of breast cancer. Self-report questionnaires were filled out prior to an initial visit at the Breast Surveillance Clinic by 70% of the women. The respondents were primarily white (96%) and had education beyond high school (61%). The percentages of women in each age group are as follows: ages 20-29 [18%], ages 30-34 [18%], ages 35-39 [17%], ages 40-49 [32%], and ages 50 and over [16%]. Seventy nine percent had one FDR with breast cancer
and the remaining 21% had two or more FDR’s with the disease. Of note, the women from these two centers were recruited through relatives who were breast cancer patients seen at the participating centers. The women in the third sample were from the Strang Cancer Prevention Center (SCPC) and they were all self-referred. The sample included 363 subjects, who were aged 20 and older and had a family history of breast cancer. The response rate for women who completed the self-report questionnaire was 73%. Again, the majority of respondents were white (90%), and 83% had education beyond high school. Percentages of women in each age group are as follows: ages 20-30 [7%], ages 30-34 [15%], ages 35-39 [19%], ages 40-49 [33%], and ages 50 and over [26%]. Approximately one-third (34%) of the subjects had one FDR with bilateral premenopausal breast cancer, 45% had one affected FDR plus one affected second-degree relative, and 21% had two or more affected FDRs.

The surveys consisted of a question that measured risk perception on a 5-point scale, questions about time since last mammogram and frequency of breast self-examination (BSE), and questions about psychological symptoms. The Brief Profile of Mood States, The Mental Health Inventory and The Brief Symptom Index were used to measure generalized psychological distress. Different psychological scales were used in each clinic to evaluate symptoms specific for breast cancer risk. Basically, all three measured intrusive thoughts and worries about the risk for the development of breast cancer.
The results show that about two-thirds of women under 50 perceive themselves as being at high risk for breast cancer (see Table 5). About three-fourths of women age 29 and younger believed that they would develop breast cancer someday. Women aged 30-34 and those aged 50 and over in the FCCC sample, were less likely to perceive themselves as being at high risk than were women in other age groups. There were no age-related differences in risk perception among the women from JHOC and SCPC. Results for breast cancer surveillance practices (i.e., mammograms and BSE) are shown in Table 5. Interestingly, about one third of women aged 29 and younger in the JHOC and SCPC samples had obtained mammograms. Over three-fourths of all women studied over the age of 35 had ever had a mammogram. Not shown in Table 5 are the proportions of women who reported having a mammogram within the past 12 months. For women aged 29 and younger in the JHOC and SCPC samples, the percentages were between 14% and 31%, respectively, for having a mammogram in the past 12 months. For women between 30-34, the percentages ranged between 24-35% and for women between 35-39, the range was 40-50%. Women aged 40-49 from the SCCC sample had the highest percentage (82%) of reporting having a mammogram in the past year. For the other two samples of women in this same age group, the percentages were from 37-39%. In the women aged 29 and younger, almost three-fourths reported practicing BSE less often than once a month. The highest rates of nonadherence to monthly BSE were among women in
the SCPC sample. Of note, the women from the SCPC sample were all self-referred.

Table 5
Perceived Risk and Breast Screening Variables by Age Group for the Three Samples Studied by Lerman, et al.

<table>
<thead>
<tr>
<th>Variable</th>
<th>&lt;30</th>
<th>30-34</th>
<th>35-39</th>
<th>40-49</th>
<th>&gt;50</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived risk</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Believe risk higher than average*</td>
<td></td>
<td>27 (64)</td>
<td>38 (83)</td>
<td>36 (80)</td>
<td>25 (54)</td>
</tr>
<tr>
<td>Believe likely to develop breast cancer+</td>
<td>30 (71)</td>
<td>34 (81)</td>
<td>31 (74)</td>
<td>59 (79)</td>
<td>26 (69)</td>
</tr>
<tr>
<td>Believe likely to develop breast cancer++</td>
<td>20 (77)</td>
<td>45 (79)</td>
<td>51 (75)</td>
<td>92 (77)</td>
<td>62 (65)</td>
</tr>
<tr>
<td>Mammography</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ever had*</td>
<td></td>
<td>24 (57)</td>
<td>35 (76)</td>
<td>40 (89)</td>
<td>40 (97)</td>
</tr>
<tr>
<td>Ever had+</td>
<td>13 (31)</td>
<td>36 (86)</td>
<td>41 (98)</td>
<td>73 (97)</td>
<td>38 (100)</td>
</tr>
<tr>
<td>Ever had++</td>
<td>9 (35)</td>
<td>39 (68)</td>
<td>58 (89)</td>
<td>101 (100)</td>
<td>91 (100)</td>
</tr>
<tr>
<td>Breast self-examination</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than once/mo*</td>
<td></td>
<td>14 (33)</td>
<td>5 (11)</td>
<td>17 (38)</td>
<td>11 (24)</td>
</tr>
<tr>
<td>Once/mo</td>
<td></td>
<td>12 (29)</td>
<td>26 (56)</td>
<td>14 (31)</td>
<td>15 (32)</td>
</tr>
<tr>
<td>Greater than once/mo</td>
<td></td>
<td>16 (38)</td>
<td>15 (33)</td>
<td>14 (31)</td>
<td>2 (44)</td>
</tr>
<tr>
<td>Less than once/mo+</td>
<td>22 (52)</td>
<td>18 (43)</td>
<td>17 (41)</td>
<td>28 (37)</td>
<td>16 (43)</td>
</tr>
<tr>
<td>Once/mo</td>
<td>17 (40)</td>
<td>19 (45)</td>
<td>14 (33)</td>
<td>35 (47)</td>
<td>17 (46)</td>
</tr>
<tr>
<td>Greater than once/mo</td>
<td>3 (8)</td>
<td>5 (12)</td>
<td>11 (26)</td>
<td>12 (16)</td>
<td>4 (11)</td>
</tr>
<tr>
<td>Less than once/mo++</td>
<td>19 (74)</td>
<td>40 (71)</td>
<td>50 (74)</td>
<td>76 (63)</td>
<td>47 (49)</td>
</tr>
<tr>
<td>Once/mo</td>
<td>3 (13)</td>
<td>14 (25)</td>
<td>15 (23)</td>
<td>37 (31)</td>
<td>40 (42)</td>
</tr>
<tr>
<td>Great than once/mo</td>
<td>3 (13)</td>
<td>2 (4)</td>
<td>1 (3)</td>
<td>7 (6)</td>
<td>9 (9)</td>
</tr>
</tbody>
</table>

Note: *FCCC, sample of FDRs of breast cancer patients (n=179)  
+JHOC, sample of FDRs of breast cancer patients (n=238)  
++SCPC, sample of self-referred breast cancer patients (n=363)  
Source: Lerman, Kash, & Stefanek (1994).
Levels of depressive symptoms and mood disturbances in women from the JHOC and FCCC samples were comparable to those in the general population. Analysis of variance was used to evaluate general psychological measures in the SCC sample and this method revealed that the highest levels of distress were among women aged 29 and younger (P = 0.002). With regard to specific worries about breast cancer, results from chi-square tests showed that the severity of worries among women in the JHOC sample did not vary by age group. Whereas, age-related effects were observed in the SCC sample. The highest levels of worry that had an impact on daily functioning were observed in women within the 30-34 (42%) and 50 and over (49%) age groups. The associations between psychological distress and surveillance practices varied by study population. In the FCCC sample, women who had not adhered to the age specific guidelines on mammography were shown to have higher intrusive thoughts about breast cancer (P =0.05). Women from this sample who practiced BSE more often than once per month were also more likely to have higher levels of intrusive thoughts about breast cancer (P = 0.008). This was in contrast to the women from the JHOC sample who had not had a mammogram in the past year. These particular women showed lower levels of breast cancer worries compared with women who had received a mammogram in the past year (P = 0.001).

Given the fact that the majority of the women under 50 years of age thought their risk of breast cancer was above average is cause for concern.
Many women may be overestimating their actual risk of breast cancer. Therefore, it is important to educate women about their personal risks for breast cancer. In this sample, the majority of women aged 39 and younger had received mammograms. The authors alluded to the possibility that this is a higher figure than what would be found in the general population. They suggest that perceptions of vulnerability may be a stronger determinant of mammography use than objective risk status.

According to the authors, these results are preliminary. The main limitations are due to variations between samples, because recruiting methods and risk profiles of the women were different. Also, some of the psychological measures differed among the study sites making it difficult to draw conclusions about associations that were obtained between psychological distress and surveillance measures. Finally, this population was homogeneous (i.e., white and educated), so the results may not be generalizable to minority or less educated women.

*Perception of Breast Cancer Risk and Psychological Distress in Women Attending a Surveillance Program*

Gagnon, et al. (1996) hypothesized that women who had an inaccurate perception of breast cancer risk would have higher levels of psychological distress that would reduce adherence to breast cancer screening measures. The following three goals of the study were to: 1) evaluate the relationship between risk perception, psychological distress and adherence to breast self-examination (BSE); 2) investigate the impact of attending a
surveillance clinic on these three factors; and 3) pilot-test the efficacy of a mailed informational newsletter to improve patients’ risk perception, reduce psychological distress and improve use of BSE.

Subjects were selected from the Memorial Sloan-Kettering Cancer Center Special Surveillance Breast Program (a program designed for women at high-risk for the development of breast cancer). They were accrued between March 1993 and March 1994. A total of 145 women were asked to participate in the study at the time of scheduling an initial appointment. If they agreed, they were mailed an informed consent and a self-administered questionnaire that took about 30 minutes to complete. Out of 145 women, 94 returned the questionnaires prior to their initial visit. The same questionnaires were sent out to these women at 2 and 4 months after their initial visit. Various valid and reliable psychological instruments were used in the questionnaire, as well as questions about past psychiatric history, social support, and socio-demographics. Perception of risk was evaluated by asking women how they perceived their own risk and the risk of an average woman of developing breast cancer by two quantitative measures. One measure was based on percentage of risk and the other on a 10-cm visual analog scale that stated on one end, ‘I have no chance at all’ and at the other end was, ‘I am absolutely certain to develop it.’ General preventive health behaviors were measured with several reliable and valid items and additional questions were added about the practice of BSE.
During the first visit to the surveillance program, women were asked to complete a questionnaire about family history of breast cancer, which was then reviewed with a breast surgeon. After a clinical breast exam (CBE) was performed and mammogram recommendations were reviewed, the breast surgeon also provided each woman with an estimate of personal risk for breast cancer based on both the Gail and Claus Empirical Risk Models. These risk counseling sessions included information about risk factors for breast cancer and current methods used for early detection, which included BSE.

Out of 82 women who returned their initial questionnaire prior to the first appointment, 41 were randomly selected to receive four issues of an educational newsletter that included topics such as, usefulness of CBE, mammography and BSE, diet and cancer, and the role of a genetics counselor in helping to determine breast cancer risk. The newsletters were sent out at different time points between entry into the program and 4 months after entering the program. Of note, 12 women out of the original 94 sent in the initial questionnaire after the randomization process and thus left 82 women for the intervention study.

In terms of actual versus perceived risk, results show that the majority of women significantly overestimated their risk of developing breast cancer (see Table 6). The mean perception of risk was between 41 to 50 percent on the categorical scale and 55% on the visual-analog scale. This was compared to actual mean risk based on the empirical risk estimate.
models, which was 18% (P<0.001). Student t-tests were performed to compare continuous variables between and within subjects.

Table 6

Women’s Perception of Their Risk of Developing Breast Cancer Prior to the Initial Visit (n=94)

<table>
<thead>
<tr>
<th>Perception of risk</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underestimation</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Accurate estimation</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Overestimation (at least doubled actual risk)</td>
<td>71</td>
<td>76</td>
</tr>
<tr>
<td>Overestimation (less than double actual risk)</td>
<td>13</td>
<td>14</td>
</tr>
</tbody>
</table>


Forty-seven women did not feel confident in their ability to perform BSE and this was inversely correlated to a high perception of risk (P=0.001). More than half of the women performed BSE less often than monthly and only 15% performed BSE on a monthly basis. About one-third reported performing BSE more often than once per month and 10% never performed BSE. There were no correlations between frequency of performing BSE and perception of risk, actual risk, social support or psychological distress. Over time, there was a significant decrease in women’s perception of risk as assessed by the two subsequent questionnaires that were completed 2 and 4 months after the initial visit. At 4 months, the perception or risk reduction went from a 41-50% interval to a 31-40% interval (P=0.004) and on the visual analog scale it decreased from 54% to 45% (P=0.009). A reduction in cancer anxiety was also seen at the 4-month period (P<0.05). Over time, however, no significant changes were found in BSE performance. Finally, no significant
differences were seen between the women who received and did not receive the newsletter with respect to performance of BSE, psychological distress, perception of risk or actual risk.

One of the main study goals, determining whether attendance in a breast cancer surveillance program would have an impact on risk perception and psychological distress, was supported: reductions in risk perception and cancer anxiety were seen over time. However, there were no changes in the performance of BSE. Although other researchers have found correlations between psychological distress and compliance with screening measures, this study found no correlations between anxiety, actual risk, perceived risk, family history of breast cancer and performance of BSE. The authors speculate that perhaps an improvement in performance of BSE may be seen over a longer period of time. This is based on the thought that a change in attitude usually comes before a change in actual behavior and many of the women in the study had reduced levels of anxiety over a 4-month period. The authors describe historical confounding as a potential reason why they did not see any difference in BSE performance rates between women who received the newsletters and those who did not. The newsletters were distributed at a time when there was substantial media coverage about problems with the National Surgical Adjuvant Breast Project trial and about the usefulness of mammograms. Women may have been more skeptical about breast cancer prevention and treatment during this time. Also, the newsletters provided
only general information on breast cancer risk as opposed to personalized information on risk, which may have led to the lack of effect from the newsletters. Evans et al. (1994) reported that women who received genetic counseling gave more precise personal risk estimations and were more likely to retain the information if they received it in a follow-up letter. This should be considered when designing psycho-educational materials for women attending a breast cancer surveillance program.

Perceptions of Breast Cancer Risk, Objective Risk, and Adherence to Screening Measures in Women Attending a High-Risk Cancer Clinic – A Pilot Study

Purpose of the Study

My goal for this small descriptive pilot-study was to determine whether women attending a high-risk cancer clinic perceived their personal risks as being different than their calculated absolute risks. A secondary goal was to assess the level of adherence to screening measures (i.e. mammography, clinical breast exam [CBE], and breast self-examination [BSE]).

Patient Selection

Women for this pilot study were identified through the University of North Carolina’s Comprehensive Cancer Center’s High-Risk Clinic. Women were eligible if they did not have a personal history of breast cancer. After determining eligibility, a woman was then asked to participate in the study that involved completing a brief questionnaire (see Appendix A). Each woman read and signed an informed consent and was
given an opportunity to ask questions before filling out the questionnaire. Consent forms were prepared in accordance with the institution’s internal review board (see Appendix B). Due to time limitations, only five women were approached about the study and all participated. Demographics collected were for age and race only. The age range of these five women was from twenty-four through fifty-three, with a mean age of 40. One woman was African American and the other four were Caucasian. With regard to family history, each woman had at least one first-degree relative with a history of breast cancer. One woman had two first-degree relatives (mother and sister) with a history of breast cancer, as well as three second-degree relatives. Another woman had two relatives with both breast and ovarian cancer (mother and maternal aunt). These two later cases would suggest a strong family history of the disease.

Measures

Perception of risk was measured by two questions using a 5-point Likert scale. The first question asked about personal chance of developing breast cancer and the second asked about chance of dying from breast cancer. The responses ranged from not at all likely to extremely likely. Screening behaviors were assessed by “yes” and “no” questions on the use of mammography, CBE, and BSE. Additional questions were asked about time since last mammogram and CBE and about the frequency of BSE practice.
Measurements of actual risk were calculated by the use of the BRCAPro computer software package (University of Texas Southwestern Medical Center, 2000). This package includes computations of risk based on the Gail and Claus empirical risk models. Both of these models predict lifetime risks for developing breast cancer by calculating percentages. Additionally, the software provides calculations for estimating probabilities of carrying a mutation in the BRCA1 and/or BRCA2 genes.

Results

Most of the women felt that their chances of developing breast cancer were either somewhat likely or likely, with only one participant choosing very likely as her response. None of the participants chose not at all likely or extremely likely for this question. The responses for the question about personal chance of dying from breast cancer were mostly somewhat likely, with only one woman choosing not at all likely and one woman chose very likely. The woman who felt that her chances of developing breast cancer, and also of dying from breast cancer, were very likely had two relatives with both breast and ovarian cancer. One of the relatives was the participant’s mother who was diagnosed with breast cancer at age forty-five and she died at age fifty-five. When perception of risk, based solely on a qualitative scale, was compared to actual mean risk (%) for each woman, it appeared that none of the women underestimated or overestimated their risk substantially (see Table 7). Only the study
participant, who had the two relatives with the diagnoses of breast and ovarian cancer, had a high probability for carrying a BRCA mutation. Her carrier probability for a BRCA1 mutation was 49% and for a BRCA2 mutation it was less than one percent. Since none of the other women had any significant chance of carrying a BRCA1 or BRCA2 mutation, their percentages are not reported in this paper.

Table 7

Comparison of Women’s Perception of Risk with their Actual Risk (%) Based on the Gail and Claus Models of Breast Cancer Risk Assessment

<table>
<thead>
<tr>
<th>Question</th>
<th>Responses</th>
<th>Gail (%)</th>
<th>Claus (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chances of developing breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subject #1</td>
<td>Very likely</td>
<td>25.6%</td>
<td>37.7%</td>
</tr>
<tr>
<td>Subject #2</td>
<td>Likely</td>
<td>20.8%</td>
<td>30.2%</td>
</tr>
<tr>
<td>Subject #3</td>
<td>Somewhat likely</td>
<td>15.9%</td>
<td>8.8%</td>
</tr>
<tr>
<td>Subject #4</td>
<td>Likely</td>
<td>16.5%</td>
<td>17.7%</td>
</tr>
<tr>
<td>Subject #5</td>
<td>Somewhat likely</td>
<td>24.2%</td>
<td>16.5%</td>
</tr>
</tbody>
</table>

With regard to screening behaviors, all but one subject reported, “yes” for ever having a mammogram and they were all within the past two year period. The one woman who never had a mammogram reported that she had a prophylactic bilateral mastectomy based on her strong family history of breast cancer. She did however continue to examine the area where her breasts were excised. All five of the women had CBE’s performed within the last two years and only two women performed BSE monthly. Results for screening behaviors for each subject are shown in Table 8.
Table 8

Breast Cancer Screening Behaviors for Each Subject

<table>
<thead>
<tr>
<th>Question</th>
<th>Subject #1</th>
<th>Subject #2</th>
<th>Subject #3</th>
<th>Subject #4</th>
<th>Subject #5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ever had a mammogram?</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>How long since your last mammogram?</td>
<td>NA</td>
<td>Less than 1 year</td>
<td>Less than 1 year</td>
<td>1-2 years</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>Ever had a clinical breast exam?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>How long since last clinical breast exam?</td>
<td>Less than 1 year</td>
<td>Less than 1 year</td>
<td>Less than 1 year</td>
<td>1-2 years</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>Do you practice breast self-examination?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>How often do you perform breast self-examination?</td>
<td>Once a month</td>
<td>Less than once/mo</td>
<td>Less than once/mo</td>
<td>NA</td>
<td>Once a month</td>
</tr>
</tbody>
</table>

Note: NA indicates not applicable.

Discussion

Although it is somewhat difficult to compare qualitative statements about breast cancer risk perception with quantitative risk calculations, some helpful information can still be derived. From this very small sample, it appears that none of the women grossly overestimated or underestimated their chances of developing breast cancer. Study participant #1 felt that her chances of developing breast cancer were very likely and her actual risk based on the two models is between 25 and 35 percent over her lifetime. This is substantially higher than for women in the general population. The general population risk is approximately 12 percent, as stated earlier. Study participant #3 had an actual risk of between 8 and 15 percent and she felt that her chances of developing breast cancer were somewhat likely. Other studies have shown that as
many as half of the women with a family history of breast cancer tend to overestimate their risks (Lerman, Kash, & Stephanek 1994; Lerman & Schwartz, 1993). In retrospect, it would have been preferable to assess perceived risk using a percentage scale. This would have allowed for a more accurate comparison with actual individual risks that are expressed as percentages. It is possible that the majority of women would be overestimating personal risk if measurements were made on a percentage scale.

All but one of the women had a mammogram and all were performed within the last 1-2 year period prior to the study. Study participant #1 never had a mammogram, but had a CBE in the last year and had undergone a bilateral mastectomy as was mentioned earlier. The other four women had CBE’s in the past 1-2 year period, with most of them occurring in less than one year. Only one woman did not perform BSE at all and two women performed BSE less than once a month. In general, these women with family histories of breast cancer were adhering to screening measures for breast cancer with regard to mammography and CBE’s. A few of the women were not following the often recommended monthly BSE, despite their higher than average risk for breast cancer.

This pilot study only provides some preliminary data on a very small study population of women seeking counseling at a high-risk cancer clinic. Suggestions for improved study design are: 1) Increasing the number of women in the study so that statistical analyses can be performed, 2) Alter
the questionnaire so that it includes a quantitative rating scale for personal risk perception and a question about comparative risk with the general population, 3) Administer the same questionnaire post-counseling and compare it with the pre-counseling questionnaire, and 4) Perform an educational intervention trial that provides a how to fact sheet on BSE, information on diet and exercise as they relate to breast cancer, information about individual risk factors and analysis of risk estimates, and stresses the importance of screening measures. The intervention should also include a demonstration of BSE by a health professional, along with a self-demonstration by the study participant. An improved study design can help answer the question about whether certain interventions can lead to more accurate risk perceptions by women with family histories of breast cancer. Additionally, valuable information may be gained about whether or not an educational intervention improves adherence to screening measures.

Conclusions

There are a considerable number of women in this country who have a family history of breast cancer. Many of these women tend to overestimate their own personal risk for developing breast cancer, which in some cases can lead to psychological distress and may alter a woman’s use of screening measures. It is, therefore, very important that health care professionals recognize these disparities when counseling and educating a woman with a family history of breast cancer. Risk models, such as the
Gail and Claus Risk Estimation Models, can provide helpful information to the clinician and patient. Used correctly, they can help a woman understand her risk and also aid in the decision-making processes about genetic testing and/or prophylactic strategies. A more accurate perception of risk may lead to a reduction in psychological distress and possibly improve adherence to breast cancer screening measures. Educational interventions have been found to improve risk perception when a post-counseling letter included information on precise personal risk estimations (Evans, et al., 1994). Also, Lerman and others (1992) found that the use of a psychoeducational booklet, focusing on mammography adherence, leads to greater annual mammography use. Rimer and Glassman (1999) have suggested that tailored print communications (TPCs) may show great promise as an aid to communicate cancer risk. TPCs are written materials that provide information that is specific for each individual based on his or her own risk factors. Evans and others (1994) used a similar strategy, but TPCs can include much more information on risk factors and on screening methods. It is likely that more studies will utilize these TPCs when attempting to improve not only risk perception, but adherence to screening measures as well. The hope for the future is that women with a family history of breast cancer will have more accurate perceptions of personal risk and increase their adherence to screening measures after attendance at high-risk cancer clinics or breast cancer surveillance clinics. The use of
TPCs in these clinics may be the best intervention to evaluate in future studies.
Appendix A

PERCEIVED RISK OF DEVELOPING BREAST CANCER AND SCREENING BEHAVIORS QUESTIONNAIRE

Please circle only ONE answer

1. What do you believe your chances are of developing breast cancer?
   Not at all likely  Somewhat likely  Likely  Very likely  Extremely likely

2. What do you believe your chances are of dying from breast cancer?
   Not at all likely  Somewhat likely  Likely  Very likely  Extremely likely

3. Have you ever had a mammogram?
   Yes  No

4. If “yes”, how long has it been since your last mammogram?
   Less than 1 year  1 to 2 years  More than 2 years  Not sure

5. Have you ever had a clinical breast exam?
   Yes  No

6. If “yes”, how long has it been since your last clinical breast exam?
   Less than 1 year  1 to 2 years  More than 2 years  Not sure

7. Do you practice Breast Self-Examinations (BSE)?
   Yes  No

8. If “yes”, how often do you perform BSE?
   Less often than once a month  Once a month  More than once a month
Appendix B

University of North Carolina-Chapel Hill
Consent to Participate in a Research Questionnaire

Title of Questionnaire: Perceived Risk of Developing Breast Cancer and Screening Behaviors

Principle Investigator: Denise Spector, ARNP, MSN, MPH candidate
UNC-CH Department: School of Public Health – Public Health Leadership
Phone number: 919-929-1949

You are being asked to take part in a research study. The investigator listed above is in charge of the study; other professional persons may be helping.

What are some general things you should know about research studies?

Research studies are designed to gain knowledge that may help other people in the future. You may not receive any direct benefit from participating. There may also be risks associated with participating in research studies.

Your participation is voluntary. You may refuse to participate, or may withdraw your consent to participate in any study at any time, and for any reason, without jeopardizing your future care at this institution or your relationship with your doctor. If you are a patient with an illness, you do not have to participate in research in order to receive treatment.

Details about this particular study are discussed below. It is important that you understand this information so that you can decide in a free and informed manner whether you want to participate. You will be given a copy of this consent form. You are urged to ask the investigator named above any questions you have about this study at any time.

What is the purpose of this study?

To examine the relationship between a woman’s perceived risk of developing breast cancer and her actual relative risk, as well as assess breast cancer screening practices. You have been invited to participate since you are a patient in the cancer high-risk clinic and you do not have a personal history of breast cancer.

How many subjects will participate in this study?

A total of approximately 25 women from this institution will participate in this study.
How long will your participation last?

Approximately 5 minutes to complete a questionnaire.

What is required of participants?

The completion of a one-time questionnaire.

Are there any reasons you should not participate?

If you have a personal history of breast cancer.

What are the possible risks or discomforts?

You may feel sad or worried when you are asked about your personal risk of developing breast cancer.

What are the possible benefits?

There are no direct health benefits to you from participating in this survey. However, future patients may benefit from a better understanding about individuals’ beliefs about developing breast cancer and the use of breast cancer screening measures.

How will your privacy be protected?

All information collected will be kept secured by the principle investigator and questionnaire data will only be identified with a study code that cannot be traced to you. No participants will be identified in any report or publication about this questionnaire.

Will you be paid for participation?

There is no financial compensation for participation in this study.

Will it cost you anything to participate?

There will be no cost to you for your participation.

Voluntary Participation

Again, your participation in this survey is voluntary. You will continue to receive your usual medical care regardless of whether or not you decide to participate in this survey.
What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have further questions, you should call Denise Spector, ARNP, MSN at 919-929-1949 or James Evans, MD, PhD at 919-966-2276. We value your consideration for taking part in this survey.

Participants Statement

I have read the information provided and have had the opportunity to ask questions about this survey. These questions have been answered to my satisfaction. My signature below indicates my voluntary participation in this survey.

_________________________  ____________________________
Signature of participant      Printed name       Date

Research Personnel Statement

I have provided an explanation of the above research study. The participant was given an opportunity to discuss the study and to ask questions. A signed copy of the consent will be given to the participant.

_________________________
Signature       Date
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