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13. ABSTRACT (Maximum 200 Words)
The study aimed to 1) describe perceived breast cancer risk, 2) compare subjective and objective risk estimates, and 3) examine the influence of heuristic reasoning in women's arguments regarding their breast cancer risk. The survey uses three probability scales (Verbal, Comparative, Numerical) and the Gail model to measure perceived and objective risk, respectively. Aim 3 is addressed with Argument and Heuristic reasoning analysis, a method based on applied logic and used to identify heuristics in narrative data. We recruited a multicultural sample of 184 English-speaking women (46±12 years old) from community settings to complete the survey. Fifty three of those women agreed to provide an in-depth interview. Most (49%) had college education. Participants held an optimistic bias regarding their breast cancer risk. They believed their risk was lower than average, they rated the risk for friends/peers higher than their own, and underestimated their objective risk. Responses on the Verbal and Comparative scales were consistent, whereas Numerical risk ratings were influenced by demographic characteristics. Older women and those with one affected first-degree relative did not perceive higher risk. Experiences with affected family members and friends, and breast symptoms influence perceived risk though various mechanisms, involving knowledge of risk factors and worry.

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Perceived risk, breast cancer screening, gail model, optimistic bias, triangulation

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INTRODUCTION

In an effort to eradicate breast cancer, social and behavioral research examines women's motivations to take an active role in protecting themselves from the disease. As health care providers we are interested in taking a closer look at the processes that bring an individual to the doorstep of health care services for breast cancer early detection. Perceived risk is an important motivator for adopting a health-protective behavior, and as an evolving thinking process is important in decision-making. The aims of this project are 1) to describe women's perceived breast cancer risk, 2) to compare their subjective risk estimates with an objective estimate of their risk, and 3) to examine the content and the structure of women's arguments regarding their breast cancer risk estimates.

BODY

During the months between May 2003 and May 2004 the following research tasks have been accomplished. Maria Katapodi (Principal Investigator – PI) in collaboration with the research team has finalized the survey questionnaire and the interview guide, has gained entrée in appropriate recruitment sites, and has completed data collection. The project recruited a total of 184 women with a diverse racial/cultural background from community settings. Fifty three of those women agreed to provide an in-depth interview. The PI with the research team concluded that conducting further interviews will not be necessary because interview data reached saturation. Forty-five interviews have been transcribed by a professional transcriber and are ready for analysis.

The only problem encountered was in gaining entrée in communities of women from diverse racial/cultural backgrounds and communities of older women. In order to overcome this obstacle the PI (Maria Katapodi) requested the assistance of community 'Gate Keepers'. These were women that are leaders in community organizations. Their assistance was limited to advertising the study in organization meetings and to suggest additional community organizations for further recruitment of study participants.

Descriptive Data Report from Survey Questionnaire

Descriptive data collected from the survey questionnaire have been analyzed using the statistical program SPSS 11.5. A detailed description of these findings will be disseminated with three manuscripts titled:

1) Optimistic bias regarding the risk of developing breast cancer in a multicultural community sample. To be submitted Annals of Behavioral Medicine
   This manuscript addresses specific aims 1) and 2) of the project.
2) When do experiences with affected family members, affected friends, and personal experiences with breast symptoms influence perceived breast cancer risk? To be submitted Journal of Behavioral Medicine
   This manuscript addresses a secondary aim of the project, which is to identify predictors of perceived breast cancer risk and potential moderators between predictive variables and perceived risk.
3) Do healthy women in the community recognize sporadic from familial breast cancer risk factors? To be submitted Oncology Nursing Forum
   This manuscript addresses a secondary and unexpected finding of the project, which is

that women in the community do not have the knowledge to distinguish between sporadic and hereditary cases of breast cancer.

A copy of the manuscripts is included in the appendix of this report. However, the manuscripts contain unpublished data. Therefore, they should be protected.

Analysis of the data obtained from the survey questionnaire revealed that women recruited in the project are representative of an urban, English-speaking population. Women were perimenopausal (46±12 years old). Forty three percent (43%) self-identified as Non-Hispanic White, 26% as Non-Hispanic Black, 14% as Hispanic, and 17% as Asian. Most (49%) had college education or higher and their median annual income was between $30,000 and $40,000.

Women underestimated their actual breast cancer risk, as it was calculated with the online version of the Breast Cancer Risk Assessment Tool (BCRAT), which was developed by the National Cancer Institute and it is based on the Gail model. Women also claimed that they are less likely than their friends/peers to get breast cancer, and that their risk is lower than average. Subjective risk estimations depend on the type of probability scale used for measuring perceived risk; responses were most consistent between Verbal and Comparative Scales, and least consistent between Comparative and Numerical Scales. Demographic characteristics influence risk perception only when the latter is measured with a Numerical Scale. This finding suggests that a Numerical Scale is not an appropriate measure to use with educational interventions in the community, because it is most likely misinterpreted. Specific findings of the analysis and a detailed discussion and interpretation of these findings is presented in Manuscript 1: Optimistic bias regarding the risk of developing breast cancer in a multicultural community sample. This paper was a poster presentation in the 9th Biennial Symposium on Minorities, the Medically Underserved, and Cancer, of the Intercultural Cancer Council, in Washington DC, in March 2004.

Predictors of perceived breast cancer risk are having one or more affected family members, knowing other women who have been affected by the disease, and having personal experiences with abnormal breast symptoms, such as having one or more breast biopsies, having the most recent Mammogram or the most recent Clinical Breast Exam for the evaluation of a breast symptom (as opposed to a routine exam), and having Current breast symptoms. Knowledge of breast cancer risk factors and Breast Cancer Worry moderate the relationship between those predictors and perceived risk. A detailed analysis of these findings and an in-depth interpretation is presented in Manuscript 2: When do experiences with affected family members, affected friends, and personal experiences with breast symptoms influence perceived breast cancer risk?

An unexpected finding of the survey was that women did not have adequate knowledge to distinguish between hereditary and sporadic breast cancer risk factors. This finding becomes even more significant if we consider that 49% of the women in the sample had at least four years of college education. Women in the study are not likely to receive genetic counseling or any form of genetic education, since only 9% have multiple affected family members. Therefore, most women depend on their primary care providers (physicians and nurse practitioners) for personalized breast cancer risk assessment and education. Our findings indicate that women do not know that having an affected family member from the father's side of the family increases

breast cancer risk, they do not know the connection between breast and ovarian cancer, and do not understand the interplay between family history and age as risk factors. An in-depth discussion and interpretation of these findings is presented in Manuscript 3: Do healthy women in the community recognize sporadic from familial breast cancer risk factors?

KEY RESEARCH ACCOMPLISHMENTS

- Complete data collection
- Data have been entered into SPSS files
- A portion of the data obtained from the survey questionnaire has been analyzed
- Data analysis from the survey questionnaire addressed specific aims 1) and 2)
- Data analysis also addressed secondary aims of the project
- Interview data have been collected. Forty-five out of the fifty-three interviews have been transcribed and are ready for analysis
- Analysis of the data obtained from the project enabled the PI (Maria Katapodi) to complete her PhD degree
- Preparation of three manuscripts that are in the process of submission for publication
- Poster presentation of specific aims 1) and 2) in the 9th Biennial Symposium on Minorities, the Medically Underserved, and Cancer, of the Intercultural Cancer Council, in Washington DC, March 2004.
- The PI (Maria Katapodi) is using knowledge obtained from the project to develop appropriate educational material. Specifically, results have been used for educating Nursing Students at the Master's Level in the courses: N262.01 Research Utilization (Faculty of Record: Dr. Ginger Karrieri-Kohlman), and N294E Current Topics in Genetics (Faculty of Record: Dr. Bradley Aouizerat), School of Nursing, University of California San Francisco. The PI (Maria Katapodi) has been a guest lecturer in both courses.

REPORTABLE OUTCOMES

- Poster presentation: "Optimistic bias regarding the risk of developing breast cancer in a multicultural community sample". 9th Biennial Symposium on Minorities, the Medically Underserved, and Cancer, of the Intercultural Cancer Council, in Washington DC, March 2004.
- Three manuscripts titled:
    1) Optimistic bias regarding the risk of developing breast cancer in a multicultural community sample. Submitted Annals of Behavioral Medicine
    2) When do experiences with affected family members, affected friends, and personal experiences with breast symptoms influence perceived breast cancer risk? Submitted Journal of Behavioral Medicine
    3) Do healthy women in the community recognize sporadic from familial breast cancer risk factors? To be submitted Oncology Nursing Forum

A copy of the manuscripts is included in the appendix of this report. However, the manuscripts contain unpublished data. Therefore, they should be protected.

CONCLUSION

The project is on-time with the approved statement of work. Significant progress has been made in the areas of data analyses, and manuscript preparation. Our findings suggest that healthy women in the community have an optimistic bias and underestimate their breast cancer risk. Although women that have personal experiences with the disease, such as women with affected family members, those who know of other women with the disease, or those who have experienced abnormal breast symptoms themselves, are less likely to underestimate their risk, our findings suggest areas that need further research and intervention. Healthy women in the community depend on their primary care providers for personalized risk assessment and education and there is lack of knowledge regarding breast cancer risk factors. Educational interventions should take into account affective reactions and cognitive factors related to information processing. Although existing educational interventions provide information regarding breast cancer risk factors, we need to further improve the format with which that information is being presented, so that it is accessible when women estimate their breast cancer risk. Analysis of the interview data will provide insight regarding the information-processing and the decision-making about breast cancer risk. During the second year of this project the PI (Maria Katapodi) and the research team will focus their efforts on analysis of interview data and on further dissecting the concept of perceived risk and its role in decision-making.

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2. M. Katapodi, M. Dodd, N. Facione, K. Lee, B. Cooper, J. Humphreys. When do personal experiences with affected family members, affected friends, and personal experiences with abnormal breast symptoms influence perceived breast cancer risk? Journal of Behavioral Medicine (Submitted).
3. M. Katapodi, B. Aouizerat. Do healthy women in the community recognize familial and sporadic breast cancer risk factors? Oncology Nursing Forum (Submitted).

APPPENDICES

THE FOLLOWING PAGES (p. 11 - p. 54)
CONTAIN UNPUBLISHED MANUSCRIPTS AND SHOULD BE PROTECTED

MANUSCRIPT 1:

OPTIMISTIC BIAS REGARDING THE RISK OF DEVELOPING BREAST CANCER IN A MULTICULTURAL COMMUNITY SAMPLE

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Abstract

Background: Perceived risk affects health-protective behaviors. Research findings are conflicting as to whether women believe their breast cancer risk to be high or low. **Purpose:** 1) describe perceived breast cancer risk, 2) examine consistency of responses across different risk measures, 3) examine the influence of demographic characteristics on perceived risk and, 4) compare subjective and objective risk estimates. **Methods:** The survey used three probability scales and the Gail model to measure perceived risk and objective risk in a multicultural sample of 184 women recruited from community settings. **Results:** Participants believed that their breast cancer risk was lower than average and rated the risk for friends/peers higher than their own (Optimistic Bias $p<0.01$). Women with one affected first-degree relative did not perceive their risk to be higher than women with no family history. Older women perceived less than average risk ($p<0.01$). Verbal and Comparative risk ratings were most consistent. Numerical risk ratings were influenced by education, income, and race/culture ($p<0.01$). Participants underestimated their actual risk ($p<0.01$). **Conclusions:** We demonstrated optimistic bias in three different ways. Comparative and Verbal risk scales better reflect perceived risk than Numerical scales. Educational interventions should focus on older women and those with one affected first-degree relative.

Word count: 200

Keywords: breast cancer, perceived risk, optimistic bias, triangulation, Gail model

Introduction

Breast cancer is the second leading cause of cancer death for women in the United States (*1*). Molecular biology and genetics have improved our understanding of breast cancer etiology. Individualized counseling and public health educational interventions provide factual knowledge about breast cancer risk factors and educate women about their own probability of developing the disease. By using the Gail model (*2*) health care providers can estimate the probability of an individual woman developing breast cancer during a defined age interval.

Presumably, a woman who is aware of her actual breast cancer risk will initiate and maintain an appropriate level of health-protective behaviors (*3*). However, some women do not take into account factual information from the Gail model when estimating their own breast cancer risk (*4*). Results of a meta-analysis that examined perceived breast cancer risk were inconclusive as to whether women overestimated or underestimated their risk, while there were indications for systematic measurement errors and selection bias (*5*).

Understanding women's perceptions of their risk of developing breast cancer might provide better insight into how risk-related messages are interpreted, thereby facilitating the development of effective interventions for communicating breast cancer risk. The aims of this study were to 1) describe women's perceived breast cancer risk 2) examine whether responses were consistent across different risk measures, 3) examine whether perceived risk is influenced by sociodemographic characteristics, and 4) compare women's risk estimates with an objective risk estimate obtained from the Gail model.

Theoretical Framework and Background

The Precaution Adoption Process (*6*) suggests that perceived risk to a health is a subjective belief about the probability that the health problem will be experienced and occurs in three stages. In the first stage people become aware of the problem, mainly when they hear general information through common communication channels. In the second stage, people acknowledge the significance of the problem and are aware of the likelihood of encountering the disease, but do not consider themselves at risk. People reach this stage when they hear credible messages about the disease from health-related sources. In the third stage, people acknowledge their personal susceptibility to the health problem. This occurs when they have a close experience with the disease or when they have information about their personal risk factors and the risk factors of others. As the individual is exposed to new information and life experiences, movement between stages can be forward or backward.

Weinstein demonstrated that people most often are at the second stage of perceived risk, claiming that they are less likely than their peers to suffer harm (optimistic bias) (*7, 8*). Although Weinstein studied optimistic bias in the context of various health problems, the phenomenon has not been adequately studied with perceived breast cancer risk. Research findings are conflicting as to whether women believe they are at a higher risk (overestimation) or at a lower risk (optimistic bias) of developing breast cancer. Some studies reported that women significantly overestimate their risk compared to an objective risk estimate (*4, 9, 10*). In contrast, other studies report that women estimate their risk as significantly lower than their peers and lower than an objective risk estimate (*11-15*).

A close examination of these studies suggested that findings are confounded by possible selection bias and measurement errors (*5*). Studies that reported an overestimation of risk recruited participants through an affected relative who had been treated for breast cancer, which suggests a selection bias. Studies that recruited participants from community settings reported

that a positive family history increased perceived risk. However, this effect was minimized over time since some women with a positive family history did not perceive that they were at a higher risk. In addition, most studies that reported overestimation of risk used a Numerical probability scale with anchors 0% to 100%. This type of scale may be misleading; some women who perceive their chance of getting the disease to be equal to that of other women might mistakenly give themselves a 50% rating, not realizing that such a rating means that they have a one in two chance of getting the disease.

Results are conflicting as to whether sociodemographic characteristics influence perceived risk. Studies suggest that younger women are more likely to perceive higher risk for developing breast cancer than older women, and that White women are more likely than women of other racial/cultural backgrounds to perceive higher risk. However, these findings are based on a small number of studies. Race/culture and education should be examined together as indicators of social class that influences perceived breast cancer risk (*5*).

Despite some lack of clarity, it appears that some women have inaccurate perceptions about their own probability of developing breast cancer and misinterpret information about risk factors in health-related messages. The present study examined perceived breast cancer risk by addressing some of the confounders identified in previous studies. The study examined whether women recruited from community settings hold an optimistic bias about their breast cancer risk compared to their friends/peers and compared to an objective estimate of their risk. The study addressed systematic measurement errors by employing a triangulation method design.

Recruitment and Procedures

For this cross-sectional survey we recruited a convenience sample of women never diagnosed with any type of cancer and willing to complete a questionnaire in English. We included women between the ages of 30 and 85. The relatively low age limit of 30 years was chosen because some aggressive types of breast cancer occur in women in their thirties (*1*). The maximum age limit was set at 85 years because that is the maximum age limit that a woman's breast cancer risk can be estimated with the Gail model. Women with a prior diagnosis of any type of cancer were excluded from the study because they would be more likely to have received education about their cancer risk and risk factors.

Recruitment was done through flyers posted on bulletin boards in community settings throughout the San Francisco Bay Area and through newspaper advertisements. Community settings included senior centers, temples, libraries, restaurants, coffee shops, homeless shelters, cultural centers, and workplaces. Potential participants responded by calling a dedicated telephone number and expressing their interest in the study. Eligibility was determined through self-report. Participants completed the survey either in person or by mail and were paid $15. The University of California San Francisco Committee on Human Rights approved the study protocol. Data collection occurred over a period of thirteen months, between February 2003 and March 2004.

Measurements

We employed a within-method triangulation design (*16*). We measured perceived risk with three different sets of questions. We used a Verbal Scale, a Comparative Scale, and a Numerical scale. Items were introduced in different sections of the questionnaire. Scales were moderately correlated: Verbal and Numerical scales $r=0.59$, Verbal and Comparative scales $r=0.50$, and Numerical and Comparative scales $r=0.33$.

The *Verbal Scale* used numbers coupled with verbal anchors. Participants rated their own chance of getting the disease by circling a number between 0 and 10. They also rated the chances for their friends/peers. The numbers were coupled with five verbal anchors: Definitely Will Not (0, 1), Probably Will Not (2, 3), Fifty-fifty (4, 5, 6), Probably Will (7, 8), and Definitely Will (9, 10). If women marked a point between two numbers, or marked a verbal anchor instead of circling a number, the corresponding number closest to the center of the scale was used.

The *Comparative Scale* asked women to compare themselves with an average woman. Participants rated their chance of getting breast cancer in a five-point scale ranging from 1 *(A Lot Lower)* to 5 *(A Lot Higher)*. Using the same five-point scale we asked women to estimate their breast cancer risk compared to women *younger* and *older* than themselves.

The Numerical Scale used only numerical ratings. In order to anchor women around a realistic percentage for developing breast cancer, we provided them with the following information: *The American Cancer Society suggests that a woman with no known breast cancer risk factors has a 12% chance (1 in 9) of developing breast cancer in her lifetime.* We provided numerical anchors in increments of approximately 12%, (e.g. 0%, 12%, 25%, etc). Participants rated the chances of their friends/peers and their own chance of getting breast cancer. In cases in which women marked a point between two anchors, we used the most proximal anchor.

Objective Risk: For every participant we calculated a *Gail Risk* score with eight questions that assess number of affected First-Degree Relatives (FDRs), number of breast biopsies, and reproductive history (*2*). For this calculation we used the online version of the Breast Cancer Risk Assessment Tool (BCRAT) developed by the National Cancer Institute and accessed at http://bcra.nci.nih.gov/brc/. We recorded the *Lifetime Population Risk* calculated by the BCRAT to represent the Gail score for women of the same age and racial/cultural group with average risk factors in the population. Participants also indicated the number of their affected Second-Degree Relatives (SDRs).

Statistical Analysis

Data were analyzed using the statistical program SPSS® (version 11.5). Descriptive statistics were used to describe the demographic characteristics of the sample, Gail scores, and measures of perceived risk. Univariate Analysis of Variance and bivariate analysis, such as Analysis of Variance (F test) with Bonferroni post hoc contrasts, Student's t-tests, paired t-tests, Pearson's correlations (r), and χ^2, was used to determine associations between demographic characteristics and perceived risk, and to compare subjective and objective risk estimates. Consistency of responses in the three risk measures was examined with a within-subjects Analysis of Variance. Significance was set at the 0.05 level with 95% confidence intervals.

Results

We recruited 184 women (mean age = 46±12 years, Range: 30-84). Forty-three percent self-identified as non-Hispanic White, 27% as non-Hispanic Black, 14% as Hispanic, and 17% as Asian. Approximately half of these women (49%) had attended four or more years of college and 8% had not completed high school. The median annual income was between $30,000 and $40,000, with 22% of the sample reporting an annual income of <$10,000 and 11% reporting an annual income of >$80,000. Eighteen women (10%) had a family history of breast cancer in a FDR, and 16 women (9%) had multiple family members affected by the disease. Approximately one in eight women had one or more affected SDRs (See Table 2.1).

There was no significant difference in mean age among women of different race/culture. White women were more likely to have higher education compared to Black and Hispanic women ($F_{(3,177)}$=15.54, p<0.01) and Asian women were more likely to report a higher income compared to Black and Hispanic women ($F_{(3,169)}$=6.69, p<0.01). Education was significantly correlated with income only for Black women (r=0.46, p=0.01).

The following section presents participants' responses on the three risk measures.

Verbal Scale: When women rated their breast cancer risk on the Verbal scale, overall they reported that they would "Probably Not" get the disease in their lifetime (mean: 3.57±1.70, range: 0 to 8.00, median=3.00). When asked to rate the risk of their friends/peers, women reported a risk that was higher than their own (mean: 4.34±1.54, range: 1.00 to 9.00, median=5.00, paired-$t_{(171)}$=5.49, p<0.01). This indicates that women in the sample had an optimistic bias and perceived that they were less likely than other women to get the disease.

Comparative Scale: Most (57%) rated their risk for breast cancer as "About the Same" as the risk of the average woman, while only 11% rated their risk as "Somewhat Higher" or "A Lot Higher" (mean: 2.63±0.88, median=3.00). The distribution of responses on the Comparative risk scale was skewed to the left, indicating an optimistic bias. Women generally believed their risk to be somewhat lower than the risk for an average woman (See Figure 2.1).

Numerical Scale: Risk ratings on the Numerical scale showed that women overestimated their risk. The mean risk rating was 30.06(±22.78, range: 0 to 100.00, median=25.00). Women also overestimated the risk of their friends/peers (mean: 32.29±21.00, range: 0 to 100.00, median= 25%). The difference between the two mean ratings was not statistically significant (paired-$t_{(175)}$=1.75, p=0.08). Approximately two thirds of responses fell within one anchor above or below 12%, whereas approximately one third (N=55) responded that their risk and the risk of their friends/peers was 50% or higher.

In order to examine whether participants were consistent in their responses on the three scales, their personal risk rating was subtracted from the risk rating they gave for their friends/peers and the three risk ratings were compared in SD units. Within-subjects Analysis of Variance revealed significant inconsistency in women's responses between the Comparative scale and the risk difference in the Numerical scale ($F_{(1,166)}$=7.88, p=0.01) and between the risk differences in the Verbal and the Numerical scales ($F_{(1,166)}$=5.97, p=0.02). Responses between the Verbal and the Comparative scale were consistent. Independent samples t-tests and χ^2 tests revealed that age, income, race/culture, and family history of breast cancer did not influence consistency in participants' responses. Women with lower education were more likely to give inconsistent responses among all three scales ($\chi^2_{(4,167)}$=9.21, p=0.05).

The following section presents the influence of demographic characteristics on the three risk measures.

Verbal scale: Age, race/culture, education, and income did not influence subjective risk ratings on the Verbal scale. However, Black women were more likely than White women to give a higher risk rating for their friends/peers ($F_{(3,178)}$=4.20, p=0.01). Women with multiple affected family members were significantly more likely to rate their risk higher than women with no family history (3.42±1.65 vs. 5.00±1.95, $F_{(3,170)}$=3.60, p=0.01). However, there was no significant difference in the mean risk rating for women with no family history and women with an affected FDR.

Comparative Scale: Family history and age were significantly associated with women's responses on the Comparative scale. The 18 women with an affected FDR did not rate their risk significantly higher than the 117 women with no family history (2.73±0.59 vs. 2.44±0.88). The

24 women with one or more affected SDRs (3.00±0.46) and the 16 women with multiple affected family members (3.55±1.04) rated their risk higher than women with no family history ($F_{(3,172)}$=10.00, p<0.01).

Age and perceived risk were negatively correlated (r= -0.21, p=0.01). The 28 women who perceived their risk to be "A Lot Lower" than the average woman were approximately eight years older (52.74±13.70), and hence at a greater risk for breast cancer, than the 105 women who perceived their risk to be "About the Same" (45.13±11.05, $F_{(3,171)}$=3.13, p=0.03).

Using the same Comparative scale, we asked women to compare their risk to women who were younger than themselves. The 19 women who perceived their risk to be "A Lot Lower" than the risk of *younger* women were on average eight years older (53.21±16.06) than the 70 women who perceived their risk to be "Somewhat Higher" compared to *younger* women (45.00±10.90) ($F_{(3,171)}$=2.50, p=0.04). However, only women with an elementary education were more likely to hold this belief ($F_{(4,177)}$=7.15, p<0.001). The 76 women who rated their risk as "About the Same" as the risk of *older* women were not different from the 30 women who rated their risk as "A Lot Lower" compared to *older* women.

Numerical Scale: Age was not significantly correlated with subjective risk ratings and with risk ratings for friends/peers on the Numerical scale. There were significant correlations between education and subjective risk ratings (r= -.28, p<0.01), and between education and risk ratings for friends/peers (r= -.22, p<0.01). Similarly, income was significantly correlated with subjective risk ratings (r= -.27, p<0.01) and risk ratings for friends/peers (r= -.17, p<0.05). After controlling for education and income, univariate Analysis of Variance revealed that there were significant differences in the Numerical risk ratings among women of different race/culture ($F_{(3,170)}$ = 2.80, p=0.042). However, pairwise comparisons with Bonferroni post hoc contrasts failed to identify significant differences between groups, probably due to small sample size. Similarly, after controlling for education and income, univariate Analysis of Variance revealed that women with multiple affected family members were significantly more likely to rate their risk higher on the Numerical scale compared to women with no family history ($F_{(3,164)}$ = 4.82, p=0.003). Table 2.2 summarizes the influence of demographic characteristics on perceived risk.

In order to examine whether women have a realistic perception of their personal risk we examined whether they could correctly identify their risk as being above or below average, compared to their actual risk based on the Gail model. First, we calculated a Gail Score and a Lifetime Population Risk score for every participant. The latter score represents the Gail score for women in the same age and racial/cultural group in the population with average risk factors. The mean Gail score for women in our sample was 10.3(±6.06, median=9.8) and the Lifetime Population Risk score was 10.06(±2.33, median=10.2). Second, for every participant we calculated an *Actual Comparative Risk* score by subtracting her Lifetime Population score from her Gail score. In cases where the Actual Comparative Risk score was a positive number, the participant had a higher than average risk of developing breast cancer, whereas the opposite was true in cases where the Actual Comparative Risk score was a negative number. The Actual Comparative Risk score for the 176 women in the sample who provided sufficient information was 0.24(±5.40). Third, we transformed every woman's Actual Comparative Risk score and her score in the Comparative risk scale into SD units [Actual Comparative Score/5.40 SD and (Comparative Scale – 3)/0.88 SD]. Finally, we did a paired-samples t-test to compare the two scores. The comparison indicated that women did not have an accurate perception of their breast cancer risk and that they significantly underestimated their personal risk ($t_{(175)}$= 4.78, p<0.01).

Figure 2 shows that women underestimated their objective breast cancer risk, since the Actual Risk scores tend to fall to the right, whereas scores from the Comparative scale fall to the left.

Discussion

The study described perceived breast cancer risk and consistency of responses among three risk measures, examined the influence of sociodemographic characteristics on perceived risk, and compared subjective risk estimates with an objective risk estimate. The majority of women in the study held an optimistic bias regarding their breast cancer risk. Our findings are consistent with the findings of other studies (*10, 12-15*). However, in contrast to previous studies we demonstrated the phenomenon of optimistic bias with a direct and an indirect way. One approach of examining optimistic bias was to ask women to directly compare their risk with the risk for an average woman. By using a Comparative scale, we noted a distribution of responses that was skewed to the left, and revealed that women directly reported that they considered their own risk to be lower than average. The indirect approach to examining optimistic bias was to ask women to independently rate the risk for their friends/peers and their own risk. By this indirect approach, we noted that women assessed a higher risk for friends/peers than for themselves. Consistent with another study (*17*), where unrealistic optimism was identified with a direct and an indirect measure, we found that the indirect method showed a more pronounced bias. However, we did not find an optimistic bias with the Numerical scale (*13*). One possible explanation for this finding is that the factual information we provided about population breast cancer risk made participants consider the risk status of their friends/peers. According to Weinstein (*18*), receiving information about the risk status of peers reduces optimistic bias.

Measuring perceived risk with the ideal probability scale has been a challenge for researchers (*19*). In the present study, within-method triangulation allowed us to neutralize the contextual, wording, and anchoring limitations of each scale. Weinstein (*20*) suggested that asking participants to place a numeric probability on the occurrence of a health outcome, and then comparing their answers with objective data, is not a meaningful or reliable measure of risk understanding. To avoid directly comparing subjective and objective risk estimates, we examined whether participants reported a realistic perception of their risk being above or below average. We compared their Gail score with the Gail score for average women in the population and examined whether the direction of this comparison was consistent with the direction of their subjective risk estimates on the Comparative scale. Women in this sample had a slightly higher breast cancer risk compared to the risk of the average female in the US population. The distribution of responses in SD units revealed that objective risk estimates were skewed to the right, whereas participants' own risk estimates were skewed to the left. This finding is an indirect indication that women underestimated their objective breast cancer risk.

Although we demonstrated optimistic bias in the sample as a whole, we did not identify individuals who had an unrealistic optimism of their breast cancer risk. When we examined previous studies we noted a negative correlation between age and perceived risk, and that participants recruited from community settings were more likely to rate their risk as average, even in the presence of hereditary risk factors (*5*). Our current findings support both these suggestions. In the Comparative scale we found a small but significant negative correlation between age and perceived risk, and that some women believed that breast cancer is lessened as they grow older. In addition, women with one affected FDR did not perceive their risk to be higher compared to women with no family history. Only women with multiple affected family

members had a significantly higher perceived risk. The latter finding was consistent in all three measures of perceived risk.

It is unclear why some women perceived their risk to be lower as they age and why women with one affected FDR do not perceive their risk to be significantly higher. One possible explanation could be lack of knowledge, since we found that women who had not attended high school were significantly more likely to rate their risk as "A Lot Lower" when comparing themselves to younger women. A second possible explanation could be that some women invoke unrealistic optimism as a coping mechanism. Weinstein (*20*) suggested that optimistic bias occurs as an effort to protect one's self-esteem, and that risk assessments seek the most comforting view of one's personal susceptibility. However, evidence supporting that optimistic bias is a coping mechanism and that it is related to the personality trait of "optimism" is conflicting. Facione (*14*) found no relation between perceived risk and the personality trait "optimism", whereas Andrykowski and colleagues (*21*) reported that "optimism" moderated the response to a threatening health event. A third explanation is related to cognitive limitations of information processing that are inherent to understanding probabilities of future events (*22*). Supporting the hypothesis that optimistic bias in women with a family history of breast cancer could be related to biased information processing, a study reported that in a laboratory model of cancer information processing, women with a family history of breast cancer exhibited excessive vigilance to cancer-related stimuli and demonstrated significant biased cognitive processing compared to controls (*23*). These findings provide important insights and suggestions for future research in the area of breast cancer perceived risk.

Race/culture, education, and income influenced women's responses on the Numerical scale, but not on the Verbal or Comparative scales. We hypothesized that the Numerical anchors *0%* and *100%* used in previous studies were misleading, so we provided participants with the average breast cancer risk incidence, expecting that responses would cluster around *12%*. Yet, 55 women gave themselves a risk rating of 50% or higher on the Numerical scale but did not indicate a consistently high personal risk when asked elsewhere in the survey. Women with lower socioeconomic status were more likely to give a high risk rating on the Numerical scale. After controlling for education and income, race/culture influenced participants' responses on the Numerical scale, although we failed to identify differences among racial/cultural groups. The relation between low education and high risk ratings can be attributed to innumeracy (*24, 25*); yet, the relation between race/culture and high risk ratings is more difficult to explain.

Taylor and colleagues proposed that item order in the questionnaire affects consistency among responses (*26*). The study found that consistency improved when the Comparative scale and the Numerical population rating were introduced before the subjective Numerical rating. Item order in the present study was similar to Taylor and colleagues; yet, we found a greater correlation between the Verbal and the Comparative scales. We agree with Taylor that only randomization of subjects to different item orders can clarify the impact of item order on consistency of responses. However, in light of the present data we suggest that the Numerical scale does not accurately reflect participants' risk estimates. Our findings suggest that many of the women who assigned themselves a high risk rating on the Numerical scale did not actually believe they were at a higher than average risk but they assigned a high value in error. This is consistent with our suggestion that a Numerical scale produces a systematic error of risk overestimation (*5*).

Potential limitations of the study are the convenience sample and that the calculation of Gail risk estimates was based on self-reports and may not be accurate. The Gail model is the

most appropriate tool for general population risk screening (*27*); yet, it may be limited in its predictive ability, since it does not calculate risk from affected SDRs and does not take into account the age at onset of the disease. Although it has been extensively validated with White women (*28*), it may underestimate breast cancer risk for White (*29*) and Black women (*30*), whereas risk estimates for Hispanic and Asian women are based on the risk of White women. Since 57% of women in our study were not White, the difference between women's perceived and objective breast cancer risk may be actually larger than we observed.

Finally, the study has implications for breast cancer risk communication. Findings suggest that most women hold an optimistic bias and are at the second stage of acknowledging their personal breast cancer risk. Comparative and Verbal scales were not influenced by socioeconomic status, reflect perceived risk more accurately than the Numerical scale, and are more likely to be understood by a wide range of audiences. Therefore, educational interventions that provide comparative risk information in a non-quantitative way might better help women acknowledge their susceptibility to the disease. Finally, as more information about the role of genetics and the environment in carcinogenesis becomes available, health professionals will face the challenge of clarifying these issues with their clients. Health professionals must clearly convey the difference in risk for women who have one affected family member compared to multiple affected family members. Likewise, they must explain the difference between sporadic versus familial breast cancer and communicate to women how risks associated with each variable shape a woman's probability of developing the disease.

Table 2.1. Demographic Characteristics

Variable		N	%
Age	X= 46.59±12.05, range: 30 to 84		
	30 to 39	63	35
	40 to 49	51	28
	50 to 69	54	29
	70 to 85	10	5
	Missing	6	3
	Total	184	
Race/Culture			
	Non-Hispanic White	79	43
	Non-Hispanic Black	50	26
	Hispanic	25	14
	Asian	30	17
Education			
	Grades 1 through 8 (Elementary)	7	4
	Grades 9 through 11 (Some high School)	8	4
	Grade 12 or GED (High School Graduate)	31	17
	College 1 year to 3 years (Some college or Technical School)	48	25
	College 4 years or more (College graduate)	90	50
Income			
	<$10,000	39	21
	$10,000 - <$20,000	16	8
	$20,000 - <$30,000	33	18
	$30,000 - <$40,000	28	16
	$40,000 - <$50,000	17	9
	$50,000 - <$60,000	16	9
	$60,000 - <$70,000	6	3
	$70,000 - <$80,000	2	1
	>$80,000	19	11
	Missing	8	4
Family History			
	No Family History	117	64
	≥1 affected SDRs	24	13
	1 affected FDR	18	10
	Multiple (>1 FDR or ≥1FDR and ≥1 SDRs)	16	9
	Missing	9	4

SDRs = Second-Degree Relatives
FDRs = First-Degree Relatives

Table 2.2. Influence of Demographic Characteristics on Personal Risk Estimations

Variables	Age	Education	Income	Race/Culture	FH
Verbal Scale	–	–	–	–	**$F_{(3,170)}$ =3.60 p=.15 Multiple vs. No FH**
Comparative Scale	**r = -.21, p= .006**	**$F_{(4,177)}$ = 7.15, p<.001 Elementary School vs. All Others**	–	–	**$F_{(3,172)}$ =10.00, p<.001 Multiple & SDRs vs. No FH**
Numerical Scale	–	**r= -.28, p=.01**	**r= -27, p=.01**	**$F_{(3,170)}$ = 2.80, p=.042 but not pairwise differences**	**$F_{(3,164)}$ = 4.82, p=.003 Multiple vs. No FH**

FH = Family History of Breast Cancer
SDRs = Second-Degree Relatives

Figure 2.1. Frequency of Risk Ratings on the Comparative Scale

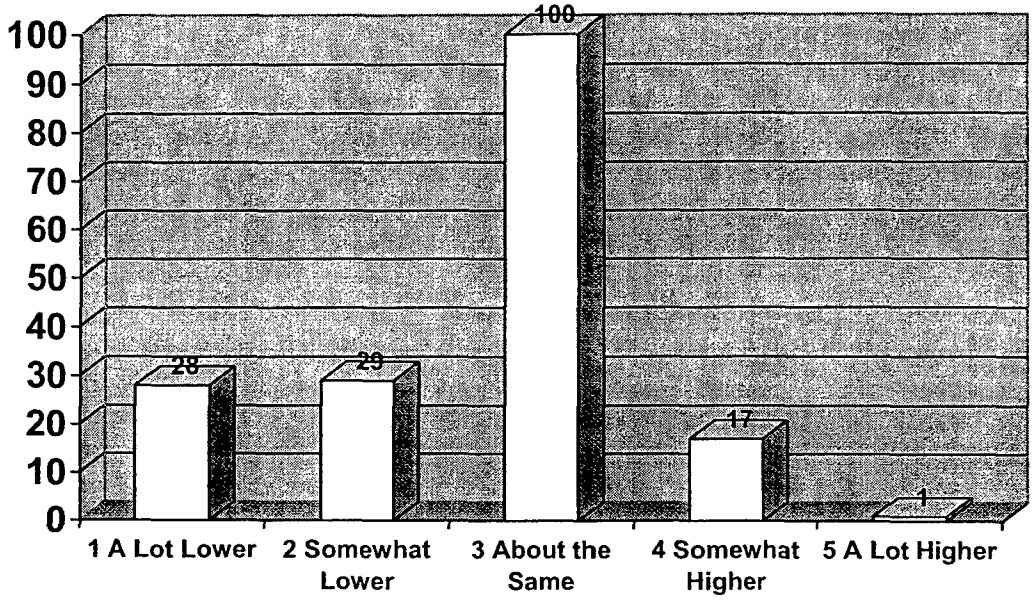
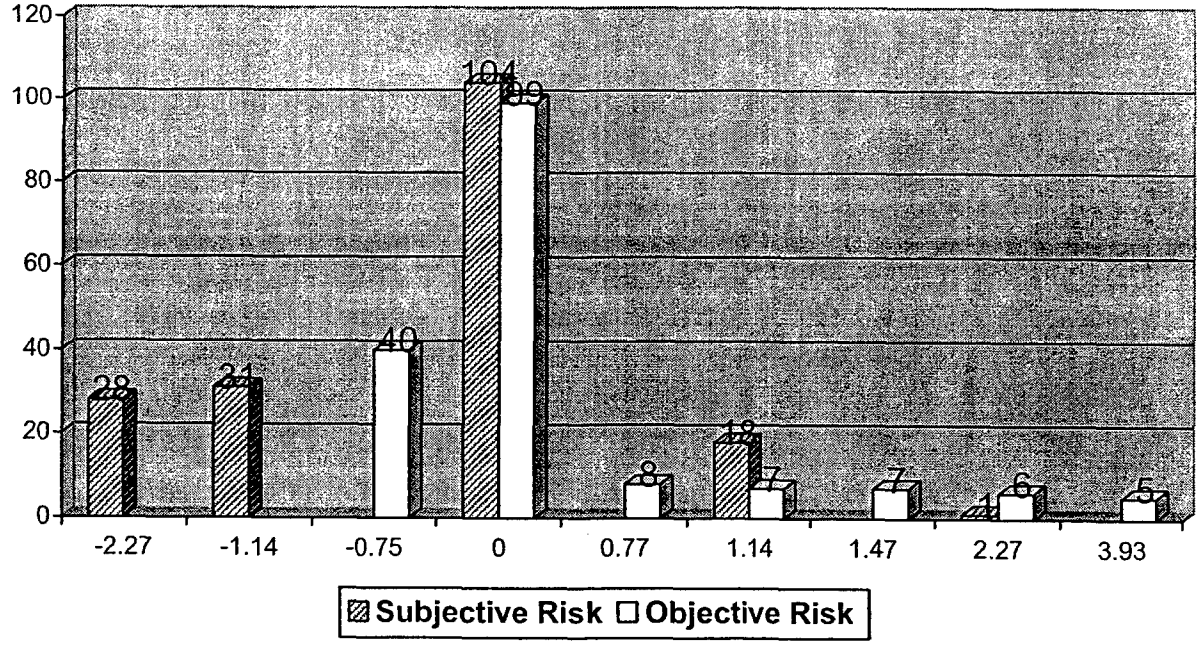


Figure 2. 2. Comparative Gail Scores & Comparative Risk Scores in SD units



MANUSCRIPT 2:

WHEN DO EXPERIENCES WITH AFFECTED FAMILY MEMBERS AND FRIENDS, AND PERSONAL EXPERIENCES WITH ABNORMAL BREAST SYMPTOMS INFLUENCE PERCEIVED BREAST CANCER RISK?

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RUNNING HEAD: PERCEIVED BREAST CANCER RISK: KNOWLEDGE & WORRY

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Abstract

We recruited 184 women from community settings to examine whether experiences with affected family members, affected friends, and abnormal breast symptoms influence perceived risk, and whether knowledge of breast cancer risk factors and worry moderated the relationships between experiences and perceived risk. Hierarchical regression analyses revealed that having a family member and a friend with breast cancer increased perceived risk and accounted for 6% and 2% in the variance of perceived risk. Having an abnormal breast symptom and worry accounted for 5% and 7% of the variance in perceived risk. Experiences with affected family members, affected friends, and abnormal breast symptoms influence perceived risk through various mechanisms involving knowledge of objective risk factors and worry. Knowledge of risk factors and worry moderated the relationships between family history, abnormal breast symptoms, and perceived risk. Educational interventions should increase knowledge about risk factors and consider worry and cognitive mechanisms of information processing.

Word count: 150
Keyword: Perceived breast cancer risk, Optimistic bias, Family history, Worry, Breast symptoms

Introduction

Breast cancer is the most common cancer in women and early detection has long been recognized for its value in reducing mortality of affected individuals (*1*). Early detection programs focus on educating women about risk factors that increase the probability of developing the disease, promote self-monitoring for early signs, and adherence to recommended screening guidelines (*31, 32*).

Results from a meta-analysis that examined predictors of perceived breast cancer risk suggest that although having a family history of breast cancer, worry, and abnormal breast symptoms are related to a heightened perception of risk, overall women hold an optimistic bias about the probability of developing breast cancer (*5*). These findings do not provide a clear understanding of why some women underestimate their breast cancer risk and how experiences with affected family members and breast symptoms influence perceived risk.

The purpose of this study was to examine 1) whether having experiences with affected family members and friends, and experiences with abnormal breast symptoms reduced optimistic bias regarding perceived breast cancer risk, and 2) whether knowledge of breast cancer risk factors and worry moderated the relationships between these experiences and perceived risk.

Theoretical Framework and Background

The *Precaution Adoption Process* (*6*) suggests that beliefs about susceptibility to a health problem represent a series of distinct stages. People at different stages hold different beliefs about the probability that they will experience harm. In the first stage individuals have heard about the hazard. In the second stage they acknowledge the significance and severity of the problem, and are aware of the likelihood of encountering the disease. However, they claim that they are less likely than their peers to experience the harm. In the third stage individuals acknowledge their personal susceptibility. This distinction reveals important differences about information processing, judgment, and the decision-making process between a 'naïve' person, who knows nothing about a hazard, and a person who has thought about it and concluded that there is no risk. The former will be open-minded about the hazard but will not actively seek information. In contrast, the latter's commitment to a particular point of view will tend to produce a biased response. This person will selectively attend to messages that support his or her own position and will show belief perseverance when faced with disconfirming evidence (*33*).

Messages from the media and information from acquaintances do not establish clearly who is likely to be affected; therefore, most people think that they are not susceptible to the disease (*6*). Movement towards the third stage is facilitated by information about personal risk factors and the risk status of peers, and by personal experiences with the hazard. Emotions, such as worry, have an important, though not clearly understood, role in this process. Worry might make the threat more vivid and personal, and reduce tendencies to deny vulnerability. In contrast, the desire to avoid feeling afraid or the need to protect one's self-esteem may lead to optimistic bias (*34, 35*).

While there is evidence that women significantly underestimate their breast cancer risk (*11, 13-15, 36*), optimistic bias regarding breast cancer risk has not been adequately examined. Researchers attributed optimistic bias to lack of knowledge regarding the seriousness of the

disease (*15*), or to not having a positive family history (*14*). However, some women underestimate their risk even in the presence of hereditary risk factors, presumably, because they lack sufficient knowledge about breast cancer risk factors (*11, 12*). These findings have also been attributed to misinterpretation of probabilistic scales (*5, 13*).

Information about the risk status of peers might also influence perceived risk and reduce optimistic bias (*18*). Studies reported that having friends diagnosed with the disease increased perceived breast cancer risk (*37*), and that some women compared themselves to affected friends in order to estimate their personal breast cancer risk (*38*). Both studies attributed these observations to cognitive biases related to information processing and the use of heuristic shortcuts.

Studies described an affective reaction related to breast cancer as worry. Some studies examined worry in relation to family history of breast cancer (*39-41*). Other studies attributed worry to personal experiences with breast symptoms. Seven studies suggest that an abnormal mammographic finding that turned out to be benign correlated with increased perceived risk (*5*). Studies also reported that a diagnostic breast biopsy was a major cause of cancer-related distress (*21*), and that symptom interpretation elicited breast cancer worry, but only among women who perceived their breast cancer risk to be high (*42*).

Findings from the above studies are consistent with suggestions that optimistic bias is reduced through individualized information and personal experiences (*6*). However, these findings do not provide a clear understanding about the phenomenon of optimistic bias as it relates to breast cancer. It is not clear whether having a positive family history increases perceived risk because women know that they share genetic material with their family members or because the experience with the disease evoked negative emotional responses and worry. The underlying connection between having an abnormal breast symptom and reporting a heightened perceived risk is unclear. The acknowledgement that having dense breast tissue increases the risk for invasive breast cancer may explain this connection on a logical level. On an affective level, the experience of an unpleasant procedure may evoke negative emotions, leading to a heightened perceived risk.

The purpose of the study was to examine whether personal experiences reduced optimistic bias and whether knowledge of breast cancer risk factors and worry moderated the relationship between experiences and perceived risk.

Recruitment and Procedures

The present analysis is part of a community-based survey that examined perceived breast cancer risk, accuracy of women's estimates, and factors that influence perceived risk (*36*). The study recruited a convenience sample of women between the ages of 30 and 85 years that had never been diagnosed with any type of cancer, and consented to complete a questionnaire in English. Recruitment was done with flyers posted on bulletin boards in community settings and workplaces, through newspaper advertisements, and through networking with community agency leaders. Women responded by calling a dedicated telephone number and expressing their interest in participating in the study. Participants completed the survey either in person or by mail and were paid $15. The University of California San Francisco Committee of Human

Rights approved the study protocol. Data collection was carried out between February 2003 and March 2004.

Measures

We assessed *Family History* of breast cancer by asking women to indicate the number of their first-degree relatives (FDRs) and their second-degree relatives (SDRs) affected by the disease. We also asked participants to indicate the *Number of their Affected Friends/Peers* to examine whether information about the risk status of other women influences perceived risk.

Current Breast Symptoms *(Breast Symptoms),* were assessed with a modified version of the Breast Cancer Symptom Knowledge Scale (*43*). We asked participants their current experiences with an abnormal breast symptom. In addition to the 15 items in the original scale, three items were added: *sharp pains in the breast, a vague change in the breast*, and *one or both breasts are different than usual.* We gave each symptom a score between '0' and '4', indicating the potential severity of the symptom. For example, "breasts feel painful and tender during menstruation" was scored as '1', whereas "a little blood is coming out my nipple" was scored as '4'. Participants could respond *Yes, No,* and *Don't Know* for each breast symptom. Items that were scored *Yes* and *Don't know* were summed to calculate each woman's score for severity of current breast symptoms. The inclusion of three additional items and the scoring of ambiguous responses (*Don't know*) as affirmative is based on findings of a pilot study regarding the ways in which women described an unidentified breast symptom in a non-threatening way (*38*). Possible scores on the Breast Symptoms Scale range between 0 and 40 and the total score represents incidence and severity of current breast symptoms.

We also asked participants whether their most recent *Clinical Breast Exam (RCBE)* and their most recent *Mammogram (RM)* were done as part of routine exams or because of a breast problem other than breast cancer. Women who never had a CBE or a Mammogram were given a score of '0', women who had a routine exam were given a score of '1', and women who had their most recent CBE or Mammogram because of an abnormal breast symptom were given a score of '2'. Finally, participants indicated the total number of Breast Biopsies *(BBs)* they underwent, and responses were dichotomized as '0' or '≥1'.

Knowledge of Breast Cancer Risk Factors was assessed with 13 items. Five of these items described risk factors identified by the Gail model (*44*). The remaining eight items were investigator-developed to examine knowledge of hereditary/genetic risk factors for breast cancer. Items asked whether 1) having multiple family members with breast cancer, 2) having had breast cancer before, 3) having a family history of breast cancer from the mother's side of the family, 4) having a family member with both breast and ovarian cancer, 5) having a genetic mutation, 6) having a family history of breast cancer from the father's side of the family, 7) having a family history of ovarian cancer, and 8) being of Ashkenazi Jewish decent were breast cancer risk factors (*45*). Participants could respond *Yes, No,* or *Don't Know.* Items scored affirmatively were summed to calculate each woman's score on the *Knowledge of Breast Cancer Risk Factors Index.* Possible scores ranged between 0 and 13 and items were highly inter-correlated (Cronbach $\alpha = .80$).

Breast Cancer Worry was assessed with four items (*42*). Two items asked participants to rate *"how often they had worried"* and *"how emotionally upset or distressed"* they had been in

the past about the possibility of getting breast cancer. These items were answered on a scale ranging from '*0' "Never/Not at all"* to '*10' "All the time/ A Great Deal"*. The remaining two items were forced choice, four-point Likert scale, and assessed *"current worry about the possibility of getting breast cancer"* and *"worry when going to the doctor"*. To form a worry score in which each of the four items contributed equal variance, each item was divided by its respective standard deviation before summing (*42*). Higher scores indicated greater worry, and internal consistency for the scale was high (Cronbach $\alpha = 0.85$).

Perceived Risk: We asked participants to rate their risk and the risk of their friends/peers on scales ranging from '0' to '10' that have been coupled with five Verbal anchors (*"Definitely Will Not"* to *"Definitely Will"*). We also used a Comparative risk scale ('1' to '5', *"A Lot Lower"* to *"A Lot Higher"*), in which participants rated their risk compared to the risk of an average women. Finally, we examined whether participants' Gail scores were higher or lower compared to the Gail scores of same age women in the population with average risk factors (Actual Comparative Risk = Participant's Gail score minus the Gail score of an average woman). We compared the direction of the Actual Comparative Risk score to the direction of women's response in the Comparative risk scale (*36*).

Women significantly underestimated their personal breast cancer risk in all measures. On the Verbal scale participants perceived that they would "Probably Not" get the disease (mean: 3.57±1.70), while they rated their friends/peers at higher risk than themselves (mean: 4.34±1.54, $t_{(171)}=5.49$, $p<0.01$). On the Comparative scale the distribution of responses was skewed to the left. Participants also underestimated their actual breast cancer risk ($t_{(174)}=4.78$, $p<0.01$) (*36*).

We performed a Principal Component Analysis using those three measures. The goal was to identify a measure of Perceived Risk that would explain the total variance shared by the three measures. The total variance reflects the sum of explained and error variance; yet, error variance is attributed to random and not systematic error (*46, 47*). All three measures loaded on a single Principal Component that represented a measure of Perceived Risk. Factor loadings were .62 for the Verbal scale, .79 for the Actual Comparative risk estimate, and .88 for the Comparative scale. The principal component explained a cumulative variance of 59.8% and the internal consistency reliability (Cronbach α) of the three measures was .65.

Statistical Analysis

Data were analyzed using the SPSS 11.5® statistical program. We calculated individual scores for scales with at least 60% of items completed. Significance was set at the 0.05 level with 95% confidence intervals for all statistical analyses. We used descriptive statistics to describe the demographic characteristics of the sample. We performed simultaneous and hierarchical regression analyses to explore whether worry and knowledge of breast cancer risk factors moderated the relationships between predictive variables and perceived risk (*48, 49*). To test for a possible interaction between two variables, both variables were entered simultaneously in the first step of a hierarchical regression followed by the interaction term in the second step. A moderator effect was present if the interaction term accounted for a statistically significant amount of the variance in the dependent variable. To reduce possible multicollinearity among predictors, variables were centered prior to use in regression analyses. This means that they were put in a SD form by subtracting the mean of each variable from each observed value. Centering variables removes non-essential multicollinearity that is due to scaling (*50*).

Results

We recruited a total of 184 women with a mean age of 46±12 years (range: 30-84). Forty-three percent self-identified as non-Hispanic White, 26% as non-Hispanic Black, 14% as Hispanic, and 17% as Asian. Forty-nine percent had attended four or more years of college, and the median annual income was $30,000 to $40,000. Eighteen women in the sample (10%) had a family history of breast cancer in a FDR, and 16 women (9%) had multiple family members affected by the disease. Approximately one in eight women had one or more affected SDRs (See Table 3.1). Approximately 67% reported having at least one friend who had been diagnosed with the disease (Mean: 1.70±1.83, Median: 1.00, Range: 0 to 7).

Approximately 20% of women had one or more Breast Biopsies. Five percent indicated that their most recent CBE was done for the evaluation of an abnormal breast symptom. Similarly, eight percent indicated that their most recent Mammogram was done for the evaluation of an abnormal breast symptom. Approximately 50% indicated that they had one or more breast symptoms at the time of the survey. The most common symptom was "breasts feel painful and tender during their menstrual period" (45%). However, some women indicated symptoms that could suggest a breast malignancy (See Table 3.2). The most commonly recognized risk factor was "having multiple family members with breast cancer" (78%). Half of the participants (50%) did not consider that having had a breast biopsy was a breast cancer risk factor. Finally, women in the sample reported average amounts of worry, with a distribution of responses that was fairly symmetrical (Mean=8.15±3.32, Median=7.96, Range: 2.51 to 18.51).

To check for the possibility that demographic characteristics such as age, education, income, and race/culture predict perceived risk we performed a simultaneous regression analysis where these demographic variables were entered into the regression equation in one step. None was significantly associated with perceived risk ($p>.05$).

To examine the extent that perceived risk is influenced by experiences with affected family members, affected friends, abnormal breast symptoms, knowledge of breast cancer risk factors, and worry, we performed a hierarchical regression analysis in which all the predictor variables were entered in different steps. Family history of breast cancer was entered in step 1. Number of affected friends was entered in step 2. In step 3 we entered the variables related to personal experiences with abnormal breast symptoms (most recent Mammogram, most recent CBE, Breast Symptoms, and Breast Biopsies). In step 4 we entered knowledge of breast cancer risk factors and worry.

Each of these steps made a significant contribution to perceived breast cancer risk and the overall model accounted for 20% of the variance in perceived risk. Family history accounted for 6% of the variance and most of this was attributed to having SDRs and multiple family members affected by the disease. Experiences with affected friends accounted for 2% of the variance in perceived risk. Personal experiences with abnormal breast symptoms accounted for 5%, most of which (2.9%) was attributed to having the most recent CBE for the evaluation of a breast symptom. Knowledge of risk factors and worry accounted for 7% of the variance in perceived risk, most of which was attributed to worry (6.9%) (See Table 3.3).

With a separate hierarchical regression we examined whether there was a significant interaction between knowledge of breast cancer risk factors and worry. The interaction term accounted for an additional 5% of the variance in perceived risk (See Table 3.4 and Figure 3.1).

We examined whether knowledge of breast cancer risk factors and worry moderated the relationship between family history and perceived risk. We performed two separate hierarchical regressions for each proposed moderator. In step 1 we entered dummy-coded variables of family history (FH1: SDRs vs. No FH; FH2: 1FDR vs. No FH; and FH3: Multiple vs. No FH) and the proposed moderator. In step 2 we entered the interaction terms [(FH1, FH2, FH3) X Knowledge] or [(FH1, FH2, FH3) X Worry]. We found a significant interaction between family history and knowledge of breast cancer risk factors (R^2 =.177, ΔR^2=.047, ΔF=3.117, p=.028). Most of the variance was attributed to the interaction of having one affected FDR with knowledge of breast cancer risk factors (See Table 3.5). A positive family history was not a significant predictor of worry (R^2 =.009, p=NS), and worry did not moderate the relationship between having affected friends and perceived risk (R^2 =.095, p=NS).

Similarly, we examined whether knowledge of breast cancer risk factors and worry moderated the relationship between perceived risk and experiences with abnormal breast symptoms. We performed two separate hierarchical regressions for each proposed moderator. We found significant interactions between worry and Breast Biopsies, and between worry and the most recent Mammogram. Knowledge of breast cancer risk factors was not a significant moderator between breast symptoms and perceived risk (See Table 3.6). Significant predictors of worry were experiencing current breast symptoms (B= .178, p=.015, sr^2=.032), and the interaction term between most recent CBE and knowledge of breast cancer risk factors (B= .17, p=.03, sr^2=.027).

Discussion

The study examined whether perceived breast cancer risk was influenced by experiences with affected family members and friends and by experiences with abnormal breast symptoms. The study also examined whether knowledge of breast cancer risk factors and breast cancer worry moderated these relationships.

Family history of breast cancer accounted for 6% of the variance in perceived risk. This was not surprising, as family history has been shown to be the strongest predictor of perceived risk across numerous studies (*5*). However, most of the variance explained by family history was contributed by women with multiple affected family members and affected SDRs and not from women with one affected FDR. According to epidemiological models of risk estimation, such as the Gail model (*2*), having one affected FDR can significantly increase a woman's risk for breast cancer. Consistent with other studies (*11, 12*), our findings suggest that some women with one affected FDR do not perceive their risk to be significantly elevated. Furthermore, the relationship between family history and perceived risk is moderated by knowledge of breast cancer risk factors, but only for women with one affected FDR. The subjective risk evaluations of women with one affected FDR, who rated their risk as significantly higher compared to women with no family history, drew on the knowledge that breast cancer in an immediate family member increased their own risk because of the close genetic similarity to their FDRs. However, knowledge of breast cancer risk factors did not moderate the relationship between having SDRs or multiple affected family members and perceived risk. Since 78% recognized that having

multiple family members with breast cancer was a risk factor, knowledge explained most of the variance in that relationship.

McCaul and Tulloch (1999) suggested that a positive family history could influence perceived risk through multiple routes, one of which is breast cancer worry. However, consistent with other studies (*51*), family history of breast cancer was not a predictor of breast cancer worry. It appears that the relationship between worry and family history is complex and time-dependent. Women with a positive family history exhibited greater worry than those with no family history, but initial levels of worry dissipated at a year follow up (*52*). Apparently, worry evoked by positive family history represents an unstable and transient emotional state that follows the diagnosis of a family member but is not long lasting for most women. The study sample was not recruited through an affected relative, which might explain why family history did not evoke worry. Alternatively, our study may not have detected a statistically significant relationship, since the number of women with a positive family history was small.

Having one or more friends diagnosed with the disease accounted for 2% of the variance in perceived risk. We examined whether number of affected friends increase perceived breast cancer risk because it evoked worry, but worry did not moderate the relationship between affected friends and perceived risk. A possible explanation for this finding could involve heuristic thinking, as described in theories of judgment and decision-making (*22*). Under conditions of uncertainty, when individuals do not have complete and accurate information about the probability of an outcome, they form a judgment based on salient memories and personal experiences (*53*). Researchers proposed that family history of breast cancer (*14, 54*) and experiences with affected friends (*37*) influence perceived risk through heuristic thinking. Our data are consistent with those suggestions.

The relationship between experiencing abnormal breast symptoms, worry, and perceived risk is more difficult to explain. Current breast symptoms directly evoked worry but did not evoke perceived risk. It is possible that the relationship between current breast symptoms and perceived risk is moderated by other variables, such as perceived control over a breast symptom (*55*). Consistent with other studies (*5*), women whose most recent Mammogram or most recent CBE was done for the evaluation of a breast symptom had a heightened perception of risk. Furthermore, we found that the interaction between knowledge of risk factors and having the most recent CBE for a breast symptom predicted worry, and that the interaction between worry and having the most recent Mammogram for the evaluation of a breast symptom predicted perceived risk.

Consistent with other studies (*21, 55*), having one or more Breast Biopsies was not a predictor of perceived risk. However, those studies found that experiences with Breast Biopsies evoked worry, a finding that was not replicated in this study. Rather, the interaction between Breast Biopsies and worry accounted for 2% of the variance in perceived risk. It appears that the relationship between perceived risk, worry, and Breast Biopsies may be time-dependent. Studies reported that after a Breast Biopsy initial levels of worry were high, but worry declined over time (*21, 56*). Finally, worry was a significant predictor of perceived risk but knowledge of breast cancer risk factors was not. Rather, the interaction of worry with knowledge of breast cancer risk factors accounted for 5% of the variance in perceived risk.

Taken together, these findings suggest that worry might be the initial response to a self-discovered breast symptom, which is consistent with the mechanism of the affect heuristic (*57, 58*). Ad hoc evaluations of those symptoms increase perceived risk mainly for women who maintain a high level of worry, which is consistent with models of symptom interpretation and

self-regulation (*59, 60*). Moreover, there may be differences in judgment and decision-making style between a woman who initiates a visit to her health provider for the evaluation of a self-discovered breast symptom (RCBE) and a woman who does not seek such an urgent evaluation. Our findings indicate that women who initiated their most recent CBE for the evaluation of a self-discovered breast symptom, and who were aware of breast cancer risk factors, might have higher levels of worry. However, this suggestion needs further investigation.

Overall, our findings indicate that experiences with affected family members and friends, and experiences with abnormal breast symptoms influence the evaluation of subjective breast cancer risk through different mechanisms. The first mechanism is based on an analytical cognitive process: family history of breast cancer influences perceived risk through the knowledge that it represents a genetic risk factor. The second mechanism is based on heuristic thinking representing logical shortcuts in the analytic mechanism: women who do not have accurate and complete information about their breast cancer risk are more likely to depend on salient memories and personal experiences for making personal risk estimations with the assistance of logical shortcuts. The third mechanism is based on affect: current breast symptoms influence perceived risk by eliciting worry. Finally, the fourth mechanism is based on the interaction of affect with the analytical mechanism: initiating a visit to a health provider for the evaluation of a self-discovered breast symptom evoked worry for women who had knowledge of breast cancer risk factors. The latter mechanism is consistent with notions of dual aspects of consciousness, the rational and the affective mechanism of information processing (*61*).

In conclusion, our findings contribute to understanding perceived breast cancer risk and have implications for risk communication and risk education interventions. Limitations of the study are that the convenience sample was primarily urban, English-speaking women, and that it relied on self-reports to obtain information on family history and experiences with breast symptoms. An educational intervention aiming at helping women acquire an accurate perception of their breast cancer risk should begin with a detailed assessment of previous experiences related to breast cancer within their family, in the woman's immediate social context, and on a broader community level. Furthermore, it should evaluate and address mechanisms in which these experiences influence perceived risk. As we gain insights into perceived breast cancer risk and the cognitive mechanisms that influence subjective probabilistic evaluations, we will be better able to design and implement successful interventions and increase screening and early detection.

Table 3.1. Demographic Characteristics

Variable		N	%
Age	X= 46.49±11.80, range: 30 to 84	178	97
	Missing	6	3
	Total	184	
Race/Culture			
	Non-Hispanic White	79	43
	Non-Hispanic Black	50	26
	Hispanic	25	14
	Asian	30	17
Education			
	≤ High School Graduate	45	25
	College 1 year to 3 years (Some college or Technical School)	49	25
	College 4 years or more (College graduate)	90	50
Income			
	<$20,000	56	30
	$20,000 - $50,000	77	42
	>$50,000	43	24
	Missing	8	4
Family History			
	No Family History	118	64
	≥1 affected SDRs	31	13
	1 affected FDR	13	10
	Multiple (>1 FDR or ≥1FDR and ≥1 SDRs)	13	9
	Missing	9	4

SDRs: Second-Degree Relatives
FDR: First-Degree Relative

Table 3.2. Experiences with Abnormal Breast Symptoms

		N	%
Breast Biopsy			
	Never had a Breast Biopsy	150	81
	≥ 1 Breast Biopsy	34	19
Most Recent CBE			
	Never had a CBE	18	10
	Routine check-up	157	85
	Breast problem other than breast cancer	9	5
Most Recent Mammogram			
	Never had a Mammogram	72	39
	Routine check-up	98	53
	Breast problem other than breast cancer	14	8
Current Breast Symptoms			
	No Symptom	90	49
	Breasts feel painful and tender during menstruation	83	45
	Itching on the skin of the breast	23	13
	Constant sharp pains on one breast	12	7
	One breast getting larger	10	5
	A vague change in the breast	8	4
	Clear liquid is coming out of one nipple	6	3
	A lump or thickening in the breast that you have not noticed before	6	3
	One or both breasts look different than usual	6	3
	A change in the shape of one breast	5	3
	One breast feels warm and swollen	5	3
	A sore or a scab in the nipple	4	2
	The skin or the nipple looks scaly	4	2
	The nipple is pooled back and is sinking into the breast	4	2
	Ridges or pitting of the skin of the breast	3	2
	One breast looks red	2	1
	A lump that is getting bigger	2	1
	The skin of the breast looks like the skin of an orange	1	.5

Table 3.3. Summary of Hierarchical Multiple Regression Analysis with Perceived Breast Cancer Risk as Criterion

Step	Predictor Variable	R^2	ΔR^2	ΔF	sr^2	B
1	Family History of Breast Cancer	.059	.059	3.385*		
	SDRs vs. No FH				.037	.491*
	1 FDR vs. No FH				.004	-.279
	Multiple vs. No FH				.020	.465*
2	Affected Friends	.079	.020	3.911*	.022	-.080*
3	Abnormal Breast Symptoms	.131	.052	2.462*		
	LM				.016	-.225
	LCBE				.029	.465*
	Symptom Severity				.011	.021
	BBB				.008	-.243
4	Knowledge of Risk Factors & Worry	.205	.074	7.329*		
	Knowledge of Risk Factors				.006	.025
	Worry				.069	.081*

*p<.05

Table 3.4. Interaction of Worry and Knowledge of Breast Cancer Risk Factors with Perceived Breast Cancer Risk as Criterion

Step	Predictor Variable	R^2	ΔR^2	ΔF	sr^2	B
1		.082	.082	7.597*		
	Worry				.075	.270*
	Knowledge				.010	.101
2	Interaction Worry X Knowledge	.135	.053	10.253*	.057	.232*

*p<.05

Table 3.5. Interaction of Family History, Worry, and Knowledge of Risk Factors with Perceived Breast Cancer Risk as Criterion

Step	Predictor Variable	R^2	ΔR^2	ΔF	sr^2	B
1	Family History & Worry	.124	.124	5.930*		
	SDRs				.029	.441*
	1 FDR				.005	-.298
	Multiple				.020	.473*
	Worry				.066	.077*
2	Family History X Worry	.139	.016	.992		
	SDRs X Worry				.0001	-.006
	1 FDR X Worry				.015	-.152
	Multiple X Worry				.0003	.014
1	Family History & Knowledge	.062	.062	2.789*		
	SDRs				.033	.470*
	1 FDR				.005	-.308
	Multiple				.017	.443
	Knowledge				.005	.022
2	Family History X Knowledge	.092	.030	1.826		
	SDRs X Knowledge				.010	.086
	1 FDR X Knowledge				.023	.225*
	Multiple X Knowledge				.002	.049

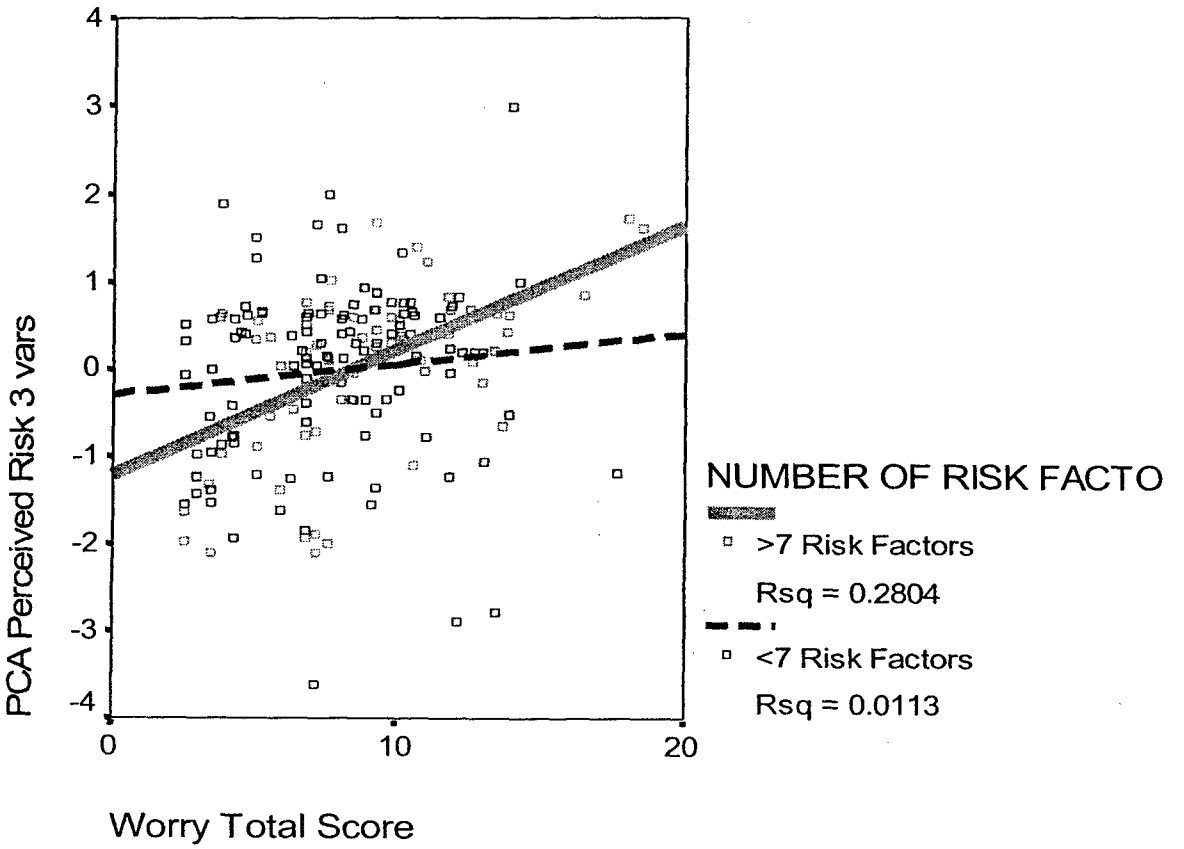
*p<.05

Table 3.6. Interaction of Breast Symptoms, Worry, and Knowledge of Risk Factors with Perceived Breast Cancer Risk as Criterion

Step	Predictor Variable	R^2	ΔR^2	ΔF	sr^2	B
1	Breast Symptoms & Worry	.128	.128	4.915*		
	Most Recent Mammogram				.021	-.251*
	Most Recent CBE				.028	.453*
	Current Breast Symptoms				.003	.011
	Breast Biopsies				.013	-.308
	Worry				.069	.081*
2	Breast Symptoms X Worry	.163	.034	1.679		
	Most Recent Mammogram X Worry				.021	.075*
	Most Recent CBE X Worry				.002	.035
	Current Breast Symptoms X Worry				.0004	-.001
	Breast Biopsies X Worry				.021	-.130*
1	Breast Symptoms & Knowledge	.064	.064	2.282*		
	Most Recent Mammogram				.016	-.221
	Most Recent CBE				.029	.468*
	Current Breast Symptoms				.013	.022
	Breast Biopsies				.009	-.253
	Knowledge				.005	.023
2	Breast Symptoms X Knowledge	.105	.041	1.859		
	Most Recent Mammogram X Knowledge				.011	.056
	Most Recent CBE X Knowledge				.003	.043
	Current Breast Symptom X Knowledge				.0006	.002
	Breast Biopsies X Knowledge				.014	.098

*p<.05

Figure 3.1 Interaction of Knowledge of Breast Cancer Risk Factors with Worry and Perceived Risk as Criterion



MANUSCRIPT 3:

DO HEALTHY WOMEN IN THE COMMUNITY RECOGNIZE HEREDITARY AND SPORADIC BREAST CANCER RISK FACTORS?

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(To be Submitted: ONCOLOGY NURSING FORUM)

Abstract

Purpose: 1) to describe knowledge of hereditary and sporadic breast cancer risk factors among healthy women in the community, and 2) to identify predictors of knowledge of breast cancer risk factors. **Design/Methods:** Cross-sectional survey, questionnaire. **Setting:** Community settings around the San Francisco Bay Area. **Sample:** We recruited 184 women, who have never been diagnosed with cancer, were between 30 and 85 years old (X=46±12), and agreed to complete a questionnaire in English. Participants were from diverse racial/cultural backgrounds (43% White, 26% Black, 17% Asian, and 14% Hispanic). Most (49%) were college graduates and had a median annual income $30,000 to $40,000. **Main Research Variables:** We assessed knowledge of hereditary and general breast cancer risk factors. **Findings:** Although most women recognized the role of heredity as a risk factor, some did not understand the impact of paternal family history on one's risk. Some women did not recognize the relation between breast and ovarian cancer, risk factors associated with the Gail model, and that getting older increases one's risk. Education was the only important predictor of knowledge of risk factors. **Conclusions:** Although age and family history are independent predictors of sporadic and familial breast cancer risk, women in the community cannot distinguish between the two forms of the disease. Although this was a sample of educated women, their knowledge of breast cancer risk factors appeared incomplete. **Implications:** Nurse practitioners should provide individualized risk assessment and education regarding breast cancer risk factors.

Word Count: 240
Key Words: Hereditary and Sporadic Breast Cancer, Risk Factors, Gail Model, Knowledge

Key Points:

1. Knowledge of breast cancer risk factors is incomplete and risk factors associated with the Gail model are overlooked
2. It appears that healthy women in the community do not recognize the difference between hereditary and sporadic breast cancer
3. Nurse practitioners should provide individualized counseling and education regarding hereditary and sporadic breast cancer to their clients

Introduction

The purpose of the study was 1) to describe knowledge of hereditary and sporadic breast cancer risk factors among healthy women in the community, and 2) to identify predictors of knowledge of breast cancer risk factors.

Theoretical Framework

Weinstein (*6*) suggested an important qualitative distinction between a person who is unaware about a health problem and associated risk factors, and a person who is aware of the health problem but considers that specific situations are not risk factors. The first person will be open-minded in learning about the health problem and risk increasing factors, although she will not actively seek out information. In contrast, a person who has thought of a health problem and reached the conclusion that specific situations are not risk factors will not be open-minded to information and educational interventions because her commitment to a particular point of view will tend to produce a biased response. The second person will selectively attend to messages that support her own position and will show belief perseverance when faced with disconfirming evidence (*33*). Therefore, educational interventions that aim to increase awareness and knowledge regarding specific health problems should take into account pre-existing knowledge and how it might bias people's open-mindedness to health messages.

Recruitment and Procedures

The present analysis is part of a community-based triangulation study that examined perceived breast cancer risk and factors that influence perceived risk. Details about recruitment methods and study procedures have been reported elsewhere (*36*). In brief, the study recruited a convenience sample of women between the ages of 30 and 85 years that have never been diagnosed with any type of cancer, and were able to complete a questionnaire in English. Women with a prior diagnosis of any type of cancer were excluded from the survey because they were more likely to have received extensive education about their cancer risk. Recruitment was done with flyers posted in bulletin boards of community settings, such as churches, senior centers, coffee shops, public libraries, and workplaces in the San Francisco Bay Area, within a radius of 50 miles from San Francisco. Also recruitment was done through a newspaper advertisement and through networking with community agency leaders. Women responded by calling a dedicated telephone number and expressing their interest in participating in the study. Participants completed the survey either in person or by mail and were paid $15. The University of California San Francisco Committee of Human Rights approved the study protocol. Data collection occurred over a period of thirteen months, from February 2003 to March 2004.

Measurements

Demographic variables assessed included age, race/culture, education, income, employment status, health insurance status, and marital status with single item questions used by the Behavioral Risk Factor Surveillance System (*62*) . We assessed Family History of breast cancer by asking women to indicate the number of their first-degree relatives (FDRs) and the

number of their second-degree relatives (SDRs) that have been affected by the disease. Based on that information women were categorized in one of four groups: No family history, one or more affected SDRs, one affected FDR, and multiple affected family members (>FDRs or 1FDR+≥1SDRs) (*63*). We assessed breast cancer risk factors that are used by the Gail model (*2*), such as age of first menstrual period (FMP), age of first live birth (FLB), and number of breast biopsies (BBs).

Knowledge of breast cancer risk factors was assessed by asking participants to indicate whether 13 situations might be risk factors for breast cancer. Five of these questions described risk factors identified by the Gail model and have been used in a previous study (*44*). The remaining seven questions examined knowledge of hereditary/genetic risk factors for breast cancer. Women could respond '*Yes*', '*No*', and '*Don't Know*'. The purpose of these items was to examine whether participants knew that specific situations increase a woman's probability of developing breast cancer. Items that were scored affirmatively were summed to calculate each woman's score for knowledge of breast cancer risk factors, and create a *Breast Cancer Risk Factor Knowledge Index (BCRFKI),* with scores ranging from 0 to 13. The 13-items were highly intercorrelated (Cronbach's $\alpha = .80$). However, current developments in psychometric theory suggest that lists of items, such as a list that examines knowledge of risk factors, should not be treated as scales but as indices. In these cases test-retest reliability is the appropriate method for assessing reliability (*64*). Since the study was a cross-sectional survey we did not have the opportunity to examine the test, re-test reliability of the Breast Cancer Risk Factor Knowledge Index.

Statistical Analysis

Data were analyzed using SPSS11.5® statistical program. For all statistical analyses significance was set at the 0.05 level with 95% Confidence Intervals. We used descriptive statistics to describe the demographic characteristics of the sample, and knowledge of breast cancer risk factors. We used bivariate analysis, such as Pearson correlations (r), and F-tests with Bonferoni post-hoc contrasts to examine significant demographic differences among women in the sample. We used simultaneous multiple regression analysis and binary logistic regression analysis to identify predictors of knowledge of breast cancer risk factors (*65*).

Results

Demographic Description of the Sample

The study recruited a total of 184 women with a mean age of 46±12 years (range 30-84). Forty three percent self-identified as non-Hispanic White, 27% as non-Hispanic Black, 14% as Hispanic, and 16% as Asian. Ten participants (5.5%) were of Ashkenazi Jewish decent. Most women (49%) had attended four or more years of college, but 8% had not completed high school. The median annual income was <$40,000, with 21% of the sample reporting an annual income of <10,000 and 10% reporting an annual income of >$80,000. Most women (55%) were employed outside the home and had health insurance (77%). Only 33% of the women in our sample were currently married or a member of an unmarried couple (See Table 1). (Insert Table 1).

Approximately two thirds (63%) of participants did not have a family history of breast cancer. Twenty-five women (14%) had one or more affected SDRs, 18 women (10%) had one affected FDR, and 16 women (9%) had multiple affected relatives. Approximately one in five women (21%) had their FMP when they were younger than 12 years of age, while 18 women

(10%) had their first baby (FLB) when they were older than 30 years. Approximately one in five women in our sample (19%) had one or more BBs. (See Table 2). (Insert Table 2).

There were no significant differences among women of different race/culture regarding their mean age and their family history of breast cancer. White women were more likely to have higher education compared to Black and Hispanic women, and Asian women were more likely to have higher education compared to Black women ($F_{(3,180)}$=15.86, p<0.001). Asian women in our sample were more likely to report higher income than women of other racial/cultural backgrounds ($F_{(3,172)}$=6.90, p<0.001). Education was significantly correlated with income only for Black women in the sample (r=0.50, p= 0.001).

Knowledge of Breast Cancer Risk Factors

Table 3 presents participants' responses on the BCRFKI. Approximately 75% of the study participants recognized that 'having multiple family members with breast cancer', 'having a family history of breast cancer from the mother's side of the family', and 'having had breast cancer before' are breast cancer risk factors. Surprisingly, only 45% of women recognized that 'having a family history of breast cancer from the father's side of the family' is a breast cancer risk factor, while 28% of women responded 'Don't know' to this item. Similarly, 43% of the study participants responded 'Yes' to the item 'having a genetic mutation', while 30% responded 'Don't know'. However, in the latter case a response 'Don't know' could indicate that women did not understand the meaning of the words 'genetic mutation'. Approximately 70% of the study participants responded 'Yes' to the item 'having a family member with both breast and ovarian cancer' is a risk factor for breast cancer, while only 40% of participants recognized that 'having a family history of ovarian cancer' could be a risk factor for breast cancer.

'Getting older' was recognized as a breast cancer risk-increasing factor by 56% of the study participants, while 22% and 15% of the women in the study responded 'No' and 'Don't Know' to this item respectively. Similarly, 50% of the study participants responded 'No' to the item asking whether 'having had a breast biopsy' is a risk factor for breast cancer, while only 40% recognized that 'late age at first pregnancy' is a risk increasing factor. Finally, approximately 50% of the women responded that they 'Don't know' whether 'late start of menopause' and 'being of Ashkenazi Jewish decent' are breast cancer risk factors. (Insert Table 3).

Predictors of Knowledge of Breast Cancer Risk Factors

Most participants correctly identified six to eight risk factors (X=6±3, range 0 to 13). We performed a simultaneous multiple regression with the dependent variable being the sum of the affirmative responses on the BCRFKI. The independent variables were age, education, income, race/culture, Ashkenazi Jewish decent, family history of breast cancer, age at FLB, age at first menstrual period, and number of breast biopsies. Race/culture, family history of breast cancer, and age of first menstrual period were entered in the regression model as dummy-coded variables. Most women (N=172) had complete responses and were included in the analysis. The overall model predicted approximately 22% in the variance of the BCRFKI (R^2 =.224, F=3.51, p<.001). Significant predictors of a higher score in the BCRFKI were education, having one or more affected SDRs, and being of Ashkenazi Jewish decent. (See Table 4). Since getting older is an established risk factor for sporadic breast cancer, we performed a logistic regression analysis with 'getting older' as a dichotomous (yes/no) criterion variable and 'age of participants' as the predictor variable. As the age of participants increased, the likelihood that

they would recognize that 'getting older' is a risk factor for breast cancer decreased (N=168, B= -.037, S.E.= .014, Wald χ^2 = 7.408, df=1, p=.006, Exp(B)= .963, 95%CI for Exp(B) = .938 - .990). (See Table 4).

Discussion

The present study examined knowledge of breast cancer risk factors in a multicultural sample. Participant women were recruited from community settings that were likely to visit in the context of their day-to-day lives, such as coffee shops, senior centers, and workplaces. The study examined knowledge of general and hereditary risk factors for breast cancer and the relation between knowledge level and risk for the disease. Most women in our sample were at an average risk for breast cancer. However, one in ten women were at increased risk for the disease because they had one affected FDR. Furthermore, 16 women (9%) had multiple affected family members and could potentially be from a family that carries a genetic mutation. One participant responded that she had a case of male breast cancer in her family and a second participant indicated that her maternal aunt has been diagnosed with a BRCA1 mutation. **(shall we omit the last sentence???)**

Our findings suggest that despite the general awareness of the role of family history in breast cancer susceptibility, some participants lacked important understanding about the impact of family history on one's risk for disease. Some women's understanding of familial risk was incomplete and at odds with epidemiology. Our findings are consistent with findings of other studies that examined knowledge of general and hereditary breast cancer risk factors (*12, 66-68*). Most participants recognized that having multiple affected family members is an important risk factor for breast cancer. However, participants were more likely to recognize that family history from the mother's side of the family is a risk factor, while only 45% recognized that having an affected family member from the father's side of the family is a breast cancer risk factor. These findings are consistent among studies that recruit participants from the general population (*69*), as well as patients with early onset of the disease (*70*), and suggest that many women are unclear about how and from whom breast cancer risk could be inherited. Therefore, those women are significantly more likely to underestimate their breast cancer risk, if affected family members are in the father's side of the family.

The second interesting finding of this study is that a significant number of women (44%) did not recognize that getting older is a risk factor for breast cancer. Our findings reveal that as the participants' age increased, the likelihood that they would recognize age as a risk factor for breast cancer decreased. Consistent with results from a meta-analysis on predictors of perceived breast cancer risk (*5*), this finding was surprising, since age is a well-established risk factor for breast cancer. Scientific literature suggests that some women lack basic knowledge about breast cancer risk factors (*11*), while others create mental images of a stereotypical person who is likely to be affected by the disease (*14, 71*). Taken together these findings indicate that when women lack the specific knowledge that getting older increases a woman's risk for developing breast cancer they are more likely to believe that the disease affects mostly younger women.

According to commonly used risk estimation models, such as the Gail model (*2*), age and having one affected FDR significantly increase a woman's probability of developing breast cancer. Age and family history are independent predictors of sporadic and familial breast cancer risk. However, interactions between these two risk factors are complicated and sometimes difficult to interpret in clinical practice. For instance, a woman carrying a genetic mutation

associated with familial breast cancer has an increased risk of an early onset of the disease, but this increased risk is reduced to an average level, as the woman grows older. Similarly, the diagnosis of a SDR with breast cancer does not significantly increase a woman's risk for the disease unless it occurs at an early onset, in which case might signify a case of familial breast cancer. These cases differ strikingly from sporadic breast cancer, which poses a greater risk as women age.

Women at risk for hereditary breast cancer are at risk for ovarian cancer and vice-versa. Our findings indicate that although most women (70%) recognized that 'having a family member with breast and ovarian cancer' is a risk factor, only 41% recognized that 'having a family member with ovarian cancer' might increase one's breast cancer risk. Taken together these findings indicate that most participants did not recognize that the etiology of hereditary breast cancer could be closely related to the etiology of ovarian cancer. This finding is consistent with a population-based sample of women at high risk for hereditary breast and ovarian cancer, which reported that almost 75% of the study participants lacked the knowledge that they were at an increased risk for ovarian cancer and they did not use existing screening methods for ovarian cancer early detection (*72*). Therefore, some women are more likely to significantly underestimate their breast cancer risk because they are not aware of the breast/ovarian cancer etiology connection.

Our findings suggest that situations that increase a woman's risk for sporadic breast cancer are less understood and acknowledged as breast cancer risk factors. Early age at menarche, late age at menopause, age at first live birth, and having had one or more breast biopsies are factors that increase a woman's probability of developing the disease. These factors have been established as risk increasing factors by epidemiological studies and are related to breast cancer etiology possibly because the breast tissue of a woman prior to pregnancy is more sensitive to canrcinogens than breast tissue that has gone through its complete hormonal development (*73*). However, on average only one in three women responded affirmatively to these items, while a large proportion of women responded 'Don't Know. Of interest is the observation that although these risk factors are clearly established and are used by the Gail model in the calculation of an individual's breast cancer risk, women are less likely to acknowledge them as risk factors. In contrast, studies report that women most often estimate their breast cancer risk based on factors whose role in breast cancer etiology has not been established yet, such as smoking, alcohol, and high fat diet (*12, 74*). These findings suggest that there is a gap in knowledge of breast cancer risk factors and that this gap reflects a lack of systematic education of women in the community.

Results from our regression analysis revealed that education was an important predictor of knowledge of breast cancer risk factors. What is most interesting is that women had an incomplete knowledge of breast cancer risk factors despite the fact that overall this was a sample of educated women; 49% had completed four or more years of college and an additional 26% had completed some college or a technical school. Furthermore, women had an incomplete knowledge of breast cancer risk factors despite their race/culture. Studies suggested that racial/cultural differences affect decision-making regarding genetic testing among Black women (*75*), and that Black women and lower income women should be the focus of public education programs (*76*). Although women of lower income and women of diverse racial/cultural backgrounds have fewer opportunities to attend health educational programs (*31*), in a previous analysis we suggested that education and race/culture should be examined together as predictors of knowledge of breast cancer risk factors (*5*). Our current data suggest that education was the

stronger predictor of a high score on the BCRFKI and that women had incomplete knowledge of risk factors, despite their high level of education. These findings highlight the knowledge gap between laywomen and health professionals. The finding that only 42% of women recognized that 'having a genetic mutation' is a breast cancer risk factor is more likely to reflect the fact that women do not understand the meaning of terms and phrases that are commonly used by health professionals (*77*). Therefore, public educational programs and individual counseling about risk factors and a woman's risk for developing the disease are important efforts aiming to increase breast cancer screening and early detection.

Other significant predictors of a high score on the BCRFKI were having one or more affected SDRs, while having an affected FDR and multiple affected family members were not significant predictors of a BCRFKI score. There are different possible explanations for these findings. One explanation is that family history of one affected FDR and multiple affected relatives did not reach statistical significance because of the small number of women with those conditions in the sample. Another possible explanation is that some women underestimate the importance of having one affected FDR as a risk factor (*11, 12*), while it is possible that women with multiple affected family members concentrate on the importance of genetic risk factors, while they underestimate the importance of other factors that increase the probability of sporadic breast cancer. Future studies, possibly stratified according to family history of breast cancer, should further examine this issue.

Limitations

Our study has significant limitations that should be considered before reaching any final conclusions. Results are based on a convenience sample of self-selected women. Although we examined knowledge of important breast cancer risk factors our list was not exhaustive. For example, we did not examine whether women knew that early onset of disease is indicative of hereditary disease and whether they knew that there might be an association between breast cancer and other forms of cancer. Despite these limitations, the strength of the study is that it recruited women from diverse socioeconomic and racial/cultural backgrounds from community settings. Recruitment from those settings ensured that participation in the study was not limited only to women that have greater access to health care services, and therefore to greater opportunities to read educational material related to breast cancer risk factors.

Implications for Nursing

Participant women were recruited from community settings and were least likely to have ever received individual counseling about their breast cancer risk. Nursing has offered stellar examples of educational and counseling interventions targeting high-risk women recruited from the community (*78*). However, until similar programs become widely available and accessible to the majority of women, healthy women in the community depend on their nurse practitioners for individual risk assessment, counseling, and education about breast cancer risk factors.

The family history is the most significant clue to a hereditary predisposition to cancer. Primary care providers, including nurse practitioners, can incorporate the calculation of a woman's risk for breast cancer and the calculation of the probability that she is a carrier of a genetic mutation into routine care, by using an appropriate risk assessment model (*79*). Obtaining a family history and calculating an individual's risk for the disease is time consuming and is not generally practiced by nurse practitioners. But unless nurse practitioners obtain adequate family information and information about breast cancer risk factors they may miss

clients at increased risk for breast cancer or clients at risk for hereditary cancer syndromes. Nurse practitioners are in a unique position to apply recent advances in cancer genetics to improve the care and education of their clients. They have the important task to inform women about the mechanisms of sporadic and hereditary cancer, and their meaning in terms of level of risk. Clarifying types of cancer, age at onset of cancer, and number of degree of relatedness of cases of both genders in defining family history might be a helpful first step (*80*).

In light of the rapid evolution in cancer genetics it will be important to track changes in knowledge regarding breast cancer risk factors and knowledge of hereditary risk factors among individuals. This is particularly true as this area continues to grow and as educational materials are developed and made available to the lay public and the professional community. Finding the most effective ways to educate individuals regarding risk for sporadic and hereditary disease would not be an easy task. Recent reports indicate that attitudes among genetic counselors towards preventive measures were influenced by cultural factors (*81*), and that individual differences in the amount of information given and the way this information was communicated to clients seeking genetic consultation had better or poorer psychosocial outcomes (*82*). Taken together these findings suggest that research should monitor the attitudes and knowledge of health care providers and the public, and as suggested by Weinstein, educational interventions need to assess pre-existing knowledge that predispose individuals to biased information processing. As the field of cancer risk assessment continues to grow educational materials should address the knowledge needs of health providers and healthy women in the community.

Table 1. Demographic Characteristics of the Sample

Variable		N	%
Age	X= 46.59±12.05, range: 30 to 84		
	30 to 39	63	35
	40 to 49	51	28
	50 to 69	54	29
	70 to 85	10	5
	Missing	6	3
	Total	184	
Race/Culture			
	Non-Hispanic White (Ashkenazi Jewish decent)	79 (10)	43
	Non-Hispanic Black	50	27
	Hispanic	25	14
	Asian	30	16
Education			
	Grades 1 to 8, Elementary School	7	4
	Grades 9 to 11, some High School	8	4
	Grade 12, or GED, High School Graduate	31	17
	College 1 to 3 years, some College or Technical School	48	26
	College ≥ 4 years, College Graduate	90	49
Annual Household Income			
	<$10,000	39	21
	$10,000 - $20,000	16	9
	$20,000 - $30,000	33	18
	$30,000 - $40,000	28	15
	$40,000 - $50,000	17	9
	$50,000 - $60,000	16	9
	$60,000 - $70,000	6	3
	$70,000 - $80,000	2	1
	>$80,000	19	10
	Missing	8	4
Employment Status			
	Employed for wages	79	43
	Self-Employed	23	12
	Out of work ≥1year	16	9
	Out of work <1year	12	6
	A Homemaker	9	5
	A Student	14	8
	Retired	14	8
	Unable to work	15	8
	Missing	2	1

Health Insurance			
	Yes	142	77
	No	38	21
	Missing	8	2
Marital Status			
	Married	45	25
	Divorced	30	16
	Widowed	17	9
	Separated	7	4
	Never Married	69	38
	A Member of an Unmarried Couple	15	8
	Missing	1	

Table 2. Breast Cancer Risk Factors in the Sample

Variable		N	%
Family History of Breast Cancer			
	No Family History	117	63
	1 or more affected SDRs	24	14
	1 affected FDR	18	10
	Multiple (>1FDR or 1 FDR and ≥1 SDRs)	16	9
	Missing	9	4
Age of First Menstruation			
	<12	38	21
	12 or 13	84	46
	≥ 14	56	30
	Missing	6	3
Age of First Live Birth			
	Nulliparous	87	47
	< 20	30	16
	20 to 24	30	16
	25 to 29	19	10
	≥30	18	10
History of Breast Biopsy			
	0	150	79
	1	25	14
	>1	9	5

Table 3. Knowledge of Breast Cancer Risk Factors

"Please, mark an X in the box that best describes whether the following situations might be risk factors for breast cancer".

Risk Factor	Yes	No	Don't Know	Missing
Having multiple family members with breast cancer	140	21	10	10
Having a family history of breast cancer from the mother's side of the family	138	23	10	10
Having had breast cancer before	131	36	4	10
Having a family member with both breast and ovarian cancer	127	24	18	12
Getting older	103	41	27	10
Having a family history of breast cancer from the father's side of the family	82	37	51	11
Having a genetic mutation	78	34	56	13
Having a family history of ovarian cancer	75	35	59	11
Late age at first pregnancy	74	46	51	10
Early start of menstruation	51	59	58	13
Having had a breast biopsy	49	91	30	11
Late start of menopause	21	57	89	13
Being of Ashkenazi Jewish decent	14	53	101	13

N=184

Table 4. Predictors of Knowledge of Breast Cancer Risk Factors

Variable	B	SEB	β
Age	.005	.021	.018
Education	.873	.274	.279*
Asian vs. White Dummy Variable	-.953	.752	-.108
Black vs. White Dummy Variable	-.520	.653	-.072
Hispanic vs. White Dummy Variable	.205	.783	.022
FMP <12 y.o. vs. FMP 12 or 13 y.o.	-.310	.300	-.081
FMP >14 y.o. vs. FMP 12 or 13y.o.	-.207	.262	-.062
Age at FLB	-.052	.020	-.211
Number of Breast Biopsies	.563	.328	.129
Ashkenazi Jewish	-2.119	1.062	-.151*
SDRs vs. No Family History Dummy Variable	.858	.630	.106*
FDRs vs. No Family History Dummy Variable	1.522	1.086	.105
Multiple Family Members vs. No Family History Dummy Variable	.155	.809	.014

*p<.05

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