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ABSTRACT.

The study aimed to describe perceived breast cancer risk, compare subjective and objective risk estimates, and examine the influence of heuristic reasoning in women's narratives. The survey used three probability scales (Verbal, Comparative, Numerical) and the Gail model to measure perceived and objective risk. Aim 3 is addressed with Argument and Heuristic reasoning analysis. We recruited a multicultural, educated sample of 184 English-speaking women from community settings. Fifty four provided an in-depth interview. Participants held an optimistic bias regarding their breast cancer risk (comparative optimism and better-than-average), and underestimated their objective risk calculated with the Gail model. Older women and those with one affected first-degree relative did not perceive higher risk, which implies that women's knowledge of breast cancer risk factors was incomplete, despite their high educational level. Age and family history are independent predictors of sporadic and hereditary/familial breast cancer risk; yet, women could not distinguish between the two forms of the disease. Moreover, higher risk women were not more likely to receive more frequent screening. There was no correlation between women's Gail score and screening behavior, such as screening mammograms. This finding possibly implies that health professionals do not provide tailored recommendations for screening. Alternatively, 70% of participants were adherent to mammography guidelines, which can be attributed to high access to screening services of the target population and intense efforts of cancer screening programs. Participants with lower education and lower income were more likely to report higher levels of breast cancer worry, while Black women in the sample were more likely than Asian and White women to report higher levels of breast cancer worry. Breast cancer worry and other affective characteristics influence decision-making for breast cancer screening. A series of simultaneous and hierarchical regression analyses revealed that having multiple affected family members, breast cancer worry, and knowledge of risk factors significantly decreased optimistic bias regarding perceived breast cancer risk. In contrast, affected friends increased optimistic bias. Breast cancer worry was a mediator between having current breast symptoms and optimistic bias. Knowledge of risk factors moderated the relation between having one or more breast biopsies and optimistic bias. Distrust in the health care system was the single most important predictor of predisposition to use health services, which in turn was a significant predictor of breast cancer screening. Interactions among distrust, age, education, and race highlight the importance of distinguishing among racial/cultural, socioeconomic, and cognitive contributors to distrust. Distrust takes the greatest toll among vulnerable groups of women in predisposition to use health services and decision-making regarding breast cancer risk screening. Initial analysis of in-depth interviews revealed that experiences with affected family members and friends, and breast symptoms influence perceived risk through affective and cognitive mechanisms. Heuristics (logical shortcuts) facilitated risk-assessments. The narrative data provide evidence that supports theories of two systems of reasoning: deliberative and associative reasoning.

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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 primary aims of this project were 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 assessments and their breast cancer screening behavior.

BODY

Between May 2003 and May 2004 the following research tasks were accomplished. Maria Katapodi (Principal Investigator – PI) in collaboration with the research team finalized the survey questionnaire and the interview guide, gained entrée in appropriate recruitment sites, and completed data collection. The project recruited a total of 184 women with a diverse racial/cultural background from community settings. Fifty four of those women agreed to provide an in-depth interview. The PI with the research team agreed that more interviews would not provide more information, because narrative data had reached saturation.

During the second year of the grant from June 2004 to October 2005 the following tasks were accomplished. The PI along with the research team completed and submitted three manuscripts, one of which has already been published (see Appendix). The PI prepared podium and poster presentations for the following conferences: 8th National Conference on Cancer Nursing Research, 38th Annual Meeting of the Western Institute of Nursing, Era of Hope Department of Defense Conference. The PI has been invited as a Guest Speaker to 2nd Intersociety Anticancer Convention (Athens, Greece), the 6th National Conference of Hellenic Nursing Students (Athens, Greece), and at the Hellenic Anticancer Society, Postgraduate Seminars (Athens, Greece) to present research findings related to the grant. Moreover, the PI has been invited as a Guest Lecturer to the University of Athens, Graduate Student's Seminars to lecture on topics related to her research study.

During the third year of the grant (No Cost Extension) from October 2005 to January 2006 the following tasks were accomplished. The PI and the research team completed additional data analyses from the survey questionnaire to address secondary aims of the project, and have been analyzing narrative data from the in-depth interviews. Abstracts presenting findings of these analyses have been accepted for a poster and a podium presentation for the 28th Annual Meeting of the Society of Medical Decision Making and the 9th Cancer Nursing Research Conference of the Oncology Nursing Society, respectively. Data analysis and all work related to the grant was ceased in January 2006, when the PI had assumed a position as an Assistant Professor at the University of Michigan School of Nursing. In order to complete the narrative data analysis and accomplish the aims of the study, the PI requested a subcontract of the grant from the University of California, San Francisco (UCSF), to the University of Michigan (UM). In order for the subcontract to take effect, IRB approval from the UM was sought. The UM IRB determined that

the study is exempt from IRB Review on 05/10/07 (HUM00011707, Exp 05/10/09), and the subcontract of the grant from UCSF to UM has yet to take effect. The delay in requesting IRB approval from the UM was due to professional and personal reasons. As a new Assistant Professor at the UM, the PI had to become familiar with the IRB process at the UM. Moreover, she has been teaching in the Winter 2006 and Fall 2006 semesters, and she was on maternity and sick leave during the Winter 2007 semester.

Data Report from Survey Questionnaire

Data collected from the survey questionnaire were analyzed using the statistical program SPSS 11.5 and SPSS 13. A detailed description of these findings has been or will be disseminated with the following manuscripts:

1. “Better-than-Average and Comparative-Optimism biases in a community sample: Effects on breast cancer screening”. This manuscript has been submitted to *Preventive Medicine* and is currently under revision. It addresses specific aims 1) and 2) of the project.
2. “Experiences with breast cancer, heuristics, and optimistic bias”. This manuscript has been submitted to the *Journal of Medical Decision Making* and is currently under revision. It addresses a secondary aim of the project, which is to identify factors that decrease optimistic bias of women in the sample, and to examine whether breast cancer worry and knowledge of risk factors act as moderators or mediators between experiences with the disease and optimistic bias.
3. “Distrust, utilization of health care services, and decision making regarding breast cancer screening”. This manuscript has been submitted to *Social Science and Medicine* and is currently under revision. The manuscript describes how cognitive biases contribute to initiation and maintenance of distrust in the health care system. Distrust influences predisposition to use health care services, which in turn is the most significant predictor of breast cancer screening behaviors.
4. “The influence of worry and emotional characteristics on breast cancer screening”. The manuscript is currently under preparation. It describes level of breast cancer worry and the contribution of affective characteristics on decision-making regarding breast cancer screening.
5. “Do women in the community recognize hereditary and sporadic breast cancer risk factors?” This manuscript addresses a secondary aim of the project, which is that women in the community do not have the knowledge to distinguish between sporadic and hereditary forms of breast cancer. This manuscript has been published in *Oncology Nursing Forum*, 2005, 32(3), 617 – 623.

Analysis of the data obtained from the survey questionnaire revealed that participant women were representative of an urban, English-speaking population. They were perimenopausal (47±12 years old); 43% self-identified as Non-Hispanic White, 26% as Non-Hispanic Black, 14% as Hispanic, and 17% as Asian. A large percentage (49%) had college education or higher, and their median annual income was between \$30,000 and \$40,000.

Participants underestimated their actual breast cancer risk, as it was calculated with the online version of the Breast Cancer Risk Assessment Tool (BCRAT). The tool was developed by the National Cancer Institute and it is based on the Gail model. Participants also claimed that they were less likely than their friends/peers to get breast cancer, and that their risk was 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 influenced risk perception only when the latter was 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 the scale is most likely misinterpreted, and addresses the important issue of systematic measurement errors. Findings of this analysis were presented as 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.

The PI and the research team examined the breast cancer screening habits of participant women (mammogram, Clinical Breast Exam (CBE), and Breast Self Exam (BSE)) and the impact that perceived breast cancer risk had on their screening behavior. Most (77%) had some form of health insurance and 70% of participants over 40 years of age had their most recent mammogram within the last 24 months. However, 10% of women in the sample who were older than 40 years reported never having a mammogram and only 24% reported performing Breast Self Exam once a month. Perceived risk did not influence breast cancer screening behavior, presumably because the majority of women in the sample had an optimistic bias and perceived their breast cancer risk to be low. However, there was no correlation between participants' Gail scores and frequency of screening mammograms or CBEs, which implies that health providers did not recommend more frequent screening for high-risk women in the sample. Findings of this analysis are presented in Manuscript 1, titled "Better-than-Average and Comparative Optimism biases in a community sample: Effects on breast cancer screening", which is currently under revision. They were presented as a **Podium presentation** at the 2nd Intersociety Anticancer Convention, Athens, Greece, March 2005, where the PI was an Invited Speaker for a 40-minute lecture, and a **Poster presentation** at the Era of Hope, Department of Defense Conference, Philadelphia, PN, June 2005.

A series of simultaneous and hierarchical regression analyses revealed that having multiple affected family members, breast cancer worry, and knowledge of risk factors significantly decreased optimistic bias about breast cancer risk. Optimistic bias was reduced for participants that had personal experiences with abnormal breast symptoms (e.g. breast biopsies); knowledge of risk factors moderated the relation between the predictor variable "number of breast biopsies" and the outcome variable "optimistic bias." Optimistic bias was also reduced for participants that reported having breast symptoms at the time of the survey; breast cancer worry was a complete mediator between the predictor variable "current breast symptoms" and the outcome variable "optimistic bias". In contrast, having friends that had been affected by the disease increased optimistic bias for women in the sample. These findings suggest different possible pathways with which past experiences are incorporated into breast cancer risk assessments. The

pathway that operates through knowledge of risk factors represents an analytical, deliberate system of reasoning, while the affective pathway that operates through breast cancer worry represents the associative, contextual system of reasoning. The analysis provides evidence of heuristic reasoning, which represents experiential learning. Findings of this analysis are presented in Manuscript 2, titled “Experiences with breast cancer, heuristics, and optimistic bias”, which is currently under revision for the Journal of Medical Decision Making. Parts of this manuscript were also presented as a **Podium presentation** at the 38th Annual Meeting of the Western Institute of Nursing, April 2005, San Francisco, CA and a **Poster presentation** at the Era of Hope Department of Defense Conference, Philadelphia, PN, June 2005.

A finding of the survey was that participants did not have adequate knowledge to distinguish between hereditary and sporadic breast cancer risk factors, despite their high educational level. This finding becomes even more significant if we consider that 49% had at least four years of college education. Participants were not likely to have received genetic counseling or any form of genetic education, since only 9% had multiple affected family members, and could potentially be at high-risk for the hereditary form of the disease. Therefore, they depended on their primary care providers (physicians and nurse practitioners) for personalized breast cancer risk assessment and education. Findings indicated that participants did not know that having an affected family member from the father’s side of the family increases breast cancer risk, they did not recognize the connection between breast and ovarian cancer, and did not understand the interplay between family history and age as independent breast cancer risk factors. Findings of this analysis are presented in Manuscript 3, titled “Do women in the community recognize hereditary and sporadic breast cancer risk factors?” that was published in *Oncology Nursing Forum*, 2005, 32(3), 617 – 623. Moreover, this analysis was a **Podium presentation** at the 8th National Conference on Cancer Nursing Research, February 2005, Ft Lauderdale, FL, a **Podium presentation** at the 38th Annual Meeting of the Western Institute of Nursing, April 2005, San Francisco, CA, and a **Poster presentation** at the Era of Hope Department of Defense Conference, June 2005, Philadelphia, PN.

An unexpected finding of the survey was that breast cancer worry was a stronger predictor of breast cancer screening than perceived risk. Therefore, the PI examined whether breast cancer worry and other affective characteristics predicted screening behaviors. Findings indicate that participants with lower education and lower income were more likely to report higher levels of breast cancer worry, whereas Black women in the sample were more likely than Asian and White women to report higher levels of worry. Breast cancer worry, affect intensity, and behavioral inhibition correlated positively with screening behaviors, whereas experiential thinking and fun seeking correlated negatively with screening behaviors. Findings of this analysis were titled “Affective characteristics as predictors of breast cancer screening” and were a **Poster presentation** at the Era of Hope Department of Defense Conference, June 2005, Philadelphia, PN. Preparation of a manuscript that addresses this analysis is underway.

We examined whether distrust in the health care system influenced predisposition to use health services and decision-making regarding breast cancer screening. We measured the cognitive processes that constitute the psychological mechanism of the “asymmetry principle” and

contribute to the self-reinforcing and self-perpetuating attributes of distrust. We also measured personal experiences with prejudice in the health care system and individual predisposition to use health services. Regression analyses revealed that distrust in the health care system was the single most important predictor of predisposition to use health services, which in turn was a significant predictor of breast cancer screening behavior. Observed interactions among distrust, age, education, and race highlight the importance of distinguishing among racial/cultural, socioeconomic, and cognitive contributors to distrust. Findings indicate that distrust took the greatest toll among vulnerable groups of women in the study, and influenced predisposition to use health services, and decision-making regarding breast cancer screening. Findings of this analysis are presented in Manuscript 4, titled: “Distrust, utilization of health care services, and decision making regarding breast cancer screening”, which is currently under revision. Different parts of this analysis were presented as a **Poster presentation** at the 28th Annual Meeting of the Society of Medical Decision Making, October 2006, Boston, MA, and a **Podium presentation** at the 9th Cancer Nursing Research Conference, February 2007, Hollywood CA.

Initial analysis of narrative data obtained from the in-depth interviews provided further evidence that participants used common heuristics and common cognitive strategies in order to make their breast cancer risk assessments. The cognitive mechanism termed “search for a dominance structure” plays an important role in symptom labeling and when participants assessed whether they are more at risk for developing breast cancer than another disease. Heuristic reasoning facilitated creating stereotypical images of high risk individuals. Affective elements and the associative, contextual system of thinking played an important role for information retrieval and information processing that preceded participants’ risk assessments. The data provided evidence that supported suggestions for two systems of reasoning: deliberative and associative reasoning. Analysis of the narrative data was ceased from January 2006 to present, until IRB approval from the University of Michigan was obtained, and a subcontract of the grant from UCSF to the UM is completed. Findings of this analysis will be presented in a manuscript.

KEY RESEARCH ACCOMPLISHMENTS

- Women who participated in the study perceived that their breast cancer risk was significantly lower than the risk of their friends/peers (comparative optimism bias). They also perceived that their breast cancer risk was lower compared to the risk of average women their age (better-than-average bias), and they significantly underestimated their objective breast cancer risk, as this was estimated with the Gail model.
- Using a Numerical scale for measuring perceived breast cancer risk most likely introduces a systematic measurement error, because the scale is likely to be misinterpreted, even by a highly-educated sample of women. Caution should be exercised when the scale is used for educational purposes with community women, similar to those who participated in the study.
- Perceived breast cancer risk was not a significant predictor of breast cancer screening behavior for this sample of women, who have average risk of developing the disease.
- Breast cancer worry was a stronger predictor of breast cancer screening behavior in this sample of women. Participants with lower education and lower income were more likely to report higher levels of breast cancer worry. Black women in the sample were more

likely than Asian women to report higher levels of breast cancer worry, whereas there were no differences among participants of other races/cultures. There was a positive correlation among breast cancer worry, behavioral inhibition, and negative affect, whereas there was a negative correlation between breast cancer worry and positive affect.

- Despite the high educational level of women in the sample, their knowledge of breast cancer risk factors appeared incomplete. Although most participants recognized the role of heredity as a risk factor, some did not understand the impact of paternal family history on one's risk, neither the relation between breast and ovarian cancer, risk factors associated with the Gail model, and that getting older increases one's risk for developing the sporadic form of the disease. Level of education was a significant predictor of knowledge of risk factors.
- Having multiple family members affected by the disease, abnormal breast symptoms, breast cancer worry, and knowledge of risk factors significantly decreased optimistic bias about breast cancer risk. The experience of having a breast biopsy reduced optimistic bias, but only for participants that knew that a breast biopsy could mean increased breast cancer risk. Having an abnormal breast symptom reduced optimistic bias through breast cancer worry. Having friends that had been affected by the disease increased optimistic bias. These findings suggest different pathways with which experiential learning related to breast cancer is incorporated into breast cancer risk assessments.
- Distrust in the health care system was the single most important predictor of predisposition to use health services, which in turn was a significant predictor of breast cancer screening behavior. Interactions among distrust, age, education, and race highlight the importance of distinguishing among racial/cultural, socioeconomic, and cognitive contributors to distrust. Distrust in the health care system took the greatest toll among vulnerable groups of women in the sample, in predisposition to use health services and decision-making regarding breast cancer screening.

OTHER ACCOMPLISHMENTS

- The PI developed educational material that was based on data collected from the present study. Specifically, findings 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 has been a guest lecturer in both courses. Moreover, the PI has been an invited lecturer to Graduate Students' Seminar of the National and Kapodistrian University of Athens, Greece, to the 6th National Conference of Hellenic Nursing Students (Athens, Greece), and to the Hellenic Anticancer Society, Postgraduate Seminars (Athens, Greece).

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. Intercultural Cancer Council, March 2004, Washington DC.

- Poster presentation: “Better-than-average and Comparative-optimism biases in a community sample: Effects on breast cancer screening”. Era of Hope, Department of Defense Conference, June 2005, Philadelphia, PN.
- Poster presentation: “Predictors of breast cancer worry: Sociodemographic and affective characteristics”. Era of Hope, Department of Defense Conference, June 2005, Philadelphia, PN.
- Poster presentation: “Knowledge of sporadic and genetic breast cancer risk factors among women in the community”. Era of Hope, Department of Defense Conference, June 2005, Philadelphia, PN.
- Poster presentation: “How do experiences with affected family members, affected friends, and breast symptoms influence perceived breast cancer risk?” Era of Hope, Department of Defense Conference, June 2005, Philadelphia, PN.
- Podium presentation: ““How do experiences with affected family members, affected friends, and breast symptoms influence perceived breast cancer risk?” 38th Annual Meeting, Western Institute of Nursing, April 2005, San Francisco, CA.
- Podium presentation: “Do women in the community recognize hereditary and sporadic breast cancer risk factors?” 8th National Conference on Cancer Nursing Research, February 2005, Ft Lauderdale, FL.
- Podium presentation: “Πρόληψη καρκίνου μαστού: Αντιλαμβάνονται οι γυναίκες τον κίνδυνο εμφάνισής του;” or “Breast cancer early detection: Do women realize their risk for developing the disease?” 2nd Intersociety Anticancer Convention, March 2005, Athens, Greece.
- Podium presentation: “How do experiences with affected family members, affected friends, and breast symptoms influence perceived breast cancer risk?” 38th Annual Meeting , Western Institute of Nursing, April 2005, San Francisco, CA.
- Poster presentation: “Distrust, utilization of health care services, and decision making regarding breast cancer screening”. 28th Annual Meeting, Society of Medical Decision Making, October 2006, Boston, MA.
- Podium presentation: “Distrust and decision making regarding breast cancer screening”. 9th Cancer Nursing Research Conference, February 2007, Hollywood, CA.
- Manuscript titled: “Do women in the community recognize hereditary and sporadic breast cancer risk factors?” that was published in *Oncology Nursing Forum*, 2005, 32(3), 617 – 623.
- Manuscript titled: “Better-than-average and comparative optimism biases: Effects on breast cancer screening” that has been submitted to *Preventive Medicine* and is currently under revision.
- Manuscript titled: “Experiences with breast cancer, heuristics, and optimistic bias” that has been submitted to *Journal of Medical Decision Making* and is currently under revision.
- Manuscript titled: “Distrust, habits of utilization of health services, and breast cancer screening” that has been submitted to *Social Science and Medicine* and is currently under revision.

- Manuscript titled: “Affective characteristics as predictors of breast cancer screening” that is in preparation.
- The PI Maria Katapodi was awarded a Doctor of Philosophy in Nursing, from the University of California San Francisco, School of Nursing, in June 2004. Her dissertation was completed thanks to the data collected from the study.
- The PI Maria Katapodi accepted an appointment as a Tenure-Tract Assistant Professor at the University of Michigan, School of Nursing, in January 2006. The study has greatly contributed to the advancement of the career of the PI.

CONCLUSION

The project is on-time with the approved statement of work. Our findings suggest that women in the community have an optimistic bias and underestimate their breast cancer risk. Our findings also address important issues regarding systematic measurement errors that have been raised in a previously published manuscript. Although women in the sample that had personal experiences with the disease, such as affected family members, affected friends, or had experienced abnormal breast symptoms were less likely to underestimate their risk, our findings suggest areas that need further research and intervention. Women in the community depend on their primary care providers for personalized risk assessment and education and our findings suggested that there is lack of knowledge regarding specific breast cancer risk factors. Breast cancer worry was a stronger predictor of breast cancer screening than perceived risk, in this sample of women. Black women in the sample and participants with lower education and lower income were more likely to report higher levels of breast cancer worry. Our findings indicate that breast cancer worry and distrust to the health care system can potentially take the greatest toll among disadvantaged groups of women, albeit socioeconomically disadvantaged or participants from an ethnic/cultural minority. Initial analysis of interview data provided insight into the cognitive and affective processes that accompany information-processing and decision-making about perceived breast cancer risk and breast cancer screening. 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 this information is being presented, so that it is accessible when women estimate their breast cancer risk. Moreover, educational interventions should take into account salient cues that enhance trust in the health care system and influence utilization of health care services. The PI has requested a no-cost extension and a subcontract of the grant from UCSF where it was originally awarded to the University of Michigan, where the PI is currently an Assistant Professor. Analysis will focus on identifying evidence of two systems of reasoning, analytical and associative, in participants’ narratives about their breast cancer risk assessments and their decision making about breast cancer screening.

REFERENCES

1. Katapodi, MC, and Aouizerat BA. (2005). Do women in the community recognize familial and sporadic breast cancer risk factors? *Oncology Nursing Forum*, 32(3), 617 – 623.

DAMD17-03-1-0356 KATAPODI, MARIA C. RN, MSc, Ph.D.
APPENDIX

Bibliography of Meeting Abstracts

1. BETTER-THAN-AVERAGE AND COMPARATIVE-OPTIMISM BIASES IN A COMMUNITY SAMPLE. EFFECTS ON BREAST CANCER SCREENING
2. HOW DO EXPERIENCES WITH AFFECTED FAMILY MEMBERS, AFFECTED FRIENDS, AND BREAST SYMPTOMS INFLUENCE PERCEIVED BREAST CANCER RISK?
3. KNOWLEDGE OF SPORADIC AND GENETIC BREAST CANCER RISK FACTORS AMONG WOMEN IN THE COMMUNITY
4. AFFECTIVE CHARACTERISTICS AS PREDICTORS OF BREAST CANCER SCREENING
5. ΠΡΟΛΗΨΗ ΚΑΡΚΙΝΟΥ ΜΑΣΤΟΥ : ΑΝΤΙΑΑΜΒΑΝΟΝΤΑΙ ΟΙ ΓΥΝΑΙΚΕΣ ΤΟΝ ΚΙΝΔΥΝΟ ΕΜΦΑΝΙΣΗΣ ΤΟΥ; (Breast cancer early detection: Do women recognize the risk of developing breast cancer?)
6. DISTRUST AND DECISION MAKING REGARDING BREAST CANCER SCREENING

BETTER-THAN-AVERAGE AND COMPARATIVE-OPTIMISM BIASES IN A COMMUNITY SAMPLE. EFFECTS ON BREAST CANCER SCREENING

Abstract

Background: Although perceived risk affects health-protective behaviors, it is not clear whether women believe their breast cancer risk to be high or low, and whether absolute or comparative risk judgments have greater impact on screening behavior. **Purpose:** 1) describe absolute and comparative breast cancer risk judgments, 2) examine consistency of responses across different risk measures, 3) compare subjective to objective risk estimates, and 4) examine the influence of risk judgments on screening behavior. **Methods:** The survey used two absolute and three comparative probability scales and the Gail model to measure perceived risk and objective risk estimates in a community sample of 184 women (age 47 ± 12). **Results:** The Verbal and Comparative scales indicated that participants believed their breast cancer risk to be lower than average ($p < 0.01$) and the risk for friends/peers higher than their own ($p < 0.01$). Most responses (63%) on the Numerical scale clustered around a 12% risk estimate, whereas there was no optimistic bias ($p = \text{NS}$). Responses were consistent between the Verbal and the Comparative scales. While 60% had received adequate screening, women underestimated their actual risk ($p < 0.01$). However, neither absolute nor comparative risk estimates influenced screening behavior. **Conclusions:** Four different measures indicated that women recruited from community settings underestimate their breast cancer risk. Comparative and Verbal scales better reflect perceived risk than Numerical scales. However, risk judgments did not influence screening behavior, which has implications for risk communication.

Word Count: 228

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

Abstract

Background: Although having a family history of breast cancer, worry, and breast symptoms have been reported to increase perceived breast cancer risk, it is not clear why some women underestimate their risk in the presence of objective risk factors. **Purpose:** To examine whether experiences with affected family members, affected friends, and breast symptoms influence perceived breast cancer risk and whether worry and knowledge of breast cancer risk factors act as mediators or moderators between these experiences and breast cancer risk assessments.

Method: We recruited 184 women (age 47 ± 12) from community settings and inquired about their family history and number of affected friends. Experiences with breast symptoms were assessed with number of breast biopsies and current breast symptoms. We assessed worry with a 4-scale instrument (Cronbach's alpha 0.85), knowledge of risk factors with a 13-item index (Cronbach's alpha 0.80), and perceived risk with a Principal Component Analysis of three probability measures (Cronbach's alpha 0.70). **Results:** Hierarchical regression analyses revealed that having multiple affected family members and abnormal breast symptoms predicted a heightened perception of breast cancer risk and accounted for 6% and 5% respectively of the variance in perceived risk ($p < 0.05$). Worry accounted for 7%, and the interaction of worry with knowledge of risk factors accounted for an additional 5% of the variance in perceived risk ($p < 0.05$). In contrast, having affected friends decreased perceived breast cancer risk. Worry mediated the relation between having current breast symptoms and perceived breast cancer risk. Knowledge of risk factors was a moderator between perceived risk and number of breast biopsies. Findings suggest possible pathways with which past experiences with breast cancer are incorporated into risk assessments. **Conclusions:** We discuss cognitive mechanisms with which experiences, worry, and knowledge of risk factors predict a lower perception of breast cancer risk. Interventions should assess knowledge and implement contextually relevant approaches to enhance information processing.

Word count: 305

KNOWLEDGE OF SPORADIC AND GENETIC BREAST CANCER RISK FACTORS AMONG WOMEN IN THE COMMUNITY

Abstract

Background: In light of the rapid evolution in cancer genetics and in order for health educators to plan future interventions, it is important to track changes in knowledge regarding breast cancer risk factors and the extent that information has been integrated into women's perceptions. **Purpose:** 1) describe knowledge of hereditary/familial and sporadic breast cancer risk factors, and 2) identify factors associated with knowledge of these risk factors. **Methods:** This community-based survey recruited 184 women (age 47±12), who have never been diagnosed with cancer to completed a questionnaire in English. Participants were 43% European-descent, 26% African-descent, 17% Asian-descent, and 14% Hispanic. Most (49%) were college graduates and had an annual family income between \$30,000 and \$40,000. We assessed knowledge of hereditary/familial and sporadic breast cancer risk factors with a 13-item index (Cronbach's alpha 0.80). **Results:** 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 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. Level of education was significantly associated with knowledge of risk factors. **Conclusions:** Although this was a sample of educated women, their knowledge of breast cancer risk factors appeared incomplete. Age and family history are independent predictors of sporadic and hereditary/familial breast cancer risk; yet, women could not distinguish between the two forms of the disease. Primary care providers should provide individualized risk assessment and education regarding breast cancer risk factors.

Word Count: 254

AFFECTIVE CHARACTERISTICS AS PREDICTORS OF BREAST CANCER SCREENING

Abstract

Background: The risk-as-feelings hypothesis suggests that decision-making and risk judgments are influenced by anticipated emotions (a consequence of an outcome) and by anticipatory emotions (experienced during the decision-making process). **Purpose:** 1) to describe breast cancer worry and other affective characteristics, and 2) examine the influence of breast cancer worry and general affect on screening behavior. **Methods:** We recruited 184 women (age 47 ± 12) from diverse racial backgrounds (57% minority) from community settings; most were highly-educated (49% attended college) with an annual income of \$30,000-\$40,000. Besides breast cancer worry, we assessed affect intensity, fun seeking, behavioral inhibition, predisposition to experiential and to rational thinking, social desirability, and positive and negative affect. **Results:** Women with lower education and lower income were more likely to report higher levels of worry ($r = -.24$, $r = -.30$, respectively $p < 0.01$). Black women were more likely than Asian and White women to report higher levels of worry $F_{(3,180)} = 4.82$, $p = .003$ ($p = .008$ and $p = .014$, respectively), whereas there were no differences among women of other races/cultures. Breast cancer worry correlated positively with affect intensity ($r = .15$, $p < .05$), behavioral inhibition ($r = .19$, $p < .05$), and negative affect ($r = .26$, $p < .01$), and negatively with positive affect ($r = -.18$, $p < .01$). Breast cancer worry, affect intensity, and behavioral inhibition correlated positively with screening behaviors, whereas experiential thinking and fun seeking correlated negatively with screening behaviors ($p < 0.05$). **Conclusions:** Breast cancer worry and other affective characteristics appear to act as anticipatory emotions that influence the decision-making process for breast cancer screening.

World count: 244

ΠΡΟΛΗΨΗ ΚΑΡΚΙΝΟΥ ΜΑΣΤΟΥ : ΑΝΤΙΛΑΜΒΑΝΟΝΤΑΙ ΟΙ ΓΥΝΑΙΚΕΣ ΤΟΝ
ΚΙΝΔΥΝΟ ΕΜΦΑΝΙΣΗΣ ΤΟΥ;

Περίληψη Εργασίας (English Abstract Follows)

Ανασκόπηση: Η αντίληψη κινδύνου θεωρείται μία από τις σημαντικές μεταβλητές που επηρεάζουν την συμπεριφορά της υγείας. Όμως δεν υπάρχει ομοφωνία μεταξύ επιστημονικών μελετών για το εάν οι γυναίκες αντιλαμβάνονται τον κίνδυνο εμφάνισης καρκίνου μαστού, και εάν υποτιμούν ή υπερεκτιμούν τις πιθανότητες να εμφανίσουν τη νόσο.

Σκοποί της παρούσας έρευνας είναι: 1) να περιγράψει εάν οι γυναίκες αντιλαμβάνονται τον κίνδυνο εμφάνισης καρκίνου μαστού, 2) να εξετάσει εάν υπάρχει συνοχή μεταξύ των απαντήσεων σε τρεις διαφορετικές κλίμακες που συμπλήρωσαν οι γυναίκες που συμμετείχαν στην έρευνα, 3) να συγκρίνει τις υποκειμενικές εκτιμήσεις κάθε γυναίκας για την πιθανότητα να εμφανίσει καρκίνο μαστού με την αντικειμενική πιθανότητα να εμφανίσει τη νόσο, και 4) να εξετάσει αν η αντίληψη κινδύνου επηρεάζει την συμπεριφορά της υγείας, συγκεκριμένα τη συχνότητα διενέργειας μαστογραφίας, κλινικής εξέτασης μαστού, και αυτοεξέτασης μαστού.

Μέθοδος: Η παρούσα έρευνα είναι επιδημιολογικής φύσεως και διεκπεραιώθηκε στο Σαν Φρανσίσκο των Η.Π.Α. από το Μάρτιο του 2003 έως και το Φεβρουάριο του 2004. Δεδομένα συγκεντρώθηκαν με ερωτηματολόγια από γυναίκες που στρατολογήθηκαν για την έρευνα με διαφημιστικά φυλλάδια από χώρους που επισκέπτονταν στην καθημερινή τους ζωή (οίκους ευγηρίας, εκκλησίες, Βουδιστικούς ναούς, δημόσιες βιβλιοθήκες, εστιατόρια κ.λ.π.), και με προβολή της έρευνας σε τοπικές εφημερίδες που έχουν πολυφυλετικό αναγνωστικό κοινό. Διαφημίσαμε την έρευνα ως «Έρευνα για την Υγεία του Μαστού» και γυναίκες μπορούσαν να συμμετάσχουν εάν ήταν ηλικίας 30 έως 85 ετών, δεν είχαν προσωπικό ιστορικό καμμίας μορφής καρκίνου, συμφωνούσαν να συμπληρώσουν ένα ερωτηματολόγιο στα Αγγλικά, και η νοητική τους κατάσταση τους επέτρεπε να δώσουν γραπτή συγκατάθεση για τη συμμετοχή τους στην έρευνα. Χρησιμοποιήσαμε τη μέθοδο του τριγωνισμού με τρεις διαφορετικές κλίμακες με τις οποίες οι γυναίκες που συμμετείχαν στην έρευνα αξιολόγησαν την πιθανότητα να εμφανίσουν καρκίνο μαστού: Λεκτική, Αριθμητική, και Συγκριτική κλίμακα. Υπολογίσαμε την αντικειμενική πιθανότητα κάθε γυναίκα να εμφανίσει καρκίνο μαστού χρησιμοποιώντας το μοντέλο Gail.

Δείγμα: Ερωτηματολόγια συμπληρώθηκαν από 184 γυναίκες (μέση ηλικία 47 ± 12 , 30 – 85 έτη) που ανήκαν σε διάφορες φυλές (43% Λευκή φυλή, 26% Μαύρη φυλή, 17% Ασιατική φυλή, και 14% Λατίνες). Οι περισσότερες γυναίκες (51%) είχαν τελειώσει πανεπιστήμιο ή άλλο κολλέγιο τριτοβάθμιας εκπαίδευσης και το διάμεσο οικογενειακό τους εισόδημα ήταν μεταξύ \$30,000 και \$40,000. Μερικές γυναίκες (6%) είχαν θετικό οικογενειακό ιστορικό καρκίνου μαστού σε συγγενή πρώτου βαθμού, περίπου 20% είχαν θετικό οικογενειακό ιστορικό σε συγγενή δευτέρου βαθμού, και 6% είχαν θετικό οικογενειακό ιστορικό σε συγγενείς πρώτου και δευτέρου βαθμού.

Αποτελέσματα: Οι περισσότερες γυναίκες πίστευαν ότι ο προσωπικός τους κίνδυνος να εμφανίσουν καρκίνο μαστού είναι μικρότερος από τον μέσο όρο. Συστηματικά, θεωρούσαν ότι έχουν μικρότερο κίνδυνο να εμφανίσουν τη νόσο από άλλες γυναίκες της ηλικίας τους και από γυναίκες που γνωρίζουν στην καθημερινή τους ζωή, όπως οι συνεργάτες και οι φίλες τους ($p < 0.01$). Υπήρχε περισσότερη συνοχή μεταξύ των απαντήσεων τους στη Λεκτική και τη Συγκριτική κλίμακα ($p < 0.01$), ενώ η λιγότερη συνοχή παρατηρήθηκε μεταξύ της Συγκριτικής

και της Αριθμητικής κλίμακας ($p=NS$). Υπολογισμός της αντικειμενικής πιθανότητας εμφάνισης καρκίνου μαστού συνιστά ότι οι γυναίκες που απάρτησαν το δείγμα της έρευνας είχαν συνολικά κίνδυνο εμφάνισης καρκίνου μαστού μεγαλύτερο από το μέσο όρο του πληθυσμού. Σύγκριση μεταξύ αντικειμενικής και υποκειμενικής εκτίμησης πιθανότητας εμφάνισης της νόσου συνιστά ότι οι γυναίκες υποτιμούσαν την πιθανότητα να εμφανίσουν τη νόσο ($p<0.001$). Δεν βρήκαμε σημαντικές συσχετίσεις μεταξύ αντίληψης κινδύνου και συμπεριφοράς της υγείας. Μόνο οι γυναίκες που είχαν την πιο πρόσφατη κλινική εξέταση μαστού για την διερεύνηση ενός κλινικού συμπτώματος, το οποίο αποδείχτηκε ότι δεν ήταν κακοήθεια, ήταν σημαντικά πιά πιθανό να πιστεύουν ότι διατρέχουν μεγαλύτερο κίνδυνο από τον καρκίνο μαστού ($p<0.05$).

Συμπεράσματα: Δείξαμε με τρεις διαφορετικού τρόπους ότι οι γυναίκες υποτιμούν την πιθανότητα εμφάνισης καρκίνου μαστού και διατηρούν μία μη-ρεαλιστική αισιοδοξία ότι δεν κινδυνεύουν από τη νόσο. Η Λεκτική και η Συγκριτική κλίμακες αποδίδουν καλύτερα την υποκειμενική αντίληψη κινδύνου εμφάνισης καρκίνου μαστού από την Αριθμητική κλίμακα και μάλλον θα πρέπει να προτιμούνται σε εκπαιδευτικές παρεμβάσεις που σκοπό έχουν την εκπαίδευση γυναικών σχετικά με παράγοντες κινδύνου, πρόληψη της νόσου, και πιθανότητα εμφάνισής της. Η αντίληψη κινδύνου επηρεάζει την συμπεριφορά της υγείας κάτω από ορισμένες προϋποθέσεις. Συγκεκριμένα, γυναίκες που ζήτησαν άμεση ιατρική βοήθεια για την διερεύνηση κλινικού ευρήματος στο μαστό, το οποίο ανακάλυψαν μόνες τους, ήταν σημαντικά πιο πιθανόν να πιστεύουν ότι υπάρχει πιθανότητα να προσβληθούν από τη νόσο.

Αριθμός Λέξεων: 687

Abstract in English

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: to 1) describe perceived breast cancer risk, 2) examine consistency of responses across different risk measures, 3) compare subjective and objective risk estimates, and 4) examine the influence of perceived risk on screening behavior.

Methods/Sample: This cross-sectional, triangulation study took place in the San Francisco Bay Area between March 2003 and February 2004. We recruited 184 women (mean age 47 ± 12 , range: 30-85) from community settings that women were likely to visit in their daily living and through newspaper advertisements targeting ethnic/cultural minority groups. Women were eligible to participate if they were between the ages 30 and 85, had no prior history of any type of cancer, agreed to complete the questionnaire in English, and were mentally able to provide informed consent. Participants were from diverse racial/cultural backgrounds (43% White, 26% Black, 17% Asian, 14% Hispanic) and most (51%) were college graduates. The median annual income was between \$30,000 and \$40,000. We used three probability scales (Verbal, Comparative, and Numerical) [10] and the Gail model [11, 12] to measure Perceived Risk and Objective Risk respectively. Some women (6%) had a positive family history of breast cancer in a first-degree relative, approximately 20% had a positive family history in a second-degree relative, and 6% had a positive family history in both first- and second-degree relatives.

Results: Participants believed that their breast cancer risk was lower than average and rated the risk for friends/peers higher than their own (Optimistic Biases, $p<0.01$). Responses were most consistent between Verbal and Comparative scales ($p<0.01$). Participants

underestimated their actual risk ($p < 0.001$). Women who had their most recent Clinical Breast Exam (CBE) for the evaluation of a breast problem were more likely to perceive higher risk ($p < 0.05$).

Conclusions: We demonstrated that women in the community hold optimistic biases and underestimate their actual breast cancer risk in three different ways. Comparative and Verbal risk scales better reflect perceived risk than Numerical scales. Perceived risk affects screening behavior under specific conditions, namely it encourages women to seek medical evaluation for a self-discovered breast symptom.

Word count: 364

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

DISTRUST AND DECISION MAKING REGARDING BREAST CANCER SCREENING

We recruited 184 women (age 47 ± 12) from community settings to examine whether distrust of the health care system influences an individual's predisposition to use health services and decision-making regarding breast cancer screening. A large percentage of participant women (49%) were college educated, 22% were low income, 77% had health insurance, and 57% were from minority backgrounds with an over-representation of non-Hispanic Blacks. We measured the cognitive processes that constitute the psychological mechanism of the "asymmetry principle" and contribute to the self-reinforcing and self-perpetuating attributes of distrust (Cronbach alpha=0.71), personal experiences with prejudice in the health care system (Cronbach alpha=0.71), and predisposition to use health services (Cronbach alpha=0.84). Regression analyses revealed that distrust of the health care system was the single most important predictor of predisposition to use health services, which in turn was a significant predictor of breast cancer screening behavior. Observed interactions among distrust, age, education, and race/culture highlight the importance of distinguishing among racial/cultural, socioeconomic, and cognitive contributors to distrust. Findings indicate that distrust takes the greatest toll among vulnerable groups of women in predisposition to use health services and decision-making regarding breast cancer screening.

Word Count: 187

Keywords: Asymmetry principle, distrust in the health care system, predisposition to use health services, breast cancer screening

Bibliography of Manuscripts

1. DO WOMEN IN THE COMMUNITY RECOGNIZE HEREDITARY AND SPORADIC BREAST CANCER RISK FACTORS?
2. BETTER-THAN-AVERAGE AND COMPARATIVE OPTIMISM BIASES IN A COMMUNITY SAMPLE: EFFECTS ON BREAST CANCER SCREENING
3. EXPERIENCES WITH BREAST CANCER, HEURISTICS, AND OPTIMISTIC BIAS
4. DISRUST AND DECISION MAKING REGARDING BREAST CANCER SCREENING

Do Women in the Community Recognize Hereditary and Sporadic Breast Cancer Risk Factors?

Maria C. Katapodi, RN, MSc, PhD, and Bradley E. Aouizerat, PhD

Purpose/Objectives: To describe knowledge of hereditary, familial, and sporadic breast cancer risk factors among women in the community and to identify characteristics associated with this knowledge.

Design: Descriptive, cross-sectional.

Setting: Community settings in the San Francisco Bay Area.

Sample: 184 women who had never been diagnosed with cancer, were 30–85 years old ($\bar{X} = 47 \pm 12$), and agreed to complete a questionnaire in English. Participants were from diverse racial and cultural backgrounds (i.e., 43% European descent, 27% African descent, 16% Asian descent, and 14% Hispanic descent). Many (49%) were college graduates, and 24% had a median annual family income of \$30,000–\$50,000.

Methods: Survey.

Main Research Variables: Knowledge of hereditary, familial, and sporadic breast cancer risk factors and characteristics associated with this knowledge.

Findings: Although most women recognized heredity as a risk factor, some did not understand the impact of paternal family history on risk. Some women did not recognize the relationship between breast and ovarian cancer, risk factors associated with the Gail model, and that aging increases risk. Education level was the most important characteristic associated with knowledge of risk factors.

Conclusions: Although age and family history are independent predictors of sporadic, hereditary, and familial breast cancer risk, women in the community could not distinguish between the three forms of the disease. Although the sample included a large number of educated women, their knowledge of breast cancer risk factors appeared incomplete.

Implications for Nursing: Advanced practice nurses should provide individualized risk assessment and education regarding breast cancer risk factors.

Key Points . . .

- ▶ Women's knowledge of breast cancer risk factors is incomplete, and some risk factors are overlooked.
- ▶ Women in the community do not seem to recognize the difference among hereditary, familial, and sporadic breast cancer.
- ▶ Advanced practice nurses should provide individualized counseling and education regarding hereditary, familial, and sporadic breast cancer.
- ▶ Reevaluation of the accuracy of breast cancer risk factor literature is necessary.

breast cancer diagnosis, family history of breast or ovarian cancer, atypical hyperplasia or lobular carcinoma in situ, and genetic factors, which are more prevalent in women of Ashkenazi Jewish descent. Suggested risk factors include exposure to hormones (e.g., estrogen replacement, early menarche), late parity (i.e., after age 30), dense breast tissue, alcohol use, and postmenopausal obesity (American Cancer Society, 2005).

Some discrepancy exists about whether information aimed at raising awareness about breast cancer risk factors has been integrated successfully into women's perceptions. A lack of balance in the mass media's presentation of certain aspects of breast cancer may affect community perceptions (Gottlieb, 2001). In light of the rapid evolution in cancer genetics, tracking changes in the knowledge regarding breast cancer risk factors is important. As the area of breast cancer research continues to expand and educational materials are developed and made available to the lay public and the professional community, healthcare educators should examine how specific knowledge about breast cancer has been understood and incorporate their findings into future planning.

Given this information, the current study explored community knowledge about breast cancer risk factors. The specific objectives were to describe women's knowledge of hereditary,

Breast cancer is the leading cancer diagnosed among women in the United States, and the American Cancer Society (2005) estimated that more than 210,000 women will be diagnosed with the disease in 2005. The disease currently is divided into three categories based on its underlying etiology. Hereditary breast cancer comprises 5%–10% of cases and is attributed to known genetic mutations (e.g., genetic lesion in breast cancer genes, *BRCA1*, *BRCA2*). Familial breast cancer comprises 20%–25% of cases and is associated with a positive family history, but no known genetic mutation can be identified. Sporadic breast cancer, for which no discernible heritability can be established, comprises approximately 70% of cases (American Cancer Society).

Research has identified factors that put women at risk for developing the disease. The most important overall risk factor for sporadic cases is age, and a majority of cases develops in women 50 years and older. Women of European descent appear to be at higher risk compared with other racial groups. Other identified risk factors include a previous

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familial, and sporadic breast cancer risk factors and to identify characteristics associated with this knowledge.

Literature Review

Efforts to promote breast cancer screening and early detection rely on dissemination of information about the disease, its risk factors, and the importance of screening. Much of this effort is made through press releases, television and radio broadcasts, and articles and advertisements in women's magazines (Curry, Byers, & Hewitt, 2003). Research has shown that, independent of physicians' advice, the media influences women's decisions to have mammograms (Yanovitzky & Blitz, 2000) and that a correlation exists between community newspaper advertisements and mammography use (Urban et al., 1995). However, others have concluded that although messages in the media can heighten awareness and increase behavioral intention, they are unlikely to assert any influence beyond awareness of breast cancer screening (Rimer, 1997). A meta-analysis summarizing the results of interventions that aimed to raise screening rates and knowledge of risk factors concluded that behavioral interventions increase the rate of breast cancer screening by 13%. Cognitive interventions that used generic education strategies had little impact, but those that used theory-based education increased screening rates by 24% (Yabroff & Mandelblatt, 1999).

Low-income and minority women are more likely to benefit significantly from educational programs (Hiatt & Pasick, 1996). For instance, among high-risk women of African descent, those who declined genetic counseling had considerably less knowledge of breast cancer genetics and associated risk factors than those who accepted genetic counseling and genetic testing (Thompson et al., 2002). Several studies provided evidence that differences in knowledge regarding risk factors exist among sociodemographically diverse samples of women (Campbell, 2002; Donovan & Tucker, 2000; Magai, Consedine, Conway, Negut, & Culver, 2004).

Therefore, an increasing need exists for refinement of outreach and intervention efforts and for continuous monitoring of the knowledge levels among community women, especially those from racially or culturally diverse communities. This study examined knowledge of risk factors for hereditary, familial, and sporadic breast cancer among community women from diverse racial or cultural backgrounds.

Theoretical Framework

Weinstein (1988) suggested that a person who knows little about a health problem and its associated risk factors will be open-minded to learning about it. In contrast, a person who is aware of the health problem but does not consider specific situations to be risk factors will not be open-minded. This person's commitment to a particular point of view tends to produce a biased response; he or she will selectively attend to messages that support his or her own position and will show belief perseverance when faced with disconfirming evidence.

These suggestions should be taken into account when conducting interventions that aim to increase knowledge about breast cancer risk factors and change women's perceptions of their risk of developing the disease. These suggestions also help to explain why educational interventions may not be successful

in increasing some women's knowledge regarding breast cancer risk factors and changing preexisting belief systems. Health educators should assess for possible preexisting biases that may affect women's open-mindedness to health messages.

Methods

Recruitment and Procedures

Assessing knowledge of breast cancer risk factors was a secondary aim of a community-based survey that examined perceived breast cancer risk and the relationship between subjective and objective risk estimates. Details about recruitment methods and study procedures have been reported elsewhere (Katapodi, Dodd, Lee, Facione, & Cooper, 2004). This study recruited a convenience sample of women, aged 30–85, who never had been diagnosed with cancer and agreed to complete a questionnaire in English. Women with a prior diagnosis of any type of cancer were excluded from the survey. Recruitment was conducted by posting flyers on bulletin boards in community settings in the San Francisco Bay Area, such as churches, senior centers, coffee shops, public libraries, and workplaces, and through a newspaper advertisement. Women responded by calling a dedicated telephone number and expressing their interest in participating in the study. Participants completed an anonymous questionnaire and were paid \$15. According to the study protocol, which was approved by the University of California, San Francisco, Committee of Human Rights, participants signed an informed consent before completing the questionnaire. Data collection occurred over a period of 13 months, from February 2003–March 2004.

Measurements

Age, race or culture, education, income, employment status, health insurance status, and marital status were assessed with single-item questions from the Behavioral Risk Factor Surveillance System (Centers for Disease Control and Prevention, 2002). Women's family history of breast cancer was assessed by asking them to indicate the number of their first- and second-degree relatives who had been affected by the disease. Women were categorized into one of four groups: no family history, one or more affected second-degree relatives, one affected first-degree relative, and multiple affected family members (i.e., more than one first-degree relative or one first-degree and one second-degree relative) ("Statement of the American Society of Clinical Oncology," 1996). Breast cancer risk factors used by the Gail model (Gail et al., 1989), such as age at first menstrual period, age at first live birth, and the number of breast biopsies, also were assessed.

Participants indicated whether 13 situations might be risk factors for breast cancer. The researchers defined women's knowledge of breast cancer risk factors as the total number of situations recognized that increased the probability of developing the disease. Five of these items described risk factors identified by the Gail model (Royak-Schaler et al., 2002). The remaining eight items were based on current literature and examined knowledge of hereditary and familial risk factors for breast cancer. Women could respond "yes," "no," or "don't know" to each item. According to the theoretical framework of the study, women who responded "don't know" to a particular item would be more open-minded to acknowledging that item as a risk factor, compared to women who responded "no" to the same item. Items that

were answered affirmatively were summed to calculate each woman's score for knowledge of breast cancer risk factors and to create the **Breast Cancer Risk Factor Knowledge Index (BCRFKI)**, with scores ranging from 0–13. These 13 items were highly intercorrelated (Cronbach's $\alpha = 0.80$). Psychometric theory suggests that lists of items, such as a list that examines knowledge of risk factors, should be treated as indexes and have reliability assessed by test-retest (Streiner, 2003). However, the cross-sectional study design did not allow for examination of the test-retest reliability of the BCRFKI.

Statistical Analysis

Data were analyzed using the SPSS® 11.5 (SPSS Inc., Chicago, IL) statistical program. For all statistical analyses, significance was set at the 0.05 level with 95% confidence intervals. Bivariate analysis, such as Pearson correlations (r), and F tests with Bonferoni post-hoc contrasts were used to examine significant demographic differences among women in the sample. Simultaneous multiple regression analysis and binary logistic regression analysis were used to identify factors associated with knowledge of breast cancer risk factors (Cohen & Cohen, 1983).

Results

In total, 184 women were recruited ($\bar{X}$ age = 47 ± 12 years; range = 30–85). Forty-three percent identified themselves as non-Hispanic and of European descent, 27% as non-Hispanic and of African descent, 16% as Asian descent, and 14% as Hispanic descent. Ten participants (6%) were of Ashkenazi Jewish descent. Many women (49%) had attended four or more years of college, but 8% had not completed high school. The median annual income was less than \$40,000, with 21% of the sample reporting an annual income of less than \$10,000 and 12% reporting an annual income of more than \$70,000. More than half of the women (55%) were employed outside of the home, and 77% had health insurance. Only 33% were married or a member of an unmarried couple (see Table 1). Although the sample was comparable to the San Francisco Bay Area population, it included an overrepresentation of non-Hispanic women of African descent and women with a college education (“San Francisco Bay Area Census,” 2000).

Approximately two-thirds (64%) of the participants did not have a family history of breast cancer. Twenty-four women (14%) had one or more affected second-degree relatives, 18 women (10%) had one affected first-degree relative, and 16 women (9%) had multiple affected relatives. Approximately one in five women had her first menstrual period before age 12 (21%) or had undergone one or more breast biopsies (18%), and 18 women (10%) had their first baby after age 30 (see Table 2).

No significant differences were found among women of different races or cultures in regard to mean age and family history of breast cancer. Women of European descent were more likely to have more education than women of African descent and Hispanic women, and women of Asian descent were more likely to be more educated than women of African descent but not Hispanic women ($F[3, 180] = 15.86$, $p < 0.001$). Women of Asian descent were more likely to report higher incomes than women of other racial or cultural

Table 1. Demographic Characteristics of the Sample

Variable	n	%
Age (years)		
$\bar{X} = 47 \pm 12$	—	—
Range = 30–85	—	—
30–39	63	34
40–49	51	28
50–69	54	29
70–85	10	5
Not available	6	3
Race or culture		
Non-Hispanic European descent	69	37
• Ashkenazi Jewish descent	10	6
Non-Hispanic African descent	50	27
Hispanic	25	14
Asian descent	30	16
Education		
Elementary school (grades 1–8)	7	4
Some high school (grades 9–11)	8	4
High school graduate (grade 12, GED)	31	17
Some college or technical school (1–3 years)	48	26
College graduate (more than 4 years)	90	49
Annual family income (\$)		
Less than 10,000	39	21
10,000–30,000	49	27
30,000–50,000	45	24
50,000–70,000	22	12
More than 70,000	21	12
Not available	8	4
Employment status		
Full-time	102	55
Unemployed, employed part-time, retired, student	80	44
Not available	2	1
Health insurance		
Yes	142	77
No	38	21
Not available	4	2
Marital status		
Married	45	25
Divorced	30	16
Widowed	17	9
Separated	7	4
Never married	69	38
Member of an unmarried couple	15	8
Not available	1	1

N = 184

backgrounds ($F[3, 172] = 6.90$, $p < 0.001$). Education was significantly correlated with income for women of African descent only ($r = 0.50$, $p = 0.001$).

Knowledge of Breast Cancer Risk Factors

Table 3 presents participants' responses on the BCRFKI. Approximately 75% recognized that multiple affected family members, a maternal family history of breast cancer, and a previous breast cancer diagnosis are risk factors. Surprisingly, only 45% recognized that a positive paternal family history is a risk factor, whereas 28% responded “don't know” to this item. Similarly, 42% responded affirmatively that having a genetic mutation is a risk factor, whereas 30% responded “don't know.” Approximately 70% recognized that a family member with both breast and ovarian cancer is a risk factor, but only 41% recognized that a family history of ovarian cancer could

Table 2. Breast Cancer Risk Factors Within the Sample

Variable	n	%
Family history of breast cancer		
No family history	117	64
One or more affected second-degree relatives	24	14
One affected first-degree relative	18	10
Multiple affected relatives ^a	16	9
Not available	9	4
Age at first menstrual period		
Younger than 12	38	21
12–13	84	46
14 or older	56	30
Not available	6	3
Age at first live birth		
Nulliparous	87	47
Younger than 20	30	16
20–24	30	16
25–29	19	11
30 or older	18	10
History of breast biopsy		
None	150	82
One	25	14
More than one	9	4

N = 184

^a More than one first-degree relative or one first-degree relative and one or more second-degree relatives

Note. Because of rounding, not all percentages total 100.

be a risk factor. Fewer women, 10% and 34%, respectively, responded “don’t know” to these items.

Aging was recognized as a risk factor by 57% of the women in the study, whereas 23% and 15% responded “no” and “don’t know” respectively. Half of the women (50%) thought that a previous breast biopsy was not a risk factor, and 17% responded “don’t know.” Similarly, 41% recognized that older age at first live birth is a risk factor, and 28% responded “don’t know.” Forty-nine and fifty-seven percent

of women responded that they did not know whether delayed onset of menopause or being of Ashkenazi Jewish descent were breast cancer risk factors, respectively.

Characteristics Associated With Knowledge of Breast Cancer Risk Factors

Most participants correctly identified between six and eight risk factors ($\bar{X} = 6 \pm 3$; range = 0–13). A simultaneous multiple regression was performed. The dependent variable was the total score on the BCRFKI, which represented knowledge of hereditary, familial, and sporadic breast cancer risk factors. The independent variables were age, education, income, race or culture, Ashkenazi Jewish descent, family history of breast cancer, age at first live birth, age at first menstrual period, and number of breast biopsies. Race or culture, family history of breast cancer, and age at first 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 the variance of the BCRFKI to be approximately 22% ($R^2 = 0.224$, $\Delta F = 3.51$, $p < 0.001$). Characteristics significantly associated with a higher score on the BCRFKI were education, one or more affected second-degree relatives, and being of Ashkenazi Jewish descent (see Table 4). A logistic regression analysis was performed using the item “getting older” as a dichotomous (i.e., yes or no) criterion variable and the age of the participants as the predictor variable. Interestingly, as the age of participants increased, the probability of recognizing “getting older” as a risk factor for breast cancer decreased (n = 168, $B = -0.037$, $SE = 0.014$, $Wald \chi^2 = 7.408$, $df = 1$, $p = 0.006$, $Exp(B) = 0.963$, 95% confidence interval for $Exp(B) = 0.938$ – 0.990).

Discussion

This study examined knowledge of sporadic, hereditary, and familial breast cancer risk factors and characteristics associated with that knowledge in a multicultural sample. Participants were recruited from community settings they

Table 3. Knowledge of Breast Cancer Risk Factors

		Yes		No		Don't Know		Not Available	
Type of Breast Cancer	Risk Factor	n	%	n	%	n	%	n	%
Hereditary or familial	Multiple family members with breast cancer	140	76	24	13	10	5	10	5
	Family history of breast cancer from the mother's side of the family	138	75	23	13	10	5	10	5
	Having had breast cancer before	131	71	39	21	4	2	10	5
	Family member with both breast and ovarian cancer	127	69	27	15	18	10	12	7
	Family history of breast cancer from the father's side of the family	82	45	40	22	51	28	11	6
	Having a genetic mutation	78	42	37	20	56	30	13	7
	Family history of ovarian cancer	75	41	35	19	63	34	11	6
	Being of Ashkenazi Jewish descent	14	8	53	29	104	57	13	7
Sporadic	Getting older	104	57	42	23	28	15	10	5
	Late age at first pregnancy	75	41	47	26	52	28	10	5
	Early start of menstruation	52	28	60	33	59	32	13	7
	Having had a breast biopsy	50	27	92	50	31	17	11	6
	Late start of menopause	22	12	58	32	90	49	14	8

N = 184

Table 4. Predictors of Knowledge of Breast Cancer Risk Factors

Variable	B	SEB	β
Age	0.005	0.021	0.018
Education	0.873	0.274	0.279*
Asian descent versus European descent (dummy variable)	-0.953	0.752	-0.108
African descent versus European descent (dummy variable)	-0.520	0.653	-0.072
Hispanic versus European descent (dummy variable)	0.205	0.783	0.022
First menstrual period before age 12 versus age 12-13	-0.310	0.300	-0.081
First menstrual period after age 14 versus age 12-13	-0.207	0.262	-0.062
Age at first live birth	-0.052	0.020	-0.211
Number of breast biopsies	0.563	0.328	0.129
Ashkenazi Jewish descent	-2.119	1.062	-0.151*
Second-degree relatives versus no family history (dummy variable)	0.858	0.630	0.106*
First-degree relatives versus no family history (dummy variable)	1.522	1.086	0.105
Multiple family members versus no family history (dummy variable)	0.155	0.809	0.014

*p < 0.05

were likely to visit within the context of their everyday lives, such as coffee shops, senior centers, and workplaces.

Despite the general awareness of the role of family history in breast cancer susceptibility, 20% of participants lacked important understanding regarding the impact of family history on the risk of developing the disease. Consistent with other studies (Grande, Hyland, Walter, & Kinmonth, 2002; Mouchawar, Byers, Cutter, Dignan, & Michael, 1999), most participants (76%) recognized that having multiple affected family members is an important risk factor. However, women were more likely to recognize maternal family history as a risk factor (75%), whereas significantly fewer (45%) recognized paternal family history as an independent risk factor. A community-based study (Vuckovic, Harris, Valanis, & Stewart, 2003) and a study that recruited patients with early-onset breast cancer (Miesfeldt, Cohn, Ropka, & Jones, 2001) suggested that many women are unsure of how and from whom breast cancer risk can be inherited. Those women are significantly more likely to underestimate their breast cancer risk if affected family members are on the father's side.

Women at risk for hereditary breast cancer also are at risk for ovarian cancer and vice versa. Although most women (69%) recognized that a family history of breast and ovarian cancer is a risk factor, only 41% recognized that a family history of ovarian cancer might increase one's risk for hereditary breast cancer. Some participants possibly did not recognize that the etiology of hereditary breast cancer could be related closely to that of ovarian cancer. Andersen, Bowen, Yasui, and McTiernan (2003) reported that 75% of women at high risk for hereditary breast and ovarian cancer did not know that they were at increased risk for ovarian cancer and did not use existing screening methods for early detection of the disease. Women in this risk group are more likely to underestimate their breast cancer risk if they are not aware of the connection between breast and ovarian cancer.

A significant number of women (38%) did not recognize aging as a risk factor for breast cancer. The older the participant, the less likely she was to recognize age as a risk factor for breast cancer. This finding was surprising because age is a well-established risk factor for sporadic breast cancer. Apparently, however, women do not always understand and integrate this information. Strecker, Williams, Bondy, Johnston, and Northrup (2002) reported that 35% of healthcare providers and

45% of laywomen did not recognize age as a breast cancer risk factor after receiving extensive education on the subject. Other studies have suggested that some women lack basic knowledge about breast cancer risk factors (Absetz, Aro, Rehnberg, & Sutton, 2000) and create mental images of a stereotypical person who is likely to be affected by the disease (Katapodi, Facione, Humphreys, & Dodd, 2005). These findings suggest that when women lack the specific knowledge that getting older increases the risk for developing breast cancer, they are more likely to believe that the disease affects mostly younger women.

Age and family history are independent predictors of sporadic, hereditary, and familial forms of breast cancer. Interactions between these two risk factors are complicated and difficult to interpret in clinical practice. Strecker et al. (2002) reported that the differences between sporadic and inherited predisposition to breast cancer were the most difficult to understand both by laywomen and healthcare providers. Women carrying genetic mutations associated with hereditary breast cancer have an increased risk of early onset of the disease that is reduced to an average level as they age. Similarly, the diagnosis of a second-degree relative with breast cancer does not significantly increase a woman's risk for the disease unless it occurs at an early onset, which might signify hereditary or familial breast cancer. These cases differ strikingly from sporadic breast cancer, which poses a greater risk as women age.

Situations that increase women's risk for sporadic breast cancer, such as early age at menarche, late age at menopause, late age at first live birth, and having one or more breast biopsies, were less acknowledged as breast cancer risk factors by participants in the study. These risk factors are related to breast cancer etiology, possibly because women's breast tissue before pregnancy is more sensitive to carcinogens than breast tissue that has gone through its complete hormonal development (American Cancer Society, 2005). An average of only one in three women responded affirmatively that these items were risk factors, whereas approximately 65% were unsure of their implications. In contrast, studies have reported that women most often estimate their breast cancer risk based on factors whose role in breast cancer etiology remain to be established, such as smoking (Aiken, Fenaughty, West, Johnson, & Luckett, 1995; Silverman et al., 2001). These findings suggest a gap in knowledge of breast cancer risk factors.

Education levels were significantly associated with knowledge of breast cancer risk factors. Despite the fact that 49% of the study participants had completed four or more years of college and an additional 26% had completed some college or a technical school, their knowledge of breast cancer risk factors was incomplete. Women also displayed an incomplete knowledge of risk factors regardless of their race or culture. Studies suggested that racial or cultural differences affect decision making regarding genetic testing among women of African descent (Hughes, Fasaye, LaSalle, & Finch, 2003). The data from this study showed that education was the strongest recorded predictor of a high score on the BCRFKI and suggested the possibility that education and race or culture should be examined together as predictors of knowledge of breast cancer risk factors. The finding that only 42% of women recognized a genetic mutation as a breast cancer risk factor most likely reflects that women do not understand the meaning of "genetic mutation." Roche et al. (1998) suggested that women often do not understand the meaning of terms and phrases commonly used by healthcare professionals.

Having one or more affected second-degree relatives was significantly associated with a high score on the BCRFKI, whereas the associations between BCRFKI scores and having one affected first-degree relative or multiple affected family members were not significant. Several explanations are possible for these findings. Family history with one affected first-degree relative or multiple affected relatives may not have reached statistical significance because of the small number of women in the sample with those conditions. Alternatively, some women underestimate the importance of having one affected first-degree relative as a risk factor (Absetz et al., 2000; Aiken et al., 1995), whereas women with multiple affected family members concentrate on the importance of genetic risk factors. Of concern in such scenarios is the underestimation of the importance of other factors that increase the probability of sporadic breast cancer. Future studies in which larger samples are stratified according to family history of breast cancer may address this issue.

Limitations

The limitations of this study should be considered to properly temper any conclusions drawn. The results were based on a convenience sample of self-selected women, and the assessment of risk factors was based on self-report. Although knowledge of important breast cancer risk factors was examined, the list was not exhaustive. Breast cancer risk factors that were not examined include alcohol consumption, obesity, Caucasian ethnicity, and postmenopausal use of hormone therapy. In addition, whether women knew that early onset is indicative of hereditary disease or about the possibility of an association between breast cancer and other forms of cancer were not examined. However, the latter seem unlikely to be of further use because of the strong likelihood that knowledge of risk related to technical genetic terminology is lacking in the general population. The cross-sectional nature of the study did not allow examination of the test-retest reliability of the BCRFKI, which may have implications for the validity of the measure. Despite these limitations, the strengths of the study include its recruitment of women from diverse socioeconomic and racial and cultural backgrounds and from community settings, which ensured that participation was not limited only to women who have greater access to healthcare services and therefore to greater access to educational material related to breast cancer risk factors.

Implications for Nursing

Nursing has offered compelling examples of educational and counseling interventions targeting high risk (Snyder et al., 2003) and medically underserved women (Lane, Martin, Uhler, & Workman, 2003) recruited from the community. Until similar programs become widely available and accessible, women in the community must depend on primary care providers for risk assessment, counseling, and education about breast cancer risk factors. Advanced practice nurses (APNs) can incorporate the calculation of a woman's risk for breast cancer and the probability that she is a carrier of a genetic mutation into routine care by using an appropriate risk assessment model (Rubinstein, O'Neill, Peters, Rittmeyer, & Stadler, 2002). Obtaining a family history and calculating an individual's risk for the disease are time consuming and not commonly practiced; however, an increasing need does exist for redirecting efforts toward personalized breast cancer risk analysis and individually tailored breast cancer screening recommendations (Strecker et al., 2002). Unless APNs obtain an adequate family history and information about breast cancer risk factors, they may not recognize clients at increased risk for the disease or for hereditary cancer syndromes. APNs can apply recent advances in cancer genetics to improve the care and education of their clients by informing women about the mechanisms of sporadic, hereditary, and familial cancer in terms of clients' level of risk. A helpful first step in defining family history might be clarifying which types of cancer, the age at onset of cancer, and the degree of relatedness of family members of both genders with the disease (McKelvey & Evans, 2003).

Finding the most effective ways to educate individuals regarding their risk for sporadic, hereditary, and familial disease is not an easy task. As suggested by the theoretical framework of the study, educational interventions should assess preexisting knowledge and personal experiences that predispose individuals to biased information processing. Women who respond "no" to a particular item may be less open-minded to accepting that situation as a risk factor compared to women who respond "don't know." For instance, more women in this study believed that having breast cancer once before and having one or more breast biopsies were not breast cancer risk factors, compared to women who responded "don't know" to these items. More effort and a different approach may be needed to persuade the first group of women that these two situations increase a woman's risk for the disease. Future studies should investigate the best way to examine open-mindedness, biased information processing, and readiness to learn. In addition, future studies should examine other factors that influence the outcome of educational interventions, such as cultural factors that influence genetic counselors' attitudes toward preventive measures (Bouchard et al., 2004) and the optimum amount of information that should be given to clients seeking genetic consultation (Lobb et al., 2004). As the field of cancer risk assessment continues to grow, educational materials should evolve to meet the knowledge needs of healthcare providers and women in the community.

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BETTER-THAN-AVERAGE AND COMPARATIVE-OPTIMISM BIASES IN A
COMMUNITY SAMPLE: EFFECTS ON BREAST CANCER SCREENING

By

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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) compare subjective and objective risk estimates, and 4) examine the relationship between perceived risk and screening behavior. **Methods:** The survey used three probability scales (Verbal, Comparative, and Numerical) and the Gail model to measure perceived risk and objective risk respectively, in a sample of 184 women (mean age 47 ± 12) 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 Biases, $p < 0.01$). Responses were most consistent between Verbal and Comparative scales. Participants underestimated their actual risk ($p < 0.01$). Women who had their most recent Clinical Breast Exam (CBE) for the evaluation of a breast problem were more likely to perceive higher risk. **Conclusions:** We demonstrated that women in the community hold optimistic biases and underestimate their actual breast cancer risk in three different ways. Comparative and Verbal risk scales better reflect perceived risk than Numerical scales. Perceived risk affects screening behavior under specific conditions.

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 US [1]. Epidemiology, molecular biology, and genetics have improved our understanding of breast cancer etiology. Individualized counseling and public health educational interventions can provide factual knowledge about breast cancer risk factors and educate women about their own probability of developing the disease. By using appropriate risk assessment tools [2], such as the Gail model [3], health care providers can estimate the probability of an individual woman developing breast cancer. Presumably, a woman who is aware of her actual risk will initiate and maintain an appropriate level of health-protective behaviors [4]. However, some women do not take into account factual information when estimating their own breast cancer risk [5], whereas it is unclear whether they overestimate or underestimate their risk [6].

There are indications that people's perceptions of vulnerability to disease are determined by social comparisons [7] that might influence self-assessment beyond absolute probability information [8, 9]. Studies have been using two different approaches for assessing perceived breast cancer risk: assessing absolute risk judgments (how likely is breast cancer to happen to me?), and assessing comparative risk judgments (how do my chances of getting breast cancer compare to those of my peers or other women my age?). Absolute risk judgments depend on the individual's perceived standing on relevant risk factors, while comparative risk judgments are made against a comparison standard. Although absolute and comparative risk judgments are closely correlated, there is no consensus whether they reflect a single construct of susceptibility and could be used interchangeably [10] or not [11, 12].

These observations have implications for risk communication and for educational interventions that aim to increase accuracy of women's perceived breast cancer risk and

screening behavior. Individualized counseling on one's risk factors addresses absolute risk judgments, while focusing on the risk factors of affected women or of influential others addresses comparative risk judgments. If absolute and comparative risk judgments cannot be used interchangeably we should examine whether screening behavior relates more to one type of risk judgment versus the other. The aims of this study were to 1) describe absolute and comparative breast cancer risk judgments, 2) examine whether participants' responses were consistent across different risk measures, 3) compare subjective risk estimates with objective risk estimates obtained from the Gail model, and 4) examine the relationship between risk judgments on breast cancer screening behaviors.

Theoretical Framework and Background

Norm theory proposes that reasoning flows both forward and backward [13]. Forward reasoning flows from anticipation and hypothesis to confirmation or revision, while backward reasoning flows from the experience of what a stimulus reminds us of or what it makes us think about. Risk judgments either express anticipation and project into the future (absolute judgment) or are constructed through comparisons of the stimulus probe with counterfactual alternatives (comparative judgment). Comparative judgments are made against a standard retrieved from stored knowledge or against an exemplar that is recruited for the judgment [13].

Perceived risk to a health problem refers to a risk judgment about the probability that the health problem will be experienced. The construct is included in numerous models applied to health behavior [14-16]. The Precaution Adoption Process [17] suggests that individuals become aware of a health problem when they hear general information from common communication channels. Messages from health-related sources are more likely to make people acknowledge the

severity of the problem and the likelihood of encountering it. However, these messages do not establish clearly who is likely to be affected; therefore, most individuals hold an optimistic bias and perceive that they are less likely than others to be affected [17]. Acknowledging personal susceptibility occurs through individualized information about personal risk factors, a close experience with the health problem, and through information about the risk status and protective behaviors of one's peers [7]. Individualized information on one's risk factors would be expected to influence absolute risk judgments, whereas information on the risk status of one's peers would be expected to influence comparative risk judgments. Individuals who perceive themselves to be at high risk for a disease are more likely to take appropriate actions in order to reduce their risk, which results in a positive correlation between perceived risk and adoption of precautions [18].

Research on comparison judgments has widely replicated phenomena of optimistic bias; participants perceived that they were less likely than their peers to encounter life's negative events. Optimistic bias can be demonstrated either with a *direct* or an *indirect* method. With the *direct method*, participants are asked directly to compare themselves to others with similar characteristics or to an average person. If unbiased, the distribution of responses should center on the average response, whereas a substantial skew in the distribution indicates a systematic bias. Studies that used a direct method of assessing comparison judgments demonstrated that people systematically believed that they were better than others in various ways [19-21], thus demonstrating a *better-than-average effect*. With the *indirect method* participants are asked, first to make an absolute risk judgment about themselves, and then to make an absolute risk judgment of others. The difference between the two risk judgments is an indirect measure of an individual's perceived risk. Studies that used an indirect method for assessing comparison

judgments reported that people systematically give a better absolute judgment to themselves than to others, thus demonstrating a *comparative-optimism effect* [7, 8, 12, 22-25].

Risk judgments and the phenomenon of optimistic bias should be studied further with perceived breast cancer risk. Research findings are conflicting as to whether women overestimate or underestimate their breast cancer risk [6]. Studies that reported an overestimation of risk recruited participants through an affected relative, a family clinic, or a mammography registry, which suggests a possible selection bias [6]. Therefore, community-based samples might be more appropriate to examine perceived breast cancer risk, in order to avoid the Hawthorne effect [26] generated when participants are recruited from health care settings, and to minimize selection bias when they are recruited through an affected family member.

Furthermore, measures of perceived breast cancer risk can generate measurement errors. Verbal single-item scales have limited discriminatory capacity [27]. Moreover, numerical scales that use as anchors 0% to 100% can 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 one in two chances of getting the disease [6]. Numerical probability assessments, although numerically precise, may have an ambiguous intuitive interpretation [28], because the interpretation depends on the standard the assessment is compared against [9]. Studies that compared women's absolute numerical judgment against an objective risk estimate reported that women overestimated their breast cancer risk, whereas studies that compared women's absolute numerical judgment to the absolute judgment women gave to their peers reported an optimistic bias [6].

Therefore, we should examine women's perceived breast cancer risk, and how women view their risk in relation to the risk of other women they know, and in relation to the average breast cancer risk that is portrayed in health messages. The present study examined absolute and comparative breast cancer risk judgments by employing direct and indirect measures of perceived risk and by recruiting a community sample. We examined whether women recruited from community settings hold a better-than-average and a comparative-optimism bias compared to their friends/peers and compared to objective estimates of their risk.

We also examined whether optimistic bias inhibited the adoption of self-protective behaviors. Perceived risk has a small, but significant, effect on mammography screening behavior [6, 29], whereas its effect on Breast Self Examination (BSE) is ambiguous [6]. In the present study we hypothesized that there will be a positive correlation between perceived risk and screening behaviors, while women who hold an optimistic bias will be less likely to follow breast cancer screening guidelines.

Recruitment and Procedures

This cross-sectional survey was advertised as "Women's Breast Health Study" and recruited a convenience sample from community settings throughout the San Francisco Bay Area. Women were eligible to participate if they were between the ages of 30 and 85, had never been diagnosed with any type of cancer, and were willing to complete a questionnaire in English. The minimum 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 that a woman's breast cancer risk can be estimated with the Gail model [3].

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 newspaper advertisements and through flyers posted on bulletin boards in community settings. To avoid a systematic sample bias and recruiting only those women who had access to health services, recruitment was done at places that women were likely to visit in their daily living, such as senior centers, libraries, restaurants, coffee shops, homeless shelters, cultural centers, churches, temples, and workplaces. Advertisements were placed at local newspapers targeting ethnic minority groups. Potential participants responded by calling a dedicated telephone number and expressing their interest in the study. Two hundred and three women called and expressed their interest in participating in the study. However, 19 women were excluded – three had a previous cancer diagnosis, 11 were younger than 30 years of age, and five decided that they were not interested in the study – leaving a final sample of N=184 women. Participants were paid \$15. The University of California San Francisco Committee on Human Rights and the Institutional Review Board of the Funding Agency approved the study protocol. Data collection occurred over a period of 12 months between March 2003 and March 2004.

Measurements

We employed a within-method triangulation design [30], which involved measuring perceived risk with three different sets of items used in previous studies [23, 25, 31]. Items were introduced in different sections of the questionnaire in the following order: Verbal, Comparative, and Numerical.

The *Comparative Scale* asked women to compare their breast cancer risk to the risk of average, same-age women (Self vs. Average woman). Participants used a five-point scale ranging from 1 (*A Lot Lower*) to 5 (*A Lot Higher*).

In the *Verbal Scale* participants were asked to make an absolute judgment of their own risk and an absolute judgment of the risk of their friends/peers by circling a number between 0 and 10. 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). Approximately 10% of participants marked a point between two numbers, or marked a verbal anchor instead of circling a number. For those cases we took a conservative approach and we used the corresponding number closest to the center of the scale.

By subtracting the absolute risk judgment women gave to their friends/peers on the Verbal scale from the absolute judgment women gave to themselves, we created a measure of *Verbal Risk Difference* (Self – Other), which is an indirect measure of a comparative risk judgment on the Verbal scale. In cases that the Verbal Risk Difference was a negative number, women had a comparative-optimism bias regarding their breast cancer risk. In cases that the Verbal Risk Difference was a positive number women were pessimistic about their risk.

In the *Numerical Scale* we wanted to anchor women around a realistic percentage of developing breast cancer, so we provided 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). We hypothesized that responses would cluster around 12% after providing participants with the average breast cancer risk incidence. Participants made an absolute judgment of their own risk and the risk of their friends/peers. In

approximately 10% of the cases that marked a point between two anchors, we used the most proximal anchor.

We also created the *Numerical Risk Difference* by subtracting participants' absolute risk judgment for their friends/peers from the absolute risk judgment for themselves (Self – Other), which is an indirect measure of a comparative risk judgment on the Numerical scale. In cases that the Numerical Risk Difference was a negative number, women had a comparative-optimism bias regarding their breast cancer risk, whereas the opposite was true in cases that the Numerical Risk Difference was a positive number.

Objective Risk: First, 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 [3]. For this calculation we used the online version of the Breast Cancer Risk Assessment Tool (BCRAT) [32], which provides an objective estimate of a woman's risk to develop breast cancer. Second, we recorded the Lifetime Population Risk that was calculated by the BCRAT for every participant. This is the Gail score of a woman in the population with average risk factors, who has the same age and the same race as the participant for whom we performed the original risk calculation. Third, for every participant we calculated a *Comparative Gail* score by subtracting her Lifetime Population Risk score from her Gail Risk score (Self – Other). The latter score represents a comparative objective risk estimate and assessed participants' risk status compared to the average female population. In cases that the Comparative Gail score was a positive number, the participant had a higher than average risk of developing breast cancer, whereas the opposite was true when the Comparative Gail score was a negative number. Participants also indicated the number of their affected Second-Degree Relatives (SDRs).

Breast Cancer Screening Behavior: We assessed breast cancer screening behavior with a series of questions used in the 2001 survey of the Behavioral Risk Factors Surveillance System [33]. We asked participants how often they have a screening mammogram, how long it has been since their last mammogram, and the reason for their most recent mammogram. We also asked how often they have a Clinical Breast Exam (CBE), how long it had been since their last CBE, and the reason for their most recent CBE. Women who never had a Mammogram or a CBE 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 Mammogram or CBE for the evaluation of an abnormal breast symptom were given a score of '2'. Finally, we asked participants how often they perform BSE.

Statistical Analysis

Data were analyzed using the statistical program SPSS® (version 11.5). Descriptive statistics were used for the demographic characteristics of the sample, Gail scores, and measures of perceived risk. Measures of perceived risk, risk differences, and objective risk estimates were treated as continuous variables. Bivariate analyses, such as Analysis of Variance (F test) with Bonferroni post hoc contrasts, paired t-tests, and Pearson's correlations (r), were used to determine associations between perceived risk and screening behavior, and to compare subjective and objective risk estimates. Skewness of distributions was examined by comparing the Skewness Statistic divided by its Standard Error to 1.96 (significant when >1.96) [34]. Consistency of responses among different risk measures was examined with a within-subjects Analysis of Variance. To examine consistency of responses and to compare distribution of responses on subjective and objective risk estimates we transformed risk measures and Gail scores into Standard Deviation units [35]. This transformation also allowed us to use parametric

statistics for skewed distributions. Significance was set at the 0.05 level with 95% confidence intervals. Degrees of freedom indicate missing data. The American Psychological Association suggests we calculate effect sizes (g) for research findings {APA, 2001 #488}. We used the computer program D-STAT® [37] to calculate effect sizes from statistical relationships.

Results

We recruited 184 women (mean age = 47 ± 12 years, Range: 30-85). 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 but 8% had not completed high school. Most (77%) had health insurance. The median annual income was between \$30,000 and \$40,000, with 22% of the sample reporting an annual income of $< \$10,000$ and 12% reporting an annual income of $> \$70,000$. One in three women (33%) were currently married or a member of an unmarried couple. Eighteen women (10%) had a family history of breast cancer in a FDR, and sixteen women (9%) had multiple family members affected by the disease. Approximately one in eight women (13%) had one or more affected SDRs (Table 1). (Insert Table 1).

1) Absolute and comparative risk judgments:

. Individual correlations among the different risk measures were significant and ranged between 0.31 and 0.62 ($p < 0.01$) (Table 2). (Insert Table 2).

Comparative Scale: Women believed their risk to be somewhat lower than the risk of an average woman (mean: 2.63 ± 0.88 , median=3.00). Only 10% rated their risk as “Somewhat Higher” or “A Lot Higher”, while 33% rated their risk as “A Lot Lower” or “Somewhat Lower”

($g=-0.58$, 95%CI -0.79 - -0.37). Although most women (57%) rated their risk for breast cancer as “About the Same” as the risk of the average woman, the distribution of responses on the Comparative risk scale was skewed to the right (Skewness Statistic =0.53, $S.E._{Skewness}=0.18$, $Z_{Skewness}=2.94>1.96$). This finding directly indicates a better-than-average bias.

Verbal Scale: When women made an absolute judgment of their breast cancer risk on the Verbal scale, overall they reported that they would “Probably Not” get the disease (mean: 3.58 ± 1.70 , range: 0 to 8.00, median=3.00). When they made an absolute judgment of the risk of their friends/peers, women reported a risk that was higher than their own (mean: 4.36 ± 1.55 , range: 1.00 to 9.00, median=5.00) (paired- $t_{(181)}=5.64$, $p<0.01$, $g=+0.42$, 95%CI +0.21 - +0.63). This indicates that women in the sample perceived that they were less likely than their friends/peers to get the disease and is an indirect measure of a comparative-optimism bias. Distribution of absolute risk judgments on the Verbal scale was not significantly skewed (Skewness Statistic =0.19, $S.E._{Skewness}=0.18$, $Z_{Skewness}=1.08<1.96$).

Numerical Scale: Absolute risk judgments on the Numerical scale showed that women overestimated their actual breast cancer risk. The mean risk rating was $30.27(\pm22.60)$, range: 0 to 100, median=25.00). Women also overestimated the risk of their friends/peers (mean: 32.41 ± 20.81 , range: 0 to 100, median= 25.00). The difference between the two mean ratings was not statistically significant (paired- $t_{(177)}=1.75$, $p=NS$). This indicates that although women overestimated their breast cancer risk on the Numerical scale by making an absolute risk judgment that was much higher than the average 12% estimate, they made similar absolute risk judgments for their friends/peers and there was no comparative-optimism effect. Approximately two thirds of responses (63%) fell within one anchor above or below 12%, whereas approximately one third ($N=65$) responded that their risk was 50% or higher. The distribution of

responses on the Numerical scale was also skewed to the right (Skewness Statistic =0.68, $S.E._{Skewness}=0.18$, $Z_{Skewness}=3.78>1.96$).

2) Consistency of responses among the risk measures:

We found a better-than-average bias with the Comparative scale and a comparative-optimism bias with the Verbal scale (Verbal Risk Difference), but not with the Numerical scale. Consequently, we wanted to examine whether participants were consistent in their responses. In other words, we wanted to examine consistency among direct and indirect measures of perceived risk. We transformed responses on the Comparative scale, the Verbal Risk Difference, and the Numerical Risk Difference into SD units [35]. Within-subjects Analysis of Variance revealed significant inconsistency among the three risk measures ($F_{(2,332)}=5.61$, $p=.004$, $g=+0.31$, 95%CI +0.10 - +0.53). Bonferroni post hoc comparisons revealed greatest inconsistency between the Comparative scale and the Numerical Risk Difference ($F_{(1,166)}=7.88$, $p=0.01$, $g=+0.22$, 95%CI +0.01 - +0.43) and between the Numerical Risk Difference and the Verbal Risk Difference ($F_{(1,166)}=5.97$, $p=0.02$, $g=+0.19$, 95%CI -0.01 - +0.41). Responses between the Verbal Risk Difference and the Comparative scale were consistent ($p=NS$).

3) Comparisons between subjective and objective risk estimates:

We examined whether women had a realistic perception of their personal risk by examining whether they correctly identified their risk as being above or below the average risk that is presented in health messages. In order to make scales comparable and to be able to compare different distributions, all measures were transformed into SD units [35]. The mean Gail score for the 177 women in our sample who provided sufficient information was

10.24(± 6.05 , median=9.8). The distribution was significantly skewed to the right, indicating that although most women had an average risk some had a high breast cancer risk (Skewness Statistic =1.69, S.E._{Skewness}=0.18, $Z_{\text{Skewness}}=9.39 > 1.96$). Similarly, women's Comparative Gail score was 0.23(± 5.38 , median= -1.30) and the distribution was also skewed to the right, indicating that some women in the sample had an actual breast cancer risk much higher than average (Skewness Statistic =2.39, S.E._{Skewness}=0.18, $Z_{\text{Skewness}}=13.05 > 1.96$).

We compared the distribution of women's Comparative Gail scores, which represents the risk status of participant women against the risk status of women in the population with average risk factors, to the distribution of women's responses on the Comparative scale, which directly asked participants to compare their risk to the average, same age, woman. The comparison of these two distributions indicated that women significantly underestimated their actual breast cancer risk when they responded on the Comparative scale that their risk was average or lower than average (Mean Comparative Gail = 0.04SD, Mean Comparative = -0.38SD, paired-samples $t_{(176)} = -4.82$, $p < 0.001$, $g = -0.36$, 95%CI -0.57 - -0.15).

4) Perceived risk and screening behavior:

Mammography history was obtained from N=122 women who were older than 40 years of age (Mean = 53.36 $\pm$ 10.12). Most of them (79%) reported having health insurance. Approximately 66% of those women reported having a screening mammogram every one to two years; 16% reported that they never had a mammogram, and five women (4%) believed that they were too young for a mammogram. Approximately 70% of this sub-sample of women had received a mammogram within the past 24 months, and 11 women (9%) reported that their most recent mammogram was performed for the evaluation of a breast symptom.

History of CBE and BSE was assessed in the whole sample. Most women (87%) reported having had at least one CBE and 59% reported having a CBE every year. Nine women (5%) reported that their most recent CBE was done for the evaluation of a breast problem other than breast cancer. Finally, 54% of the women in the sample reported performing BSE at least every other month. (Table 3). (Insert Table 3).

Table 4 presents the correlations between screening behavior and Gail scores, and the correlations between screening behavior and measures of perceived risk. Contrary to the expectation that high-risk women receive more screening recommendations, high-risk women in the sample (women with higher Gail scores) were not more likely to receive screening mammograms, CBEs, or perform BSE more often. They were only more likely to have received their most recent mammogram and their most recent CBE for the evaluation of a breast problem other than breast cancer ($r=0.21$, $p=0.05$, and $r=0.29$, $p=0.01$ respectively). The 11 women whose most recent mammogram was performed for the evaluation of a breast problem were significantly more likely to make a higher absolute risk judgment, but only with the Verbal scale ($r=0.22$, $p=0.05$). The nine women who reported that their most recent CBE was done for the evaluation of a breast problem were also significantly more likely to perceive higher risk, but with all risk measures (correlations ranging from 0.15 to 0.22, $p<0.05$). (Insert Table 4).

Discussion

The study described absolute and comparative breast cancer risk judgments, examined consistency of responses among direct and indirect risk measures, compared subjective risk and objective risk estimates, and examined the influence of risk judgments on screening behavior. The unique contribution of this study to the growing body of evidence regarding perceived breast cancer risk is that it demonstrated phenomena of optimistic biases with different ways and it

examined the impact of absolute and comparative risk judgments on screening behavior.

Moreover, the study implemented an analysis plan that neutralized the contextual, wording, and anchoring limitations of measurements.

Absolute risk judgments on the Verbal scale were normally distributed and indicated that women perceived that they probably would not get breast cancer in their lifetime. Similar to other community-based studies [38-41], women recruited from community settings perceived that their breast cancer risk is low. Moreover, in the Verbal scale women systematically rated the risk of their friends/peers as higher than their own risk, thus, holding a systematic comparative-optimism bias. Similarly, the distribution of responses on the Comparative scale was skewed to the right, indicating that some women directly reported that their risk is lower than the risk of average, same age women, thus demonstrating a better-than-average effect. Therefore, we demonstrated that women held optimistic biases with both a direct and an indirect measure. Our findings indicated that the direct method showed a more pronounced bias than the indirect method ($g=0.58$ vs. $g=0.42$ respectively).

It is more difficult to interpret the meaning of absolute and comparative risk judgments on the Numerical scale. On one hand, the mean absolute Numerical risk judgment was approximately 30%, which as an absolute numerical probability value indicates that women ignored the information we provided and overestimated their actual breast cancer risk. However, the distribution of responses on the Numerical scale was skewed to the right, with approximately two thirds of responses clustering one anchor above or below 12%, while 65 women rated their risk as 50% or higher. In addition, we did not find an optimistic bias with the Numerical scale, which means that women made similar risk judgments for themselves and their friends/peers. One possible explanation for this finding is that the factual information we provided about the

12% average population breast cancer risk made participants consider more carefully the risk status of their friends/peers. Receiving information about the risk status of peers reduces optimistic bias, because it removes the focus from oneself and directs attention to others and to possible protective measures they are taking [22]. Moreover, risk judgments for a target group depend on information about a context group; when immediate context information is salient, such as information about the 12% average risk, it becomes the primary comparison standard [9]. Since we found no comparative-optimism with the Numerical scale, it appears that women who rated their risk as 12% were more likely to rate the risk of their friends/peers also as 12%. It also appears that women who rated their risk as 50% or higher were more likely to rate the risk of their friends/peers as 50% or higher.

The latter finding is intriguing. Optimistic biases have various origins, such as having incorrect information [17], or serving a motivation for self-enhancement [7, 8]. Also, it is unclear whether optimistic bias is related to the personality trait of “optimism”. Facione [40] found no relation between perceived risk and “optimism”, whereas Andrykowski and colleagues [42] reported that “optimism” moderated the response to a threatening health event. Finally, the source of bias could be non-motivational, but located within the judgment process and the information-processing system [43, 44]. Supporting the latter hypothesis 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 [45]. In the present study, it appears that optimistic biases could be attributed both to motivational sources, for women that made risk judgments close to 12% population average risk, and to limitations of information-processing for those women that misinterpreted the Numerical scale.

Moreover, within-subjects analysis revealed that responses among the different risk measures were not consistent. Consistency of responses was greater between the Comparative scale and the Verbal Risk Difference measure, whereas the least consistency was observed between the Comparative scale and the Numerical Risk Difference measure. There are different possible explanations for this finding. First, many of the women who assigned themselves a high risk rating on the Numerical scale did not actually believe that they were at a higher than average risk but they assigned a high value in error, since they did not indicate a consistently high personal risk when asked elsewhere in the survey. Second, item order in the questionnaire affects consistency of responses. Taylor and colleagues found that consistency improved when the Comparative scale and the Numerical rating for friends/peers were introduced before the Numerical rating for oneself [46]. Item order in the present study was similar to Taylor and colleagues; yet, we found a greater correlation between the Verbal Risk Difference 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 most likely explanation is that the Numerical scale does not accurately reflect participants' risk judgments. This is consistent with our suggestion that a Numerical scale produces a false value for some portion of the sample [6].

Weinstein [47] 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. In the present study we did not examine whether women had an accurate perception of their absolute numerical probability of breast cancer risk, and we avoided directly comparing subjective and objective risk estimates. Rather, we examined whether participants had a realistic perception of their risk as being above or below

average. Since it is not clear at what percentage a woman's risk can be considered "somewhat higher than average" or "much higher than average", different cut off percentages used by various studies are arbitrary [48, 49]. Comparing distributions of actual and perceived risk in SD units overcomes this weakness in research methodology and makes a unique contribution to the growing body of research regarding perceived risk. Women in the sample had a slightly higher than average breast cancer risk, whereas their responses on the Comparative scale indicated that they believed their risk to be average or lower than average. This finding is a direct indication that women underestimated their actual breast cancer risk.

The majority (80%) of women older than 40 years of age reported having a mammogram and half of those women reported having a mammogram within the past 12 months. Similarly, 87% reported having a CBE and more than half reported having a CBE within the past 12 months. Consistent with a previous study [50], the screening rates of the target population in this geographic area are likely to be higher than the screening rates of the population at large. However, as presented in Table 4 we did not find significant correlations between women's Gail scores and their screening behavior. This means that high-risk women did not receive screening more often. This finding is consistent with a national survey reporting that one third of women who were at high risk for developing breast cancer did not receive screening appropriate to their level of risk [49]. Our data suggest that failure of high-risk women to undergo screening may be attributed to optimistic biases.

Our original hypothesis for a positive correlation between screening behavior and perceived risk was only partially confirmed. Therefore, the question whether perceived risk influences screening behavior remains to be answered. Since screening does not reduce susceptibility to breast cancer, on a logical level, women's perceived breast cancer risk should be

independent from adherence to screening guidelines. In the present study we found positive correlations between perceived risk and reasons for women's most recent screening. Women whose most recent mammogram was performed for the evaluation of a breast symptom were more likely to make a high absolute risk judgment on the Verbal scale. Similarly, women who initiated their most recent CBE for the evaluation of a breast symptom were significantly more likely to make high risk judgments in all risk measures. It appears that women who had experienced a breast symptom comprise a different group in terms of perceived risk than asymptomatic women. However, it is not clear whether symptomatic women sought evaluation of their symptom because they perceived higher risk, or their risk perception increased as a response to the breast symptom. Research including larger samples of symptomatic women should further examine this phenomenon. Finally, as suggested in a previous study [51], lack of significant correlations between BSE frequency and perceived risk may reflect women's over-reliance on the healthcare provider to monitor breast changes.

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 [52]; 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 [53], it may underestimate breast cancer risk for Black women [54]. However, 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. Although we demonstrated optimistic bias in the sample as a whole, we did not identify individuals who held such biases. Finally, interpretation of correlations between measures of perceived risk and screening behavior

should be done with caution, since the number of women who initiated a CBE for the evaluation of a breast symptom was small.

The study has implications for breast cancer risk communication. Our findings suggest that Comparative and Verbal scales 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 risk information in a non-quantitative way might better influence perceived susceptibility to breast cancer. Most women recruited from community settings hold a better-than-average and comparative-optimism biases and underestimate their actual breast cancer risk. We did not specifically examine whether absolute and comparative risk judgments reflect a single construct of perceived susceptibility to disease. However, it appears that perceived risk is a variable with clinical significance, since it might have influenced those women who initiated a CBE for the evaluation of a self-discovered breast symptom. A longitudinal design with a larger sample of women might better help us derive conclusions regarding the influences on perceived risk over time and the causal relation of perceived risk and screening behavior.

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Appendix

Table 1. Demographic Characteristics

Variable	N	%
Age		
X= 47.59±12.05, range: 30 to 84		
30 to 39	56	30
40 to 49	50	27
50 to 85	72	40
Missing	6	3
Total	184	
Race/Culture		
Non-Hispanic White	79	43
Non-Hispanic Black	50	27
Hispanic	25	14
Asian	30	16
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 - <\$30,000	49	26
\$30,000 - <\$50,000	45	25
\$50,000 - <\$70,000	22	12
>\$70,000	21	12
Missing	8	4
Marital Status		
Married or Member of an Unmarried Couple	60	33
Divorced or Separated	37	20
Widowed	17	9
Never Married	69	38
Missing	1	
Family History		
No Family History	117	64
≥1 affected SDRs	24	13
1 affected FDR	18	10
Multiple	16	9
(>1 FDR or ≥1FDR and ≥1 SDRs)		
Missing	9	4

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

Table 2. Correlations between absolute and comparative measures of risk

	Comparative Risk	Absolute Verbal Risk	Absolute Numerical Risk	Verbal Risk Difference	Numerical Risk Difference
Comparative Risk	1	0.49**	0.33**	0.29**	0.38**
Absolute Verbal Risk		1	0.59**	0.62**	0.31**
Absolute Numerical Risk			1	0.31**	0.47**
Verbal Risk Difference				1	0.33**
Numerical Risk Difference					1

** Correlation is significant at the 0.01 level (2-tailed).

Table 3. Breast Cancer Screening Behavior

Screening Behavior		N	%
How often do you have a mammogram? (N=122, age $\geq$ 40)	Never	19	16
	Once or twice before	17	14
	Every one to two years	81	66
	Missing	5	4
How long has it been since your last mammogram? (N=122)	I am too young to have a mammogram	5	4
	past 1 year (<12 months ago)	62	51
	past 2 years (12 to 24 months ago)	23	19
	past 3 years (24 to 36 months ago)	5	4
	past 5 years (36 to 60 months ago)	4	3
	5 or more years ago	5	4
	Missing	18	15
What was the reason for your last mammogram? (N=122)	Routine Check-up	86	71
	Problem other than breast cancer	11	9
	Missing	25	20
How often do you have a CBE? (N=184)	Never	19	10
	Once before	11	6
	Every 2 to 3 years	41	22
	Every year	108	59
	Missing	5	3
How long has it been since your last CBE? (N=184)	past 1 year (< 12 months ago)	98	54
	past 2 years (12 to 24 months ago)	36	20
	past 3 years (24 to 36 months ago)	11	6
	past 5 years (36 to 60 months ago)	2	1
	$\geq$ 5 years ago	9	5
	Missing	28	14
What was the reason for your last CBE? (N=184)	Routine Check-up	145	79
	Problem other than breast cancer	9	5
	Missing	30	16
How often do you do BSE? (N=184)	Never	14	8
	Rarely	69	37
	Occasionally (every other month)	55	30
	Regularly (every month)	33	18
	Very often (more than monthly)	11	6
	Missing	2	1

Table 4. Pearson's correlations (r) between Screening Behavior, Gail Scores, & Perceived Risk Measures

	Gail Score	Verbal Absolute Risk	Numerical Absolute Risk	Comparative Risk	Verbal Risk Difference	Numerical Risk Difference
Often has a Mammogram	-0.12 N=116	-0.02 N=115	0.07 N=114	-0.06 N=117	-0.07 N=115	0.01 N=112
Long since LAST Mammogram	0.05 N=103	-0.03 N=102	0.10 N=102	-0.05 N=104	-0.02 N=102	0.11 N=101
Reason for LAST Mammogram	0.21* N=96 g=0.43 (0.17-0.69)	0.22* N=95 g=0.45 (0.16-0.74)	0.13 N=95	0.08 N=97	0.02 N=95	-0.09 N=94
Often has CBE	-0.05 N=172	0.04 N=177	0.10 N=176	0.12 N=179	0.12 N=177	-0.02 N=174
Long since LAST CBE	-0.01 N=163	0.001 N=166	0.06 N=165	0.04 N=168	-0.10 N=166	0.11 N=163
Reason for LAST CBE	0.29** N=159 g=0.61 (0.39-0.83)	0.22** N=164 g=0.44 (0.22-0.66)	0.16* N=163 g=0.33 (0.11-0.55)	0.15* N=166 g=0.31 (0.09-0.53)	0.19* N=164 g=0.40 (0.18-0.61)	0.20* N=163 g=0.40 (0.18-0.62)
Often does BSE	-0.13 N=175	0.12 N=180	0.13 N=178	0.06 N=182	-0.05 N=180	0.03 N=176

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

EXPERIENCES WITH BREAST CANCER, HEURISTICS, AND OPTIMISTIC BIAS

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Abstract

Background: Studies reported that some women perceive that they are less likely than others to be affected by breast cancer, and that this optimistic bias persists despite tailored educational interventions. **Purpose:** To identify contextual and informational processing factors that decrease optimistic bias regarding breast cancer risk. We examined 1) whether experiences with affected family members, affected friends, and abnormal breast symptoms, namely current symptoms and previous biopsies, decrease optimistic bias, and 2) whether worry and knowledge of risk factors acted as mediators or moderators between these experiences and risk assessments. **Methods:** This cross-sectional community-based survey recruited 184 middle-aged (47 ± 12), well-educated women from diverse racial/cultural backgrounds. **Results:** Participants had moderate worry and moderate knowledge regarding breast cancer risk factors. Optimistic bias was not influenced by demographic characteristics. A series of simultaneous and hierarchical regression analyses revealed that having multiple affected family members, worry, and knowledge of risk factors significantly decreased optimistic bias. In contrast, affected friends increased optimistic bias. Worry mediated the relation between having current breast symptoms and optimistic bias. Knowledge of risk factors was a moderator between optimistic bias and participants with one or more breast biopsies and a subset of participants with a positive family history. Findings suggest three possible pathways with which experiences are incorporated into risk assessments. **Conclusions:** We discuss cognitive mechanisms with which experiences, worry, and knowledge of risk factors decrease optimistic bias. Interventions should assess knowledge, take into account inappropriate use of heuristics, and implement contextually relevant approaches to enhance information processing.

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Keywords: Breast Cancer Worry, Knowledge of Risk Factors, Family History, Affected Friends,
Breast Symptoms

Introduction

Breast cancer is the most common cancer in U.S. women, and early detection has long been recognized for its value in reducing mortality of affected individuals (1). A great effort from the press, television and radio broadcasts, and women's magazines is devoted to disseminating information about the disease (2). Although messages from the media and health-related sources enhance acknowledgement of a health problem, they are unlikely to assert their influence beyond awareness of screening, because they do not clearly differentiate who is likely to be affected (3). As a consequence, most individuals perceive that they are not at risk for the disease, or perceive they are less likely than others to be affected. This phenomenon has been termed "optimistic bias" (4). Optimistic bias has been demonstrated extensively in research studies (5-8), and has been documented for perceived breast cancer risk (9-13). Inaccurate perceptions of breast cancer risk may either interfere with recommended precautions for women at increased risk, or provoke inappropriate behaviors in those at low risk (14-16).

Programs that aim to promote the adoption of protective behaviors focus on educating women about breast cancer risk factors (17). However, inaccurate perceptions of risk persist despite tailored educational interventions. A meta-analysis that summarized results of interventions aiming to increase breast cancer screening rates concluded that behavioral interventions increased screening rates by 13.2%; cognitive interventions that used generic education strategies had little impact, and those that used theory-based education increased screening rates by 23.6% (18).

A possible explanation for these observations is that a person who is unaware about a health problem and associated risk factors is responsive in learning about the problem, whereas a person who considers that specific situations are not risk factors maintains a biased opinion (4).

If a woman is committed to a particular point of view, she will selectively attend to messages that support her own position. She will show belief perseverance when faced with disconfirming evidence, and she will not be responsive to formal messages regarding causes and risk factors. Alternative avenues to accurate perceptions of risk might operate through experiential learning. Opportunities for experiential learning present when women encounter the disease in their daily living, such as with experiences with affected family members, affected friends, and mammography recalls or other abnormal breast symptoms. Therefore, research needs to determine the factors that influence women's responsiveness to information regarding their breast cancer risk.

Judgment and decision-making theory suggests that predictions and judgments are often mediated by a small number of distinctive mental operations called heuristics (19, 20). Heuristics are logical shortcuts that are used during information processing to reduce complex mental operations to simpler cognitive tasks and save cognitive resources and time. In addition to logical shortcuts, the affective evaluation of a stimulus, and conscious or unconscious feeling states make great contributions to risk assessments (21, 22). Affective evaluations might make a threat more vivid and personal, and therefore, might reduce tendencies to deny vulnerability. Alternatively, the desire to reduce worry and to avoid feeling afraid may lead to discounting threatening information, and therefore, create an optimistic bias (23, 24). Others have suggested a bidirectional relation between risk assessments and affect (25-27). Although heuristics facilitate risk assessments, they can produce both valid and invalid judgments, and can lead to characteristic systematic errors.

Research regarding the possible influence of heuristic thinking on perceived breast cancer risk revealed a connection between personal experiences, risk perceptions, and specific

heuristics. Experiences with affected family members are incorporated into risk perceptions through the availability, representativeness, and anchoring and adjustment heuristics (28), and through the availability and perceived control heuristics (12). Experiences with affected friends are incorporated into risk perceptions through the availability heuristic (29). In previous work we expanded our understanding of the connections between perceived breast cancer risk, and the simulation, perceived control, affect, and loss aversion heuristics (30). Inappropriate use of heuristics resulted in subsequent risk assessments that were not accurate. Some women with a positive family history made claims of being at lower risk; although they were aware that heredity is a risk factor, they claimed being at lower risk because they were not emotionally close to their mother or they did not physically look like her (30).

Therefore, tailored educational interventions should aim to discount risk assessments that are based on information that is subject to heuristics and biases, and foster risk assessments that are based on factual information. Research should examine the substantive variables that in combination with heuristic thinking act as barriers to comprehension and responsiveness to health messages. The purpose of the present study was to examine the connections between personal experiences, heuristic thinking, and optimistic bias. First, we examined whether experiences with affected friends helped women decrease their optimistic bias. Second, we examined whether women with objective breast cancer risk factors, such as a positive family history and abnormal breast symptoms had an optimistic bias. Third, we examined whether optimistic bias was reduced through factual knowledge of risk factors or through affective responses. Consequently, we examined whether knowledge of risk factors and breast cancer worry acted as moderators or mediators between personal experiences and optimistic bias. In

other words, we examined whether women's experiences with the disease decrease optimistic bias via affective reactions or via inferential reasoning.

Recruitment and Procedures

The present analysis is part of a community-based survey that examined perceived breast cancer risk, compared subjective and objective risk estimates, and examined factors that influence perceived risk (31). This cross-sectional survey recruited a convenience sample from community settings throughout the San Francisco Bay Area. The study was advertised as "Women's Breast Study". Women were eligible to participate if they were between the ages of 30 and 85, had never been diagnosed with any type of cancer, and were willing to complete a questionnaire in English. The minimum 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 breast cancer risk can be estimated with the Gail model (32). 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 cancer risk factors.

Recruitment was done through newspaper advertisements and through flyers posted on bulletin boards in community settings. Advertisements were placed at local newspapers targeting different ethnic groups. Flyers were posted at places that women were likely to visit in their daily living, such as senior centers, libraries, restaurants, coffee shops, homeless shelters, cultural centers, churches, temples, and workplaces. Potential participants responded by calling a dedicated telephone number and expressed their interest for the study. The first author assessed eligibility for study participation, and administered the survey questionnaires face-to-

face in places that were comfortable and convenient for every participant. Participants were paid \$15. The University of California San Francisco Committee on Human Rights and the Institutional Review Board of the funding agency approved the study protocol. Data collection occurred over a period of 13 months between February 2003 and March 2004.

Measures

Family History (FH) of breast cancer was assessed by asking women to indicate whether their First-Degree Relatives (FDRs) and their Second-Degree Relatives (SDRs) have been affected by the disease. Women were categorized in one of four groups: No family history, one or more affected SDRs, one affected FDR, or multiple affected family members (>1 FDRs or 1 FDR+ ≥ 1 SDRs) (33). In order to examine whether information about the risk status of other women influences optimistic bias, we asked participants to indicate the *Number of their Affected Friends/Peers*.

We assessed experiences with abnormal breast symptoms by asking women to indicate number of breast biopsies and current breast symptoms. Responses for the total number of *Breast Biopsies* were dichotomized as ‘0’ and ‘ ≥ 1 ’.

Current Breast Symptoms (CBSs), were assessed with a modified version of the Breast Cancer Symptom Scale (Modified-BCSS) (34). 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*. According to a panel of four nurses (M.D., N.F., K.L., and J.H.), who are experts in research on symptom management (35), each symptom was assigned a score between ‘1’ 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 represent each woman’s report of incidence of breast symptoms. This was based on reports that ambiguous or unlabelled symptoms did not elicit more information seeking than labeled symptoms (30, 36), and that some individuals avoid seeking information if it will cause mental discomfort or dissonance (37).

Knowledge of Breast Cancer Risk Factors was assessed with 13 items. Five of these items described risk factors identified by the Gail model (38). The remaining eight items were investigator-developed to examine knowledge of hereditary/genetic risk factors for breast cancer. Items asked whether having multiple affected family members, having had breast cancer before, having a family history of breast cancer from the mother’s or the father’s side of the family, having a family history of ovarian cancer, having a family member with both breast and ovarian cancer, having a genetic mutation, and being of Ashkenazi Jewish decent were breast cancer risk factors. 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 (BCRFKI)* and possible scores ranged between 0 and 13 (39). The 13-items were highly intercorrelated (Cronbach’s $\alpha = 0.80$).

Breast Cancer Worry was assessed with four items used in previous studies (25). Two items asked participants to rate “*how often they had worried*” and “*how emotionally upset or distressed*” they had been 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, items were standardized before summing, which means that each item was divided by its respective standard deviation (25). Higher scores indicate greater worry, and internal consistency for the scale was high (Cronbach's $\alpha = 0.85$).

Optimistic Bias: Initially we measured perceived risk with items used in previous studies (6, 40). We asked participants to rate their breast cancer risk and the risk of their friends/peers on a scale ranging from '0' to '10'. The numbers were coupled with five Verbal anchors: '0' and '1' were coupled with "*Definitely Will Not*", '2' and '3' with "*Probably will Not*", '4', '5', and '6' with "*Fifty-fifty*", '7' and '8' with "*Probably Will*", and '9' and '10' with "*Definitely Will*". We used the verbal anchors in order to provide women with appropriate context and to avoid misinterpretation of the scale that has been reported elsewhere (41). In approximately nine percent of the cases that women marked either a point between two numbers or a verbal anchor, we used a conservative approach and gave them a score towards the middle of the scale.

Participants reported that they "*Probably Will Not*" get the disease ($X=3.57\pm1.70$), while they rated their friends/peers at higher risk ($X=4.35\pm1.56$) (31). Paired samples t-test revealed that women held an optimistic bias, perceiving that they were significantly less likely than their peers to be affected ($t_{(179)}=5.64$, $p<.001$). Based on these findings, we created a measure of *Optimistic Bias* by subtracting the risk value that women assigned to themselves from the risk value they assigned to their peers (Optimistic Bias = Risk of Others – Personal Risk). Values of the measure were normally distributed ($X= 0.78\pm1.85$, $Md=0$, Range: -7.00 to 8.00), with positive scores indicating an Optimistic Bias.

Statistical Analysis

Data were analyzed using the SPSS 13® statistical program. We calculated individual scores when at least 60% of items were completed. Distributions were checked for normality. Significance was set at the 0.05 level with 95% Confidence Intervals for all statistical analyses. We used descriptive statistics for demographic characteristics. We performed simultaneous and hierarchical regression analyses to identify predictors of optimistic bias, and to explore whether worry and knowledge of breast cancer risk factors mediated or moderated the relationships between predictive variables and optimistic bias. To test for a moderator effect, predictors 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 change in R-squared of optimistic bias (42). To test for a mediator effect we examined first, whether variations in the mediator (worry or knowledge) predicted variations in optimistic bias; second, whether variations in the independent variables predicted variations in the mediator (worry or knowledge); and third, whether the effect of the independent variables on optimistic bias becomes non-significant when the mediator is controlled (42). To reduce expected multicollinearity among predictors, variables were centered prior to use in regression analyses. Centering removes non-essential multicollinearity that is due to scaling and consists of subtracting the mean of each variable from each observed value (43).

Results

We recruited a multicultural sample of 184 women (See Table 1). According to the US Census (44), although the sample was broadly comparable to the San Francisco Bay Area population, there was an over-representation of non-Hispanic black women and women with college education. (Insert Table 1).

Approximately two thirds of participants did not have a family history of breast cancer, while fewer women had one affected FDR or multiple affected relatives. Most women (N=120, 65%) reported having at least one friend diagnosed with the disease (Mean: 1.70 ± 1.83).

Approximately one in five women (19%) had ≥ 1 Breast Biopsies (mean= 0.28 ± 0.71).

Approximately 50% indicated that they had breast symptoms at the time of the survey. The most common symptom was “breasts feel painful and tender during their menstrual period” (45%).

However, twelve women (7%) indicated symptoms that could suggest a breast malignancy (See Table 2). (Insert Table 2).

Women in the sample reported moderate worry (Mean= 8.15 ± 3.32 , Median=7.96, Range: 2.51 to 18.51) and, despite their somewhat higher-than-average educational level, had moderate levels of knowledge regarding breast cancer risk factors (Mean: 5.96 ± 3.19 , Median: 7.00, Range: 0-13). A detailed analysis of women’s knowledge of breast cancer risk factors is reported elsewhere (39).

Predictors of Optimistic Bias

To check for the possibility that demographic characteristics such as age, education, income, and race/culture were predictors of optimistic bias we performed a simultaneous regression analysis; demographic variables were entered into a regression equation in one step. None was a significant predictor of optimistic bias, which is consistent with a previous report (40). Moreover, in the subsequent analyses reported below none of these variables had a significant effect on the overall model, therefore, we excluded them from analyses presented in this paper.

To examine the extent to which optimistic bias was related to experiences with affected family members, affected friends, abnormal breast symptoms, worry, and knowledge of breast cancer risk factors, we performed a simultaneous regression analysis, in which all variables were entered into a regression model in one step. The overall model was significant and the unique contribution of each variable (sr^2) is reported (see Table 3). (Insert Table 3).

Worry and Knowledge as Moderators between Experiences and Optimistic Bias

We examined whether worry and knowledge moderated the relationship between experiences with the disease and optimistic bias. 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), number of Affected Friends, Current Symptoms, ≥ 1 Breast Biopsy, and the proposed moderator. In step 2 we entered the interaction terms [(FH1, FH2, FH3, Affected Friends, Current Symptoms, ≥ 1 Breast Biopsy) X Worry] or [(FH1, FH2, FH3, Affected Friends, Current Symptoms, ≥ 1 Breast Biopsy) X Knowledge].

We did not find a significant interaction between worry and the variables examined. Most of the variance was attributed to the interaction of worry with the experience of having multiple affected family members. ($R^2=0.198$, $\Delta R^2=0.050$, $\Delta F=1.675$, $p=NS$, $B_{\text{Multiple} \times \text{Worry}} = -0.322$, $p<0.05$, $95\%CI_B -0.616 - -0.028$).

In contrast, there was a significant interaction between knowledge of breast cancer risk factors and experiences with the disease ($R^2=0.235$, $\Delta R^2=0.111$, $\Delta F=4.658$, $p=0.001$). Most of the variance was attributed from the interaction of having affected SDRs and ≥ 1 Breast Biopsies with knowledge of breast cancer risk factors (See Table 4). (Insert Table 4).

Worry and Knowledge as Mediators between Experiences and Optimistic Bias

Since both worry and knowledge were significant predictors of optimistic bias, the first condition for a mediation effect to occur was satisfied. This allowed us to examine whether these two variables acted as mediators between experiences and optimistic bias. To test for the mediating effect of worry we performed a simultaneous regression analysis in which family history, affected friends, current breast symptoms, and breast biopsies were examined as predictors of worry. The overall model was not significant; the only significant predictor of worry was having current breast symptoms ($R^2 = 0.037$, $\Delta R^2 = 0.037$, $\Delta F = 1.084$, $p = \text{NS}$, $B_{\text{Current Breast Symptom}} = 0.100$, $p < 0.05$, $95\% \text{CI}_{\text{Current Breast Symptom}} 0.001 - 0.199$). This finding suggests that worry was a complete mediator between current breast symptoms and optimistic bias.

Similarly we performed a simultaneous regression analysis in which family history, affected friends, breast biopsies, and current breast symptoms were examined as predictors of knowledge of risk factors. The overall model did not reach statistical significance; most of the variance in knowledge of risk factors was contributed by having multiple affected family members and affected SDRs. ($R^2 = 0.056$, $\Delta R^2 = 0.056$, $\Delta F = 1.693$, $p = \text{NS}$, $B_{\geq 1 \text{ SDRs vs. NoFH}} = 1.241$, $p < 0.05$, $95\% \text{CI}_{\geq 1 \text{ SDRs vs. NoFH}} 0.042 - 2.440$ & $B_{\text{Multiple vs. NoFH}} = 2.513$, $p < 0.05$, $95\% \text{CI}_{\text{Multiple vs. NoFH}} 0.268 - 4.757$).

Figure 1 represents findings from the above mentioned analyses. (Insert Figure 1).

Discussion

The study examined whether experiences with affected family members, affected friends, and breast symptoms decreased optimistic bias about breast cancer risk, and whether knowledge

of risk factors and worry acted as mediators or moderators between predictors and optimistic bias.

As expected, findings confirmed the significant role of family history in decreasing optimistic bias. From the four conditions of family history examined (no family history, one affected FDR, ≥ 1 affected SDRs, or multiple affected family members), having one affected FDR did not decrease optimistic bias. This was an unexpected finding. Women with one affected FDR appear to be able to maintain an optimistic assessment regarding their breast cancer risk. This claim is in conflict with research quantifying breast cancer risk, which suggests that having one affected FDR can significantly increase one's risk for the disease (32). Although the study included a small and volunteer sample, our findings are consistent with other studies that included larger samples (9, 10). This finding, and in combination with the moderate levels of knowledge of risk factors reported by study participants, implies a knowledge deficit. Health care providers either need to increase their efforts for educating community women about breast cancer risk factors, or need to implement a different approach when they deliver the message that having even one affected FDR can significantly increase breast cancer risk.

Despite the small number, having multiple affected family members had the greatest impact on optimistic bias. This experience was incorporated into risk assessments through two possible pathways: through a direct pathway and through an interaction with breast cancer worry. Since worry did not mediate the relation between family history and optimistic bias, findings do NOT support a causal pathway between family history, affect, and optimistic bias. This is consistent with reports that family history did not evoke worry among high risk women (45). Moreover, the interaction of worry with family history did not have a significant overall effect on optimistic bias. Most of the variance was contributed from a weak moderation between

worry and having multiple affected relatives. These findings, and in combination with the moderate amounts of participants' worry, imply that family history could reduce optimistic bias through an affective pathway, but ONLY when affect reaches a threshold. This affective pathway could be activated either by contextual variables that increase breast cancer worry, or by individual psychological differences (46). In our data having current breast symptoms was a contextual variable that significantly increased breast cancer worry.

One would expect that the subjective risk evaluations of women with a positive family history would draw on the knowledge that their own risk is increased due to genetic/hereditary risk factors. We were expecting to observe a causal pathway between family history and optimistic bias that operates through knowledge of risk factors. The first condition for the mediating role of knowledge between family history and optimistic bias was satisfied for multiple affected relatives and affected SDRs. However, subsequent analyses did not support such a mediating relation. This was a very surprising finding, given that 76% of the sample recognized that having affected family members was a risk factor (39). Instead, knowledge acted as a moderator between having affected SDRs and a decreased optimistic bias. The latter relation represents a mediated moderation (47), in which the magnitude of the overall effect of having affected SDRs on optimistic bias depends on individual differences in factual knowledge of risk factors.

Taken together these findings suggest that experiences with affected family members might be incorporated into risk assessments through a direct pathway, an affective pathway, and a pathway that involves knowledge of actual risk factors. The first two pathways likely represent heuristic thinking. The strongest effect was observed from the direct pathway generated from the experience of having multiple affected family members. The availability, representativeness,

and possibly other heuristics influence assessments of personal risk. Similarly, the affective pathway influences assessments of personal risk, and appears to be activated after contextually relevant affect reaches a critical threshold. Another likely explanation for our findings is that repeated experiences with affected family members represent opportunities for experiential learning towards more accurate risk assessments. Having multiple and SDRs affected by the disease were significant predictors of knowledge of risk factors. In addition, the observed moderation between SDRs and knowledge suggests that optimistic bias could be maintained due to knowledge deficits among some women with a positive family history. The connections between family history, optimistic bias, and knowledge of risk factors need to be further examined for successful implementation of interventions that aim to facilitate information processing.

Consistent with findings from seven studies (48), abnormal breast symptoms decreased optimistic bias. Worry was a complete mediator between current symptoms and optimistic bias, which implies a causal pathway from symptom appraisal to risk assessments that operates through affect. However, having one or more breast biopsies did not decrease optimistic bias. Another study reported that breast biopsies evoked worry (49), which was not true for participants in this study. Breast biopsies reduced optimistic bias through an interaction with knowledge of risk factors. This implies that having one or more breast biopsies represents opportunities for more accurate risk assessments through experiential learning.

It is not clear why these two experiences with abnormal breast symptoms were incorporated into risk assessments through different pathways: current breast symptoms appear to follow an affective pathway, whereas experiences with breast biopsies appear to follow an analytical pathway that depends on knowledge of risk factors. One possible explanation relates

to the timing of the experience and the cross-sectional design of the study. It is possible that breast symptoms that were present when the study took place were concurrently being evaluated for their catastrophic potential by the individual, whereas past experiences with breast biopsies have been resolved. Evidence indicates that immediately after a breast biopsy women experienced high levels of worry, which decreased over time (49, 50). Worry probably is the initial response to a self-discovered breast symptom. Ad hoc evaluations of such experiences decrease optimistic bias, but ONLY for women who are aware that having dense breast tissue that needs to be assessed with a breast biopsy constitutes a risk factor. It is possible that in order to reduce worry and fear that follow the evaluation of the threat posed by a breast symptom, women maintain an optimistic bias through other variables or other heuristic mechanisms, such as perceived control (51, 52), and an inappropriate use of the illusion of control heuristic (30). These findings imply that worry and inappropriate use of the illusion of control heuristic might interfere with responsiveness to health messages and inhibit information processing and retention. Therefore, timing of an intervention might be a crucial factor that affects the effectiveness of the intervention. In support of this suggestion, evidence indicated that women's responses to risk information were influenced by pre-counseling levels of worry (53).

Women who had one or more friends/peers diagnosed with the disease were more likely to have an optimistic bias. This was a surprising finding, because it is conflicting with previous reports (12, 29). One possible explanation is that the 120 women who had affected friends made the assessment of being at lower risk compared to those friends, based on the reasonable assumption that having had breast cancer before increases the likelihood of a second primary breast cancer and for recurrence of the disease. Although we elicited women's knowledge of this particular risk factor, knowledge did not moderate the relation between optimistic bias and

affected friends. Affected friends had a direct, positive effect on optimistic bias, which can be attributed to the availability heuristic. The availability heuristic may influence optimistic bias in two ways. On one hand, women with none or one affected friend do not have enough available examples to recall, and thus find it harder to imagine being personally affected by the disease (12, 29). On the other hand, it has been suggested that the self-relevance of the recalled information dictates whether the individual will use a heuristic or a deliberate information processing strategy for subsequent risk assessments (54). In the context of the present study, it is possible that knowing women with breast cancer promotes a heuristic evaluation of the risk of friends/peers. This heuristic evaluation increases the likelihood judgment for *others getting breast cancer*, thus contributing to optimistic bias. This suggestion has direct implications for educational interventions that aim to increase accuracy of risk assessments by presenting general risk factors or exemplars of women that have been affected by the disease. It is possible that such interventions actually increase optimistic bias.

The limitations of the study should be considered, to properly temper any conclusions. The results are based on a convenience sample of self-selected, English-speaking, and mostly inner-city women. Assessment of risk factors and breast symptoms was based on self-report. Although we examined knowledge of important breast cancer risk factors our list was not exhaustive. Moreover, the stability of these relationships is limited by the fact that our sample was not large enough to include a large number of women with a positive family history and other risk factors. Finally, we acknowledge that optimistic bias might be related to psychological variables that serve self-enhancement and adaptation (55, 56), which were not examined in this study. Despite these limitations, the strength of the study is that it recruited women from diverse socioeconomic and racial/cultural backgrounds from community settings,

which ensured that participation in the study was not limited to women that have greater access to health care services, and thus have greater opportunities to attend health related messages.

Our findings have implications for interventions that aim to facilitate information processing and decision-making by providing tailored health messages. They help explain why educational interventions are not always successful among individual women in changing pre-existing belief systems. Health educators need to assess pre-existing bias that affects women's responsiveness to health messages. Besides assessing knowledge deficits, they need to consider inappropriate use of heuristics, and assess whether contextual variables activate different information processing mechanisms. These suggestions might open new avenues to risk communication research.

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Appendix

Table 1. Demographic Characteristics of the Sample

Variable		N	%
Age	X= 46.59±12.05, range: 30 to 84		
	Missing	6	3
	Total	184	
Race/Culture			
	Non-Hispanic White	79	43
	Non-Hispanic African-descent	50	27
	Hispanic	25	14
	Asian-descent	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 Family 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	21	11
	Missing	8	5

Table 2. Experiences with Breast Cancer

Family History			
	No Family History	117	64
	≥1 affected SDRs	24	13
	1 affected FDR	18	10
	Multiple	16	9
	(>1 FDR or ≥1FDR and ≥1 SDRs)		
	Missing	9	4
Breast Biopsy		N	%
	Never had a Breast Biopsy	150	81
	≥1 Breast Biopsy	34	19
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
	A little blood is coming out of the nipple	0	0

SDRs: Second-Degree Relatives

FDR: First-Degree Relative

Table 3. Summary of Simultaneous Multiple Regression Analysis with Optimistic Bias as Criterion

Predictor Variable	R^2	ΔR^2	ΔF	sr^2	B	95%CI for B	
	0.163	0.163	4.040**				
≥1 SDRs vs. No FH				0.012	-0.534	-1.306	0.063
1FDR vs. No FH				0.002	0.378	-0.314	1.610
Multiple vs. No FH				0.034	-1.682*	-1.745	-1.578
Affected Friends				0.034	0.135*	0.033	0.241
Current Breast Symptom Severity				0.001	-0.014	-0.060	0.045
Breast Biopsies				0.000	-0.001	-0.356	0.338
Knowledge (of Risk Factors)				0.021	-0.088*	-0.191	-0.019
Worry				0.042	-0.117*	-0.205	-0.044

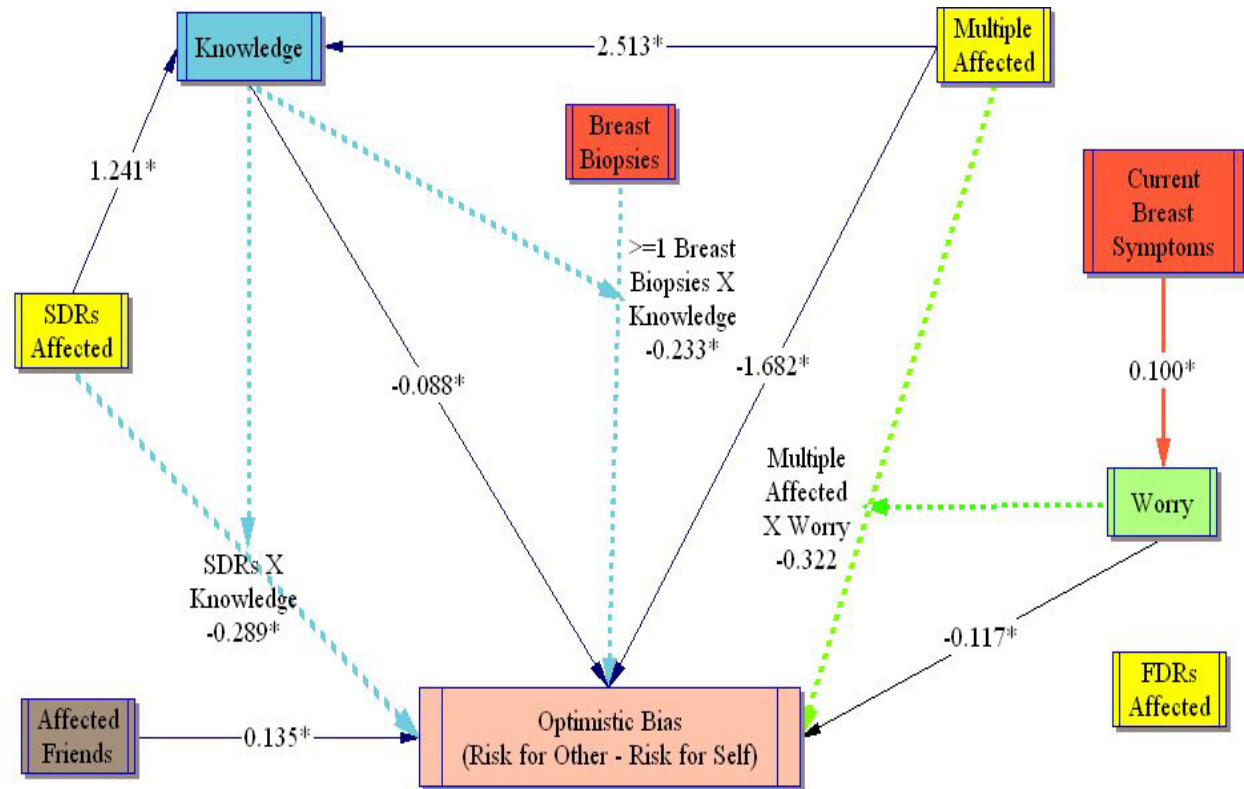
*p<0.05, **p<0.001

Table 4. Interaction of Experiences with Knowledge of Risk Factors. Optimistic Bias as Criterion

Step	Predictor Variable	R ²	ΔR ²	ΔF	sr ²	B	95%CI for B	
1		0.124	0.124	3.368*				
	SDRs				0.016	-0.588	-1.287	0.112
	1 FDR				0.002	0.338	-0.834	1.509
	Multiple				0.046	-1.888*	-3.201	-0.574
	Affected Friends				0.037	0.135*	0.029	0.241
	Current Breast Symptoms				0.006	-0.028	-0.082	0.026
	≥1 Breast Biopsy				0.003	0.250	-0.436	0.936
	Knowledge				0.023	-0.089*	-0.178	0.000
2	Interaction Terms	0.235	0.111	4.658*				
	SDRs × Knowledge				0.037	-0.289*	-0.518	-0.060
	1 FDR × Knowledge				0.006	-0.192	-0.582	0.199
	Multiple × Knowledge				0.022	-0.501	-1.022	0.019
	Affected Friends × Knowledge				0.000	0.001	-0.026	0.028
	Current Breast Symptoms × Knowledge				0.010	0.013	-0.007	0.032
	≥1 Breast Biopsy × Knowledge				0.070	-0.233*	-0.365	-0.101

*p<0.05, **p<0.001

Figure 1. Graphic representation of findings



* $p < 0.05$

----- Moderation

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Title: DISTRUST, HABITS OF UTILIZATION OF HEALTH SERVICES, AND DECISION- MAKING REGARDING BREAST CANCER SCREENING

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Abstract:

*DISTRUST, HABITS OF UTILIZATION OF HEALTH SERVICES, AND DECISION- MAKING
REGARDING BREAST CANCER SCREENING*

Abstract

Research suggests that the “asymmetry principle” explains why trust is fragile - easy to destroy but difficult to create (Slovic, 1999) - and that it stems from cognitive biases that affect choice behavior. We recruited 184 women (age 47 ± 12) from community settings to examine whether personal experiences with prejudicial treatment and distrust to the health system influence habits of utilization of health services and breast cancer screening behavior. Most women (49%) were college educated, 22% were low income, 77% had health insurance, and 57% were from minority backgrounds with an over-representation of non-Hispanic Blacks. We measured distrust to the health system with items capturing the cognitive biases that contribute to the self-reinforcing and self-perpetuating attribute of distrust (Cronbach $\alpha=0.71$); personal experiences with prejudice in the health care system (Cronbach $\alpha=0.71$); and habits of utilization of health services (Cronbach $\alpha=0.84$). Regression analyses revealed that distrust was the single most important predictor of habits of utilization of health services, which in turn was a significant predictor of breast cancer screening behavior. Observed interactions among distrust and age, and between perceived prejudice with education and with race indicate the significance of distinguishing among racial/cultural, socioeconomic, and cognitive contributors of habits of utilization of health services. Findings highlight the importance of instilling habits of routine breast cancer screening behavior, especially among vulnerable groups of women. Cognitive biases that reinforce and perpetuate distrust influence decision-making and initiation and maintenance of routine screening behavior.

Word Count: 238

Keywords: Asymmetry principle, distrust in the health care system, habits of utilization of health services, breast cancer screening, cognitive biases, decision-making

Breast cancer is the second leading cause of cancer death among women in the U.S. and more than 40,000 American women are expected to die from the disease during 2006 (American Cancer Society, 2006). Despite progress in reducing overall breast cancer mortality, significant disparities exist in diagnosis, treatment, and survival among American women from different racial/ethnic backgrounds. Li and colleagues (Li, Malone, & Daling, 2003) evaluated data from 11 tumor registries containing information on approximately 125,000 women from all major racial/ethnic populations in the U.S. who were diagnosed with breast cancer between 1992 and 1998. They reported that women of specific racial/ethnic subgroups were 20% to 260% more likely to be diagnosed with late-stage breast cancer compared to non-Hispanic Whites. Individual beliefs (Hubbell, 2006; Russell, Champion, & Skinner, 2006) and attitudes about medical care and the health system (Facione, 1999; Yu & T.y., 2005) contribute to perceptions of lack of access to care, and compromise efforts of breast cancer early detection programs. Distrust in the health system might be a significant factor that influences the decision to obtain routine medical care, such as breast cancer screening.

Habits of utilization of health services, distrust in the health care system, decision-making regarding cancer screening, and the asymmetry principle

Cultural beliefs, personal values, and perceived social discrimination might influence expectations of access to care that account for much of the observed differences in cancer screening behavior (Facione & Katapodi, 2000; Hiatt & Pasick, 1996; Suarez, Roche, & Nichols, 1997). Attitudinal and belief variables are not considered to be a direct reason for using health services; rather they affect women's predisposition to use these services (Andersen & Newman, 1973; Facione, 1999). Predisposition to use health services is manifested through habits of utilization of such services.

Habits are considered an important construct in models of human behavior; they are tendencies to repeat responses given a stable supporting context (Triandis, 1980). Frequency of actions or choices reflects habitual patterns that are guided by automated cognitive processes, rather than being preceded by elaborate decision-making (Aarts, Verplanken, & van Knippenberg, 1998). With repetition of a behavior in a given setting the cognitive processes that initiate and control the response can be performed quickly, in parallel with other activities, and with allocation of minimal focal attention. In contrast, the initiation and execution of non-routine responses or responses in novel contexts require controlled processing, which is relatively slow and limited by the capacity of the short term memory. Therefore, habitual responses are likely to occur due to the speed and ease with which they can be performed, and help save cognitive resources and time (Quellette & Wood, 1998; Ronis, Yates, & Kirscht, 1989).

Narrative data enrich our understanding of the role of habits in health-related behavior. Research findings suggest that health-related habits stemmed from preferences, while norms and moral attitudes emerged as important dimensions of decision-making (Lindblach & Lyttkens, 2002). However, the latter factors were not important alternative governing mechanisms to habits. Rather, the moral attitude towards the ubiquitous notion of habit-governed behavior was perceived as more important. Habits saved resources by facilitating the assessment of expected utilities. The degree of utility attached to a habit depended on the objective scope of decision-making. When the amount of resources has been scarce and few opportunities to choose between alternatives have been offered, the dependency upon the energy-saving habit increased. In contrast, a continuous exposure to calculated choices on a daily or systematic basis predisposed individuals to deliberate decision-making, which meant that energy-related costs to deliberate decision-making were reduced (Lindblach & Lyttkens, 2002).

Distrust in the health care system might influence utilization of health services and decision-making regarding cancer screening. Distrust to the health care system has been mainly attributed to

cultural expectations of prejudicial treatment and institutional racism (Rajaram & Rashidi, 1998), and research studies have repeatedly reported cultural, racial, and ethnic differences in distrust. In a nationwide random-digit-dial survey of 6,722 adults in the U.S., large proportions of non-Hispanic Blacks, Hispanics, and Asians reported being treated with disrespect and that they would have received better care if their race had been different (Blanchard & Lurie, 2004). Distrust to the health care system was a significant barrier for participation in cancer screening programs for African Americans (Wolff, Bates, Beck, Young, Ahmed, & Maurana, 2003). Beliefs that health providers and the medical establishment do not protect patients' interests made African-Americans reluctant to participate in colorectal (Greiner, Born, Nollen, & Ahluwalia, 2005) and prostate cancer screening (Forrester-Anderson, 2005), and guided decisions to refuse treatment in cases of African American men with prostate cancer (Jones & Wenzel, 2005), male veterans with lung cancer (Sharf, Stelljes, & Gordon, 2005), and Muslim women with breast cancer (Remmenich, 2006).

However, distrust toward health services might also stem from individual characteristics. One of the most fundamental qualities of trust is that it is fragile. It is created rather slowly, but it can be destroyed in an instant by a single act of betrayal (Barber, 1983). The fact that trust is easier to destroy than to create reflects a psychological mechanism which social psychology termed the "asymmetry principle" (Slovic, 1993). The asymmetry principle implies that when it comes to winning trust, the playing field is not level, but rather it is tilted toward distrust. Explanations for the asymmetry principle draw on cognitive biases, such as "negativity bias", "confirmatory bias", and other choice biases. Negative and trust-destroying events are more visible and noticeable, carry greater weight, and are perceived as more diagnostic or informative than positive events (Slovic, 1999). "Negativity bias" hinges on the notion that people pay more attention to and are more influenced by trust-destroying than by trust-building information (Siegrist & Cvetkovich, 2001). Often the diagnostic and informative value of an

event depends on its specificity. Events with low specificity, such as general beliefs and stereotypes, are often seen as representative of the norm and therefore are perceived as more diagnostic of future performance compared to specific incidences. In the absence of trust, the diagnostic value of an event becomes very important (White & Eiser, 2005).

An underlying assumption of the asymmetry principle is that people have to continuously re-evaluate and adapt their ideas about the trustworthiness of others. However, people do not always have the time, cognitive resources, or willingness to make elaborate assessments as to whether someone can be trusted or not. Trust judgments are often based on perceived similarity and stereotypes rather than on carefully reasoned arguments or direct evidence (Cvetkovich, Siegrist, Murray, & Tragesser, 2002). The “confirmatory bias” draws on the notion that trust binds people who share similar social identities and worldviews (Dake, 1991), because people discount evidence that contradicts their own views, while they select information that supports their existing beliefs and attitudes (White, Pahl, Buehner, & Haye, 2003).

Once distrust is initiated, it is self-reinforcing and self-perpetuating. It inhibits personal interactions that are necessary to overcome distrust, resulting in a lack of opportunities for learning about trustworthiness (Slovic, 1999). Trust may be especially vulnerable when people are uncertain or ambivalent about a particular risk issue. In such cases, and in cases that people are already distrustful negative information is perceived as far more informative (Poortinga & Pidgeon, 2004), and negative events have great trust-decreasing impact (Cvetkovich, Siegrist, Murray et al., 2002).

Studies of cancer screening behavior have attributed distrust to the health care system to beliefs and attitudes that stem from cultural and ethnic differences. Although these differences exist and are important barriers to cancer screening and utilization of health services, significantly less attention has been given to cognitive processes that contribute to the self-reinforcing and self-perpetuating attributes of distrust. Examining cognitive factors that enhance or maintain distrust to the health system might help

understand women's decisions to utilize cancer screening services in a habitual or inconsistent manner, and provide additional tools for more effective communication between health providers and lay people.

The purpose of the study was to examine the role of distrust to the health care system as a cognitive factor that influences habits of utilization of health services and decision making regarding breast cancer screening. Specifically the study examined 1) the influence of distrust on habits of utilization of health services and 2) the influence of attitudinal and habitual characteristics on obtaining screening Mammograms and Clinical Breast Exams (CBEs).

Design, Recruitment, and Procedures

The present analysis is part of a community-based survey that examined perceived breast cancer risk, the relation between subjective and objective risk assessments, and decision making (Katapodi, Dodd, Lee, Facione, & Cooper, 2004). This cross-sectional survey was advertised as "Women's Breast Study" and recruited a convenience sample from community settings throughout the San Francisco Bay Area. Women were eligible to participate if they were between the ages of 30 and 85, had never been diagnosed with any type of cancer, and were willing to complete a questionnaire in English. The minimum and the maximum age limits were chosen according to the aims of the parent study, so that an objective assessment of women's breast cancer risk was estimated with the Gail model (Gail, Brinton, Byar, Corle, Green, Schairer et al., 1989). Women with a prior diagnosis of any type of cancer were excluded because the focus was on secondary prevention of breast cancer.

Recruitment was done through local newspapers targeting different ethnic groups, and through flyers posted in places that women were likely to visit in their daily living, such as senior and cultural centers, homeless shelters, libraries, restaurants, coffee shops, churches, temples, and workplaces. Potential participants responded by calling a dedicated telephone number and expressing their interest in

the study. The first author assessed eligibility for study participation, and administered the survey questionnaires face-to-face in places that were comfortable and convenient for every participant. Participants were paid \$15. The University of California San Francisco Committee on Human Rights and the Institutional Review Board of the funding agency approved the study protocol. Data collection occurred over a period of 13 months between February 2003 and March 2004.

Methods

Measures

The challenge in measuring *distrust* was to capture the asymmetry principle and the underlying assumption that people are naturally inclined toward it. Based on findings regarding cognitive biases related to perceived breast cancer risk (Katapodi, Facione, Humphreys, & Dodd, 2005), Katapodi developed four items to directly target distrust as a factor influencing breast cancer risk management. The four items were created in order to capture distrust to the health system and both the negativity and confirmatory biases, such as “I trust my health care provider” and “I always believe someone when they say that their health provider hasn’t been nice to them.” Participants were asked to indicate the degree to which they agreed with each of the four statements on a four-point Likert-type scale (strongly agree to strongly disagree).

The internal consistency reliability of the items was evaluated using factor analytic methods. The four items loaded on a single principal component and explained 54% of the variance in distrust to the health care system. Individual loadings ranged from 0.63 to 0.78. Internal consistency reliability (Cronbach alpha) of the items was 0.71. Based on these analyses, the four items were summed to create the measure of *Distrust in the Health Care System (DHCS)* used in the study. Based on the assumption that individuals are inclined towards distrust, higher scores indicate greater distrust.

The four items have face validity (i.e., “I trust my health care providers”). In addition, convergent validity of the DHCS was evaluated for non-black Hispanic and Asian women in the study by examining the association between acculturation and distrust. Acculturation represents the extent to which a member of an ethnic group embraces the traditions, values, beliefs, assumptions, and practices of the host society. Lower acculturation is expected to be associated with higher distrust. Assessment of acculturation was based on spoken language and was measured with a six-item acculturation scale (Marin, Sabogal, Marin, Otero-Sabogal, & Perez-Stable, 1987). There was a moderate but significant negative correlation between acculturation and distrust for the 55 women in the study who were Hispanic or Asian ($r=-0.27$, $p<0.05$).

Based on the assumption that personal experience with prejudicial treatment within the health system would enhance the cognitive processes that reinforce and perpetuate distrust, we used the *Personally Experienced Prejudice (PEP)* scale, which was developed by Facione to measure women’s personal experiences and perceived prejudice. The validity of the scale has been established with a significant Pearson correlation ($r=0.78$) with a measure of perceived racism; items have an internal consistency of 0.71-0.79 (Cronbach alpha) (Facione, 1999; Facione & Facione, Under Review). The scale contains four items; each item is scored -2 to +2 to correspond with absence or presence of perceived prejudice. Possible total scores range from -8 to +8, with positive scores affirming the perception of prejudice and negative scores denying it.

Utilization of health services was measured with the *Habit of Health Services Utilization (HHSU)* scale (Facione, Miaskowski, Dodd, & Paul, 2002). The scale contains seven items that address seeking a provider visit for illness symptoms and wellness checkups, such as “Going to the doctor regularly is a normal part of how I take care of myself”, and “I usually follow all the recommendations of getting check

ups.” Responses are rated on a four-point Likert-type scale (strongly agree to strongly disagree). Cronbach alpha for the HHSU scale was 0.84 in this sample.

Breast Cancer Screening Behaviors and *Demographic Characteristics* were assessed with questions used in the 2001 survey of the Behavioral Risk Factors Surveillance System (CDC, 2002). We asked participants how often they have a screening mammogram and a CBE, how long it has been since their last mammogram and their last CBE, and what was the reason for their most recent mammogram and CBE. We also asked them to indicate whether their first-degree or second-degree relatives had been affected by the disease. For the purposes of this analysis *Family History (FH)* was dichotomized as “0” indicating a negative family history of breast cancer and “1” indicating a positive family history.

Statistical Analyses

Data were analyzed using the SPSS 13® statistical program. We calculated individual scores when at least 60% of items were completed. Distributions were checked for normality. Power analysis indicated that a sample of $N=147$ would provide $\text{Power}=0.80$ to detect moderate correlations among predictive variables ($R^2=0.13$) with $\alpha=0.05$. We used descriptive statistics for demographic characteristics. We used bivariate analysis (Pearson correlation, independent samples t-test) and multivariate analysis (ANOVA) with Bonferroni post hoc contrasts to describe differences in distrust, perceived prejudice, and utilization of health services. We performed simultaneous regression analyses to identify first, predictors of utilization of health services, and second, predictors of breast cancer screening behaviors. To reduce expected multicollinearity among predictors, variables were centered prior to use in regression analyses. Centering removes non-essential multicollinearity that is due to scaling and consists of subtracting the mean of each variable from each observed value (Cohen, Cohen, West, & Aiken, 2002).

Results

Sample

This community-based survey recruited a multicultural sample (43% non-Hispanic White, 27% non-Hispanic Black, 14% Hispanic, 16% Asian) of 184 women with a mean age of 47 ± 12 (range 30 to 84). This sample size provides adequate power for the analyses to follow. 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 12% reporting an annual income of $> \$70,000$. Most women (77%) had some form of health insurance and approximately two thirds (64%) did not have a family history of breast cancer. Although the sample was broadly comparable to the San Francisco Bay Area population, there was an over-representation of non-Hispanic Black women and women with college education (US Census, 2000).

There were no significant differences among women of different race/ethnicity regarding their mean age and their family history of breast cancer. Asian and Non-Hispanic White women were more likely to have higher education compared to non-Hispanic Black and Hispanic women, but not compared to each other ($F_{(3,180)}=15.86$, $p<0.001$). Asian women were more likely to report higher income than women of other racial/ethnic backgrounds ($F_{(3,172)}=6.90$, $p<0.001$). Education was significantly correlated with income only for non-Hispanic Black women ($r=0.50$, $p=0.001$).

Scores were normally distributed in the DHCS (9.17 ± 2.12 , range: 4-16), the PEP (-1.49 ± 3.57 , range: -8- 8), and the HHSU (34.94 ± 5.50 , range: 18-46) scales. As hypothesized, there was a significant correlation between distrust (DHCS) and personal experiences with prejudice (PEP) ($r=0.58$, $p<0.001$). Moreover, there were small but significant negative correlations between distrust and age ($r=-0.17$, $p<0.05$) and habits of health services utilization (HHSU) ($r=-0.28$, $p<0.001$). Women with a positive

family history were not more likely to report higher utilization of health services compared to those with no family history. There were no significant differences in levels of reported distrust and habits of utilization of health services among women of different race/ethnicities. However, women with lower income were significantly more likely to report more experiences with prejudicial treatment within the health system ($r = -0.22$, $p < 0.001$), while Asian women were significantly less likely to report perceived prejudice compared to all other women in the sample ($F_{(3,179)} = 3.72$, $p = 0.013$).

The influence of perceived prejudice and distrust on habits of health services utilization

We performed a simultaneous regression analysis to examine the influence of perceived prejudice, distrust, age, education, income, health insurance, family history of breast cancer, and race/ethnicity on habits of health services utilization. The model was significant ($R^2 = 0.17$ $\Delta F = 3.20$, $p = 0.002$) with distrust in the health care system being the single most significant predictor of habits of utilization of health services ($B = -0.55$, $p = 0.029$, $95\%CI_B -1.05 - -0.06$, $sr^2 = 0.10$).

We examined whether perceived prejudice and distrust acted as moderators between individual characteristics and habits of utilization of health services. To test for a moderator effect, predictors were entered simultaneously in the first step of a hierarchical regression followed by the interaction term in the second step. A moderator effect is present if the interaction term accounts for a statistically significant change in R-squared of the dependent variable (habits of utilization of health services) (Baron & Kenny, 1986). We tested for possible interactions in a two step process. First we examined whether interactions between demographics and perceived prejudice (PEP) influence the dependent variable (HHSU). Second we examined whether interactions between demographics and distrust (DHCS) influence the dependent variable (HHSU) above and beyond interactions involving perceived prejudice (PEP). The order in

which we tested for possible interactions was based on the assumption that women who had more personal experiences with prejudicial treatment would be more distrustful of the health system.

There were significant interactions of PEP with education and with being non-Hispanic Black that accounted for an additional 9% of the variance in habits of utilization of health services ($R^2=0.17$, $\Delta R^2=0.09$, $\Delta F=2.19$, $p=0.031$, $B_{PEP \times Black} = 0.85$, 95%CI 0.03 - 1.70, $sr^2 = 0.03$, $p=0.49$, $B_{PEP \times Education} = -0.44$, 95%CI -0.88 - -0.06, $sr^2 = 0.04$, $p=0.22$). A significant interaction between DHCS and age accounted for an additional 10% in the variance of habits of utilization of health services, which was above and beyond contributions made by experiences with prejudicial treatment ($R^2=0.36$, $\Delta R^2=0.10$, $\Delta F=2.44$, $p=0.015$, $B_{Age \times DHCS} = -0.07$, 95%CI -0.11 - -0.03, $sr^2 = 0.10$, $p<0.001$).

Predictors of breast cancer screening

From the 115 women in the study who were older than 40 years of age, the majority (69%) reported having a screening mammogram every one to two years. However, 12% reported never having one or that it had been more than 24 months since their last mammogram. We examined behaviors related to CBE for all women in the sample (N=184). Most women (59%) reported having a CBE every year; however, 16% reported that it had been more than 24 months since their last CBE. (See Table 1).

(Insert Table 1 about here)

In order to examine the influence of perceived prejudice, distrust, and habits of utilization of health services on decision making regarding breast cancer screening, we performed four simultaneous regression analyses in which each screening behavior was the dependent variable, whereas distrust, habits of utilization of health services, and demographic characteristics were the predictor variables. All models explained significant variance in screening behavior. Distrust in the health system and perceived

prejudice were not significant predictors of any screening behavior, while habits of utilization of health services were a significant predictor for three out of the four screening behaviors. Other significant predictors included age, income, insurance, and race/ethnicity (See Table 2). There were no significant interactions between perceived prejudice, distrust, and other predictors of screening behavior.

(Insert Table 2 about here).

Figure 1 is a graphic representation of the findings of the study.

(Insert Figure 1 about here).

Discussion

The study examined distrust to the health care system as a cognitive factor that influences habits of utilization of health services and breast cancer screening. The major findings of the study were that habits of utilization of health services were a significant predictor for breast cancer screening behavior. Distrust to the health care system did not have a direct effect on screening but was the most significant predictor of habits of utilization of health services. Moreover, there were significant interactions between demographics, distrust, and personal experiences with prejudice that accounted for additional variance in the habits of utilization of health services.

Although women that had personal experiences with prejudicial treatment were significantly more likely to have higher distrust in the health care system, perceived prejudice did not predict habits of utilization of health services. This finding suggests that experiences with prejudicial treatment are a necessary but not a sufficient condition for an individual not to utilize health services. Rather, perceived prejudice is likely to enhance the cognitive processes that maintain distrust to the health system. Distrust was the single most important predictor of habits of utilization of health services, which in turn was a significant predictor of screening behavior. Although we did not find a direct relation between distrust

and screening behavior, our findings are consistent with research suggesting that trust is a significant component of decision-making regarding risk management (Slovic, 1999). Our findings suggest that distrust to the health system can significantly compromise women's decisions to adopt habitual breast cancer screening behaviors. This finding has significant clinical implications since early detection of breast cancer depends primarily on routine screening and educational interventions strive to instill these behaviors.

Habits of utilization of health services were a significant predictor of women's decision-making regarding breast cancer screening. The majority of women in the study (70%) had a routine mammogram and CBE, and more than 50% had a mammogram or CBE within the past 12 months. Based on these findings we can assume that most women in the sample utilized cancer screening services on a routine basis. This means that for those women decisions to obtain cancer screening were made repeatedly over time, were relatively simple, less deliberate and elaborate, and entailed low perceived risk. For few women (5-10%) that had their most recent mammogram or CBE for a breast problem, we can assume that their decision to obtain screening was made in the novel context of having an unusual breast symptom that needed medical evaluation.

Understanding habits of utilization of health services and distrust to the health system is an important milestone in the quest of understanding decisions regarding routine breast cancer screening versus decisions that are made in the presence of an unusual breast symptom or in an unfamiliar context (i.e., immigrant women). In these latter situations, habit of utilization of health services and distrust to the health system appear to play an important role in guiding women's decision-making process. If unusual symptoms or an unfamiliar context are used as cues to reproduce a habitual behavior, they do not have the power to trigger the deliberate, norm-based system (Schwartz & Howard, 1981). Research findings suggest that habits are a strong moderator between attitudes and norms and behavior (Klockner

& Matthies, 2004). If habits are strong, subsequent decision making in novel contexts will occur according to existing behavioral schemata. If habits are weak, a more deliberate norm-based decision is possible. The study did not support that habits moderate the relationship between attitudes and behavior. However, our findings suggest that in situations of existing distrust to the health system it is difficult to establish routine breast cancer screening, possibly because distrust inhibits the development of habitual behavior and leads to inconsistent screening behaviors. This finding has significant clinical implications, especially in situations that women have to seek medical evaluation in an unfamiliar context or for an unusual symptom. Exploration of the salience of cues that motivate personal health behaviors is an area for further study. Some prior work has focused on the individual information processing cues that are instrumental in making health care decisions (Pierce, 1996; Pierce & Hicks, 2001), but little attention has been given to the salience of cognitive cues that are embedded in the social discourse between patient and provider.

The observed interactions between distrust and age, and between perceived prejudice, education, and self-identifying as non -Hispanic Black, and their impact on habits of utilization of health services, emphasize that in situations requiring long term relationships, such as breast cancer screening, distrust and possibly other naturalistic and rule-of-thumb based approaches in utilization of health services may take the greatest toll among vulnerable groups of women. Early research on risk analysis suggested that attitudes towards the role of power, social status, political worldviews, and other sociopolitical factors determine trust and acceptance of experts as risk managers. Individuals with higher education and higher income are more likely to have a greater sense of affiliation with experts and trust risk managers, whereas the opposite is true for individuals who lack these characteristics (Flynn, Slovic, & Mertz, 1994; Slovic, 1999).

It is very difficult to distinguish whether differences in distrust and habits of utilization of health services can be attributed to racial/cultural characteristics, to socioeconomic factors, or to cognitive biases in decision-making. Although non-Hispanic Black women in the sample had lower education and lower income, they were not more likely to be distrustful compared to other women. This finding is in contrast with other studies reporting that non-Hispanic Blacks are more distrustful than non-Hispanic Whites (Gorbie-Smith, Thomas, & St George, 2002; Keating, Gandhi, Orav, Bates, & Ayanian, 2004; Wolff, Bates, Beck et al., 2003). In addition, although Asian participants were more likely to have higher socioeconomic status and were less likely to report experiences with prejudicial treatment, they did not report less distrust to the health system. Although they were obtaining screening mammograms, they were significantly less likely to present for a CBE, presumably as a means to preserve modesty (Hoeman, Ku, & Roth, 1996; Lu, 1995; Mo, 1992). It is possible that trust in health providers might partially help overcome barriers that are imposed by expectations of culturally appropriate behavior. However, future studies, with larger, stratified samples might help distinguish among racial/cultural, socioeconomic, and cognitive determinants of distrust and habits of utilization of health services.

Moreover, non-Hispanic Black women possibly had more opportunities to learn trustworthiness to the health system. Self-identifying as non-Hispanic Black was the second most significant predictor of obtaining screening mammograms, which is consistent with another study reporting that non-Hispanic Blacks were more likely than non-Hispanic Whites to receive optimal cancer screening (Blanchard & Lurie, 2004). Since we did not recruit participants from health care settings, this finding likely reflects outcomes of community outreach programs that focused their efforts on promoting screening in underserved and minority groups. Although this finding cannot be generalized to the entire female U.S. population, it is possible that cancer screening programs are able to address health disparities within specific geographic areas.

The same explanation likely holds true for the negative correlation observed between age and distrust. In the present study, age was the most significant predictor of mammography screening, accounting for 44% of the variance in frequency of obtaining a mammogram. It appears that older women have more opportunities to learn about trustworthiness of the health system through efforts that promote mammography screening among older and socioeconomically disadvantaged women (Bush & Langer, 1998; Miller & Champion, 1996; Rawl, Champion, Menon, & Foster, 2000). Efforts of the health system to target older women for screening mammograms can outweigh commonly reported barriers, such as income and health insurance.

The limitations of the study should be considered, to properly temper any conclusions. The results are based on a convenience sample of self-selected, English-speaking, and mostly urban women. Assessment of screening behavior was based on self-report. Although the overall sample provided adequate power, the stability of the examined relationships might be limited by the small number of women who self-identified as Hispanic and Asian, and due to the number of women who were older than 40 years. Since convergent validity of the DHCS scale was evaluated only for Hispanic and Asian women, it is possible that DHCS is not useful for non-Hispanic Black and non-Hispanic White women. Finally, in the present analysis we did not include characteristics of the health system, such as availability of resources, i.e., free-of-charge mammograms. Despite these limitations, the strength of the study is that it recruited women from diverse socioeconomic and racial/cultural backgrounds from community settings, which ensured that participation in the study was not limited to women that had greater access to health services.

Distrust in the health system is a significant barrier for habitual and routine breast cancer screening and effective breast cancer risk management. The study has significant implications for health policy, decision-making, and risk communication. Policy makers, health providers, and decision-making

researchers need to pay closer attention to distrust to health services as an important factor that indirectly influences cancer control, through habits of utilization of health services. Establishing a mutually respectful relationship between lay women and the experts in breast cancer risk management requires more than a respectful relationship between an individual and her provider. It requires structural, institutional, and legal transformations that allow women to perceive a positive feedback when making the decision to utilize health services and to pursue routine breast cancer screening.

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Appendix

Table 1. Breast Cancer Screening Behavior

Screening Behavior		N	%
How often do you have a mammogram? (N=115, Age ≥40)	Never	14	12

	Once or twice before	17	15
	Every one to two years	80	69
	Missing	4	4
How long has it been since your last mammogram? (N=115, Age ≥ 40)	I am too young to have a mammogram	1	
	past 1 year (<12 months ago)	62	54
	past 2 years (12 to 24 months ago)	23	20
	past 3 years (24 to 36 months ago)	4	4
	past 5 years (36 to 60 months ago)	4	4
	5 or more years ago	5	4
	Missing	16	14
Reason for most recent mammogram? (N=115, Age ≥ 40)		98	85
	Routine checkup		
	Breast problem other than breast cancer	14	12
	Missing	3	3
How often do you have a CBE? (N=184)			
	Never	19	10
	Once before	11	6
	Every 2 to 3 years	41	22
	Every year	108	59
	Missing	5	3
How long has it been since your last CBE? (N=184)			
	past 1 year (< 12 months ago)	99	54
	past 2 years (12 to 24 months ago)	38	21
	past 3 years (24 to 36 months ago)	12	6
	past 5 years (36 to 60 months ago)	4	2
	≥ 5 years ago	15	8
	Missing	16	9
Reason for most recent CBE? (N=184)			
	Routine checkup	157	85
	Breast problem other than breast cancer	9	5
	Missing	18	10

Table 2. Predictors of Screening Behavior

Screening Behavior												
	Often Mammogram			Long since Last Mammogram			Often CBE			Long since Last CBE		
	R ² =0.53 ΔF=14.91 p<0.001			R ² =0.19 ΔF=2.71 p=0.004			R ² =0.16 ΔF=2.60 p=0.005			R ² =0.22 ΔF=3.60 p<0.001		
Predictors	sr ²	B	95%CI	sr ²	B	95%CI	sr ²	B	95%CI	sr ²	B	95%CI
Age	0.45	0.05**	0.04 – 0.06	0.08	0.03**	0.01 – 0.05	0.01	0.00	-0.01 – 0.01	0.01	-0.01	-0.02 – 0.01
Education	0.01	-0.01	-0.13 – 0.12	0.03	-0.25	-0.50 – 0.01	0.01	0.03	-0.14 – 0.21	0.01	-0.05	-0.28 – 0.17
Income	0.03	0.05*	0.01 – 0.09	0.04	0.09*	0.01 – 0.18	0.01	0.01	-0.05 – 0.07	0.01	-0.04	-0.11 – 0.04
Insurance	0.01	-0.11	-0.41 – 0.18	0.08	-1.08**	-1.71 – -0.46	0.01	0.09	-0.32 – 0.50	0.03	-0.61*	-1.12 – -0.10
Family History	0.01	0.07	-0.17 – 0.31	0.01	0.27	-0.18 – 0.73	0.01	-0.05	-0.40 – 0.28	0.01	0.06	-0.35 – 0.48
Asian vs. White	0.01	-0.08	-0.04 – 0.25	0.02	-0.47	-1.15 – 0.21	0.03	-0.52*	-0.97 – -0.06	0.01	0.06	-0.54 – 0.67
Black vs. White	0.05	0.37*	0.09 – 0.66	0.01	-0.17	-0.70 – 0.36	0.01	-0.18	-0.58 – 0.22	0.01	0.19	-0.30 – 0.68
Hispanic vs. White	0.01	0.03	-0.32 – 0.38	0.01	-0.18	-0.86 – 0.49	0.01	-0.16	-0.65 – 0.33	0.01	0.05	-0.56 – 0.67
HSUS	0.04	0.02*	0.01 – 0.04	0.02	-0.03	-0.07 – 0.01	0.13	0.07**	0.04 – 0.10	0.14	-0.08**	-0.12 – -0.05
DHCS	0.01	-0.01	-0.02 – 0.01	0.01	-0.01	-0.04 – 0.02	0.01	0.01	-0.01 – 0.03	0.03	-0.02	-0.05 – 0.01
PEP	0.01	-0.01	-0.05 – 0.03	0.01	-0.01	-0.08 – 0.07	0.00	0.00	-0.06 – 0.06	0.01	-0.03	-0.10 – 0.03

*p<0.05, **p<0.01

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	sr ²	B	95%CI	sr ²	B	95%CI	sr ²	B	95%CI	sr ²	B	95%CI
Age	0.45	0.05**	0.04 – 0.06	0.08	0.03**	0.01 – 0.05	0.01	0.00	-0.01 – 0.01	0.01	-0.01	-0.02 – 0.01
Education	0.01	-0.01	-0.13 – 0.12	0.03	-0.25	-0.50 – 0.01	0.01	0.03	-0.14 – 0.21	0.01	-0.05	-0.28 – 0.17
Income	0.03	0.05*	0.01 – 0.09	0.04	0.09*	0.01 – 0.18	0.01	0.01	-0.05 – 0.07	0.01	-0.04	-0.11 – 0.04
Insurance	0.01	-0.11	-0.41 – 0.18	0.08	-1.08**	-1.71 – -0.46	0.01	0.09	-0.32 – 0.50	0.03	-0.61*	-1.12 – -0.10
Family History	0.01	0.07	-0.17 – 0.31	0.01	0.27	-0.18 – 0.73	0.01	-0.05	-0.40 – 0.28	0.01	0.06	-0.35 – 0.48
Asian vs. White	0.01	-0.08	-0.04 – 0.25	0.02	-0.47	-1.15 – 0.21	0.03	-0.52*	-0.97 – -0.06	0.01	0.06	-0.54 – 0.67
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HSUS	0.04	0.02*	0.01 – 0.04	0.02	-0.03	-0.07 – 0.01	0.13	0.07**	0.04 – 0.10	0.14	-0.08**	-0.12 – -0.05
DHCS	0.01	-0.01	-0.02 – 0.01	0.01	-0.01	-0.04 – 0.02	0.01	0.01	-0.01 – 0.03	0.03	-0.02	-0.05 – 0.01
PEP	0.01	-0.01	-0.05 – 0.03	0.01	-0.01	-0.08 – 0.07	0.00	0.00	-0.06 – 0.06	0.01	-0.03	-0.10 – 0.03

*p<0.05, **p<0.01

