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EXPRORING PERCEIVED BREAST CANCER RISK:
A TRIANGULATION STUDY IN A MULTICULTURAL COMMUNITY SAMPLE

By

MARIA C. KATAPODI, RN, MSN

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

In

NURSING

In the

GRADUATE DIVISIONS

Of the

UNIVERSITY OF CALIFORNIA SAN FRANCISCO



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By

MARIA C. KATAPODI

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I dedicate this work to the memory of my father, Chryssanthos Katapodis, since I am half of who he was.

Thank you.

Maria C. Katapodi, RN, MSN

This dissertation project contains published material; one published article and a second article currently (June 2004) in press. The published article is titled "Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review". The student Maria Katapodi was responsible for approximately 90% of the work involved for the completion of the article: selection of articles, meta-analysis of findings, interpretation of the findings, and writing of the manuscript. The work is comparable with a chapter representing the literature review in a standard dissertation. The article in press is titled "Perceived breast cancer risk: Heuristic reasoning and search for dominance structure". The student Maria Katapodi was responsible for approximately 90% of the work involved for the completion of the article: selection of interviews, analysis of the data, interpretation of the findings, and writing of the manuscript. The work is comparable with a chapter addressing findings of a standard dissertation.

The Dissertation Chair



Marilyn J. Dodd, RN, PhD, FAAN

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MARIA C. KATAPODI, RN, MSN

ABSTRACT

Background: Perceived risk is a predictor of adopting health-protective behaviors. People construct risk perceptions by using inferential rules, called heuristics. Meta-analysis of studies suggested that women do not have accurate perceptions of their breast cancer risk. Having a positive family history, worry, and breast symptoms predicted perceived risk, but results were confounded by measurement errors and selection bias.

Purpose: To 1) describe perceived breast cancer risk, 2) examine consistency of responses across different risk measures, 3) examine the influence of demographic characteristics on perceived risk, 4) compare subjective and objective risk estimates, 5) examine whether experiences with affected family members and friends, and having breast symptoms influence perceived risk, 6) examine whether knowledge of breast cancer risk factors and worry moderate the relationships between experiences and perceived risk, and 7) identify heuristic rules that influence perceived risk.

Methods: This cross-sectional, triangulation survey used three probability scales (Verbal, Comparative, Numerical) and the Gail model to measure perceived and objective risk, respectively. Argument and Heuristic reasoning analysis, a method based on applied logic, was used to identify heuristics in narrative data. We recruited a multicultural sample of 184 English-speaking women from community settings to complete the survey.

We performed secondary analysis of 11 interviews that were previously conducted in a similar sample.

Findings: Participants held an optimistic bias regarding their breast cancer risk. They believed their breast cancer risk was lower than average, they rated the risk for friends/peers higher than their own, and underestimated their objective risk. Responses on the Verbal and Comparative scales were consistent, whereas Numerical risk ratings were influenced by demographic characteristics. Older women and those with one affected first-degree relative did not perceive higher risk. Experiences with affected family members and friends, and breast symptoms influence perceived risk through various mechanisms, involving knowledge of risk factors, worry, and heuristics. Assessment of a breast symptom was facilitated by the search for a dominance structure. Experiences with affected family members and friends were incorporated into perceived risk through the availability, simulation, representativeness, and affect heuristics. Heuristics created predictable biases. Perceived breast cancer risk is based on common cognitive patterns.

Word Count: 350

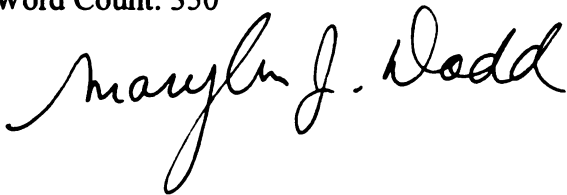
A handwritten signature in black ink that reads "Marilyn J. Dodd". The signature is written in a cursive, flowing style.

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Introduction

Breast cancer is the most common type of cancer in women and the second leading cause of cancer death for women in the United States (American Cancer Society, 2003). Molecular biology and genetics have improved our understanding of breast cancer etiology. By using the Gail model (Gail et al., 1989) health care providers can estimate the probability of an individual woman developing breast cancer during a defined age interval. Individualized counseling and public health educational interventions use this factual knowledge and aim to educate women about their own probability of developing breast cancer, and promote self-monitoring for early signs and adherence to screening guidelines (Altpeter, Earp, & Schopler, 1998; Hiatt & Pasick, 1996; Skinner et al., 1998). The goal of such programs is to bring an individual's perceived risk of developing breast cancer in line with her actual risk. Presumably, a more realistic perceived breast cancer risk will motivate the initiation and maintenance of health-protective behaviors at a level that is appropriate for the individual's level of risk (Leventhal, Kelly, & Leventhal, 1999). This is a common assumption of many theoretical models, such as the Adoption Precaution Model (Weinstein, 1988), suggesting that the decision to adopt a self-protective behavior is a cost-benefit analysis of consequential outcomes, and is reached through an analysis of susceptibility, potential actions, potential costs, and anticipated outcomes.

However, there is evidence that some women do not take into account factual information from the Gail model (Daly et al., 1996) and instead underestimate their breast cancer risk (N.C. Facione, 2002). Moreover, evidence is conflicting as to whether educational interventions that aim to change perceptions of risk can improve subsequent

cancer screening (Vernon, 1999), presumably, because women do not understand the meaning of terms and phrases that are commonly used in breast cancer prevention messages, such as “risk factors” and “at risk” (Roche et al., 1998).

Therefore, the question is how individuals assess their own susceptibility to disease. How do they decide whether they are at risk for one or the other health problem? There is compelling evidence that the term “risk” has different meaning for different groups of people, namely the experts and the public (Slovic, 2000). Existing gaps in risk assessment services and inadequacy of the media to address individual concerns and to resolve conflicting information, force individuals to make subjective estimations of the likelihood of disease based on subjective understandings of probabilities, understanding of risk factors, and meanings they attach to risk attributes (Kelly, 1996).

Whenever people estimate the probability of future risks, instead of making elaborate calculations of all relevant information, all potential courses of action, and all potential outcomes, they seek to make fast decisions that lead to adaptation and survival (Simon, 1982). Judgment and decision-making theory suggests that in cases of uncertain information, judgments and behaviors are influenced by both rational and irrational information processing mechanisms (Kahneman, Slovic, & Tversky, 1982; Nisbett & Ross, 1980). These are distinctive mental operations, called heuristics, and help save cognitive resources and time. Although heuristics facilitate risk assessments, they can produce both valid and invalid judgments, and sometimes they lead to characteristic systematic errors. Heuristics act in combination with other cognitive mechanisms, such as “satisficing” (Simon, 1955), and facilitate cognitive structures, such as the “search for a dominance structure” (Montgomery, 1989).

In the area of breast cancer, it has been suggested that personal experiences with the disease are incorporated into risk perceptions through various heuristics (N.C. Facione, 2002; Montgomery, Erblich, DiLorenzo, & Bovbjerg, 2003; Rees, Fry, & Cull, 2001). While these studies have uncovered a connection between heuristics and risk perception, research is needed in order to understand precisely how heuristic thinking impacts breast cancer risk perception. There are several reasons why the study of heuristics in decision-making is advantageous over other approaches. First, the study of systematic errors in risk assessments can illuminate the psychological processes that underlie perception and judgments (Kahneman & Tversky, 1996). Second, identifying heuristics that lead to predictable biases can have practical implications for clinical judgment and risk assessment. Educational interventions at the individual or the community levels might be able to incorporate messages that counterbalance invalid risk perceptions that stem from heuristic thinking and impede the adoption of health-protective behaviors (Montgomery et al., 2003). Third, study of heuristics and bias might facilitate risk communication and the transmission of risk-related messages that are better received by lay people.

The purpose of this dissertation project was to use triangulation of methods, within-method triangulation and between-method triangulation (Burns & Grove, 1997) to describe perceived breast cancer risk, to describe predictors of perceived risk, and to uncover the impact of heuristic thinking on perceived risk. The dissertation is organized in five chapters.

The first chapter (Chapter 1) is titled: "Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic

review”. The text of this chapter is a reprint of the material as it appears in (Katapodi, Lee, Facione, & Dodd, 2004), Preventive Medicine, 38:388-402. The co-authors listed in this publication directed and supervised the research that forms the basis for the dissertation. The article presents a meta-analytic review of current scientific literature. The purpose of the meta-analysis was to synthesize research findings on perceived breast cancer risk. The study examined demographic, psychological, and physiological variables as predictors of perceived breast cancer risk, and the relationship between perceived risk and breast cancer prevention and early detection.

The second chapter (Chapter 2) is titled: “Optimistic bias regarding the probability of developing breast cancer in a multicultural community sample”, (Katapodi, Dodd et al., 2004). It was presented in the 9th Biennial Symposium on Minorities, the Medically Underserved, and Cancer of the Intercultural Cancer Council, and it will be submitted to Annals of Behavioral Medicine. This article presents findings from a survey that used within-method triangulation. The survey recruited a multicultural community sample of 184 English-speaking women. It used three probability scales (Verbal, Comparative, and Numerical) to measure perceived risk and the Gail model to measure objective risk. The purpose of this chapter was to 1) describe perceived breast cancer risk, 2) examine consistency of women’s responses across different risk measures, 3) examine the influence of demographic characteristics on perceived risk, and 4) to compare subjective and objective risk estimates.

The third chapter (Chapter 3) is titled: “How and when do experiences with affected family members and friends, and personal experiences with abnormal breast symptoms influence perceived breast cancer risk?” and it will be submitted to the Journal

of Behavioral Medicine. We performed a Principal Component Analysis using the three probability measures to create a new measure of Perceived Risk, which accounted for all shared variance among the three probability measures. The purpose of this chapter was to 1) examine whether experiences with affected family members, affected friends, and abnormal breast symptoms influence perceived risk, and 2) whether knowledge of breast cancer risk factors and worry moderated the relationships between experiences and perceived risk.

The fourth chapter (Chapter 4) is titled: “Perceived breast cancer risk: Heuristic reasoning and search for dominance structure”. The text of this chapter is a reprint of the material as it appears in (Katapodi, Facione, Humphreys, & Dodd, In Press) Social Science and Medicine. The co-authors listed in this publication directed and supervised the research that forms the basis for the dissertation. The article addresses the between-method triangulation design, and presents findings from a secondary analysis of 11 interviews that have been conducted with women with similar characteristics recruited from comparable community settings. The purpose of this article was to use Argument and Heuristic reasoning analysis, a method that is based on applied logic, to identify heuristics that influence perceived breast cancer risk.

Finally, the fifth chapter (Chapter 5) summarizes findings from the previous articles and addresses the current state of knowledge regarding perceived breast cancer risk.

Chapter 1.

Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review

Katapodi, M.C., Lee, K.A., Facione, N.C., Dodd, M.J. (2004). *Preventive Medicine*, 38, 388-402.

Abstract

Background: Perceived risk is a principal variable in theoretical models that attempt to predict the adoption of health-protective behaviors. **Methods:** This meta-analysis synthesizes findings from 42 studies, identified in PubMed and PsycInfo from 1985 onward. Studies examined demographic and psychological variables as predictors of perceived breast cancer risk and the relationship between perceived risk and breast cancer screening. Statistical relationships, weighted for sample size, were transformed to effect sizes and 95% CIs. **Results:** Women do not have accurate perceptions of their breast cancer risk (N= 5,561, g=1.10). Overall they have an optimistic bias about their personal risk (g=0.99). However, having a positive family history (N= 70,660, g=0.88), recruitment site, and measurement error confounded these results. Perceived risk is not weakly influenced by age (N=38,000, g=0.13) and education (N=1,979, g=0.16), and was moderately affected by race/culture (N=2,192, g=0.38) and worry (N=6,090, g=0.49). There is an association between perceived risk and mammography screening (N=52,766, g=0.19). It is not clear whether perceived risk influences adherence to breast self-examination. Women who perceived a higher breast cancer risk were more likely to pursue genetic testing or undergo prophylactic mastectomy. **Conclusion:** Perceived breast cancer risk depends on psychological and cognitive variables and influences adherence to mammography screening guidelines.

Word Count = 200

Key Words: perceived risk, breast cancer, prevention, screening, meta-analysis, optimistic bias

Introduction

Breast cancer is the most common type of cancer in women (American Cancer Society, 2003). Breast cancer screening has long been recognized for its value in improving survival and quality of life for individuals affected by the disease (C.B.C.R.P., 2001). In an effort to promote breast cancer early detection, health professionals attempt to bring an individual's perceived risk of developing breast cancer in line with her actual risk. Presumably, a more realistic perceived breast cancer risk will motivate the initiation and maintenance of health-protective behaviors at a level that is appropriate for the individual's level of risk (Leventhal et al., 1999). Along these lines, breast cancer early detection programs focus their efforts on ongoing public education about risk factors that increase a woman's probability of developing the disease (Altpeter et al., 1998; Hiatt & Pasick, 1996). However, evidence is conflicting as to whether educational interventions that aim to change perceptions of risk can improve subsequent cancer screening (Vernon, 1999). There is some indication that women do not understand the meaning of terms and phrases that are commonly used in breast cancer prevention messages, such as "risk factors" and "at risk" (Roche et al., 1998).

The term "risk" has a different meaning for different groups of people, namely the experts and the public (Slovic, 1987). Studies that explored perceived breast cancer risk suggest that lay women hold a different set of beliefs about the causes, curability, and risk factors of breast cancer than health care experts (N. C. Facione, Giancarlo, & Chan, 2000; Silverman et al., 2001). Understanding women's perceptions of their risk of developing breast cancer might give us better insight into how women see breast cancer

and how risk-related messages are interpreted, thereby facilitating the development of effective interventions for improving risk communication.

The purpose of this study was to synthesize research findings by presenting a meta-analysis of studies on perceived breast cancer risk. The study examined demographic, psychological, and physiological variables as predictors of perceived breast cancer risk and the relationship between perceived breast cancer risk and breast cancer prevention and early detection.

Theoretical Framework

Educational interventions that aim to improve breast cancer screening have been based on theoretical models that attempt to explain how and why individuals adopt a health protective behavior. The majority of these models adopt a decision-making perspective that is focused on a cost-benefit analysis of consequential outcomes. Examples of such theoretical models are the Health Belief Model (Rosenstock, 1975), the Self Regulatory Model (Leventhal, Meyer, & Nerenz, 1980), the Theory of Reasoned Action (Ajzen & Fischbein, 1980), and the Protection Motivation Theory (Rogers, 1975). One of the principal variables in these models is the individual's *perceived susceptibility* to the disease. *Perceived susceptibility* or *perceived risk* in these models refers to one's belief about the likelihood or probability of harm, namely the probability that a health problem will be experienced if no precautions or behavioral changes occur.

At a fundamental level, these models assume that the decision to adopt a self-protective behavior is reached through an analysis of susceptibility, potential actions, potential costs, and anticipated outcomes. Although there is no agreement as to how

these variables influence health-related behavior, theoretical models combine these variables in some explicit or empirically derived equation in order to predict the adoption of a health-protective behavior (Weinstein, 1988).

Research Methods

The databases PUBMED and PSYCINFO were queried from 1985 onward using the key words *breast cancer* and *perceived risk* and *breast cancer screening* and *perceived risk* in combination. Limitations of this query were English language and human subjects. Because breast cancer is most prevalent in women (American Cancer Society, 2003), this query was also limited to female gender. Unpublished studies and studies published in other languages were excluded due to time and resources limitations.

The initial query identified 126 articles. Articles were excluded if they were reviews, letters, commentaries or conference abstracts, dissertation abstracts, multiple publications of the same data set, theoretical frameworks, or qualitative data analyses, or if their sample consisted partially or wholly of women who were already affected by breast cancer. The present meta-analysis is based on 42 research articles. Although review articles were excluded, a meta-analysis by McCaul and colleagues (McCaul, Branstetter, Glasgow, & Schroeder, 1996) that examined the relationship between perceived breast cancer risk and mammography screening was included for comparison of study findings and for building on existing knowledge. Finally, only cross-sectional data are included in this study since our research query resulted only in one study that included longitudinal data (Aiken, Fenaughty, West, Johnson, & Luckett, 1995).

Consequently, there were not enough studies to analyze longitudinal data on perceived breast cancer risk.

Coding and Analysis

Data were placed into two major categories. The first category included data in which breast cancer perceived risk was reported in relation to demographic, psychological, and physiological variables. The second category included data in which breast cancer perceived risk was reported in relation to breast cancer prevention and early detection behaviors (See Summary Table 1.1). Data were synthesized using meta-analysis methods described by Petitti (Petitti, 1994). The computer program DSTAT® (Johnson, 1990) was used to calculate effect sizes (g) from statistical relationships (Means and SDs, t-tests, chi-square tests, F-tests, r-correlations, frequencies or proportions, and p-values). When frequency data were reported, an odds ratio from 2X2 tables was calculated (Triopoulos, 1982). Reported average effect sizes were weighted by sample size. Based on conventional standards, effect sizes of a magnitude of $g=0.20$ were considered small, $g=0.50$ were considered medium, and $g=0.80$ were considered large (Cohen & Cohen, 1983).

Results

Results of the meta-analysis of these 42 studies are presented in four sections. In the first section we present studies that compared women's perceived breast cancer risk in relation to an objective estimate of their risk. In the next two sections we present

predictors of perceived breast cancer risk. In section four we present the relation between perceived breast cancer risk and breast cancer screening.

- a. Perceived Risk: Optimistic bias vs. Overestimation of Risk. The confounding effects of recruitment setting, family history, and measurement.

There was inconsistency among twelve studies as to whether women believe they were at a lower risk (optimistic bias) or at a higher risk (overestimation) of developing the disease (Table 1.2). Some researchers concluded that women held an optimistic bias, believing either that it was unlikely they would, ever in their lifetime or during the next years, develop breast cancer (perceived subjective risk) (Absetz, Aro, Rehnberg, & Sutton, 2000; Aiken et al., 1995), or that they were at a significant lower risk than other women (perceived comparative risk) (Aiken et al., 1995; Clarke, Lovegrove, Williams, & Machperson, 2000; N.C. Facione, 2002; Lipkus, Kuchibhatla et al., 2000; McDonald, Thorne, Pearson, & Adams-Campbell, 1999). Other researchers concluded that women overestimated their risk, either when comparing themselves with other women (perceived comparative risk) (Evans, Blair, Greenhalgh, Hopwood, & Howell, 1994; Foster et al., 2002), or when comparing their estimates to their actual risk estimates (perceived subjective risk) (Daly et al., 1996; Dolan, Lee, & McGrae-McDermott, 1997; Evans et al., 1994; Foster et al., 2002; Meiser et al., 2001; Metcalfe & Narod, 2002).

The majority of these 12 studies compared women's risk estimates with an objective risk estimate using the Gail model (Aiken et al., 1995; Daly et al., 1996; Dolan et al., 1997; Lipkus, Kuchibhatla et al., 2000), the Claus model (Evans et al., 1994), or other statistical methods for estimating the probability of carrying a genetic mutation (Foster et al., 2002; Meiser et al., 2001; Metcalfe & Narod, 2002). Some researchers did

not measure the accuracy of women's risk assessments (Absetz et al., 2000; Clarke et al., 2000; N.C. Facione, 2002; McDonald et al., 1999). The total sample size of the twelve studies was $N = 5,561$ women and the average effect size, weighted by sample size, was $g = 1.10$ (95%CI 1.06 - 1.14). This indicates that when researchers compared women's risk estimates to an objective estimate of their risk, women did not have an accurate perception of their actual risk.

Researchers who concluded that women overestimated their breast cancer risk recruited their samples either through a relative who was concurrently treated for breast cancer or from a health care setting, such as hospital registry, primary care, or genetic counseling clinic (see Table 1.2). The average effect size, weighted for sample size, for the six studies that recruited their sample from affected relatives or from health care settings was $g = 1.24$ (95%CI 1.18 - 1.30). By contrast, the six studies that reported that women hold an optimistic bias recruited their samples from the community (average effect size, weighted for sample size, $g = 0.99$, 95%CI 0.94 - 1.04).

We investigated whether there might be a selection bias in the studies that reported an overestimation of risk. Women recruited from a hospital registry or a genetic counseling clinic, and women with an affected relative concurrently being treated for breast cancer are more likely to have a more personal experience with the disease and be more aware of their risk. Therefore, we investigated whether these reports are confounded by the effect of a positive family history on perceived breast cancer risk.

There were 12 studies that examined the relationship between having a positive family history of breast cancer and perceived breast cancer risk (Table 1.3). As expected, women with a positive family history, defined as having at least one first or second

degree relative with breast cancer, were significantly more likely to perceive their risk of developing the disease as higher than that of other women (Total N= 70,660, $g= 0.88$, 95%CI 0.87 – 0.89). However, there were three studies that reported that although having a positive family history was positively correlated with an increased perception of risk (average effect size, weighted for sample size, $g=0.61$, 95%CI 0.50 – 0.72), overall women held an optimistic bias about their breast cancer risk (average effect size, weighted for sample size, $g= 0.72$, 95%CI 0.66 - 0.78) (Absetz et al., 2000; Aiken et al., 1995; N.C. Facione, 2002). Those three studies recruited their sample from community settings and included women with a positive family history in percentages ranging from 15% to 23%. There was one study that recruited participants from both an affected relative and from the community through newspaper advertisements (Lipkus, Iden, Terrenoire, & Feaganes, 1999). However, the study did not examine whether women who were recruited through an affected relative had a heightened perception of risk compared to women with a positive family history who were recruited from the community.

Another possible explanation for these findings could lie in the type of scale used to measure perceived risk: Numerical or Verbal. Some studies used a numerical scale from 0% to 100% for women to rate their risk of developing breast cancer. This type of measurement is more likely to result in an overestimation of risk, because the anchors used can be misleading. For example, some women who perceive their chance of getting the disease as equal to that of other women might mistakenly give themselves a 50% rating, not realizing that a 50% rating means that they have a one in two chance of getting

the disease. The average effect size for the six studies with numerical scales was $g=1.48$ (95%CI 1.42 – 1.54) (see Table 1.2).

Other studies used verbal, Likert-type scales to measure perceived risk, using questions such as, “how likely are you to get breast cancer in your lifetime”, or “how likely are you to get breast cancer compared with other women your age or compared with your peers.” This type of measurement is more likely to produce an optimistic bias, especially if it asks women to rate their risk compared with other women with similar characteristics. This observation was validated in one study that used both verbal and numerical scales to measure perceived risk; women held an optimistic bias in the verbal scale but significantly overestimated their risk in the numerical scale (Lipkus, Kuchibhatla et al., 2000). The mean effect size for the seven studies using a verbal scale to rate perceived risk was $g=0.82$ (95%CI 0.76 – 0.86). Finally, two studies used a single-item verbal scale to measure perceived risk. Although single-item scales are brief and have face validity, they also have major limitations (Nunnally & Bernstein, 1994). First, they have limited discriminatory capacity, especially if distributions are skewed. Since many risk factors are positively skewed for most women at the lowest risk level, Likert-type, single-item verbal scales are most likely to produce an optimistic bias. Second, single-item scales are assumed to be at the interval level for the purposes of statistical analysis, and therefore, have limited reliability due to measurement error. Third, some researchers measured perceived risk with single-item scales related more to other constructs than to perceived risk. For example, one study (Foxall, Barron, & Houfek, 2001) measured perceived risk by asking, “how worried are you about getting breast cancer?” This item is related more to breast cancer distress than to perceived risk.

The mean effect size for the two studies that used single-item verbal scales was large: $g=1.26$ (95%CI 1.16 – 1.36).

In order to understand the individual influences of recruitment site and type of scale on perceived breast cancer risk, we examined the interaction between recruitment site and type of scale, numerical or verbal that was used to measure perceived risk (see Table 1.4). There were six studies that recruited their sample from an affected relative and family or genetic counseling clinics. Four of those studies used a numerical scale to measure perceived risk (Total N= 1,914, $g= 1.26$, 95%CI 1.19 – 1.33), while the remaining two studies used a verbal scale to measure perceived risk (Total N= 520, $g= 1.14$, 95%CI 1.00 – 1.27). There were six studies that recruited participants from community settings. One of those studies included both a numerical and a verbal scale for measuring perceived risk (Lipkus, Kuchibhatla et al., 2000), and therefore an effect size was calculated for each measurement. Two studies used a numerical scale to measure perceived risk (Total N= 745, $g= 2.04$, 95%CI 1.92 – 2.17), and five studies used a verbal scale to measure perceived risk (Total N=2,963, $g= 0.76$, 95%CI 0.71 – 0.81). Although these findings are not conclusive, it appears that a numerical scale results in a larger difference between measured subjective risk and objective risk, which indicates that this type of measurement introduces a systematic error in the measurement of perceived risk. In studies that used a verbal scale to measure perceived risk, studies that recruited participants from community settings consistently reported an optimistic bias, whereas studies that recruited their sample from an affected relative or a family clinic, consistently reported that women overestimated their risk of developing breast cancer, which suggests a possible selection bias in the later studies.

b. Breast Cancer Perceived Risk and Demographic Characteristics

There were few studies that addressed the influence of demographic characteristics on breast cancer perceived risk, and results were inconclusive. Twelve studies addressed the relationship between age and perceived risk (Table 1.5). Seven of those studies concluded that younger women were more likely to perceive higher risk for developing breast cancer than were older women, but the effect size was very low (Total $N=38,000$, $g=0.13$, 95%CI 0.12 – 0.14). Four studies concluded no significant relationship between age and perceived risk. The latter studies did not provide adequate data for calculation of an effect size. Overall, results from these 12 studies indicate no relationship between older age and increased perceived risk.

There were no reported relationships between income level and breast cancer perceived risk in any of the studies. Facione (N.C. Facione, 2002) reported that there were no differences in the perception of risk by income level, and Daly and colleagues (Daly et al., 1996) reported that employed women were more likely to overestimate their risk compared to their actual risk. However, these reports could not generate meaningful comparisons. Findings between education and perceived risk were more consistent (Table 1.6). In five studies (Total $N= 1,979$, $g=0.16$, 95%CI 0.10 – 0.23) researchers concluded that women with high school or less education were more likely to be either unaware of their risk or overestimate their risk, whereas women with college education were less likely to have an optimistic bias. One study (Donovan & Tucker, 2000) reported no association between educational level and accuracy of perceived risk, but did not provide adequate data for calculating an effect size.

Overall, 42% of the 42 studies included in this meta-analysis included women of diverse racial/cultural backgrounds in percentages ranging from 14% to 100%, whereas 58% of the studies reviewed included mostly or exclusively White women. Only two studies included exclusively Black women (Lipkus et al., 1999; McDonald et al., 1999). Five studies examined the relationship between race/culture and breast cancer perceived risk in samples consisting of 14% to 49% minority women (Table 1.7). In these five studies, White women were more likely to perceive themselves as being at increased risk for developing breast cancer compared with other women, whereas Black women were more likely to be unaware that diagnosis of a first-degree relative with breast cancer increased their risk of developing the disease (Total N=2,192, $g=0.38$, 95%CI 0.28 – 0.47). Two studies with an overrepresentation (>60%) of women from diverse racial/cultural backgrounds reported no significant differences in breast cancer perceived risk among women of diverse ethnic/cultural groups and White women (Erblich, Bovbjerg, Norman, Valdimarsdottir, & Montgomery, 2000; N.C. Facione, 2002). However, these two studies did not provide sufficient data for calculating effect sizes.

c. **Breast Cancer Perceived Risk, Psychological, and Physiological Variables**

Seven studies examined the relationship between emotional responses to breast cancer and perceived risk (Table 1.8). They employed different concepts and utilized different measures to describe a negative emotional response to breast cancer, such as breast cancer worry, breast cancer anxiety, and breast cancer concern. In all of these studies, there was a positive correlation between perceived risk and intensity of emotional response to breast cancer (Total N= 6,090, $g= 0.49$, 95%CI 0.46 – 0.53).

Four studies examined the influence of having breast symptoms on breast cancer perceived risk (Aiken et al., 1995; N.C. Facione, 2002; Lipkus, Halabi, Strigo, & Rimer, 2000; Vernon, Vogel, Halabi, & Bondy, 1993). Since these studies did not include women diagnosed with breast cancer, it was assumed that a breast symptom was a benign breast symptom. As expected, all four studies reported a positive association between having a breast symptom and perceiving to be at increased risk for developing the disease (Total N=34,106, $g=0.25$, 95%CI 0.23 – 0.28). Individual effect sizes in these four studies ranged from 0.22 to 0.49.

d. Breast Cancer Perceived Risk, Early Detection, and Breast Cancer Prevention Behavior

Many researchers have examined the influence of perceived breast cancer risk on health-protective behaviors. McCaul and colleagues (McCaul, Branstetter et al., 1996) examined the relationship between adherence to mammography screening and breast cancer perceived risk by synthesizing data from 19 studies published between 1980 and 1994. They reported a positive association between breast cancer perceived risk and adherence to mammography screening (N= 11,678, $g=0.16$). While the effect size was low, only one of these 19 studies did not demonstrate a positive association between perceived risk and adherence to mammography screening.

Thirteen additional studies published between 1993 and 2002 examined the influence of perceived breast cancer risk on adherence to screening mammography. These studies were not included in the McCaul and colleagues meta-analysis. The majority of these studies also suggest a positive association between perceived risk and adherence to mammography screening (Table 1.9). The total number of subjects was N=

41,093, and the average effect size, weighted by sample size was $g = 0.20$ (95%CI 0.18 – 0.23). Only four of these 13 studies did not demonstrate a positive association between perceived risk and mammography screening. Adding the data from the present analysis to the data from the meta-analysis by McCaul resulted in a total sample size of 52,766 women from 32 studies. The average effect size, weighted by sample size was $g = 0.19$, which suggests that perceived risk has a small but significant effect on adherence to mammography screening.

Fewer researchers have examined the influence of perceived risk on adherence to Breast Self Examination (BSE) guidelines, and results from these studies were inconclusive (Aiken et al., 1995; Brain, Norman, Gray, & Mansel, 1999; Lindberg & Wellisch, 2001; Vernon et al., 1993). Two studies (Aiken et al., 1995; Brain et al., 1999) reported a weak association between perceived risk and BSE performance, whereas two studies reported that higher levels of perceived risk resulted in poorer adherence to BSE guidelines (Lindberg & Wellisch, 2001) and that there was no association between perceived risk and adherence to BSE (Vernon et al., 1993). (Total $N = 1,381$, $g = 0.06$, 95%CI $-0.05 - +0.17$). Individual effect sizes ranged from -0.49 to $+0.19$.

Finally, the discovery of two genes associated with hereditary breast and ovarian cancer (BRCA1 and BRCA2) provides the option for women to undergo genetic testing for breast and ovarian cancer susceptibility. Not surprisingly, women who perceived their risk for breast and ovarian cancer to be higher were more likely to be interested in, or to undergo, genetic testing (Bowen et al., 1999; Culver, Burke, Yasui, Durfy, & Press, 2001; Jacobsen, Valdimarsdottir, Brown, & Offit, 1997; Lipkus et al., 1999) (Total $N = 1,145$, $g = 0.29$, 95%CI 0.21 – 0.37) and were also more likely to undergo prophylactic

mastectomy as a means for breast cancer prevention (Hatcher, Fallowfield, & A'Hern, 2001; Stefanek, Helzlsouer, Wilcox, & Houn, 1995) (Total N= 307, $g= 0.49$, 95%CI 0.25 – 0.74). One study reported that women, who chose prophylactic mastectomy as a means for risk reduction, reported a mean reduction of perceived breast cancer risk of 83.3% (range 0% - 100%) post surgery (Metcalf & Narod, 2002).

Discussion

Because perceived risk is an important motivator for protective health-related behaviors, we need to understand associations between perceived risk, psychosocial characteristics, and the way in which perceived risk acts as a motivator for these behaviors. One major limitation of this meta-analysis is that it is based only on published data. Moreover, many studies that did not find a significant relationship between perceived risk and other variables did not report adequate data for calculating an effect size. Therefore, many of the reported effect sizes are based on a limited number of studies. However, even though some findings are not conclusive, they can provide researchers with insights for future research.

The findings of this meta-analysis are inconclusive as to whether some or most women hold an optimistic bias about their risk of developing breast cancer. Results are confounded by the interaction between family history, recruitment site, and measurement scale. From the studies reviewed, it would be reasonable to conclude that women have an optimistic bias about their risk of developing breast cancer ($g= 0.99$). Weinstein consistently demonstrated that people have the tendency to claim that they are less likely than their peers to suffer harm (Weinstein, 1982, 1984, 1987, 1989; Weinstein & Klein,

1995). Accordingly, we would expect that women perceive their risk of developing breast cancer as low, especially when compared to other women with similar characteristics.

Having a family history of breast cancer was positively correlated with a heightened perception of risk ($g = 0.88$). This is consistent with Weinstein's findings that optimistic biases are less likely to occur if a person has some personal experience with the hazard (Weinstein, 1983, 1989). Having a close relative diagnosed with breast cancer affects a woman's risk perception, presumably by making her more aware of her own probability of developing the disease and the possible role of heredity as a risk-increasing factor. However, women who were recruited from community settings held overall an optimistic bias about their personal breast cancer risk, although some of them had a positive family history. Women who did not have a family history of breast cancer may erroneously believe that their risk is lower than average, whereas other women estimate their risk to be average, even in the presence of hereditary risk factors. This explanation is consistent with the suggestion that a subjective risk assessment seeks the most comforting view of one's personal susceptibility that fits within the bounds of available evidence (Weinstein, 1999).

It is also possible that the observed discrepancies in perceived risk by recruitment site are related to the stability of risk assessments over time. In the studies reviewed, it was assumed that perceived risk is a one-dimensional construct that lies on a continuum, from no risk to extreme risk, and that it is stable over time. However, it has been suggested that there is a temporal pattern in the development of subjective risk assessments (Weinstein, 1988). It is possible that the effect of family history as a risk-

increasing factor is magnified when women are recruited from an affected relative or from a health-related setting, whereas it is minimized over time when women were recruited from community settings in the context of their day-to-day lives. Longitudinal data would help illuminate the temporal pattern of the concept as well as the interaction between family history and recruitment site.

In addition, findings are confounded by weaknesses in the measures used to assess breast cancer perceived risk. From the 42 studies reviewed, eight studies (19%) reported on the validity or reliability of the measure that they used (Aiken et al., 1995; Brain et al., 1999; Carney, Harwood, Weiss, Eliassen, & Goodrich, 2002; Drossaert, Boer, & Seydel, 1996; Evans et al., 1994; Finney & Iannotti, 2001; McCaul, Schroeder, & Reid, 1996; McDonald et al., 1999), whereas the vast majority of these studies used a single-item measure that had face validity (see Table 1).

It is well documented in the literature that lay people have great difficulty understanding and assessing probabilities of risk and risk-related information, especially when that information was presented to them in a quantitative, numerical format (Hallowell, Green, Statham, Murton, & Richards, 1997; L. M. Schwartz, Woloshin, Black, & Welch, 1997). Researchers have used many different approaches in their search for the ideal probability scale and Diefenbach and colleagues (Diefenbach, Weinstein, & O'Reilly, 1993) examined the effectiveness of commonly used probability scales. Weinstein (Weinstein, 1999) 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 one of the least meaningful and least reliable measures of risk understanding. In addition, Windschitl (Windschitl, 2002) suggested three reasons to

avoid comparing subjective and objective probability estimates in order to determine whether people have appropriate expectations about the possibility of an event. First, respondents misuse or misinterpret the numeric probability scale. Second the numeric probability measures fail to address non-analytic components that mediate the decision-making process. Third, subjective probabilities often reflect ad hoc processes rather than stable beliefs, and therefore, can be highly susceptible to wording and context effects. From the existing instruments that measure perceived susceptibility, the scales developed by Champion and colleagues have repeatedly demonstrated high validity and reliability and are valuable means for measuring perceived breast cancer susceptibility (V. Champion & Scott, 1997; V. L. Champion, 1984, 1993). However, these scales were developed to measure concepts of the Health Belief Model and do not address concepts that are not included in the model, such as comparative optimistic bias that appears to be an important factor that influences perceived breast cancer risk.

Daly and colleagues (Daly et al., 1996) first suggested that demographic variables are poor predictors of perceived breast cancer risk. The present study supports this suggestion. There was a weak association between perceived risk and sociodemographic characteristics. Higher perceived risk was observed in younger women ($r = 0.13$). However, four of the twelve studies that examined the relationship between age and perceived risk included women younger than 30 years. Although it is possible for women younger than 30 years to be affected by aggressive types of breast cancer, the disease is rare in that age group (American Cancer Society, 2003). Therefore, inclusion of women younger than 30 years could indicate a selection bias for those studies. On the other hand, researchers who did not include women younger than 30 years do not report

that older age is associated with increased perceived risk. This finding is surprising, since older age is a well-established risk factor for breast cancer. These findings suggest that either women have a misconception that breast cancer affects mostly younger women, or that older women do not perceive themselves to be at a higher risk. One possible explanation could be suggested by examining cognitive biases that are inherent to understanding and interpreting the probabilities of future events. The probability that a woman will develop breast cancer by the age of 40 years is small, approximately 0.0044, or one in 229 (American Cancer Society, 2003). Kahneman and Tversky (Kahneman & Tversky, 1984) suggested that decision weights are very unstable when the probability of an event is small. In the area of small probabilities events are either neglected or over-weighted. It is possible that women amplify the probability of developing breast cancer in younger age. Therefore, health care providers need to clarify the message that getting older is a well-established risk factor that increases a woman's probability for developing the disease.

Perceived risk is weakly associated with higher education ($g = 0.16$) that seems contradictory to Weinstein's findings that optimistic biases are largely unrelated to level of education (Weinstein, 1987). Researchers reported that women with high school education or less were more likely to be unaware of their individual risk and that women with higher education were more likely not to have an optimistic bias. These findings suggest that women with higher education are more likely to have an accurate perception of their actual risk, whereas less educated women are more likely to have inaccurate perceptions, either underestimating or overestimating their risk. In addition, some researchers concluded that white women are more likely to perceive higher risk for breast

cancer than women of other racial/cultural backgrounds ($g=0.38$). However, this finding was based on the reports of five studies, whereas two other studies that included an overrepresentation of women of diverse racial/cultural backgrounds reported that there was no difference in perceived risk between those groups. One possible explanation for this finding is that education is a confounder of the relationship between race/culture and perceived risk; those two variables should be examined together as an indicator of social class and a predictor of knowledge of breast cancer risk factors. Four studies that examined both education and race/culture, as predictors of perceived risk also examined the interaction between them. From those studies, Facione (N.C. Facione, 2002) reported that there is no association between race/culture and perceived risk, whereas three studies (Audrain et al., 1995; Donovan & Tucker, 2000; Hughes, Lerman, & Lustbader, 1996) reported that race/culture is a predictor of perceived risk. This meta-analysis suggests that educational level ($g= 0.16$) was a weaker predictor of perceived risk when compared to race/culture ($g= 0.38$). Since there were only four studies that suggested a relationship between race/culture and perception of risk, it would not be appropriate to conclude that women of diverse backgrounds are unaware of their breast cancer risk.

Women that were recruited through an affected relative had a strong emotional response towards breast cancer (Bowen et al., 1999), especially if they were closely involved in the care of the affected relative (Lipkus et al., 1999). Findings of this meta-analysis suggest that there is a consistent association between heightened perceived risk and negative emotional responses towards breast cancer, conceptualized as either worry, anxiety, or concern ($g= 0.49$). In addition, having a personal experience with a benign breast symptom was also correlated with a moderate increase in risk perception ($g= 0.25$).

In confirming those suggestions, a significant interaction between experiencing breast symptoms, breast cancer worry, perceived control, and perceived risk was noted in one study (Cunningham et al., 1998). Easterling and Leventhal (Easterling & Leventhal, 1989) proposed that breast cancer risk assessments are stimulated by environmental or somatic cues, such as having an affected relative or a benign breast symptom respectively. This cognitive appraisal further elicits an emotional response. However, the one-dimensional nature of the data in the present meta-analysis does not provide further insight about the possible interaction between having a benign breast symptom and emotional responses to breast cancer and the effect of this interaction on perceived breast cancer risk.

The relationship between perceived breast cancer risk and screening behavior appears to be complex. There was a weak association between adherence to screening mammography and perceived risk ($g = 0.19$). Aiken and colleagues (Aiken et al., 1995) reported that the correlation between initial mammography screening and perceived risk was significant. However, there was no evidence of a significant correlation between initial perceived risk and mammography screening at four years follow up. The relation between perceived risk and BSE appears to be even more complex. Four studies examined the effect of perceived risk on BSE performance and the findings were inconclusive. One possible explanation would be that health care professionals do not make strong recommendations about adherence to BSE guidelines, which results from recent controversies about the effectiveness of BSE.

At first glance, these findings seem to undermine the utility of perceived risk in predicting health-protective behavior. However, Leventhal and colleagues (Leventhal et

al., 1999) suggested that it is not surprising to observe such a modest effect size with respect to screening mammography and perceived risk. They suggested that screening behaviors, such as mammography uptake, are not solely controlled by individual volition, and therefore, do not necessarily reflect individual risk perceptions. Second, personal experiences with mammography, especially negative experiences, can affect how mammography is viewed and can influence the magnitude of the relationship between mammography and perceived cancer risk. Weinstein (Weinstein, 1988) also suggested that a belief of being at increased risk is a necessary but not sufficient condition for action. The decision to act depends on the interaction of numerous factors, such as perceived severity, perceived effectiveness, and perceived costs, and other decision rules, such as framing of the decision as gains or losses, the time frame within which costs and benefits occur, the role of emotions, and the existence of other conditions that compete for the same resources. Therefore, it appears that perceived risk has an indirect effect on breast cancer early detection behavior.

Of increasing interest are the suggestions that perceived risk is influenced by the degree to which the disease is believed to be controllable by personal actions (Leventhal et al., 1999; Weinstein, 1987), and that perceived control is a significant predictor of intentions (Ajzen & Madden, 1986). There has been reported a significant relationship ($g = -0.41$) between perceived risk and perceived control over breast cancer (Lipkus et al., 1999) and perception of personal control in detecting breast lumps was associated with a higher frequency of BSE (Mamon & Zapka, 1986). Findings of this meta-analysis suggest that women who perceive themselves to be at a heightened risk for breast cancer are more likely to undergo genetic testing for mutations that predispose to the disease

($g=0.29$) and are more likely to undergo prophylactic mastectomy ($g=0.49$) as a means for breast cancer prevention. Moreover, it has been suggested that perceived internal control was predictive of adherence to screening mammography (Russell, Champion, & Perkins, 2003). These findings indicate that women with heightened perceptions of breast cancer risk are more likely to take actions in an attempt to gain a sense of control over the disease. Perceived control over the disease appears to be an important factor that mediates the relationship between perceived breast cancer risk and adopting a health protective behavior.

In conclusion, our knowledge is very limited on the effects of perceived breast cancer risk on decision-making about breast cancer prevention and early detection. Addressing women's concerns and the impact of guidelines on risk communication needs to be evaluated in terms of improving risk knowledge in the population at large. Future research needs to employ study designs and methodologies that will enable researchers to probe how women estimate their personal risk for breast cancer, how this perception varies with available information, and how perceived risk affects decision-making for adopting a health-protective behavior. Risk assessment and risk management involves both scientific and public beliefs, as well as issues of power and trust. For policy-makers who are interested in promoting education and intervention strategies to lower health risks, understanding the different ways in which the general public and health professionals perceive risks is imperative.

Chapter 2.

**Optimistic bias about the risk of developing breast cancer in a multicultural
community sample**

**Paper presented at the Intercultural Cancer Council. 9th Biennial Symposium on
Minorities, the Medically Underserved and Cancer, Washington D.C., March 2004**

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Abstract

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

Word count: 200

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

Introduction

Breast cancer is the second leading cause of cancer death for women in the United States (American Cancer Society, 2003). Molecular biology and genetics have improved our understanding of breast cancer etiology. Individualized counseling and public health educational interventions provide factual knowledge about breast cancer risk factors and educate women about their own probability of developing the disease. By using the Gail model (Gail et al., 1989) health care providers can estimate the probability of an individual woman developing breast cancer during a defined age interval.

Presumably, a woman who is aware of her actual breast cancer risk will initiate and maintain an appropriate level of health-protective behaviors (Leventhal et al., 1999). However, some women do not take into account factual information from the Gail model when estimating their own breast cancer risk (Daly et al., 1996). Results of a meta-analysis that examined perceived breast cancer risk were inconclusive as to whether women overestimated or underestimated their risk, while there were indications for systematic measurement errors and selection bias (Katapodi, Lee et al., 2004).

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

Theoretical Framework and Background

The Precaution Adoption Process (Weinstein, 1988) suggests that perceived risk to a health is a subjective belief about the probability that the health problem will be experienced and occurs in three stages. In the first stage people become aware of the problem, mainly when they hear general information through common communication channels. In the second stage, people acknowledge the significance of the problem and are aware of the likelihood of encountering the disease, but do not consider themselves at risk. People reach this stage when they hear credible messages about the disease from health-related sources. In the third stage, people acknowledge their personal susceptibility to the health problem. This occurs when they have a close experience with the disease or when they have information about their personal risk factors and the risk factors of others. As the individual is exposed to new information and life experiences, movement between stages can be forward or backward.

Weinstein demonstrated that people most often are at the second stage of perceived risk, claiming that they are less likely than their peers to suffer harm (optimistic bias) (Weinstein, 1982, 1987). Although Weinstein studied optimistic bias in the context of various health problems, the phenomenon has not been adequately studied with perceived breast cancer risk. Research findings are conflicting as to whether women believe they are at a higher risk (overestimation) or at a lower risk (optimistic bias) of developing breast cancer. Some studies reported that women significantly overestimate their risk compared to an objective risk estimate (Daly et al., 1996; Dolan et al., 1997; Lipkus, Kuchibhatla et al., 2000). In contrast, other studies report that women estimate their risk as significantly lower than their peers and lower than an objective risk estimate

(Absetz et al., 2000; Aiken et al., 1995; Clarke et al., 2000; N.C. Facione, 2002; McDonald et al., 1999).

A close examination of these studies suggested that findings are confounded by possible selection bias and measurement errors (Katapodi, Lee et al., 2004). Studies that reported an overestimation of risk recruited participants through an affected relative who had been treated for breast cancer, which suggests a selection bias. Studies that recruited participants from community settings reported that a positive family history increased perceived risk. However, this effect was minimized over time since some women with a positive family history did not perceive that they were at a higher risk. In addition, most studies that reported overestimation of risk used a Numerical probability scale with anchors 0% to 100%. This type of scale may be misleading; some women who perceive their chance of getting the disease to be equal to that of other women might mistakenly give themselves a 50% rating, not realizing that such a rating means that they have a one in two chance of getting the disease.

Results are conflicting as to whether sociodemographic characteristics influence perceived risk. Studies suggest that younger women are more likely to perceive higher risk for developing breast cancer than older women, and that White women are more likely than women of other racial/cultural backgrounds to perceive higher risk. However, these findings are based on a small number of studies. Race/culture and education should be examined together as indicators of social class that influences perceived breast cancer risk (Katapodi, Lee et al., 2004).

Despite some lack of clarity, it appears that some women have inaccurate perceptions about their own probability of developing breast cancer and misinterpret

information about risk factors in health-related messages. The present study examined perceived breast cancer risk by addressing some of the confounders identified in previous studies. The study examined whether women recruited from community settings hold an optimistic bias about their breast cancer risk compared to their friends/peers and compared to an objective estimate of their risk. The study addressed systematic measurement errors by employing a triangulation method design.

Recruitment and Procedures

For this cross-sectional survey we recruited a convenience sample of women never diagnosed with any type of cancer and willing to complete a questionnaire in English. We included women between the ages of 30 and 85. The relatively low age limit of 30 years was chosen because some aggressive types of breast cancer occur in women in their thirties (American Cancer Society, 2003). The maximum age limit was set at 85 years because that is the maximum age limit that a woman's breast cancer risk can be estimated with the Gail model. Women with a prior diagnosis of any type of cancer were excluded from the study because they would be more likely to have received education about their cancer risk and risk factors.

Recruitment was done through flyers posted on bulletin boards in community settings throughout the San Francisco Bay Area and through newspaper advertisements. Community settings included senior centers, temples, libraries, restaurants, coffee shops, homeless shelters, cultural centers, and workplaces. Potential participants responded by calling a dedicated telephone number and expressing their interest in the study. Eligibility was determined through self-report. Participants completed the survey either

in person or by mail and were paid \$15. The University of California San Francisco Committee on Human Rights approved the study protocol. Data collection occurred over a period of thirteen months, between February 2003 and March 2004.

Measurements

We employed a within-method triangulation design (Burns & Grove, 1997). We measured perceived risk with three different sets of questions. We used a Verbal Scale, a Comparative Scale, and a Numerical scale. Items were introduced in different sections of the questionnaire. Scales were moderately correlated: Verbal and Numerical scales $r=0.59$, Verbal and Comparative scales $r=0.50$, and Numerical and Comparative scales $r=0.33$.

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

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

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

Objective Risk: For every participant we calculated a *Gail Risk* score with eight questions that assess number of affected First-Degree Relatives (FDRs), number of breast biopsies, and reproductive history (Gail et al., 1989). For this calculation we used the online version of the Breast Cancer Risk Assessment Tool (BCRAT) developed by the National Cancer Institute and accessed at <http://bcra.nci.nih.gov/brc/>. We recorded the *Lifetime Population Risk* calculated by the BCRAT to represent the Gail score for women of the same age and racial/cultural group with average risk factors in the population. Participants also indicated the number of their affected Second-Degree Relatives (SDRs).

Statistical Analysis

Data were analyzed using the statistical program SPSS® (version 11.5). Descriptive statistics were used to describe the demographic characteristics of the sample, Gail scores, and measures of perceived risk. Univariate Analysis of Variance and bivariate analysis, such as Analysis of Variance (F test) with Bonferroni post hoc contrasts, Student's t-tests, paired t-tests, Pearson's correlations (r), and χ^2 , was used to

determine associations between demographic characteristics and perceived risk, and to compare subjective and objective risk estimates. Consistency of responses in the three risk measures was examined with a within-subjects Analysis of Variance. Significance was set at the 0.05 level with 95% confidence intervals.

Results

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

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

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

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

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

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

In order to examine whether participants were consistent in their responses on the three scales, their personal risk rating was subtracted from the risk rating they gave for

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

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

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

Comparative Scale: Family history and age were significantly associated with women's responses on the Comparative scale. The 18 women with an affected FDR did not rate their risk significantly higher than the 117 women with no family history (2.73 ± 0.59 vs. 2.44 ± 0.88). The 24 women with one or more affected SDRs (3.00 ± 0.46)

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

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

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

Numerical Scale: Age was not significantly correlated with subjective risk ratings and with risk ratings for friends/peers on the Numerical scale. There were significant correlations between education and subjective risk ratings ($r= -.28, p<0.01$), and between education and risk ratings for friends/peers ($r= -.22, p<0.01$). Similarly, income was significantly correlated with subjective risk ratings ($r= -.27, p<0.01$) and risk ratings for friends/peers ($r= -.17, p<0.05$). After controlling for education and income, univariate Analysis of Variance revealed that there were significant differences in the Numerical

risk ratings among women of different race/culture ($F_{(3,170)} = 2.80, p=0.042$). However, pairwise comparisons with Bonferroni post hoc contrasts failed to identify significant differences between groups, probably due to small sample size. Similarly, after controlling for education and income, univariate Analysis of Variance revealed that women with multiple affected family members were significantly more likely to rate their risk higher on the Numerical scale compared to women with no family history ($F_{(3,164)} = 4.82, p=0.003$). Table 2.2 summarizes the influence of demographic characteristics on perceived risk.

In order to examine whether women have a realistic perception of their personal risk we examined whether they could correctly identify their risk as being above or below average, compared to their actual risk based on the Gail model. First, we calculated a Gail Score and a Lifetime Population Risk score for every participant. The latter score represents the Gail score for women in the same age and racial/cultural group in the population with average risk factors. The mean Gail score for women in our sample was $10.3(\pm 6.06, \text{median}=9.8)$ and the Lifetime Population Risk score was $10.06(\pm 2.33, \text{median}=10.2)$. Second, for every participant we calculated an *Actual Comparative Risk* score by subtracting her Lifetime Population score from her Gail score. In cases where the Actual Comparative Risk score was a positive number, the participant had a higher than average risk of developing breast cancer, whereas the opposite was true in cases where the Actual Comparative Risk score was a negative number. The Actual Comparative Risk score for the 176 women in the sample who provided sufficient information was $0.24(\pm 5.40)$. Third, we transformed every woman's Actual Comparative Risk score and her score in the Comparative risk scale into SD units [Actual Comparative

Score/5.40 SD and (Comparative Scale – 3)/0.88 SD]. Finally, we did a paired-samples t-test to compare the two scores. The comparison indicated that women did not have an accurate perception of their breast cancer risk and that they significantly underestimated their personal risk ($t_{(175)} = 4.78, p < 0.01$). Figure 2.2 shows that women underestimated their objective breast cancer risk, since the Actual Risk scores tend to fall to the right, whereas scores from the Comparative scale fall to the left.

Discussion

The study described perceived breast cancer risk and consistency of responses among three risk measures, examined the influence of sociodemographic characteristics on perceived risk, and compared subjective risk estimates with an objective risk estimate. The majority of women in the study held an optimistic bias regarding their breast cancer risk. Our findings are consistent with the findings of other studies (Aiken et al., 1995; Clarke et al., 2000; N.C. Facione, 2002; Lipkus, Kuchibhatla et al., 2000; McDonald et al., 1999). However, in contrast to previous studies we demonstrated the phenomenon of optimistic bias with a direct and an indirect way. One approach of examining optimistic bias was to ask women to directly compare their risk with the risk for an average woman. By using a Comparative scale, we noted a distribution of responses that was skewed to the left, and revealed that women directly reported that they considered their own risk to be lower than average. The indirect approach to examining optimistic bias was to ask women to independently rate the risk for their friends/peers and their own risk. By this indirect approach, we noted that women assessed a higher risk for friends/peers than for themselves. Consistent with another study (Welkenhuysen, Evers-Kiebooms,

Decruyenaere, & Van Den Berghe, 1996), where unrealistic optimism was identified with a direct and an indirect measure, we found that the indirect method showed a more pronounced bias. However, we did not find an optimistic bias with the Numerical scale (Clarke et al., 2000). One possible explanation for this finding is that the factual information we provided about population breast cancer risk made participants consider the risk status of their friends/peers. According to Weinstein (Weinstein, 1983), receiving information about the risk status of peers reduces optimistic bias.

Measuring perceived risk with the ideal probability scale has been a challenge for researchers (Diefenbach et al., 1993). In the present study, within-method triangulation allowed us to neutralize the contextual, wording, and anchoring limitations of each scale. Weinstein (Weinstein, 1999) suggested that asking participants to place a numeric probability on the occurrence of a health outcome, and then comparing their answers with objective data, is not a meaningful or reliable measure of risk understanding. To avoid directly comparing subjective and objective risk estimates, we examined whether participants reported a realistic perception of their risk being above or below average. We compared their Gail score with the Gail score for average women in the population and examined whether the direction of this comparison was consistent with the direction of their subjective risk estimates on the Comparative scale. Women in this sample had a slightly higher breast cancer risk compared to the risk of the average female in the US population. The distribution of responses in SD units revealed that objective risk estimates were skewed to the right, whereas participants' own risk estimates were skewed to the left. This finding is an indirect indication that women underestimated their objective breast cancer risk.

Although we demonstrated optimistic bias in the sample as a whole, we did not identify individuals who had an unrealistic optimism of their breast cancer risk. When we examined previous studies we noted a negative correlation between age and perceived risk, and that participants recruited from community settings were more likely to rate their risk as average, even in the presence of hereditary risk factors (Katapodi, Lee et al., 2004). Our current findings support both these suggestions. In the Comparative scale we found a small but significant negative correlation between age and perceived risk, and that some women believed that breast cancer is lessened as they grow older. In addition, women with one affected FDR did not perceive their risk to be higher compared to women with no family history. Only women with multiple affected family members had a significantly higher perceived risk. The latter finding was consistent in all three measures of perceived risk.

It is unclear why some women perceived their risk to be lower as they age and why women with one affected FDR do not perceive their risk to be significantly higher. One possible explanation could be lack of knowledge, since we found that women who had not attended high school were significantly more likely to rate their risk as “A Lot Lower” when comparing themselves to younger women. A second possible explanation could be that some women invoke unrealistic optimism as a coping mechanism. Weinstein (Weinstein, 1999) suggested that optimistic bias occurs as an effort to protect one’s self-esteem, and that risk assessments seek the most comforting view of one’s personal susceptibility. However, evidence supporting that optimistic bias is a coping mechanism and that it is related to the personality trait of “optimism” is conflicting. Facione (N.C. Facione, 2002) found no relation between perceived risk and the

personality trait “optimism”, whereas Andrykowski and colleagues (Andrykowski et al., 2002) reported that “optimism” moderated the response to a threatening health event. A third explanation is related to cognitive limitations of information processing that are inherent to understanding probabilities of future events (Kahneman et al., 1982). Supporting the hypothesis that optimistic bias in women with a family history of breast cancer could be related to biased information processing, a study reported that in a laboratory model of cancer information processing, women with a family history of breast cancer exhibited excessive vigilance to cancer-related stimuli and demonstrated significant biased cognitive processing compared to controls (Erblich, Montgomery, Valdimarsdottir, Cloitre, & Bovbjerg, 2003). These findings provide important insights and suggestions for future research in the area of breast cancer perceived risk.

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

M. Schwartz et al., 1997; Woloshin, Schwartz, Black, & Welch, 1999); yet, the relation between race/culture and high risk ratings is more difficult to explain.

Taylor and colleagues proposed that item order in the questionnaire affects consistency among responses (K. L. Taylor et al., 2002). The study found that consistency improved when the Comparative scale and the Numerical population rating were introduced before the subjective Numerical rating. Item order in the present study was similar to Taylor and colleagues; yet, we found a greater correlation between the Verbal and the Comparative scales. We agree with Taylor that only randomization of subjects to different item orders can clarify the impact of item order on consistency of responses. However, in light of the present data we suggest that the Numerical scale does not accurately reflect participants' risk estimates. Our findings suggest that many of the women who assigned themselves a high risk rating on the Numerical scale did not actually believe they were at a higher than average risk but they assigned a high value in error. This is consistent with our suggestion that a Numerical scale produces a systematic error of risk overestimation (Katapodi, Lee et al., 2004).

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 (Euhus, Leitch, Huth, & Peters, 2002); 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 (Constantino et al., 1999), it may underestimate breast cancer risk for White (Amir et al., 2003) and Black women (Bondy & Newman, 2003), whereas risk estimates for Hispanic and Asian

women are based on the risk of White women. Since 57% of women in our study were not White, the difference between women's perceived and objective breast cancer risk may be actually larger than we observed.

Finally, the study has implications for breast cancer risk communication.

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

Chapter 3.

When do experiences with affected family members and friends, and personal experiences with abnormal breast symptoms influence perceived breast cancer risk?

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Abstract

Do women with a positive family history perceive higher breast cancer risk because they understand that they share genetic material with their family members or because of worry? We examined 1) whether having experiences with affected family members or friends, and experiences with abnormal breast symptoms increased perceived breast cancer risk and, 2) whether knowledge of breast cancer risk factors and worry moderated the relationships between these experiences and perceived risk. We recruited 184 women from community settings to complete a questionnaire in English. Participants have never been diagnosed with cancer and were between 30 and 85 years old ($X=46\pm 12$). Most (49%) were college graduates and had a median annual income \$30,000 to \$40,000. We measured Perceived Risk with a Principal Component Analysis of three scales, we used the Breast Cancer Risk Factor Knowledge Index, a Worry scale (Cronbach $\alpha=.75$, $\alpha=.80$, and $\alpha=.85$ respectively), and four indicators of abnormal breast symptoms. Hierarchical regression revealed that having a family member and a friend with breast cancer accounted for 6% and 2% respectively of the variance in perceived risk. Symptoms and worry accounted for 5% and 7% respectively of the variance in perceived risk. Experiences with affected family members and friends, and symptoms influenced perceived risk through knowledge of risk factors and worry. Knowledge of risk factors moderated the relationship between family history and perceived risk, and worry moderated the relationship between symptoms and perceived risk. Educational interventions should address knowledge about risk factors, worry, and cognitive mechanisms of information processing.

Word count: 249

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

Introduction

Breast cancer is the most common cancer in women and early detection has long been recognized for its value in reducing mortality of affected individuals (American Cancer Society, 2003). Early detection programs focus on educating women about risk factors that increase the probability of developing the disease, promote self-monitoring for early signs, and adherence to recommended screening guidelines (Hiatt & Pasick, 1996; Skinner et al., 1998).

Results from a meta-analysis that examined predictors of perceived breast cancer risk suggest that although having a family history of breast cancer, worry, and abnormal breast symptoms are related to a heightened perception of risk, overall women hold an optimistic bias about the probability of developing breast cancer (Katapodi, Lee et al., 2004). These findings do not provide a clear understanding of why some women underestimate their breast cancer risk and how experiences with affected family members and breast symptoms influence perceived risk.

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

Theoretical Framework and Background

The *Precaution Adoption Process* (Weinstein, 1988) suggests that beliefs about susceptibility to a health problem represent a series of distinct stages. People at different stages hold different beliefs about the probability that they will experience harm. In the first stage individuals have heard about the hazard. In the second stage they acknowledge the significance and severity of the problem, and are aware of the likelihood of encountering the disease. However, they claim that they are less likely than their peers to experience the harm. In the third stage individuals acknowledge their personal susceptibility. This distinction reveals important differences about information processing, judgment, and the decision-making process between a 'naïve' person, who knows nothing about a hazard, and a person who has thought about it and concluded that there is no risk. The former will be open-minded about the hazard but will not actively seek information. In contrast, the latter's commitment to a particular point of view will tend to produce a biased response. This person will selectively attend to messages that support his or her own position and will show belief perseverance when faced with disconfirming evidence (Brickman, 1972).

Messages from the media and information from acquaintances do not establish clearly who is likely to be affected; therefore, most people think that they are not susceptible to the disease (Weinstein, 1988). Movement towards the third stage is facilitated by information about personal risk factors and the risk status of peers, and by personal experiences with the hazard. Emotions, such as worry, have an important, though not clearly understood, role in this process. Worry might make the threat more vivid and personal, and reduce tendencies to deny vulnerability. In contrast, the desire to

avoid feeling afraid or the need to protect one's self-esteem may lead to optimistic bias (Weinstein, 1980, 1989).

While there is evidence that women significantly underestimate their breast cancer risk (Absetz et al., 2000; Clarke et al., 2000; N.C. Facione, 2002; Katapodi, Dodd et al., 2004; McDonald et al., 1999), optimistic bias regarding breast cancer risk has not been adequately examined. Researchers attributed optimistic bias to lack of knowledge regarding the seriousness of the disease (McDonald et al., 1999), or to not having a positive family history (N.C. Facione, 2002). However, some women underestimate their risk even in the presence of hereditary risk factors, presumably, because they lack sufficient knowledge about breast cancer risk factors (Absetz et al., 2000; Aiken et al., 1995). These findings have also been attributed to misinterpretation of probabilistic scales (Clarke et al., 2000; Katapodi, Lee et al., 2004).

Information about the risk status of peers might also influence perceived risk and reduce optimistic bias (Weinstein, 1983). Studies reported that having friends diagnosed with the disease increased perceived breast cancer risk (Montgomery et al., 2003), and that some women compared themselves to affected friends in order to estimate their personal breast cancer risk (Katapodi et al., In Press). Both studies attributed these observations to cognitive biases related to information processing and the use of heuristic shortcuts.

Studies described an affective reaction related to breast cancer as worry. Some studies examined worry in relation to family history of breast cancer (M. A. Diefenbach, A. M. Miller, & M. Daly, 1999a; Kim, Valdimarsdottir, & Bovbjerg, 2003; McCaul, Branstetter, O'Donnell, Jacobson, & Quinlan, 1998). Other studies attributed worry to

personal experiences with breast symptoms. Seven studies suggest that an abnormal mammographic finding that turned out to be benign correlated with increased perceived risk (Katapodi, Lee et al., 2004). Studies also reported that a diagnostic breast biopsy was a major cause of cancer-related distress (Andrykowski et al., 2002), and that symptom interpretation elicited breast cancer worry, but only among women who perceived their breast cancer risk to be high (Easterling & Leventhal, 1989).

Findings from the above studies are consistent with suggestions that optimistic bias is reduced through individualized information and personal experiences (Weinstein, 1988). However, these findings do not provide a clear understanding about the phenomenon of optimistic bias as it relates to breast cancer. It is not clear whether having a positive family history increases perceived risk because women know that they share genetic material with their family members or because the experience with the disease evoked negative emotional responses and worry. The underlying connection between having an abnormal breast symptom and reporting a heightened perceived risk is unclear. The acknowledgement that having dense breast tissue increases the risk for invasive breast cancer may explain this connection on a logical level. On an affective level, the experience of an unpleasant procedure may evoke negative emotions, leading to a heightened perceived risk.

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

Recruitment and Procedures

The present analysis is part of a community-based survey that examined perceived breast cancer risk, accuracy of women's estimates, and factors that influence perceived risk (Katapodi, Dodd et al., 2004). The study recruited a convenience sample of women between the ages of 30 and 85 years that had never been diagnosed with any type of cancer, and consented to complete a questionnaire in English. Recruitment was done with flyers posted on bulletin boards in community settings and workplaces, through newspaper advertisements, and through networking with community agency leaders. Women responded by calling a dedicated telephone number and expressing their interest in participating in the study. Participants completed the survey either in person or by mail and were paid \$15. The University of California San Francisco Committee of Human Rights approved the study protocol. Data collection was carried out between February 2003 and March 2004.

Measures

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

Current Breast Symptoms (*Breast Symptoms*), were assessed with a modified version of the Breast Cancer Symptom Knowledge Scale (N.C. Facione, Miaskowski,

Dodd, & Paul, 2002). We asked participants their current experiences with an abnormal breast symptom. In addition to the 15 items in the original scale, three items were added: *sharp pains in the breast, a vague change in the breast, and one or both breasts are different than usual*. We gave each symptom a score between '0' and '4', indicating the potential severity of the symptom. For example, "breasts feel painful and tender during menstruation" was scored as '1', whereas "a little blood is coming out my nipple" was scored as '4'. Participants could respond *Yes, No, and Don't Know* for each breast symptom. Items that were scored *Yes* and *Don't know* were summed to calculate each woman's score for severity of current breast symptoms. The inclusion of three additional items and the scoring of ambiguous responses (*Don't know*) as affirmative is based on findings of a pilot study regarding the ways in which women described an unidentified breast symptom in a non-threatening way (Katapodi et al., In Press). Possible scores on the Breast Symptoms Scale range between 0 and 40 and the total score represents incidence and severity of current breast symptoms.

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

Knowledge of Breast Cancer Risk Factors was assessed with 13 items. Five of these items described risk factors identified by the Gail model (Royak-Schaler et al., 2002). The remaining eight items were investigator-developed to examine knowledge of hereditary/genetic risk factors for breast cancer. Items asked whether 1) having multiple family members with breast cancer, 2) having had breast cancer before, 3) having a family history of breast cancer from the mother's side of the family, 4) having a family member with both breast and ovarian cancer, 5) having a genetic mutation, 6) having a family history of breast cancer from the father's side of the family, 7) having a family history of ovarian cancer, and 8) being of Ashkenazi Jewish descent were breast cancer risk factors (Katapodi & Aouizerat, Submitted). Participants could respond *Yes*, *No*, or *Don't Know*. Items scored affirmatively were summed to calculate each woman's score on the *Knowledge of Breast Cancer Risk Factors Index*. Possible scores ranged between 0 and 13 and items were highly inter-correlated (Cronbach $\alpha = .80$).

Breast Cancer Worry was assessed with four items (Easterling & Leventhal, 1989). Two items asked participants to rate "*how often they had worried*" and "*how emotionally upset or distressed*" they had been in the past about the possibility of getting breast cancer. These items were answered on a scale ranging from '0' "*Never/Not at all*" to '10' "*All the time/ A Great Deal*". The remaining two items were forced choice, four-point Likert scale, and assessed "*current worry about the possibility of getting breast cancer*" and "*worry when going to the doctor*". To form a worry score in which each of the four items contributed equal variance, each item was divided by its respective standard deviation before summing (Easterling & Leventhal, 1989). Higher scores

indicated greater worry, and internal consistency for the scale was high (Cronbach $\alpha = 0.85$).

Perceived Risk: We asked participants to rate their risk and the risk of their friends/peers on scales ranging from '0' to '10' that have been coupled with five Verbal anchors ("*Definitely Will Not*" to "*Definitely Will*"). We also used a Comparative risk scale ('1' to '5', "*A Lot Lower*" to "*A Lot Higher*"), in which participants rated their risk compared to the risk of an average women. Finally, we examined whether participants' Gail scores were higher or lower compared to the Gail scores of same age women in the population with average risk factors (Actual Comparative Risk = Participant's Gail score minus the Gail score of an average woman). We compared the direction of the Actual Comparative Risk score to the direction of women's response in the Comparative risk scale (Katapodi, Dodd et al., 2004).

Women significantly underestimated their personal breast cancer risk in all measures. On the Verbal scale participants perceived that they would "Probably Not" get the disease (mean: 3.57 ± 1.70), while they rated their friends/peers at higher risk than themselves (mean: 4.34 ± 1.54 , $t_{(171)} = 5.49$, $p < 0.01$). On the Comparative scale the distribution of responses was skewed to the left. Participants also underestimated their actual breast cancer risk ($t_{(174)} = 4.78$, $p < 0.01$) (Katapodi, Dodd et al., 2004).

We performed a Principal Component Analysis using those three measures. The goal was to identify a measure of Perceived Risk that would explain the total variance shared by the three measures. The total variance reflects the sum of explained and error variance; yet, error variance is attributed to random and not systematic error (Afifi & Clark, 1997; Bryant & Yarnold, 1995). All three measures loaded on a single Principal

Component that represented a measure of Perceived Risk. Factor loadings were .62 for the Verbal scale, .79 for the Actual Comparative risk estimate, and .88 for the Comparative scale. The principal component explained a cumulative variance of 59.8% and the internal consistency reliability (Cronbach α) of the three measures was .65.

Statistical Analysis

Data were analyzed using the SPSS 11.5® statistical program. We calculated individual scores for scales with at least 60% of items completed. Significance was set at the 0.05 level with 95% confidence intervals for all statistical analyses. We used descriptive statistics to describe the demographic characteristics of the sample. We performed simultaneous and hierarchical regression analyses to explore whether worry and knowledge of breast cancer risk factors moderated the relationships between predictive variables and perceived risk (Baron & Kenny, 1986; Bennett, 2000). To test for a possible interaction between two variables, both variables were entered simultaneously in the first step of a hierarchical regression followed by the interaction term in the second step. A moderator effect was present if the interaction term accounted for a statistically significant amount of the variance in the dependent variable. To reduce possible multicollinearity among predictors, variables were centered prior to use in regression analyses. This means that they were put in a SD form by subtracting the mean of each variable from each observed value. Centering variables removes non-essential multicollinearity that is due to scaling (Cohen, Cohen, West, & Aiken, 2002).

Results

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

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

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

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

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

With a separate hierarchical regression we examined whether there was a significant interaction between knowledge of breast cancer risk factors and worry. The

interaction term accounted for an additional 5% of the variance in perceived risk (See Table 3.4 and Figure 3.1)

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

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

Discussion

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

Family history of breast cancer accounted for 6% of the variance in perceived risk. This was not surprising, as family history has been shown to be the strongest predictor of perceived risk across numerous studies (Katapodi, Lee et al., 2004). However, most of the variance explained by family history was contributed by women with multiple affected family members and affected SDRs and not from women with one affected FDR. According to epidemiological models of risk estimation, such as the Gail model (Gail et al., 1989), having one affected FDR can significantly increase a woman's risk for breast cancer. Consistent with other studies (Absetz et al., 2000; Aiken et al., 1995), our findings suggest that some women with one affected FDR do not perceive their risk to be significantly elevated. Furthermore, the relationship between family history and perceived risk is moderated by knowledge of breast cancer risk factors, but only for women with one affected FDR. The subjective risk evaluations of women with one affected FDR, who rated their risk as significantly higher compared to women with no family history, drew on the knowledge that breast cancer in an immediate family member increased their own risk because of the close genetic similarity to their FDRs. However, knowledge of breast cancer risk factors did not moderate the relationship between having SDRs or multiple affected family members and perceived risk. Since

78% recognized that having multiple family members with breast cancer was a risk factor, knowledge explained most of the variance in that relationship.

McCaul and Tulloch (1999) suggested that a positive family history could influence perceived risk through multiple routes, one of which is breast cancer worry. However, consistent with other studies (Loescher, 2003), family history of breast cancer was not a predictor of breast cancer worry. It appears that the relationship between worry and family history is complex and time-dependent. Women with a positive family history exhibited greater worry than those with no family history, but initial levels of worry dissipated at a year follow up (McCaul, Schroeder et al., 1996). Apparently, worry evoked by positive family history represents an unstable and transient emotional state that follows the diagnosis of a family member but is not long lasting for most women. The study sample was not recruited through an affected relative, which might explain why family history did not evoke worry. Alternatively, our study may not have detected a statistically significant relationship, since the number of women with a positive family history was small.

Having one or more friends diagnosed with the disease accounted for 2% of the variance in perceived risk. We examined whether number of affected friends increase perceived breast cancer risk because it evoked worry, but worry did not moderate the relationship between affected friends and perceived risk. A possible explanation for this finding could involve heuristic thinking, as described in theories of judgment and decision-making (Kahneman et al., 1982). Under conditions of uncertainty, when individuals do not have complete and accurate information about the probability of an outcome, they form a judgment based on salient memories and personal experiences

(Tversky & Kahneman, 1973). Researchers proposed that family history of breast cancer (N.C. Facione, 2002; Rees et al., 2001) and experiences with affected friends (Montgomery et al., 2003) influence perceived risk through heuristic thinking. Our data are consistent with those suggestions.

The relationship between experiencing abnormal breast symptoms, worry, and perceived risk is more difficult to explain. Current breast symptoms directly evoked worry but did not evoke perceived risk. It is possible that the relationship between current breast symptoms and perceived risk is moderated by other variables, such as perceived control over a breast symptom (Cunningham et al., 1998). Consistent with other studies (Katapodi, Lee et al., 2004), women whose most recent Mammogram or most recent CBE was done for the evaluation of a breast symptom had a heightened perception of risk. Furthermore, we found that the interaction between knowledge of risk factors and having the most recent CBE for a breast symptom predicted worry, and that the interaction between worry and having the most recent Mammogram for the evaluation of a breast symptom predicted perceived risk.

Consistent with other studies (Andrykowski et al., 2002; Cunningham et al., 1998), having one or more Breast Biopsies was not a predictor of perceived risk. However, those studies found that experiences with Breast Biopsies evoked worry, a finding that was not replicated in this study. Rather, the interaction between Breast Biopsies and worry accounted for 2% of the variance in perceived risk. It appears that the relationship between perceived risk, worry, and Breast Biopsies may be time-dependent. Studies reported that after a Breast Biopsy initial levels of worry were high, but worry declined over time (Andrykowski et al., 2002; Brett, Austoker, & Ong, 1998).

Finally, worry was a significant predictor of perceived risk but knowledge of breast cancer risk factors was not. Rather, the interaction of worry with knowledge of breast cancer risk factors accounted for 5% of the variance in perceived risk.

Taken together, these findings suggest that worry might be the initial response to a self-discovered breast symptom, which is consistent with the mechanism of the affect heuristic (Loewenstein, Weber, Hsee, & Welch, 2001; Slovic, Finucane, Peters, & MacGregor, 2002). Ad hoc evaluations of those symptoms increase perceived risk mainly for women who maintain a high level of worry, which is consistent with models of symptom interpretation and self-regulation (Cameron & Leventhal, 1995; Leventhal et al., 1980). Moreover, there may be differences in judgment and decision-making style between a woman who initiates a visit to her health provider for the evaluation of a self-discovered breast symptom (RCBE) and a woman who does not seek such an urgent evaluation. Our findings indicate that women who initiated their most recent CBE for the evaluation of a self-discovered breast symptom, and who were aware of breast cancer risk factors, might have higher levels of worry. However, this suggestion needs further investigation.

Overall, our findings indicate that experiences with affected family members and friends, and experiences with abnormal breast symptoms influence the evaluation of subjective breast cancer risk through different mechanisms. The first mechanism is based on an analytical cognitive process: family history of breast cancer influences perceived risk through the knowledge that it represents a genetic risk factor. The second mechanism is based on heuristic thinking representing logical shortcuts in the analytic mechanism: women who do not have accurate and complete information about their

breast cancer risk are more likely to depend on salient memories and personal experiences for making personal risk estimations with the assistance of logical shortcuts. The third mechanism is based on affect: current breast symptoms influence perceived risk by eliciting worry. Finally, the fourth mechanism is based on the interaction of affect with the analytical mechanism: initiating a visit to a health provider for the evaluation of a self-discovered breast symptom evoked worry for women who had knowledge of breast cancer risk factors. The latter mechanism is consistent with notions of dual aspects of consciousness, the rational and the affective mechanism of information processing (Epstein, Pacini, Denes-Raj, & Heier, 1996).

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

Chapter 4.

Perceived breast cancer risk: Heuristic reasoning and search for dominance structure

By

Katapodi, MC, Facione, NC, Humphreys, JC, Dodd, MJ. (In Press)

Social Science and Medicine

Abstract

Studies suggest that people construct their risk perceptions by using inferential rules called heuristics. The purpose of this study was to identify heuristics that influence perceived breast cancer risk. We examined 11 interviews from women of diverse ethnic/cultural backgrounds that were recruited from community settings. Narratives in which women elaborated about their own breast cancer risk were analyzed with Argument and Heuristic Reasoning Analysis methodology, which is based on applied logic. The availability, simulation, representativeness, affect, and perceived control heuristics, and the search for a dominance structure were commonly used for making risk assessments. Risk assessments were based on experiences with an abnormal breast symptom, experiences with affected family members and friends, and beliefs about living a healthy lifestyle and trust in health providers. Assessment of the potential threat of a breast symptom was facilitated by the search for a dominance structure. Experiences with family members and friends were incorporated into risk assessments through the availability, simulation, representativeness, and affect heuristics. Mistrust in health providers led to an inappropriate dependence on the perceived control heuristic. Identified heuristics appear to create predictable biases and reveal that perceived breast cancer risk is based on common cognitive patterns.

Word Count: 195

Key words: Breast cancer, perceived risk, heuristics, interview data, argument analysis, search for dominance structure

Introduction

How do individuals assess their own susceptibility to disease? How do they decide whether they are at risk for one or the other health problem? Kelly (Kelly, 1996) argued that existing gaps in risk assessment services and inadequacy of the media to address individual concerns and to resolve conflicting information, force individuals to make subjective estimations of the likelihood of disease based on subjective understandings of probabilities, subjective understanding of risk factors, and subjective meanings that they attach to risk attributes.

Simon (Simon, 1982) argued that people most often are forced to make decisions about future risks under constraints of limited time, limited information, and limited computational abilities. Whenever people estimate the probability of future risks, instead of making elaborate calculations of all relevant information, all potential courses of action, and all potential outcomes, they seek to make fast decisions that lead to adaptation and survival. Judgment and decision-making theory suggests that in cases of uncertain information, judgments and behaviors are influenced by both rational and irrational information processing mechanisms (Kahneman et al., 1982; Nisbett & Ross, 1980). Predictions and judgments are often mediated by a small number of distinctive mental operations, which are called heuristics. Heuristics are logical shortcuts that people use when processing information; they help reduce complex mental operations to simpler cognitive tasks (Kahneman et al., 1982). Heuristics help in decision-making when a complete and exhaustive consideration of all possibilities would have proved to be too slow or inefficient (Gigerenzer & Todd, 1999). Therefore, heuristics save cognitive resources and time. Some risk assessments may be answered strictly analytically through

an algorithmic analysis, e.g. what are the chances of beating a given hand in poker?

Other questions demand a more subjective analysis e.g. did John Doe kill his wife? It is in these latter cases that people are more likely to rely on heuristic thinking (Tversky & Kahneman, 1983). Although heuristics facilitate risk assessments, they can produce both valid and invalid judgments, and sometimes they lead to characteristic systematic errors.

Besides logical shortcuts, people often rely on affective reactions as a means to facilitate information processing and judgment. The contribution of feelings in risk assessments represents the “affect heuristic” (Loewenstein et al., 2001; Slovic et al., 2002). The affect heuristic acts in two ways. First, it acts as a conscious or unconscious feeling state (e.g. fear, anger) that the individual experiences during the decision-making process. Second, it represents the affective evaluations, positive or negative, of an external or internal stimulus or of a mental image. Table 4.1. presents some commonly used heuristics.

Simon (Simon, 1982) suggested that because people have limited information-processing and computational abilities, during the decision-making process various alternatives are examined sequentially. The first alternative that meets or exceeds a specific aspiration level is selected. This phenomenon, termed “satisficing” helps in terminating the search for alternatives and speeds the decision-making process. Montgomery (Montgomery, 1989) further suggested that decision-making under uncertainty is facilitated by a cognitive mechanism called “search for a dominance structure”. This mechanism is based on heuristic shortcuts and on “satisficing”. By this mechanism, individuals structure information such that one alternative choice is perceived to be better than other choices. The search for a dominance structure occurs in

four phases. In the first phase, termed pre-editing, individuals consider the various alternative choices. In the second phase, they select one alternative that they believe has a better chance to be seen as dominant over the others. In the third phase, they examine whether the promising alternative has any disadvantages compared to other alternatives or to other general values. In the final phase, the drawbacks of the dominant alternative are evaluated and the dominance structure is created. The resulting dominance structure can be in good contact with reality or not, depending on the cognitive mechanisms that the individual uses for choosing the dominant alternative. De-emphasizing the disadvantages of the chosen alternative or bolstering its advantages may create a dominance structure that is not in good contact with reality, whereas counter-balancing disadvantages with advantages, and collapsing two or more attributes to one, more comprehensive, attribute are more rational operations (Montgomery, 1989). In summary, search for a dominance structure is another mechanism that facilitates choice. It relates new information to pre-existing knowledge by activating mental images and schemata and could also lead to systematic errors and predictable biases.

Although various heuristics have generally been described separately, it has been suggested that individuals use multiple heuristics simultaneously to make a risk assessment. For instance, the availability and the simulation heuristics influenced perceived risk for fatal weather events (Greening, Dollinger, & Pitz, 1996), and for future job-related accidents (Greening, 1997). The simulation and the perceived control heuristics influenced perceptions for the efficacious treatment of osteoporosis (Satterfield, Johnson, Slovic, Neil, & Schein, 2000), and for contracting AIDS from sexual practices (Prohaska, Albrecht, Levy, Sugrue, & Joung-Hwa, 1990).

Since breast cancer is the most common cancer diagnosis in women (American Cancer Society, 2003) studies examined how do individual women decide whether they are at risk for breast cancer. It has been suggested that personal experiences are incorporated into risk perceptions through the availability, representativeness, and anchoring and adjustment heuristics (Rees et al., 2001) , through the availability and perceived control heuristics (N.C. Facione, 2002), and through the availability heuristic (Montgomery et al., 2003). While these studies have uncovered a connection between heuristics and risk perception, further research is needed in order to understand precisely how heuristic thinking impacts breast cancer risk perception.

The purpose of this study was to identify heuristics that are specific to women's expressed beliefs about getting breast cancer and to examine how these heuristics inform their own sense of risk. Previous studies examined the impact of heuristic thinking on breast cancer risk assessments by examining whether experiences with affected family members and friends predict perceived breast cancer risk in a hierarchical regression model. The current study represents an attempt to identify heuristic thinking in narrative data, and to assess whether such an analysis could be feasible with a larger sample.

There are several reasons why the study of heuristics in decision-making is advantageous over other approaches for studying perceived risk. First, the study of systematic errors in risk assessments can illuminate the psychological processes that underlie perception and judgments (Kahneman & Tversky, 1996). Second, identifying heuristics that lead to predictable biases can have practical implications for clinical judgment and risk assessment. Educational interventions at the individual or the community levels might be able to incorporate messages that counterbalance invalid risk

perceptions that stem from heuristic thinking and impede the adoption of health-protective behaviors (Montgomery et al., 2003). Third, study of heuristics and bias might facilitate risk communication and the transmission of risk-related messages that are better received by lay people.

Methodology

The study examined open-ended interview data. First, we analyzed each interview line by line in order to identify emerging themes. Second, the identified narratives were examined for evidence of heuristic thinking and search for a dominance structure. This second step of analysis is based on applied logic (Toulmin, 1964; Toulmin, Reike, & Janik, 1979), implementing a method described by Facione and Facione (N.C. Facione & Facione, 2001). Analysis begins by identifying women's arguments within emerging themes. Each argument is broken down to its structural components: grounds, claims, and warrants. The grounds represent the beliefs, values, and information about breast cancer that each woman holds to be true. The main claim represents the final assessment of the probability of an expected outcome. The warrants represent the rational process with which each set of beliefs is connected to an anticipated outcome. A step-by-step analysis of warrants revealed the specific heuristic shortcuts that were used by each individual woman in the course of the argument, while the chronological order of the arguments revealed possible search for dominance structure. Argument structures were represented in diagrammatic maps using Inspiration 6[®] software (Inspiration Software, 2000). Narratives are presented in a text form and heuristics are presented on the left hand side. The annotation "Search for Dominance"

indicates that the phrase is part of a dominance structure. Trustworthiness of the findings was established through the diagrammatic maps.

Sample and procedure

Interviewees were participants in a large community-based survey of breast health behavior reported elsewhere (N.C. Facione et al., 2002). In order to examine help-seeking behavior for a self-discovered breast symptom 33 women, who indicated that they had had experiences with abnormal breast symptoms, were re-contacted for an interview. A new informed consent was obtained from each participant in accordance with an approved institutional review board protocol. A research assistant skilled in interview techniques conducted the in-depth interviews, which were audiotaped, and lasted approximately 90 minutes. Interviews were semi-structured to explore help-seeking behavior and decision-making processes. All participants were asked three common questions: a) How did you make the decision about whether or when to have your breast symptoms evaluated? b) Have you had any problems with access to health care services? c) What do you think is your risk for getting breast cancer?

This paper reports analysis of 11 of those interviews. Selection of these 11 interviews was purposeful and was based on two criteria. First, they included an elaborate narrative on the woman's own sense of breast cancer risk that allowed us to examine the narrative for heuristics and cognitive strategies. Second, they represent a maximum variation sample of women from diverse socioeconomic and racial/cultural backgrounds. Two participants were from an affluent, middle-upper class background. Five participants from diverse racial/cultural backgrounds had some college education

and were employed full-time as a librarian, a secretary, a middle-school teacher, a child development specialist, and in fundraising. One participant was employed part-time; she was a Hispanic immigrant who was the caretaker of an elderly person. One participant was widowed and was living on welfare. Finally, two women were former drug users living on minimal income; one was an AIDS patient living on welfare, and the other was recruited from an assisted living facility for substance abusing parents. Participants' age ranged from 28 to 63 years. All names used in the analysis are pseudonyms.

Results

Our first finding was that most participants held an optimistic bias for their breast cancer risk. Of the 11 women, eight said that they perceived themselves as being at a lower risk compared with the average woman, whereas two participants expressed uncertainty about being at a higher risk, and one participant considered herself as being at a higher than average risk. Risk assessments were based on assessments of the potential threat of a breast symptom. The second theme emerged from the fact that beliefs were formed through women's experiences with an affected family member or friend. The third theme emerged from women's perceived control over the disease, which involved their lifestyle choices and trust of health care providers.

In all 11 interviews we could identify arguments that supported the main claim and antithetical arguments, which were addressing evidence that did not support the main claim. In most interviews, these two argument structures were interwoven, often expressed in the same sentence. Rather than balancing the opposing arguments, interviewees usually made many more arguments to support the main claim, or they

emphasized that those arguments were more convincing. Arguments revealed various heuristics and search for a dominance structure. Table 4.2 presents excerpts of different heuristics within themes..

Breast Symptom: "It's not a breast lump"

Search for a Dominance Structure, Affect, and Perceived Control

All participants had had personal experiences with abnormal clinical or mammographic findings that were subsequently determined to be benign. However, three participants, each reported that they had not yet sought medical evaluation for a breast symptom that they had first noticed several months prior to the interviews. Having a personal experience with a breast symptom was not associated with heightened perceptions of risk. Most participants claimed that their breast symptom was not a palpable mass but a vague change in their breast. Women claimed that they knew what characteristics of a breast symptom are potential signs of breast cancer. Since they had assessed their symptom as not having those characteristics, each concluded that it was not a sign of breast cancer and it did not pose a threat to their health. Eight participants made this argument irrespective of age, social, and racial/cultural characteristics.

Since current early detection guidelines suggest that women seek medical evaluation for any change in their breast, the three participants who had not sought medical evaluation for a breast symptom had either not known these guidelines, or had chosen to ignore them. It is not clear how these women were able to reconcile the acknowledgment of the presence of a breast symptom with perceptions of being at a lower risk. One possible explanation is that they use the search for a dominance structure

to create an alternative explanation about the identity of a breast symptom. Identifying a woman's search for a dominance structure could only be inferred from the data. The process of pre-editing, which for these women involves identifying the various alternative explanations for the breast symptom, presumably is not always conscious and is not likely to be verbalized in an interview.

The following three examples illustrate how women were able to create a dominance structure around an alternative explanation about the identity of a breast symptom. Participants claimed that the breast symptom could be attributed to other causes, such as a fat deposit, extra tissue, and hormonal changes. In these cases, the search for a dominance structure appears to be a powerful influence on symptom appraisal.

Lily is a 56 year old, college educated, white, married woman who has health insurance. Lily argued that the lump in her breast is a fat deposit:

Affect	"... there is one thing that my partner's noticed that I have a lump here (points). ...that's partly what makes [partner] valuable, he cares. He is observing and he cares.
Search for Dominance	and [partner] is pretty sure that it's a lym- lypoma?(<i>sic</i>) (Lipoma) ...[partner] has something on his back, which is a lypoma (<i>sic</i>) (Lipoma) and from what he knows about that he's pretty sure that's what this is. ...obviously, [partner] is not a medical person.
Search for Dominance	And [doctor] was telling me, you can put a piece of ice on it for minutes and if it hardens, if it is soft, if it is movable, and if it hardens, it is most probably a lypoma. (<i>sic</i>) (Lipoma) Hey, it better get hard when you put ice on it.
Search for Dominance	It's not actually breast tissue; it's lower than that. It's really on the ribs...I mean it's a fat deposit (emphasis). ...I didn't even find it. I have trouble finding it... It's not something that I am very concerned about; it can't be serious."

Elena is a 42 year old, college educated, Hispanic woman who was working full time and had recently been separated from her husband. She attributed her lump to having extra tissue.

Affect Antithetical Search for Dominance	<p>"I got really scared because I have like extra tissue on one breast.</p> <p>I don't know if that [extra tissue] is normal or what.</p>
Affect Simulation	<p>... 'cause the pains I get, do scare me sometimes... [pause] since it is only on one side, not on both breasts that does worry me a little bit ... something that kept growing and growing... Then you figure that something is wrong.</p>
Search for Dominance	<p>I'm real ignorant when it comes to...[breast cancer] If I found anything [a symptom during a breast self-exam] I wouldn't know. I would probably go to a dermatologist... rather than thinking it was something in the breast.... I'd probably think it's a vein or something.</p>
Perceived Control	<p>I really don't check my breasts frequently...but I do check the one spot."</p>

Beth is a 62-year-old, widowed, black woman who is living on welfare.

Affect, Antithetical	<p>"When I have the little sharp pains... makes me... little afraid. But not real afraid. Sometimes [breasts] get tender.</p>
Search for Dominance	<p>I kind of wonder about it. And then I say "Well maybe I'm still going through. ...[Indicates agreement when the interviewer says, "menopause?"]</p>
Affect	<p>Well the first time, I was...(worried, confused tone). Now when they do it [mammography] it doesn't bother me. It always comes out negative".</p>

Montgomery (Montgomery, 1989) suggests that the anchoring and adjustment heuristic facilitates the search for a dominance structure in the pre-editing phase. With its assistance women used their experiences and preexisting knowledge as an initial reference point. Beth created a dominance structure based on her experience that mammography "always comes out negative". Often, women made arguments in apparent attempts to neutralize or cancel the logical implications of arguments that implied higher

breast cancer risk. Elena cancelled the logical implications that symptom asymmetry could be a sign of breast cancer by arguing that if she found a breast symptom she would think, “it’s a vein or something”. She reinforced her assessment of being at a lower risk with the perceived control heuristic by arguing that she checks “that one spot”. The affect heuristic also influences the search for a dominance structure by providing an initial anchoring point. Lily created a dominance structure around the explanation that her symptom is a fat deposit due to the fact that this suggestion came from her partner, for whom she expressed positive emotions. Although Lily acknowledged that her partner “is not a medical person”, because of their emotional bond, she canceled the logical implication that his assessment could be wrong. The resulting dominance structure was biased toward the initial assessment.

Experiences with Family and Friends: “It doesn’t run in my family”

Availability, Simulation, Representativeness, Search for a Dominance Structure, and Affect

In order to estimate their risk of developing breast cancer, participants retrieved information from past experiences with family and friends. These experiences were integrated into risk perception through the simulation, the availability, and the representativeness heuristics. With the availability heuristic existing information becomes easily retrievable and readily available to be incorporated into risk estimates. Through the simulation heuristic, women created a mental image in which they could either foresee themselves developing the disease or not. With the representativeness heuristic, they created a stereotype image of a high-risk individual.

Participants compared themselves to that stereotype image and subsequently decided that they were at a lower risk. This was particularly true for the eight participants who did not have a family history of breast cancer. While acknowledging that a negative family history does not make a woman invulnerable to the disease, Lily argued that her family history placed her at a lower risk. By using the availability and the simulation heuristics, she addressed the probability that she might develop a heart-related health problem and created a dominance structure around the argument that she is more at risk for heart disease than for breast cancer.

Antithetical Availability Simulation, Search for Dominance	<p>“...as far as I know, there is not a history of breast cancer in my family. I know that doesn’t rule it out.</p> <p>... my mother died of a stroke, my father’s had heart problems, ... so that’s more of a real threat in my life.</p> <p>My brother’s had heart problems and he’s only three years older than me”.</p>
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Tania is a 52 year old, married, white schoolteacher. She said that when her mother-in-law developed breast cancer the family was in a shock.

Perceived Control	<p>“She’s always been a “doer” ... she’s also one not to be sick and not to complain... She’s that kind of woman; she’s a fighter, a lady gracious. (SIC) ...so [breast cancer] was a shock to the family.”</p>
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Lily described her surprise when one of her acquaintances developed the disease.

Availability, Simulation, Affect	<p>“A friend... a couple years ago was diagnosed with breast cancer. A woman about my age, two children a little younger than mine and ...that was pretty frightening.</p>
Perceived Control	<p>And [the family of the friend with breast cancer] are people who are concerned with health, and eating right, and living well. And educated. and you don’t... you don’t expect, you never expect that to happen.”</p>

Describing the experience as surprising or shocking suggests that participants had a preexisting belief about a stereotypical type of woman who is more likely to develop

the disease. The diagnosis of a relative or of a friend who did not fit that stereotypical image contradicted that pre-existing belief about breast cancer and created a new and unexpected image. These examples reveal how the misuse of the representativeness heuristic led these participants to believe that developing breast cancer can be reliably avoided either by lifestyle choices or by personality characteristics.

Experiences with affected family members and friends were a source for information for participants and were used as an initial anchoring point for creating a dominance structure. Using the availability and the simulation heuristics, participants envisioned themselves playing out the experience of a friend, in order to identify similarities and differences between themselves and their friends and then to make an estimate of their own risk.

Sara is a 39 year old, college educated, black woman that has a six-week-old baby and lives in a residence for pregnant and parenting substance abusers. When her nurse practitioner suggested she had a mammogram, Sara referred to a friend's experience with a breast symptom in order to estimate her own risk.

Availability "...[friend] had found a lump and [pause] she went to the doctor and stuff [pause] and it came out that it was benign.

Simulation [Pause] And we're the same age and she's pregnant too. And she had this during her pregnancy. It was earlier in her pregnancy; she's about six or seven months now.

Perceived Control She put me more at peace of mind...."

Teresa is a Hispanic, 56-year-old woman, with a high school education who argued that breast cancer is not a serious disease because, compared to other types of cancer, its progression is slow.

Availability "...I know a woman who had an operation 10 years ago, and she is alive and has only one
Affect [Breast cancer] does not worry me much.

Availability It is not the same as if the cancer shows up in the stomach or the uterus, [pause] where
Search for it's very harmful. One of my sisters died of stomach cancer... it was quick; she did not
Dominance have time to do anything at all.
With [stomach] cancer there is no time to do anything, unlike breast cancer".

Finally, some experiences were considered self-relevant and were recruited into risk assessments while others were dismissed, possibly through the affect heuristic. In the following narratives risk assessments are colored by the positive or negative emotions and the degree of closeness and involvement participant women felt towards the affected person.

Rose, is a 28 year old, college educated, black, single woman. Her risk assessment was influenced by her emotional response towards her mother's experience with a benign breast symptom, rather than by the fact that her aunt had breast cancer.

Simulation "...my mother was going through, [pause] they found some abnormal lump in her breast. ...we would go through together, through it,
but I guess nothing ever happened. I guess it was normal or something. [Pause]. 'Cause I don't remember her having a discussion with me. But I just can remember talk around the house about that; [mother] had an abnormal breast something....
...my aunt...she had breast cancer and she had one of her breasts removed.

Affect So. Just being interested and really concerned".

Ann is a 48 year old, divorced, white woman with a high school education, who has AIDS and lives on welfare. She achieved a dominance structure around the argument that in contrast to her mother's actions, she can control the risk posed by hereditary factors through early detection.

Availability
Perceived Control

“...my Mom had breast cancer and she lost her breast because of it.
But I keep a good eye on it ‘cause I hear it’s hereditary.

Search for
Dominance

I don’t think [mother examined her own breasts]. She’s backwards...[she lives on a] farm
out in the....in the middle of nowhere. And she’s not very bright.
I’m not that close to my mother.

Perceived Control
Search for
Dominance

I check my own self. And I make sure I have my mammograms.
I guess after you catch them early they just cut ‘em, cut out the lump, right? That’s what
I try for.”

The observation that the degree of emotional closeness influences risk perception can only be inferred in these two narratives. This inference is based on the assumption that during the interview participants narrated about experiences and thoughts that they considered relevant to the interview topic. Consequently, we assume that Rose’s narrative and Ann’s comparison of herself to her mother were relevant to their own breast cancer risk assessment, even though this was not specifically verbalized.

*Lifestyle and Trust in Health Providers: “I can deal with it myself, I don’t need to go in”
Perceived Control and Search for a Dominance Structure*

Almost all participants argued that they could exert some control over the disease through lifestyle choices such as diet, exercise, and having less stress. Some participants implied that they had little control or were ambivalent, whereas others claimed to have a lot of control over the chance of getting breast cancer.

Claire is a 48-year-old, white, college-educated woman, who was ambivalent about whether her personal actions could make a difference in her developing breast cancer.

Correct Inferential
Reasoning
Perceived Control

“...I don’t think there is a lot I can do in my life,
except just stop drinking coffee to eliminate those lumps, and I think mammography and
breast exams by my doctor.

Correct Inferential I don't think that [mother] has any risk behavior that caused [breast cancer]. So it makes me realize that you can do everything, not 100% right, but pretty right and still get it.

Search for Dominance I can live healthy and so I do. As far as diet and exercise and not doing things that I know that are bad for my body. ...if I keep doing what I'm doing I'd catch it, even within a year of it's starting or something, it's very treatable."

On the other hand Daphne, a 28-year-old, college educated, white woman argued that her sexual orientation places her at an increased risk for breast cancer. However, she provided a counterargument about making appropriate lifestyle changes that could reverse that specific negative effect.

Search for Dominance "[Breast cancer] was on my mind. I attached the symptoms that I had to the list that I had read before. I remember reading ... that lesbians were at higher risk for breast cancer. I am actually bisexual.

Availability Representativeness Search for Dominance I remember reading the thing about being overweight, and I thought, OK, so that means that I am at a higher risk, so I sort of put myself in a slightly higher risk

Perceived Control But then I also thought, ... I'm only 28, so I'm probably going to be higher risk when I'm 40 or 45, and so that means that I should lose weight before that time, to make sure that I'm not in a higher risk group.

Search for Dominance I pretty much decided that I was [at a higher risk], having read that. Lesbians are more aware of breast cancer than other groups.

Perceived Control Search for Dominance There would be a lot I could do to help myself. ...doing a conscious effort not to expose myself to a lot of toxics chemicals. We use non-toxic cleaners in the house. I don't smoke...
The other aspects of my lifestyle, I think they are pretty healthy besides those that I mentioned."

Participants turned to their health care providers for an effective management of their risk. Trust in health providers led to a sense of personal control and minimized perceived risk. Some participants argued that a positive relationship with a health provider and adherence to breast cancer screening guidelines are protective factors.

Tania, the 52-year-old married, white schoolteacher, argued that her good relationship with her health care provider makes her feel at less risk.

Perceived Control “Watch your diet, exercise, pay attention to all the signs, do your self-exam, see your doctor...I think you have control over [breast cancer], if you feel something right away, call the doctor right away.

Search for Dominance When I go to the doctor now [after an abnormal mammogram that turned out benign] he does more of an exam...[pause]. It’s good to know he is aware. He’s reassuring ...And I feel satisfied. Comfortable with it. I believe in the medical profession ...”

Most participants argued that a healthy lifestyle gave them some control over the probability of developing breast cancer. However, some women amplified that reasonable belief, that they had a small amount of control, and created a belief of almost complete control. Mistrust of health care providers might be a factor that led these participants to misuse the perceived control heuristic and create an illusion of control. The interplay between mistrust in health care providers and the belief that one’s lifestyle can lower breast cancer risk made some participants to create an illusion of control that breast cancer can be managed without medical intervention.

The cases of Lily and Beth best illustrate this observation. Lily argued that she has always been healthy because of her positive outlook on life and her self-care actions.

Affect “My feeling is that doctors ...for something that’s vague don’t have a great deal of knowledge. It’s a mixture of distrust in doctors and fear...”

Loss Aversion With the breast cancer thing, I don’t want to be told...

Perceived Control I want to take responsibility and know what’s happening. ...I don’t think that’s denial. That’s wanting to be in control. [I can keep myself healthy with] diet, exercise, less stress.

Perceived Control I am not thinking that I’m going to stay healthy if I do this, but I am pretty good in taking care for...exercise...and stress usually hasn’t been a problem in my life. I think there are mental factors, spiritual factors in any disease that can make one more problem. ...I think one’s mind set, one’s being positive to life... the importance of positive attitude and of acceptance...

Search for Dominance I don't know if those are factors in my having been relatively healthy...I almost never [get sick].
 Perceived Control [I am] doing something. Whether staying on vitamin C or not eating junk... not feeling a victim to doctors, or the doctors that I can't control."

Beth acknowledged the value of health care providers, but emphasized that she would rather trust God and her own self-sufficiency to protect her from the disease.

Affect " [after feeling a lump] I would be concerned but not very concerned until I see the doctor.
 Loss Aversion I don't want to get myself all worked up until I see them.

Search for Dominance I pray all the time (emphasis). But I guess after I saw the doctor it would be a more deeper prayer... God put us here, and put the doctors here... most of them.
 [Doctors] say that I am pretty healthy although I do have things, ...that I have to take pills for.

Perceived Control I believe that certain things you can eat can kind of help [prevent breast cancer]... certain exercise... And a lot of praying (emphasis).
 ...as far as exercise, I do mostly walking... And I keep busy around the house... 'cause I have stairs. ...I eat more vegetables than I eat fruit. For now I feel less [at risk]."

These two examples best demonstrate that mistrust in health care providers could have a potentially dangerous effect by leading some women to create an illusion of personal control over breast cancer and to make erroneous judgments that might jeopardize their health.

Discussion

The study examined 11 narratives in order to identify specific heuristics that might influence perceived breast cancer risk. Participant women came from various socioeconomic and racial/cultural backgrounds. Three women perceived or were ambivalent about being at a higher risk and stated very different reasons for their risk estimations. However, eight women perceived that they were at a lower breast cancer risk and offered similar reasons for their assessments. The aim of the study was to

identify heuristic shortcuts in women's narratives about their breast cancer risk assessments. As such, we focused on a deductive approach to data analysis. Although we acknowledge that argumentation is a social process and occurs within a sociocultural context (Tindale, 1999), the analysis was based on the philosophical premises that arguments convey meanings internal to the persons uttering them (Searle, 1983) and their own perceptions, belief system, and thoughts (Dretske, 2000). Examining risk assessments as a thought process revealed that this thought process was similar for all women irrespective of whether they believed they were at a higher or lower risk. Heuristic thinking and the search for a dominance structure played important roles in risk assessments. We identified a dominance structure in the arguments of eight women and heuristic thinking in ten of the 11 interviews. The most commonly used heuristics were availability, simulation, representativeness, perceived control, and affect.

In the present study eight out of 11 women perceived themselves to be at a lower breast cancer risk. Weinstein (Weinstein, 1983, 1987) suggested perceptions of being at a lower risk demonstrate an optimistic bias, which occurs because perceptions of heightened risk can be threatening to the individual. Assessments of being at a lower risk were made despite the fact that some of these women had had a personal experience with an abnormal breast symptom. Other studies have reported a positive association between having an abnormal breast symptom and perceiving an increased breast cancer risk (Aiken et al., 1995; Lipkus, Halabi et al., 2000). Although we cannot provide a complete explanation, we suggest that the search for a dominance structure played an important role in assessing the identity and the potential threat of a breast symptom. All women argued that their symptom did not have the typical characteristics of a breast lump,

irrespective of whether they had received a medical diagnosis of a benign lesion or they had chosen not to seek medical evaluation. In the former cases, a medical diagnosis of having a benign lesion likely confirmed women's perceptions of being at a lower risk. In the latter cases, a pronounced breast lump was likely perceived as a known and alarming breast cancer symptom. When simulating the consequences of having such a symptom was threatening, women claimed that they were at a lower breast cancer risk. This is consistent with Weinstein's suggestions that optimistic bias occurs because the individual feels threatened. Since these women had, in fact, characterized their breast symptom as atypical, their bias suggested that they had created a dominance structure around a less threatening alternative explanation. According to Simon's suggestions about "satisficing", these alternative explanations, which were achieved through the search for a dominance structure, allowed these women to end the search process for the identity of the symptom, at least temporarily. A dominance structure around an unlabelled symptom and a perception of a low breast cancer risk led these women to choose not to seek medical evaluation. Consistent with our findings, a study failed to find empirical support for the hypothesis that ambiguous or unlabeled symptoms elicit more information seeking than labeled symptoms (Prohaska, Keller, Leventhal, & Leventhal, 1987).

Weinstein (Weinstein, 1989) also suggested that optimistic bias occurs because people compare themselves to a stereotypical high-risk individual and conclude that they are at a lower risk. Using the availability, simulation, and representativeness heuristics most women who did not have a family history of breast cancer imagined a stereotypical breast cancer afflicted woman as having a positive family history, and consequently argued that they were not likely to get the disease since they themselves did not have a

positive family history. Moreover, women used experiences with family members to create a dominance structure around different diseases that potentially could pose a threat to their health, and made one overall argument about their breast cancer risk. Lily created a dominance structure around the argument that if it were a real threat to her health, it would be heart disease. Consistent with this, a study reported that women who perceived that they were at a higher risk for breast cancer were neglecting other serious health threats such as heart disease (Erblich et al., 2000). Health care providers should be aware of this bias and should emphasize the fact that, while a positive family history is a risk-increasing factor, the majority of breast cancer cases occur in women with no known risk factors (American Cancer Society, 2003).

Extensive research in the area of human responses to natural hazards has indicated that a perception of control over the hazard influences risk assessments (Slovic, 1987). Researchers have suggested that perceived control over disease influences beliefs of vulnerability (Cameron & Leventhal, 1995). Beliefs that cancer can be controlled by personal actions, by physicians, and by treatment fulfill a need for mastery and lead to an overall positive adjustment to illness (S. E. Taylor, 1983). Most women in our study believed that they had some control over the disease and some women argued that adherence to screening guidelines and forming a close relationship with a health care provider could even prevent breast cancer. Slovic (Slovic, 1999) suggested that since the expert's mission is to help control a hazard, trust between the layperson and the expert is a fundamental aspect of risk management. Our data suggest that trust towards health care providers is a core element of breast cancer risk assessment. Women that had a trusting relationship with their provider had a sense of control over the disease and perceived that

they were at a lower risk. However, perceived control over breast cancer risk factors can also have negative effects. Silverman and colleagues (Silverman et al., 2001) suggested that the perception that breast cancer risk factors are controllable might introduce an assumption that afflicted women had indulged in some risky behavior and therefore, were responsible for the disease. In addition, with the public message that controllable factors, such as diet and exercise, affect breast cancer etiology (McTienan, 2003), some women are likely to form a misconception that they have absolute control over breast cancer and that diet and lifestyle can reverse the onset of the disease. This can become dangerous in the cases where women decide that they can self-medicate a breast symptom rather than seek medical evaluation. Health care providers have the responsibility to communicate the message that adherence to recommended screening, dietary, and exercise regimens does not make women invulnerable to breast cancer.

Finally, affective elements facilitated the recruitment or dismissal of self-relevant information into risk assessments and led one woman to cancel the logical drawbacks of a chosen explanation for a breast symptom. These suggestions are consistent with the notion that affective evaluations that are attached to an image influence risk assessments and is gaining significant support (Hanoch, 2002).

In summary, heuristic reasoning analysis provides an important framework within which researchers can examine health-related decision-making. Studying heuristic reasoning can potentially explain how these beliefs are formed and how they guide decision-making. If specific heuristics are associated with specific types of experiences, we might be able to identify predictable biases, improve our understanding of our clients, and help them make better decisions.

Chapter 5.

Summary

Because perceived risk is an important motivator for adopting health-protective behaviors, we need to understand the way in which people construct their perceptions of risk and the way these perceptions act as a motivator for these behaviors.

This research project revealed that women recruited from community settings hold an optimistic bias for their breast cancer risk. We demonstrated optimistic bias in three different ways. Participants systematically rated the risk for their friends/peers as higher than their own risk. When they compared their risk with the risk of average women, the distribution of responses was skewed to the left, showing an underestimation of risk. Finally, participants underestimated their actual breast cancer risk obtained from the Gail model. Overall, these findings confirm Weinstein's suggestions (Weinstein, 1988); most women are in the second stage of perceived risk, claiming that their risk for developing breast cancer is lower than it actually is. A likely clinical implication of this finding is that this bias will cause many women to present with disease in the late stages, which in turn increases breast cancer morbidity and mortality.

Measuring perceived risk with the ideal probability scale has been a challenge for researchers (Diefenbach et al., 1993). Consistent with Weinstein's research, our findings indicate that risk ratings were not influenced by demographic characteristics, such as education, income, and race/culture on the Verbal and Comparative scales. In contrast, risk ratings on the Numerical scale were influenced by education, income, and race/culture. The Numerical scale also showed that women overestimated their risk. After controlling for education and income, racial/cultural differences persisted, but pairwise comparisons did not indicate significant differences, probably because of inadequate sample size. The correlation between education, income, and high risk ratings

on the Numerical scale can be attributed to low literacy, innumeracy, and misinterpretation and misuse of the scale. However, the correlation between race/culture and high risk ratings on the Numerical scale is more difficult to explain. Nevertheless, in light of our findings we suggest that Numerical scales do not accurately reflect perceived breast cancer risk and produce a systematic error of risk overestimation.

Our findings revealed that women with one affected first-degree relative did not perceive their risk to be significantly higher compared to women with no family history of breast cancer. Only women with multiple affected family members were more likely to perceive higher breast cancer risk. Moreover, there was a negative correlation between age and perceived risk in the Comparative scale. Women who perceived their own risk to be “A Lot Lower” than that of younger women, were on average twelve years older (mean age of 53 years), than women who perceived their risk to be higher than the risk of younger women (mean age 41 years). Both these findings have significant clinical implications. According to epidemiological models of risk estimation, such as the Gail model, being older and having one affected first-degree relative significantly increase a woman’s probability of developing breast cancer. However, our findings indicate that a large proportion of women are not aware of these risk factors. Moreover, these findings bring to light the interaction between family history and age, and the different role each variable plays in cases of sporadic versus familial breast cancer. As more knowledge about genetic and environmental factors become available, health care professionals will face the challenge of explaining the risk associated with each variable and how they influence one another.

Factors that influenced perceived breast cancer risk were worry, having multiple affected family members, worry, and whether a woman's most recent Mammogram or most recent Clinical Breast Exam had been done for the evaluation of a breast symptom. Knowledge of breast cancer risk factors and worry moderated some of the relationships between experiences with affected family members, breast symptoms, and perceived risk, presumably through different mechanisms. The first mechanism is based on an analytical cognitive process: family history of breast cancer influences perceived risk through the knowledge that it represents a genetic risk factor. The second mechanism is based on heuristic thinking representing logical shortcuts in the analytic mechanism: women who do not have accurate and complete information about their breast cancer risk are more likely to depend on salient memories and personal experiences for making personal risk estimations with the assistance of logical shortcuts. The third mechanism is based on affect: current breast symptoms influence perceived risk by eliciting worry. Finally, the fourth mechanism is based on the interaction of affect with the analytical mechanism: initiating a visit to a health provider for the evaluation of a self-discovered breast symptom evoked worry for women who had knowledge of breast cancer risk factors.

Heuristic thinking played an important role in subjective estimations of breast cancer risk. Analysis of the 11 interviews generated the same findings as the survey questionnaire, even though the interviews were conducted in a different sample of women with similar characteristics with the women in the survey. More specifically, our finding that women hold an optimistic bias regarding their breast cancer risk was replicated, in the interview study. Risk assessments were based on experiences with an abnormal breast symptom, experiences with affected family members and friends, beliefs

about living a healthy lifestyle, and trust in health providers. Experiences with affected family members and affected friends were incorporated into risk estimations through the availability, simulation, representativeness, and affect heuristics. Mistrust in health providers led to an inappropriate dependence on the perceived control heuristic.

Assessment of the potential threat of a breast symptom was facilitated by the search for a dominance structure, which for some women was anchored around an affective response related to the symptom.

Our finding that women hold an optimistic bias regarding their breast cancer risk improves our understanding of the relationship between perceived risk and screening behavior. Our meta-analysis revealed that perceived risk had only a small effect (0.19) on adherence to mammography screening, while results are inconclusive as to whether perceived risk influences adherence to breast self-exam. Considering that a significant proportion of women underestimate the probability of developing breast cancer, it is no surprise that adherence to screening guidelines is not a priority in their lives. From a theoretical perspective it is also possible that perceived risk does not directly impact behavior. Its impact on behavior could be mediated by other variables not tested in the present study.

In conclusion, the study provided significant insights about perceived breast cancer risk. It helped clarify systematic measurement errors in perceived breast cancer risk, it helped identify women who are more likely to underestimate their breast cancer risk, and it identified ways in which women estimate their breast cancer risk. Our knowledge is very limited about the effects of perceived breast cancer risk on decision-making about breast cancer prevention and early detection. However, our findings

suggest that educational interventions that aim to improve adherence to screening guidelines solely by increasing knowledge about breast cancer risk factors ignore the role of risk perception in decision-making and a significant amount of the variance in perceived risk. Heuristic reasoning analysis provides an important framework within which researchers can examine health-related decision-making. Studying heuristic reasoning may explain how these beliefs are formed and how they guide decision-making. If specific heuristics are associated with specific types of experiences, we may be able to identify predictable biases, improve our understanding of our clients, and help them make better decisions. Thus, future research needs to examine how differences in perceived risk shape decisions to adopt health-protective behaviors. For policy makers who are engaged in promoting education and interventions to help lower health risks, understanding the ways in which different women estimate their breast cancer risk is imperative.

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APPENDICES

LIST OF TABLES

TABLE 1.1. Relationship between Perceived Risk, Demographic and Psychological Variables, and Breast Cancer Prevention & Early Detection Behavior

Author/Year	Recruitment	N Age	Instrument for Perceived Risk	Variables	g	OR (95% CI)
Absetz, Aro, Rehnberg, Sutton, 2000 (Absetz et al., 2000)	Random, population registry	1,157 49-51	Two items, subjective risk, Verbal	Optimistic bias Family History	+0.48 +0.56	- 0.28 (0.16 - 0.51)
Aiken, Fenaughty, West, Johnson, Lockett, 1995 (Aiken et al., 1995)	Convenient, community	335 37-77	Two items, subjective & comparative risk, Verbal	Optimistic bias Family History Breast Symptom Breast Self-Exam Mammography	+0.45 +0.79 +0.49 +0.10 -0.59	- 0.19 (0.11 - 0.35) - - 3.53 (0.94-13.30)
Andrykowski, Carpenter, Studts, Cordova, Cunningham, et al., 2001 (Andrykowski et al., 2001)	Convenient, Breast Health Center, with Benign Breast Symptom	103 19-84	Two items for subjective & comparative risk, Numerical			
Audrain, Lerman, Rimer, Cella, Steffens, et al., 1995 (Audrain et al., 1995)	Convenient, affected relative	395 30-75	One item of subjective risk, Verbal	Education Race/culture Mammography	+0.31 +0.69 +0.27	2.10 (1.29 - 3.44) 4.01 (2.41 - 6.67) 1.65 (1.01 - 2.68)
Black, Nease, Tosteson, 1995 (Black, Nease, & Tosteson, 1995)	Random, Medical Center directory	145 40-49	Eight items, quantitative & probability estimates of subjective & comparative risk	Education	+0.57	2.81 (0.83 - 9.46)
Bondy, Vogel, Halabi, Lustbader, 1992 (Bondy, Vogel, Halabi, & Lustbader, 1992)	Convenient, cancer screening program	30,352 ≥35	Not Reported	Family History	+0.62	4.28 (4.01 - 4.57)
Bowen, McTiernan, Burke, Powers, Pruski, et al., 1999 (Bowen et al., 1999)	Convenient, affected relative & community	793 18-74	One item, subjective risk, Numerical	Family History	+0.29	-
Brain, Norman, Gray, Mansel, 1999 (Brain et al., 1999)	Convenient, affected relative referred by physicians	833 17-77	Two items, subjective & comparative risk, Verbal	Age Worry Breast Self Exam	+0.26 +0.69 +0.19	- - -
Carney, Harwood, Weiss, Eliassen, Goodrich, 2002 (Carney et al., 2002)	Random, Mammography registry	539 ≥50	Not Reported	Mammography	+0.07	1.01 (0.71 - 1.44)
Clarke, Lovegrove, Williams, Machperson, 2000 (Clarke et al., 2000)	Systematic, from local telephone directory	164 50-70	One item, subjective risk, Numerical	Optimistic bias	+5.08	-
Clemow, Costanza, Haddad, Luckmann, White, et al., 2000 (Clemow et al., 2000)	Convenient, HMOs directory	2,423 50-80	Two items, subjective & comparative risk, Verbal	Mammography	+0.13	3.38 (1.80 - 6.35)
Cockburn, Sutherland, Cappiello, Hevern, 1997 (Cockburn, Sutherland, Cappiello, & Hevern, 1997)	Random, electoral registry	180 50-69	Not Reported	Mammography	+0.43	2.33 (1.09 - 5.00)
Cole, Bryant, McDermott, Sorrell, Flynn, 1997 (Cole, Bryant, McDermott, Sorrell, & Flynn, 1997)	Convenient, community	391 40-90	One item, comparative risk, Verbal	Mammography	-0.36	0.49 (0.27 - 0.88)
Culver, Burke, Yasui, Durfy, Press, 2001 (Culver et al., 2001)	Convenient, community, genetic testing	97 30-60	One item, subjective risk, Verbal	Genetic Testing	+0.40	0.46 (.21 - 1.03)
Daly, Lerman, Ross, Schwartz, Burke, et al., 1996 (Daly et al., 1996)	Convenient, affected relative	969 35-75	One item, subjective risk, Numerical	Optimistic bias Race/culture	+2.07 +0.35	- 0.42 (0.27 - 0.66)
Diefenbach, Miller, Daly, 1999 (M. A. Diefenbach, S. M. Miller, & M. B. Daly, 1999b)	Convenient, Family Risk Assessment program	213 26-72	One item, subjective risk, Verbal	Mammography	+0.13	0.74 (-)

Dolan, Lee, McGrac, McDermott, 1997 (Dolan et al., 1997)	Convenient, primary care setting	552 30-70	One item, subjective risk, Numerical (1 in X)	Optimistic bias Age	+0.34 -	- 0.89 (0.60 – 1.33)
Donovan, Tucker, 2000 (Donovan & Tucker, 2000)	Convenient, Medical Clinics University hospital	220 ≥18	One item, comparative risk, Verbal or Numerical Not Reported	Race/culture Family History	+0.32 +0.75	1.9 (0.1 – 1.2) 4.5 [0.9 – 2.1]
Drossaert, Boer, Seydel, 1996 (Drossaert et al., 1996)	Random, municipality registry	3,401 50-69	Four items, subjective & comparative risk, combination of Numerical & Verbal	Family History Age Anxiety Mammography	+0.38 +0.18 +0.32 +0.18	2.02 [1.63 – 2.50] - - -
Erlich, Bovbjerg, Norman, Valdimarsdottir, Montgomery, 2000 (Erblich et al., 2000)	Convenient, three Medical Centers	177 42±10	One item, subjective risk, Numerical	Family History	+0.57	-
Evans, Blair, Greenhalgh, Hopwood, Howell, 1994 (Evans et al., 1994)	Convenient, Family History Clinic referrals	293	Two items, subjective & comparative risk, Verbal	Optimistic bias	+0.35	-
Facione, 2002 (N.C. Facione, 2002)	Convenient, community	770 19-99	One item, comparative risk, Verbal	Optimistic bias Education Family History Breast Symptom Mammography	+1.20 +0.19 +0.62 +0.26 +0.23	- 1.66 (1.19 – 2.31) - - -
Finney, Iannotti, 2001 (Finney & Iannotti, 2001)	Convenient, Women's Health Clinic	378 ≥40	Three items, subjective risk, Verbal	Family History	+0.91	-
Foster, Evans, Eeles, Eccles, Ashley, et al., 2002 (Foster et al., 2002)	Convenient, family from Clinical Genetic Centers	315 ≥18	Two items, subjective & comparative risk, Verbal	Optimistic bias	+2.17	-
Foxall, Barron, Houfek, 2001 (Foxall et al., 2001)	Random, residential list & convenient, community	233 ≥19	One item, subjective risk, Verbal	Race/culture Mammography	-0.21 +0.52	- -
Hatcher, Fallowfield, A'Hern, 2001 (Hatcher et al., 2001)	Convenient, Clinical Genetic Center	143 22-57	Five items, subjective & comparative risk, combination Numerical & Verbal	Prophylactic Mastectomy	+0.25	0.43 [0.13 – 1.46]
Hughes, Leman, Lustbader, 1996 (Hughes et al., 1996)	Convenient, affected relative	336 ≥30	One item, comparative risk, Verbal	Race/culture Age Education Worry	+0.51 +0.31 +0.28 +0.98	2.96 (1.78 – 4.92) 1.99 (1.21 – 3.26) 1.91 (1.16 – 3.13) 5.98(2.96 – 12.05)
Jacobsen, Heiddis, Valdimarsdottir, Brown, Offit, 1997 (Jacobsen et al., 1997)	Convenient, screening programs	74 32-59	One item, subjective risk, Numerical	Genetic Testing	+0.51	-
Lindberg, Wellisch, 2001 (Lindberg & Wellisch, 2001)	Convenient, Breast Clinic with Family History	213 15-78	One item, subjective risk, Numerical	Mammography Breast Self Exam	-0.59 -0.49	- -
Lipkus, Iden, Terrenoire, Feaganes, 1999 (Lipkus et al., 1999)	Convenient, affected relative & matched pairs, community	253 ≥30	One item, subjective risk, Verbal	Family History Worry Perceived Control	+0.75 +1.25 -0.41	2.11 (1.12 – 3.98) - -
Lipkus, Halabi, Strigo, Rimer, 2000 (Lipkus, Halabi et al., 2000)	Random, Blue Cross/ Blue Shield Mammography registry	1,047 40-55	Four items, subjective & comparative risk, combination Numerical & Verbal	Breast Symptom	+0.22	-
Lipkus, Kuchibhatla, McBride, Bosworth, Pollak, et al., 2000 (Lipkus, Kuchibhatla et al., 2000)	Random, household telephone directory	581 45-54	Three items, subjective & comparative risk, combination Numerical and Verbal	Optimistic bias Worry	+0.74 +0.67	- -
McCaul, Branstetter, Schroeder, Glasgow, 1996 (McCaul, Branstetter et al., 1996)	Meta-Analysis	11,678		Mammography	+0.16	-
McCaul, Schroeder, Reid, 1996 (McCaul, Schroeder et al., 1996)	Convenient, community	353 40-75	Two items, subjective & comparative risk, Numerical	Worry	+0.47	-

McDonald, Thorne, Pearson, Adams-Campbell, 1999 (McDonald et al., 1999)	Random, public housing registry	120 31-90	One item, V comparative	Optimistic bias	+1.65	-
Meiser, Butow, Barratt, Gattas, Erichaan, et al., 2001 (Meiser et al., 2001)	Convenient, Family and Outreach Clinics	333 18-75	One item, subjective risk, Numerical (X% options)	Optimistic bias Age Education Anxiety	+0.53 +0.35 +0.15 +0.44	- - - -
Metcalfe, Narod, 2002 (Metcalfe & Narod, 2002)	Convenient, Hospital registry, mastectomy	60 23-75	One item, Subjective risk, Numerical	Optimistic bias Prophylactic Mastectomy	+0.88 +1.73	- -
Mouchawar, Byers, Cutter, Dignan, Michael, 1999 (Mouchawar, Byers, Cutter, Dignan, & Michael, 1999)	Random, Mammography registry	310	Two items, subjective & comparative risk, Numerical & Verbal	Family History	+0.79	0.14 (0.08 – 0.28)
Polednak, Lane, Burg, 1991 (Polednak, Lane, & Burg, 1991)	Convenient, community	820	Two items, subjective & comparative, Numerical & Verbal	Family History	+0.72	4.05 (2.80 – 5.85)
Schwartz, Rimer, Daly, Sands, & Lerman, 1999 (M. D. Schwartz, Rimer, Daly, Sands, & Lerman, 1999)	Convenient, affected relative	200 40-84	One item, subjective risk, Numerical	Mammography	+0.48	1.21 (0.97 – 1.50)
Stefanek, Helzlsouer, Wilcox, Houn, 1995 (Stefanek et al., 1995)	Convenient, affected relative	164 18-60	One item, subjective risk, Numerical	Prophylactic Mastectomy	+0.71	-
Vernon, Vogel, Halabi, Bondy, 1993 (Vernon et al., 1993)	Convenient, community	32,485 ≥35	One item, subjective risk, Verbal	Family History Race/culture Age Breast Symptom Mammography Breast Self Exam	+1.23 +0.12 +0.12 +0.25 +0.24 -0.05	11.30(10.34– 12.35) 1.40 (1.17 – 1.74) 1.53 (1.42 – 1.65) 1.61 (1.45 – 1.79) 1.62 (0.48 – 1.77) 0.85 (0.79 – 0.91)

TABLE 1.2. Optimistic Bias vs. Overestimation of Risk

Author/ Year	Recruitment/ Setting	N % (+) FH	Measurement	Findings	Effect Size	95%CI
Absetz, Aro, Rehnberg, Sutton, 2000 (Absetz et al., 2000)	Random, population registry	1,157 (15%)	Two items Verbal, comparative	Optimistic bias	+0.48	+0.39 - +0.56
Aiken, Fenaughty, West, Johnson, Luckett, 1995 (Aiken et al., 1995)	Convenient, community	335 (23%)	Two items Verbal, subjective, & comparative	Optimistic bias	+0.45	+0.30 - +0.60
Clarke, Lovegrove, Williams, Machperson, 2000 (Clarke et al., 2000)	Systematic, telephone directory	164 (NR)	One item Numerical, comparative	Optimistic bias	+5.08	+1.05 - +9.11
Daly, Lerman, Ross, Schwartz, Burke, et al., 1996 (Daly et al., 1996)	Convenient, Affected Relative	969 (100%)	One item Numerical, subjective vs. actual	Overestimate d	+2.07	+1.96 - + 2.18
Dolan, Lee, McGrae, McDermott, 1997 (Dolan et al., 1997)	Convenient, Primary Care	552 (NR)	One item Numerical (1 in X), subjective	Overestimate d	+0.34	+0.22 - +0.46
Evans, Blair, Greenhalgh, Hopwood, Howell, 1994 (Evans et al., 1994)	Convenient, Family History Clinic	293 (100%)	Two items Verbal, subjective & comparative	Overestimate d	+0.35	+0.18 - +0.51
Facione, 2002 (N.C. Facione, 2002)	Convenient, community	770 (15%)	One item Verbal, comparative	Optimistic bias	+1.20	+1.09 - +1.31
Foster, Evans, Eccles, Eccles, Ashley, et al., 2002 (Foster et al., 2002)	Convenient, Clinical Genetic Center, known mutations	227 (100%)	Two items Verbal, subjective & comparative	Overestimate d	+2.17	+1.94 - +2.40
Lipkus, Kuchibhatla, McBride, Bosworth, Pollak, et al., 2000 (Lipkus, Kuchibhatla et al., 2000)	Random, household telephone directory	581 (NR)	Three items Verbal, comparative Numerical, subjective	Optimistic bias V optimistic bias N overestimate d	+0.74 +1.18	+0.62 - +0.85 +1.05 - +1.30
McDonald, Thorne, Pearson, Adams- Campbell, 1999 (McDonald et al., 1999)	Random, public housing registry	120 (NR)	One item Verbal, comparative	Optimistic bias	+1.64	+1.20 - +2.09
Meiser, Butow, Barratt, Gattas, Erichaan, et al., 2001 (Meiser et al., 2001)	Convenient, Family & Outreach Clinics	333 (100%)	One item Numerical (X%), subjective	Overestimate d	+0.52	+0.37 - +0.68
Metcalfe, Narod, 2002 (Metcalfe & Narod, 2002)	Convenient, Hospital Registry, Prophylactic Mastectomy	60 (100%)	One item Numerical, subjective	Overestimate d	+0.88	+0.49 - +1.26
		Total N=5,561			g=+1.10	+1.06 - +1.14

(+)FH: Family History of Breast Cancer, NR: Not Reported

TABLE 1.3. Family History & Perceived Risk

Author /Year	Recruitment/ Setting	N % (+) FH	Measurement	Findings	Effect size	95%CI
Absetz, Aro, Rehnberg, Sutton, 2000 (Absetz et al., 2000)	Random, population registry	1,157 (15%)	Two items Verbal, subjective	(+) FH increased perceived risk	+0.55	+0.32 - +0.78
Aiken, Fenaughty, West, Johnson, Luckett, 1995 (Aiken et al., 1995)	Convenient, community	335 (23%)	Two items Verbal, subjective, & comparative	(+) FH increased perceived risk	+0.79	+0.54 - +1.06
Bondy, Vogel, Halabi, Lustbader, 1992 (Bondy et al., 1992)	Convenient, screening program registry	30,352 (21%)	NR	(+) FH increased perceived risk	+0.62	+0.59 - +0.65
Donovan & Tucker, 2000 (Donovan & Tucker, 2000)	Convenient, medical center	220 (27%)	One item, NR, comparative	(+) FH increased perceived risk	+0.74	+0.44 - +1.05
Drossaert, Boer, Seydel, 1996 (Drossaert et al., 1996)	Random, municipality registry	3,401 (11%)	Six items, Numerical, Verbal, subjective, & comparative	(+) FH increased perceived risk	+0.38	+0.28 - +0.49
Erblich, Bovbjerg, Norman, Valdimarsdottir, Montgomery, 2000 (Erblich et al., 2000)	Convenient, medical center	177 (41%)	One item, Numerical, subjective	(+) FH increased perceived risk	+0.57	+0.27 - +0.87
Facione, 2002 (N.C. Facione, 2002)	Convenient, community	770 (15%)	One item Verbal, comparative	(+) FH increased perceived risk	+0.62	+0.47 - +0.76
Finney & Iannotti, 2001 (Finney & Iannotti, 2001)	Convenient, women's health clinic	378 (42%)	Three items, Verbal, subjective	(+) FH increased perceived risk	+0.91	+0.69 - +1.12
Lipkus, Iden, Terrenoire, Feaganes, 1999 (Lipkus et al., 1999)	Convenient, affected relative, & matched pairs - newspaper ads	253 (51%)	One item, Verbal, subjective	(+) FH increased perceived risk	+0.75	+0.49 - +1.00
Mouchawar, Byers, Cutter, Dignan, Michael, 1999 (Mouchawar et al., 1999)	Convenient, mammography registry	310 (61%)	Three items, Verbal comparative & Numerical subjective	(+) FH increased perceived risk	+0.79	+0.56 - +1.03
Polednak, Lane, Burg, 1991 (Polednak et al., 1991)	Convenient, community	820 (19%)	Two items, Verbal, Numerical (1 in X), subjective	(+) FH increased perceived risk	+0.72	+0.54 - +0.90
Vernon, Vogel, Halabi, Bondy, 1993 (Vernon et al., 1993)	Convenient, screening program registry	32,485 (10%)	One item, Verbal, subjective	(+) FH increased perceived risk	+1.23	+1.19 - +1.27
		Total N=70,660			g= 0.88	+0.87 - +0.89

(+) FH: Family History of Breast Cancer. NR: Not Reported

TABLE 1.4. Confounding effect of Recruitment Site and Measurement Scale

		TYPE OF MEASUREMENT			
		Numerical	Verbal		
R E C R U I T M E N T	Affected Relative, Family, or Genetic Counseling Clinic	Daly, Lerman, Ross, Schwartz, Burke, et al., 1996(Daly et al., 1996)	Overestimation	Evans, Blair, Greenhalgh, Hopwood, Howell, 1994 (Evans et al., 1994)	Overestimation
		Dolan, Lee, McGrae, McDermott, 1997 (Dolan et al., 1997)	Overestimation	Foster, Evans, Eeles, Eccles, Ashley, et al., 2002 (Foster et al., 2002)	Overestimation
		Meiser, Butow, Barratt, Gattas, Erichaan, et al., 2001 (Meiser et al., 2001)	Overestimation		
		Metcalfe, Narod, 2002 (Metcalfe & Narod, 2002)	Overestimation		
		Total N	1,914	520	
	Effect size (95% CI)	+1.26 (+1.19 - +1.33)	+1.14 (+1.00 - +1.27)		
	Community	Clarke, Lovegrove, Williams, Machperson, 2000 (Clarke et al., 2000)	Optimistic bias	Absetz, Aro, Rehnberg, Sutton, 2000 (Absetz et al., 2000)	Optimistic bias
		Lipkus, Kuchibhatla, McBride, Bosworth, Pollak, et al., 2000 (Lipkus, Kuchibhatla et al., 2000)	Overestimation	Aiken, Fenaughty, West, Johnson, Lockett, 1995 (Aiken et al., 1995)	Optimistic bias
				Facione, 2002 (N.C. Facione, 2002)	Optimistic bias
				Lipkus, Kuchibhatla, McBride, Bosworth, Pollak, et al., 2000 (Lipkus, Kuchibhatla et al., 2000)	Optimistic bias
			McDonald, Thorne, Pearson, Adams-Campbell, 1999 (McDonald et al., 1999)	Optimistic bias	
Total N	745	2,963			
Effect size (95% CI)	+2.04 (+1.92 - +2.17)	+0.76 (+0.71 - +0.81)			

TABLE 1.5. Age & Perceived Risk

Author/Year	N Mean Age±SD, range	Findings	Effect Size	95%CI
Aiken, Fenaughty, West, Johnson, Luckett, 1995 (Aiken et al., 1995)	*335 53±11, 37-77 y/o	Higher perceived risk is correlated with younger age	+0.04	-0.19 - +0.11
Audrain, Lerman, Rimer, Cella, Steffens, et al., 1995 (Audrain et al., 1995)	395 46±12, 30-75 y/o	Age was not a significant predictor of increased perceived risk		
Brain, Norman, Gray, Mansel, 1999 (Brain et al., 1999)	*833 41±10, 18-77 y/o	Higher perceived risk is correlated with younger age	+0.26	+0.16 - +0.35
Daly, Lerman, Ross, Schwartz, Burke, et al., 1996 (Daly et al., 1996)	969 M=48, 35-75 y/o	Age was not a significant predictor of increased perceived risk		
Dolan, Lee, McGrae, McDermott, 1997 (Dolan et al., 1997)	552 30-70 y/o	Age was not a significant predictor of increased perceived risk		
Donovan & Tucker, 2000 (Donovan & Tucker, 2000)	220 41 ±15, >18 y/o	Age was not a significant predictor of increased perceived risk		
Drossaert, Boer, Seydel, 1996 (Drossaert et al., 1996)	*3,401 50-69 y/o	Higher perceived risk is correlated with younger age	+0.18	+ 0.13- +0.22
Facione, 2002 (N.C. Facione, 2002)	770 49±15, 19-99 y/o	Higher perceived risk is correlated with younger age		
Foster, Evans, Eeles, Eccles, Ashley, et al., 2002 (Foster et al., 2002)	*277 M=41, 21-72 y/o	Higher perceived risk is correlated with younger age	+0.48	+0.17 - +0.78
Hughes, et al., 1996 (Hughes et al., 1996)	*336 > 30y/o	Higher perceived risk is correlated with younger age	+0.31	+0.09 - +0.53
Meiser, Butow, Barratt, Gattas, Erichaan, et al., 2001 (Meiser et al., 2001)	*333 M=39, 18-75y/o	Higher perceived risk is correlated with younger age	+0.35	+0.11 - +0.59
Vernon, Vogel, Halabi, Bondy, 1993 (Vernon et al., 1993)	*32,485 >35 y/o	Higher perceived risk is correlated with younger age	+0.12	+0.10 - +0.15
	Total *N=38,000		g= +0.13	+0.12 - +0.14

M= Median

TABLE 1.6. Education & Perceived Risk (≤High School vs. ≥College)

Author/Year	N	Educational Level	Findings	Effect Size	95%CI
Audrain, Lerman, Rimer, Cella, Steffens, et al., 1995 (Audrain et al., 1995)	*395	59% ≤high school	≤high school, unaware of increased risk	+0.31	+0.11- +0.51
Black, Nease, Tosteson, 1995 (Black et al., 1995)	*145	35% ≤high school	≤high school, more likely to overestimate risk	-0.57	-0.92 - -0.22
Donovan & Tucker, 2000 (Donovan & Tucker, 2000)	220	X=13.5 years of school	Education was not related to perceived risk		
Facione, 2002 (N.C. Facione, 2002)	*770	40% ≤high school	> high school related to decreased optimism	+0.19	+0.05- +0.32
Hughes, et al., 1996 (Hughes et al., 1996)	*336	47% ≤high school	≤high school unaware of increased risk	+0.28	+0.06- +0.49
Meiser, Butow, Barratt, Gattas, Erichaan, et al., 2001 (Meiser et al., 2001)	*333	31% ≤high school	>high school weakly related to decreased optimism	+0.14	-0.09- +0.39
Metcalfe, Narod, 2002 (Metcalfe & Narod, 2002)	60	Data not shown	Education was not related to perceived risk		
Total	*N=1,979			g=+ 0.16	+0.10 - +0.23

TABLE 1.7. Race/culture & Perceived Risk (White vs. Other Racial/cultural Groups)

Author/Year	N	Sample	Findings	Effect Size	95%CI
Audrain, Lerman, Rimer, Cella, Steffens, et al., 1995 (Audrain et al., 1995)	*395	78% White 22% Minority	Minority more likely to be unaware of risk	+0.69	+0.45- +0.94
Daly, Lerman, Ross, Schwartz, Burke, et al., 1996 (Daly et al., 1996)	*969	86% White 14% Minority	Whites more likely to overestimate risk	+0.35	+0.17 -+0.53
Donovan & Tucker, 2000 (Donovan & Tucker, 2000)	*220	51% White 49% Black	Whites more likely to overestimate risk	+0.32	+0.05 - +0.58
Erlich, Bovbjerg, Norman, Valdimarsdottir, Montgomery, 2000 (Erblich et al., 2000)	177	36% White 64% Minority	No difference of perceived risk between racial/cultural groups		
Facione, 2002 (N.C. Facione, 2002)	770	33% White 67% Minority	No difference of perceived risk between racial/cultural groups		
Foxall, Barron, Houfek, 2001 (Foxall et al., 2001)	*233	59% White 41% Minority	Minority more likely to overestimate risk	-0.21	-0.41 - +0.05
Hughes, Leman, Lustbader, 1996 (Hughes et al., 1996)	*375	60% White 40% Black	Blacks more likely to be unaware of risk	+0.51	+0.28 -+0.74
Total *N=2,192				g= +0.38	+0.28 - +0.47

Minority: Includes Black, Hispanic, and Native American women

TABLE 1. 8. Breast Cancer Worry, Anxiety & Perceived Risk

Author/Year	N	Findings	Effect Size	95%CI
Brain, Norman, Gray, Mansel, 1999 (Brain et al., 1999)	833	Worry & perceived risk positively correlated (six-item scale)	+0.69	+0.60 - +0.79
Drossaert, Boer, Seydel, 1996 (Drossaert et al., 1996)	3,401	Anxiety & perceived risk positively correlated (eight-item scale)	+0.32	+0.27 - +0.37
Hughes, Leman, Lustbader, 1996 (Hughes et al., 1996)	336	Concern & perceived risk positively correlated (one item, Likert type)	+0.98	+0.63 - +1.33
Lipkus, Iden, Terrenoire, Feaganes, 1999 (Lipkus et al., 1999)	253	Concern & perceived risk positively correlated (women with (-) FH) (one item, Likert type)	+1.25	+0.98 - +1.52
Lipkus, Kuchibhatla, McBride, Bosworth, Pollak, et al., 2000 (Lipkus, Kuchibhatla et al., 2000)	581	Worry & perceived risk positively correlated (one item, Likert type)	+0.67	+0.56 - +0.79
Meiser, Butow, Barratt, Gattas, Erichaan, et al., 2001 (Meiser et al., 2001)	333	Anxiety & perceived risk positively correlated (one item, from IES)	+0.44	+0.19 - +0.68
McCaul, Schroeder, Reid, 1996 (McCaul, Schroeder et al., 1996)	353	Worry & perceived risk positively correlated (three-item scale)	+0.47	+0.32 - +0.62
	Total N=6,090		g= +0.49	+0.46 - +0.53

TABLE 1.9. Screening Mammography & Perceived Risk

Author/Year	Recruitment	N	Findings	Effect Size	95%CI
Andrykowski, Carpenter, Studts, Cordova, Cunningham, et al., 2001 (Andrykowski et al., 2001)	Breast Health Centers	103	Mammography & perceived risk Negative correlation	-0.59	-1.00 - -0.17
Audrain, Lerman, Rimer, Cella, Steffens, et al., 1995 (Audrain et al., 1995)	Affected Relative	395	Mammography & perceived risk Positive correlation	+0.27	+0.05 - +0.48
Carney, Harwood, Weiss, Eliassen, Goodrich, 2002 (Carney et al., 2002)	Mammography Registry	539	Mammography & perceived risk Weakly correlated	+0.007	-0.16 - +0.17
Clemow, Costanza, Haddad, Luckmann, White, et al., 2000 (Clemow et al., 2000)	HMOs	2,423	Mammography & perceived risk Positive correlation	+0.13	+0.02 - +0.25
Cockburn, Sutherland, Cappiello, Hevern, 1997 (Cockburn et al., 1997)	Electoral Registry	189	Mammography & perceived risk Positive correlation	+0.43	+0.05 - +0.80
Cole, Bryant, McDermott, Sorrell, Flynn, 1997 (Cole et al., 1997)	Community	386	Mammography & perceived risk Negative correlation	-0.36	-0.65 - -0.07
Diefenbach, Miller, Daly, 1999 (Diefenbach et al., 1999b)	Family Risk Program	213	Mammography & perceived risk Weakly correlated	+0.13	-0.16 - +0.43
Drossaert, Boer, Seydel, 1996 Netherlands (Drossaert et al., 1996)	Municipality Registry	3,401	Mammography & perceived risk Positive correlation	+0.18	+0.13 - +0.23
Facione, 2002 (N.C. Facione, 2002)	Community	403	Mammography & perceived risk Negative correlation	-0.23	-0.45 - -0.009
Foxall, Barron, Houfek, 2001 (Foxall et al., 2001)	Community	138	Mammography & perceived risk Positive correlation	+0.52	+0.27 - +0.75
Lindberg & Wellisch, 2001 (Lindberg & Wellisch, 2001)	Health Clinic	213	Mammography & perceived risk Negative correlation	-0.58	-0.92 - -0.25
Schwartz, Rimer, Daly, Sands, & Lerman, 1999 (M. D. Schwartz et al., 1999)	Affected Relative	200	Mammography & perceived risk Positive correlation	+0.45	+0.09 - +0.79
Vernon, Vogel, Halabi, Bondy, 1993 (Vernon et al., 1993)	Community	32,485	Mammography & perceived risk Positive correlation	+0.23	+0.21 - +0.26
		Total N=41,088		g= +0.20	+0.18 - +0.23
McCaul, Branstetter, et al., 1996 (McCaul, Branstetter et al., 1996)	Meta-Analysis	11,678	Mammography & perceived risk Positive correlation	g= +0.16	
		Total N=52,766		g= +0.19	

TABLE 2.1. Demographic Characteristics

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

SDRs = Second-Degree Relatives

FDRs = First-Degree Relatives

TABLE 2.2. Influence of Demographic Characteristics on Personal Risk Estimations

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

FH = Family History of Breast Cancer

SDRs = Second-Degree Relatives

TABLE 3.1. Demographic Characteristics

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

SDRs: Second-Degree Relatives

FDR: First-Degree Relative

TABLE 3.2. Experiences with Abnormal Breast Symptoms

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

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

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

*p<.05

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

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

*p<.05

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

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

*p<.05

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

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

*p<.05

TABLE 4.1. Common Heuristics

<i>Affect</i>	1) Positive or negative feelings that are experienced as a conscious or unconscious feeling state. 2) Positive or negative quality of a stimulus or a mental image.
<i>Anchoring and Adjustment</i>	The estimation of the probability of an event starts from an initial point, which is suggested by the formulation of the problem or is the result of partial computation. Final estimates are adjusted towards initial values.
<i>Availability</i>	The probability of an event is judged by the ease with which instances of that event come to mind.
<i>Loss Aversion</i>	If choices are framed as gains, then people are risk averse and favor the status quo. When choices are framed as losses, people become risk seeking.
<i>Perceived Control</i>	People behave as if chance events are subject to control. Hindsight bias of prior events leads to heuristic assertion of control over “similar” events.
<i>Representativeness</i>	As long as A is significantly similar to B, the probability that A originates from B is judged to be high and vice versa.
<i>Simulation</i>	Mental scenarios of an event and its consequences. From those mental scenarios people rehearse the event and estimate its likelihood to occur.

TABLE 4.2. Themes and Heuristics

Breast Symptom	<i>"It's not a breast lump"</i>
Search for Dominance	<i>"I kind of wonder about [breast symptom]. And then I say, well maybe I'm still going through.... [menopause]."</i>
Affect	<i>"...[partner] is valuable because he cares. ...from what [partner] knows about [a lipoma on his back] he's pretty sure that's what [my breast symptom] is."</i>
Perceived Control	<i>"I don't really check my breasts frequently... but I do check that one spot."</i>
Past Experiences	<i>"It doesn't run in my family."</i>
Availability	<i>"...I know a woman who had an operation 10 years ago, and she is alive and has only one breast."</i>
Simulation	<i>"A woman about my age, two children a little younger than mine..."</i>
Representativeness	<i>"She's always been a "doer"...not to be sick and not to complain...so [breast cancer] was a shock to the family."</i>
Affect	<i>"...they found some abnormal lump in [my mother's] breast. ...we would go through together, through it."</i>
Anchoring and Adjustment	<i>"...my probability based on my age and my mother's age when she came down with [breast cancer]."</i>
Search for Dominance	<i>"[heart disease] is more of a real threat in my life [than breast cancer]."</i>
Lifestyle and Trust in Health Providers	<i>"I can deal with it myself, I don't need to go in."</i>
Search for Dominance	<i>"...I am pretty healthy although I do have.... to take pills..."</i>
Perceived Control	<i>"...I almost never [get sick]. [I am] doing something. staying on vitamin C or not eating junk...not feeling a victim to doctors...."</i>

LIST OF FIGURES

FIGURE 2.1. Frequency of Risk Ratings on the Comparative Scale

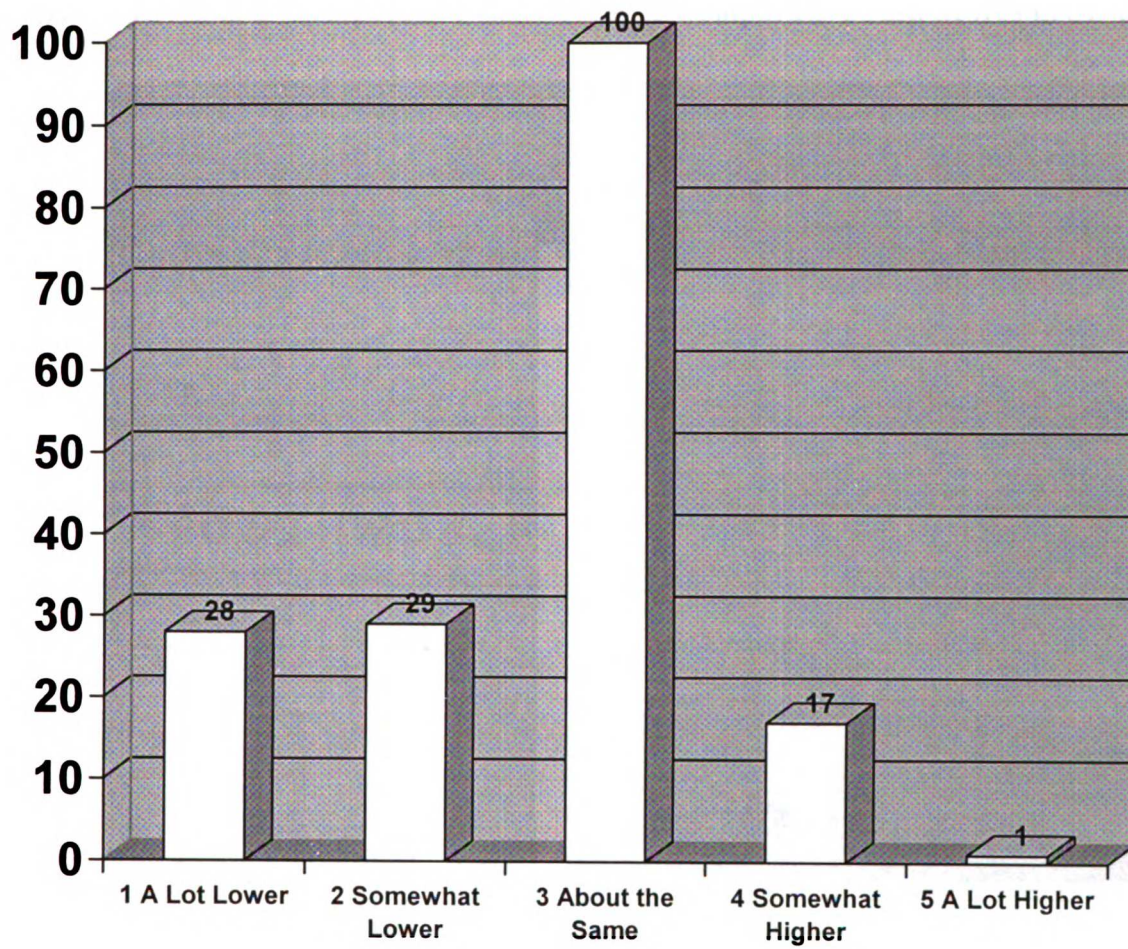
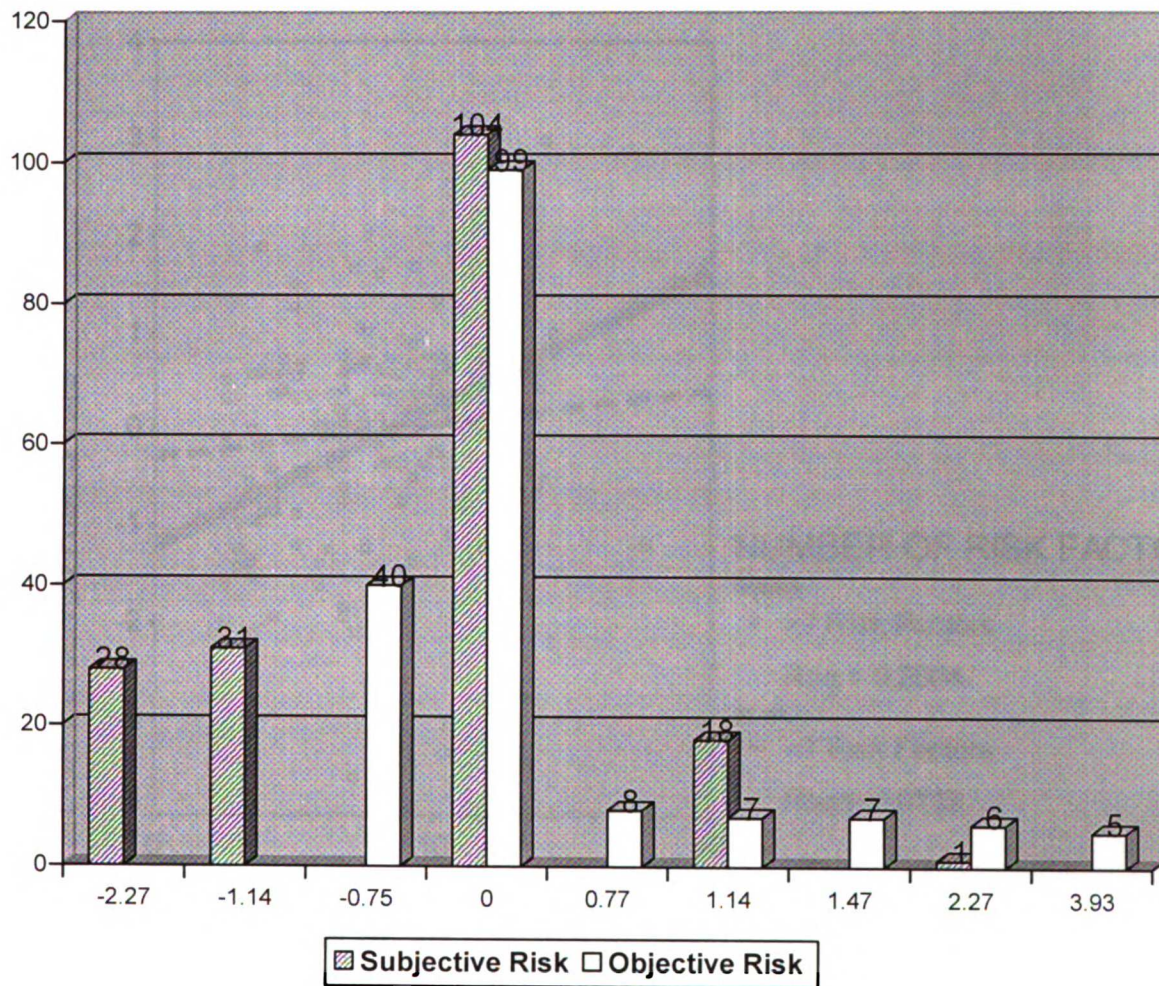
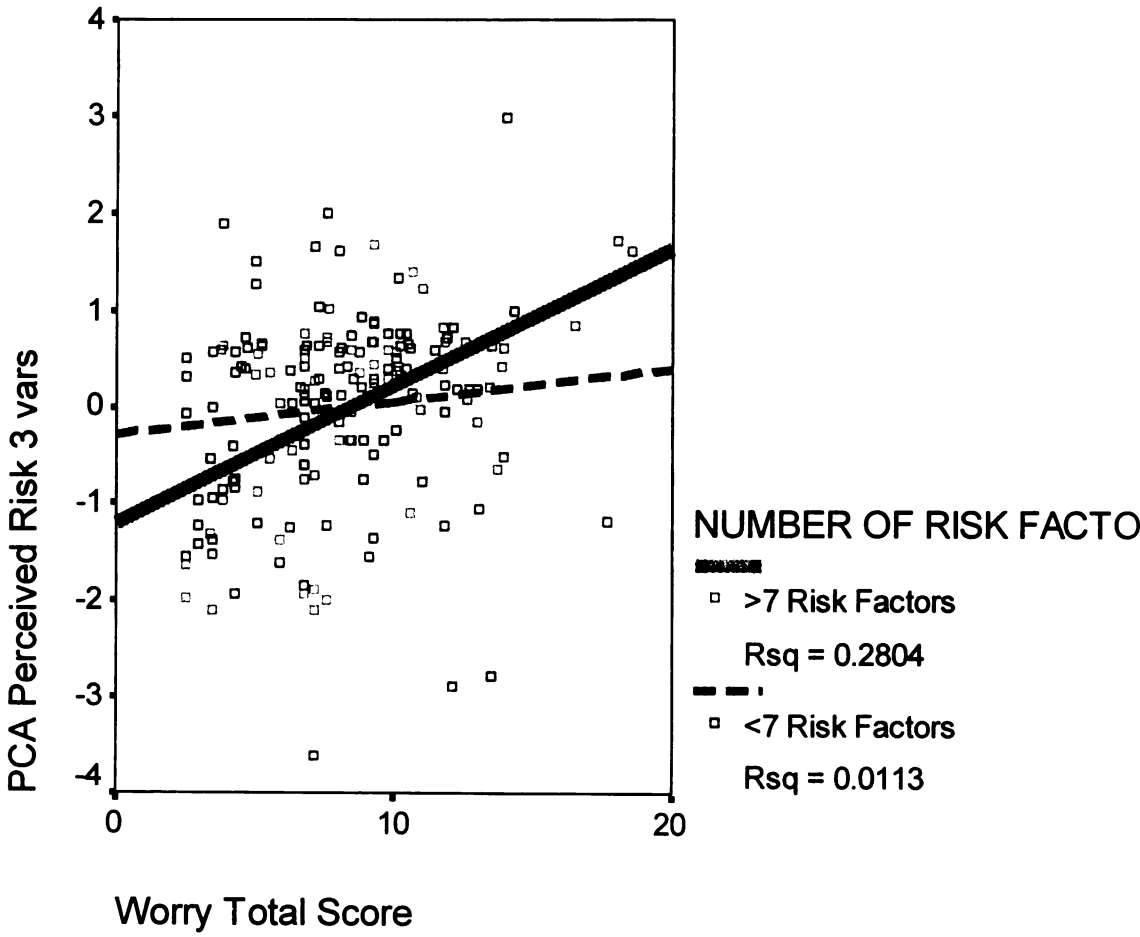


FIGURE 2.2. Comparative Gail Scores & Comparative Risk Scores in SD units



**FIGURE 3.1 Interaction of Worry with Knowledge of Breast Cancer Risk Factors
with Perceived Risk as Criterion**





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Department of Physiological Nursing
University of California San Francisco
2 Koret Way, Box 0610
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Maria C. Katapodi, RN, MSN, PhD
Department of Physiological Nursing
University of California San Francisco
2 Koret Way, Box 0610
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Fax: ++1 415 476-8899

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To: <mkatapo@itsa.ucsf.edu>

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> USA

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> Ryan Mowat, PhD
> Managing Editor
> Social Science & Medicine
> 4 Lilybank Gardens
> Glasgow G12 8RZ
> Scotland, UK

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Managing Editor
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Glasgow G12 8RZ
Scotland, UK

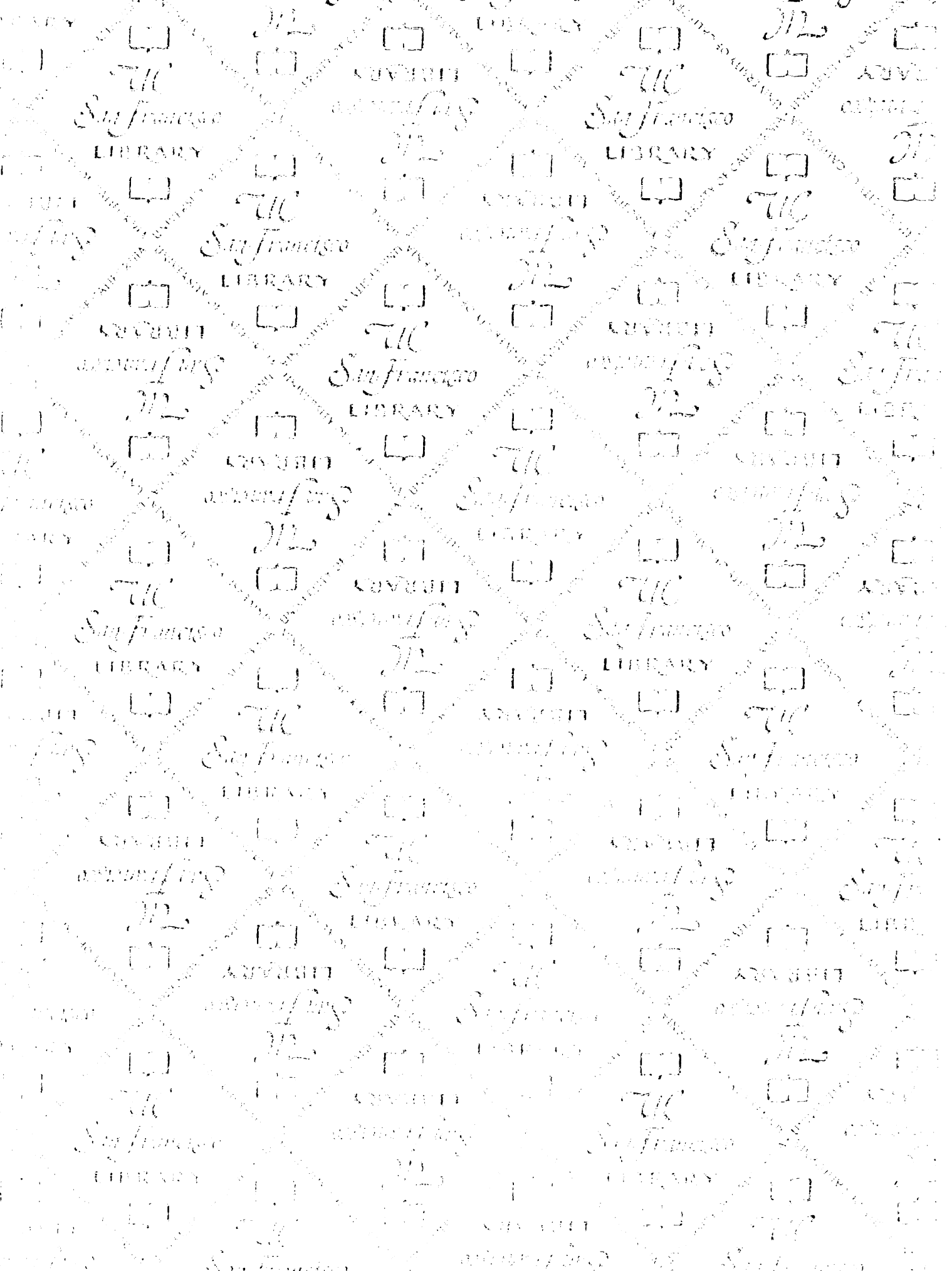
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