Breast Cancer Risk, Risk Perception and Lifestyle Behaviors among Women with a Family History of the Disease: A Mixed-Method Approach

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ABSTRACT

Denise Spector: Breast Cancer Risk, Risk Perception and Lifestyle Behaviors among Women with a Family History of the Disease: A Mixed-Method Approach
(Under the direction of Merle Mishel, Dale Sandler, Celette Sugg Skinner, Catherine Zimmer, Marcia Van Riper, and Barbara Germino).

Family history is one of the most influential breast cancer risk factors. Several lifestyle factors are also related to elevated breast cancer risk. Little is known about relationships between a family history of breast cancer, risk perception, and lifestyle behaviors.

We explored relationships between participant characteristics, Gail Model risk estimates, risk perceptions and lifestyle behaviors. Overall aims were to: 1) determine if objective risk and family burden of disease relate to lifestyle behaviors, 2) explore whether there are differences between Black and White women in lifestyle behaviors and 3) increase understanding about factors involved in breast cancer risk perception and how they relate to lifestyle behaviors.

This study utilized a mixed-method design. The quantitative portion involved analyses of risk-related variables from the baseline questionnaire of the Sister Study (N=19,418), a national epidemiological study assessing links between exposures to potential risk factors and subsequent development of breast cancer in women between the ages of 35-74 who do not have breast cancer, but have at least one sister diagnosed with breast cancer. Multivariable logistic regression was conducted to determine whether associations existed between objective risk and lifestyle behaviors (e.g., physical activity, diet, alcohol intake, and smoking). Women were then stratified on race and logistic regression was conducted to

detect any differences between Black and White women. A qualitative descriptive approach (i.e., personal interviews) was used in a complementary fashion to explore factors involved in risk perception formulation. Eligibility criteria were active enrollment in the Sister Study and living in North Carolina.

Lifestyle behaviors did not significantly differ among women at varying levels of perceived risk or objective breast cancer risk. Qualitative descriptive findings revealed that many women were unaware of associations between lifestyle-related behaviors and breast cancer risk. Most women were not adhering to lifestyle-related recommendations for breast cancer risk-reduction.

Results improve knowledge about relationships between objective risk, perceived risk and lifestyle behaviors. Further study is needed to support these results and to explain the lack of relationships between perceived risk/objective risk and modification of lifestyle behaviors in women at elevated breast cancer risk.

I dedicate this work to the amazing women that I have known, and in many cases have had the privilege of caring for, who have been personally affected by breast cancer. They have been an inspiration and they truly are the motivating force behind this endeavor. I would also like to acknowledge the wonderful women from the Sister Study who graciously took the time to share their familial experiences with breast cancer.

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CHAPTER I

INTRODUCTION

Breast cancer is one of the most common female health problems in our society and accounts for 26% of all cancers in women (Jemal, Siegel, Ward, Hao, Xu, Murray et al., 2008). In 2008, approximately 182,400 American women were expected to be diagnosed with breast cancer and breast cancer deaths were estimated to occur in roughly 40,500 women (Jemal et al., 2008). The clinical and genetic epidemiology of breast cancer include a myriad of risk factors, such as age, race, family history, presence of a BRCA1 or BRCA2 genetic mutation, hormonal factors, history of benign breast disease, and certain lifestyle factors. Modifiable lifestyle factors known to be associated with an elevated breast cancer risk are overweight/obesity and lifetime weight gain (post-menopausal breast cancer), physical inactivity, excessive alcohol intake, and exposure to cigarette smoke (Band, Le, Fang, & Deschamps, 2002; Byers, Nestle, McTiernan, Doyle, Currie-Williams, Gansler, 2002; Couch, Cerhan, Vierkant, Grabrick, Therneau, Pankratz et al., 2001; Galanis, Kolonel, Lee, & Le Marchand, 1998; Key, Schatzkin, Willett, Allen, Spencer, & Travis, 2004; McTiernan, 2003; Rock, & Demark-Wahnefried, 2002; Thune & Furberg, 2001). Although the relationship between diet and breast cancer is less clear it is well known that a diet high in fat typically leads to increased caloric intake, which is likely to result in overweight and obesity. Avoidance of weight gain may be best attained through a low-fat diet high in fruits and vegetables and through regular physical activity (Byers et al., 2002; McTiernan, 2003).

Therefore, an important approach to breast cancer risk reduction may be through engagement in healthy lifestyle behaviors. This may be particularly important for women with a breast cancer family history. In general, there is lack of information regarding the relationship between positive family history of breast cancer and lifestyle behaviors in White women and even less is known about Black women.

A family history of breast cancer is a well recognized breast cancer risk factor and little research has addressed the relationship between familial history of the disease and lifestyle risk-reduction behaviors. Both objective breast cancer risk and perceived breast cancer risk may influence a woman's decision to engage in healthy lifestyle behaviors such as regular physical activity, increasing fruit and vegetable intake and consumption of a low-fat diet for weight control, and limiting alcohol intake. Perceived risk (i.e., an individual's subjective opinion about personal risk for disease) is a central construct in many theories of health behavior, such as the Health Belief Model, the Precaution Adoption Model, Protection Motivation Theory, and the Self-Regulation Model, and is considered a motivational factor related to adoption of preventive and protective health behaviors (Leventhal, Brissette, & Leventhal, 2003; Rogers, 1975; Rosenstock, 1974; Weinstein, 1988).

For engagement in healthy lifestyle behaviors to occur in women at elevated risk for breast cancer, theory suggests that women would first have to develop a personal perception of risk for breast cancer. Increased perceived risk (i.e., subjective risk) for breast cancer has been found to be associated with screening behaviors, such as mammography use (Katapodi, Lee, Facione, & Dodd, 2004; McCaul, Branstetter, Schroeder, & Glasgow, 1996). However, the processes involved in personal breast cancer risk awareness are complex and may involve many components including psychological, spiritual, and cognitive factors (i.e., cancer

knowledge and beliefs), past experiences with cancer, and physiologic factors such as history of benign breast disease. A noted limitation in the literature is that many studies that have addressed family history and breast cancer risk perception have only used a single-item measure for perceived risk (Katapodi et al., 2004). Most importantly is that these measures fail to capture the many dimensions that may encompass a woman's perceived risk for breast cancer and there is little research focusing on the meaning of personal breast cancer risk in either White or Black women at elevated risk for breast cancer. Although many researchers have addressed breast cancer risk perception and family history, there is scant research that relates these two factors with lifestyle behaviors. The majority of the studies conducted have focused on risk perception and secondary prevention behaviors (i.e., mammography adherence and breast self-examination), as opposed to primary preventive behaviors. In this study the above limitations were addressed by exploring perceived risk through a qualitative descriptive approach that allowed women to discuss not only their personal level of breast cancer perceived risk, but also what that risk meant to them and how it related to their current lifestyle behaviors.

There appear to be racial differences in breast cancer risk perception between Black and White women at elevated risk for the disease. Several studies have found that Black women were significantly less likely than White women to report a heightened sense of personal risk after a breast cancer diagnosis in a family member (Audrain, Lerman, Rimer, Cella, Steffens, & Gomez-Caminero, 1995; Hughes, Lerman, & Lustbader, 1996; Katapodi et al., 2004). Data in these studies were generated from quantitative measures and an approach of the current study was to qualitatively explore whether family history affected the perception of risk among both Black and White women. Lack of awareness of elevated risk for breast

cancer may reduce the likelihood that women will adhere to recommendations on lifestyle behaviors that could potentially reduce breast cancer risk.

A lack of healthy lifestyle behaviors exists not only in the general population, but also in women at elevated risk for breast cancer due to family history. A previous study in female relatives of breast cancer patients found the majority of unaffected relatives did not make lifestyle changes as a result of their relative's cancer diagnosis (Lemon, Zapka, & Clemow, 2004). In the study by Lemon et al. (2004) there was a lack of change in health behavior despite the fact that the majority of women, 77%, rated themselves to be at higher than average risk for breast cancer. A limitation in the study by Lemon et al. (2004) was that it was conducted in predominantly White women. The qualitative descriptive component of the current study addressed lifestyle behavioral changes made by Black and White women following a sister's diagnosis.

Study Purpose and Rationale for the Use of Mixed Methodology

Healthy lifestyle behaviors may be influenced by a myriad of factors. Those factors may be based upon both subjective and objective risk of women with a family history of breast cancer, which have not been fully addressed in prior research. Therefore the purpose of this dissertation is two-fold. The overall purposes of the study are to 1) provide a comprehensive understanding of personal breast cancer risk perception and how it relates to lifestyle behaviors in both Black and White women with a family history of breast cancer; and 2) examine whether a multi-faceted index of breast cancer risk (i.e., Gail Model), as well as other factors that may be determinants of breast cancer risk perception predict healthy lifestyle behaviors. Study goals will be addressed through a mixed-methodology approach using both qualitative descriptive data (i.e., personal interviews) and quantitative data.

The primary purposes of the study are in alignment with one of the three principle goals of the Office of Behavioral and Social Sciences Research (OBSSR), which is to integrate a biobehavioral interdisciplinary perspective in National Institutes of Health research (OBSSR, 2005). This study integrates epidemiologic and behavioral science perspectives through the exploration of both epidemiologic data on breast cancer risk factors and lifestyle behavior data obtained through qualitative descriptive interviews from women with a family history of breast cancer. Additionally, the OBSSR (2005) has a mission to advance basic behavioral research in the areas of perception, cognition, motivation, and cultural practices to name a few. The qualitative descriptive component of the study addressed this mission by providing further information on breast cancer risk perception, beliefs about the causes of breast cancer, and beliefs about lifestyle factors as they relate to breast cancer. Additionally, the study identified some racial differences in perception of risk, causal beliefs, and healthy lifestyle practices between Black and White women at increased risk for breast cancer.

This study took advantage of the National Institute of Environmental Health Sciences' Sister Study, a breast cancer research study led by Dale Sandler, PhD, which is a prospective study of environmental and genetic risk factors for breast cancer among women ages 35-74 with at least one sister with breast cancer. Data from the Sister Study include many objective risk factors well known to be related to breast cancer risk, however actual risk probabilities based on these objective risk factors can differ widely from subjective probabilities **(**i.e., perceived risk) for breast cancer. A recent study by Gerend et al. (2004) provides evidence of a relationship between objective medical risk factors and perceived susceptibility (i.e., subjective risk) to breast cancer. In fact, the set of individual risk factors included in the Gail Model accounted for 25% of the variance in perceived susceptibility to breast cancer, which

is considered a large effect size (Cohen, 1988). Objective risk may be a component of subjective risk for some individuals and together they may influence health behaviors, whereas for others objective risk factors may be disregarded and it is then subjective risk perception that may govern behavior (Aiken, West, Woodward, & Reno, 1994; Rees, Fry, & Cull, 2001; Slovic, Peters, Finucane, & MacGregor, 2005). It is therefore of utmost importance to capture both objective and subjective risk for breast cancer when studying health behaviors. Because perceived risk was not captured in the baseline data for the Sister Study, a mixed-method strategy with a complementary qualitative descriptive component was used for this study to explore the meaning of personal risk perception and how it relates to objective risk, risk-reducing strategies and lifestyle behaviors in both White and Black women with a family history of breast cancer. Since very little information exists regarding lifestyle behaviors in women at elevated risk (Madlensky, Vierkant, Vachon, Pankratz, Cerhan, Vadaparampil et al., 2005), especially among Black women, the quantitative portion of the study examined participant characteristics, objective risk factors, family burden of disease (i.e., more than one affected sister, any sister diagnosed < 50 years of age, affected mother, and any sister diagnosed within the past 4 years) and their relationships with current lifestyle behaviors in a large sample (N =19,418) including both White and Black women with a family history of breast cancer.

Aims for the Quantitative Analysis

AIM 1: Determine if objective risk (i.e., Gail Model risk estimates calculated from quantitative data) and family burden of disease (i.e., more than one affected sister, any sister diagnosed < 50 years of age, affected mother, and any sister diagnosed within the past 4 years) is associated with current lifestyle behaviors (i.e., physical activity, caloric intake, fruit

and vegetable consumption, dietary fat intake, alcohol use and smoking status) among women with a family history of breast cancer.

Research Questions:

1) Is objective risk based on a Gail Model risk estimate predictive of lifestyle behaviors among Black and White women with a family history of breast cancer?

2) Is family burden of disease associated with current lifestyle behaviors among women with a family history of breast cancer?

Sub-Aim 1a: Identify whether differences exist, based on the above factors, among Black and White women.

AIM 2: Determine whether there are lifestyle behavioral differences between Black and White women with a family history of breast cancer.

Research Questions:

3) Do Black and White women with a family history of breast cancer differ on engagement in physical activity, caloric intake, fruit and vegetable consumption, dietary fat intake, alcohol consumption, and smoking?

4) Do Black and White women with a family history of breast cancer differ on adherence to the ACS Guidelines on Nutrition and Physical Activity for Breast Cancer Prevention?

Aims for the Qualitative Descriptive Analysis

AIM 1: Describe factors involved in development of personal breast cancer risk perception and describe the relationship of perceived risk to lifestyle behaviors in women with a family history of breast cancer.

Research Questions:

1) What factors are involved in development of personal risk perception for breast cancer among Black and White women with a family history of the disease?

2) Do Black and White women with a family history of breast cancer make lifestyle changes as a result of their perceived risk for breast cancer?

The purpose of Chapter IV (i.e., manuscript #1, "Familial Breast Cancer Risk and Lifestyle Behaviors in the Sister Study"), was to explore whether any statistically significant relationships existed between lifestyle behaviors and Gail Model risk estimates, as well as family burden of disease. This was addressed through quantitative AIM 1, research questions 1 and 2. Differences among Black women with higher Gail risk estimates compared to Black women with lower Gail risk estimates were examined through Sub-Aim 1a. Differences among Black women with high versus low family burden scores were also examined through Sub-Aim 1a. Parallel analyses were conducted for White women and they were included in the same chapter. The goals of Chapter V (i.e., manuscript #2, "Lifestyle Differences Among Black and White Women with a Family History of Breast Cancer in the Sister Study"), were addressed through AIM 2, research questions 3 and 4. The aim of this study was to determine whether there are lifestyle behavioral differences between Black and White women with a family history of breast cancer and to determine the extent to which Black and White women with a family history of breast cancer adhere to American Cancer Society (ACS) Guidelines on Nutrition and Physical Activity for Breast Cancer Prevention. Because both perceived risk (i.e., subjective risk) and objective risk may influence a woman's decision-making processes regarding lifestyle behaviors, the goal of Chapter VI (i.e., manuscript #3, "Breast Cancer Risk Perception and Lifestyle Behaviors among Black

and White Women with a Family History of the Disease") was to qualitatively explore both the meaning of perceived risk and the factors involved in the development of breast cancer perceived risk, as well as to explore whether perceived risk was related to lifestyle behaviors among Black and White women. The corresponding aim is qualitative AIM 1, research questions 1 and 2. Through the qualitative study came the identification of several important predictors related to perceived risk. Additionally, comparisons of lifestyle behavioral changes and current lifestyle behaviors were made among Black and White women. Thus, this is a complementary manuscript to both quantitative manuscripts. This paper not only allowed for the comprehensive exploration of perceived risk and how it related to lifestyle behaviors, but it also provided the insight that was needed to help explain why some women may or may not be engaging in healthy lifestyle behaviors. Also change in lifestyle behavior as a result of a breast cancer family history was assessed; this was not examined quantitatively. Additionally, the qualitative study led to the discovery of factors that were related to heightened perceived risk which were subsequently incorporated into the quantitative measure, Family Burden of Disease. Because this finding appeared to be an important determinant of elevated perceived risk, a decision was made to examine family burden of disease in the quantitative analysis (Chapter IV, manuscript #1). Racial differences in current lifestyle-related factors were also found through qualitative exploration and this was further examined in Chapter V (manuscript #2). Therefore the qualitative descriptive component enhanced the quantitative analysis and helped explain the quantitative findings.

Overall, current lifestyle behaviors were examined in all three manuscripts (Chapters IV-VI) with manuscript #1 (Chapter IV) addressing them in relation to Gail Model risk and

family burden of disease and in manuscript #2 (Chapter V) lifestyle behavioral comparisons were made between Black and White women. Relationships between perceived risk, family burden of disease and lifestyle behaviors were explored in manuscript #3 (Chapter VI). As in manuscript #2, comparisons were also made between Black and White women on their adherence to ACS guidelines on nutrition and physical activity for breast cancer prevention.

CHAPTER II

REVIEW OF THE LITERATURE

Several non-modifiable risk factors have been incorporated into objective breast cancer risk assessment models, such as the Gail Model, that are often used clinically to help women at elevated risk make decisions regarding screening and risk-reduction strategies. Gail Model risk estimates are calculated based on the following information: current age, age at menarche, age at first live birth, number of first-degree relatives with a history of breast cancer, number of previous biopsies, and a history of atypical hyperplasia (Gail, Brinton, Byar, Corle, Green, Schairer et al., 1989). Because this study utilizes the Gail Model for quantifying risk, a review of the model is included followed by a discussion of the risk factor components used to determine Gail Model risk estimates.

Next, a review of perceived (i.e., subjective) risk is presented, which includes information on determinants of risk perception that were found to be important in the qualitative interviews. Many objective factors may influence a woman's perception of her own risk for breast cancer; however additional factors that are cognitively, psychologically or emotionally based are also likely to be contributory.

A review of medical breast cancer risk-reducing strategies (i.e., anti-estrogen therapy and prophylactic mastectomy) follows the discussion on perceived risk. These strategies were explored in the qualitative interviews and they were also descriptively analyzed in paper #1 (Chapter IV) to characterize the study sample. Although research is scant in the area of

current lifestyle practices and use of medical risk-reducing strategies among women at increased risk for breast cancer, there are a few studies that warrant mentioning.

Quantifying Objective Breast Cancer Risk with the Gail Model

Results from large epidemiologic population-based studies that focused on breast cancer incidence and risk factors have led to the development of breast cancer risk assessment models. These risk assessment models are used to calculate absolute risks for invasive breast cancer and have been utilized for decision-making purposes regarding breast cancer risk reduction strategies, screening and genetic testing. One of the most commonly used models, based on several known epidemiologic breast cancer risk factors, is the Gail Model. As previously mentioned, the Gail Model incorporates current age, age at menarche, age at first live birth, number of first-degree relatives with a history of breast cancer, number of previous biopsies, and a history of atypical hyperplasia, into a statistical model that generates risk figures (Gail et al., 1989). These risk figures are estimates for 5-year and lifetime absolute risks that are compared to a woman of the same age at average risk for breast cancer. The original Gail Model was based on The Breast Cancer Detection Demonstration Project (BCDDP) which enrolled more than two hundred thousand White women in the early to late 1970's and the model was validated a few years later using data from the Nurse's Health Study (Spiegelman, Colditz, Hunter, & Hertzmark, 1994). A modified Gail risk model, called the NCI Gail model, was developed over a decade later for use in The Breast Cancer Prevention Trial, which was designed to test the efficacy of Tamoxifen (Fisher, Costantino, Wickerham, Redmond, Kavanah, Cronin et al., 1998). This modified model includes the same relative-risk factors as the original, but it also incorporates breast cancer estimations specific to Black women (O'Neill, 2000). However, a recent study including a larger sample

of Black women revealed that the Gail Model underestimated risk for Black women (Gail, Costantino, Pee, Bondy, Newman, Selvan et al., 2007). Although these models have widespread clinical utility and the risk calculators are readily available on hand-held devises and computer programs, limitations need to be considered. In addition to the limitation related to race another notable weakness of the model is that it only includes first-degree relatives (i.e., mother and sisters) and neglects to consider paternal history or other second-degree relatives with a breast cancer history, which leads to a tendency towards an under-prediction of risk in women with a family history. Another limitation is that no consideration is given to the age at diagnosis of the relatives, which could be important in distinguishing between sporadic and hereditary breast cancers (O'Neill, 2000). Some of these limitations have been discussed in Chapters IV and VI. Therefore, the Gail model may not be appropriate for all women with a positive family history, especially if a woman has a very strong family history indicative of a familial genetic mutation. Another factor to consider when using the model is the fact that women who have had breast biopsies may not know the results and especially not know the term atypical hyperplasia (O'Neill, 2000). Despite the limitations, the Gail model is an effective tool used to screen women for chemoprevention trials and for referrals to comprehensive risk assessment clinics.

Although predictive models are extremely useful in quantifying risk they do not incorporate environmental and behavioral risk factors into the estimated risk figures even though such factors as obesity, physical inactivity and regular consumption of more than one alcoholic drink per day have all been found to increase breast cancer risk. The relative risk calculations based on these various factors should also be considered in a comprehensive clinical approach to breast cancer risk assessment. Even if more comprehensive objective

models were developed in the future to assist with clinical breast cancer risk evaluation, health care providers also must be cognizant of the fact that perceived breast cancer risk (i.e., subjective risk for developing breast cancer) may not coincide with objective risk measures.

Gail Model Components

Age and Race

There are many factors associated with an increased risk of breast cancer. Two well known uncontrollable risk factors are age and race. Although the incidence of breast cancer steadily increases with age in both Black and White women there are notable racial differences. Age-specific breast cancer incidence rates reveal that Black women under the age of 50 are more likely to develop breast cancer compared to White women in the same age group (Ries, Eisner, & Kosary, 2003; National Cancer Data Base, 2002). After the age of 50, the incidence rate in White women begins to rise substantially leading to the overall higher lifetime risk for White women (Ries et al., 2003). It has also been demonstrated in the large ethnically diverse Women's Health Initiative (WHI) study that postmenopausal Black women affected with breast cancer often have tumors with poorer prognostic factors, such as higher grade (i.e., poorly differentiated) tumors compared with women of different ethnic/racial backgrounds (Chlebowski, Chen, Anderson, Rohan, Aragaki, Lane et al., 2005). Carey et al. (2006) reported a higher prevalence of a specific breast cancer subtype, basal-like tumors which are known to be more aggressive than other tumor types, in premenopausal Black women. These differences in biologic tumor characteristics between Black women and women of other races are most likely multi-factorial with speculations regarding the role of genetic, environmental, cultural, socioeconomic, and lifestyle factors being mentioned in the literature (Carey, Perou, Livasy, Dressler, Cowan, Conway et al.,

2006; Chlebowski et al., 2005; Newman, Griffith, Jatoi, Simon, Crowe, & Colditz, 2006). This is discussed further in paper #2 (Chapter V).

Family History

Because all participants in this study have had at least one sister diagnosed with breast cancer, a background on the significance of family history is relevant and is discussed in all three papers. Family history as it related to causal beliefs about breast cancer and its relationship to personal risk were explored in paper 3 (Chapter VI).

Familial breast cancers account for approximately 15% to 20% of overall breast cancer cases (Thull & Farengo-Clark, 2003). In a meta-analysis from 52 epidemiological studies on familial breast cancer, risk ratios increased as the number of affected first-degree relatives increased (Collaborative Group on Hormonal Factors in Breast Cancer [CGHFBC], 2001). The statistically significant risk ratios for one, two, and three or more affected first-degree relatives, when compared with women not having a first-degree relative with a history of breast cancer, were 1.8, 2.9, and 3.9 respectively. An additional finding from a subset of the studies was that risk ratios were even higher in women whose relatives were younger than 50 when they were diagnosed (i.e., 3.18 if the relative was a sister) (CGHFBC, 2001). A recent finding from the Contraceptive and Reproductive Experiences (CARE) study, which included 2,676 White and 1,525 Black women, confirmed that White women with at least one affected first-degree relative have higher cumulative lifetime risks of breast cancer than Black women, 22.4% for White women compared to 14.5% for Black women (Simon, Korczak, Yee, Malone, Ursin, Bernstein, et al. 2006). These studies confirm that any woman with an affected first-degree relative, especially one with a relative diagnosed at a young age, is at significantly higher risk for breast cancer compared to women in the general population.

Endogenous Hormones

Not only are these factors included in the Gail Model, they were also reported to be risk factors by several women who participated in the qualitative interviews (Chapter VI).

The link between endogenous reproductive hormones and breast cancer has been well-documented in the literature with elevated risks being associated with early age of menarche, late age of menopause, and nulliparity or age at live birth over 30 (Harris, Lippman, Veronesi, & Willett, 1992). Essentially, the longer a woman is exposed to endogenous circulating estrogens, predominantly estradiol, the greater her risk for breast cancer.

Benign Breast Disease

Benign breast disease, a component of the Gail Model, also factors in atypical hyperplasia. Benign breast disease was also mentioned as a personal risk factor by several women during qualitative interviewing and is included in the qualitative descriptive analysis of paper 3 (Chapter VI).

Histologic changes in breast tissue that result in benign breast disease can place a woman at higher risk for developing breast cancer. Atypical hyperplasia, the most serious of the benign lesions is very similar histologically to ductal carcinoma in situ and confers relative risks ranging from 4.0 to 11.0 in women with a family history, which is more than double the relative risk in women without a family history (Dupont & Page, 1985; Hartmann, Sellers, Frost, Lingle, Degnim, Ghosh et al., 2005). Hartmann et al. (2005) found that more women with atypia had a stronger family history than women without atypia, revealing that family history is an independent risk factor. Young age at diagnosis (i.e., < 45) was also related to a greater risk. Overall, among women with benign breast disease it appears that age, family

history and histologic characteristics all play significant roles in the development of breast cancer.

Perceived Breast Cancer Risk

A primary aim of the qualitative descriptive study was to gain a better understanding about perceived risk and how it related to lifestyle behaviors in women with a history of breast cancer. Therefore, a detailed overview of the concept, perceived risk, is provided in this section and a more brief description is provided in the introduction and discussion sections of paper 3 (Chapter VI). Because it was discovered through qualitative exploration that several family associated factors (i.e., more than one affected sister, any sister diagnosed < 50 years of age, affected mother, and any sister diagnosed within the past 4 years) corresponded with heightened perceived risk it was important to include information related to the familial breast cancer experience as well.

Introduction

Perceived risk relates to an individual's belief about the probability or likelihood of developing some specified illness (Weinstein, 2000). Since personal perceptions of health risk may be influential in promoting healthy behaviors, researchers have become very interested in examining the concept of perceived risk and its relationship with health practices. However, a number of methodological problems have arisen with investigation of perceived risk. One such problem stems from that fact that researchers often measure perceived risk based only on a single likelihood question, which fails to capture factors (e.g., family history/genetics, physiologic and psychological attributes, causal beliefs, and cultural beliefs) that can affect an individual's personal risk judgments (Rothman, Klein, & Weinstein, 1996). Without this information it may be difficult to understand how perceived

risk relates to behavior. The perceived risk questions are typically based on numerical estimates or probability statements, which are difficult for the majority of individuals to fully understand (Rothman & Kiviniemi, 1999). Researchers often compare subjective risk measures with objective risk estimates, but research has shown that lay perceptions of risk encompass much more than objective risk estimates (Rothman et al., 1999, Slovic et al., 2005). Prior to delving further into these areas, a brief overview will be provided of the role of perceived risk in the Health Belief Model, which has been utilized extensively in the cancer-related literature, followed by a discussion on determinants of perceived risk.

The Health Belief Model and Perceived Risk

The Health Belief Model (HBM) was one of the first models that described perceived susceptibility as a central component involved in an individual's motivation to engage in a health protective behavior (Rosenstock, 1974). The HBM is based on the assumptions that individuals will take action to protect themselves from an illness if they believe they are susceptible (perceived susceptibility), if they believe the illness will have serious consequences (perceived severity), if they feel there is a health action that may decrease the chance of developing an illness (perceived benefits,) and if they believe that the perceived benefits of the health action outweigh the costs or perceived barriers (Strecher & Rosenstock, 1997). Over the years other concepts have been added to the HBM to help explain behavior, such as perceived control. The HBM has been perhaps the most widely used theoretical framework for explaining health behavior and for guiding health-related behavior change interventions in practice (Strecher & Rosenstock, 1997). Although the HBM was not the framework for this study, certain concepts (i.e., perceived risk, perceived control, and perceived barriers) from the model guided portions of the qualitative interview.

Determinants of Perceived Risk

Because perceived risk may be an influential factor in motivating individuals to engage in healthy lifestyle behaviors, it is important to gain a better understanding about the various determinants of perceived risk for breast cancer in women with a family history. Because individuals might consider a multitude of factors when formulating their risk perceptions, conceptualization and measurement of perceived risk for breast cancer can be challenging. Some factors a woman might consider are objective risk factors, such as age, history of atypical hyperplasia and other benign breast disease, family history of breast cancer, young age at onset of breast cancer (i.e., $\leq$ 50 years of age) in affected family members, nulliparity or $\geq$ 30 years of age at first live birth, and young age at the start of menarche (i.e., <12). Many of these objective risk factors are incorporated into the Gail Risk Assessment Model. Although objective risk estimates (e.g., Gail Model) have been documented to be important in the formulation of perceived risk, there are other factors that might be more salient and have a greater influence on risk perception (Avis, Smith, & McKinlay, 1989; Kreuter & Strecher, 1995).

According to Rothman et al. (1996) both contextual and psychological factors can affect perception of risk. Contextual factors related to breast cancer might include such things as family history/genetics, one's own health behaviors, history of benign breast disease, and beliefs about breast cancer causation (Rees et al., 2001; Kwate, Thompson, Valdimarsdottir, & Bovbjerg, 2005; Rothman et al., 1996; Weinstein & Lachendro, 1982; & Weinstein & Klein, 1995). Psychological factors related to breast cancer risk perception might include breast cancer worry and anxiety (Aiken, Gerend, & Jackson, 2001; Rothman et al., 1996; Weinstein et al., 1982). Although breast cancer worry was not measured in the baseline Sister

Study questionnaire the qualitative descriptive portion of the study assessed cancer-related worry or anxiety through the personal interviews.

An example of how both contextual factors and psychological factors become intertwined in the formulation of risk perception can be elucidated when considering the experience of cancer in the family. If a woman has had several family members with a breast cancer diagnosis and she was intimately involved with caring for one or more of them during treatments and/or the dying process it is likely that her experiences will have an effect on her personal judgment about her own susceptibility (Rees et al., 2001). This 'lived experience of cancer' can have a profound impact on risk perception….and this can lead to overestimation of risk..." (Hopwood, 2000, p. 389). The qualitative descriptive component of this study allowed for exploration of the familial breast cancer experience, which elucidated how emotional and cognitive factors came together in the formulation of perceived risk.

Risk perception is often affected by beliefs about breast cancer causation. Women may be unfamiliar with breast cancer risk factors and have false beliefs about the causes of breast cancer. A number of studies have shown that first-degree relatives of breast cancer patients are not aware that previous breast biopsies, age at menarche, age at menopause, and age of relative at time of diagnosis are risk factors (Daly, Lerman, Ross, Schwartz, Sands, & Masny, 1996; Ryan & Skinner, 1999). One interesting finding from several studies is that women are often unaware that advancing age is a risk factor for breast cancer when in fact age is recognized as the single most important risk factor for breast cancer (Dolan, Lee, & McDermott, 1997; Pohls, Fasching, Beck, Kaufmann, Kiechle, von Minckwitz et al., 2005; Rabin & Pinto, 2005; & Vogel, 2003). In addition to family history and heredity, the risk factors commonly cited by women and documented in the literature are stress, physiology,

environmental toxins, diet, and smoking (Kristeller, Hebert, Edmiston, Liepman, Wertheimer, Ward et al., 1996; Kwate et al., 2005; Lemon et al., 2004; Lipkus, Rimer, & Strigo, 1996; Ryan et al., 1999). All of these factors were mentioned as risk factors by women through personal interviews conducted in paper #3 (Chapter VI).

Taking into consideration all of the aforementioned aspects of risk and risk perception, it is no wonder that conceptual and measurement problems frequently occur in this field of study. Slovic (1999) has claimed that the concept of risk can not be confined to one definition and it also is far too complex to be easily quantified into an objective estimate, and has written that "risk does not exist out there, independent of our minds and cultures, waiting to be measured" (p. 690). Risk perceptions are created within the minds of individuals and are based on a multitude of factors, which often includes knowledge of risk factors. Therefore it is no surprise that researchers continue to confront methodological problems when studying this concept especially in relationship to health behaviors. Overall, what is gleaned from research findings is that investigators in the area of behavior change require a better understanding of the myriad of variables involved in the formulation of risk perception before advances in the science of risk perception and health behaviors can be made. This provides a strong rationale for the use of mixed methodology, because qualitative data can be essential for enhancing our knowledge about risk perception and how it relates to behavior change. A more comprehensive understanding of both objective and subjective determinants of perceived risk for breast cancer emerged through this study's qualitative descriptive component.

Medical Risk-Reducing Strategies

The use of anti-estrogen therapy (i.e., Tamoxifen) and a history of prophylactic mastectomy were examined through descriptive statistics in paper #1 (Chapter IV) and they were also explored through qualitative interviews in paper #3 (Chapter VI). Due to lack of information regarding Raloxifene use as a risk-reducing measure in the baseline questionnaire of the Sister Study it was not included in the quantitative portion of this study, but was explored in the qualitative interviews.

Anti-Estrogen Therapy

Some women at high risk for breast cancer may choose medical risk-reducing strategies that exert their effects through hormonal manipulation. One such strategy is the use of the anti-estrogen agent Tamoxifen. Tamoxifen, a selective estrogen receptor modulator or SERM, has been used successfully in breast cancer treatment for over 20 years and more recently has been prescribed in breast cancer prevention with women at high risk for breast cancer. In an attempt to identify whether other SERMS might have similar risk-reduction potential, the Study of Tamoxifen and Raloxifene, or STAR, was initiated and included over 19,700 post-menopausal women (NCI, 2005). Results were that Raloxifene is as effective as Tamoxifen in reducing the incidence of invasive breast cancer (Vogel, Costantino, Wickerham, Cronin, Cecchini, Atkins et al., 2006).

Although Tamoxifen is an effective breast cancer risk-reducing strategy there is little information about its use specifically in women with a family history of breast cancer. Two recent reports indicate that women with at least one affected first- or second-degree relative infrequently choose to take Tamoxifen or Raloxifene for breast cancer risk reduction (MacDonald, Sarna, Uman, Grant, & Weitzel, 2006; Madlensky et al., 2005). An additional

finding by Madlensky et al. (2005) was that only 11% of 274 women at high risk (i.e., defined as a woman with at least two relatives affected with breast cancer and least one of them was a first-degree relative) ever used anti-estrogens for risk-reduction.

Prophylactic Mastectomy

Prophylactic mastectomies have been shown to significantly reduce the risk for breast cancer in women at high risk. One study conducted in women with BRCA1 or BRCA2 genetic mutations found that bilateral prophylactic mastectomies can decrease breast cancer risk 10-fold (Grann, Jacobson, Whang, Hershman, Heitjan, Antman et al., 2000). Although surgical risk-reduction therapies have been demonstrated to reduce breast cancer risk, they are typically recommended only for women considered to be at very high risk, such as women with known or suspected BRCA1 or BRCA2 genetic mutations or a history of lobular carcinoma in situ (National Comprehensive Cancer Network [NCCN], 2005). Considering the recommendations there is a relatively small percentage of women who would be eligible for a prophylactic mastectomy. The majority of women at higher than average risk for breast cancer would generally be considered for nonsurgical risk-reduction strategies (e.g., anti-estrogen therapy) (NCCN, 2005). Even though this risk-reducing surgery may be recommended to women at very high risk, not all women will view this procedure as a viable option.

Madlensky et al. (2005) compared medical risk-reducing behaviors among women with varying levels of breast cancer risk, based on family history, and found that women in the highest risk group used anti-estrogen therapy more often than those women in the moderate-risk group, although only 10% of the high-risk group reported using anti-estrogens. Prophylactic mastectomy was chosen by only 1% of the high-risk women and by under 0.5%

of the women in the moderate risk group; a total of 10 mastectomies were performed among approximately 3,000 women.

Lifestyle Behaviors among Women with a Familial History

Over the past few years there have been a few reports on the relationship between lifestyle behaviors and family history of breast cancer. A prospective study conducted by Lemon and colleagues (2004) found that in 600 women with a family history of breast cancer 37% were smokers and 20% consumed 4 or more alcoholic drinks per week at the time of their first-degree relatives (FDRs) diagnosis. As a result of their FDRs diagnosis, 21% of smokers cut down or quit smoking, but only 6% of women, reporting any alcohol consumption, reduced their intake. Results of overall behavior change revealed that 42% of the women made at least one healthy lifestyle behavior change, with 25% reporting an increase in physical activity and approximately one-fifth reporting improvement in their diets. In a more recent cross-sectional study, Madlensky et al. (2005) examined the relationships between preventive health behaviors and varying levels of familial breast cancer risk in more than 3,000 women from the Minnesota Breast Cancer Family Study. Women in this study were classified as high-risk, moderate-risk, or average- to low-risk (i.e., marry-ins) depending on the number of family members with breast cancer and the degree of relationship, such as first- or second-degree. There were no appreciable differences among the three groups in diet, physical activity, alcohol consumption and vitamin/supplement use but reported rates of smoking were lower in the average risk group.

Risk perception was not examined in the study by Madlensky et al. (2005) and although risk perception was assessed in the study by Lemon et al. (2004) the researchers did not directly address the relationship between personal risk perception and lifestyle behaviors.

Although these study findings provide information about familial history of breast cancer and lifestyle behaviors, further research is needed to address the relationships among risk perception, risk determinants, both subjective and objective, and health behaviors. Also because a limitation of these studies is that they were conducted with primarily White women, a study in a sample including a more representative number of Black women would be beneficial to understanding racial differences.

In conclusion, many factors are related to breast cancer risk and breast cancer risk perception. The preceding review of the literature highlights many objective breast cancer risk factors, as well as determinants of perceived risk found to be relevant in previous research. Only a few studies have actually examined relationships between objective breast cancer risk, perceived risk and modifiable lifestyle-related behaviors in women with a family history of breast cancer.

CHAPTER III

MIXED-METHODOLOGY

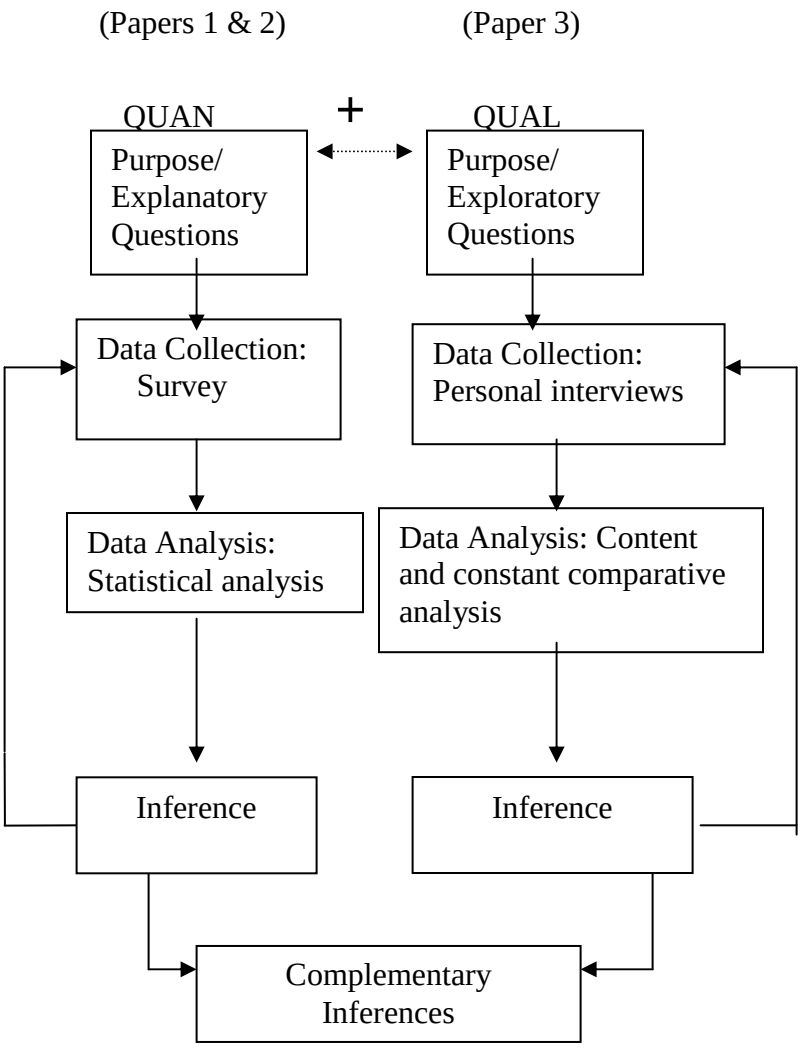
Overview

The study was conducted using a mixed-methods design, which involved analysis of quantitative survey data (Chapters IV & V, papers #1 & #2) and collection and analysis of qualitative open-ended interview data (Chapter VI, paper #3). A concurrent (i.e., nested or coordinated sub-study) mixed-model design was used, which is characterized by the simultaneous collection and analysis of both quantitative and qualitative data. Results from the two methods were integrated (e.g., "between-method triangulation") during the interpretation phase of the study which is discussed in Chapter VII (Denzin, 1978; Erzberger & Kelle, 2003). The method of triangulation for this study was based on a complementarity model emphasizing use of different methods to investigate breast cancer risk from two different perspectives or viewpoints (Erzberger & Prein, 1997; Erzberger & Kelle, 2003). Jick (1979) has argued that the goal of triangulation is to provide "a more complete, holistic, and contextual portrayal of the unit(s) under study (p. 138). Recently, this view has been strengthened by other researchers who view the mixed-method approach as complementary (Kelle & Erzberger, 2000). Flick (2002) has stated that, "triangulation is less a strategy for validating results and procedures than an alternative to validation…which increases scope, depth and consistency in methodological proceedings" (p. 227). The complementary view provides the notion of "filling in the gaps" or extending and expanding our understanding of

some phenomenon through two different methods. Complementarity models are typically utilized when a single research method is not sufficient to capture enough data to support the assumptions of the study (Erzberger et al., 2003). Results from the two different methods become combined or integrated with a purpose "to produce an adequate image of reality" (Erzberger et al., 1997, p. 144). Quantitative findings are enhanced or elaborated through the qualitative findings.

Mixed-methodology approaches, which have been advocated for public health research on complex issues, have been meaningfully applied in studies investigating lifestyle behavior change where both subjective and objective data are valued and together lead to more comprehensive programs of research (Baum, 1995; Bryant, Forthofer, McCormack Brown, Alfonso, & Quinn, 2000; Erzberger et al., 2003). Because conceptualizations of breast cancer risk and relationships to lifestyle behaviors are often based on objective risk factors, as well as subjective experiences, it was important to explore both dimensions which were done through mixed-methodology in this case.

A visual representation of the concurrent complementarity design appears on the following page (Adapted from Creswell, 2003 & Tashakkori & Teddlie, 2003):


(Papers 1 & 2)
(Paper 3)
QUAN
+
QUAL
Purpose/ Explanatory Questions
Purpose/ Exploratory Questions
Data Collection: Survey
Data Collection: Personal interviews
Data Analysis: Statistical analysis
Data Analysis: Content and constant comparative analysis
Inference
Inference
Complementary Inferences

Data Integration

Morse and Field (1994) have contended that quantitative and qualitative data sets need to be analyzed separately because they are derived from very different data collection techniques. The data should come together once both aspects of the study are complete and the results, not the actual data, get triangulated. This makes the most intuitive and practical sense since confusion abounds as to the best way to combine data that is both numerical and literal in the analysis. Therefore results from both quantitative studies and the qualitative study were integrated in the last chapter (Chapter VII) and findings were further explained in relation to both aspects of the study. Overall findings provided a basis for discussing future research recommendations.

In conclusion, a mixed-method design was utilized to address the complex phenomena of breast cancer risk and risk perception and how they related to lifestyle behaviors among women at increased risk for breast cancer. A complementarity approach was used, which begins from the assumption that qualitative and quantitative research methods investigate different aspects of complex phenomena. The weaknesses of one method of inquiry are often compensated for by the strengths of the other. Results from both methods become integrated and together help establish a more complete understanding of the phenomenon of interest.

CHAPTER IV

PAPER ONE

Familial Breast Cancer Risk and Lifestyle Behaviors in the Sister Study

Introduction

Breast cancer accounts for 26% of all new cancers in women (Jemal, Siegal, Ward, Hao, Xu, Murray et al., 2008). The epidemiology of breast cancer includes both non-modifiable and modifiable risk factors. Non-modifiable factors include age, race, and family history. Family history accounts for approximately 15% to 20% of breast cancer cases and having multiple affected relatives and young age of a relative at diagnosis significantly increases risk (Collaborative Group on Hormonal Factors in Breast Cancer, 2001; Thull, & Farengo-Clark, 2003). There is also evidence that family history and certain modifiable lifestyle-related factors (obesity, physical inactivity, and alcohol intake) may interact to further increase breast cancer risk (Carpenter, Ross, Paganini, & Bernstein, 2003; Cerhan, Vierkant, & Sellers, 2001; Sellers, Kushi, Potter, Kaye, Nelson, McGovern et al., 1992; Swerdlow, Stavola, Floderus, Holm, Kaprio, Verkasalo et al., 2002; Verloop, Rookus, van der Kooy, & van Leeuwen, 2000).

Modifiable factors associated with an elevated breast cancer risk are adult weight gain and obesity (postmenopausal breast cancer), physical inactivity, and alcohol intake (Ballard-Barbash, 2006; Byers, Nestle, McTiernan, Doyle, Currie-Williams, Gansler et al., 2002; Galanis, Kolonel, Lee, & Le Marchand et al., 1998; Key, Schatzkin, Willett, Allen, Spencer,

& Travis, 2004; McTiernan, 2003; Thune & Furberg, 2001). Although the relationship between diet and breast cancer is less clear it is well known that a diet high in fat typically will lead to increased caloric intake, which is likely to result in overweight and obesity. Avoidance of weight gain may be best attained through a low-fat diet also high in fruits and vegetables and through regular physical activity (Byers et al., 2002; McTiernan, 2003).

Few studies have examined lifestyle behaviors, and factors they may influence these behaviors, among women with a familial breast cancer history. One study of female relatives of breast cancer patients found the majority of unaffected relatives did not make lifestyle changes as a result of their relative's cancer diagnosis (Lemon, Zapka & Clemow, 2004). Madlensky et al. (2005) examined the relationships between preventive health behaviors and varying levels of familial breast cancer risk in more than 3,000 women and they found no appreciable differences among groups in diet, physical activity, and alcohol consumption.

Objective risk estimates (i.e., Gail Model) have been shown to be important in formulation of perceived risk. However, other factors such as experiences of cancer in the family may be more salient and have a greater influence on risk perception (Gerend, Aiken, West, & Erchull, 2004; Hopwood, 2000; Kreuter & Strecher, 1995). Burden of cancer in the family, which may include the number of affected relatives, having an affected mother, young age at diagnosis, and timing of the illness, may have a profound impact on perceived risk (Hopwood, 2000). Although previous studies have assessed either perceived risk or objective risk for breast cancer in relation to lifestyle behaviors, this study examined both objective risk based on the Gail Model and familial burden of disease in association with lifestyle behaviors in a large sample.

The primary aims of this study were to explore whether Gail Model risk estimates and family burden of disease, which was comprised of factors obtained from qualitative descriptive data (Chapter VI), are associated with current lifestyle behaviors (e.g., physical activity, fruit and vegetable consumption, dietary fat intake, alcohol use, and smoking) among women with a family history of breast cancer. We also examined whether these associations differed after stratifying women on race (Black and White). For example, Black women with high family burden of disease were compared to Black women with low family burden of disease.

Methods

Participants

Data were obtained from the baseline questionnaire of the NIEHS Sister Study (www.SisterStudy.org), a prospective study of environmental and genetic risk factors for breast cancer in approximately 50,000 women who have had a sister with breast cancer. Participants are volunteers recruited through professional and volunteer organizations, breast cancer advocacy groups, health professionals, media, the Internet, recruitment volunteers, and word of mouth. Eligibility criteria include residence in the U.S. or Puerto Rico, age 35 to 74 years, speaking English or Spanish, no personal history of breast cancer, and having a full or half-sister who has had breast cancer. The Sister Study began in four U.S. cities in August 2003 and then opened nationally in October 2004. Approximately 100,500 women have been screened for eligibility to date and 75% were eligible. Of 58,200 eligible women who agreed to enroll, about 45,000 completed all baseline enrollment activities as of October 19, 2008.

Women who agree to participate are mailed written consent documents, three self-administered questionnaires (family history, diet, use of personal care products), and support materials for telephone interviews and home visits. A home visit is conducted for blood collection, measurement of height, weight, waist circumference and blood pressure, and retrieval of questionnaires. Computer-assisted telephone interviews collect data over two sessions on known and suspected breast cancer risk factors, as well as other information on potential environmental exposures. Participants provided written consent and all procedures were approved through the Institutional Review Boards of the National Institutes of Health and Copernicus Group.

Data were available for the first 21,618 women that completed all baseline enrollment activities by August 24, 2006. Women were excluded for the following reasons: a) being adopted, because a complete family history was unlikely to be known; b) a prior history of cancer, with the exception of non-melanoma skin cancer and c) being from racial/ethnic groups classified as "other". Thus, we analyzed data from 19,418 women (18,739 Whites and 679 Blacks).

Measures

Demographic variables included age, race (White or Black), education and income levels, employment status and marital status. Body mass index (BMI) (kilograms/meters squared) was calculated from height and weight measurements obtained from the enrollment visit by trained in-home interviewers. BMI (kg/m^2) was categorized as follows: <18.5 (underweight), 18.5-24.9 (normal), 25.0-29.9 (overweight), and ≥ 30.0 (obese) (Centers for Disease Control, 2008).

Gail Model: The Sister Study baseline questionnaire included items needed to estimate lifetime breast cancer risk using the original model developed by Gail (Gail, Brinton, Byar, Corle, Green, Schairer, et al., 1989). Gail Model relative risk estimates were calculated from the following data: age < or ≥ 50, age at menarche, number of first-degree relatives with breast cancer, age at first live birth, and number of previous breast biopsies. Gail Model risk estimates were not normally distributed. Therefore, the raw scores were transformed to their natural logarithm. A dichotomous summary variable was defined as Gail risk estimates equal to and above the median versus Gail risk estimates below the median. Data on 19,376 women were used for calculating Gail risks due to missing values on the following variables: age at menarche, age at first live birth, and number of previous breast biopsies. Missing values were 0.1% for each variable.

Family Burden Measure: A variable was created to measure the level of burden from breast cancer in the family. A qualitative descriptive study (Spector, Mishel, Sugg-Skinner, DeRoo, VanRiper, & Sandler, in press) was the basis for selecting the variables to comprise the Family Burden Score. Family Burden Score was based on four variables; having more than one affected sister, having any sister diagnosed < 50 years of age, having an affected mother, and having any sister diagnosed within the past 4 years. Each of the four variables was coded as yes (1) versus no (0) and a composite score was generated for each participant by adding the four values (scores ranged from 0-4). A low Family Burden Score ranged from 0-1 and a high Family Burden Score ranged from 2-4.

Perceived Stress: Perceived level of stress during the past 30 days was measured based on Cohen's (1983) Perceived Stress Scale – 4 item (PSS-4) Score (0-16). The greater the PSS-4 score, the greater an individual's level of perceived stress. Perceived stress was examined

because of a possible relationship to the variable, Family Burden Score (FBS), and to aid in characterizing the sample. The assumption was that women with high FBSs may be more likely to have higher perceived stress than women with low FBSs.

Lifestyle Measures: From the Sister Study survey, six lifestyle behavioral outcome variables were assessed, physical activity, total daily caloric intake, percent of total kcals from fat/day, fruit and vegetable intake, alcohol use and smoking status. Physical activity was assessed based on self-reported sports and exercise activities (e.g., walking for exercise, yoga, dance classes, etc.). Questions included, "In the past 12 months, have you done any sports or exercise activities at least once a week for at least one month?", "How many months out of the past 12 have you done this?", "How many days per week or per month did you do this?" and "On days that you did this activity, about how much time did you spend on average each day you did this?". From these responses frequency (total hours/week) of physical activity was calculated and then categorized based on quartiles (Matthews, 2002).

Current dietary practices were assessed using a food frequency questionnaire (FFQ) based on usual consumption over the past 12 months (modified Block 1998. Block Dietary Data Systems, Berkeley, CA.). Total daily caloric intake was calculated and categorized based on quartiles. Dietary fat intake was based on percentage of energy from total fat intake and was categorized based on quartiles. Assessment of fruits and vegetables was based on servings per day over the past 12 months and categorized from less than once per day, 1-2 per day, 3-4 per day and $\geq$ 5 per day.

Alcohol consumption was assessed based on several items including: "Have you had an alcoholic beverage in the past 12 months?", "During the past 12 months, about how many days per week, per month, or in total have you had alcoholic beverages?", and "During the

past 12 months, about how many drinks would you have on the days that you drank?. Additional questions assessed alcohol consumption in decades over a woman's lifetime. For this analysis alcohol consumption was categorized as never drinker, former drinker, current drinker < 1 drink/day, 1 drink/day, 1.1-1.9 drinks/day, and ≥ 2 drinks/day. Smoking status was categorized as never, past or current.

Analysis

The Statistical Package for Social Sciences (SPSS) Version 16 was used for all analyses. To address aim 1 we stratified women by Gail Scores (equal to and above the median versus below the median) and for aim 2 we stratified by Family Burden Scores (high versus low). Initial analyses involved two-way contingency table analyses with frequencies and percentages and chi-square statistics to characterize the study sample based on Gail Scores and Family Burden scores. An independent-samples *t* test was conducted to evaluate whether the mean value of perceived stress differed between women with high versus low Family Burden Scores. Multivariable logistic regression analyses were performed to generate odds ratios (OR) with 95% confidence intervals adjusted for race, age and education, which have all been found to be associated with lifestyle behaviors (American Cancer Society, 2007; Liang, Shediac-Rizkallah, Celentano, & Rohde, 1999; Pronk, Anderson, Crain, Martinson, O'Connor, Sherwood et al., 2004). To explore whether information was lost by characterizing women on Gail risk estimates based on below or equal to and above the median, we reanalyzed results for Gail risk estimates comparing women at the highest risk (e.g., at or above the 75^{th} percentile) to women with lower risk estimates. No significant differences were found among women with the highest breast cancer risk and therefore data are not shown.

Finally we repeated analyses stratified on race so that comparisons could be made between Black women at ≥ the median Gail risk vs. Black women below the median Gail risk and between Black women with high Family Burden Scores vs. Black women with low Family Burden Scores. Comparable analyses were also performed for White women. Analyses were conducted using quartiles based on the entire sample.

Results

Gail risk estimates ranged from 2.61 to 23.65, with a median of 3.32 (Table 4.1). A significantly higher percentage of women with a Gail risk estimate ≥ the median were 50 years of age or older compared to women with a Gail risk estimate < the median (73% vs. 65%). The majority of women from both groups had at least a college degree. Women in ≥ the median Gail risk group were more likely to be overweight or obese compared to women in the < the median Gail risk group (57% vs. 55%). Most women did not perceive high stress based on the perceived stress scale-4 with a mean of 2.66 for women in ≥ the median Gail Score group and a mean of 2.62 for women in the < the median Gail Score group. As expected, women with higher Gail risk estimates had higher family burden scores (scores 2-4) than women with lower Gail risk estimates (51% vs. 23%).

The majority of women had low Family Burden Scores (0-1) compared to those with a high FBS (2-4) (Table 4.1). A lower percentage of women with a high Family Burden Score (FBS) were 50 years of age or older compared to women with a low FBS (55% vs. 79%). Approximately 60% of women in both groups had a college degree or above. Women with a high FBS were less likely to be overweight or obese than women with a low FBS (54% vs. 57%). Although women in the high FBS group had higher perceived stress scores compared

to those in the low FBS group (mean=2.80 versus mean=2.54, $P<0.001$) these scores revealed low perceived stress.

The odds of exercising at the highest level of physical activity (e.g., 4th quartile) rather than the lowest level (e.g., 1st quartile) was 12% greater for women with Gail risk ≥ the median compared to women with < the median Gail risk in the unadjusted model (Table 4.2). After adjustments for race, age and education the association remained, but was attenuated and no longer significant (OR, 1.07; 95% CI, 0.98-1.16). Women in the higher Gail risk group were more likely to be past smokers than women in the lower Gail risk group (OR, 1.05; 95% CI, 0.99-1.16). There were no differences between the groups with regard to dietary measures or with alcohol use.

Table 4.3 shows the comparisons between groups based on FBS and lifestyle behaviors. In the unadjusted model women with a high FBS were 12% less likely than women with a low FBS to exercise at the highest level. After adjustments were made for race, age and education this inverse relationship no longer remained (OR, 1.02; CI, 0.93-1.11). There is also a suggestive pattern that women in the high FBS group consumed less fruits and vegetables a day compared to women in the low FBS group. Women with high FBS were slightly more likely to be current smokers than women with low FBS (OR, 1.02; CI, 0.91-1.14).

Lifestyle behavioral comparisons by Gail risk groups and stratified by race are shown in Table 4.4. Although there were no differences between the groups on dietary measures, alcohol use or smoking after adjusting for age and education, the association between physical activity and Gail risk was stronger among Blacks than Whites. Black women with ≥ median Gail risk compared to Black women with < median Gail risk were 60% more likely

to engage in the highest level of physical activity versus the lowest level of physical activity after adjusting for age and education (OR, 1.60; CI, 1.00-2.47), whereas among White women the corresponding OR was only 1.10 (CI, 0.97-1.14).

As shown in Table 4.5, there were no significant associations with Family Burden Score in either group, after adjustments were made for age and education although there was a trend for White women with a high FBS compared to a low FBS to engage in less physical activity, consume less fruits and vegetables, and be a current smoker. Black women with a high FBS were more likely to have a greater daily caloric intake (OR, 1.07; CI, 0.70-1.64) and be current smokers (OR, 1.30; CI, 0.78-2.17) than those with lower FBS.

Discussion

Neither Gail risk estimates nor Family Burden Scores were consistently related to healthy lifestyle behaviors. In spite of the fact that all Sister Study participants are likely to be aware that they are at increased risk for breast cancer due to a diagnosis in at least one biological sister, higher Gail Model risk estimates (i.e., objective risk) did not predict healthy lifestyles. The one exception was the significant finding from Black women with higher Gail scores who were more likely to engage in higher levels of physical activity compared to Black women with lower Gail scores. This may be an important finding that warrants further investigation. The general finding that women with the highest objective risk for breast cancer do not report healthier lifestyle behaviors corresponds with results from a familial breast cancer study in which no differences in lifestyle preventive behaviors were found (Madlensky et al., 2005). In a qualitative study with a small number of Sister Study participants we found that the components of the Family Burden Score (i.e., more than one affected sister, mom affected, a sister < 50 years of age when diagnosed, and a sister's

diagnosis in less than 5 years) were related to higher perceived risk (Spector, Mishel, Skinner, DeRoo, Van Riper, & Sandler, in press). However, higher Family Burden Scores were not predictive of healthier behaviors in the current study. It is likely that a family history, familial breast cancer experiences, or factors included in the Gail Model are not enough to motivate women towards healthier behaviors. Unless women have received risk counseling, they may not be familiar with Gail Model risk estimates or what they imply for them personally. Furthermore, women may not be aware that the factors that comprise the risk estimates are associated with enhanced risk. Although the Gail model is useful in quantifying risk it does not incorporate environmental and behavioral risk factors into the estimated risk figures even though such factors as obesity, physical inactivity and regular consumption of ≥ one alcohol drink per day have all been found to increase breast cancer risk. The relative risk calculations based on these various factors should also be considered in a comprehensive clinical approach to breast cancer risk assessment. Also, heightened perceived risk does not necessarily relate to engagement in healthy lifestyle behaviors. Other factors are more likely to play a role in influencing women's health behaviors. Inadequate knowledge about known risk factors, lack of personal control, lack of motivation and additional roadblocks towards healthy behaviors are worth investigating further in women at elevated breast cancer risk.

A few studies examined relationships between lifestyle preventive behaviors and history of breast cancer in a first-degree relative (FDR). In a report by Audrain et al. (2001) 45% of women with an affected FDR engaged in at least 30 minutes of leisure physical activity a week, which was higher than the physical activity level in the general population at that time. A study examining health behavior change among women with a FDR recently diagnosed

with breast cancer found that 25% increased physical activity, 20% decreased fat intake, and 6% reduced alcohol intake (Lemon et al., 2004). Overall, about 40% made some lifestyle behavioral change. Although these two studies suggest that some women make healthy lifestyle changes after a relative's diagnosis, the majority of women did not alter their behaviors. Both studies focused on women considered at moderate risk for breast cancer and did not make any differentiation between moderate and high risk.

There appeared to be a trend of more unhealthy behaviors (e.g., less physical activity, higher daily caloric intake, lower consumption of fruits and vegetables, and tobacco use) among women with high Family Burden Scores (FBS) versus those with low Family Burden Scores (FBS). Women with high Family Burden Scores were more likely to be under 50 years of age, actively employed, and have higher perceived stress scores (PSS-4) than those with low family burden. However, the PSS scores were relatively low for both groups. This finding of less healthy behaviors was more apparent in White women with high FBS compared to those with low FBS. One possible explanation is that White women with high family burden of disease feel that they have less control over their own chances of developing breast cancer. If multiple family members have been affected, especially first-degree relatives, and if they were young when diagnosed, women may have a sense that they will inevitably develop breast cancer because of strong family history/genetics. This may lead them to believe that there is little they can do to reduce their breast cancer risk and that lifestyle behaviors will not have an impact on their risk. In fact, findings from a qualitative investigation of women from the Sister Study found that many who had a higher burden of disease in their families reported that they had "little" personal control related to their own breast cancer risk (Spector et al., in press). Higher family burden of disease may adversely

affect lifestyle behaviors in White women by creating more barriers (i.e., time demands, inconvenience, and lack of energy or motivation) towards the engagement in healthy lifestyle behaviors.

Another intriguing possibility worth investigating further is that women with high family burden of disease may be from families that generally have less healthy lifestyle behaviors, which may further increase their breast cancer risk. In this case the family environment, in addition to family genetics, might also be a contributory factor in the higher degree of disease in the family. A consideration for future studies would be to include an investigation of family members' lifestyle behaviors in addition to the individual's behaviors.

There has been little research addressing psychological factors in relationship to breast cancer risk-reduction lifestyle behaviors. However, in one study of women with an FDR diagnosed with breast cancer, researchers found a positive relationship between higher levels of breast cancer perceived risk and increased levels of leisure activity (Audrain et al., 2001). Additionally, women with a positive affect, compared to those with a negative affect, were more likely to engage in at least 2.5 hours of leisure activity a week, but no relationship existed between cancer-specific distress and physical activity. Another study did not find any relationship between perceived risk, general anxiety, depression, or breast cancer worry and lifestyle behaviors (e.g., low-fat diet, fruit and vegetable intake, and physical activity) among a population based sample of women aged 18-74 years (Bowen et al., 2004). To extrapolate from our findings, it is possible that increased stress from the familial cancer experience may adversely affect healthy lifestyle behaviors due to barriers from family care-giver demands. Additional research examining psychological factors (i.e., specific breast cancer worry and distress, optimism, perceived control, and perceived barriers) that might

mediate the relationship between perceived risk and lifestyle behaviors in women with a breast cancer family history is warranted.

Limitations and Strengths

Early participants in the Sister Study may not be representative of other women with a family history of breast cancer as this group was the most responsive to reports in the media inviting participants. Although we included Black women, the percentage was small compared to the national average (4% vs. 13%). Most of the women in this analysis had a college degree or higher and had annual household incomes above $50,000. Perceived risk was not measured directly, but we were able to examine family burden of disease, which is comprised of determinants known to be related to perceived risk. The study was cross-sectional and therefore the temporal relationship between the timing of an FDR's diagnosis and lifestyle behaviors could not be examined. Although lifestyle variables were measured comprehensively, data were based on self-report and therefore subject to error. There is the potential for bias from self-reporting lifestyle behaviors, which is known to be an issue with survey data for dietary and physical activity variables (Ferrari, Friedenreich, & Matthews, 2007; Herbert, Ebbeling, Matthews, Hurley, Druker, Ma et al., 2002). Herbert et al. (2002) found that college-educated women with higher social desirability scores were more likely to underestimate their dietary energy intake obtained through a food frequency questionnaire than women with less education and lower social desirability scores. Accuracy of physical activity questionnaires has been found to be higher in men than women, in younger versus older individuals, and for those with lower body mass index (Ferrari et al., 2007). Measurement error may also result from physical activity questionnaires that require long-term memory retrieval (Matthews, 2002).

Although the use of the Gail model for estimating risk has widespread clinical utility, limitations need to be considered. Recently, the Gail Model was found to underestimate risk for Black women (Gail et al., 2007). Another notable weakness of the model is that it only includes first-degree relatives (i.e., mother and sisters) and neglects to consider second-degree relatives with a breast cancer history and age of relative at time of diagnosis, which leads to a tendency towards an under-prediction of risk in women with a family history. An additional limitation is that no consideration is given to behavior related breast cancer risk factors (i.e., elevated BMI, physical inactivity, and alcohol intake). Relative risk calculations based on these various factors should be considered in a comprehensive clinical approach to breast cancer risk assessment.

All women had at least one sister with breast cancer and many may perceive themselves to be at increased risk. It is possible that these women as a whole may differ with regard to lifestyle behaviors from women without a sister with breast cancer or those who did not volunteer. Thus by comparing women with some risk to women with a greater level of risk, we may have missed associations between lifestyle behaviors and level of breast cancer risk. However, the high prevalence of obesity and relatively low levels of exercise in this cohort suggest that these women are not leading healthier lifestyles than other women.

Strengths of the study include the large sample size for comparing women at varying levels of risk for breast cancer and the inclusion of Black women to explore whether differences exist based on race. Further research is required to examine lifestyle behaviors among women from other racial/ethnic backgrounds who have at least a FDR with a breast cancer history.

Conclusion

In summary, our findings reveal that lifestyle behaviors do not significantly differ among women at varying levels of breast cancer risk although there is a suggestion that White women who have higher family burden of disease may have less healthy behaviors compared to White women with low family burden of disease. The clinical implications are that there may be a need for targeted and/or tailored educational interventions to improve lifestyle behaviors among women who are at elevated risk for breast cancer due to family history of the disease. A sub-population to consider for targeted interventions is women with a high level of family burden of disease.

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Table 4.1

Participant Characteristics by Gail Model Risk Estimates and Family Burden Score

Variables	Gail Score Equal to and Above the Median (*n*=10,495) *n* (%)	Gail Score Below the Median (*n*=8,881) *n* (%)	High Family Burden Score (n=7,467) *n* (%)	Low Family Burden Score (n=11,951) *n* (%)
Demographic Factors				
Age				
35-39	360 (3.4)	493 (5.6)	582 (7.8)	274 (2.3)
40-49	2429 (23.1)	2573 (29.0)	2762 (37.0)	2250 (18.8)
50-64	5939 (56.6)	4518 (50.9)	3530 (47.3)	6950 (58.2)
65-75	1767 (16.8)	1297 (14.6)	593 (7.9)	2477 (20.7)
Race				
Black	357 (3.4)	317 (3.6)	256 (3.4)	423 (3.5)
White	10 138 (96.6)	8564 (96.4)	7211 (96.6)	11528 (96.5)
Education				
<College	1424 (13.6)	1227 (13.8)	1009 (13.5)	1649 (13.8)
College degree	6232 (59.4)	5415 (61.0)	4538 (60.8)	7131 (59.7)
> BS degree	2837 (27.0)	2239 (25.2)	1919 (25.7)	3170 (26.5)
Annual Household Income				
<$20,000	356 (3.6)	279 (3.3)	204 (2.8)	432 (3.8)
$20,000-$49,999	2020 (20.2)	1719 (20.1)	1306 (18.1)	2444 (21.5)
$50,000-$99,999	4176 (41.7)	3587 (41.9)	3043 (42.1)	4733 (41.6)
$100,000-$200,000	2679 (26.7)	2336 (27.3)	2054 (28.4)	2969 (26.1)
>$200,000	788 (7.9)	637 (7.4)	616 (8.5)	812 (7.1)
Marital Status				
Never married	529 (5.0)	416 (4.7)	377 (5.0)	569 (4.8)
Legally married/living as married	8049 (76.7)	6941 (76.2)	5921 (79.3)	9102 (76.2)
Widowed	521 (5.0)	369 (4.2)	223 (3.0)	668 (5.6)
Employment				
Current full-/part-time work	6802 (64.8)	6130 (69.1)	5436 (72.8)	7521 (63.0)

Housewife	1280 (12.2)	1027 (11.6)	962 (12.9)	1351 (11.3)
Retired	2132 (20.3)	1469 (16.6)	861 (11.5)	2749 (23.0)
Unemployed, student, other	277 (2.6)	249 (2.9)	208 (2.8)	320 (2.8)
Body mass index (kg/m^2)				
<18.5 (underweight)	107 (1.0)	94 (1.1)	76 (1.0)	125 (1.0)
18.5-24.9 (normal)	4436 (42.4)	3871 (43.7)	3331 (44.7)	5000 (42.0)
25.0-29.9 (overweight)	3318 (31.7)	2722 (30.7)	2269 (30.4)	3785 (31.8)
≥30.0 (obese)	2605 (24.9)	2171 (24.5)	1776 (23.8)	3004 (25.2)
Breast Cancer Risk Factors				
More than one affected sister	2050 (19.5)	0-	1859 (24.9)	194 (1.6)
Mother affected	3679 (35.7)	0-	3075 (41.9)	612 (5.3)
Any sister's diagnosed <50 yrs. of age	6253 (59.7)	5189 (58.5)	6342 (84.9)	5127 (43.0)
Personal history of benign breast condition	8763 (83.8)	5047 (57.3)	5330 (71.7)	8503 (71.6)
Ever use of HRT	5100 (48.8)	5360 (51.2)	2647 (35.5)	6486 (54.5)
Additional Factors				
Prophylactic mastectomy	92 (0.9)	7 (0.1)	75 (1.0)	24 (0.2)
Ever use of Tamoxifen	419 (4.0)	49 (0.6)	273 (3.7)	196 (1.7)
Any sister diagnosed within 4 years	4523 (43.3)	4523 (43.3)	5406 (72.5)	3228 (27.2)
Family Burden Score			--	--
0	1127 (10.7)	1661 (18.7)	--	--
1	3976 (37.9)	5158 (58.1)	--	--
2	3825 (36.4)	2062 (23.2)	--	--
3	1389 (13.2)	0 -	--	--
4	178 (1.7)	0 –	--	--
Perceived Stress Scale (0-16) (means)	2.66	2.62	2.80	2.54

Note. Negligible missing data; variables with numbers unequal to *n* due to missing data (ranged from < 0.1 to 4.1%). Missing data for income was 4.1% (n=805).

Table 4.2

Associations of Gail Model Risk Estimates with Lifestyle Behaviors

Variables	Gail Risk Equal to and Above the Median (*n*=10,495)		Gail Risk Below the Median (*n*=8,881)		Crude OR	Adjusted OR (race, age, & education)
	n	%	*n*	%		OR (95% CI)
Physical activity (total hrs/wk)						
1st quartile (0-0.69 hrs)[a]	2567	(24.5)	2279	(25.7)	1.00	1.00 (reference)
2nd quartile (0.70-2.24 hrs)	2597	(24.8)	2227	(25.1)	1.04	1.03 (0.95-1.12)
3rd quartile (2.25-4.25 hrs)	2609	(24.9)	2226	(25.1)	1.04	1.01 (0.93-1.10)
4th quartile (4.26-34.87 hrs)	2716	(25.9)	2145	(24.2)	1.12*	1.07 (0.98-1.16)
Total daily caloric intake (kcals/day)						
1st quartile (0-1157.1) [a]	2589	(25.0)	2177	(25.0)	1.00	1.00 (reference)
2nd quartile (1157.2-1485)	2590	(25.0)	2173	(25.0)	1.00	1.01 (0.93-1.10)
3rd quartile (1485.1-1872.5)	2587	(25.0)	2175	(25.0)	1.00	1.01 (0.93-1.09)
4th quartile (1872.6-9289)	2584	(25.0)	2174	(25.0)	1.00	1.02 (0.94-1.11)
Percent of total kcal from fat/day						
1st quartile (4.35-33.31) [a]	2604	(25.2)	2155	(24.8)	1.00	1.00 (reference)
2nd quartile (33.32-38.28)	2593	(25.1)	2178	(25.0)	0.99	1.01 (0.93-1.09)
3rd quartile (38.29-43.42)	2545	(24.6)	2214	(25.5)	0.95	0.98 (0.90-1.06)
4th quartile (43.43-101.81)	2605	(25.2)	2150	(24.7)	1.00	1.02 (0.94-1.11)
Fruit & vegetable intake (servings/day)						
<1 [a]	151	(1.5)	124	(1.4)	1.00	1.00 (reference)
1-2	2562	(24.8)	2359	(27.1)	0.89	0.88 (0.69-1.12)
3-4	3216	(31.1)	2751	(31.6)	0.96	0.91 (0.71-1.16)
≥5	4421	(42.7)	3465	(39.8)	1.05	0.96 (0.75-1.23)
Alcohol use						
Never drinker [a]	324	(3.1)	269	(3.0)	1.00	1.00 (reference)
Former drinker	1424	(13.6)	1220	(13.8)	0.97	0.98 (0.82-1.17)

Current drinker <1 drink/day	7218	(68.9)	6099	(68.8)	0.98	0.99 (0.84-1.17)
1 drink/day	275	(2.6)	215	(2.4)	1.06	1.06 (0.84-1.35)
1.1-1.9 drinks/day	675	(6.4)	571	(6.4)	0.98	1.00 (0.82-1.21)
≥ 2 drinks/day	565	(5.4)	493	(5.6)	0.95	0.96 (0.78-1.17)
Smoking status						
Never [a]	5724	(54.5)	4977	(56.0)	1.00	1.00 (reference)
Past	3972	(37.9)	3170	(35.7)	1.09*	1.05 (0.99-1.16)
Current	798	(7.6)	734	(8.3)	1.16*	0.99 (0.89-1.11)

Note. [a] indicates referent group. OR = odds ratio; CI = confidence interval.

Table 4.3

Association of Family Burden Score with Lifestyle Behaviors

Variables	High Family Burden Score (*n*=7467)		Low Family Burden Score (*n*=11 951)		Crude OR	Adjusted OR (race, age, & education)
	n	%	*n*	%		OR (95%CI)
Physical activity (total hrs/wk)						
1st quartile (0-0.69)[a]	1934	(25.9)	2921	(24.5)	1.00	1.00 (reference)
2nd quartile (0.70-2.24)	1911	(25.6)	2926	(24.5)	0.99	1.00 (0.92-1.09)
3rd quartile (2.25-4.25)	1826	(24.5)	3021	(25.3)	0.91*	0.99 (0.91-1.08)
4th quartile (4.26-34.87)	1791	(24.0)	3078	(25.8)	0.88*	1.02 (0.93-1.11)
Total daily caloric intake (kcal/day)						
1st quartile (0-1157.1) [a]	1797	(24.5)	2976	(25.3)	1.00	1.00 (reference)
2nd quartile (1157.2-1485)	1829	(24.9)	2945	(25.1)	1.03	0.99 (0.91-1.08)
3rd quartile (1485.1-1872.5)	1812	(24.7)	2960	(25.2)	1.01	0.97 (0.89-1.06)
4th quartile (1872.6-9289)	1900	(25.9)	2872	(24.4)	1.10*	0.99 (0.91-1.08)
Percent of kcal from total fat/day						
1st quartile (4.35-33.31) [a]	1779	(24.3)	2994	(25.5)	1.00	1.00 (reference)
2nd quartile (33.32-38.28)	1869	(25.5)	2910	(24.8)	1.08	1.01 (0.93-1.10)
3rd quartile (38.29-43.42)	1855	(25.3)	2915	(24.8)	1.07	0.98 (0.90-1.06)
4th quartile (43.43-101.81)	1832	(25.0)	2932	(25.0)	1.05	0.99 (0.91-1.08)
Fruit & vegetable intake (servings/day)						
<1 [a]	125	(1.7)	150	(1.3)	1.00	1.00 (reference)
1-2	2088	(28.5)	2842	(24.2)	0.88	0.94 (0.73-1.21)
3-4	2267	(30.9)	3717	(31.6)	0.73*	0.87 (0.67-1.12)
≥5	2858	(38.9)	5044	(42.9)	0.68*	0.88 (0.69-1.13)
Alcohol use						
Never drinker [a]	239	(3.2)	356	(3.0)	1.00	1.00 (reference)

Former drinker	988	(13.2)	1665	(14.0)	0.94	0.95 (0.79-1.15)
Current drinker <1 drink/day	5144	(69.0)	8199	(68.7)	0.87	0.87 (0.73-1.04)
1 drink/day	192	(2.6)	298	(2.5)	1.11	1.10 (0.86-1.42)
1.1-1.9 drinks/day	492	(6.6)	754	(6.3)	0.96	0.93 (0.75-1.14)
≥ 2 drinks/day	403	(5.4)	660	(5.5)	0.84	0.84 (0.68-1.04)
Smoking status						
Never [a]	4274	(57.2)	6449	(54.0)	1.00	1.00 (reference)
Past	2523	(33.8)	4635	(38.8)	0.82*	0.94 (0.88-1.01)
Current	669	(9.0)	867	(7.3)	1.16*	1.02 (0.91-1.14)

Note. [a] indicates referent group. OR = odds ratio; CI = confidence interval.

Table 4.4

Association of Gail Model Risk Estimates with Lifestyle Behaviors Stratified by Race

Variables	Whites – Gail Risk ≥ the median (*n*=10,138) *n* (%)	Whites – Gail Risk < the median (*n*=8,564) *n* (%)	Whites Crude OR	Whites Adjusted OR (age, education) OR (95% CI)	Blacks – Gail Risk ≥ the median (*n*=357) *n* (%)	Blacks – Gail Risk < the median (*n*=317) *n* (%)	Blacks Crude OR	Blacks Adjusted OR (age, education) OR (95% CI)
Physical activity (total hrs/wk)								
1st quartile(0-0.69) [a]	2459 (24.3)	2159 (25.2)	1.00	1.00	108 (30.3)	120 (37.9)	1.00	1.00
2nd quartile(0.70-2.24)	2505 (24.7)	2150 (25.1)	1.00	1.00 (0.94-1.10)	92 (25.8)	77 (24.3)	1.30*	1.30 (0.86-1.93)
3rd quartile(2.25-4.25)	2524 (24.9)	2156 (25.2)	1.00	1.00 (0.92-1.09)	85 (23.8)	70 (22.1)	1.30	1.30 (0.84-1.90)
4th quartile(4.26-34.87)	2644 (26.1)	2095 (24.5)	1.10*	1.10 (0.97-1.14)	72 (20.2)	50 (15.8)	1.60*	1.60* (1.00-2.47)
Total daily caloric intake (kcal/day)								
1st quartile(0-1157.1) [a]	2476 (24.8)	2086 (24.8)	1.00	1.00	113 (32.7)	91 (31.0)	1.00	1.00
2nd quartile(1157.2-1485)	2521 (25.2)	2104 (25.0)	1.00	1.00 (0.94-1.10)	69 (19.9)	69 (23.5)	0.81	0.82 (0.53-1.28)
3rd quartile(1485.1-1872.5)	2529 (25.3)	2127 (25.3)	1.00	1.00 (0.93-1.09)	58 (16.8)	48 (16.3)	0.97	1.00 (0.63-1.60)
4th quartile(1872.6-9289)	2478 (24.8)	2088 (24.8)	1.00	1.00 (0.94-1.11)	106 (30.6)	86 (29.3)	0.99	1.00 (0.72-1.60)
Percent of kcal from total fat/day								
1st quartile(4.35-33.31) [a]	2497 (25.0)	2077 (24.7)	1.00	1.00	107 (30.9)	78 (26.5)	1.00	1.00
2nd quartile(33.32-38.28)	2519 (25.2)	2101 (25.0)	1.00	1.00 (0.94-1.11)	74 (21.4)	77 (26.2)	0.70	0.73 (0.47-1.13)
3rd quartile(38.29-43.42)	2467 (24.7)	2135 (25.4)	0.96	0.99 (0.91-1.07)	78 (22.5)	79 (26.9)	0.72	0.74 (0.48-1.15)
4th quartile(43.43-101.81)	2518 (25.2)	2090 (24.9)	1.00	1.00 (0.94-1.11)	87 (25.1)	60 (20.4)	1.10	1.10 (0.71-1.73)

Fruit & vegetable intake (servings/day)								
<1 [a]	148 (1.5)	119 (1.4)	1.00	1.00	3 (0.9)	5 (1.7)	1.00	1.00
1-2	2450 (24.5)	2254 (26.8)	0.88	0.86 (0.67-1.11)	112 (32.4)	105 (35.7)	1.80	1.70 (0.40-7.48)
3-4	3120 (31.2)	2656 (31.6)	0.95	0.89 (0.70-1.14)	96 (27.7)	95 (32.3)	1.70	1.50 (0.35-6.68)
≥5	4286 (42.8)	3376 (40.2)	1.00	0.93 (0.73-1.20)	135 (39.0)	89 (30.3)	2.50	2.30 (0.54-10.18)
Alcohol use								
Never drinker [a]	304 (3.0)	264 (3.1)	1.00	1.00	13 (3.6)	12 (3.8)	1.00	1.00
Former drinker	1425 (14.1)	1135 (13.3)	1.10	1.10 (0.91-1.30)	52 (14.6)	39 (12.3)	1.20	1.20 (0.49-2.92)
Current drinker <1 drink/day	6936 (68.6)	5899 (68.9)	1.00	1.00 (0.86-1.20)	245 (68.6)	227 (71.6)	1.00	0.98 (0.44-2.21)
1 drink/day	258 (2.5)	212 (2.5)	1.10	1.10 (0.83-1.36)	9 (2.5)	11 (3.5)	0.76	0.74 (0.23-2.43)
1.1-1.9 drinks/day	638 (6.3)	570 (6.7)	0.97	0.98 (0.80-1.20)	21 (5.9)	16 (5.0)	1.20	1.20 (0.42-3.25)
≥ 2 drinks/day	557 (5.5)	476 (5.6)	1.00	1.00 (0.82-1.23)	17 (4.8)	12 (3.8)	1.30	1.40 (0.46-4.07)
Smoking status								
Never [a]	5506 (54.3)	4790 (55.9)	1.00	1.00	218 (61.1)	187 (59.0)	1.00	1.00
Past	3871 (38.2)	3078 (35.9)	1.09*	1.06 (0.99-1.12)	101 (28.3)	92 (29.0)	0.94	0.88 (0.61-1.25)
Current	760 (7.5)	696 (8.1)	0.95	1.00 (0.89-1.11)	38 (10.6)	38 (12.0)	0.86	0.92 (0.56-1.51)

Note. [a] indicates referent group. OR = odds ratio; CI = confidence interval.

Table 4.5

Association of Family Burden Score (FBS) with Lifestyle Behaviors Stratified by Race

Variables	Whites High FBS (*n*=7206)	Whites Low FBS (*n*=11523)	Whites Crude OR	Whites Adjusted OR (age, education)	Blacks High FBS (*n*=256)	Blacks Low FBS (*n*=423)	Blacks Crude OR	Blacks Adjusted OR (age, education)
	n (%)	*n* (%)		OR (95% CI)	*n* (%)	*n* (%)		OR (95% CI)
Physical activity (total hrs/wk)								
1st quartile(0-0.69) [a]	1850 (25.7)	2777 (24.1)	1.00	1.00	84 (32.8)	144 (34.0)	1.00	1.00
2nd quartile(0.70-2.24)	1849 (25.7)	2819 (24.5)	0.99	1.00 (0.91-1.09)	62 (24.2)	107 (25.3)	0.99	1.09 (0.71-1.68)
3rd quartile(2.25-4.25)	1763 (24.5)	2927 (25.4)	0.90*	0.98 (0.90-1.07)	63 (24.6)	94 (22.2)	1.15	1.33 (0.86-2.06)
4th quartile(4.26-34.87)	1744 (24.2)	3000 (26.0)	0.87*	1.01 (0.93-1.10)	47 (18.4)	78 (18.4)	1.03	1.11 (0.69-1.78)
Total daily caloric intake (kcal/day)								
1st quartile(0-1157.1) [a]	1724 (24.3)	2844 (25.1)	1.00	1.00	73 (30.0)	132 (32.8)	1.00	1.00
2nd quartile(1157.2-1485)	1773 (25.0)	2861 (25.2)	1.02	0.98 (0.90-1.07)	56 (23.0)	84 (20.9)	1.21	1.19 (0.75-1.88)
3rd quartile(1485.1-1872.5)	1777 (25.0)	2889 (25.5)	1.02	0.98 (0.89-1.06)	35 (14.4)	71 (17.7)	0.89	0.78 (0.47-1.31)
4th quartile(1872.6-9289)	1821 (25.7)	2757 (24.3)	1.09*	0.99 (0.91-1.08)	79 (32.5)	115 (28.6)	1.24	1.07 (0.70-1.64)
Percent of kcal from total fat/day								
1st quartile(4.35-33.31) [a]	1705 (24.0)	2882 (25.4)	1.00	1.00	74 (30.5)	112 (27.9)	1.00	1.00
2nd quartile(33.32-38.28)	1806 (25.5)	2821 (24.9)	1.08	1.01 (0.93-1.10)	63 (25.9)	89 (22.1)	1.07	1.01 (0.64-1.60)
3rd quartile(38.29-43.42)	1803 (25.4)	2809 (24.8)	1.09	0.99 (0.91-1.08)	52 (21.4)	106 (26.4)	0.74	0.67 (0.42-1.06)
4th quartile(43.43-101.81)	1778 (25.1)	2837 (25.0)	1.06	1.00 (0.91-1.09)	54 (22.2)	95 (23.6)	0.86	0.80 (0.50-1.28)
Fruit & vegetable intake (servings/day)								
<1 [a]	120 (1.7)	147 (1.3)	1.00	1.00	5 (2.1)	3 (0.7)	1.00	1.00

1-2	1995 (28.1)	2716 (23.9)	0.90	0.97 (0.75-1.25)	93 (38.3)	126 (31.3)	0.44	0.38 (0.08-1.69)
3-4	2205 (31.1)	3587 (31.6)	0.75*	0.90 (0.69-1.16)	62 (25.5)	130 (32.3)	0.29	0.29 (0.06-1.31)
≥5	2775 (39.1)	4901 (43.2)	0.70*	0.91 (0.70-1.17)	83 (34.2)	143 (35.6)	0.35	0.35 (0.08-1.57)
Alcohol use								
Never drinker [a]	235 (3.3)	335 (2.9)	1.00	1.00	10 (3.9)	15 (3.5)	1.00	1.00
Former drinker	1016 (14.1)	1546 (13.4)	0.94	0.95 (0.78-1.15)	37 (14.5)	54 (12.8)	1.03	1.06 (0.42-2.69)
Current drinker <1 drink/day	4880 (67.8)	7986 (69.4)	0.87	0.87 (0.73-1.04)	173 (67.6)	304 (71.9)	0.85	0.87 (0.37-2.04)
1 drink/day	205 (2.8)	265 (2.3)	1.10	1.10 (0.85-1.42)	9 (3.5)	11 (2.6)	1.23	1.18 (0.34-4.04)
1.1-1.9 drinks/day	485 (6.7)	724 (6.3)	0.96	0.92 (0.74-1.13)	15 (5.9)	22 (5.2)	1.02	1.14 (0.39-3.31)
≥ 2 drinks/day	380 (5.3)	654 (5.7)	0.83	0.84 (0.67-1.04)	12 (4.7)	17 (4.0)	1.06	0.88 (0.29-2.74)
Smoking status								
Never [a]	4118 (57.1)	6196 (53.7)	1.00	1.00	156 (60.9)	253 (59.8)	1.00	1.00
Past	2459 (34.1)	4506 (39.1)	0.82*	0.94 (0.88-1.00)	64 (25.0)	129 (30.5)	0.81	1.05 (0.72-1.54)
Current	633 (8.8)	826 (7.2)	1.15*	1.00 (0.89-1.13)	36 (14.1)	41 (9.7)	1.42	1.30 (0.78-2.17)

Note. [a] indicates referent group. OR = odds ratio; CI = confidence interval.

CHAPTER V

PAPER TWO

Lifestyle Differences Among Black and White Women with a Family History of Breast Cancer in the Sister Study

Introduction

Modifiable lifestyle factors such as overweight/obesity and adulthood weight gain (post-menopausal breast cancer), physical inactivity, and alcohol consumption have been linked with breast cancer risk (Key, Schatzkin, Willett, Allen, Spencer, Travis et al., 2004; Thune & Furberg, 2001; World Cancer Research Fund/American Institute for Cancer Research [WCRF/AICR], 2007). The relationship between diet and breast cancer is less certain, but a diet high in fat typically will lead to increased caloric intake, which is likely to result in overweight and obesity. The extent to which these factors contribute to breast cancer risk in Black women is not clear. Some studies have shown that higher levels of physical activity have a protective effect against breast cancer and that higher body mass index (BMI) and higher waist-to-hip ratio increases risk in both pre- and post-menopausal Black women (Adams-Campbell, Rosenberg, Rao, & Palmer, 2001; Bernstein, Patel, Ursin, Sullivan-Halley, Press, Deapen et al., 2005; Hall, Newman, Millikan, & Moorman, 2000; Millikan, Newman, Tse, Moorman, Conway, Smith et al., 2008). Furthermore, family history of breast cancer may enhance the relationship between breast cancer risk and factors such as obesity and physical inactivity (Carpenter et al., 2003; Sellers et al., 1992; Verloop et al., 2000).

Additional behaviors found to elevate risk in women with family histories of breast cancer are alcohol consumption and cigarette smoking (Couch, Cerhan, Vierkant, Grabrick, Therneau, Pankratz et al., 2001; Vachon, Cerhan, Vierkant, & Sellers, 2001).

Although family history is not modifiable, women with a family history may also have modifiable risk factors. Studies of the impact of family history of breast cancer on modifiable lifestyle behaviors have included predominantly White women. Lemon et al. (2004) reported that among 600 women with a family history of breast cancer 21% of smokers cut down or quit smoking and 6% of women reporting any alcohol consumption reduced their intake as a result of their relative's diagnosis. Overall 42% made at least one healthy lifestyle behavior change, with 25% reporting an increase in physical activity and approximately one-fifth reporting dietary improvements. In a study by Madlensky et al. (2005), which only measured current lifestyle behaviors and not behavior change, the investigators found no appreciable differences in diet, physical activity, and alcohol consumption among women with a family history compared to marry-ins who were considered at average- to low-risk.

As a result of the accumulating evidence linking several modifiable lifestyle-related factors with breast cancer, the American Cancer Society (ACS) has issued guidelines for breast cancer prevention that include the adoption of a physically active lifestyle through engagement in moderate-to-vigorous physical activity for 45-60 minutes or more on five or more days a week, minimizing lifetime weight gain through calorie restriction and physical activity, and avoiding or limiting alcohol to no more than one drink/day (Byers, Nestle, McTiernan, Doyle, Currie-Williams, Gansler et al., 2002; Kushi, Byers, Doyle, Bandera, McCullough, Gansler et al., 2006).

Lifestyle-related behavioral differences between White and Black women have been reported in the general population (Bernstein, Teal, Joselyn, & Wilson, 2003; Bernstein, Patel, Ursin, Sullivan-Halley, Press, Deapen et al., 2005; CDC, 2007; National Center for Health Statistics (NCHS), 2007), but little is known about the differences in women at elevated breast cancer risk. The aim of this study was to determine whether there are lifestyle behavioral differences between Black and White women with a family history of breast cancer and to determine the extent to which Black and White women with a family history of breast cancer adhere to American Cancer Society guidelines on nutrition and physical activity.

Methods

Study participants, and some of the measures, parallel those in quantitative paper #1 (Chapter IV), but the study questions are different.

Participants

Data were obtained from the baseline questionnaire of the NIEHS Sister Study (www.SisterStudy.org), a prospective study of environmental and genetic risk factors for breast cancer in approximately 50,000 women who have had a sister with breast cancer. Participants are volunteers recruited through professional and volunteer organizations, breast cancer advocacy groups, health professionals, media, the Internet, recruitment volunteers, and word of mouth. Eligibility criteria include residence in the U.S. or Puerto Rico, age 35 to 74 years, speaking English or Spanish, no personal history of breast cancer, and having a full or half-sister who has had breast cancer. The Sister Study began in four U.S. cities in August 2003 and then opened nationally in October 2004. Of 59,600 eligible women, 45,700 completed all baseline enrollment activities as of December 1, 2008.

Women who agree to participate are mailed written consent documents, three self-administered questionnaires (family history, diet, use of personal care products), and support materials for telephone interviews and home visits. A home visit is conducted for blood collection, measurement of height, weight, waist circumference and blood pressure, and retrieval of questionnaires. Computer-assisted telephone interviews collect data over two sessions on known and suspected breast cancer risk factors, including lifestyle factors. Participants provided written consent and all procedures were approved through the Institutional Review Boards of the National Institutes of Health and Copernicus Group.

Data for this analysis were from the first 21,618 women that completed all baseline enrollment activities by August 24, 2006. Women were excluded for the following reasons: a) being adopted (because a complete family history was unlikely to be known); b) a prior history of cancer, with the exception of non-melanoma skin cancer and c) being from racial/ethnic groups classified as "other", because there were two few for separate analyses. Thus, we analyzed data from 19,418 women (18,739 Whites and 679 Blacks).

Measures

Demographic variables included age, race (White or Black), education and income levels, employment status and marital status. Body mass index (BMI) (kilograms/meters squared) was calculated from height and weight measurements obtained from the enrollment visit by trained in-home interviewers. BMI (kg/m^2) was categorized as: <18.5 (underweight), 18.5-24.9 (normal), 25.0-29.9 (overweight), and ≥ 30.0 (obese) (Centers for Disease Control, 2008).

Six lifestyle behaviors were assessed: physical activity, total daily caloric intake, percent of total kcals/day from fat, fruit and vegetable intake, alcohol use, and smoking. Current

physical activity was assessed based on self-reported sports and exercise activities (e.g., walking for exercise, yoga, dance classes, etc.). Questions included, "In the past 12 months, have you done any sports or exercise activities at least once a week for at least one month?", "How many months out of the past 12 have you done this?", "How many days per week or per month did you do this?" and "On days that you did this activity, about how much time did you spend on average each day you did this?". From these responses frequency (total hours/week) of physical activity was calculated and then categorized based on quartiles (Matthews, 2002).

Current diet was assessed using a food frequency questionnaire (FFQ) (modified Block 1998. Block Dietary Data Systems, Berkeley, CA.) based on usual consumption over the past 12 months. Total daily caloric intake and percent of calories from fat were categorized in quartiles based on distributions in the entire sample. Fruits and vegetables consumption over the past 12 months was categorized as less than once per day, 1-2, 3-4, and ≥ 5 servings per day.

Alcohol consumption was based on responses to several questions including: "Have you had an alcoholic beverage in the past 12 months?", "During the past 12 months, about how many days per week, per month, or in total have you had alcoholic beverages?", and "During the past 12 months, about how many drinks would you have on the days that you drank?. Additional questions assessed alcohol consumption in decades over a woman's lifetime. For this analysis alcohol consumption was categorized as never drinker, former drinker, current drinker < 1 drink/day, 1 drink/day, 1.1-1.9 drinks/day, and ≥ 2 drinks/day. Smoking status was categorized as never, past or current.

Analysis

The Statistical Package for Social Sciences (SPSS) Version 16 was used for all analyses. For all analyses we compared women by race (e.g., Black and White women). Initial analyses involved two-way contingency tables with frequencies and percentages and chi-square statistics to characterize the study sample. Multivariable logistic regression analyses were performed for each of the six behavioral outcome variables to generate odds ratios (OR) with 95% confidence intervals adjusted for age and education, which have been found to be related to lifestyle behaviors (American Cancer Society, 2007; Liang, Shediac-Rizkallah, Celentano, & Rohde, 1999; Pronk, Anderson, Crain, Martinson, O'Connor, Sherwood et al., 2004). Further analyses were conducted to control for additional demographic characteristics (e.g., income, employment and marital status) found to be associated with race and behaviors in this sample.

Results

Slightly more Black women were under 50 years of age compared to White women (33.7% vs. 30.1%) (Table 5.1). Most women had at least a college degree without any significant differences based on race. Black women were more likely then White women to have a household income < $50,000, never have been married or be divorced, and be employed full- or part-time. Overweight and obesity (e.g., BMI ≥ 25) were more prevalent in Black women than White women (81.5% vs. 55.1%). Black women were also more likely to be current smokers than White women (11.3% vs. 7.8%).

Black women were 42% less likely than White women to engage in the highest level of physical activity compared to the lowest level (OR, 0.58; 95% CI, 0.46-0.73) after adjustment for all demographic variables (Table 5.2). There was a non-significant trend for

Black women to be less likely than White women to consume higher percentages of kcal from total fat/day. Black women were 31% more likely to be past smokers than White women (OR, 0.69; 95% CI, 0.58-0.83). There were no significant differences for fruit & vegetable consumption or alcohol use between Black and White women.

Black women were less likely than White women to meet the ACS recommendation for BMI < 25 (18.4% vs. 45%) and were less likely to engage in at least four hours of physical activity a week (19.3% vs. 26.7%) (Table 5.3). Most women were drinking less than or equal to one alcoholic drink/day with a slightly higher percentage of Black women meeting the ACS recommendation than White women (90.3 vs. 88.0%).

Discussion

Women in our study appeared no more likely to have a normal range BMI or engage in healthy lifestyle behaviors than women in the general population despite their greater risk for breast cancer due to family history. In a national sample, the majority of both White and Black women were overweight or obese, although Black women had a substantially higher prevalence of obesity than White women (45% versus 24%) (CDC, 2007; National Center for Health Statistics (NCHS), 2007).

Increasing BMI has long been associated with increased risk for post-menopausal breast cancer, although inverse relationships between BMI and breast cancer have been observed in pre-menopausal women (World Cancer Research Fund/American Institute for CancerResearch, 2007). Studies investigating BMI and breast cancer have largely included White women. The relationship between obesity and post-menopausal breast cancer likely involves serum sex hormone levels in that body fat increases serum estrogen, although the exact mechanisms are not known (Ballard-Barbash, 2006; Institute of Medicine, 2001).

Researchers have also theorized about other physiologic mechanisms involved with the development of breast cancer in overweight and obese women, such as increased serum hormone concentrations of leptin, insulin, and insulin-like growth factors (Eyre, Kahn, Robertson, & ACS/ADA/AHA Collaborative Writing Committee 2004; Gerber et al., 2003).

Overweight/obesity is higher among Black women of all ages, both pre- and post-menopausal, yet breast cancer incidence is lower in post-menopausal Black women compared to post-menopausal White women. Although in general, overweight/obesity is related to post-menopausal breast cancer it is unclear whether it is related to breast cancer risk in Black women. The few studies that have been conducted among Black women have yielded conflicting results. Schatzkin et al. (1987) found that a high BMI increased risk in pre-menopausal Black women. In contrast were findings from Palmer et al. (2007) who found an inverse relationship between high current BMI and pre-menopausal breast cancer, but found no association for post-menopausal breast cancer. Hall et al. (2000) found no association between an elevated BMI and pre- or post-menopausal breast cancer in Black women, but found that a high waist-to-hip ratio increased breast cancer risk in both pre-menopausal Black and White women. The positive relationship between high waist-to-hip ratio and breast cancer suggests that central fat distribution may have more influence on breast cancer risk than BMI in some populations (McTiernan, Gralow, & Talbott, 2000). A more recent study investigated the relationships between race, risk factors, and sub-types of breast cancer and found that basal-like tumors are more prevalent in pre-menopausal Black women who had higher body mass indices and elevated waist-to-hip ratios (Millikan et al., 2008). The authors suggested that approximately two-thirds of aggressive basal-like breast

cancers could be prevented by decreasing abdominal obesity and increasing breast-feeding among younger Black women.

With regard to physical activity, Black women were less likely to engage in regular physical activity compared to White women in our study. Other reports had similar findings (Bernstein, Teal, Joselyn, & Wilson, 2003; Bernstein, Patel, Ursin, Sullivan-Halley, Press, Deapen et al., 2005; Centers for Disease Control and Prevention, 2007). Many studies have examined the relationship between physical activity and breast cancer risk and the majority showed decreased risk with increasing physical activity (Patel & Bernstein, 2006; Thomson, Chen, & Lutz, 2005; World Cancer Research Fund (WCRF), 2007). Although it is well known that physical inactivity is related to higher breast cancer risk in White women, some studies have supported this relationship in Black women as well (Adams-Campbell et al., 2001; Bernstein et al., 2005) Bernstein et al. (2005) found a protective effect with higher levels of lifetime recreational activity among both White and Black women. A number of biologically plausible explanations by which physical activity may exert a protective effect have been discussed in the literature and include hormonal mediation, influence on energy balance and body composition, enhancement of the immune system, reduction in insulin resistance and a decrease in circulating insulin-like growth factor-1 (IGF-1) (Astrup, 1999; Hoffman-Goetz, Apter, Demark-Wahnefried, Goran, McTiernan, & Reichman, 1998; Keizer, & Rogol, 1990; Nguyen et al. 1998; Patel et al., 2006; Thomson, Chen, & Lutz, 2005; Westerland, 2003).

While Black women in our study reported lower levels of physical activity than White women, the majority of White women were also not meeting the 2002 American Cancer Society's (ACS) Physical Activity guidelines of moderate-to-vigorous physical activity for

four hours a week. The guidelines may be unrealistic for many women with busy schedules, but considering that regular moderate-to-vigorous physical activity has been consistently found to decrease breast cancer risk this is an important area to address among Black women, as well as among White women.

The specific amount of physical activity (e.g., frequency, duration, and intensity) required to reduce breast cancer risk is unclear at this time, but many studies indicate that 3 or more hours per week may be needed (Patel et al., 2006; WCRF, 2007). Data from several reports are what led the ACS to recommend at least four hours a week of physical activity for breast cancer risk reduction. In general, many factors are involved in a women's decision to develop a physical activity routine, including knowledge about health risks, sense of personal risk, perceived control, perceived efficacy of physical activity to reduce health risk, and of course perceived or real barriers to physical activity (i.e., time, cost, physical limitations). Even though many sources of media have addressed the relationship between increased breast cancer risk and lack of exercise, many women may be unaware of this relationship. Also women may have life conditions which are not conducive to physical activity. Either inadequate knowledge or lack of perceived efficacy of physical activity on breast cancer risk has been found to be an issue for women with a family history of breast cancer. Lemon et al. (2004) found that approximately 60% of women in their study, who had at least one FDR with breast cancer, felt that regular exercise had either no effect or very little effect on breast cancer risk. It would be important to address all of these factors in any intervention study aimed at motivating women at elevated risk for breast cancer to increase their physical activity.

Our finding that there is no significant difference between Black women and White women with regard to dietary fat intake appears to be similar to data from NHANES III. Forshee, Storey, & Rittenbaugh (2003) found Black women across all ages consumed the same amount of total fat as White women while controlling for income, region, and urban dwelling. Analyses from NHANES III also revealed that Black women had lower intake of fruits and vegetables compared to White women, which we found in bivariate analyses. The prevalence of current cigarette smoking among Black women was higher than in White women in our study which is in contrast to prevalence rates reported elsewhere (17.3% vs. 20.0%, respectively) (ACS, 2007). No appreciable differences existed between White and Black women on alcohol use although Black women, who were current drinkers, were slightly less likely to consume more than one alcoholic drink a day. Results from NHANES III data also showed that Black women consumed less alcohol than White women (Forshee et al., 2003). Because there is strong evidence that alcohol consumption raises breast cancer risk the American Cancer Society has recommended that women avoid or limit intake to no more than one drink a day (Byers et al., 2002; Kushi et al., 2006). The majority of all women in this study met this recommendation. Tailored educational messages to address this risk factor among women who are not limiting alcohol intake should be incorporated into lifestyle interventions aimed at breast cancer risk-reduction.

To our knowledge this is the first study to examine lifestyle behavioral differences specifically among Black as compared to White women with a family history of breast cancer. Although the percentage of Black women in this study was lower than in the general profiles of Black women in the general population their lifestyle-related behaviors were not

markedly different. White women in the study were also similar to White women in the general population, which supports generalizability and hence external validity of the study.

Early participants in the Sister Study may not be representative of other women with a family history of breast cancer as this group was the most responsive to reports in the media inviting participants. Most of the women in this analysis had a college degree or higher and had annual household incomes above $50,000.

Although lifestyle variables were measured comprehensively, data were based on self-report and therefore subject to error. There is the potential for bias from self-reporting lifestyle behaviors, which is known to be an issue with survey data for dietary and physical activity variables (Ferrari, Friedenreich, & Matthews, 2007; Herbert, Ebbeling, Matthews, Hurley, Druker, Ma et al., 2002). Herbert et al. (2002) found that college-educated women with higher social desirability scores were more likely to underestimate their dietary energy intake obtained through a food frequency questionnaire than women with less education and lower social desirability scores. Accuracy of physical activity questionnaires has been found to be higher in men than women, in younger versus older individuals, and for those with lower body mass index (Ferrari et al., 2007). Measurement error may also result from physical activity questionnaires that require long-term memory retrieval (Matthews, 2002).

Conclusions

Despite having a family history of breast cancer, women in our study appear no more likely than women in the general population to engage in healthy lifestyle behaviors. This is concerning because obesity is consistently associated with post-menopausal breast cancer risk, albeit in studies of primarily White women. Furthermore, there is evidence to suggest that the impact of lifestyle factors on breast cancer risk may be even greater among women

with a positive family history and lifestyle factors are modifiable whereas family history is not (Carpenter et al., 2003; Sellers et al., 1992; Sellers et al., 2002 Swerdlow et al., 2002). Whether or not such factors interact with family history to increase breast cancer risk, it may be possible to reduce breast cancer risk among women with a family history by appropriate lifestyle interventions.

Although Black women are more likely to be overweight than White women, in this study and in the US as a whole, Black women do not have increased risk for breast cancer overall. Obesity may however play a role in the higher breast cancer mortality among Blacks and the higher incidence of basal-like breast cancer in younger Black women. Furthermore, BMI alone may not sufficiently characterize obesity or the relationship between body size and breast cancer in some populations. To the extent that physical activity accounts for a significant proportion of breast cancer risk, there is also a paradox in that Black women are less physically active than White women yet they have lower incidence rates of breast cancer. In contrast, Black women in this study were less likely to report currently drinking more than one drink a day. The direction of this difference is consistent with the lower incidence of breast cancer among Black women, although the overall frequency of alcohol consumption in the population is low, regardless of race.

Clearly more research is needed in the area of lifestyle behaviors and breast cancer risk among women with familial breast cancer histories, especially among Black women. However, this study does provide support for improving educational efforts aimed at motivating women to engage in healthier lifestyle behaviors that may reduce breast cancer risk and at the very least benefit overall health.

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Table 5.1

Participant Characteristics by Race

Variables	Black Women (*n*=679)		White Women (*n*=18,739)		*P*-value
	n	%	*n*	%	
Demographic Factors					
Age					.003
35-39	44	(6.5)	812	(4.3)	
40-49	185	(27.2)	4827	(25.8)	
50-64	369	(54.3)	10111	(54.0)	
65-75	81	(11.9)	2989	(16.0)	
Education					.09
<College	75	(11.0)	2583	(13.8)	
College degree	412	(60.7)	11257	(60.1)	
> BS degree	192	(28.3)	4897	(26.1)	
Annual Household Income					<.001
<$20,000	38	(5.7)	598	(3.3)	
$20,000-$49,999	177	(26.8)	3573	(19.9)	
$50,000-$99,999	275	(41.6)	7501	(41.8)	
$100,000-$200,000	139	(21.0)	4884	(27.2)	
>$200,000	32	(4.8)	1396	(7.8)	
Marital Status					<.001
Never married	87	(12.8)	859	(4.6)	

Legally married/living as married	372	(54.8)	14651	(78.2)	
Widowed	48	(7.1)	843	(4.5)	
Divorced/separated	172	(25.4)	2384	(12.7)	
Employment Status					<.001
Current full-/part-time status	483	(71.1)	12474	(66.6)	
Housewife	37	(5.4)	2276	(12.2)	
Retired	126	(18.6)	3484	(18.6)	
Unemployed, Student, Other	33	(4.9)	495	(2.6)	
Body Mass Index					<.001
<18.5 (underweight)	1	(0.1)	200	(1.1)	
18.5-24.9 (normal)	124	(18.3)	8201	(43.9)	
25.0-29.9 (overweight)	251	(37.0)	5803	(31.1)	
≥30.0 (obese)	302	(44.5)	4478	(24.0)	

Note. Negligible missing data; variables with numbers unequal to *n* due to missing data.

Table 5.2

Associations Between Race and Lifestyle Behaviors

Variables	Black Women (*n*=679)		White Women (*n*=18739)		Adjusted OR[b] (Referent group – whites)	Adjusted OR[c] (Referent group - whites)
	n	%	*n*	%	OR (95% CI)	OR (95% CI)
Physical activity (total hrs/wk)						
1st quartile (0-0.69 hrs)[a]	228	(33.6)	4627	(24.7)	1.00	1.00
2nd quartile (0.70-2.24 hrs)	169	(24.9)	4668	(24.9)	0.72* (0.59-0.88)	0.76* (0.62-0.94)
3rd quartile (2.25-4.25 hrs)	157	(23.1)	4690	(25.0)	0.66* (0.54-0.82)	0.74* (0.59-0.91)
4th quartile (2.25-4.25 hrs)	125	(18.4)	4744	(25.3)	0.52* (0.42-0.65)	0.58* (0.46-0.73)
Total daily caloric intake (kcal/day)						
1st quartile (0-1157.1) [a]	205	(31.8)	4568	(24.8)	1.00	1.00
2nd quartile (1157.2-1485)	140	(21.7)	4634	(25.1)	0.67* (0.53-0.83)	0.68* (0.54-0.85)
3rd quartile (1485.1-1872.5)	106	(16.4)	4666	(25.3)	0.50* (0.39-0.63)	0.51* (0.40-0.65)
4th quartile (1872.6-9289)	194	(30.1)	4578	(24.8)	0.92 (0.75-1.12)	0.96 (0.78-1.18)
Percent of total kcal from fat/day						
1st quartile (4.35-33.31) [a]	186	(28.8)	4587	(24.9)	1.00	1.00
2nd quartile (33.32-38.28)	152	(23.6)	4627	(25.1)	0.80* (0.64-1.00)	0.82 (0.66-1.03)
3rd quartile (38.29-43.42)	158	(24.5)	4612	(25.0)	0.83 (0.67-1.04)	0.85 (0.69-1.07)
4th quartile (43.43-101.81)	149	(23.1)	4615	(25.0)	0.79* (0.64-0.99)	0.82 (0.65-1.03)

Fruit & vegetable intake (servings/day)						
<1 [a]	8	(1.2)	267	(1.4)	1.00	1.00
1-2	219	(34.0)	4711	(25.5)	1.55 (0.76-3.16)	1.71 (0.83-3.52)
3-4	192	(29.8)	5792	(31.4)	1.10 (0.54-2.25)	1.26 (0.61-2.61)
≥5	226	(35.0)	7676	(41.6)	0.96 (0.47-1.98)	1.13 (0.55-2.34)
Alcohol use						
Never drinker [a]	25	(3.7)	570	(3.0)	1.00	1.00
Former drinker	91	(13.4)	2562	(13.7)	0.82 (0.52-1.29)	0.80 (0.51-1.26)
Current drinker <1 drink/day	477	(70.3)	12866	(68.8)	0.85 (0.57-1.29)	0.81 (0.53-1.22)
1 drink/day	20	(2.9)	470	(2.5)	0.98 (0.54-1.78)	1.01 (0.55-1.86)
1.1-1.9 drinks/day	37	(5.4)	1209	(6.5)	0.70 (0.42-1.18)	0.68 (0.40-1.14)
≥ 2 drinks/day	29	(4.3)	1034	(5.5)	0.65 (0.38-1.12)	0.63 (0.36-1.10)
Smoking history						
Never [a]	409	(60.3)	10314	(55.0)	1.00	1.00
Past	193	(28.4)	6965	(37.2)	0.72* (0.61-0.86)	0.69* (0.58-0.83)
Current	77	(11.3)	1459	(7.8)	1.34* (1.04-1.72)	1.04 (0.80-1.36)

Note. [a] indicates referent group. [b] indicates adjustments for age and education. [c] indicates adjustments for age, education, marital status, income, and occupation. OR = odds ratio; CI = confidence interval.

Table 5.3

Women Meeting 2002 ACS Nutrition and Physical Activity Recommendations for Breast Cancer Prevention

Variables	Black Women (*n*=679)		White Women (*n*=18730)	
	n	%	*n*	%
Meets physical activity recommendations (≥4hours/week)				
Yes	131	(19.3)	5001	(26.7)
Meets BMI (<25 kg/m^2) recommendation				
Yes	125	(18.4)	8407	(45.0)
Meets ACS alcohol recommendations (≤1 serving/day)				
Yes	613	(90.3)	16468	(88.0)

CHAPTER VI

PAPER THREE

Breast Cancer Risk Perception and Lifestyle Behaviors among Black and White Women with a Family History of the Disease

Introduction

One of the most influential risk factors for breast cancer is familial history. Approximately 15% to 20% of breast cancer cases occur in women with a family history (Thull, & Farengo-Clark, 2003) A meta-analysis of 52 epidemiologic studies on familial breast cancer showed risk ratios increase as the number of affected first-degree relatives (FDRs) increases (1.8, 2.9, and 3.9 respectively for 1, 2, and ≥ 3 affected FDRs) (Collaborative Group on Hormonal Factors in Breast Cancer, 2001). However, little is known about what women with a family history think about the causes of breast cancer and how it may relate to risk-reduction lifestyle behaviors (e.g., healthy weight management, regular physical activity, and avoidance or moderation of alcohol consumption).

Several modifiable lifestyle factors have been consistently related to elevated breast cancer risk; these include overweight and obesity (among postmenopausal women), physical inactivity, and alcohol intake (Byers, Nestle, McTiernan, Doyle, Currie-Williams, Gansler et al., 2002; Galanis, Kolonel, Lee, & Le Marchand, 1998; Key, Schatzkin, Willett, Allen, Spencer, & Travis, 2004; McTiernan, 2003). The relationship

between diet and breast cancer is not clearly understood but a high-fat diet typically leads to increased caloric intake, which may result in overweight. Studies of women with a family history of breast cancer have reported that physical activity and healthy weight, at least early in life, may be protective (Carpenter, Ross, Paganini-Hill, & Bernstein, 2003; King, Marks, & Handell, 2003). For women with affected FDRs, investigators have found that breast cancer risk increased 2.45-fold among daily alcohol drinkers compared with non-drinkers and was 5.8-fold greater in those who ever (versus never) smoked cigarettes (Couch, Cerhan, Vierkant, Grabrick, Themeau, Pankratz et al., 2001; Vachon, Cerhan, Vierkant, & Sellers, 2001). As research more clearly elucidates health behaviors related to familial breast cancer, understanding determinants of perceived risk and lifestyle behaviors will be important for designing effective interventions for women at elevated risk.

To engage in healthy lifestyle behaviors, theories suggest a need for perception of personal risk (Prentice-Dunn, & Rogers, 1986; Rosenstock, 1974; Weinstein, 1988). Many factors may influence risk perceptions. Family history is one of the most important factors influencing risk perception and is the most frequently cited risk factor among women with above-average breast cancer risk perceptions (Posluszny, & Baum, 2001; Aiken, Fenaughty, & West, 1995; McCaul, & O'Donnell, 1998). Although several studies have found that awareness of risk increases with number of affected FDRs, there are subsets of women unaware of their elevated risk due to family history (Audrain-McGovern, Hughes, & Patterson, 2003; Nayfield, Karp, Ford, Dorr, & Kramer, 1991; Vernon, Vogel, Halabi, & Bondy, 1993). There may be racial differences in beliefs about breast cancer risk factors which, in turn, affect risk perceptions: among women with a

family history of breast cancer, White women have been found to be more aware of their elevated breast cancer risk compared to Black women, 81% versus 50% respectively, in one study (Audrain, Lerman, & Rimer, Cella, Steffens, & Gomez-Caminero, 1995; Hughes, Lerman, & Lustbader, 1996).

Other factors affecting risk perception are personal history of benign breast disease, breast cancer worry, and perceived control (Gerend, Aiken, West, & Erchull, 2004; Hopwood, 2000). Although researchers have investigated the role of these factors in risk perception, there is still a need for qualitative exploration of perceived risk for breast cancer and how it relates to risk-reduction behaviors in breast cancer affected families.

This qualitative descriptive exploratory study examined factors involved in breast cancer risk perception and explored the relationship between risk perception and lifestyle behaviors among both White and Black who are at increased risk because of family history. The qualitative research approach allowed for exploration of thoughts and beliefs about breast cancer through personal interviews.

Methods

Participants and Procedures

Women were recruited from the National Institute of Environmental Health Sciences' Sister Study (www.SisterStudy.org). The Sister Study is a prospective study of environmental and genetic risk factors for breast cancer in approximately 50,000 women who have had a sister with breast cancer. Participants are volunteers recruited through professional and volunteer organizations, breast cancer advocacy groups, health professionals, media, the Internet, recruitment volunteers, and word of mouth. Eligibility criteria include residence in the U.S. or Puerto Rico, age 35 to 74 years, speaking English

or Spanish, no personal history of breast cancer, and having a full or half-sister who has had breast cancer. The Sister Study began in four U.S. cities in August 2003 and then opened nationally in October 2004. Of 58,200 eligible women who agreed to enroll, about 45,000 completed all baseline enrollment activities as of October 19, 2008.

Women who agreed to participate are mailed written consent documents, three self-administered questionnaires (family history, diet, and use of personal care products), and support materials for telephone interviews and home visits. A home visit is conducted for blood collection, measurement of height, weight, waist circumference and blood pressure, and retrieval of questionnaires. Computer-assisted telephone interviews collect data over two sessions on known and suspected breast cancer risk factors, as well as other information on potential environmental exposures.

Our eligibility criteria were active enrollment in the Sister Study, North Carolina residency, and speaking English. Exclusion criteria were: a) being adopted, because a complete family history was unlikely to be known; b) history of cancer, except non-melanoma skin cancer; and c) race other than White or Black. Only White and Black women were included because the number of women from other racial groups was too small for meaningful sample selection. The study was approved by the Institutional Review Board at the NIH.

Maximum variation sampling, a purposeful sampling technique, was used to seek phenomenal variation and demographic variation in race, age, and education. This resulted in representation of both White and Black women from various socioeconomic backgrounds and with various levels of breast cancer risk based on age and number of affected FDRs. We identified all Sister Study participants who met criteria (White

women, n = 618; Black women, n = 43) and then stratified by a) race, b) age (<50 or ≥50), c) education, and d) number of affected FDRs. Women were randomly selected from each stratum. Invitations were initially mailed to 36 women along with stamped, pre-addressed opt-out cards, which were returned by two White women. Women were given the option to opt out if they were uninterested. These women could either call the Sister Study toll-free number or mail back the opt-out card indicating that they did not wish to be contacted. We attempted to contact the remaining 34 by telephone to explain the study and assess interest in participating. Three Black women were not available after three phone call attempts. Three women, two Black and one White, declined to participate when called. Reasons for declining were related to lack of time and interest. Two Black women scheduled interviews but were unreachable for the scheduled call. Ten additional invitation letters were mailed to replace these women. After the second mailing, five women (one White and four Black) were unreachable by telephone. In all, 46 letters of invitation were mailed and 32 participated in the study (overall response rate of 70% of those who received letters; 82% of those reached by telephone).

We obtained verbal informed consent prior to interviewing. Participants were instructed to send back a signed copy of the consent form which had been mailed to them. An audio-recorded semi-structured telephone interview was conducted with each participant; interview times ranged from 20 to 60 minutes (mean, 42 minutes). To establish rapport and stimulate thinking about breast cancer, interviews began with general statements and questions about breast cancer. After a discussion of general views, the interviews became more specific. The interview guide is shown in Table 6.1. To protect confidentiality, code numbers were assigned to participants, and recordings

were deleted after transcription. All participants received a $25 incentive following return of their signed consent form. After all interviews were completed, additional data on participant characteristics were obtained from the baseline questionnaires completed for the Sister Study.

Data Analysis

Demographic information, body mass index (kilograms per meter squared), and medical risk information were obtained directly from baseline questionnaires completed at the time of enrollment in the Sister Study. These data were analyzed using the Statistical Package for Social Sciences Version 16. Gail Model 5-year risk estimates were calculated using the National Cancer Institute's Breast Cancer Risk Assessment Tool, available from http://www.cancer.gov/bcrisktool. Data required for these calculations are as follows: current age, age at menarche, age at first live birth, number of first-degree relatives with breast cancer, and number of previous breast biopsies showing atypical hyperplasia. The Gail Model is a statistical model used to estimate breast cancer risk and assist clinicians in decision-making with regard to chemoprevention. An estimate of 1.7 or greater is generally considered to represent elevated risk (Fisher, Costantino, Wickerham, Redmond, Kavanah, Cronin et al., 1998).

We used ATLAS.ti (version 5.2) computer software to conduct content analysis using an *a priori* coding frame based on previous breast cancer risk perception research (Aiken, Fenaughty, & West, 1995; Audrain-McGovern, Hughes, & Patterson, 2003; Audrain, Lerman, & Rimer, Cella, Steffens, & Gomez-Caminero, 1995; Lemon, Zapka, & Clemow, 2004; Ryan, & Skinner, 1999). After interviews were transcribed verbatim and rechecked against the original digital recordings for accuracy purposes, a more intense

line-by-line review was conducted and text that pertained to the research objectives were highlighted. Code words or descriptors of important components of the interviews relating to risk, beliefs, lifestyle changes, and behaviors were entered in the margins of each transcript. After this process, transcripts were entered into ATLAS.ti, which aided in the systematic review of data. After relevant codes were identified, interviews were then systematically reviewed to find the number of times content associated with each code occurred in interviews (Grbich, 2007; Liamputtong, & Ezzy, 2005). "Constant comparative analysis" was used to compare themes and patterns in each interview with those of other interviews (Thorne, 2000). Through this process, we identified themes indicating overarching ideas. Perceived risk varied widely among the women. We categorized women into three perceived risk categories: 1) *below-to-average, slightly elevated,* and *moderate-to-high*, based on specific statements from women who expressed their personal risk qualitatively (e.g., "...I would think that I would be moderately at risk"), quantitatively (e.g., "I'd say maybe 25%") or a combination of both. A visual display table, developed to further facilitate data analysis both within and across cases, (Ayres, Kavanaugh, & Knafl, 2003; Huberman, & Miles, 1994) aided the identification of patterns among participants who were categorized based on perceived risk and race. Each participant's data were entered into the table under one of the three perceived risk categories, which was also subdivided by race. Table rows were constructed based on major themes from all participants and on subthemes identified within the more general themes. This strategy allowed for ease in making comparisons across and within cases and aided in the identification of commonalities and differences across individual accounts. The table also enabled us to easily visualize how the themes and subthemes

related to one another within cases. We then identified exemplary participant statements related to specific themes and compared the responses of White and Black women. Data saturation was achieved once no new information or themes emerged from the interviews.

Expert feedback, memo writing, and descriptive statistics were used to demonstrate validity (Stanley, 2006; Whittemore, Chase, & Mandle, 2001). Two researchers familiar with qualitative methodology and with the phenomena of interest provided feedback after reviewing a random sample of interviews and an outline of identified themes. Writing memos, both within ATLAS.ti and in a journal, preserved coders' ideas about the data. Descriptive statistics helped support the results of the study by determining the amount of evidence in the data that supported a particular theme (Maxwell, 1998). For example, the frequency of subthemes or patterns was counted and represented in the form of percentages. Counting of qualitative themes has been referred to as "quantitizing" data, which aids in describing and interpreting the phenomenon under study (Tashakkori, & Teddlie, 1998; Sandelowski, 2001). The numerical display of qualitative information has been found to allow patterns in the data come forth with greater clarity (Dey, 1993). The usefulness of numbers in qualitative research goes beyond representing experiences by also enhancing documentation, verification, and testing of researcher interpretations (Sandelowski, 2001).

Coding Scheme

Data were coded into four main themes: 1) causal beliefs, 2) perceived control, 3) changes made as a result of sister's diagnosis, and 4) current lifestyle behaviors. Breast cancer causal beliefs were explored because of the influence they have on risk perception.

The theme, “changes made as a result of sister’s diagnosis”, arose from the aim to explore the relationship between risk perception and lifestyle behaviors.

We explored cognitive and emotional factors derived from the breast cancer risk perception literature: disease burden in the family (i.e., number of affected FDRs, mom affected, young age at diagnosis, time since sister’s diagnosis, and death from breast cancer), personal history of benign breast changes, breast cancer worry, causal beliefs and personal control (Gerend, Aiken, & West, 2004; Hopwood, 2000) .

Results

Thirty-two women participated in the study (Table 6.2). Black participants were younger than White participants, with 67% versus 40%, respectively, younger than 50 years. Most participants were married (72%) and had annual incomes more than $49,999 (78%); 58% of Black women and 55% of White women had at least a college degree. More than half of the White women and 80% of the Black women were overweight or obese. According to Gail Model 5-year risk estimates, 90% of White women and 33% of Black women were at clinically increased risk for breast cancer (score $\geq$ 1.7). Overall, most women perceived themselves to be at increased risk for breast cancer, but more Black women than White women perceived their risk as moderate-to-high (66% and 30%, respectively). A few women perceiving below-to-average risk had Gail estimates above 1.7, indicating elevated risk. Conversely, several women with moderate-to-high perceived risk had Gail estimates below 1.7.

Table 6.3 outlines the most common themes and patterns according to perceived risk level. For this report, *common* is operationally defined as occurring in more than 50% of women within each perceived risk category, which is a strategy suggested by an expert in

qualitative research (Sandelowski, 2001). Table 6.4 presents risk characteristics, causal beliefs, and current healthy lifestyle behaviors among women in the three perceived risk categories. Because current lifestyle behaviors are incorporated into Tables 6.3 and 6.4, results are not shown below.

Below-to-Average Perceived Risk

Although four of five women in this group had Gail risk estimates above 1.7, they reported below-to-average risk:

> "I would say that I'm probably below average risk...I just don't feel like I'm at risk." (White participant)

Prophylactic mastectomy and negative BRCA 1 and 2 genetic testing in a family member were cited as reasons for low perceived risk. Women in this perceived risk category expressed no significant breast cancer worry.

Causal Beliefs

Although most women acknowledged that breast cancer likely has many contributing factors, from genetics to chemicals and hormones in food, there was a general sense of uncertainty about breast cancer causes.

> "It makes you sit and think could it be in our foods, and other things that are out there, cause there's so many more manipulation of the animals we eat and with all the hormonal injections and everything that they're doing." (White participant)

Perceived Control

Three women felt they had some personal control over their risk, whereas two felt a lack of control.

"I don't have any control over it. If it's going to happen, it will probably happen." (White participant)

A participant who had undergone a prophylactic mastectomy felt she had significant control.

"I think I have the ultimate control in the sense of I can remove my breasts." (White participant)

Perceived control through diet, exercise, and weight management was also mentioned. Among women who expressed lack of control, there was also a sense of uncertainty about specific breast cancer causes.

Changes Made as a Result of Sister's Diagnosis

Three women had made dietary changes, mostly reductions in fatty foods. One had also increased her exercise. Two women made no changes.

"Yes, it has changed my life, my way of thinking, which I've always for years tried to be kind of health conscious and exercise...then I kind of got myself a little bit stricter (referring to improvements in diet) with what I was already doing." (Black participant)

Slightly Elevated Perceived Risk

Thirteen perceived their risk as slightly higher than that of women in the general population.

"I believe my risk is higher than the average person walking around; however, I don't think that it's destiny either." (White participant)

Ten had only one affected FDR; none had a mother with breast cancer. None expressed major personal concern about breast cancer when asked, "Can you tell me a little bit about your feelings about being at risk?".

Causal Beliefs

Nine women believed that family history/genetics and environmental factors were involved in breast cancer development. Six believed that hormonal factors such as HRT and menstrual and reproductive history were related to risk. The relationship between overweight and hormones was also mentioned.

> "Well, I know that, or I've heard that if you're overweight that your body produces more hormones, or holds more hormones, and that can be a factor. I know that for my sister, she was, or is, still is, both overweight and doesn't exercise." (White participant).

Perceived Control

Nine women felt they had some personal control through diet and exercise and through avoidance of HRT, although some said that their only control was through early detection.

> "I'm just one who believes whatever's going to happen is going to happen. I just try to do my yearly mammograms right now. You know, just catch it early." (Black participant)

Changes Made as a Result of Sister's Diagnosis

Only one woman made a behavioral change after her sister's diagnosis, which was quitting smoking. Two discontinued HRT and three began anti-estrogen therapy. Five

mentioned that any healthy lifestyle changes they made evolved over time and were primarily done to improve overall health.

> "I do try really hard to eat right and exercise and it's not so much because my sister had cancer, it's more as you're getting older you have to undo what you've done for the last forty years. It's really not a result of her cancer or my intentional reducing my chances of cancer." (White participant)

Moderate-to-High Perceived Risk

Fourteen women were categorized as having moderate-to-high perceived risk. Although most of these women had a significant disease burden in their families (e.g., most had an affected sister and mother), five had Gail risk estimates below 1.7, indicating low risk.

> "I've had two aunts and my mother and my sister have also had breast cancer, so it's kind of like a joke with my other four sisters, it's not if but when we get it." (White participant-sister diagnosed in her early forties)

Refer to Table 6.4 for prominent patterns related to familial experiences found among these women. Overall, eleven did not express great concern or worry about breast cancer. However, three were very concerned, particularly at times of breast cancer screenings, and one was concerned enough to take out a cancer insurance policy.

Causal Beliefs

Most of these women associated family history/genetics, environmental factors, and stress with breast cancer.

> "Stress, definitely. Stress hammers your immune system, makes you less able to cope with whatever's coming at you from the environment." (White participant)

Perceived Control

Ten felt they had "*little*" to "*some*" control over whether they developed breast cancer; only four perceived no personal control. Views of women who did not perceive control were that breast cancer occurred by chance or that God controlled their destiny.

"Well, everything is up, you know, up to the Man Upstairs I think." (Black participant)

Several mentioned that breast cancer affects women who lead healthy lifestyles as well as women who do not. This led them to perceive very little control over whether they get breast cancer and implied that they had little reason to change lifestyle behaviors.

"Is seems like if you're going to get breast cancer, you're going to get breast cancer. Like I know a lot of people who get breast cancer and they live impeccably clean, pristine lifestyles." (White participant)

Factors through which women felt some control over their breast cancer risks were quitting smoking, exercise, healthy diet and stopping HRT.

Changes Made as a Result of Sister's Diagnosis

Half the women made some changes, with most reporting improvements in diet. Two stopped HRT; one started anti-estrogens. Five said they needed no behavior change because they had already been leading healthy lifestyles and their sisters' diagnosis raised awareness of the importance to continue.

"I thought that it was definitely more important than ever, just to keep up and try to keep my weight down." (White participant)

Differences across Perceived Risk Groups

Women reporting moderate-to-high risk perceptions more often cited family history, environment, and stress as risk factors for breast cancer. These women also carried a slightly greater family burden of disease. Many of these women had some sense of personal control and tended to make dietary improvements more than any other behavior change. Although women with slightly elevated perceived risk also cited the importance of family history, the same general feeling of uncertainty was not found and women reported more personal control compared with those with below-to-average risk perception. Even so, most had not made any behavioral changes as a result of a sister's diagnosis, and this group tended to be less physically active. Women with below-to-average risk perception recognized the importance of family history but otherwise reported an overall sense of uncertainty over the causes of breast cancer and perceived little or no control.

Comparison of White and Black Women

More Black women (66% vs. 30% of White women) reported moderate-to-high risk perception even though their overall Gail Model risk estimates were lower. Among Black women, 67% had Gail risk estimates below 1.7 compared to 10% of White women. A higher percentage of White women, 55%, perceived slightly elevated risk compared with 17% of Black women. Majority of both groups believed that family history/genetics and environmental factors were involved in breast cancer causation, but few recognized the importance of age. Unhealthy diet was reported as a risk factor by 58% of Black women compared to 30% of White women, whereas obesity was mentioned only by White women. A slightly higher proportion of White than Black

women reported lack of exercise as a risk factor for breast cancer. Many more White women discussed hormones as risk factor. Improvements in diet, mostly dietary fat reduction, were made by more Black women compared with White women (42% and 10%, respectively). More White than Black women increased physical activity (15% vs. 8%).

Discussion

Findings suggest that risk perception is greatly influenced by family history. Roughly 80% of both racial groups believed that family history played a role in their breast cancer risk, whereas previous studies found that Black women with a family history were less likely than White women to relate family history to breast cancer (Audrain, Lerman, Rimer, Cella, Steffens, & Gomez-Caminero, 1995; Hughes, Lerman, & Lustbader, 1996). The fact that women in this study are participating in the Sister Study may, in part, account for this difference because recruitment materials cite the enhanced risk of women with an affected sister. However, degree of family burden was also associated with higher risk perception among both White and Black women. This included having more than one affected FDR, having an affected mother, young age at diagnosis, sister's death from breast cancer, and a diagnosis within the past 4 years. These findings reveal that familial breast cancer experiences are at the core of risk representation for many women.

Most study participants had a heightened sense of personal risk. Of the 16% who considered themselves at below-to-average risk, burden of disease (e.g., affected mom, sister died from breast cancer, and diagnosis within 4 years) was less compared with women with moderate-to-high perceived risk. In many cases, Gail Model risk estimates did not correspond well to self-reported perceived risk. Women perceiving moderate-to-

high risk had the greatest familial burden of disease and were more likely to have had benign breast disease. A higher percentage reported family history/genetics and stress as risk factors compared with women in the other perceived risk groups. Although a higher percentage of White versus Black women had greater 5-year Gail risk estimates, there were more Black women who perceived moderate-to-high risk. It is possible that these Black women have higher projected breast cancer risks than their calculated Gail Model risk estimates because recent studies have revealed that the Gail Model underestimates risk for Black women (Gail, Costantino, Pee, Bondy, Newman, Selvan et al., 2007). Contrary to the above finding is a qualitative report on predominantly Black women attending a high-risk breast cancer clinic that revealed that most women did not feel they were at high risk despite their increased 5-year Gail risk estimates (Salant, Ganschow, Olopade, & Lauderdale, 2006).

Similar to previous studies (Kristeller, Hebert, Edmiston, Liepman, Wertheimer, Ward et al., 1996; Rabin, & Pinto, 2006), a high percentage of women in both racial groups believed environmental toxins were associated with breast cancer, although there was uncertainty about how environmental factors played a role in breast cancer. Most of the women in our study who reported moderate-to-high perceived risk believed that stress was a contributing factor to breast cancer, which was also a common belief among women attending a familial cancer clinic (Rees, Gaff, Young, & Martin, 2007).

Few women mentioned advancing age and reproductive factors included in the Gail Model; this was especially true among Black women and is consistent with other studies in which women with a family history of breast cancer have demonstrated lack of awareness that advancing age, early age at menarche, and late age at menopause were

risk factors (Daly, Lerman, Ross, Schwartz, Burke-Sands, & Masny, 1996; Rabin, & Pinto, 2006; Ryan, & Skinner, 1999).

Most women identified at least one lifestyle behavior as a breast cancer risk factor, mostly a diet high in fat, even though the evidence for this relationship is inconclusive. One-third identified lack of exercise and 40%, White women only, mentioned overweight/obesity as risk factors despite many studies consistently showing associations between these factors and breast cancer. It is concerning that most participants were unaware of the importance of exercise and weight control because most were overweight or obese. Knowledge about the relationship between alcohol consumption and breast cancer was completely lacking despite it being one of the most consistently reported associations in the literature (Byers, Nestle, McTiernan, Doyle, Currie-Williams, Gansler, & Thun, 2002; Key, Schatzkin, Willett, Allen, Spencer, & Travis, 2004; McTiernan, 2003).

Perceived control over breast cancer was generally lacking or minimal, which may have to do with the fact that many women related breast cancer with nonmodifiable risk factors, such as family history/genetics and environmental contaminants. With regard to health behaviors, both White and Black women had the notion that breast cancer is indiscriminate and occurs in both women who do and do not lead healthy lifestyles. This view may result in women perceiving limited control even if they actively engage in healthy behaviors. Other investigators also found that lack of control over breast cancer risk was a common theme among women receiving breast cancer genetic counseling, although some women decided to engage in healthy lifestyle behaviors to make them feel better about their risk (Rees, Gaff, &Young, 2007). Personal control over risk

influenced healthy behavior change for several women in our study. However, for some, there was ambiguity related to risk factor beliefs, personal control, and lifestyle practices. For example, one Black woman who related lack of exercise with breast cancer felt she had some control over her risk, but yet was not engaging in regular physical activity. Real or perceived barriers to lifestyle behavioral changes may play a role.

Use of medical risk-reducing strategies, such as anti-estrogen use or prophylactic mastectomy, affected risk perception and was seen by women as something they could personally control. However, some women felt that they were still at moderate-to-high risk even though they had used these strategies that substantially reduce risk. Some women may merely be taking anti-estrogens at the recommendation of their healthcare provider without understanding their risk-reduction benefit. Alternatively, disease burden in a family may override knowledge about risk-reduction related to these strategies.

Elevated perceived risk was related to healthy lifestyle behavior change for only a third of the women. The most common lifestyle behavior changes were dietary. Despite current lack of evidence supporting the relationship between diet and breast cancer, dietary change may be a crucial factor in healthy weight maintenance, and this may be important for women concerned about overweight and breast cancer risk. Also, diet is a behavior that women may feel they can control. The dietary changes were consistent with women's beliefs about dietary fat and breast cancer, especially among Black women. Overall, 34% reported having made some healthy lifestyle change. This is fairly consistent with findings by Lemon et al. (2004) who reported that 42% of FDRs, who were primarily White, reported behavior change after diagnosis of breast cancer in a

FDR. Although several women believed that lack of exercise was related to breast cancer, most were not exercising regularly. Perceived and real barriers may interfere with women's abilities to engage in regular exercise. Some were unaware of the relationship between physical activity and breast cancer. Two women continued to smoke despite their beliefs that it increases breast cancer risk.

This exploratory qualitative study is subject to limitations. The small sample size and sampling method are typical of qualitative research; therefore, findings cannot be generalized to other women at increased risk. Although these women are participants in a larger study addressing epidemiological breast cancer risk factors, their beliefs and health behaviors were not markedly different from those of women with a family history included in other studies. A strength of the methodology is that it allowed for in-depth exploration of the topic that would not be easily obtained through quantitative research.

Conclusions

Findings from this study highlight the importance of understanding risk perceptions and beliefs about causal attributes of breast cancer among women with a family history. The finding that there was some disconnect between perceived risk and Gail Model risk estimates is noteworthy because behavior changes are more likely to result from perceived risk rather than objective risk. Women need to be informed about basic breast cancer risk factors before they can be expected to make risk-reducing lifestyle modifications. Cancer nurses and other health educators should provide women with opportunities to discuss their thoughts about and experiences with breast cancer in the family. This information offers insight into how women develop their risk perceptions and provides a basis for educating women about breast cancer risk factors and the

benefits of healthy lifestyle practices. Educational interventions that address barriers to change are needed for women who identify lifestyle behavioral breast cancer risk factors yet make no changes. Further investigation would improve understanding of other influential factors, such as personal motivation, cost, and time that may be involved in decision making about healthy lifestyle practices among women with a family history of breast cancer.

In addition to providing insight into the formulation of risk perception, this study identified similarities and differences among White and Black women. Knowledge of racial differences in beliefs, perceptions, and lifestyle practices is important for cancer nurses involved in research and development of breast cancer education programs for women at increased risk. Although information linking some lifestyle risk factors and breast cancer is inconclusive, any nursing intervention based on healthy lifestyle recommendations must be anchored in women's beliefs about the disease and their perceived ability to control outcomes. Cancer nurses need to be responsible for engaging women at increased risk in conversations that explore personal risk perception and related thoughts and feelings about lifestyle risk-reduction behaviors. This will lead to improved understanding about women's decision making with regard to lifestyle practices. Future areas for research include further qualitative investigation in a sample of ethnically diverse women, as well as targeted intervention studies aimed at motivating women with a family history of breast cancer to adopt healthy lifestyle behaviors.

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Table 6.1

Interview Guide

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1. Many women are concerned about breast cancer. Can you tell me about your own thoughts and concerns about breast cancer?

2. What do you think causes breast cancer? (Probe as needed: “What about the environment?”, “Family history or genetics?”, “Lifestyle?”, “Stress?”)

3. Can you tell me about your sister and any other family members who have had breast cancer?

4. Can you tell me what risk for breast cancer means to you?

5. Do you consider yourself to be at risk for breast cancer? (Probe: “Why do you think you are at risk?”, “Why do you think you are not at risk?”)

6. How much at risk do you think you are?

7. Can you tell me a little bit about your feelings about being at risk [or about why you don’t feel at risk?] (Probes: “Are you concerned?’’, “Are you anxious or distressed in any way?”)

8. Is there anything that you can think of that may increase your risk? (Probes: “Family history or genetics?”, “Your lifestyle?”, “Your environment?”)

9. Is there anything that you can think of that may decrease your risk?

10. How much control do you think you have over whether you get breast cancer or not?

11. What do you generally do to stay healthy? (Probes: “Does it involve diet, exercise, meditation, avoidance of alcohol and/or tobacco?)

12. Have you made any changes in what you do to stay healthy since your sister’s diagnosis? (Probes: **If yes**, “What were the changes?” “When did you make these changes”, **If no**, “Have you thought about making any changes?”)

13. Why did you decide to make these changes? (Probe: “Have any changes in your family or life influenced these changes?)

14. What would you say are the most common roadblocks or barriers to making these lifestyle changes?

15. Did you receive any advice or support from family, friends, or health care providers about health changes? (Probes: a. “what type of support/information did you receive?” b. “who provided the support?” i.e. sister, husband, child, friend or colleague, nurse, physician c. “what did you think about the support?”)

Table 6.2

Participant Demographic Characteristics and Gail Model Risk Estimates by Race (N=32)

	n (%) White Women	*n* (%) Black Women
Age, y		
35-49	8 (40)	8 (67)
50-74	12 (60)	4 (33)
Marital status		
Married/living as married	15 (75)	8 (67)
Not married	5 (25)	4 (33)
Education		
High school	8 (40)	4 (33)
Some college	1 (5)	1 (8)
≥ College degree	11 (55)	7 (58)
Annual household income		
<$20,000-$49,999	3 (15)	4 (33)
$50,000-$99,999	10 (50)	2 (17)
≥$100,000	6 (30)	5 (41)
Missing income data	1 (5)	1 (8)
BMI (body mass index)		
<25	9 (45)	2 (17)
25-29 (overweight)	5 (25)	3 (25)
≥30 (obese)	6 (30)	7 (58)
5-year Gail Model risk		
<1.7	2 (10)	8 (67)
1.7-5.0	12 (60)	3 (25)
>5.0	6 (30)	1 (8)

Note. Demographic and risk factor data obtained from the baseline Sister Study questionnaire.

Table 6.3

Common Themes and Patterns by Level of Perceived Risk

Below-to-Average Perceived Risk

Themes	*Patterns*
Causal Beliefs	Family history and/or genetics Chemicals or hormones in food General uncertainty about causes of breast cancer
Perceived Control	Little or no control
Behavioral Changes	Reduction in dietary fats
Current Lifestyle Behaviors	Adherence to a reduced-fat diet Physical activity ≥ 150 mins/week ≤ 1 alcoholic drink/day Avoidance of smoking tobacco

Slightly Elevated Perceived Risk

Themes	*Patterns*
Causal Beliefs	Family history and/or genetics Pesticides, pollution, hormones in food
Perceived Control	Some control
Behavioral Changes	The majority had made no changes
Current Lifestyle Behaviors	Adherence to a reduced-fat diet ≤ 1 alcoholic drink/day Avoidance of smoking tobacco

Moderate-to-High Perceived Risk

Themes	*Patterns*
Causal Beliefs	Family history and/or genetics Stress Pesticides, pollution, hormones in food
Perceived Control	Little to some control
Behavioral Changes	Dietary improvements

Current Lifestyle Behaviors	Adherence to a reduced-fat diet ≤ 1 alcoholic drink/day Avoidance of smoking tobacco

Table 6.4

Risk Characteristics, Causal Beliefs and Current Healthy Lifestyle Behaviors by Level of Perceived Risk

Risk Characteristics	Below-to-Average (*n*=5) *n* (%)	Slightly Elevated (*n*=13) *n* (%)	Moderate-to-High (*n*=14) *n* (%)
Women with > 1 affected FDR	3 (60)	3 (23)	10 (71)
Women with affected mom	2 (40)	0 -	8 (57)
Women with a sister diagnosed < age 50	4 (80)	8 (62)	9 (64)
Women with a sister diagnosed less than 5 years ago	2 (40)	2 (15)	5 (36)
Women who had a sister or mom die of breast cancer	2 (40)	4 (31)	8 (57)
Gail Model risk estimates			
<1.7	1 (20)	4 (31)	5 (36)
1.7-5.0	4 (80)	6 (46)	5 (36)
>5.0	0 -	3 (23)	4 (29)
Negative BRCA 1/2 genetic testing in family	2 (40)	1 (8)	3 (21)
Prophylactic mastectomy	1 (20)	0 -	1 (7)
Anti-estrogen use	0 -	3 (23)	1 (7)
Causal Beliefs			
Family history/genetics	4 (80)	9 (69)	13 (93)
Environmental factors	4 (80)	9 (69)	12 (86)
Stress	1 (20)	3 (23)	11 (79)

Lifestyle factors:			
Unhealthy diet	3 (60)	4 (31)	6 (43)
Lack of exercise	1 (20)	6 (46)	4 (29)
Overweight/Obesity	2 (40)	4 (31)	2 (14)
Tobacco use/2nd hand exposure	0	1 (8)	5 (36)
Alcohol	0	0	0
Hormonal factors			
Exogenous (HRT, OC)	0	2 (15)	6 (43)
Endogenous (early menarche/late menopause)	0	4 (31)	3 (21)
Older age	1 (20)	1 (8)	0
Physical abuse/breast trauma	0	1 (8)	1 (7)
Lifestyle Behaviors			
Physical Activity (e.g. exercise for fitness) ≥ 150 mins/week	3 (60)	5 (38)	5 (36)
Low-fat or Reduced-fat diet			
Consumes red meat ≤ 3 times/week	4 (80)	11 (85)	13 (93)
Consumes mostly non-fat or low-fat dairy	3 (60)	10 (77)	11 (79)
Fruit & Vegetable intake ≥ 5 servings/day	2 (40)	4 (31)	2 (14)
Alcohol Consumption ≤ 1 drink/day	5 (100)	11 (85)	14 (100)
Non-smoker	5 (100)	13 (100)	12 (86)

Note. Data obtained through personal interviews. OC = oral contraceptives.

CHAPTER VII

DATA INTEGRATION, INTERPRETATION, AND CONCLUSIONS

This study examined questions from two different research approaches and was based on a concurrent mixed method design. The goals of this design were to utilize the strengths of both qualitative descriptive and quantitative research to cross-validate or corroborate findings within one larger research study, as well as gain a broader perspective on the concept of perceived risk and whether it relates to lifestyle behaviors. Because perceived risk is a complex phenomenon that is not easily quantified, exploration through a qualitative descriptive approach was deemed appropriate for this research. This approach is referred to as complementary, and Greene et al. (1989) have stated that the goal of complementarity is, "to measure overlapping but also different facets of a phenomenon, yielding an enriched, elaborated understanding of that phenomenon" and the purposes have been summarized as obtaining, "clarification of the results from one method with the results from the other method" (pp. 258-259). With the complementarity approach, quantitative strategies are utilized to describe data objectively and qualitative strategies are more often used to analyze individual's interpretations of a situation (i.e. personal relevance, motivation to change) or of some phenomenon and to further support existing findings from quantitative data (Erzberger & Prein, 1997). In essence, this strategy enables researchers to gain perspectives from different types of data

and findings from both aspects of the study have raised further questions for future inquiry.

The qualitative descriptive component of this research was necessary to explore the multi-faceted concept of perceived risk for breast cancer among women with a family history of the disease and to explore whether perceived risk and family history affected lifestyle behaviors. Additionally, this study further supported the results from the quantitative study.

Because heightened risk perception has been found to be a motivating factor for engagement in healthy behaviors we need to improve our understanding of how perceived risk for breast cancer relates to lifestyle behaviors among women at elevated risk for the disease. Personal interviews not only provided information about the degree of breast cancer risk perception (e.g., below-to-average, slightly elevated, and moderate-to-high), they also led to a better understanding about other factors involved in risk perception formulation, such as breast cancer causal beliefs. The qualitative descriptive study also allowed for exploration of perceived control over risk, which is likely to play a role in behavioral change. Another important research question addressed through the personal interviews was whether women made a change in behavior as a direct result of a sister's breast cancer. Data on this type of temporal relationship between the sister's diagnosis and lifestyle behavior change was not obtained through the baseline Sister Study questionnaire. Exploration of the temporal relationship was important for understanding what affects the breast cancer family history had on the individual's lifestyle behaviors (e.g., what motivates these women to change behavior).

During the data collection and analysis phase of the qualitative descriptive study it was discovered that certain aspects of the familial breast cancer experience were related to moderate-to-high perceived risk. These factors included having more than one affected sister, young age of a sister at diagnosis, having an affected mother, death of sister or mother from breast cancer, and sister's diagnosis less than five years from time of interview. The term family burden of disease was used to represent these various aspects of the familial breast cancer experience. This information served as a source of hypothesis testing for the quantitative analyses to determine whether family burden of disease was associated with lifestyle behaviors. After discovering that these variables related to heightened risk perception, a decision was made to incorporate them into the composite variable, Family Burden Score, which was then examined in the quantitative data analyses. Therefore, the qualitative descriptive findings not only enhanced the quantitative analysis, but they also aided in the interpretation of the quantitative results.

Integration and Interpretation

Overall, findings from both qualitative descriptive and quantitative analyses revealed that higher Gail risk estimates (e.g., objective risk) did not predict healthier lifestyle behaviors among women with a family history of breast cancer. These findings confirm those by Madlensky et al. (2005) who found no significant differences in lifestyle preventive behaviors (e.g., exercise, diet, and alcohol intake) among women at varying levels of familial breast cancer risk. From the quantitative analyses comparing women at below the median Gail risk to women at or above the median Gail risk on lifestyle behaviors, it was determined that women at higher objective risk were no more likely to engage in healthy behaviors than women with lower objective risk after controlling for

age, education, and race. Qualitative descriptive results revealed that 22 of the 32 women had elevated Gail risk estimates (i.e., ≥ 1.7). Eighteen of these 22 women perceived elevated breast cancer risk (i.e., slightly elevated or moderate-to-high). In most cases perceived risk was aligned with objective risk, however elevated risk perception did not necessarily relate to healthier lifestyles. Overall, most women perceived moderate-to-high personal risk, but less than 40% of them were exercising ≥ 150 minutes/week and only 14% were consuming 5 or more fruits and vegetables/day. The majority reported adhering to a reduced-fat diet and all but two were not drinking more than one alcoholic drink/day.

Findings from this mixed-method investigation were also that higher family burden scores were not predictive of healthier lifestyles. There appeared to be a trend in the quantitative analysis of more unhealthy behaviors (e.g., less physical activity, higher daily caloric intake, lower consumption of fruits and vegetables, and tobacco use) among women with high family burden scores, although these results were not statistically significant. Qualitative descriptive results showed that women with higher family burden of disease were often those reporting moderate-to-high perceived risk and these women were no more likely than women reporting lower perceived risk to engage in healthy lifestyle behaviors.

Another cross-validated finding was that the majority of women in the study were either overweight or obese; however Black women had a substantially higher prevalence of overweight and obesity than White women. Quantitative results revealed that approximately 45% of White women had normal, healthy weights compared to only about 18% of Black women. The majority of women interviewed from North Carolina

were overweight or obese according to their BMI (Whites – 55% versus Blacks – 83%), which was obtained from the baseline Sister Study questionnaire. Qualitative descriptive data on physical activity and alcohol intake also appeared to be in accordance with the quantitative data in that White women were more likely to exercise regularly and Black women were less likely to consume more than one alcoholic drink/day. Both aspects of the study revealed that only one-third of Black women were exercising ≥ 150 mins/wk compared to roughly 45% of White women. Out of the 32 women in the qualitative descriptive study, 13 were engaging in regular physical activity ≥ 150 minutes/week, which was the ACS recommendation for cancer risk-reduction. More White women than Black women were meeting this recommendation. A slightly higher percentage of Black women than White women met the ACS alcohol intake recommendation, although the majority of both groups did not consume more than one alcoholic drink/day. With regard to smoking and fruit and vegetable consumption, there were discrepancies between the qualitative descriptive and quantitative data, this was likely due to the small number of participants in the qualitative descriptive study. The qualitative descriptive analysis revealed that none of the Black women consumed the generally recommended five or more fruits and vegetables a day compared to 40% of White women. Findings from the quantitative data were that 35% of Black women consumed ≥ 5 fruits and vegetables/day versus approximately 42% of White women. As far as the data on smoking, none of the Black women who participated in the personal interviews were current smokers compared to 11% from the quantitative analysis. A smaller percentage of White women were current smokers, 5% (qualitative descriptive data) versus 8% (quantitative data). Some of these findings also support those found among women in the general population.

For example, in a national study the majority of both White and Black women were overweight or obese, although Black women had a substantially higher prevalence of obesity than White women (45% versus 24%) (Centers for Disease Control (CDC), 2007; National Center for Health Statistics, 2007). Other reports had similar findings in that Black women are less likely to engage in regular physical activity compared to White women and that Black women consume less alcohol than White women (Bernstein, Teal, Joselyn, & Wilson, 2003; Bernstein, Patel, Ursin, Sullivan-Halley, Press, Deapen et al., 2005; CDC, 2007; Forshee, Storey, & Ritenbaugh, 2003).

Additional qualitative descriptive findings provided insight into why women at elevated breast cancer risk may not be engaging in healthy lifestyle behaviors. With regard to causal beliefs about breast cancer, most women cited non-modifiable factors such as family history/genetics and environmental factors as playing a role in breast cancer development. Very few mentioned advancing age or hormonal-related factors that are incorporated into the Gail model. Most relevant was the finding that many women were unaware of well-established modifiable risk factors for breast cancer (e.g., obesity/overweight for post-menopausal breast cancer, sedentary lifestyle, and alcohol intake). When women were asked through the personal interviews about their beliefs regarding breast cancer causation, only 8 of the 32 women mentioned overweight/obesity as a risk factor and all of them were White women. Only about one-third discussed lack of exercise as a risk factor and not one related alcohol to breast cancer risk. More White women mentioned lack of exercise, whereas more Black women related dietary fat intake to breast cancer. Unhealthy diet was reported as a risk factor by 58% of Black women compared to 30% of White women. As far as lifestyle behavioral changes made as a

result of a sister's diagnosis, more White than Black women increased physical activity (15% vs. 8%), although few women made a change in this behavior. Improvements in diet were made by more Black women, mostly dietary fat reduction, compared to White women (42% and 10%, respectively). This may in part be due to their beliefs about dietary fat as a risk factor for breast cancer and their ability to do something about it. This is an important finding even though dietary fat has not been confirmed as a breast cancer risk factor, but it is essential for healthy weight reduction. Interestingly, the quantitative analysis revealed that Black women consumed less kcal/day through total fat than White women, although the finding was not significant in the fully adjusted model.

Through qualitative descriptive exploration we also found that perceived control over breast cancer was a factor that influenced lifestyle behaviors. Most women who perceived moderate-to-high perceived risk felt they had "*little*" to "*some*" control over whether they developed breast cancer and some expressed that healthy lifestyle practices would not reduce their risk. If a woman's belief is that she has little to no control over her breast cancer risk she may be less likely to incorporate healthy lifestyle behaviors into her daily routine (Thompson & Schlehofer, 2009).

The aggregate of these findings support the idea that women with higher levels of perceived risk, as well as women with higher objective risk, are no more likely than women with lower perceived risk and/or objective risk to make healthy lifestyle choices. Although most women were not meeting the American Cancer Society's guidelines for cancer prevention (i.e., maintaining a healthy weight and moderate to vigorous exercise for ≥150 mins/wk), more White women were adhering to them than Black women. Although the ACS does not address specific dietary improvements in the breast cancer

prevention guidelines they are important for achieving and maintaining a healthy weight. Interestingly, this was one lifestyle behavior that Black women were more likely to modify as a result of their breast cancer family history and this must not be overlooked.

Strengths and Limitations

Strengths and limitations existed within each research approach. Strengths of the quantitative research include the large sample size for comparing women at varying levels of risk for breast cancer and the inclusion of enough Black women to make quantitative comparisons. The quantitative method provided the systematic measurement of specified variables for all subjects and thus allowed for direct comparison of variables across subgroups (i.e., based on Gail risk estimates and race) for hypotheses testing. The use of inferential statistics improves the validity of the study and allows for the comparison of results from similar studies to help determine the importance of the findings. An additional strength of the quantitative data is that it provided sufficient information to generate two separate quantitative studies and findings from both studies will be useful for the development of subsequent studies addressing breast cancer risk in women with a family history of the disease.

One limitation of the quantitative component was that data were obtained from a data set which did not include measurement of perceived risk or perceived control that might influence lifestyle behaviors in women with a family history of breast cancer. Also, the study was cross-sectional and therefore the temporal relationship between the timing of a sister's diagnosis and lifestyle behaviors could not be examined. A limitation of the study sample is that Sister Study participants may not be representative of other women with a family history of breast cancer as this group was the most responsive to reports in

the media inviting participants. Although lifestyle variables were measured comprehensively, data were based on self-report and therefore subject to error.

The main limitation of the qualitative descriptive approach was the small sample size, especially of Black women. This weakness made it difficult to make comparisons across subgroups based on perceived risk, objective risk, and race and to consider these qualitative descriptive findings as valid. Another limitation was that a semi-structured interview format was used as opposed to an unstructured format that may have led to the discovery of additional factors involved in the formulation of perceived risk. A limitation was that the theme of personal control was introduced by the investigator, but it was elaborated on by women in the sample. However, the semi-structured interview guide was based on breast cancer risk perception research and variables previously found to be important were incorporated into the interview questions. Also, some of interview questions were developed to be complementary to the quantitative data.

The predominant strength of the qualitative descriptive study was that the findings enhanced our understanding of why women at elevated objective breast cancer risk may not be engaging in healthier lifestyle behaviors. First, although all of the women in the study were at elevated risk for breast cancer not all women interviewed perceived themselves as being at risk, which was counter to their Gail risk estimates in some cases. If a woman does not believe she is at risk for breast cancer then she may be less likely to engage in risk-reduction lifestyle behaviors. Although there were only five women who perceived below-to-average risk, two were not engaging in regular exercise and only one woman reported a relationship between lack of exercise and breast cancer. None of them consumed more than one alcoholic drink/day and all were non-smokers. If a woman is

unaware that certain lifestyle behaviors are related to breast cancer risk she might be less inclined to maintain a healthy weight, exercise regularly, and limit alcohol intake. This was supported by the interview findings that revealed that most women possessed a lack of knowledge regarding the relationships between breast cancer and overweight/obesity, physical activity, and alcohol. Therefore, the investigation of causal beliefs was a very important part of the study and aided in our understanding about perceived risk and lifestyle practices of these women.

With information gained from the interviews it became clear as to why women at the highest Gail risk are no more likely to have healthier lifestyle practices then women with Gail risks below the median. In some cases women perceiving the highest risk were not aware of modifiable breast cancer risk factors and/or they perceived lack of control over their personal risk. There were those women who identified specific risk factors and perceived some control through lifestyle behaviors, but yet made no change in their behavior. In these cases, other factors are likely to be involved with decision-making about risk-reducing lifestyle choices, such as roadblocks or barriers that interfere with healthy weight management, good nutrition and regular physical activity. These must be explored with women when educating them about personal breast cancer risk and risk-reducing behaviors.

Implications for Future Research

Despite the studies' limitations, this investigation has generated information that is important to consider for additional studies in the area of breast cancer risk perception and lifestyle behaviors among women with a family history of the disease. Considerations for future quantitative investigations of lifestyle behaviors in women at

elevated breast cancer risk might involve analyses that include comprehensive measurements of perceived risk and the assessment of behavioral lifestyle changes made as a result of a familial breast cancer history. Additionally, other important variables have been identified that can be useful for hypotheses testing, such as perceived control which may mediate the relationship between perceived risk and lifestyle behaviors. Beliefs about modifiable lifestyle risk factors are also important to assess quantitatively because they will likely influence a women's decision about whether she chooses to engage in healthy lifestyle behaviors. There is also a need for further inquiry addressing the sub-population of White women with high family burden of disease because of results revealing a trend that they appeared to have less healthy lifestyle behaviors than White women with low family burden of disease. Future qualitative investigations focused specifically on Black women at elevated breast cancer risk, and on women from other racial backgrounds at elevated risk, could shed more light on ethnic differences in perceived risk, causal beliefs, perceived control, and lifestyle practices if they included lifestyle changes that were culturally relevant.

Implications for Nursing Practice and Conclusions

Although further study is needed prior to the development of any successful educational program, nurses must consider the health beliefs and current behaviors of their target audience. Findings from the current study suggest a need to counsel women with a family history of breast cancer about their elevated risk and plan interventions with aims of increasing awareness about links between breast cancer and specific lifestyle behaviors. Counseling sessions should incorporate specific information about breast cancer risk reduction from the American Cancer Society's Guidelines on Nutrition and

Physical Activity. Nurses must also explore both real and perceived barriers, as well as motivators for healthy lifestyle behaviors and educate women about strategies to overcome identified barriers towards the engagement of healthy behaviors. Although results from this study can help provide the basis for addressing educational needs of both White and Black women at elevated risk, further research on perceived risk, perceived control, and perceived motivators/barriers to healthy lifestyle behaviors are needed on women with a family history of breast cancer, especially among minority women.

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