



Published in final edited form as:

*Cancer Nurs.* 2009 ; 32(4): 299. doi:10.1097/NCC.0b013e31819deab0.

## Breast Cancer Risk Perception and Lifestyle Behaviors among White and Black Women with a Family History

Denise Spector<sup>a</sup>, Merle Mishel<sup>a</sup>, Celette Sugg Skinner<sup>b</sup>, Lisa A. DeRoo<sup>c</sup>, Marcia VanRiper<sup>a</sup>, and Dale P. Sandler<sup>c</sup>

<sup>a</sup>School of Nursing, University of North Carolina at Chapel Hill, Carrington Hall, Campus Box 7460, Chapel Hill, NC 27599-7460, USA

<sup>b</sup>Department of Clinical Sciences, Division of Behavioral & Communication Sciences, UT, Southwestern Medical Center, 5323 Harry Hines Blvd., E-506, Dallas, TX 75390-9066, USA

<sup>c</sup>Epidemiology Branch, National Institute of Environmental Health Sciences, PO Box 12233, MD A3-05, 111 T.W. Alexander Drive, Research Triangle Park, NC 27709, USA

### Abstract

Little is known about relationships between a positive family history of breast cancer, perception of risk, and lifestyle behaviors. This qualitative study explored factors involved in formulation of perceived breast cancer risk and the association between risk perception and lifestyle behaviors in white and black women with a family history of breast cancer. Eligible participants were North Carolina residents in the Sister Study, a nationwide study of environmental and genetic risk factors for breast cancer among women aged 35 to 74 who have at least one sister diagnosed with breast cancer. Personal interviews were conducted with thirty-two women, twenty white and twelve black. While many had a heightened sense of risk and perceived family history as a main risk factor, 16% considered themselves at low or average risk for breast cancer and Gail risk scores did not correspond to perceived risk. Many women were unaware of associations between lifestyle behaviors and breast cancer risk. Eleven women, six black and five white, reported making healthy lifestyle changes because of family history; dietary change was most frequently reported. These findings may be important for future developers of breast cancer education programs for both white and black women with a family history of breast cancer.

### Introduction

Many women are concerned about breast cancer which may be especially true among women with a family history of the disease. 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 (risk ratios of 1.8, 2.9, and 3.9 respectively for one, two, and three or more affected FDRs compared to women without 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 its prevention.

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 than 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 about 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, theory suggests a need for perception of personal risk (Rosenstock, 1974). Conceptualization of one's risk is a complex process that involves many factors. Family history is one of the most important factors influencing risk perception (Posluszny & Baum, 2001). Heredity has been the most frequently cited determinant of breast cancer risk among women with above-average breast cancer risk perceptions (Aiken, Fenaughty, West, Johnson & Luckett, 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). Two studies found white women to be more aware of their elevated breast cancer risk as a result of family history compared to black women (Audrain, Lerman, Rimer, Cella, Steffens, & Gomez-Caminero, 1995; Hughes, Lerman, & Lustbader, 1996). These results suggest there are racial differences in beliefs about breast cancer risk factors which, in turn, affect risk perceptions.

Other factors found to affect risk perception are personal history of benign breast disease, breast cancer worry, and perceived control (Gerend, Aiken, West, & Erchull, 2004; Hopwood, 2000). Availability and representative cognitive heuristics have been identified as correlates to perceived risk (Gerend, et al., 2004; Hopwood, 2000; Kahneman, Slovic, & Tversky, 1982). The availability heuristic is a mental shortcut involved in risk formulation that suggests the ease of remembering a family member's or friend's illness increases perceived likelihood of developing the illness. The representative heuristic is based on beliefs that one is similar in some way to the individual with the illness (Gerend et al., 2004). Although researchers have begun investigating the role of these factors in risk formulation, there is still a need for further qualitative exploration of the development of risk perception and how it relates to preventive behaviors in breast cancer affected families.

The purpose of this qualitative study was to examine factors involved in breast cancer risk perception and explore the relationship between risk perception and lifestyle behaviors. The strength of the qualitative research approach is that it allowed for exploration of thoughts and beliefs about breast cancer through in-depth personal interviews with women at elevated risk due to family history.

## Methods

### Participants and procedures

Participants were enrolled in the Sister Study, a national cohort study of environmental and genetic risk factors for breast cancer sponsored by the National Institute of Environmental Health Science [NIEHS]. The Sister Study aims to follow up 50,000 U.S. women between the ages of 35 and 74 who do not have breast cancer at baseline, but have at least one sister diagnosed with the disease. Our eligibility criteria were active enrollment in the Sister Study, living in North Carolina, and being an English speaker. Exclusion criteria were: a) being

adopted, because a complete family history was unlikely; b) prior history of cancer, except non-melanoma skin cancer and c) race other than white or black. 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 the study criteria and then stratified by: a) race, b) age (<50 or >50), c) education ( $\leq$  high school or > high school), d) number of affected FDRs, e) Tamoxifen use, and f) previous prophylactic mastectomy. Two white and two black women were randomly selected from each stratum except for the last two which included only white women. Invitations were mailed to 36 women (20 white and 16 black) along with stamped, pre-addressed opt-out cards, which were returned by two white women. We attempted to contact the remaining 34 women by telephone to explain the study aims and methods and assess interest in participating. Three black women were not available after at least three phone call attempts. Three women, two black and one white, declined to participate when called. Two black women scheduled interviews but were unreachable for the scheduled call. Ten additional letters of invitation were mailed to replace these women. After the second mailing, five women (one white, four black) were unreachable by phone. In all, 46 letters of invitation were mailed with a response rate of 82% among women who could be reached by telephone. The overall response rate was 70%.

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 20–60 minutes (mean = 42 minutes). To establish rapport and stimulate participant's thinking about breast cancer, interviews began with general statements and questions about breast cancer such as, "Many women are concerned about breast cancer. Can you tell me about your own thoughts and concerns about breast cancer?" After a discussion of general views, the interviews became more specific. Questions included, "Do you consider yourself to be at risk for breast cancer?", "Is there anything you can think of that may increase your risk?", and "Have you made any changes in what you do to stay healthy since your sister's diagnosis?". Interviews were transcribed and verified against the original digital recordings and then checked for accuracy through line-by-line review. 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 was obtained from the baseline questionnaires completed for the Sister Study.

## Data Analysis

We used ATLAS.ti computer software to conduct content analysis using an *a priori* coding frame based on previous breast cancer risk perception research. Relevant categories or codes were identified, and interviews were systematically reviewed to find the number of times relevant 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. A visual display table was developed to further facilitate data analysis both within and across cases (Ayres, Kavanaugh, & Knafl, 2003; Huberman & Miles, 1994). The table aided in identification of similar and unique patterns among participants grouped based on level of perceived risk and race. We then identified exemplary participant statements that related to specific themes or sub-themes and compared

responses of white and black women. Data saturation was achieved once no new information or themes emerged from the interviews.

Expert feedback, “memoing”, and descriptive statistics were used to demonstrate validity (Stanley, 2006; Whittemore, Chase, & Mandle, 2001, p. 534). Two researchers provided feedback after reviewing a random sample of interviews and an outline of identified themes and sub-themes. Writing memos, both within ATLAS.ti and in a journal preserved coders’ ideas about the data. Descriptive statistics helped support overall claims of the study (Maxwell, 1998). Counting of qualitative themes has been referred to as “quantitizing” data, which aids in describing and interpreting the phenomenon under study (Tashakkori & Teddlie, 1998, p. 126; Sandelowski, 2001).

### Coding Scheme

Data were coded into four main themes: perceived breast cancer risk, causal beliefs, changes made as a result of sister’s diagnosis, and current lifestyle behaviors. Perceived breast cancer risk was sub-categorized as *below-to-average*, *slightly elevated*, and *moderate-to-high perceived risk*. Breast cancer causal beliefs were explored because of the influence they have on risk perception. Beliefs were further divided into six sub-themes (i.e. *family history*, *environmental factors*, *stress*, *lifestyle factors*, *hormonal factors*, and *miscellaneous factors*). 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. Sub-themes derived from this category were *dietary changes*, *physical activity*, *hormones*, *prophylactic surgery* and *lack of change*. The current lifestyle behaviors theme was divided into five sub-themes: *physical activity*, *dietary fat*, *fruit and vegetable intake*, *alcohol intake*, and *tobacco use*.

After detailed review of individual accounts, it became apparent that the perceived risk theme required further division. We developed categories 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 (“High...high risk. On a scale of 1 to 10, probably from 8 to 10”). 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, & Erchull, 2004; Hopwood, 2000). Availability and representative cognitive heuristics were identified among women categorized as moderate-to-high risk perception. For clarity of concepts, we included statements relating to availability or representative heuristics.

## Results

### Participants

A total of 32 women, 20 white and 12 black, participated in the study (Table 1). A greater proportion of black women (67%) were under 50 years old than were white women (40%). Most were married and had annual incomes above \$49,999; 58% of black women and 55% of white women had at least a college degree. Over 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 elevated risk for breast cancer (score  $\geq 1.7$ ).

### Perceived Breast Cancer Risk

Overall, the majority of women perceived themselves to be at elevated risk for breast cancer, but more black women, 66%, felt they were moderate-to-high risk compared to 30% of the

white women. Table 2 shows the distribution of several factors affecting breast cancer risk in relation to self-reported perceived risk.

**Below-to-Average Perceived Risk**—Five women reported below average or average perceived risk. One woman had a prophylactic mastectomy after two sisters were diagnosed in their thirties. She reported previously feeling at high risk due to family history but as a result of the prophylactic mastectomy, she now feels at low risk:

Not much. I mean I've had my nipples removed. I've had, as much, you know, the docs think they got as much of the breast tissue as they possibly could.

Another woman indicated that she was at average risk as expressed in the following statement,

I don't think we're at risk because of that (refers to family history and diet) but we are at risk because we have breasts.

A woman whose two family members tested negative for BRCA genetic mutations said these findings decreased her sense of personal risk.

Two women had only one affected FDR who was alive and well. The other three had at least one living affected sister diagnosed over 5 years ago. Three women expressed some worry about breast cancer but also indicated a positive attitude:

*I'm just trying to be positive that I don't.* (Referring to risk of developing breast cancer)

...the only thing I can change is myself; that's what I do. I try to pull out something positive in every negative situation.

One black woman was uncertain about any specific risk factor for breast cancer and felt a lack of personal control over breast cancer. One white woman also perceived a lack of control:

If it's going to happen, it will probably happen.

Two women perceived a high amount of personal control. One had undergone a prophylactic mastectomy. They both believed they had control over healthy eating, which they considered a risk-reduction measure. One perceived some control through diet, exercise and weight management.

**Slightly Elevated Perceived Risk**—Thirteen women perceived their risk as slightly higher than that of a woman in the general population.

I do have a slight risk, but I am less and less concerned about it than I was a number of years ago.

I believe my risk is higher than the average person walking around; however, I don't think that it's destiny either. I don't think it's a given that I'm going to get breast cancer...

Ten of these 13 women had only one affected FDR; none had a mother diagnosed with breast cancer. Ten had at least one affected sister still living. Eleven women had sisters diagnosed with breast cancer five or more years ago; two had sisters diagnosed within four years of the interview. None expressed any major personal concern about breast cancer, for example:

I'd be lying if there wasn't a tiny little dot back here in my subconscious about it. But I've chosen to live my life, not as if I'm going to get sick, but just to live it and enjoy it.

When asked, “Can you tell me a little bit about your feelings about being at risk?, one white woman said she worried at the time of her breast screenings. Eight white women and one black woman felt they had some personal control as exemplified in the statements:

*You know, I have control with exercise and diet,...maybe 50-50”*

I don’t know that I have any control over whether I get it or not other than making sure that I do stay healthy as much as I can. Stay away from hormones.

**Moderate-to-High Perceived Risk**—Fourteen women were categorized as having moderate-to-high perceived risk based on statements such as these:

I would say that certainly my risk is much higher than someone who doesn’t have a family member and particularly three family members with breast cancer. And so I would think that I would be moderately at risk.

I feel on a scale of 1 to 10 I’m right at number 10.

The majority of these 14 women had a significant burden of disease within their families. Ten had more than one affected FDR; eight had both an affected sister and mother. One woman whose sister, mother, and two aunts were affected stated:

It was kind of hard just because it brought the realization to our generation that it was still there, again, it was my mom and then my sister.

Both time since diagnosis and young age at diagnosis (i.e. <50) appeared to be important factors with eight women reporting that a FDR was diagnosed within the last four years and eleven reporting a sister or mom diagnosed at a young age. Statements made by two black women were:

I have a strong family history of breast cancer. And my mother was diagnosed at the age of 47...and she was the first...and then in 2002, my next to oldest sister was diagnosed with breast cancer...and then in 2003, the oldest sister was diagnosed...So it’s somewhat of a family legacy.

I’ve been getting mammograms since I was 26 years old, because that was during the time that my sister was diagnosed.

Another prominent pattern was most of the women ( $n=9$ ) lost either a sister or mother to breast cancer. Six had a personal history of a benign breast lump or discharge which related to their heightened sense of risk as exemplified by one black participant.

I had been having a discharge from my right breast. I had a mammogram, it didn’t show anything so I went to see a specialist, he did an ultrasound, it didn’t show anything but I was still having concerns with the family history [sister and mom affected], so now I’m going to be seeing the doctor my sister was seeing.

Cognitive heuristics were involved in formulation of risk for several women. One statement illustrating the representative heuristic (i.e. elevated risk perception arising from perceived similarity to an affected relative) was,

And my sister, we’re only about 14 months apart. So definitely, I think its right up there for me to possibly have it.

A salient example representing the availability heuristic (i.e. over-estimation of risk with remembrance of experiences with those affected) was:

I don’t know if I think it’s just – it’s not a matter of if. It’s a matter of when....It is prevalent in my family and, for whatever reason, it seems to be prevalent in my social circle as well...I guess you would say I feel a little bit like it’s just surrounding me.

Overall, most of the 14 women with moderate-to-high risk perception did not express great concern or worry about breast cancer as exemplified by a black participant:

It doesn't make me anxious. I don't dwell on it.

However, three women mentioned they were very concerned, particularly at times of breast cancer screenings, and one was concerned enough to take out a cancer insurance policy.

Four women perceived no control over whether they developed breast cancer. Others felt they had “*little*” to “*some*” control. Views of women who lacked perceived personal control were that breast cancer occurred by chance or implied that God controlled their destiny as exemplified by two black women:

I really don't think I have control over it to tell you the truth. I think it's just what you're meant to deal with.

Well, everything is up, you know, up to the man upstairs I think.

Factors over which women felt they had some control were: quitting smoking, exercise, healthy diet and stopping hormone replacement therapy. All women mentioned family history and/or genetics as breast cancer risk factors, with the exception of one woman who was uncertain about the relationship.

Gail Model risk estimates did not correspond well in many cases with self-reported perceived risk. Four women in the below-to-average group had Gail estimates above 1.7, indicating elevated risk. Conversely, five women with moderate-to-high perceived risk had Gail estimates below 1.7. Based on Gail Model risk estimates there were more white women than black women at clinically higher risk yet more black women perceived higher risk (data not shown).

### Breast Cancer Causal Beliefs

Table 3 presents breast cancer causal beliefs by perceived risk category. Most women believed the causes of breast cancer are multi-factorial. One woman said, “I think part of it is genetic and I do think that a lot of these drugs that we do take such as Premarin might be causes.”

**Family History**—Family history or genetics were the most commonly cited breast cancer risk factors as reflected in these remarks:

I would immediately think family history

Well, I've always considered genetics, that it was in your genes and if you were going to get it you were going to get it.

All six white women in the moderate-to-high perceived risk group viewed family history or genetics as risk factors, whereas only seven of the eleven white women who perceived themselves to be at slightly elevated risk mentioned these risk factors. Family history or genetics were discussed by the two black women in the slightly elevated risk group and by all but one of the eight black women in the moderate-to-high perceived risk group. Of all study participants, only six did not specifically mention family history or genetics as a cause or risk factor.

**Environment**—Environmental factors were the second most commonly cited cause of breast cancer; women mentioned a wide range of factors including pesticide exposure, hormones in food, contaminated water and air pollution. Although there was uncertainty about how environmental factors played a role in breast cancer, 80% of white women and 75% of black women thought the environment plays some role:

Oh, I just feel like there's so many chemicals floating around in the air that are really possibly having more to do with more women having breast cancer.

We put all this fertilizer and all these chemicals in our lawns and in your foods. We put growth hormones in our chicken and I figure if it makes the chicken fat it's going to cause us to grow and have growths. I just don't know but I do think it's something that is manmade, something that we're doing that's causing our bodies to have cancers.

**Stress and Lifestyle**—Roughly half of the participants thought stress influenced breast cancer development and most of these women felt themselves to be moderate-to-high risk.

Fewer than half cited unhealthy diet or lack of exercise as a risk factor for breast cancer and 25%, all of whom were white, mentioned overweight/obesity. Not one woman discussed alcohol as a risk factor.

**Hormones**—Slightly less than half of the women, mostly white, related hormonal factors with breast cancer. The most commonly cited exogenous hormonal risk factor was hormone replacement therapy (HRT). Among the specific endogenous risk factors mentioned were early menses, late menopause, never giving birth or late age at first birth, and lack of breastfeeding.

**Miscellaneous Factors**—Only two white women mentioned older age and two women, one white and one black, stated physical trauma to the breast as risk factors.

### Changes Made as a Result of Sister's Diagnosis

Among all participants, six black and five white women reported having made some lifestyle change as a result of their family history. Of these 11 women, three (two white, one black) perceived themselves to be below-to-average risk, one white women had a slightly elevated risk perception and seven (two white, five black) had moderate-to-high risk perceptions. All but two perceived some personal control over their breast cancer risk through healthy lifestyle behaviors.

**Diet**—Improvements in diet, mostly dietary fat reduction, were made by four black women with moderate-to-high risk perception. Three women (two white, one black) from the below-to-average risk perception group made concerted efforts to improve their diets.

I really try to stay away from foods with a lot of fat in them...I don't eat a lot of fast foods like I used to.

I initially changed my eating habits, as far as just really amped up my workouts and all that stuff, and probably lost 25 pounds.

**Physical Activity**—One white and one black woman from the moderate-to-high perceived risk group and two white women who perceived below-to-average risk increased physical activity.

**Hormones**—Four women, two white from the slightly elevated perceived risk group and two black from the moderate-to-high perceived risk group had stopped HRT. An additional four women (three white, one black) took Tamoxifen and/or Raloxifene as a risk-reduction measure. Of those, three white women perceived their risk as slightly elevated, whereas the black woman had moderate-to-high risk perception.



**Prophylactic Mastectomy**—Two white women had prophylactic mastectomies; one felt at moderately high risk even after the surgery and the other felt her risk was below average as a result of the procedure.

**Lack of Change**—Twelve white and five black women reported having made no health changes resulting from their sisters' diagnosis. Two of these women, one black and one white, considered themselves as below-to-average risk, nine women (two black, seven white) had a slightly elevated risk perception and six (two black, four white) perceived moderate-to-high risk. Of the 17 who made no changes, eight, two black and six white, mentioned their healthy lifestyle changes had evolved over time and were primarily done to improve overall health. Three women, one black and two white, said they did not need to change behavior because they had already been leading healthy lifestyles and their sisters' diagnosis made them more aware of the importance to continue.

### Current Health Behaviors

Table 4 presents current healthy behaviors by perceived risk category.

**Physical Activity**—Thirteen women were exercising regularly for 150 minutes a week -- the minimal physical activity level recommended by health organizations, such as the American Cancer Society (ACS), for breast cancer risk-reduction. Most of these women were white, had elevated risk perceptions and mentioned a lack of exercise as a breast cancer risk factor. Another twelve women exercised regularly, but not enough to meet recommendations. The remaining seven women were not engaging in any regular physical activity even though three of them related lack of exercise to breast cancer risk.

**Dietary Fat**—Many women believed that dietary fat plays a role in breast cancer development, as previously indicated, and had made dietary changes as a result of sisters' diagnoses. Four were making attempts to reduce dietary fats and 26 reported adherence to a reduced-fat diet (decreased red meat intake, consumption of low-fat dairy, avoidance of fried foods). The two remaining women, both white, did not relate diet with breast cancer risk and were making no attempts to follow a low-fat diet.

**Fruit and Vegetable Intake**—Only eight women, all white, were consuming the general recommended five or more servings of fruits and vegetables per day. Fourteen women reported 3–4 servings per day; ten consumed 1–2 servings a day. One mentioned low fruit and vegetable intake as a breast cancer risk factor and she consumed 3–4 servings per day. Only one specifically remarked that she increased her intake as part of her overall dietary improvements following her sister's diagnosis.

A lot less fried or fatty food...we're doing more grilled and healthier preparation. A lot more vegetables...Probably at least two servings of fruits and three of vegetables.

**Alcohol Intake**—Not one woman mentioned alcohol as a risk factor. In fact, one woman made the following remark:

I don't really associate alcohol with breast cancer. I don't think there's ever been an alcohol link. Cigarette smoking, yes.

Six women were non-drinkers and twelve consumed alcohol once or twice a month or less. Ten women drank alcohol on a weekly basis (2–6 drinks per week). Four white women were daily drinkers, two of whom exceeded the ACS guidelines recommending no more than one drink a day to reduce breast cancer risk. Neither of these last two women had made any lifestyle changes as a result of their sister's diagnosis.

**Tobacco Use**—Two white women were smokers; one woman smoked approximately a pack per day and the other smoked two to three cigarettes a day. Both considered themselves at moderate-to-high risk and felt that smoking may play a role in causing breast cancer. They also recognized that quitting smoking is something they could personally control as an effort to reduce their breast cancer risk even though neither one was actively trying to quit.

## Discussion

Our findings suggest that risk perception is greatly influenced by family history and burden of disease for both white and black women. Roughly 80% of both groups believed family history played a role, which is contrary to previous reports that found black women with a family history were less likely than whites to relate family history to breast cancer (Audrain, et al., 1995; Hughes, et al., 1996). The fact that women in this study are participating in the Sister Study may, in part, account for this difference since recruitment materials for that study cite the enhanced risk of women with an affected sister. However, burden of disease in the family was also associated with higher risk perception among both white and black women. This included having more than one affected FDR, an affected mom, young age at diagnosis, death from breast cancer and a relative's diagnosis within the past 4 years. These findings reveal that the "lived" familial breast cancer experiences are at the core of risk representation for many women.

Most women in the study had a heightened sense of personal risk. Although a higher percentage of white women had greater 5-year Gail risk estimates, there were more black women who perceived their risk as moderate-to-high. It is unclear why more black women than white women perceived higher risk, but it may point to the impact of family history. There were more black women in the  $\leq 50$  age group and it is possible they felt more vulnerable than older women. Interestingly, not one black woman mentioned older age as a risk factor.

Similar to previous studies (Kristeller et al., 1996; Rabin & Pinto, 2005), a high percentage of women in both racial groups believed environmental toxins and stress were associated with breast cancer. The scientific literature does not strongly support a causal role for stress in breast cancer etiology, and there have been mixed results for different environmental toxins. Uncertainty regarding risk factors may be due in part to the evolving nature of cancer research. Conflicting results are often reported in the media, which may lead to confusion about causes. Few women mentioned advancing age and reproductive hormonal factors that are included in the Gail Model; this was especially true among black women and is consistent with other studies on women with a family history of breast cancer that reported a lack of awareness that advancing age, early age at menarche, and late age at menopause were risk factors (Daly, Lerman, Ross, Schwartz, Sands & Masny, 1996; Rabin & Pinto, 2005; Ryan & Skinner, 1999). The fact that age was infrequently mentioned as a risk factor is a concern because age is one of the most important breast cancer risk factors. Most women identified at least one lifestyle behavior as a risk factor for breast cancer, mostly a diet high in fat, even though the evidence for this relationship is inconclusive. Only one third of the women identified lack of routine exercise and 40%, white women only, mentioned overweight/obesity as risk factors despite several studies showing associations with these factors and breast cancer. It is concerning that most women were unaware of the importance of exercise and weight control because 55% of white women and 83% of black women 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.

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 non-modifiable 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 lead and do not lead healthy lifestyles. This view may result in women perceiving limited control even if they actively engage in healthy behaviors. Personal control over lifestyle behaviors influenced healthy behavior change for several women. 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, 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, had an impact on risk perception and was something women could personally control. However, some women felt they were still at high risk even though these strategies substantially reduce risk. Some women may merely be taking anti-estrogens at the recommendation of their health care provider without understanding the risk reduction associated with their use. Alternatively, disease burden in a family may override knowledge about risk reduction related to these strategies. This points to the need to explore the psychological impact of breast cancer in the family before effective educational strategies can be employed.

Elevated perceived risk was related to healthy lifestyle behavior change for approximately one 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. Among black participants, 50% made one or more lifestyle behavior change as a result of family history, whereas only 25% of white participants made one or more changes. 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 mother, sister, or daughter. Although several women believed that lack of exercise was related to breast cancer, most were not exercising regularly. Some may be unaware of the relationship between physical activity and breast cancer. Two women continued to smoke despite their beliefs that it increases breast cancer risk, but this may be due to the addictive nature of smoking.

This exploratory qualitative study is subject to limitations. The small sample size and sampling method are typical of qualitative research; therefore findings may not be generalized to other women at elevated risk. Also these women were participants of a larger study addressing epidemiological breast cancer risk factors; however their beliefs and health behaviors were not markedly different from those of women with a family history from other studies. Strength of the methodology is that it allowed for in-depth exploration of the topic, which captured nuances of women's familial experiences that would not be easily obtained through quantitative research.

Findings from this study highlight the importance of understanding perceptions of risk 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 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. Health educators should provide women with an opportunity to discuss their thoughts about and experiences with breast cancer in the family. This information can offer insight into how women develop their perception of risk and provide a basis for educating women about breast cancer risk factors and the benefit

of healthy lifestyle practices. Targeted educational interventions that incorporate information about objective risk would be beneficial for FDRs to improve their understanding of personal risk. Educational interventions that address barriers to change may be needed for those 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, the study identified both similarities and differences among white and black women. Knowledge of racial differences in beliefs, perceptions and lifestyle practices are important for developers of breast cancer education programs. Although information linking some lifestyle risk factors and breast cancer is inconclusive, any intervention based on healthy lifestyle recommendations must be anchored in women's beliefs about the disease and their perceived ability to control outcomes.

## References

- Aiken LS, Fenaughty AM, West SG, Johnson JJ, Lockett TL. Perceived determinants of risk for breast cancer and the relations among objective risk, perceived risk, and screening behaviors over time. *Women's Health: Research on Gender, Behavior, and Policy* 1995;1:27–50.
- Audrain J, Lerman C, Rimer B, Cella C, Steffens R, Gomez-Caminero A. Awareness of heightened breast cancer risk among first-degree relatives of recently diagnosed breast cancer patients. *Cancer Epidemiology, Biomarkers, & Prevention* 1995;4:561–565.
- Audrain-McGovern J, Hughes C, Patterson F. Effecting behavior change: Awareness of family history. *American Journal of Preventive Medicine* 2003;24:183–189. [PubMed: 12568825]
- Ayres L, Kavanaugh K, Knafel KA. Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research* 2003;13:871–883. [PubMed: 12891720]
- Byers T, Nestle M, McTiernan A, Doyle C, Currie-Williams A, Gansler T, Thun M. American Cancer Society guidelines on nutritional and physical activity for cancer prevention: Reducing the risk of cancer with healthy food choices and physical activity. *CA: A Cancer Journal for Clinicians* 2002;52:92–119. [PubMed: 11929008]
- Carpenter CL, Ross RK, Paganini-Hill A, Bernstein L. Effect of family history, obesity and exercise on breast cancer risk among postmenopausal women. *International Journal of Cancer* 2003;106:96–102.
- Collaborative Group on Hormonal Factors in Breast Cancer. Familial breast cancer: Collaborative reanalysis of individual data from 52 epidemiological studies including 58 209 women with breast cancer and 101 986 women without the disease. *The Lancet* 2001;358:1389–1399.
- Couch FJ, Cerhan JR, Vierkant RA, Grabrick DM, Themeau TM, Pankratz VS, et al. Cigarette smoking increases risk for breast cancer in high-risk breast cancer families. *Cancer Epidemiology, Biomarkers, & Prevention* 2001;10:327–332.
- Daly MB, Lerman C, Ross E, Schwartz MD, Burke-Sands C, Masny A. Gail model breast cancer risk components are poor predictors of risk perception and screening behavior. *Breast Cancer Research and Treatment* 1996;41:59–70. [PubMed: 8932877]
- Fisher B, Costantino JP, Wickerham DL, Redmond CK, Kavanah M, Cronin WM, et al. Tamoxifen for prevention of breast cancer: Report of the National Adjuvant Breast and Bowel Project P-1 Study. *Journal of the National Cancer Institute* 1998;90:1371–1388. [PubMed: 9747868]
- Galanis DJ, Kolonel LN, Lee J, Le Marchand L. Anthropometric predictors of breast cancer incidence and survival in a multi-ethnic cohort of female residents of Hawaii, United States. *Cancer Causes and Control* 1998;9:217–224. [PubMed: 9578299]
- Gerend MA, Aiken LS, West SG, Erchull MJ. Beyond medical risk: Investigating the psychological factors underlying women's perceptions of susceptibility to breast cancer, heart disease, and osteoporosis. *Health Psychology* 2004;23:247–258. [PubMed: 15099165]
- Grbich, C. *Qualitative data analysis: An introduction*. London: Sage; 2007.
- Hopwood P. Breast cancer risk perception: What do we know and understand? *Breast Cancer Research* 2000;2:387–391. [PubMed: 11250730]

- Huberman, A.; Miles, M. Data management and analysis methods. In: Denzin, N.; Lincoln, Y., editors. *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage; 1994. p. 428-444.
- Hughes C, Lerman C, Lustbader E. Ethnic differences in risk perception among women at increased risk for breast cancer. *Breast Cancer Research and Treatment* 1996;40:25–35. [PubMed: 8888150]
- Kahneman, D.; Slovic, P.; Tversky, A. *Judgment under uncertainty: Heuristics and biases*. Cambridge: Cambridge Press; 1982.
- Key TJ, Schatzkin A, Willett WC, Allen NE, Spencer EA, Travis RC. Diet, nutrition and the prevention of cancer. *Public Health Nutrition* 2004;7:187–200. [PubMed: 14972060]
- King M, Marks JH, Handell JB. Breast and ovarian cancer risks due to inherited mutations BRCA1 and BRCA2. *Science* 2003;302:643–646. [PubMed: 14576434]
- Kristeller JL, Hebert J, Edmiston K, Liepman M, Wertheimer M, Ward A, Luippold R. Attitudes toward risk factor behavior of relatives of cancer patients. *Preventive Medicine* 1996;25:162–169. [PubMed: 8860281]
- Lemon SC, Zapka JG, Clemow L. Health behavior change among women with recent familial diagnosis of breast cancer. *Preventive Medicine* 2004;39:253–262. [PubMed: 15226033]
- Liamputtong, P.; Ezzy, D. *Qualitative research methods*. 2nd ed.. Oxford, UK: Oxford University Press; 2005.
- Maxwell, JA. Designing a qualitative study. In: Bickman, L.; Rog, DJ., editors. *Handbook of applied social research methods*. Thousand Oaks: Sage; 1998. p. 69-100.
- McCaul KD, O'Donnell SM. Naive beliefs about breast cancer risk. *Women's Health: Research in Gender, Behavior, and Policy* 1998;4:93–101.
- McTiernan A. Behavioral risk factors in breast cancer: Can risk be modified? *The Oncologist* 2003;8:326–334. [PubMed: 12897329]
- Nayfield SG, Karp JE, Ford LG, Dorr FA, Kramer BS. Potential role of tamoxifen in prevention of breast cancer. *Journal of the National Cancer Institute* 1991;83:1450–1459. [PubMed: 1920492]
- Posluszny, DM.; Baum, A. Psychological management of women at risk for breast cancer. In: Vogel, VG., editor. *Management of patients at high risk for breast cancer*. Malden, MA: Blackwell Sciences; 2001. p. 228-244.
- Rabin, C.; Pinto, B. Cancer-related beliefs and health behavior change among breast cancer survivors and their first-degree relatives [Electronic version]. *Psycho-Oncology*. 2005 [Retrieved December 12, 2005]. from <http://www3.interscience.wiley.com.libproxy.lib.unc.edu/cgi-bin/fulltext/112153841/PDFSTART>
- Rosenstock IM. The health belief model and preventive health behavior. *Health Education Monographs* 1974;2:354–386.
- Ryan EL, Skinner CS. Risk beliefs and interest in counseling: Focus-group interviews among first-degree relatives of breast cancer patients. *Journal of Cancer Education* 1999;14:99–103. [PubMed: 10397486]
- Sandelowski M. Real qualitative researchers do not count: The use of numbers in qualitative research. *Research in Nursing & Health* 2001;24:230–240. [PubMed: 11526621]
- Stanley, M. A grounded theory of the wellbeing of older people. In: Finlay, L.; Ballinger, C., editors. *Qualitative research for allied health professionals: Challenging choices*. Sussex, England: John Wiley & Sons; 2006. p. 63-78.
- Tashakkori, A.; Teddlie, C. *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage; 1998.
- Thorne S. Data analysis in qualitative research. *Evidence-Based Nursing* 2000;3:68–70.
- Thull, DL.; Farengo-Clark, D. Genetics of breast cancer. In: Vogel, VG.; Bevers, T., editors. *Handbook of breast cancer risk assessment: Evidence-based guidelines for evaluation, prevention, counseling, and treatment*. Boston: Jones and Bartlett; 2003. p. 20-40.
- Vachon CM, Cerhan JR, Vierkant RA, Sellers TA. Investigation of an interaction of alcohol intake and family history on breast cancer risk in the Minnesota Breast Cancer Family Study. *Cancer* 2001;92:240–248. [PubMed: 11466675]

- Vernon SW, Vogel VG, Halabi S, Bondy ML. Factors associated with perceived risk of breast cancer among women attending a screening program. *Breast Cancer Research and Treatment* 1993;28:137–144. [PubMed: 8173066]
- Whittemore R, Chase SK, Mandle CL. Validity in qualitative research. *Qualitative Health Research* 2001;11:522–537. [PubMed: 11521609]

**Table 1**

## Participant Demographic Characteristics and Gail Model Estimates by Race

	<i>n</i> (%) White Women	<i>n</i> (%) 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 or higher	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 estimate		
<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. Gail Model 5-year risk estimates calculated using the National Cancer Institute's Breast Cancer Risk Assessment Tool available from <http://www.cancer.gov/bcrisktool>. An estimate of  $\geq 1.7$  is generally considered to represent elevated risk.

**Table 2**

## Breast Cancer Risk Factor Profiles by Perceived Risk Category

<b>Factors Affecting Risk</b>	<b>Below-to-Average (n=5) n %</b>	<b>Slightly Elevated (n=13) n %</b>	<b>Moderate-to-High (n=14) n %</b>
Women with >1 affected FDR	3 (60)	3 (23)	10 (71)
Women with affected mom	2 (40)	0 -	8 (57)
Women with a sister dx. < age 50	4 (80)	8 (62)	9 (64)
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)



**Table 3**

## Breast Cancer Causal Beliefs by Perceived Risk Category

<b>Causal Beliefs</b>	<b>Below-to-Average (n=5) n %</b>	<b>Slightly Elevated (n=13) n %</b>	<b>Moderate-to-High (n=14) n %</b>
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/2 <sup>nd</sup> hand exposure	0 -	1 (8)	5 (36)
Alcohol	0 -	0 -	0 -
Hormonal Factors			
Exogenous (HRT, OCs)	0 -	2 (15)	6 (43)
Endogenous (early menarche/late menopause)	0 -	4 (31)	3 (21)
Older Age	1 (20)	1 (8)	0 -
Physical abuse/trauma to the breast	0 -	1 (8)	1 (7)

*Note.* Data obtained through personal interviews.

OC = oral contraceptives.

**Table 4**

## Current Healthy Lifestyle Behaviors by Perceived Risk Category

	<b>Below-to-Average (n=5) n (%)</b>	<b>Slightly Elevated (n=13) n (%)</b>	<b>Moderate-to-High (n=14) n (%)</b>
<b>Lifestyle Behaviors</b>			
Physical Activity (e.g. exercise for fitness)			
≥ 150 min/week	3 (60)	5 (38)	5 (36)
Low-fat or Reduced-fat diet			
Consumes red meat ≤ 3 times a 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.