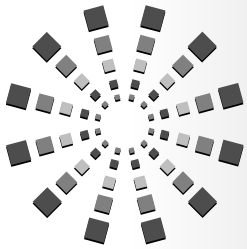

Denise Spector, MSN, MPH, RN
Merle Mishel, PhD, RN
Celette Sugg Skinner, PhD
Lisa A. DeRoo, PhD
Marcia VanRiper, PhD, RN
Dale P. Sandler, PhD

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

KEY WORDS
Breast cancer
Family history
Lifestyle behaviors
Risk perception

Although researchers have investigated the relationships between perceived risk and behavioral risk factors for breast cancer, few qualitative studies have addressed the meaning of risk and its impact on decision making regarding lifestyle behaviors. This qualitative study explored factors involved in the formulation of perceived breast cancer risk and associations 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 risk factors for breast cancer among women who have at least 1 sister diagnosed with breast cancer. Personal interviews were conducted with 32 women. Although most had heightened perceived risk, almost 20% considered themselves below-to-average risk. Participants with moderate-to-high perceived risk were more likely to report an affected sister and mother, a first-degree relative's diagnosis within 4 years, and death of a first-degree relative from breast cancer. Many women were unaware of associations between lifestyle behaviors and breast cancer risk. Only one-third of the women reported healthy lifestyle changes because of family history; dietary change was most frequently reported. Findings may be important for cancer nurses involved in developing breast cancer education programs for women with a family history of breast cancer.

Authors' Affiliations: School of Nursing, University of North Carolina at Chapel Hill (Ms Spector and Drs Mishel and VanRiper); Department of Clinical Sciences, Division of Behavioral and Communication Sciences, Southwestern Medical Center, Dallas, Texas (Dr Skinner); and Epidemiology Branch, National Institute of Environmental Health Sciences, Research Triangle Park, North Carolina (Drs DeRoo and Sandler).

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Corresponding author: Denise Spector, MSN, MPH, RN, 318 Sunset Creek Circle, Chapel Hill, NC 27516 (dspector@email.unc.edu).

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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.[1] A meta-analysis of 52 epidemiologic studies on familial breast cancer showed that 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).[2] 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 (eg, healthy weight management, regular physical activity, and avoidance or moderation of alcohol consumption).

Several modifiable lifestyle factors have been consistently related to increased breast cancer risk; these include overweight and obesity (among postmenopausal women), physical inactivity, and alcohol intake.[3–6] 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.[7,8] For women with affected FDRs, investigators have found that breast cancer risk increased 2.45-fold among daily alcohol drinkers compared with nondrinkers and was 5.8-fold greater in those who ever (vs never) smoked cigarettes.[9,10] As research more clearly elucidates health behaviors related to familial breast cancer, understanding the determinants of perceived risk and lifestyle behaviors will be important for designing effective interventions for women at increased risk.

To engage in healthy lifestyle behaviors, theories suggest a need for perception of personal risk.[11–13] 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.[14–16] Although several studies have found that awareness of risk increases with number of affected FDRs, there are subsets of women unaware of their increased risk due to family history.[17–19] 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 increased breast cancer risk compared with black women, 81% versus 50%, respectively, in one study.[20,21]

Other factors affecting risk perception are personal history of benign breast disease, breast cancer worry, and perceived control.[22,23] 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 study examined factors involved in breast cancer risk perception and explored the relationship between risk perception and lifestyle behaviors among both white and black women who are at increased risk because of family history. The qualitative research approach allowed for exploration of thoughts and beliefs about breast cancer through in-depth personal interviews.

■ Materials and 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 United States 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 4 US 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 agreed to participate are mailed written consent documents, 3 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 2 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 nonmelanoma 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 y), (*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, preaddressed opt-out cards, which were returned by 2 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 3 telephone call attempts. Three women, 2 black and 1 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, 5 women (1 white and 4 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 before interviewing. Participants were instructed to send back a signed copy of the consent form that had been mailed to them. An audio-recorded semistructured 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 1. To protect confidentiality, code numbers were assigned to participants, and recordings were deleted after transcription. All participants received a $25 incentive after 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 FDRs 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 increased risk.[24]

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.[15,17,20,25,26] After interviews were transcribed verbatim and rechecked against the original digital recordings for accuracy, 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.[27,28] "Constant comparative analysis"

Table 1 • Interview Guide

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 healthcare providers about health changes? (Probes: "What type of support/information did you receive?" "Who provided the support (ie, sister, husband, child, friend or colleague, nurse, physician)?" "What did you think about the support?")

was used to compare themes and patterns in each interview with those of other interviews.[29] Through this process, we identified themes indicating overarching ideas. Perceived risk varied widely among the women. We categorized women into 3 perceived risk categories: below-to-average, slightly elevated, and moderate-to-high, based on specific statements from women who expressed their personal risk qualitatively (eg, "…I would think that I would be moderately at risk"), quantitatively (eg, "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,[30,31] 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 1 of the 3 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.[32,33] 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.[34] 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.[35,36] The numerical display of qualitative information has been found to allow patterns in the data come forth with greater clarity.[37] The usefulness of numbers in qualitative research goes beyond representing experiences by also enhancing documentation, verification, and testing of researcher interpretations.[36]

Coding Scheme

Data were coded into 4 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 (ie, number of affected FDRs, mother 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.[22,23]

■ Results

Thirty-two women participated in the study (Table 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 ≥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 increased risk. Conversely, several women with moderate-to-high perceived risk had Gail estimates below 1.7.

Table 2 • Participant Demographic Characteristics and Gail Model Risk Estimates by Race (n = 32)

	White Women, n (%)	Black Women, n (%)
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)
Body mass index, kg/m^2		
<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)

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

Table 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.[36] Table 4 presents risk characteristics, causal beliefs, and current healthy lifestyle behaviors among women in the 3 perceived risk categories. Because current lifestyle behaviors are incorporated into Tables 3 and 4, results are not shown below.

Table 3 • Common Themes and Patterns by Level of Perceived Risk

Perceived Risk	Themes	Patterns
Below-to-average	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 min/wk
		≤1 alcoholic drink per day
		Avoidance of smoking tobacco
Slightly elevated	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 per day
		Avoidance of smoking tobacco
Moderate-to-high	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 per day
		Avoidance of smoking tobacco

Below-to-Average Perceived Risk

Although 4 of 5 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 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 much 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 2 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)

Table 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 first-degree relative	3 (60)	3 (23)	10 (71)
Women with affected mother	2 (40)	0	8 (57)
Women with a sister diagnosed age <50 y	4 (80)	8 (62)	9 (64)
Women with a sister diagnosed <5 y ago	2 (40)	2 (15)	5 (36)
Women who had a sister or mother 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)
Antiestrogen 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/second-hand exposure	0	1 (8)	5 (36)
Alcohol	0	0	0
Hormonal factors			
Exogenous (HRT or 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 (eg, exercise for fitness) ≥150 min/wk	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 nonfat or low-fat dairy	3 (60)	10 (77)	11 (79)
Fruit and vegetable intake ≥5 servings per day	2 (40)	4 (31)	2 (14)
Alcohol consumption ≤1 drink per day	5 (100)	11 (85)	14 (100)
Nonsmoker	5 (100)	13 (100)	12 (86)

Abbreviation: OC, oral contraceptive.
Data obtained through personal interviews.

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 hormone replacement therapy (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 1 woman made a behavioral change after her sister's diagnosis, which was quitting smoking. Two discontinued

HRT and 3 began antiestrogen 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 40 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 (eg, most had an affected sister and mother), 5 had Gail risk estimates below 1.7, indicating low risk.

> I've had 2 aunts and my mother and my sister have also had breast cancer, so it's kind of like a joke with my other 4 sisters, it's not if but when we get it. (White participant—sister diagnosed in her early forties)

Refer to Table 4 for prominent patterns related to familial experiences found among these women. Overall, 11 did not express great concern or worry about breast cancer. However, 3 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 4 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.

> It 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 antiestrogens. 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 perception 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 with 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 with 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 factors. 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%, respectively).

■ 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.[20,21] 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 (eg, affected mother, sister died of 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.[38] 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.[39]

Similar to previous studies,[40,41] a high percentage of women in both racial groups believed that 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.[42]

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.[26,41,43]

Most women identified at least 1 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.[3,5,6]

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.[42] 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, 1 black woman who related lack of exercise with breast cancer felt that 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 antiestrogen 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 antiestrogens 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,[25] who reported that 42% of FDRs, who were primarily white, reported behavior change after diagnosis of breast cancer in an 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 the 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 the 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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