
Isaac M. Lipkus, Deborah Iden, Jennifer Terrenoire, and John R. Feaganes
Duke University Medical Center, Durham, North Carolina 27701

Abstract
There has been very little research exploring the relationships among perceptions of, and concern about, getting breast cancer and interest in genetic testing for breast cancer among African-American women with and without a family history of breast cancer. This study explored these issues among 130 and 136 African-American women with and without a family history of breast cancer, respectively. Women with a family history reported having greater perceived breast cancer risks and concerns than women without a family history of breast cancer. Knowledge of breast cancer risk factors was very poor and correlated weakly with perceptions of risk and concern. In attributional analyses, acknowledging one’s family history status was the strongest predictor of perceived risk only among women with a family history. Women with a family history of breast cancer expressed greater interest in genetic testing for breast cancer susceptibility than women without a family history, although interest in testing was high overall. Increasing perceptions of breast cancer risks and concerns were related to a greater interest in genetic testing, and this relationship was not moderated by family history status.

Attributions of risk and knowledge of breast cancer risk factors generally were not related to interest in testing. Overall, these results suggest that: (a) African-American women with a family history are more concerned about and do recognize their greater risk of breast cancer; (b) knowledge of risk factors and attributions of risk are not directly related to interest in genetic testing; and (c) concerns, rather than beliefs about one’s risk, are more powerfully related to interest in genetic testing, independent of family history status.

Introduction
Since the discovery of BRCA1 and BRCA2, increased research attention has been devoted to factors that promote interest in, and reactions toward, genetic testing for breast cancer susceptibility. Most of our knowledge in these areas is derived from Caucasian women rather than other racial groups, such as African-Americans. What little is known suggests that African-Americans, despite having more positive attitudes about the benefits of genetic testing than Caucasians, are less interested in genetic testing for breast cancer and are less likely to attend educational or counseling sessions about BRCA1 (1-4). Unfortunately, these studies have not examined interest in genetic testing for breast cancer susceptibility comparing African-American women with and without a family history of breast cancer. By assessing correlates of, and interest in, genetic testing among African-American women with and without a family history of breast cancer, community and clinical interventions can provide targeted educational programs addressing the specific needs of women at different risks. Such programs would address issues and misperceptions most pertinent to African-American women at different risks about the appropriateness of genetic testing to help them make informed decisions.

This paper has three goals: (a) we assess whether family history status among African-American women differentially predicts interest in genetic testing for breast cancer susceptibility; (b) we assess whether interest in genetic testing is related to two factors correlated with the desire for testing, perceptions of breast cancer risk and concerns (5-8), and whether family history status moderates these relationships. In so doing, we examine whether these two groups differ in their perceived breast cancer risks and concerns; and (c) we assess whether attributions of risk and knowledge of breast cancer risk factors are related to perceived risk and interest in genetic testing. Studies show that knowledge of personal risk factors may not predict interest in testing independently of overall perceived risk and worry (6, 9). Thus, although attributions and knowledge may be related to breast cancer risks, they also may relate directly to interest in testing.

We first provide a brief theoretical review as to why breast cancer risk and concerns should be related to interest in genetic testing for breast cancer susceptibility. We then review African-Americans’ perceptions of their breast cancer risks and worries, and we state the study predictions.

Theory Linking Breast Cancer Risk Perceptions, Concerns, and Interest in Genetic Testing. This study examines two processes that can affect intentions to be tested for breast cancer susceptibility: cognitions (i.e., perceived risk) and affect (i.e., breast cancer concerns). Models of health behavior, such as the Health Belief Model, Protection Motivation Theory, and the Precaution Adoption Model, suggest that increased perceived risk should facilitate behavior change (10-14), and that emo-
tions (e.g., fear, anxiety, or worry) may serve a similar purpose (15–18). Moreover, high levels of perceived risk may lead to modest increases in breast cancer worries and distress (19). On the basis of the Parallel Response Model and the Extended Parallel Process Model (20–21), when people experience high threat (i.e., high risk + severity) and negative affect (e.g., fear), they may engage in two processes: danger control and fear control. Danger control is aimed at removing or reducing the source of threat; fear control is aimed at removing or reducing the negative emotions produced by the threat.

Genetic testing can accommodate both of these processes. Knowing that one is not a carrier of a BRCA1 or BRCA2 mutation should reduce heightened perceived breast cancer risk and negative affect (e.g., anxiety; Ref. 22). Learning that one is a mutation carrier may lead to actions to increase a person’s control over the danger of getting breast cancer. For example, carriers may choose to undergo a prophylactic mastectomy to reduce risk. Indeed, Lerman and colleagues (6, 23) found that even the expectation of testing positive for a BRCA1 mutation was related to feelings of greater control. In sum, greater perceived breast cancer risks and concerns can promote interest in genetic testing because: (a) a negative test result should reduce perceived risk and one’s negative affect surrounding perceived risk; and (b) a positive test result can lead to decisions and medical procedures that enhance one’s sense of control over reducing the risk.

Perceptions of Breast Cancer Risk among African-American Women. African-American women typically view themselves to be at low risk of developing cancer generally and breast cancer specifically (24–30; see Refs. 19 and 31 for exceptions). This is even true for those with a family history (32–33), perhaps because they fail to recognize family history as a predictor of risk (31). This interpretation is consistent with African-Americans’ generally poor knowledge of breast cancer risk factors (30, 34) and suggests that: (a) educating these women about breast cancer risk factors is needed; and (b) erroneous knowledge of breast cancer risk factors and causes (i.e., attribution) may ultimately affect interest in genetic testing directly or by affecting perceptions of risk.

Of import, if perceived risk is linked to interest in genetic testing, then it is worthwhile to understand: (a) correlates that increase or decrease perceived risk, such as knowledge of breast cancer risk factors and attributions of risk (i.e., reasons why women report a specific level of risk; Refs. 35–37); and (b) whether these correlates are related to interest in testing. This information would address whether interventions pertaining to interest in genetic testing need to target overall perceived risk and/or specific underlying correlates of risk that promote interest in testing differently among African-American women at different risk. This study begins to explore these issues.

Perception of Breast Cancer Concerns. Studies of African-American women’s worries about getting breast cancer show inconsistent findings. Some studies show that older African-American women express low levels of breast cancer worry (38), whereas other studies, including those with a family history of breast cancer, show elevated levels of worry (31, 33). Moreover, African-Americans appear to be more concerned about breast cancer compared with Caucasian women (33, 39).

Study Hypotheses. Using a sample of African-American women with and without a family history of breast cancer, the present paper tested the following predictions:

Hypothesis 1. Women with a family history of breast cancer will report greater perceived breast cancer risks and concerns than women without a family history of breast cancer.

Hypothesis 2. Women will most often mention heredity and personal action causes (e.g., diet, exercise, get mammograms) as determinants of their perceived lifetime breast cancer risk.

Hypothesis 3. Women with a family history of breast cancer will report greater interest in genetic testing for breast cancer than women without a family history of breast cancer.

Hypothesis 4. Perceptions of breast cancer risk and concern will be related to greater interest in genetic testing for breast cancer susceptibility. However, family history status will interact with (i.e., moderate) these relationships. Specifically, breast cancer risks and concerns will be related more powerfully to interest in genetic testing among women with, rather than without, a family history.

Hypothesis 5. Knowledge that family history is related to breast cancer risk will be related to interest in genetic testing. Similarly, attribution of risk to heredity will be related to interest in genetic testing.

Materials and Methods

Participants. Women with a family history were recruited by first contacting a first-degree relative (n = 91) diagnosed with breast cancer based on the information provided by Duke University Medical Center’s Tumor Registry. Data on stage, length since and mean age at diagnosis were available on 69 of the 81 breast cancer patients who consented to give the names of their relative(s)—this information can be obtained from the first author upon request. Referring patients at times provided the names and phones numbers of more than one first-degree relative.

The sample of African-American women without a family history of breast cancer (i.e., controls) was obtained from a sampling frame of all of the African-American women who attended the Duke Radiology Department within the last 3½ years. To obtain comparability between groups, controls were matched with women with a family history based first on age (within ± 6 months), and then on mammography history (± 3 months of most recent mammogram). Because this study was aimed primarily at affecting mammography screening, age and most recent mammogram were viewed as the two most critical matching variables based on the limited sample size of African-American women. Including other matching variables, such as education, would have resulted in fewer successful complete matches.

Attempts were made by phone to recruit 384 women (233 controls and 151 with a family history). Of these 384 attempts, 194 controls and 151 women with a family history were reached. Among those reached, 45 controls and 15 women with a family history refused to participate, and one control and two women with a family history initially consented to participate and later revoked consent at the time of the baseline interview. In addition, 12 controls and four women with a family history could not participate for other reasons (e.g., health reasons, wrong race). The final sample consisted of 130 (86% response rate) and 136 (70% response rate) African-American women with and without a family history of breast cancer, respectively. The demographic characteristics of study participants are presented in Table 1. The groups did not differ significantly on any of the demographic characteristics. Overall, 111 successful matches were made on age, including 75 matches on both age and screening history. Only 15 women with a family history of breast cancer could not be matched with a control.

Procedure. Data presented here are based on all of the participants who completed a baseline telephone interview and
agreed to be part of a larger mammography intervention study; results will be presented in forthcoming articles. Study participants were mailed a cover letter stating that the purpose of the study was to educate African-American women about breast cancer risk factors and mammography. Within 2 weeks of the mail-out, a trained telephone interviewer from the Duke Risk Communication Laboratory contacted potential participants, reminded them of the purpose of the study, and completed a 15-min baseline interview. The interview consisted of obtaining information on the following variables relevant to this paper: Demographics. Age, education (ranged from less than high school to graduate work), marital status (married, living as married, single, divorced, widowed, and separated), and work status (full/part-time, unemployed, full-time homemaker, retired).

Perceptions of Risk. Perceived lifetime risk was assessed, using a five-point Likert scale, by asking “What do you think is your chance of getting breast cancer in your lifetime?” Response options were: very unlikely, unlikely, moderate chance, likely, and very likely.

Attributions of Risk. After responding to their perceived lifetime risk, women were asked: “In the previous question, you mentioned that your risk of getting breast cancer was (repeat response woman gave). What things did you think about that led you to choose that answer?” Responses were subsequently coded by two coders (99% agreement) into one of the categories used by Aiken et al. (35) based on Weinstein’s (37) scheme: personal actions (e.g., exercise, diet, do not smoke, get mammograms), heredity (e.g., family history), physiological causes (e.g., lumps in breast(s), no children, age), environment (e.g., pesticides), psychological (e.g., personality, being optimistic), and chance (e.g., luck).

Knowledge of Breast Cancer Risk Factors. Women were asked (yes/no) whether nine variables were related to getting breast cancer. Variables were selected from the epidemiological literature and other knowledge questionnaires (34, 40–42) and included: (a) being older; (b) having a family history; (c) having lots of stress; (d) having a breast injury (e.g., bruise); (e) being older (e.g., >30) when you have the first child; (f) never having children; (g) late age of menopause (>55); (h) early menarche (<12); and (i) never having breast-fed. Alpha for the knowledge scale was 0.59.

Breast Cancer Concerns. Participants were asked on a five-point likert scale, “How concerned are you about getting breast cancer?” Response options were: not at all concerned, slightly concerned, somewhat concerned, concerned, and very concerned.

Interest in Genetic Testing for Breast Cancer. This was assessed using the following question: “There are some new blood tests that may be able to tell you if you have a greater chance of getting breast cancer because of something that might have been passed down to you from your blood relatives, that is, through your genes. If this test was free, how interested would you be in having it done?” Response options were: not at all interested, slightly interested, somewhat interested, interested, and very interested.

Results

Overview. We first discussed whether there were differences in breast cancer risk perceptions and concerns, attributions of risk, and knowledge of breast cancer risk factors between women with and without a family history of breast cancer. The purpose of these analyses was to establish group differences that may subsequently relate to interest in genetic testing, which formed the basis for the second set of analyses.

Perceptions of Breast Cancer Risk and Worry as a Function of Family History Status. It was expected that women with a family history of breast cancer would report greater perceived breast cancer risk and concerns than women without a family history. As predicted, bivariate relationships revealed that women with a family history perceived themselves at greater risk ($\chi^2(1) = 31.2; P < 0.0001$ for trend), and were more concerned about getting breast cancer than women without a family history ($\chi^2(1) = 7.4; P < 0.007$ for trend). Whereas 24, 52, and 14% of women without a family history reported below-average, average, or above-average risk, respectively, 14, 40, and 46% of women with a family history reported below-average, average, or above-average risk, respectively. Similarly, whereas 40, 27, and 33% of women without a family history reported being not at all/slightly concerned, somewhat concerned, and concerned/very concerned about getting breast cancer, respectively, 31, 21, and 48% of women with a family history reported not at all/slightly concerned, somewhat concerned, and concerned/very concerned about getting breast cancer, respectively. On the basis of the contingency table phi statistic, risk and concern were positively correlated among women with and without a family history ($\phi = 0.59$ and 0.53; $P < 0.001$, respectively). Mammography screening did not affect perceived risk or concern.

Attributions of Risk. Having established that perceptions of risk differed among these two groups of women, we sought to further understand the underlying correlates of women’s perceptions of risk by analyzing their attributions of risk. These relationships were analyzed via three different strategies: (a) we examined the pattern of relationships between attributional domains and women’s ratings of their risk, controlling for family history status; (b) we examined whether women with and without a family history differed in the frequency with which they mentioned a specific category; and (c) we examined whether family history status interacted with attributional domains to predict perceptions of risk. Because environmental, psychological, and chance causes were mentioned by less than 1% of the participants, these domains will not be discussed further.

There were no significant overall bivariate relationships between risk perceptions and heredity and physiological causes.

### Table 1 Demographic characteristics of women with and without (control) a family history of breast cancer

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Controls</th>
<th>Family History</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;40</td>
<td>25</td>
<td>43.1</td>
</tr>
<tr>
<td>40–49</td>
<td>52</td>
<td>54.7</td>
</tr>
<tr>
<td>≥50</td>
<td>59</td>
<td>52.2</td>
</tr>
<tr>
<td>High school education or less</td>
<td>48</td>
<td>35.5</td>
</tr>
<tr>
<td>Married or living as married</td>
<td>69</td>
<td>51.1</td>
</tr>
<tr>
<td>Work full-time</td>
<td>82</td>
<td>60.7</td>
</tr>
<tr>
<td>Afflicted family member</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>72</td>
<td>55.9</td>
</tr>
<tr>
<td>Sister</td>
<td>41</td>
<td>31.5</td>
</tr>
<tr>
<td>Daughter</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Mother and one sister</td>
<td>9</td>
<td>6.9</td>
</tr>
<tr>
<td>Mother and two sisters</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Two sisters</td>
<td>5</td>
<td>3.8</td>
</tr>
<tr>
<td>Three sisters</td>
<td>1</td>
<td>.8</td>
</tr>
</tbody>
</table>
However, women who reported personal action causes were significantly more likely to report less risk than women who did not mention personal action causes ($X^2 (1) = 20.1; P < 0.001 for trend). Taking into account family history status, women, rather than without, a family history of breast cancer were more likely to mention heredity causes (66.9 versus 47.7%; $X^2 (1) = 9.9; P < 0.002), and less likely to mention physiological (22.3 versus 34.8%; $X^2 (1) = 4.9; P < 0.03) and personal action causes (16.9 versus 52.2%; $X^2 (1) = 36.4; P < 0.001). The pseudo-homogeneity statistic (43), which tests whether the homogeneity of effect between attributions of risk and perceived risk differ by strata, revealed that the relationship between perceived risk and heredity differed by family history status ($X^2 (1) = 17.5; P < 0.001). Women with a family history who mentioned heredity causes (e.g., having a family history of breast cancer) were more likely to report greater risk ($X^2 (1) = 17.5; P < 0.001). Among women without a family history, there was no relationship between the mentioning of heredity causes (e.g., not having a family history) and perceived risk ($X^2 (1) = 2.6; P > 0.10).

Knowledge of Breast Cancer Risk Factors as a Function of Family History Status. It was predicted that knowledge of breast cancer risk factors would be low. Degree of knowledge was scored as follows: (a) a correct response to each of the nine potential risk factors received a score of 1; and (b) incorrect or “don’t know” responses received a score of 0. The percentage of correct responses to each of the nine knowledge items by family history status is presented in Table 2.

Inspection of Table 2 reveals that women with and without a family history had poor knowledge of breast cancer risk factors. Less than 45% of women in both groups correctly knew that growing older, having no children or having the first child after age 30, late age of menopause, early menarche, and never having breast-fed were related to an increased breast cancer risk. Furthermore, only 42% knew that stress was not related to breast cancer risk, and 28–34% knew that injury to the breast(s) did not increase breast cancer risk. However, a high proportion of women in both groups (>88%) correctly mentioned family history as a risk factor. Subsequent $X^2$ tests revealed no significant differences in proportions of correct responses to each knowledge item between women with and without a family history of breast cancer. Creating a total knowledge score by summing across items revealed that both groups of women correctly identified a median of three items.

Relationships between individual knowledge items and perceived risk revealed only one significant finding after controlling for the number of tests performed ($0.05/9, \alpha = 0.005$). Women who correctly responded that having a child after age 30 increases risk were more likely to perceive themselves at higher risk ($X^2 (1) = 10.9; P < 0.001 for trend). Relationships between each knowledge item and risk did not differ by family history status. Spearman correlations were conducted to assess relationships between the total knowledge score and perceived breast cancer risk and concern by group. Among women with a family history, those who had more knowledge reported greater risk ($r = 0.19; P < 0.04$) and felt more concerned about getting breast cancer ($r = 0.22; P < 0.02$). Among women without a family history, knowledge was unrelated to perceived risk and concern ($P = 0.12$ and $0.13$, respectively).

Relationships between Interest in Genetic Testing and Family History Status. It was predicted that women with a family history of breast cancer would report more interest in being tested for breast cancer susceptibility than women without a family history. As predicted, there was a significant linear bivariate relationship between interest in genetic testing and family history status ($X^2 (1) = 6.3; P < 0.02 for trend). Among women with a family history, 11, 17, and 72% reported being not at all/slightly interested, somewhat interested, and interested/very interested, respectively. Among women without a family history, 25, 16, and 58% reported being not at all/slightly interested, somewhat interested, and interested/very interested, respectively.

Relationship between Interest in Genetic Testing and Perceived Breast Cancer Risks and Concerns. It was predicted that women who perceived greater risk and were more concerned about breast cancer would report greater interest in genetic testing. This prediction was confirmed for both perceived risk ($X^2 (1) = 4.4; P < 0.04 for trend) and concern ($X^2 (1) = 13.3; P < 0.001 for trend).3

Relationship between Interest in Genetic Testing and Knowledge of Breast Cancer Risk Factors. It was expected that knowledge of family history as a risk factor would be related to interest in genetic testing for breast cancer susceptibility. No other a priori predictions were made. Bivariate relationships were computed between each of the nine knowledge items and interest in genetic testing stratifying by family history status. Because of the number of tests conducted, we used a more conservative type 1 error of 0.005. As predicted, there was an overall significant trend between acknowledging family history status as a risk factor and interest in genetic testing ($X^2 (1) = 12.7; P < 0.0001$). Specifically, among both groups, women who knew that family history was related to increased breast cancer risk expressed a stronger desire to get tested than women who did not ($Ps < 0.02$ for trend within groups). Among women without a family history who correctly attributed family history with greater risk, 61% were more than somewhat interested in genetic testing, compared with 33% who were not aware of this association. Among women with a family history, 74 versus 53% were more than somewhat interested. No other significant effects were found.

Relationship between Interest in Genetic Testing and Attributions of Risk. It was expected that interest in genetic testing would be most strongly associated with heredity explanations. Bivariate analyses, stratified by group, revealed no significant trends between interest in genetic testing and any attributional domain overall or within groups. There were no

---

3 The 5 x 5 contingency tables can be obtained from the first author upon request.
Multivariate Analyses Relating Interest in Genetic Testing for Breast Cancer Susceptibility and Breast Cancer Perceived Risk and Concern. It was predicted that risk and concern would be related more powerfully to interest in genetic testing among women with, rather than without, a family history. To test these predictions, we conducted hierarchical proportional logistic regression models. Step one included age, education, and marital and family history status; step two included the main effects of risk or concern, and step three included risk/concern by family history status interactions. In these analyses, having a high school education or less, being married or living as married, not having a family history of breast cancer, perceiving oneself as being very unlikely to get breast cancer, and being not at all concerned about getting breast cancer served as reference groups (coded 0). We assessed the fit of each model by testing the $\chi^2$ difference between each successive step (e.g., $\chi^2$ difference between main effects and interaction models).

The initial models revealed a violation of the proportional odds assumption regressing interest in genetic testing onto the risk main effect and interaction model. The assumption continued to be violated when interest in genetic testing was collapsed into three tiers: (a) not at all and slightly interested; (b) somewhat interested; and (c) interested and very interested. Consequently, interest in testing was collapsed into two categories for all of the analyses: being somewhat, slightly or not at all interested versus being interested and very interested.

Overall, there were no significant risk main effects or risk by family-status interactions. Interest in genetic testing was related to being concerned about getting breast cancer as a main effect but not as an interaction. The final logistic regression model including concern is reported in Table 3. Women who reported being very concerned were significantly more likely to report being interested or very interested in genetic testing for breast cancer susceptibility than women who reported being not at all concerned. In addition, women who were not married expressed less interest in genetic testing than those who were married.

We also examined whether the single significant bivariate relationship between knowledge of family history status as a risk factor continued to predict interest in genetic testing using the same multivariate modeling procedures. There was no significant main effect for knowledge of family history as a risk factor or an interaction with family history status. Because none of the attributional domains were significantly related to interest in genetic testing, multivariate modeling was not performed.

**Discussion**

The major aim of this study was to assess differential interest in breast cancer genetic testing among African-American women with and without a family history of breast cancer and the correlates of interest. Overall, 72% of our sample of African-American women with a family history expressed being interested or very interested in genetic testing compared with 58% of the women without a family history. These rates among women with a family history are comparable, though lower, than other studies using primarily Caucasian first-degree relatives of women with a family history of breast or breast and ovarian cancer. Among those studies, interest in genetic testing for breast cancer susceptibility has ranged from 75 to 95% (6, 7, 23). We are unaware of any study to compare directly our results with a comparable sample of African-American women with a family history. Similarly, only indirect comparisons can be made between our results pertaining to women without a family history and those of two other studies. In a statewide telephone survey in Kentucky, Andrykowski et al. (2) found that among non-Caucasian women, of which African-Americans constituted the largest subgroup, 76% expressed interest in being told of their personal genetic breast cancer predisposition. On the basis of women enrolled in an healthcare management organization, Tambor et al. (1) found that among those not interested in genetic testing, 20% were African-American. Thus, comparing our findings with these two studies and assuming that in the latter two studies, African-American women had no family history, we conclude that our sample expressed less interest in testing.

Women with a family history expressed significantly greater interest in testing than women without a family history, in the bivariate analysis only. We examined whether breast cancer risk perceptions and concerns could partly explain differences in interest in testing among these two groups. Specifically, it was expected that differences in interest would be reflected by different levels of perceived breast cancer risk and concern such that these two mechanisms would predict more powerfully interest among women with, rather than without, a family history of breast cancer. Whereas perceived risk and concern were related to interest in testing in bivariate analyses, there were no significant interactions between these constructs and family history status.

Given that perceived lifetime risk was related to interest in testing, we addressed two relevant issues: (a) the underlying correlates of risk, specifically knowledge of breast cancer risk factors and attributions of risk; and (b) the extent to which knowledge of breast cancer risk factors and attributions of risk correlated with interest in genetic testing. With respect to correlates of risk, attributions to heredity were related more strongly to increased perceived risk among women with a family history. Among women without a family history, attributions to heredity were unrelated to perceived risk. Knowledge of breast cancer risk factors was a very weak correlate of risk and concern. With respect to interest in genetic testing, correctly acknowledging family history status as a risk factor...
was related in bivariate but not in multivariate analyses. None of the attributional domains were related to interest in testing.

What are the implications of these findings for pretest genetic counseling and decision-making among African-American women at different risk? We offer three suggestions:

(a) although perceptions of risk and concern both were related to interest in genetic testing, being concerned about getting breast cancer was related more strongly to testing. Indeed, in an exploratory logistic regression analysis controlling for family history status, when the main effects of perceived lifetime risk were added to a model with the main effects of being concerned, only being very concerned was related to greater interest in genetic testing compared with women not at all concerned. Therefore, genetic counselors should focus on the emotional precursors and aftermath of testing, such as women’s concerns about getting breast cancer (44). Although not investigated in this study, women who are very concerned about getting breast cancer may be highly receptive to, and perhaps process more thoroughly, information pertaining to genetic testing for breast cancer;

(b) genetic counselors and other health educators should discuss how breast cancer risk is related to family history status, which may then affect desire to test. Counseling and educational programs emphasizing family history may dissuade women at lower risk from testing. Unlike other studies (32), the majority of this sample knew that having a family history increased one’s risk for breast cancer, but a significant proportion (i.e., about 10% in both groups) did not identify correctly family history status with being at increased risk. Therefore, there is a need to continue educating African-American women about how family history status and other risk factors (e.g., age) contribute to breast cancer risk. However, among the two groups of women studied, those without a family history may need the link between family history status and risk reinforced. As the attributional analyses revealed among these women, perceived risk was unrelated to attributions to heredity causes; and

(c) attributions may ultimately influence testing through their effects on risk perceptions. In this regard, efforts to help women make informed decisions about testing should focus on personal action causes (e.g., exercise, dietary habits, smoking behavior, getting mammograms, and so forth) in relation to perceived risk. Women who mentioned “beneficial” personal action causes (e.g., diet, exercise, getting mammograms) were significantly less likely to report increased risk than women who did not mention personal action causes. What is relevant for counseling is that women who think that they engage in detrimental behaviors may also think themselves to be at higher risk, which may then be related to a greater interest in testing. Therefore, counseling may affect interest in testing by targeting life-style factors that women think may put them at higher risk. Life-style factors may be the most salient reasons why women without a family history desire testing for breast cancer susceptibility. Indeed, women without a family history mentioned significantly more personal action causes to explain their perceptions of risk than women with a family history.

Our findings need to be interpreted in light of several methodological issues:

(a) we used as controls women who attended a radiology clinic. It is unclear to what extent the results might have differed if controls had been obtained through a random community sample;

(b) we used single measures of the main outcomes, a method that commonly raises questions about item reliability and validity. Single-item measures of perceived breast cancer risk are commonly used in studies with African-American women (e.g., Refs. 19 and 45), and to date, there is no measure of perceived risk that is clearly superior (46) or consistently used to study risk in African-American populations. Similarly, there is no “gold standard” question(s) to evaluate interest in genetic testing among African-American women. The results pertaining to breast cancer concerns might have differed had we used more in-depth measures such as the Lerman et al. (47) worry scale or the three-item worry scale used by McCaul et al. (48). However, given that the baseline interview had to assess several constructs to reduce respondent burden, we thought that face valid single-items would suffice. Nonetheless, future research should use more comprehensive measures of the constructs explored in this study;

(c) we did not collect additional data pertaining to knowledge about BRCA1 or BRCA2 testing (e.g., have they ever heard of these genes) and reasons for getting tested; data are being collected on these issues. Preliminary results suggest that for both groups, the main reason to test is to find out whether they are at higher risk (approximately 50% mentioned this reason). Neither did we assess how many of these women, if offered testing, would accept and attend.

(d) we assessed only one emotional reaction to getting breast cancer (i.e., concerns); other emotional responses, such as fear and anxiety, should be assessed; and

(e) although we assessed attributions for risk, we did not ask women why they felt concerned about getting breast cancer. We suspect that our population would have had a difficult time separating attributions for risk and concern, thereby resulting in highly similar responses. Future research should address specifically the underlying causes of concern related to breast cancer risk.

Lastly, readers are cautioned to interpret these findings in terms of women’s hypothetical interest in genetic testing. A more “realistic” portrayal of interest in testing would have been achieved if these women had been given information concerning the complexities involved in genetic testing. For example, we did not provide information about the risks and benefits related to genetic testing. We did not mention the likelihood of breast cancer occurrence among women who do test positive. Being informed of the high likelihood of occurrence may dissuade some women from testing. Nor did we discuss some of the potential ramifications of testing positive for issues related to family decisions (e.g., having children), potential negative emotional side effects of testing, possible treatment options, and issues related to confidentiality and health insurance. The failure to discuss these issues likely desensitized women to the complexities involved in genetic testing, some of which may have served to reduce interest in testing. Future studies exploring interest in genetic testing for breast cancer susceptibility among African-American women at different risks should provide information regarding these issues, to more powerfully assess how they affect interest in, and actual, testing. Despite these limitations, this study provides rather detailed information about perceptions of breast cancer risk and also preliminary data about interest in genetic testing in two rarely compared groups of African-American women.

Acknowledgments

We thank Celette Sugg Skinner, Barbara Rimer, Angela Womack, and two anonymous reviewers for the helpful comments on an earlier version of this manuscript.
References


Isaac M. Lipkus, Deborah Iden, Jennifer Terrenoire, et al.


Updated version
Access the most recent version of this article at:
http://cebp.aacrjournals.org/content/8/6/533

Cited articles
This article cites 38 articles, 3 of which you can access for free at:
http://cebp.aacrjournals.org/content/8/6/533.full#ref-list-1

Citing articles
This article has been cited by 11 HighWire-hosted articles. Access the articles at:
http://cebp.aacrjournals.org/content/8/6/533.full#related-urls

E-mail alerts
Sign up to receive free email-alerts related to this article or journal.

Reprints and Subscriptions
To order reprints of this article or to subscribe to the journal, contact the AACR Publications Department at pubs@aacr.org.

Permissions
To request permission to re-use all or part of this article, contact the AACR Publications Department at permissions@aacr.org.