

# Sociocultural Predictors of Breast Cancer Risk Perceptions in African American Breast Cancer Survivors

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## Abstract

Although African American breast cancer survivors are at increased risk for developing breast cancer again, empirical data are not available on breast cancer risk perceptions in these women. This study characterized perceived risk of developing breast cancer in African American breast cancer survivors at risk for having a BRCA1 or BRCA1 (BRCA1/2) mutation and identified factors having significant independent associations with risk perceptions. Participants were 95 African American breast cancer survivors at an increased risk for having a BRCA1/2 mutation. Risk perceptions and sociodemographic, clinical, treatment, and sociocultural factors were collected during a structured telephone interview. Most women reported that they had the same or lower risk of developing breast cancer again compared with other women (53%); however, a substantial minority of women (47%) reported that they had a higher or much

higher risk. Factors having significant independent associations with heightened risk perceptions included having a  $\geq 10\%$  prior probability of having a BRCA1/2 mutation [odds ratio (OR), 2.91; 95% confidence interval (95% CI), 1.09-7.72;  $P = 0.03$ ] and more years of formal education (OR, 2.74; 95% CI, 1.02-7.36;  $P = 0.05$ ). In addition, women who thought about the past a lot were three times more likely to report heightened risk perceptions compared with those who did not think about the past a lot (OR, 3.72; 95% CI, 1.45-9.57;  $P = 0.01$ ). These results suggest that it may be important to ensure adequate risk comprehension among African American women as part of genetic counseling for inherited breast-ovarian cancer risk. Discussion of risk perceptions within the context of existing beliefs and values may facilitate this process. (Cancer Epidemiol Biomarkers Prev 2007;16(2):244-8)

## Introduction

Each year, thousands of African American women are diagnosed with breast cancer (1, 2). Epidemiologic studies have shown that about 16% to 28% of African American women who have a personal and family history of breast and/or ovarian cancer that is suggestive of hereditary disease carry BRCA1 or BRCA2 (BRCA1/2) mutations (3-5). Although women with a personal history of breast cancer have a 0.56% to 1.0% risk per year of developing a second primary breast cancer, women who carry BRCA1/2 mutations have a substantially higher risk, approaching a 50% lifetime risk (6-9). Breast cancer risk perceptions are important to utilization of genetic testing for BRCA1/2 mutations (10), which may be low among African American women (11). Prior research has shown that African American women without a personal history of breast cancer may not believe that they have an increased risk for developing disease, although known risk factors (e.g., family history of breast cancer in a first-degree relative) are present (12). However, risk perceptions have not been evaluated in African American breast cancer survivors at increased risk for having a BRCA1/2 mutation.

Risk perception is an important construct in the Health Belief Model; according to this model, perceived risk is likely to be influenced by sociodemographic factors, such as education level (13). However, factors associated with breast

cancer risk perceptions may also vary within specific ethnic groups (12) and may also be influenced by sociocultural factors, such as temporal orientation. Temporal orientation, or attitudes about specific domains of time (e.g., past, present, and future), is one of the primary contexts through which individuals understand and give meaning to experiences (14). Temporal orientation is an aspect of one's cultural worldview, which is a set of interrelated beliefs about reality (15-17). Previous research has shown that temporal orientation related to health behaviors may differ among African Americans and Caucasians (18). Because perceived risk of developing cancer implies a specific time trajectory in that these beliefs are an estimate of one's probability of developing breast cancer again at some point in the future, temporal orientation may also be important to risk perceptions in specific ethnic groups. There is evidence that temporal orientation is an important factor in decisions about breast cancer screening in African American women and participation in genetic counseling and testing for inherited breast cancer risk in Caucasian and African American women (19-21). Previous research has also suggested that temporal orientation may contribute to breast cancer risk perceptions in African American women (12); however, empirical data are not available on the relationship between temporal orientation and risk perceptions in African American breast cancer survivors at increased risk for hereditary disease.

The objective of this study was to characterize breast cancer risk perceptions in African American breast cancer survivors at increased risk for having a BRCA1/2 mutation. Although ethnic group comparisons have been critical to characterizing differences in risk perceptions between African American and Caucasian women (12, 22), a better understanding of within-group variation in risk perceptions is needed to develop more effective genetic counseling and education protocols for African American breast cancer survivors at increased risk

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for having a BRCA1/2 mutation. Therefore, we conducted an exploratory study to describe risk perceptions and identify factors having significant independent associations with perceived risk in African American women with a personal and family history of breast cancer that is suggestive of hereditary disease. Based on prior research (13), we evaluated the relationship between risk perceptions and sociodemographic factors. Because attitudes about time have been shown to influence acceptance of cancer risk information in African American women (19), we also explored the relationship between risk perceptions and temporal orientation. In addition, we evaluated whether risk perceptions varied among women who received a lumpectomy versus mastectomy because type of surgical treatment has implications for ipsilateral breast cancer (23, 24). We also evaluated the relationship between risk perceptions and clinical factors, including family history of cancer and BRCA1/2 prior probability. We predicted that more years of formal education, future temporal orientation, having had a lumpectomy, stronger family history of cancer, and a higher BRCA1/2 prior probability would be associated with heightened risk perceptions.

## Materials and Methods

**Study Population.** This study was conducted at the University of Pennsylvania (Philadelphia, PA) following approval from the Institutional Review Board. Participants were African American women at increased risk for having a BRCA1/2 mutation who were enrolled in a clinical genetic counseling research study. To be eligible for participation, women had to have at least a 5% to 10% prior probability of having a BRCA1/2 mutation based on their personal and family history of breast and/or ovarian cancer. Women who had a 5% to 10% prior probability were eligible to participate in the study because this is considered to be the lower bound for offering clinical genetic testing for BRCA1/2 mutations (25). Because cancer survivorship begins at diagnosis (26, 27), women who were newly diagnosed with cancer were eligible for participation. To be included in the analysis, women had to self-report a personal history of breast cancer, have completed surgical treatment (mastectomy or lumpectomy), and have one intact breast. Of the total number of women diagnosed with breast cancer who met these criteria ( $n = 105$ ), 6 were excluded from the analysis because information on perceived risk or breast cancer treatment was not available and 4 were excluded because they had not yet received treatment. Thus, the final sample for this report was 95 African American breast cancer survivors at increased risk for having a BRCA1/2 mutation.

**Procedures.** Our study recruitment procedures have been described in detail elsewhere (28) and are summarized here. Briefly, women were recruited to participate in the study through a clinical and community-based referral network that included health care facilities and community oncology resources (e.g., breast cancer support groups and health fairs) in the metropolitan Philadelphia area. At each site, women were given information about the study by physicians, clinic staff, or research personnel. It should be noted that some women ( $n = 23$ ) were referred to the study from an epidemiologic study designed to identify genetic risk factors for breast cancer. However, neither genetic counseling nor clinical genetic testing for BRCA1/2 mutations was provided to women as part of the epidemiologic study. Moreover, referral from the epidemiologic study was not associated with decisions about study enrollment (28). Women who were interested in learning more about genetic counseling completed a referral form that obtained information on race, personal and family history of breast and ovarian cancer, mailing address, and telephone number. Women who were eligible for study participation were mailed an invitation letter; those who did not opt out of study

participation were contacted for study enrollment that included completion of a structured baseline telephone interview. Sixty-two percent of all eligible women contacted enrolled in the study and completed the baseline telephone interview (28). There were no differences in study enrollment among women with and without a personal history of cancer. This report focuses on data collected during the baseline telephone interview before participation in genetic counseling.

## Measures

**Sociodemographic Characteristics.** Age, income [1 (<\$20,000) to 5 (>\$75,000)], marital status, education, and employment status were obtained during the baseline telephone interview. With the exception of age, sociodemographic characteristics were recoded into dichotomous variables based on the distribution of responses.

**Clinical Factors.** Clinical factors included prior probability of having a BRCA1/2 mutation, family history of disease, and experiences with breast cancer. Prior probability of having a BRCA1/2 mutation (5-9% or  $\geq 10\%$ ) was estimated based on each woman's personal and family history of breast and/or ovarian cancer using risk estimation models and mutation prevalence tables (25). We evaluated prior probability of having a BRCA1/2 mutation as 5% to  $\geq 10\%$  because this is the method used in clinical practice to distinguish women at different risks for having a mutation. Women were also categorized as having two or more or less than two affected relatives based on the total number of family members diagnosed with breast and/or ovarian cancer (29). We also evaluated age at diagnosis, time since diagnosis, and type of surgical treatment. Specifically, women were categorized as being  $\leq 50$  years of age or  $> 50$  years of age at diagnosis because this is one criterion used to determine if one's personal history of cancer is suggestive of hereditary disease. In addition, women were asked to provide the month and year in which they were diagnosed with breast cancer. We recoded time since diagnosis as  $< 1$  year, 1 to 5 years, or  $> 5$  years. Women also provided information on the type of surgical treatment received (mastectomy or lumpectomy).

**Temporal Orientation.** We used three questions from the Temporal Orientation Scale (30) to evaluate past, present, and future temporal orientation. This instrument has been validated extensively in previous research with African Americans and Caucasians (30).<sup>5</sup> Because our prior research showed that this instrument has good internal consistency among African American breast cancer survivors at increased risk for hereditary disease (19), we selected one item that had a high factor loading with its respective subscale in prior research<sup>5</sup> or had acceptable face validity to minimize respondent burden. These items were as follows: "I think about the past a lot" (past temporal orientation, factor loading = 0.84); "I try to do things that help me get what I want in the future" (future temporal orientation); and "If I take care of the present, the future will take care of itself" (present temporal orientation, factor loading = 0.50). Women were asked to indicate if they agreed or disagreed with each item (1 = strongly disagree; 2 = disagree; 3 = neutral; 4 = agree; 5 = strongly agree). We recoded these items into dichotomous variables (strongly agree/agree versus strongly disagree/disagree/neutral) for analysis because responses to these questions were skewed.

**Breast Cancer Perceived Risk.** We used one Likert-style item to evaluate breast cancer risk perceptions. Specifically, women were asked what their chances of getting breast cancer again were compared with other women their age (1 = much lower;

<sup>5</sup> J.M. Jones, et al. A temporal orientation scale: focusing attention on the past, present, and future, unpublished data.

2 = a little lower; 3 = about the same; 4 = a little higher; 5 = much higher). This item has been validated in prior reports (31) and has been used to measure breast cancer risk perceptions in African American women (12).

**Data Analysis.** First, we generated descriptive statistics to characterize the study sample in terms of sociodemographics, clinical factors, temporal orientation, and perceived risk. We then conducted bivariate analyses using  $\chi^2$  tests of association to evaluate the relationship between risk perceptions and sociodemographics, clinical factors, and temporal orientation. As in previous research (12), we recoded breast cancer risk perceptions into a dichotomous variable (much/little lower/same risk versus much/little higher risk) to facilitate interpretation of the bivariate analyses. Next, we used logistic regression analyses to identify factors having independent associations with perceived risk of developing breast cancer. Because the sample size was limited, we used a conservative criterion to select variables for inclusion to avoid overfitting the model; variables that had a bivariate association of  $P < 0.10$  with perceived risk were included in the logistic regression model.

## Results

As shown in Table 1, most participants were not married, had some college education or were college graduates, and had incomes  $> \$35,000$ . Most women also had a  $\geq 10\%$  prior probability of having a BRCA1/2 mutation. The mean age of participants was 49 (SD, 10.9). In terms of experiences with breast cancer, most women were  $< 50$  years of age when they were diagnosed, had a lumpectomy, and were diagnosed

**Table 1. Sample characteristics (n = 95)**

Variable	Level	n (%)
<b>Sociodemographics</b>		
Age (y)	$\geq 50$	44 (46)
	$< 50$	51 (54)
Marital status	Not married	61 (64)
	Married	34 (36)
Education level	$\geq$ Some college	63 (66)
	$\leq$ High school	32 (34)
Employment status	Employed	61 (64)
	Not employed	34 (36)
Income	$> \$35,000$	49 (52)
	$\leq \$35,000$	46 (48)
<b>Clinical factors</b>		
Family history of breast and/or ovarian cancer	$\geq 2$ relatives	43 (45)
	$< 2$ relatives	52 (55)
BRCA1/2 prior probability (%)	$\geq 10$	59 (62)
	5-9	36 (38)
Age at diagnosis (y)	$\geq 50$	18 (19)
	$< 50$	77 (81)
Surgery type	Mastectomy	39 (41)
	Lumpectomy	56 (59)
Time since diagnosis (y)	$< 1$	24 (25)
	1-5	44 (46)
	$> 5$	27 (29)
<b>Temporal orientation*</b>		
Past	Agree	51 (55)
	Disagree	42 (45)
Present	Agree	65 (70)
	Disagree	28 (30)
Future	Agree	83 (89)
	Disagree	10 (11)
<b>Breast cancer perceived risk</b>		
Perceived risk of developing breast cancer again	Much lower	10 (10)
	A little lower	10 (10)
	About the same	30 (32)
	A little higher	15 (16)
	Much higher	30 (32)

\*Two subjects were missing data for temporal orientation items.

**Table 2. Bivariate association between heightened breast cancer risk perceptions and sociodemographics, clinical factors, and temporal orientation**

Variable	Level	% Higher risk	$\chi^2$	P
<b>Sociodemographics</b>				
Age (y)	$\geq 50$	39	2.51	0.11
	$< 50$	55		
Marital status	Not married	44	0.66	0.42
	Married	53		
Education level	$\geq$ Some college	57	5.03	0.02
	$\leq$ High school	31		
Employment status	Not employed	47	0.002	0.96
	Employed	48		
Income	$> \$35,000$	53	1.32	0.25
	$\leq \$35,000$	41		
<b>Clinical factors</b>				
Family history of breast and/or ovarian cancer	$\geq 2$ relatives	53	1.18	0.28
	$< 2$ relatives	42		
BRCA1/2 prior probability (%)	$\geq 10$	54	2.95	0.09
	5-9	36		
Age at diagnosis (y)	$\geq 50$	50	0.06	0.80
	$< 50$	47		
Surgery type	Mastectomy	49	0.05	0.83
	Lumpectomy	46		
Time since diagnosis (y)	$< 1$	42	0.83	0.66
	1-5	52		
	$> 5$	44		
<b>Temporal orientation</b>				
Past	Agree	59	7.20	0.007
	Disagree	31		
Present	Agree	51	0.35	1.78
	Disagree	36		
Future	Agree	47	0.18	0.67
	Disagree	40		

NOTE: Age was evaluated as a continuous variable [age: low/same risk (mean, 50.2; SD, 12.3) versus high risk (mean, 46.9; SD, 9.0);  $t = 1.50$ ;  $P = 0.14$ ].

within the past 5 years (e.g., short-term survivors). All women had completed surgical treatment for breast cancer. Frequencies for temporal orientation items and perceived risk of developing breast cancer are shown in Table 1.

Table 2 shows the results of the bivariate analysis of heightened perceived risk. Education level and past temporal orientation were associated significantly with perceived risk of developing breast cancer again. Women who had more years of formal education and those who thought about the past a lot were most likely to believe that they had a high risk of developing breast cancer again compared with women with less education and those who did not think about the past a lot. Women who had a  $\geq 10\%$  prior probability of having a BRCA1/2 mutation were also likely to report that they had a high risk of developing breast cancer.

The results of the logistic regression model of heightened risk perceptions are provided in Table 3. Women who thought about the past a lot were about four times more likely than women who did not think about the past a lot to report that they had a high risk of developing breast cancer again. Compared with women with a 5% to 9% prior probability of having a BRCA1/2 mutation, those with a  $\geq 10\%$  prior probability were most likely to report that they had a high risk of developing breast cancer. Women with more years of formal education were also most likely to report that they had a high risk of developing breast cancer.

## Discussion

To our knowledge, this is the first empirical study to evaluate perceived risk of developing breast cancer again in African American breast cancer survivors at increased risk for having a

**Table 3. Logistic regression model of heightened risk perceptions**

Variable	Level	Odds ratio (95% confidence interval)
Education	≥Some college ≤High school (referent)	2.74 (1.02-7.36)
BRCA1/2 prior probability (%)	≥10 5-9 (referent)	2.91 (1.09-7.72)
Past temporal orientation	Agree Disagree (referent)	3.72 (1.45-9.57)

NOTE: *n* = 93 because of missing data.

BRCA1/2 mutation. Although the majority of women reported that they had the same or lower risk of developing breast cancer again, it is important to note that almost half of women reported that they had a higher or much higher risk. Previous research has shown that objective risk factors for developing breast cancer may not be correlated with women's perceived risk of disease (32); heightened breast cancer risk perceptions were only attributed to subjective experiences with disease among unaffected African American women (12). Although risk factors, such as family history of cancer, were not associated with risk perceptions in the present study, women who had a ≥10% prior probability of having a BRCA1/2 mutation were most likely to report that they had a high risk of developing breast cancer again. We also found that more years of formal education were associated significantly with heightened risk perceptions. It could be that more years of formal education increases exposure to cancer-related information (33, 34). Another possible explanation is that women with more years of formal education may be better able to comprehend complex information about breast cancer risk, especially the ways in which their personal and family history of disease contribute to their chances of developing breast cancer. Similarly, women with a higher BRCA1/2 prior probability may recognize aspects of their personal and family history of disease that increase their risk of disease.

Although women reported positive attitudes related to future and present temporal orientation, only women who thought about the past a lot were most likely to report that they had a high risk of developing breast cancer again. Past temporal orientation is characterized by thinking about past experiences; memories of past events are important to how individuals think, feel, and behave (35, 36). Individuals who think about the past a lot may also have a tendency to relive past events, especially those that are highly emotional (36). Previous research has shown that experiences with breast cancer may remain salient to African American women several years after diagnosis and treatment (37, 38). It is possible that women who think about the past a lot focus on and continue to think about their personal and family experiences with breast cancer diagnosis and treatment. Because past experiences with disease may still be salient to women who think about the past a lot, these women may be likely to believe that they have a high risk of developing breast cancer again. Thus, risk perceptions may be based on a continued sense of vulnerability among African American breast cancer survivors who think about the past a lot. However, our measure of temporal orientation was not specific to breast cancer experiences. Future studies are needed to evaluate the extent to which breast cancer survivors think about specific experiences with diagnosis and treatment.

In considering the results of this study, some limitations should be noted. First, the sample was limited to 95 African American breast cancer survivors who were interested in genetic counseling. Several studies have described the difficulties recruiting African American women to participate in

cancer research (39, 40), including studies on hereditary breast cancer research (41, 42). Despite these challenges, our enrollment rates (62%) are similar to the rates observed for participation in hereditary breast cancer research among Caucasian samples (43, 44). The cross-sectional nature of the study is an additional limitation that underscores the importance of prospective studies to evaluate changes in breast cancer risk perceptions in African American breast cancer survivors at increased risk for hereditary disease following genetic counseling and testing for BRCA1/2 mutations. An additional limitation may be that we only evaluated comparative risk perception within the context of age using one Likert-style item. This approach may not reflect all of the ways in which women assess their subjective risk of developing breast cancer (e.g., compared with women from other races and with women without a personal history of cancer) and does not provide an assessment of women's absolute perceived risk. However, definitive data on the best methods for evaluating risk perception are not yet available (45) and a recent study showed that there is a high degree of correlation among different types of risk perception measures (e.g., comparative, numerical, and verbal risk perception measures; ref. 46). Moreover, prior research has shown that the item we used predicts acceptance of BRCA1/2 test results (10) and is sensitive to changes in risk perception after genetic counseling and receipt of BRCA1/2 test results among individuals at increased risk (47). Nonetheless, additional research is needed to determine the most effective ways of evaluating risk perceptions (e.g., comparative measures based on age, race, and cancer history or absolute measures) among African American women. Another possible limitation is that data on clinical factors (e.g., family history of cancer and cancer treatment) were collected by self-report, which may be subject to recall bias. However, recent studies have shown that information on family history and breast cancer treatment may be accurate in women diagnosed with breast cancer (48, 49). It is also important to evaluate whether perceived risk of developing breast cancer again is associated with receipt of adjuvant therapy and prognostic indicators, such as stage of disease, nodal status, and tumor size. Because we did not evaluate ethnic group differences in breast cancer risk perceptions, future studies are also needed to determine if risk perceptions differ among African American and Caucasian breast cancer survivors at increased risk for having a BRCA1/2 mutation.

Despite these potential limitations, the results of the present study show that the majority of African American breast cancer survivors at increased risk for hereditary breast cancer do not believe that they have an increased risk for developing breast cancer again. Provision of information about risks of having a BRCA1/2 mutation and the likelihood of developing cancer are integral aspects of genetic counseling for inherited breast cancer susceptibility (50). Our findings suggest that it may be important to place greater emphasis on provision of cancer risk information during genetic counseling with African American breast cancer survivors. As part of these efforts, it may be especially important to ensure adequate risk comprehension among women with lower levels of formal education. This could be achieved by discussing the basis of risk perceptions during genetic counseling with African American breast cancer survivors to identify factors and experiences that contribute to these beliefs. This may identify knowledge deficits that need to be addressed as well as specific experiences that are salient to women's beliefs about their chances of developing breast cancer again. Because risk perceptions may also be important to decisions about genetic testing for BRCA1/2 mutations (10), exploration of the basis of risk perceptions may also facilitate testing decisions by putting this choice into the context of existing beliefs and motivations for testing.

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