

Psychosocial Predictors of *BRCA* Counseling and Testing Decisions among Urban African-American Women¹

Hayley S. Thompson,² Heiddis B. Valdimarsdottir, Chantal Duteau-Buck, Josephine Guevarra, Dana H. Bovbjerg, Cassandra Richmond-Avellaneda, David Amarel, Diana Godfrey, Karen Brown, and Kenneth Offit

Ruttenberg Cancer Center [H. S. T., H. B. V., J. G., D. H. B.] and Department of Human Genetics [K. B.], Mount Sinai School of Medicine, New York, New York 10029, and Department of Medicine [C. D-B., C. R-A., D. A., K. O.] and Breast Examination Center of Harlem [D. G.], Memorial Sloan-Kettering Cancer Center, New York, New York 10021

Abstract

Genetic counseling and testing for mutations in *BRCA1/2* genes that increase breast cancer susceptibility potentially offer a number of benefits (e.g., more informed decision making regarding breast cancer prevention options) but also raise potential problems (e.g., issues of discrimination). However, the literature suggests that African-American women underuse genetics-related services. Therefore, the primary aim of the current study was to investigate predictors of the use of genetic counseling and testing for breast cancer susceptibility in this population. Participants were 76 African-Americans at increased risk for breast cancer attributable to their family history of the disease. Participants were recruited from an urban cancer screening clinic and completed measures assessing sociodemographic information, breast cancer knowledge, breast cancer-specific emotional distress, and perceived benefits of and barriers to *BRCA* testing. Free *BRCA* counseling and testing were offered to all interested participants, and measures were completed before counseling sessions. On the basis of their subsequent acceptance or refusal of these services, participants were described as having either: (a) declined *BRCA*-related genetic counseling (GC-); (b) participated in genetic counseling but refused genetic testing (GC+GT-); or (c) participated in both genetic counseling and testing (GC+GT+). Results revealed that participants who declined counseling had significantly less knowledge of breast cancer genetics than those who accepted both counseling and testing. No differences emerged among the three groups in terms of perceived benefits of testing.

However, participants declining counseling demonstrated significantly higher perceived barrier scores compared with those accepting counseling and testing. Specifically, those who did not participate in counseling reported greater anticipation of negative emotional responses to testing and more concern about stigmatization, whereas those who underwent both counseling and testing had significantly lower family-related guilt. Finally, cancer-specific distress was positively associated with participation in counseling, regardless of participation in testing. The current findings underscore the need for refinement of outreach and intervention efforts that both increase awareness of *BRCA* counseling and testing among African-American women and provide information to those considering these options.

Introduction

One of the strongest predictors of a woman's lifetime risk of developing breast cancer is her family history of the disease. It is now estimated that between 5 and 10% of breast cancers are attributable to inherited mutations in one of two genes, *BRCA1*³ and *BRCA2* (1–3). Research has shown considerable variability in cancer risk, reporting that individuals with mutations in *BRCA1/2* have anywhere from 40 to 85% cumulative risk of developing breast cancer and a 5–60% cumulative risk of developing ovarian cancer (4, 5). Despite increasing recognition of the utility of genetic risk information, initial reports suggest that African-American women may underuse genetic counseling and testing services (6). Lerman *et al.* (7) reported that significantly fewer African-American women provided a blood sample for analysis after pretesting education and/or counseling compared with the Caucasian women in their sample. Similarly, a retrospective study by Hughes *et al.* (8) found that Caucasian women were significantly more likely to report use of genetic testing services in general than African-American women. This is likely attributable, in part, to perceived testing benefits and barriers that are more salient in this ethnocultural group. Unfortunately, few studies have focused on the perceptions of African-American women toward genetic testing.

The assessment of individual genetic risk for breast cancer has a number of potential benefits, including the facilitation of more informed decisions regarding breast cancer prevention (e.g., prophylactic mastectomy), the determination of family members' risks, and personal reassurance (9, 10). Agreement with such advantages of genetic testing has been shown to be fairly high among African-American women (8, 11, 12). A number of potential disadvantages to genetic testing also tend to be strongly endorsed by African-American women, e.g., studies

Received 1/25/02; revised 8/26/02; accepted 9/9/02.

The costs of publication of this article were defrayed in part by the payment of page charges. This article must therefore be hereby marked *advertisement* in accordance with 18 U.S.C. Section 1734 solely to indicate this fact.

¹ Supported in part by Grant CA81137 from the National Cancer Institute and Grant DAMD17-96-1-6293 from the Department of Defense.

² To whom requests for reprints should be addressed, at Ruttenberg Cancer Center, Mount Sinai School of Medicine, One Gustave Levy Place, Box 1130, New York, NY 10029.

³ The abbreviations used are: BECH, Breast Examination Center of Harlem; IES, impact of event scale.

have shown that African-American women strongly endorse concerns about how *BRCA* testing might affect their family, as well as the expectation that knowing that one carried a *BRCA* mutation would increase worry about their daughters and other family members (6, 8, 11). In addition, anticipation of difficulty in emotionally handling *BRCA* testing has been high, both in studies with African-American women alone (6) and in comparison with Caucasian women (8, 12). Another potential barrier to *BRCA* testing may be concern about confidentiality of *BRCA* test results, because Donovan and Tucker (12) reported that 72% of African-American women in their sample reported concerns about confidentiality. Finally, a variable that does not represent perceptions but appears to be an important barrier nonetheless is lack of knowledge about *BRCA* testing. Previous work has demonstrated that specific knowledge about breast cancer genetics is associated with stronger interest in *BRCA* testing among African-American women (13).

The studies cited above have begun to establish trends in the endorsement of barriers to *BRCA* testing by African-American women. However, additional exploration is needed because regional and other sociodemographic differences may exist between study samples, and studies are not consistent in terms of barriers assessed. Addressing group-salient barriers to *BRCA* testing may be an important strategy in increasing breast cancer prevention and control in a population that carries greater breast cancer burden in terms of higher mortality and lower survival when compared with all other ethnic groups (14). In addressing these barriers, it is important to note that the studies cited above are limited. Specifically, these studies primarily explore factors that may be related to *BRCA* testing, although the process of genetic risk assessment typically includes an initial, separate decision regarding participation in pretest genetic counseling. Genetic counseling sessions include education (*i.e.*, the presentation of basic genetics principles, the specific risks of *BRCA* mutations, and cancer surveillance strategies) and exploration of the psychological and social consequences of testing (15). Such counseling is strongly endorsed by the American Society of Clinical Oncologists as part of standard clinical practice (16) and in many settings is a prerequisite that must be fulfilled before genetic testing is conducted. Women who are not tested because they have declined counseling are likely to have different perceptions of the genetic testing process and its risks and benefits compared with women who are not tested because they have decided against it after a counseling session with a genetic risk professional and women who participate in both counseling and testing. It is important to isolate these decisions when exploring barriers to these services because women who forgo counseling represent a group that has more limited information on which to base their breast cancer risk management strategies.

Research designed to further investigate African-American women as well as acknowledge the separate components of the genetic testing process will provide critical information that may strengthen breast cancer prevention and control efforts. The results of such research may guide the development of tailored interventions and outreach programs that are more sensitive to the distinction between the decision to participate in counseling and the subsequent decision to participate in testing. As a result of such interventions, African-American women may make more informed decisions regarding their participation in these services and report greater satisfaction with the services they receive.

The present study is a prospective investigation of psychosocial predictors of genetic counseling and testing among African-American women who were offered free *BRCA*-related

services. The advantages of *BRCA* counseling and testing, as well as cognitive and emotional barriers, were assessed among African-American women who either: (a) refused genetic counseling to discuss *BRCA* genes; (b) participated in genetic counseling but refused *BRCA* testing; or (c) participated in both genetic counseling and *BRCA* testing. Differences among the three groups in terms of perceived advantages and barriers were then examined.

Materials and Methods

Participants

Participants were 76 African-American women enrolled in a longitudinal study examining the psychological and behavioral impact of genetic counseling and testing for breast cancer susceptibility. The women were recruited from the BECH, a satellite community clinic affiliated with Memorial Sloan-Kettering Cancer Center in New York City. BECH provides comprehensive diagnostic breast and cervical screening services (*e.g.*, mammogram, clinical breast exam, and pap smear). BECH advertises its services widely in the Harlem community and provides services regardless of ability to pay. To be eligible for the study, the women had to: (a) self-identify as African-American or Black; (b) be ≥ 18 years of age; (c) have at least one first-degree relative diagnosed with breast cancer; (d) report no previous breast cancer diagnosis; (e) report no previous genetic counseling for breast cancer risk; (f) be able to read and write English; and (g) provide informed consent.

Procedure

Study participants were enrolled through one of two strategies. In the first strategy, an African-American research assistant briefly outlined the study and eligibility criteria to groups of women waiting for services in a public area at BECH. Interested women then approached the research assistant who verified eligibility criteria, briefly described the study, and obtained contact information. The research assistant contacted the women later via telephone to describe the study in greater detail, and, if women continued to express interest in the study, an informed consent form and assessment materials were mailed to them. Women were asked to return these forms via mail. In the second strategy, women who met the eligibility criteria were identified by nurse practitioners at BECH or the Clinical Genetics Service at Memorial Sloan-Kettering Cancer Center. Nurse practitioners did not recruit women but referred eligible women to the research assistant. Nurse practitioners described the study briefly as an investigation of attitudes and feelings about breast cancer and obtained contact information from women interested in learning more about the study. The research assistant then contacted these referred women, verified eligibility, and described the study in detail. If women continued to express interest in the study, an informed consent form and the assessment were mailed to them, and they were asked to return these forms via mail. All assessment was completed through self-administered mailed questionnaires. Data were collected from 1996 to 2000.

Recruitment and the presentation of information on which participation interest and agreement were based were conducted by the research assistant, who informed women that they could: (a) refuse participation; (b) discontinue their participation at any time; (c) fill out the questionnaires without going for genetic counseling or testing; (d) attend the counseling session without undergoing genetic testing; and (e) decide not to learn their mutation status once their test results were available. It

was also emphasized that the women could not undergo genetic testing unless they attended the counseling session. Three to 5 days later, the women were contacted again by telephone to verify that they received assessment materials, to review the consent form, and to answer any questions that they might have. Counseling session appointments were confirmed for interested women. Those with appointments were asked to return the signed consent form and the assessment before their genetic counseling session. The total number of interested women who were mailed consent forms and assessment was 141. Only 54% of these women ($n = 76$) returned these materials.

The counseling sessions were conducted by an African-American master's level genetic counselor and lasted 1–2 h. The counselor followed standard clinical practice (17). Briefly, after construction of the pedigree, the following issues were addressed: (a) possible reasons for familial clusterings of cancer; (b) the likelihood of the occurrence of cancer in the pedigree to be “hereditary” (*i.e.*, conforming to the criteria for a hereditary cancer syndrome) or “familial” (*i.e.*, not meeting those criteria); (c) limitations of pedigree analysis, including the inability to distinguish between a sporadic and inherited cancer; (d) the relative importance of various risk factors other than family history; (e) risk estimates for developing cancer based on family history and/or associated with *BRCA* mutations; (f) options for early detection and prevention and the limitations of those options; (g) limitations and benefits of genetic testing for *BRCA1/2*; and (h) risks of receiving test results, including insurance discrimination and adverse psychological consequences.

At the end of the counseling session, women were asked if they wished to undergo genetic testing. A separate informed consent for DNA testing was reviewed for participants who decided to be tested. The women were urged to consider the impact of negative, positive, and ambiguous results, and it was stressed they could choose not to learn their results once they became available.

Measures

Sociodemographic Information. Basic sociodemographic information was obtained from each participant, including age, marital status, education, and income, using a standard self-report format.

Breast Cancer Knowledge. Twenty-two items ($\alpha = 0.76$), currently being evaluated in a larger study were developed by the research team to assess knowledge about risk factors for breast cancer using a “true or false” response format. Eight questions assessed knowledge about general risk factors for breast/ovarian cancer (*e.g.*, “True or false: A woman is at a greater risk for developing breast cancer if she has an early age of her childbirth, a late age of her first menstrual period”). Fourteen questions assessed knowledge about inheritance of breast/ovarian cancer disposition [*e.g.*, “True or false: A woman who has a sister with an altered gene for breast cancer has a 50% chance (1 in 2) of also having an altered gene for breast cancer” and “A woman is at a greater risk of developing breast cancer if she has a father with an altered gene for breast cancer”].

IES. The intrusive thoughts subscale of the IES was used to assess breast cancer-specific distress (18). This subscale includes seven items that assess intrusive stress reactions to a specific stressor, in this case, the threat of breast cancer. Participants were asked to rate how frequently each thought or behavior occurred during the past week. The internal consistency of the measure in the present sample was high ($\alpha = 0.90$).

Table 1 Demographic characteristics

Age	
Mean (SE)	43.4 (1.2)
Range	21.6–68.5
Education n (%)	
High school graduate or less	24 (31.6%)
Partial college	25 (32.9%)
University graduate	20 (26.3%)
Graduate degree	7 (9.2%)
Living arrangements	
n (%) living with partner	31 (40.8%)
Income n (%) ^a	
Less than \$20,000	24 (32.0%)
Between \$20,000–\$40,000	24 (32.0%)
Between \$40,000–\$100,000	24 (32.0%)
Greater than \$100,000	3 (04.0%)

^aMissing information for one participant.

Perceived Benefits and Barriers of *BRCA* Testing. Twenty-one items, currently being evaluated in a larger study, were developed by the research team to assess participants' perceptions of the potential benefits (pros) and barriers (cons) of genetic testing for breast cancer susceptibility. These items were based on our previous research (19), as well as that of others (8, 10). Participants indicated the extent to which they agreed or disagreed with each question using a Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). Seven questions ($\alpha = 0.66$) assessed the potential pros of genetic testing (*e.g.*, “Knowing that I carry the gene would help me decide whether to go for more frequent mammograms”). Fourteen questions ($\alpha = 0.76$) were used to assess potential cons of testing. The con items included five subsets: (a) anticipation of negative emotional reactions (*e.g.*, “Knowing that I carry the gene would leave me in a state of hopelessness and despair”); (b) confidentiality (*e.g.*, “If I were found to carry the gene, I would worry that the results would not stay confidential”); (c) stigma related to testing (*e.g.*, “If I were found to have the gene, I would feel singled out”); (d) family-related worry (*e.g.*, “If I were found to carry the gene for breast cancer, I would worry about passing the gene to my children”); and (e) family-related guilt (*e.g.*, “I would feel guilty if one of my relatives had the gene and I did not”). The internal consistency of each of the five subsets of items in the current sample are as follows: negative emotional reactions, $\alpha = 0.46$; confidentiality, $\alpha = 0.60$; family-related worry, $\alpha = 0.63$; family-related guilt, $\alpha = 0.60$; and stigma, $\alpha = 0.70$.

Results

Sample Characteristics. As shown in Table 1, the mean age of the sample was 43.4 years (SE 1.1), 64% had less than \$40,000 in annual income, 68% reported greater than a high school education (some college, bachelor's, or graduate degree), and 41% were married or living with a partner. Seventeen women (22.4%) did not undergo genetic counseling (GC– group), 19 women (25.0%) underwent genetic counseling but declined *BRCA* testing (GC+GT– group), and 40 women (52.6%) underwent both genetic counseling and *BRCA* testing (GC+GT+ group).

There were no significant differences among the groups based on any of the sociodemographic variables, but there was a trend for women in the GC+GT– to be younger than the women in the other two groups [$F_{(2,73)} = 2.64, P = 0.07$] and for the GC+CT+ to have higher income than women in the

Table 2 Breast cancer knowledge

Group membership	General breast cancer knowledge	Knowledge about genetics of cancer
GC-	38.9 (4.9) ^a	33.1 (4.9) ^a
GC+GT-	41.5 (4.6) ^a	43.6 (4.7) ^{a,b}
GC+GT+	41.3 (3.2) ^a	47.4 (3.2) ^b

^a Means (SE) for percentages of correct answers.

^b Means within each column that do not have the same superscript letter are significantly different.

Table 3 Perceived benefits of testing

	Strongly agree or agree
Knowing that I carry the gene would motivate me to perform breast self-examination more frequently.	90%
If I were found to carry the gene, it would help my daughter(s) or sister(s) decide whether to undergo genetic testing.	89%
My concerns about developing (having a recurrence of) breast cancer would be reduced if I knew I did not carry the gene.	89%
Knowing that I carry the gene would help me decide whether to go for more frequent mammograms.	81%
Knowing whether or not I carry the gene would increase my sense of personal control.	74%
Knowing whether or not I carry the gene would help me make important life decisions (e.g., getting married and having children).	70%
Knowing that I carry the gene would help me to decide whether to undergo bilateral mastectomy (an operation to move both breasts).	44%

other two groups [$\chi^2(4, n = 75) = 8.6, P = 0.06$]. A portion (63%) of the women was referred to the research assistant by nurse practitioners. There were no significant differences among the groups in terms of being referred by a nurse practitioner *versus* having the research assistant be the only source of contact [$\chi^2(2, n = 76) = 2.6, P = 0.25$].

Breast Cancer Knowledge and Genetic Counseling/Testing Decisions. Scores summarizing participants' general breast cancer knowledge about genetics of cancer were computed by calculating the percentage of correctly answered questions. On average, participants were correct on 42.5% (SD = 18.2) of the general breast cancer questions (score range: 12.5–87.5%). The average knowledge score for genetics of cancer was 45.4% (score range: 7.1–100%). As shown in Table 2, the results from ANOVAs showed that the groups did not differ on general knowledge about breast cancer [$F_{(2,71)} = 1.5, P = .21$], but they were significantly different on knowledge about genetics of breast cancer [$F_{(2,73)} = 2.9, P < 0.05$]. Planned comparisons revealed that the women in the GC- group had significantly less knowledge about genetics of breast cancer than women in the GC+GT+ group.

Perceived Benefits and Barriers of Genetic Testing. The most commonly perceived benefits and barriers were identified by tabulating the percentages of women who agreed or strongly agreed with each of the pros and cons items (Tables 3 and 4). Six of the seven benefits were endorsed by $\geq 70\%$ of the women with the majority of the women indicating that the knowledge that they were mutation carriers would motivate them to perform breast self-examination more frequently and help their daughters or sister to decide about testing. Seven of the 14 barriers were endorsed by $>50\%$ of the women with the

Table 4 Perceived barriers of testing

	Strongly agree or agree
If I were found to carry the gene for breast cancer, I would worry about passing the gene to my children.	87%
Knowing that I carry the gene would cause me to worry more about other family members who could be carriers (e.g., mother, sisters, and daughters).	79%
I would be ashamed if I were found to carry the gene.	78%
I would be frightened if I were found to have the gene.	73%
Being testing for the gene could jeopardize my insurance coverage.	58%
If I were found to carry the gene, I would worry that the results would not stay confidential.	56%
If I were found to carry the gene for breast cancer, I feel guilty if my daughter(s) developed breast cancer.	55%
I would be angry if I were found to carry to gene	47%
I would feel guilty if one of my relatives had the gene and I did not.	25%
Knowing that I carry the gene would cause me to feel less healthy than other people.	22%
If I were found to carry the gene, it would cause others to view me negatively.	21%
If I were found to carry the gene, I would feel singled out.	19%
Knowing that I carry the gene would leave me in a state of hopelessness and despair.	18%
I would consider suicide if I were found to carry the gene for breast cancer.	3%

most commonly cited barriers being worry about passing the gene to their children and worry about other family members who might be carriers.

To examine whether the three groups differed on perceived benefit and barriers of testing, the average score for the benefit questions and the barrier questions was computed. In addition, the average scores for the five subsets of the barrier questionnaire were computed. The results of ANOVAs indicated that the groups did not differ on perceived benefits of testing, but there was a trend for the groups to differ on perceived barriers of testing [$F_{(2,73)} = 2.79, P < 0.06$]. The ANOVAs for the five barrier subsets indicated that there was a significant difference among the groups on anticipated negative emotional reactions to test results [$F_{(2,73)} = 2.91, P < 0.05$], family-related guilt [$F_{(2,73)} = 2.97, P < 0.05$], and fear of stigmatization [$F_{(2,73)} = 6.48, P < 0.05$]. As shown in Table 5, a planned comparison revealed that the women in the GC- group reported greater concerns about stigmatization than the women in the other two groups, and they anticipated higher levels of negative emotional reactions to positive test results than the women in the GC+GT+ group. Lastly, the women in the GC- and the GC+GT- demonstrated stronger anticipation of guilt about family members if they were found to be mutation carriers than the women in the GC+GT+ group.

Breast Cancer-specific Distress. The mean score for IES intrusive thoughts subscale across the entire sample was 9.9 (SE 1) with a score range from 0 to 35. This is consistent with other studies of women at increased risk for breast cancer that report mean intrusive thought scores ranging from 8.3 to 14.6 (20, 21). In the current sample, 14.5% of the women had scores >19 , the range of total IES scores that is reported as warranting clinical concern (22, 23) and predictive of post-traumatic stress disorder (24). Means for each decision group are presented in Table 5. Because of the skewed distribution, a median split was used to classify individuals as below or above the median on intrusive thoughts. The χ^2 analysis revealed that 18% of the women in

Table 5 Perceived barriers to genetic testing for breast cancer susceptibility

Group	Perceived barriers total score	Item subsets of the perceived barrier questionnaire					Breast cancer-specific distress
		Emotional reactions	Confidentiality	Worry	Guilt	Stigma	
GC-	2.7 (0.16) ^a	2.6 (0.18) ^a	2.8 (0.29) ^a	3.5 (0.25) ^a	2.3 (0.26) ^a	2.3 (0.24) ^a	5.5 (2.2) ^a
GC+GT-	2.5 (0.16) ^{a,b}	2.2 (0.17) ^{a,b}	2.8 (0.28) ^a	3.6 (0.24) ^a	2.3 (0.24) ^a	1.6 (0.22) ^b	11.9 (2.0) ^b
GC+GT+	2.2 (0.11) ^b	2.1 (0.12) ^b	2.5 (0.19) ^a	3.6 (0.16) ^a	1.8 (0.17) ^b	1.3 (0.16) ^b	9.5 (1.5) ^{a,b}

^a Means (SE) for the perceived barrier scale and the five subsets.

^b Means within each column that do not have the same superscript letter are significantly different.

the GC- group were above the median in intrusive thoughts compared with 73 and 58% of the women in the GC+GT- and GC+GT+ groups, respectively [χ^2 (1, $n = 75$) = 11.2, $P = 0.004$].

Relative Contribution of Demographic Characteristics, Knowledge, Perceived Barriers, and Intrusive Thoughts to Genetic Counseling and Testing. To determine the unique contribution of the variables found to be related to genetic counseling/testing in univariate analyses, a logistic regression was computed entering group membership as the dependent variable and income, age, knowledge about genetics, perceived barriers of testing, and intrusive thoughts as independent variables. The results revealed a significant association between group membership and perceived barriers of testing ($P = 0.003$) and intrusive thoughts about breast cancer ($P = 0.05$). There was a trend for knowledge about genetics about breast cancer to be significantly related to group membership ($P = 0.09$), but age and income were not related to group membership (P s > 0.20).

Discussion

The results of the current study indicate that African-American women who differ in their *BRCA* counseling and testing decisions also differ across variables associated with these decisions. These findings are based on a prospective investigation in which women completed and returned assessment materials via mail before any genetic risk assessment services. First, it was reported that women in the three decision groups, those who refused counseling, those who accepted counseling but declined testing, and those who participated in both, differed significantly in their knowledge of breast cancer genetics. Specifically, those who declined counseling demonstrated significantly lower knowledge compared with those who accepted both counseling and testing. Interestingly, there were no significant differences across the three decision groups in terms of more general knowledge of breast cancer. Although previous work suggests that knowledge of genetic risk for breast cancer is associated with interest in testing (13), the current research is the first to find that such knowledge is associated with women's actual counseling and testing choices.

There were no differences observed in endorsement of genetic testing pros across groups. In fact, endorsement of all but one of the pros was $\geq 70\%$. This finding is consistent with previous studies in which African-American ethnicity was associated with the high endorsement of the advantages of genetic testing (8, 12). However, the three decision groups did differ with regard to perceived disadvantages of genetic testing. As might be expected, women who declined both genetic counseling and testing endorsed significantly more barriers to genetic testing than women who accepted both counseling and testing. An investigation of subgroups of barrier items revealed further differences among all three groups. Women who declined

counseling were more likely to anticipate negative emotional reactions to testing than women who accepted counseling whether they participated in testing or not. These results suggest that the expectation that one will experience distress may deter women from initiating the genetic risk assessment process. However, an opposite trend was observed in terms of intrusive thoughts about breast cancer, with women who accepted genetic counseling (regardless of testing decision) reporting more intrusive thoughts compared with women who declined counseling. These findings highlight the distinction between anticipated *versus* current distress because anticipated distress may lead one to avoid counseling, whereas currently experienced distress may drive one to participate in counseling. The high prevalence of currently experienced distress is further evidenced by finding that 14.5% of the sample had intrusive thought scores in a range that may be interpreted as pathological (22–24). It is possible that, in these cases, the engagement of genetic counseling and testing services was less about information seeking and actually represented an emotion management strategy.

The present research also found that women who declined counseling were also more likely to anticipate stigmatization because of *BRCA* mutation carrier status compared with women who participated in counseling, regardless of testing decision. This is similar to other reports that stigma, shame, and secrecy surrounding breast cancer are barriers to breast cancer screening (*e.g.*, mammography) in the African-American community (25, 26). Other research has shown that African-American women are more likely to endorse the belief that males respond unfavorably to breast cancer and that relationships with men would be affected by such information (27). Anticipated negative effects on interactions with male partners and significant others may also contribute to stigma and shame related to breast cancer. It is plausible that these stigma-related beliefs may extend beyond breast cancer diagnosis and be applicable as barriers to *BRCA* counseling and testing, because the confirmation of mutation status may increase a woman's perceived (and actual) likelihood of eventually being diagnosed with breast cancer.

Interestingly, no differences in concern about the confidentiality of *BRCA* test results were observed among women in the three groups. There are two possible explanations for the failure to observe differences in this area. First, the confidentiality item used in the current study may have lacked sensitivity to the context of confidentiality, which may include issues of disclosure to one's employer, insurance company, or family. One's concerns about confidentiality may vary considerably based on each of these contexts. Indeed, Durfy *et al.* (28) found that African-American women reported stronger belief in the increased flow of information of test results to family members and physicians compared with other groups. A second reason that differences in confidentiality concerns were not

observed across groups may be the sample's overall high endorsement of worry about the confidentiality of genetic testing results. The strong endorsement of this concern across all participants may have decreased the likelihood that group differences would emerge.

There were also no group differences observed in family-related worries regarding genetic testing. However, women who refused testing had significantly greater anticipated guilt regarding the carrier status of relatives than women who participated in testing. Such concern, specifically concern about feelings of guilt, may be caused by the view that knowledge of one's *BRCA* test results and their ramifications in terms of disease risk and emotional and financial stability represents a burden that is not carried by the patient alone but potentially by many family members. Such family concern may be a result of a collectivist or group-centered decision making style that has been observed previously among African-American women. Baldwin (29) asserts that decision making practices among African-American women are tied to daily living that centers on a core family or extended family group. She proposes that for African-American women, decisions occur by mutual aid and cooperation among community members. Therefore, African-American women may be less likely to pursue a health-related issue if it does not meet with the support of significant others or disrupts these relationships.

One of the limitations of the current study is that the pros and cons of *BRCA* testing were assessed, but there was no separate examination of the pros and cons of *BRCA* counseling. It is possible that counseling attitudes represent a distinct set of attitudes across which the three decision groups may have differed significantly. Furthermore, in addition to the pros and cons assessed in the current study and others, there may be evaluations of the procedural aspects of genetic risk assessment that are associated with one's decision to participate in counseling and testing, *e.g.*, one may indicate that it is undesirable to disclose medical information to someone other than one's physician or have one's blood drawn. The exploration of *BRCA* counseling perceptions and procedural aspects of *BRCA* counseling and testing is an important focus of future research. Within the perceptions that were assessed, the internal consistency of the item subsets assessing disadvantages of testing is of concern. The alphas for most item subsets were marginal. The marginal reliability coefficients for item subsets is likely attributable to the low number of items within each subset and small total sample size, which made it more difficult to demonstrate internal consistency. The future development of additional items for each subset and their evaluation in a larger sample is likely to result in greater reliability, especially given their substantial face validity. It is also important to note here that the study was not originally powered to address differences among decision groups. Post hoc power analyses do show that the sample size of 76 achieved 84% power to detect significant group differences in stigma items and 80% power to detect significant group differences in breast cancer-specific distress. For the findings related to other item subsets, we cannot completely rule out Type II error.

Another limitation of the current study is a question of the generalizability of findings attributable to the low rate of informed consent forms returned by potential participants. Low rates of return of consent forms may have been attributable, in part, to low perceived urgency of participation in genetic risk assessment because participants did not have a breast cancer diagnosis. These low rates affect generalizability, because women who ultimately did not provide informed consent and complete baseline measures may differ significantly from those

who did participate in terms of demographic and psychological characteristics. However, the low rates of research participation, along with the observation that women who declined genetic counseling had less knowledge and reported more negative attitudes about genetic testing, underscore the need for outreach interventions designed to inform women of genetic counseling and testing options. The importance of outreach is supported by earlier work indicating that African-American women may underuse genetic counseling and testing services (6).

Our findings further suggest that not only intervention content but also the stage at which specific content is presented is an important consideration in the development of such interventions, *e.g.*, based on the current results, outreach into the African-American community intended to educate individuals about initiating the genetic testing process may focus more on barriers to genetic counseling participation, specifically issues related to negative emotional reactivity and stigmatization. Current findings also suggest that standard genetic counseling sessions may need to place greater emphasis on areas that are particularly salient for African-American women, especially family-related guilt.

References

- Miki, Y., Swensen, J., Shattuck-Eidens, D., Futreal, P. A., Harshman, K., Tavtigian, S., Liu, Q., Cochran, C., Bennett, L. M., and Ding, W. A strong candidate for the breast and ovarian cancer susceptibility gene *BRCA1*. *Science* (Wash. DC), 266: 66–71, 1994.
- Wooster, R., Neuhausen, S. L., Mangion, J., Quirk, Y., Ford, D., Collins, N., Nguyen, K., Seal, S., Tran, T., and Averill, D. Localization of a breast cancer susceptibility gene, *BRCA2*, to chromosome 13q12–13. *Science*, 265: 2088–2091, 1994.
- Malkin, D., Li, F. P., Strong, L. C., and *et al.* Germline p53 mutations in a familial syndrome of breast cancer, sarcomas, and other neoplasms. *Science*, 250: 1233–1238, 1990.
- Struwing, J. P., Hartge, P., Wacholder, S., Baker, S. M., Berlin, M., McAdams, M., Timmerman, M. M., Brody, L. C., and Tucker, M. A. The risk of cancer associated with specific mutations of *BRCA1* and *BRCA2* among Ashkenazi Jews. *N. Eng. J. Med.*, 336: 1401–1408, 1997.
- Schrag, D., Kuntz, K. M., Garber, J. E., and Weeks, J. C. Decision analysis—Effects of prophylactic mastectomy and oophorectomy on life expectancy among women with *BRCA1* or *BRCA2* mutations. *N. Eng. J. Med.*, 336: 1465–1471, 1997.
- Matthews, A. K., Cummings, S., Thompson, S., Wohl, V., List, M., and Olopade, O. Genetic testing of African Americans for susceptibility to inherited cancers: use of focus groups to determine factors contributing to participation. *J. Psychosoc. Oncol.*, 18: 1–19, 2000.
- Lerman, C., Hughes, C., Benkenorf, J. L., Biesecker, B., Kerner, J., Willison, J., Eads, N., Hadley, D., and Lynch, J. Racial Differences in testing motivation and psychological distress following pretest education for *BRCA1* gene testing. *Cancer Epidemiol. Biomark. Prev.*, 8: 361–367, 1999.
- Hughes, C., Gomez-Caminero, A., Benkenorf, J., Kerner, J., Isaacs, C., Barter, J., and Lerman, C. Ethnic differences in knowledge and attitudes about *BRCA1* testing in women at increased risk. *Patient Education and Counseling*, 32: 51–62, 1997.
- Julian-Reynier, C., Eisinger, F., Chabal, F., Aurran, Y., Bignon, Y. J., Nogues, C., Machelard, M., Maugard, C., Vennin, P., and Sobol, H. Cancer genetic clinics: why do women who already have cancer attend? *Eur. J. Cancer*, 34: 1549–1553, 1998.
- Lerman, C., Narod, S., Schulman, K., Hughes, C., Gomez-Caminero, A., Bonney, G., Gold, K., Trock, B., Main, D., Lynch, J., Fulmore, C., Snyder, C., Lemon, S. J., Conway, T., Tonin, P., Lenoir, G., and Lynch, H. *BRCA1* testing in families with hereditary breast-ovarian cancer: a prospective study of patient decision making and outcomes. *JAMA*, 275: 1885–1892, 1996.
- Kinney, A. Y., Croyle, R. T., Dudley, W. N., Bailey, C. A., Pelias, M. K., and Neuhausen, S. L. Knowledge, attitudes, and interest in breast-ovarian cancer gene testing: a survey of a large African-American kindred with a *BRCA1* mutation. *Prev. Med.*, 33: 543–551, 2001.
- Donovan, K. A., and Tucker, D. C. Knowledge about genetic risk for breast cancer and perceptions of genetic testing in a sociodemographically diverse sample. *J. Behav. Med.*, 23: 15–36, 2000.

13. Lipkus, I. M., Iden, D., Terrenoire, J., and Feaganes, J. R. Relationships among breast cancer concern, risk perceptions, and interest in genetic testing for breast cancer susceptibility among African-American women with and without a family history of breast cancer. *Cancer Epidemiol. Biomark. Prev.*, *8*: 533–539, 1999.
14. SEER Cancer Statistics Review, 1973–1997. Bethesda, MD: National Cancer Institute, 2000.
15. Schneider, K. A. Genetic counseling for *BRCA1/BRCA2* testing. *Genetic Testing*, *1*: 91–98, 1997.
16. American Society of Clinical Oncology Statement of the American Society of Clinical Oncology: genetic testing for cancer susceptibility. *J. Clin. Oncol.*, *14*: 1730–1736, 2002.
17. Offit, K. (ed.). *Clinical Cancer Genetics*. New York: Wiley-Liss, 1998.
18. Horowitz, M., Wilner, N., and Alvarez, W. Impact of event scale: a measure of subjective stress. *Psychosom. Med.*, *41*: 209–218, 1979.
19. Jacobsen, P. B., Valdimarsdottir, H. B., Brown, K. L., and Offit, K. Decision making about genetic testing among women at familial risk for breast cancer. *Psychosom. Med.*, *59*: 459–466, 1997.
20. Schwartz, M. D., Lerman, C., Miller, S. M., Daly, M., and Masny, A. Coping disposition, perceived risk, and psychological distress among women at increased risk for ovarian cancer. *Health Psychol.*, *14*: 232–235, 1995.
21. Lerman, C., Daly, M., Sands, C., Balshem, A. M., Lustbader, E., Heggan, T., Goldstein, L., James, J., and Engstrom, P. Mammography adherence and psychological distress among women at risk for breast cancer. *J. Natl. Cancer Inst.*, *85*: 1074–1080, 1993.
22. Horowitz, M. J. Stress response syndromes and their treatment. In: H. Goldbert (ed.), *Handbook of Stress*, pp. 711. New York: Free Press, 1982.
23. Joseph, S. Psychometric evaluation of Horowitz's Impact of Events Scale: a review. *Journal of Traumatic Stress*, *13*: 101–113, 2000.
24. Shalev, A. Y., Peri, T., and Canetti, L. Predictors of PTSD in injured trauma survivors: a prospective study. *Am. J. Psychiatry*, *153*: 219–225, 1996.
25. Pierce, R. L. African-American cancer patients and culturally competent practice. *J. Psychosoc. Oncol.*, *15*: 1–17, 1997.
26. Bailey, E. J., Erwin, D. O., and Belin, P. Using cultural beliefs and patterns to improve mammography utilization among African-American women: the Witness Project. *J. Natl. Med. Assoc.*, *92*: 136–142, 2000.
27. Lannin, D. R., Mathews, H. F., Mitchell, J., Swanson, M. S., and Edwards, M. S. Influence of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. *JAMA*, *279*: 1801–1807, 1998.
28. Durfy, S. J., Bowen, D. J., McTiernan, A., Sporleder, J., and Burke, W. Attitudes and interest in genetic testing for breast and ovarian cancer susceptibility in diverse groups of women in western Washington. *Cancer Epidemiol. Biomark. Prev.*, *8*: 369–375, 1999.
29. Baldwin, D. A model for describing low-income African American women's participation in breast and cervical cancer early detection and screening. *Advances in Nursing Science*, *19*: 27–42, 1996.

Psychosocial Predictors of *BRCA* Counseling and Testing Decisions among Urban African-American Women

Hayley S. Thompson, Heiddis B. Valdimarsdottir, Chantal Duteau-Buck, et al.

Cancer Epidemiol Biomarkers Prev 2002;11:1579-1585.

Updated version Access the most recent version of this article at:
<http://cebp.aacrjournals.org/content/11/12/1579>

Cited articles This article cites 23 articles, 9 of which you can access for free at:
<http://cebp.aacrjournals.org/content/11/12/1579.full#ref-list-1>

Citing articles This article has been cited by 7 HighWire-hosted articles. Access the articles at:
<http://cebp.aacrjournals.org/content/11/12/1579.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, use this link
<http://cebp.aacrjournals.org/content/11/12/1579>.
Click on "Request Permissions" which will take you to the Copyright Clearance Center's (CCC) Rightslink site.