Ethnic, Racial and Cultural Identity and Perceived Benefits and Barriers Related to Genetic Testing for Breast Cancer among At-Risk Women of African Descent in New York City

K.M. Sussner^a T.A. Edwards^a H.S. Thompson^{a, b} L. Jandorf^a N.O. Kwate^c
A. Forman^e K. Brown^d N. Kapil-Pair^a D.H. Bovbjerg^f M.D. Schwartz^g
H.B. Valdimarsdottir^{a, h}

^aMount Sinai School of Medicine, Department of Oncological Sciences, Division of Cancer Prevention and Control, New York, N.Y., ^bWayne State University School of Medicine, Department of Oncology, Population Studies and Disparities Research, Karmanos Cancer Institute, Detroit, Mich., ^cColumbia University Mailman School of Public Health, Department of Sociomedical Sciences, and ^dMount Sinai School of Medicine, Department of Genetics and Genomic Sciences, Division of Medical Genetics, New York, N.Y., ^eFox Chase Cancer Center, Cancer Prevention and Control, Philadelphia, Pa., and ^fUniversity of Pittsburgh Cancer Institute and Department of Psychiatry, University of Pittsburgh, Pittsburgh, Pa., ^gLombardi Comprehensive Cancer Center, Georgetown University, Washington, DC., USA, ^hUniversity of Iceland, Department of Psychology, Reykjavik, Iceland

Key Words

Breast cancer · Cultural identity · Ethnic identity · Genetic testing · Racial identity

Abstract

Background: Due to disparities in the use of genetic services, there has been growing interest in examining beliefs and attitudes related to genetic testing for breast and/or ovarian cancer risk among women of African descent. However, to date, few studies have addressed critical cultural variations among this minority group and their influence on such beliefs and attitudes. **Methods:** We assessed ethnic, racial and cultural identity and examined their relationships with perceived benefits and barriers related to genetic testing for cancer risk in a sample of 160 women of African descent (49% self-identified African American, 39% Black-West Indian/Caribbean, 12% Black-Other) who met genetic risk criteria and were participating in a larger longitudinal study including the opportunity for free genetic counseling and testing

in New York City. All participants completed the following previously validated measures: (a) the multi-group ethnic identity measure (including ethnic search and affirmation subscales) and other-group orientation for ethnic identity, (b) centrality to assess racial identity, and (c) Africentrism to measure cultural identity. Perceived benefits and barriers related to genetic testing included: (1) pros/advantages (including family-related pros), (2) cons/disadvantages (including family-related cons, stigma and confidentiality concerns), and (3) concerns about abuses of genetic testing. **Results:** In multivariate analyses, several ethnic identity elements showed significant, largely positive relationships to perceived benefits about genetic testing for breast and/or ovarian cancer risk, the exception being ethnic search, which was positively associated with cons/disadvantages, in general, and family-related cons/disadvantages. Racial identity (centrality) showed a significant association with confidentiality concerns. Cultural identity (Africentrism) was not related to perceived benefits and/or barriers. **Conclusions:** Ethnic and racial identity may influence perceived benefits and

barriers related to genetic testing for breast and/or ovarian cancer risk among at-risk women of African descent. Genetic counseling services may want to take into account these factors in the creation of culturally-appropriate services which best meet the needs of this heterogeneous population.

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Introduction

Family history is one of the strongest predictors of a woman's lifetime risk of developing breast and/or ovarian cancer, with individuals carrying mutations in *BRCA1* or *BRCA2* genes having between a 40–66% cumulative risk of developing breast cancer and a 13–46% cumulative risk of developing ovarian cancer [1]. Despite increasing recognition of the importance of genetic risk information and availability of genetic counseling and testing for *BRCA1/2* mutations [2], numerous studies show that high risk African-American women may substantially under-use genetic services [2–8]. Indeed, White women have been reported to be 5 times more likely to undergo genetic counseling for *BRCA1/2* testing compared to African-American women [6]. Such findings are alarming, given that African-American women have higher rates of early-onset breast cancer and higher mortality rates compared to other groups [9, 10].

Research suggests that racial disparities in genetic counseling and testing use are partly attributable to limited knowledge [2, 11–13] as well as differences in perceived testing benefits and barriers related to *BRCA* genetic testing among African-American women. Perceived benefits previously shown to be rated higher by African-American women include: the opportunity for better informed screening and treatment decisions, the potential prevention of cancer and/or cancer recurrence, determination of family members' risks as well as personal reassurance and reduction of uncertainty via genetic testing [2, 11, 13, 14]. Perceived barriers have included concerns about testing abuses, potential stigmatization that may accompany learning mutation status and confidentiality concerns [11, 15]. These perceived barriers may be especially applicable for individuals of African descent given a long social history in the U.S. including the eugenics movement which misused genetic information to falsely warrant the assumed superiority or inferiority of specific racial/ethnic groups to others, promoting discrimination and unfavorable racial stereotypes [15–18]. Yet surprisingly, despite calls for the creation of culturally-sensitive health interventions for genetics services [8, 18–21], very

few studies have examined cultural variables as they relate to genetic testing beliefs and attitudes among diverse groups of women of African descent to promote more culturally-sensitive care by genetic risk professionals [15]. Combined with an ever-growing body of research that underscores the importance of examining the heterogeneity of the African experience as it relates to health [21–25], there is clearly a need for research that examines such culturally-related factors which may vary at the individual level among women of African descent and their possible influence on beliefs and attitudes about genetic testing for cancer risk. The few published studies to date have demonstrated significant associations with perceived advantages and disadvantages of genetic testing among women of African descent, with regard to: nativity [26], temporal orientation [27] and medical mistrust [15, 28] as well as have shown more fatalistic beliefs and future orientation among genetic test accepters compared to decliners [29]. These findings suggest that other ethnic, racial and cultural identity factors may also influence culturally relevant attitudes about genetic testing in this group. Furthermore, the evolving field of multicultural genetic counseling has recently made calls for the incorporation of the client's psychological view of his/her racial and cultural group as the main indicators of culture over racial phenotype [30], underscoring the importance of studies to determine the influence of these factors on beliefs and attitudes about genetic services. Better understanding of how ethnic, racial and cultural identity factors influence benefits and barriers to genetic testing will help inform the development of culturally-sensitive interventions for diverse groups of women of African descent [8, 18, 20, 21] and ultimately contribute to more culturally competent care.

The purpose of this cross-sectional secondary analysis was to explore the influences of ethnic, racial and cultural identity on perceived benefits and barriers related to genetic testing for breast and/or ovarian cancer risk among at-risk women of African descent in New York City. We hypothesize that these aspects of identity will be differentially related to perceived benefits and barriers to genetic testing for cancer risk among at-risk individuals of African descent. This research is guided by an overarching sociocultural perspective which emphasizes the role of membership in a specific group and its influence over daily life [31, 32] as well as incorporates both psychological identity theory and race-based cultural typology. Identity theory posits that the choices individuals make are largely a function of the extent to which those choices are related to a personally relevant role-identity [33, 34]. Given that the concepts of ethnic, racial and cultural

identity are closely intertwined within this larger identity theory, we chose to examine all 3 components in this study. Ethnic identity theory stems from literature in psychology supporting the view that it is more informative to explore psychological aspects of ethnicity compared to self-described racial group labels, although the terms of race and ethnicity have often been used interchangeably [35, 36]. In fact, ethnicity is considered here different than race, with ethnicity focused on perceived common ancestry [37], thereby theoretically allowing people of the same race to have different ethnicities based on this ancestry. Included under the umbrella of ethnic identity is often other-group orientation, as research shows that understanding the attitudes African Americans have toward other ethnic and cultural groups is a necessary component to understanding African-American ethnicity [36]. Racial identity theory accepts a race-based cultural typology, in which identity is understood as a function of racialized experiences based on the assumption that 'experience of belonging to a racial group transcends all other experiences' [30, 38]. Other research suggests that although phenotypical traits are a salient aspect of identity for individuals of African descent, racial identity is closely aligned with cultural identity rooted in an Afrocentric worldview paradigm [36, 39]. Furthermore, although ethnic identity measures aim to examine the identity component of ethnicity, such measures may not be specific to Africentric cultural values, underscoring the need for distinct cultural identity measures, such as Africentrism [40]. These identity factors may have particular relevance in metropolitan areas such as New York City where individuals of African descent have diverse cultural backgrounds and non-Hispanic Caribbean immigrants make up 21% of the foreign-born population [41].

Methods

Study Setting and Population

We conducted a cross-sectional secondary analysis of baseline information available on 160 women of African descent from a larger randomized control trial examining the psychosocial impact of standard genetic counseling versus culturally-tailored genetic counseling in women at increased risk of breast and/or ovarian cancer (see previously published cross-sectional results [26, 27]). Participants in the original longitudinal parent study were recruited in the greater New York City area through an existing study on biobehavioral factors and breast cancer risk, through genetic counselors in the clinical service and via community outreach, including physician referral and participant initiation. Most participants were recruited following women's initiation of contact with the study team via physician referral or community outreach, and therefore, the total number of women referred to

the study is unknown. A trained research assistant or genetic counselor explained the study to all interested potential participants and completed a family history form to determine eligibility based on family history suggestive of breast and/or ovarian cancer. Eligibility criteria included: women who self-identified as being of African descent, age 18 or older, English speaking, able to provide consent, had not previously undergone genetic counseling or testing for hereditary breast and/or ovarian cancer, and had a family history suggestive of the hereditary breast-ovarian cancer syndrome. Family history criteria were developed for the study in accordance with current clinical guidelines for identifying individuals at increased risk for hereditary breast-ovarian cancer. For this study, women were considered eligible if they met at least a 10% mutation probability by any of one of the 3 commonly used *BRCA1/2* mutation probability models (BRCAPro, Penn and Myriad) [42–44]. Pregnant women were excluded, as pregnancy-related distress could influence concerns about genetic testing for breast and/or ovarian cancer. Consent forms were mailed to all eligible women who met the study criteria. All participants completed a baseline survey through a telephone interview and were then given the option of receiving free genetic services for *BRCA1/2*, including being randomly assigned to either standard genetic counseling or culturally-tailored genetic counseling. Participants were given the option to obtain genetic testing after counseling. Participants were then followed up at 1 month post-counseling to determine their decision-making related to *BRCA1/2* genetic testing. For the cross-sectional secondary data analysis conducted in this study, we report only information obtained from the baseline data collected prior to randomization to genetic counseling, including information about socio-demographics; ethnic, racial, and cultural identity; breast/ovarian cancer, personal and family history; and attitudes and beliefs about *BRCA* genetic testing. Approval was obtained through Mount Sinai's Institutional Review Board for all study protocols. Participants received no monetary payment, however, genetic counseling and testing were provided at no cost.

Measures

Specific measures for ethnic, racial and cultural identity are outlined in table 1 and described here as follows:

Ethnic Identity

(a) *The Multi-Group Ethnic Identity Measure*. The multi-group ethnic identity measure (MEIM), originally developed by Phinney [35], has been used in dozens of studies as a universal measure of ethnic identity across a range of ethnic groups, with consistently strong reliability. This 12-item scale includes 2 factors: ethnic identity search (hereafter referred to as ethnic search) and affirmation, belonging and commitment (hereafter referred to as ethnic affirmation), with the preferred scoring using the mean of the 12-items for a total score as well as the mean of the 5 items for search and the 7 items for affirmation as subscale scores. The range of scores follows a Likert-type scale from 1–4 (strongly disagree to strongly agree), with higher scores indicating more positive ethnic identity. The MEIM total score showed strong internal reliability in this study ($\alpha = 0.88$).

Ethnic Search Subscale. The mean ethnic search score is comprised of 5 items from the MEIM related to time spent trying to

Table 1. Description of ethnic, racial and cultural identity predictors

Items included	Internal reliability, alpha
<i>Ethnic identity</i>	
MEIM Total (12 items)	0.88
Ethnic Search Subscale (5 items)	0.76
<ul style="list-style-type: none"> I have spent time trying to find out more about my own ethnic group, such as its history, traditions and customs I am active in organizations or social groups that include mostly members of my own ethnic group I think a lot about how my life will be affected by my ethnic group membership In order to learn more about my ethnic background, I have often talked to other people about my ethnic group I participate in cultural practices of my own group, such as special food, music, or customs 	
Ethnic affirmation subscale (7 items)	0.86
<ul style="list-style-type: none"> I have a clear sense of my ethnic background and what it means for me I am happy that I am a member of the group I belong to I have a strong sense of belonging to my ethnic group I understand pretty well what my ethnic group membership means to me, in terms of how to relate to my own group and other groups I have a lot of pride in my ethnic group and its accomplishments I feel a strong attachment towards my own ethnic group I feel good about my cultural or ethnic background 	
Other-Group Orientation Scale (6 items)	0.67
<ul style="list-style-type: none"> I like meeting and getting to know people from ethnic groups other than my own I sometimes feel it would be better if different ethnic groups didn't try to mix together I often spend time with people from ethnic groups other than my own I don't try to become friends with people from other ethnic groups I am involved in activities with people from other ethnic groups I enjoy being around people from ethnic groups other than my own 	
<i>Racial identity</i>	
Centrality Subscale (8 items)	0.79
<ul style="list-style-type: none"> Overall, being Black has very little to do with how I feel about myself In general, being Black is an important part of my self-image My destiny is tied to the destiny of other Black people Being Black is unimportant to my sense of what kind of person I am I have a strong sense of belonging to Black people I have a strong attachment to other Black people Being Black is an important reflection of who I am Being Black is not a major factor in my social relationships 	
<i>Cultural identity</i>	
Africentrism (15 items)	0.76
<ul style="list-style-type: none"> Black people should make their community better than it was when they found it The problems of other Blacks are their problems, not mine The unity of the African race is very important to me I am more concerned with reaching my own goals than with working for the Black community I have very little faith in Black people I owe something to Black people who suffered before me Black people need to stop worrying so much about 'the community' and take care of their own needs I am doing a lot to improve my neighborhood The success I have had is mainly because of me, not anyone else I have more confidence in White professionals, like doctors and teachers, than in Black professionals Black people should build and maintain their own communities I must do all I can to restore Black people to their position of respect in the world I make it a point to shop at Black businesses and use Black-owned services It hurts me when I see another Black person discriminated against It is important that Black people decide for themselves what to be called and what their needs are 	

find out about one's ethnic group, activity in organizations and social groups related to one's ethnic group, time spent thinking about ethnic group membership, and extent of participation in cultural practices unique to one's ethnic group. These 5 items demonstrated good internal reliability in this study ($\alpha = 0.76$).

Ethnic Affirmation Subscale. The mean ethnic affirmation score is computed with 7 items from the MEIM including sense of one's ethnic group and meaning, happiness, belonging, pride and attachment towards one's own ethnic group. This subscale was highly reliable ($\alpha = 0.86$).

(b) Other-Group Orientation. The other-group orientation scale is a distinct identity scale which was developed in tandem with the original MEIM [35] and is often used in conjunction with the MEIM to assess relationship to ethnic groups different than one's own. The scale includes 6 items scored on a Likert-type scale 1–4 (strongly disagree to strongly agree), measuring how often one meets and gets to know people from other ethnic groups, participates in activities with people from other groups as well as how one feels about people from different ethnic groups spending time together. This scale demonstrated adequate internal reliability ($\alpha = 0.67$).

Racial Identity

(a) Centrality. The centrality subscale of the Multidimensional Inventory of Black Identity is a well-known validated measure for assessing African-American racial identity [34]. This inventory measures the extent to which race is a core part of an individual's self-concept. The Centrality subscale of the Multidimensional Inventory of Black Identity consists of 8 items on a Likert-type scale ranging from strongly disagree to strongly agree (1–4). The Centrality subscale demonstrated good internal reliability for our sample ($\alpha = 0.79$).

Cultural Identity

(a) Africentrism. The Africentrism scale examines the cultural component of ethnicity, by assessing Africentric cultural values, traditions and behavioral beliefs [40]. This previously validated 15-item scale is based on the principles of the African cultural celebration of Kwanzaa, called the Nguzo Sabo, and includes measures of unity, self-determination, collective work and responsibility, cooperative economics, purpose, creativity, and faith. All items are measured on a 1–4 Likert-type scale (strongly disagree to strongly agree), with a higher score indicating more endorsement of Afrocentric values and behaviors. The internal reliability of the Africentrism scale was considered good for our sample ($\alpha = 0.76$).

Covariates

Sociodemographic Factors. Sociodemographic factors assessed participants' age, self-identified race/ethnicity, education, income, and insurance status.

Breast and/or Ovarian Cancer History. Information about participants' personal diagnosis and family history of breast and/or ovarian cancer was also obtained.

Outcomes

The original baseline interview examined in this study included a one-paragraph description in layman's terms of the hereditary basis of breast and ovarian cancer and how genetic tests may be used to determine which family members have inherited a genetic mutation. Participants were asked how much they agreed or disagreed with a series of statements about potential perceived

benefits and barriers related to genetic testing, knowing that a blood test for inherited breast cancer is currently available. In this study, we examined the following perceived benefits and barriers related to genetic testing as outlined in table 2, including: (1) pros/advantages (including family-related pros subscale) of genetic testing, (2) cons/disadvantages (including family-related cons, stigma and confidentiality concerns subscales) of genetic testing, and (3) concerns about abuses of genetic testing. These outcomes have been previously created and validated for use in African-American women as they relate to *BRCA* testing [8, 14, 45, 46]. All questions were measured on a 5-point Likert-type scale (strongly disagree to strongly agree), with total scores computed by summing individual questions and taking the average (range = 1–5). Internal reliability of all scales was good (range = 0.67–0.84).

Analytic Plan

We computed basic descriptive statistics, as reported in table 3. Initial univariate linear regression analyses examined each predictor (ethnic, racial and cultural identity) and covariate individually and determined its association with study outcomes. We also computed individual correlations among the identity measures. In cases of missing data, we omitted those individuals from analysis. We developed multivariate linear regression models separately for each study outcome with the following steps: We explored all significant variables ($p < 0.10$) in univariate analyses as potential covariates for inclusion in the candidate short list for multivariate models. We conducted a forward selection test as the automatic statistical procedure of choice to control for potential problems of multicollinearity among variables in the models. Due to a relatively small sample size, we chose a level of significance of $p < 0.10$ as most appropriate for determining initial entry into the forward selection test. We then included variables significant from the forward selection test in final multivariate linear regression models. We added all other covariates independently associated with the outcomes one by one to test for potential confounding. We considered any such covariates producing a change of at least 20% in the Beta weights of predictors already in the model (from forward selection) as potential confounders and included them in final models. We also included any theoretically critical sociodemographic variables (i.e. age, personal and family history of breast and/or ovarian cancer). We used a level of $p < 0.05$ to determine overall statistical significance of variables in the final model. We used an R^2 test to determine the percentage of the variability explained by the final multivariable linear regression model. All statistical procedures used SAS software package v.9.1.3.

Results

Sample Characteristics

Sample characteristics are presented in table 3, where the total sample size (n) refers to number of participants responding to individual questionnaire items and changes based upon mode of questionnaire administration, interviewer versus self-administered. As such, since not all participants completed all phases of these questionnaires,

Table 2. Description of outcomes: perceived benefits and barriers related to genetic testing for cancer risk

Items included	Internal reliability, alpha
<i>Pros/advantages of GT (9 items)</i>	0.79
<ul style="list-style-type: none"> • My concerns about getting breast cancer again would be reduced if I knew I did not carry the gene mutation • Knowing whether I had the gene mutation would increase my sense of personal control • Knowing whether I have the gene mutation or not would help me make important life decisions • Knowing that I carry the gene mutation would motivate me to perform breast self-examination more frequently • Knowing that I carry the gene mutation would help me decide whether to go for more frequent mammograms 	
<i>Family-related pros (4 items)</i>	0.84
<ul style="list-style-type: none"> • If I were found to carry the gene mutation, it would help my daughters or sisters decide whether to undergo genetic testing • My genetic test results could give my family members useful information about their risk of getting cancer • My genetic test results could help my family members make better decisions about how to take care of their health • Genetic testing would help me learn if my children were at increased risk for getting breast cancer 	
<i>Cons/disadvantages of GT (14 items)</i>	0.78
<i>Family-related cons (5 items)</i>	0.66
<ul style="list-style-type: none"> • If I underwent genetic testing for cancer, I would be concerned about the effect it would have on my family • If I were found to carry the gene mutation for breast cancer, I would worry about passing the gene to my children • Knowing that I carry the gene mutation would cause me to worry more about other family members who could be carriers (mother, sisters, daughters) • If I were found to carry the gene mutation for breast cancer, I would feel guilty if my daughter(s) developed breast cancer • I would feel guilty if one of my relatives had the gene mutation and I did not 	
<i>Cons-stigma related to GT (3 items)</i>	0.72
<ul style="list-style-type: none"> • If I were found to carry a gene mutation for cancer, I would feel singled out • If I were found to carry a gene mutation for cancer, it would cause others to view me negatively • I would be ashamed if I were found to carry the gene mutation 	
<i>Confidentiality concerns (2 items)</i>	0.67
<ul style="list-style-type: none"> • If I were found to carry the gene mutation, I would worry that the results would not stay confidential • Being tested for the gene mutation could jeopardize my insurance coverage 	
<i>Other cons (4 items)</i>	
<ul style="list-style-type: none"> • I would be frightened if I were found to carry the gene mutation • Knowing that I carry the gene mutation would leave me in a state of hopelessness and despair • I would consider suicide if I were found to carry the gene mutation for breast cancer • If I underwent genetic testing for cancer, I would not be able to handle it emotionally 	
<i>Concerns about abuses of GT (5 items)</i>	0.83
<ul style="list-style-type: none"> • The results of genetic tests are used to treat certain people unfairly • Genetic testing allows doctors and scientists to 'play God' • Genetic testing is used to show that my ethnic or racial group is not as good as other groups • Genetic testing is used to interfere with the way God intended people to be • Genetic testing is used to interfere with the 'natural order' of life 	

there are instances of missing data for some participants. The mean age of participants in the sample was 45.3 years (SD = 9.5; min. = 22; max. = 79). Close to half of participants in the sample self-identified themselves as Black/African American (49.4%), more than a third identified as Black/West Indian/Caribbean (39.4%), with the others (11.2%) identifying as Black-Other (Black-African, Black-Multiethnic, Black-Other-Hispanic). The majority (71%) had more than a high school diploma, made more than USD 20,000/year (71%), and were insured (84%). Most participants had a personal history of breast and/or ovarian cancer (64%), while the majority had a family history of breast and/or ovarian cancer (76%). Meanwhile, almost

half of participants reported both a personal and family history of breast and/or ovarian cancer (41%). The majority of participants completed free genetic counseling for breast and/or ovarian cancer risk offered as part of the longitudinal study, with 88% completing the first session and 84% completing the second session. The majority of participants also completed genetic testing for breast/ovarian cancer risk (84%). In terms of the identity predictors of interest, the mean scores for ethnic identity were: 3.0 (SD = 0.4) for total MEIM, 2.7 (SD = 0.6) for the ethnic search subscale, 3.3 (SD = 0.4) for the ethnic affirmation subscale and 3.2 (SD = 0.4) on the other-group orientation scale. For racial identity, the mean score for the centrality subscale

Table 3. Baseline statistics: ethnic, racial and cultural identity predictors and perceived benefits and barriers related to genetic testing (GT) for cancer risk

Predictor variables	Sample, mean (SD)	Range	n (%)*
<i>Ethnic, racial and cultural identity predictors**</i>			
Ethnic identity			
Total MEIM score (high = more positive ethnic identity)	3.0 (0.4)	1.9, 3.9	140
Total ethnic search score	2.7 (0.6)	1.0, 4.0	140
Total ethnic affirmation score	3.3 (0.4)	1.0, 4.0	140
Other-group orientation scale (high = more other-group orientation)	3.2 (0.4)	2.2, 4.0	140
Racial identity			
Centrality subscale (high = more centrality)	2.6 (0.5)	1.1, 4.0	140
Cultural identity			
Total Africentrism score (high = more Africentrism)	2.9 (0.3)	2.3, 3.9	139
<i>Covariates</i>			
Sociodemographics			
Age	45.3 (9.5)	22, 79	160
Self-identified race/ethnicity			
Black/African American	n/a	n/a	79 (49.4)
Black-West Indian/Caribbean	n/a	n/a	63 (39.4)
Black-Other	n/a	n/a	18 (11.2)
Education			
≤High school diploma	n/a	n/a	46 (29)
>High school diploma	n/a	n/a	114 (71)
Income USD			
≤19,999/year	n/a	n/a	44 (29)
≥20,000/year	n/a	n/a	108 (71)
Insurance status			
Insured (public & private)	n/a	n/a	135 (84)
Non-insured	n/a	n/a	25 (16)
Cancer history			
Personal history of breast/ovarian cancer			
Yes	n/a	n/a	102 (64)
No	n/a	n/a	58 (36)
Family history of breast/ovarian cancer			
Yes	n/a	n/a	121 (76)
No	n/a	n/a	39 (24)
Both personal/family history breast/ovarian			
Yes	n/a	n/a	66 (41)
No	n/a	n/a	94 (59)
Participation in free genetic counseling (GC) as part of larger study			
First GC session status			
Completed	n/a	n/a	141 (88)
Cancelled/passive refuser	n/a	n/a	10 (6)
Did not attend	n/a	n/a	9 (6)
Genetic testing completed	n/a	n/a	134 (84)
Second GC session status			
Completed	n/a	n/a	128 (80)
Cancelled/passive refuser	n/a	n/a	2 (1)
Did not attend	n/a	n/a	30 (19)
<i>Outcome variables: perceived benefits and barriers related to GT for cancer risk</i>			
Pros/advantages of GT (9 items)	4.2 (0.5)	2.8, 5.0	160
Family-related pros of GT (4 items)	4.4 (0.5)	2.0, 5.0	159
Cons/disadvantages of GT (14 items)	2.4 (0.4)	1.3, 3.8	160
Family-related cons/disadvantages of GT (5 items)	3.2 (0.6)	1.4, 4.8	160
Stigma related to GT (3 items)	1.8 (0.6)	1.0, 4.0	160
Confidentiality concerns related to GT (2 items)	2.2 (0.8)	1.0, 5.0	160
Concerns about abuses of GT (5 items)	1.9 (0.6)	1.0, 3.4	158

* Where the total sample size (n), referring to number of participants responding to individual questionnaire items changes based upon mode of questionnaire administration, interviewer vs. self-administrated. ** Where there was strong collinearity ($0.18 \leq r \leq 0.90$; $0.03 \leq p \leq 0.0001$) found between all of these identity measures with the exception of the relationship between centrality and other group orientation, which was not significant ($r = 0.08$; $p = 0.33$).

Table 4. Significant unadjusted predictor estimates of perceived benefits and barriers related to genetic testing (GT) for cancer risk outcomes

Perceived benefits and barriers related to GT	Significant unadjusted predictors*	β coefficient/ parameter estimate (SE)	p value
Pros/advantages of GT	MEIM (total)	0.26 (0.09)	0.007
	Ethnic search	0.17 (0.08)	0.03
	Ethnic affirmation	0.24 (0.09)	0.01
	Other-group orientation	0.27 (0.11)	0.01
Family-related pros/advantages of GT	MEIM (total)	0.21 (0.10)	0.05
	Ethnic affirmation	0.29 (0.10)	0.005
	Other-group orientation	0.33 (0.11)	0.004
Cons/disadvantages GT	Ethnic search	0.14 (0.07)	0.04
Family-related cons	Ethnic search	0.24 (0.10)	0.02
Stigma associated with GT	Ethnic affirmation	-0.19 (0.11)	0.08
	Other-group orientation	-0.28 (0.13)	0.03
	Age	0.01 (0.005)	0.03
Confidentiality concerns related to GT	Ethnic affirmation	-0.33 (0.15)	0.04
	Centrality	0.20 (0.13)	0.10
	Income		
	≤USD 19,999/year vs. ≥USD 20,000/year	-0.32 (0.15)	0.04
	Education		
	≤High school vs. >high school	-0.24 (0.15)	0.10
Concerns about abuses of GT	Other-group orientation	-0.27 (0.11)	0.02
	Age	0.009 (0.004)	0.04

* Significance level $p \leq 0.10$.

was 2.6 (SD = 0.5), while for cultural identity, the mean score for Africentrism was 2.9 (SD = 0.3). There was strong collinearity ($0.18 \leq r \leq 0.90$; $0.03 \leq p < 0.0001$) found between all of these identity measures with the exception of the relationship between centrality and other group orientation, which was not significant ($r = 0.08$; $p = 0.33$). In terms of the outcome variables of interest, beliefs and attitudes about genetic testing for cancer risk, mean scores were the following: 4.2 (SD = 0.5) for pros/advantages of genetic testing, 4.4 (SD = 0.5) for family-related pros, 2.4 (SD = 0.5) for cons/disadvantages of genetic testing, 3.2 (SD = 0.6) for family-related cons/disadvantages, 1.8 (SD = 0.6) for stigma related to genetic testing, 2.2 (SD = 0.8) for confidentiality concerns related to genetic testing, and 1.9 (SD = 0.6) for concerns about abuses of genetic testing.

Univariate Results

Table 4 reports the significant ($p < 0.10$) unadjusted associations in univariate analysis.

Pros/Advantages of Genetic Testing

The total MEIM score, including ethnic search and affirmation subscales, as well as other-group orientation, were positively associated with pros/advantages about genetic testing for cancer risk.

(a) *Family-Related Pros/Advantages of Genetic Testing.* For family-related pros/advantages of genetic testing, the total MEIM including ethnic affirmation, as well as other-group orientation, were positively associated with family-related pros/advantages about genetic testing for cancer risk in univariate analyses.

Cons/Disadvantages of Genetic Testing

Ethnic search was independently related to cons/disadvantages of genetic testing.

(a) *Family-Related Cons/Disadvantages of Genetic Testing.* Ethnic search was independently associated with family-related cons/disadvantages.

(b) *Stigma Associated with Genetic Testing.* Ethnic affirmation and other-group orientation were negatively related to stigma associated with genetic testing in uni-

variate analyses, while age was positively related to stigma associated with genetic testing.

(c) *Confidentiality Concerns Related to Genetic Testing.* Ethnic affirmation, income and education were negatively related to confidentiality concerns related to genetic testing, while centrality was positively related to confidentiality concerns.

Concerns about Abuses of Genetic Testing

Independent associations with concerns about abuses of genetic testing included other-group orientation (negatively related) and age (positively related).

Multivariate Results

Table 5 displays the final multivariate results for all models which included significant adjusted estimates of perceived benefits and barriers related to genetic testing for cancer risk. In these final models, age, family and personal history of breast cancer were considered theoretically critical (if not otherwise previously entered into the model), as they have been shown to influence breast cancer risk and screening practices, beliefs, attitudes, and concerns about genetic testing in women of African descent [47, 48].

Pros/Advantages of Genetic Testing

In multivariate analysis, results indicated that the total MEIM score was positively related to pros/advantages of genetic testing ($\beta = 0.20$; SE = 0.10; $p = 0.05$).

(a) *Family-Related Pros/Advantages of Genetic Testing.* Ethnic affirmation was positively related to family-related pros/advantages in multivariate analysis ($\beta = 0.28$; SE = 0.10; $p = 0.007$).

Cons/Disadvantages of Genetic Testing

Ethnic search was positively related to cons/disadvantages of genetic testing in multivariate analysis ($\beta = 0.14$; SE = 0.07; $p = 0.04$).

(a) *Family-Related Cons/Disadvantages of Genetic Testing.* Ethnic search was significantly associated with family-related cons/disadvantages related to genetic testing in multivariate analysis ($\beta = 0.24$; SE = 0.10; $p = 0.02$).

(b) *Stigma Associated with Genetic Testing.* In multivariate analysis, other-group orientation was negatively related to perceived stigma associated with genetic testing ($\beta = -0.28$; SE = 0.12; $p = 0.03$).

(c) *Confidentiality Concerns Related to Genetic Testing.* There was a negative relationship between ethnic affirmation and confidentiality concerns related to genetic

testing ($\beta = -0.56$; SE = 0.17; $p = 0.002$), while centrality showed a positive relationship ($\beta = 0.34$; SE = 0.14; $p = 0.01$). Individuals who made $\leq$ USD 20,000/year were less likely to have confidentiality concerns compared to individuals who made $\geq$ USD 20,000/year ($\beta = -0.42$; SE = 0.15; $p = 0.008$). In addition, individuals with personal history of breast/ovarian cancer ($\beta = 0.32$; SE = 0.15; $p = 0.03$) were more likely to have confidentiality concerns compared to those without personal history, although results should be considered cautiously as this variable had not previously been significant in univariate analyses.

Concerns about Abuses of GT

Other-group orientation was negatively related to concerns about abuses of genetic testing in multivariate analysis ($\beta = -0.29$; SE = 0.12; $p = 0.02$).

Discussion

Study results reveal that ethnic and racial identities are associated with perceived benefits and barriers related to genetic testing for cancer risk among a diverse sample of at-risk women of African descent. Study results largely demonstrated that having a strong sense of ethnic identity was related to having more positive beliefs and attitudes about genetic testing. Specifically, results indicated a positive association between total MEIM score and pros/advantages of genetic testing as well as for the relationship between ethnic affirmation and family-related pros/advantages. There was also a negative, yet potentially protective relationship found between ethnic affirmation and confidentiality concerns associated with genetic testing as well as for other-group orientation and its relationship to both stigma associated with genetic testing and concerns about abuses of genetic testing. Ethnic search was the only ethnic identity factor measured in this study that demonstrated a negative relationship with beliefs about genetic testing in multivariate analyses, in that individuals with higher ethnic search scores reported more cons/disadvantages and family-related cons/disadvantages of genetic testing. Racial identity assessed in this study via the centrality subscale of the Multidimensional Inventory of Black Identity was related to perceived barriers, as results indicated that women with higher centrality scores reported more confidentiality concerns related to genetic testing. Finally, cultural identity, as measured in this study by Africentrism, showed no significant relationship to perceived benefits or barriers related to genetic testing for cancer risk.

Table 5. Final multivariate models: significant adjusted predictor estimates of perceived benefits and barriers related to genetic testing (GT) for cancer risk outcomes

Perceived benefits and barriers related to GT	Final multivariable model	β coefficient/ parameter estimate (SE)	p value	R ²
Pros/advantages of GT	MEIM (total)	0.20 (0.10)	0.05*	0.07
	Other-group orientation	0.18 (0.12)	0.13	
	Age	0.00 (0.004)	0.89	
	Family history of breast/ovarian cancer Yes vs. no	−0.02 (0.11)	0.88	
	Personal history of breast/ovarian cancer Yes vs. no	−0.02 (0.09)	0.82	
Family-related pros/advantages of GT	Ethnic affirmation	0.28 (0.10)	0.007*	0.07
	Age	0.00 (0.00)	0.90	
	Family history of breast/ovarian cancer Yes vs. no	−0.10 (0.12)	0.41	
	Personal history of breast/ovarian cancer Yes vs. no	0.04 (0.10)	0.69	
Cons/disadvantages of GT	Ethnic search	0.14 (0.07)	0.04*	0.05
	Age	0.005 (0.004)	0.24	
	Family history of breast/ovarian cancer Yes vs. no	0.05 (0.10)	0.61	
	Personal history of breast/ovarian cancer Yes vs. no	−0.07 (0.08)	0.41	
Family-related cons/disadvantages of GT	Ethnic search	0.24 (0.10)	0.02*	0.06
	Age	0.002 (0.01)	0.73	
	Family history of breast/ovarian cancer Yes vs. no	0.05 (0.14)	0.72	
	Personal history of breast/ovarian cancer Yes vs. no	−0.09 (0.13)	0.48	
Stigma associated with GT	Other-group orientation	−0.28 (0.12)	0.03*	0.06
	Age	0.01 (0.005)	0.07	
	Family history of breast/ovarian cancer Yes vs. no	0.02 (0.12)	0.85	
	Personal history of breast/ovarian cancer Yes vs. no	−0.06 (0.11)	0.61	
Confidentiality concerns related to GT	Ethnic affirmation	−0.52 (0.17)	0.002*	0.16
	Centrality	0.34 (0.14)	0.01*	
	Income ≤USD 19,999/yr vs. ≥USD 20,000/yr	−0.42 (0.15)	0.008*	
	Age	0.004 (0.01)	0.57	
	Family history of breast/ovarian cancer Yes vs. no	0.23 (0.17)	0.19	
	Personal history of breast/ovarian cancer Yes vs. no	0.32 (0.15)	0.03*	
Concerns about abuses of GT	Other-group orientation	−0.29 (0.12)	0.02*	0.07
	Age	0.09 (0.05)	0.06	
	Family history of breast/ovarian cancer Yes vs. no	−0.07 (0.12)	0.56	
	Personal history of breast/ovarian cancer Yes vs. no	−0.003 (0.10)	0.98	

* Significance level $p \leq 0.05$. Final multivariate models include variables significant from forward selection procedure plus confounders and any theoretically necessary covariates (age, family and personal history of breast/ovarian cancer).

A primary strength of this study lies in its inclusion of a group of complex, yet interrelated ethnic, racial and cultural identity factors, which allowed examination of their combined influence on perceived benefits and barriers to genetic testing for cancer risk. While a few previous studies have begun to examine culturally informed attitudes about genetic testing in women of African descent, including associations with medical mistrust as well as nativity [15, 26], to our knowledge, this is the first study to examine ethnic, racial and cultural identity as they relate to beliefs and attitudes about genetic testing. As described earlier, this research builds upon the evolving field of multicultural genetic counseling and transitions away from the assessment of traditionally visible racial and cultural groups to understand a more fully integrated cognitive-affective racial and cultural identity. From this multicultural perspective, greater consideration is given to the range of variation among racial and cultural groups [30]. In fact, a review of existing literature related to genetic counseling by Wang [30] found that only 9% of articles discussed cultural issues; meanwhile, amongst those few who did, 75% considered a cross-cultural, group-specific approach rather than one which values understanding variation among group members. The study results presented here, which treat ethnic, racial and cultural identity as distinct, but closely related constructs, thus, uniquely add to the multicultural counseling literature by following the shift from exploring race alone to understanding the impact of ethnic, racial and cultural identities [30, 36, 39].

Although ethnic identity has been well understood and examined widely by psychologists as an important multicultural construct [36, 49] related to overall psychological well-being [50], to date, ethnic identity has been largely overlooked in terms of its relationship to other health-related outcomes [51–53]. In one study, adolescent African-American males with high ethnic identity scores had lower mean blood pressures compared to those with low scores [54]. However, in the cancer prevention realm, a recent review examining the use of sociocultural constructs in cancer-screening research among African Americans determined that there has been no clear link found between ethnic identity and health behaviors to date; therefore, further work is needed [32]. To our knowledge, thus far, there have been only 2 studies examining ethnic identity as it relates to cancer prevention outcomes [53, 55]. In the first [55], the self-chosen racial pride label of 'African American' versus 'Black' was found to be the only predictor of mammography screening for African-American women, with women who self-identified as 'African American' being more likely to report intentions to obtain a mammo-

gram. Results suggest that women who self-label with a more ethnic, cultural 'African American' may feel less defined by or at odds with a racial infused dominant culture, compared to women who identify with a more racial, other-defined imposed label of 'Black'. In the second known study in this area [53], 113 African-American women were assessed as they underwent breast cancer risk counseling, and predictors of risk and worry changes as a result of this counseling were evaluated. Women with higher levels of societal identity related to the Black or African-American community were found to have larger reductions in perceived risk and cancer worry, highlighting the role of psychosocial counseling interventions for women of African descent as they learn to cope with breast cancer risk [53].

The results of our study further underscore the role of ethnic identity as a psychosocial factor which warrants consideration in shaping women's perceptions of genetic testing for cancer risk. Specifically, study results suggest that having a positive ethnic identity may be associated with having a positive influence on perceived benefits about genetic testing among women of African descent, as demonstrated by the findings of total MEIM score, ethnic affirmation and other-group orientation. However, as a possible negative influence, women with higher ethnic search scores reported both more cons/disadvantages and family-related cons/disadvantages related to genetic testing. Considered in light of previous literature, it is possible that ethnic search may behave similarly to the immersion/emersion stage of Cross' Nigrescence Theory of racial identity, in which an individual searches for ways to be comfortable with his/her identity, becoming deeply ingrained in 'becoming Black', and there is initially a strong, if not highly emotionally charged in-group membership [56, 57]. This transitional stage has previously been associated with a range of negative health outcomes in African Americans including low self-esteem, personal distress and elevated blood pressure [14, 56, 58]. Considered in this context, the negative association of ethnic search to both cons and family-related cons associated with genetic testing may not be all that surprising. Ultimately, even though this analysis included a select sample of women who had already agreed to participate in a study offering free genetic counseling, our results highlight critical ethnic identity factors which may influence benefits and barriers to genetic testing among at-risk women of African descent. These findings are critical given previous research suggesting that perceived benefits and barriers may impact uptake of genetic counseling and testing in African Americans [14], warranting consideration by genetic counselors and educators.

Racial and cultural identity, although related closely to ethnic identity, allow for the study of identity as a result of minority status with a specific focus on potential discriminatory treatment as well as consideration of Afro-specific racial and cultural influences [36]. A wealth of previous research has focused on psychological aspects of African-American identity [34], including associations with self-esteem [59] and academic performance [60]. Yet, there is no clear consensus among psychological identity theorists over whether strong identification with racial group places individuals of African descent at risk for adverse effects or whether such identification serves as a protective factor which promotes resiliency against racism and discrimination [34, 61–63]. In the case of the results presented here, a strong racial identity (individuals with higher centrality scores) was associated with higher confidentiality concerns related to genetic testing in multivariate analyses, controlling for relevant factors. This finding may not be surprising in light of research conducted among African Americans which has found a positive relationship between medical mistrust and concerns about abuses of genetic testing [15] as well as the larger body of research discussed above linking specific stages of racial identity to negative health outcomes [56–58]. Further, as the centrality items may be more closely tied to an individual's sense of self and esteem, in comparison to the other identity measures evaluated here which may incorporate more focus on group membership, it would make intuitive sense that centrality would be closely aligned with any invasion of this private self (i.e. confidentiality concerns). Given that concerns about confidentiality may inhibit an individual with regard to considering or seeking out genetic counseling and testing [11, 63, 64], it is possible that having a strong racial identity (as measured by higher centrality) may have a potentially detrimental effect on uptake of genetic testing among at-risk women of African descent. However, the potential effect of our results in determining uptake is very limited in this, given the highly select sample of women in this analysis had already agreed to participate in the research which included the opportunity for free genetic counseling. One could argue such interest was artificially high due to these services being free. Meanwhile, although Africentrism may be considered an important aspect in terms of cultural identity with previous effects found on alcohol initiation and consumption [65], drug use and related attitudes [66], and rebelliousness [50], in this study, this specific measure had no influence on perceived benefits or barriers to genetic testing.

Given substantial disparities evident in the uptake of *BRCA* genetic counseling and testing services among women of African descent [3–8], research that identifies cultural influences on perceived benefits and barriers to genetic testing is important if we are to develop truly culturally competent care. While a few studies have begun to examine such cultural influences within and among African Americans [15], it is imperative that researchers consider the possible range of culturally-specific variations and heterogeneity of experience among individuals of African descent [22–25]. Research conducted by members of our team has attempted to understand such heterogeneity in the area of genetic testing for cancer risk, finding associations between cultural factors such as medical mistrust [15], as described above, and for nativity [26]. In Sussner et al. [26], being foreign born was a significant predictor of anticipated negative emotional reactions about genetic testing ($\beta = 0.26$; $SE = 0.11$; $p = 0.01$). Further, in that prior study, breast cancer-specific distress scores (avoidance symptoms) were positively related to anticipated negative emotional reactions, confidentiality concerns and family-related guilt associated with genetic testing. Considered in light of findings presented here, this research emphasizes the need to better understand such cultural specificity among individuals of African descent to not only avoid potential stereotyping and inaccurate generalizations across broad categories of people [24], but moreover better inform the design, development and implementation of much needed culturally-sensitive interventions which address the perceived benefits and barriers related to genetic services among diverse women of African descent [8, 18, 20, 21]. Specifically, such culturally-based interventions which are grounded in a greater understanding of how cultural background may influence beliefs, attitudes and reactions to genetic services will ultimately influence the design of more culturally-sensitive protocols [8, 26] that not only consider group-specific beliefs, but incorporate individual variation and the range of perceptions held by individuals of African descent. For example, given study findings, it may be important to design interventions which target women of African descent with high ethnic search and racial identity (centrality) scores to counter possible negative beliefs they may experience about genetic testing. At the same time, it may be useful to develop interventions which foster a strong sense of ethnic identity in other individuals of African descent due to the association found here with positive beliefs and attitudes about genetic testing. Ultimately, genetic counselors may be able to use this information to ensure that decisions

related to genetic testing for cancer risk are fully informed and culturally appropriate within women of African descent.

Study Limitations

There are several limitations of the study which should be noted. First, there were some variables with missing data, resulting in smaller sample sizes where individuals with missing data were deleted from analyses. Second, since this study examined women who were participating in a larger longitudinal study which offered free genetic counseling (which the majority accepted), this highly selected sample may be biased by the decision of these high-risk women to participate in the larger study, some of whom may have been predisposed to be responsive to genetic counseling/testing. In other words, those least interested in genetic counseling would have never agreed to participate in the study. Unfortunately, it is not possible to determine if any of the predictors correlated with uptake of genetic counseling or testing. Specifically, there is no actual way of knowing what the true denominator was (those not interested) for potential participants in the larger longitudinal study due to the nature of the recruitment via physician referral and community outreach. Future research should thus explore the uptake of genetic counseling and testing as behavioral outcomes. Third, and related to the above, the generalizability of study results and ability to make inferences about the larger population is limited given this highly select sample. Generalizability is also limited as study results may not be applicable to other racial/ethnic groups beyond women of African descent and only relevant to similarly diverse, metropolitan samples in the U.S. which include similarly representative samples of individuals of African descent. Fourth, given the sample consisted of mostly middle-class educated and insured women of African descent, it is likely that these women did not face the same access-related barriers which other individuals from this population group may experience in relation to obtaining genetic services. In fact, research with women of African descent shows that cost of genetic services is one of the most influential factors inhibiting decision to receive genetic services [19]. Fifth, as research underscores the value of examining perceived benefits and barriers to genetic counseling separate from those of testing [14], this study is limited as it only assessed pros and cons related to genetic testing and thus may not be applied directly to counseling. Sixth, while these results

are suggestive of an association between ethnic and racial identity, and beliefs and attitudes about genetic testing, such findings cannot determine direction of causation. Related to this point, the predictive value of several of the final multivariate models may be small, given the relatively low coefficient of determination, although this may be of secondary importance since the regression is not being used to make predictions per se. Seventh, given our limited understanding of how ethnic, racial and cultural identity may differentially influence beliefs and attitudes about genetic testing, it is suggested that future research address these complex relationships through open-based, qualitative studies. Finally, although we found no significant associations between any of the self-identified racial/ethnic identity categories (Black/African American, Black-West Indian/Caribbean and Black-Other) with perceived benefits and barriers to genetic testing, we acknowledge that future research with larger sample sizes may wish to explore this possible association and examine how self-identified race/ethnicity categories maps onto ethnic, racial and cultural identity and in turn influences beliefs about genetic testing. For example, our previously published cross-sectional secondary analysis of the same dataset found important acculturation-related differences (US vs. foreign born) that influenced perceived barriers to genetic testing among women of African descent [26].

Conclusions and Implications for Practice

Study results contribute to the literature by identifying critical ethnic, racial and cultural identity factors that may influence perceived benefits and barriers to genetic testing for breast and ovarian cancer among at-risk women of African descent. Specifically, findings related to ethnic and racial identity may help inform the development of more culturally-sensitive protocols which more adequately meet the needs of this heterogeneous population.

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