



Attitudes Toward Breast Cancer Genetic Testing in Five Special Population Groups

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## Attitudes Toward Breast Cancer Genetic Testing in Five Special Population Groups

### Abstract

**Purpose:** This study examined interest in and attitudes toward genetic testing in 5 different population groups.

**Methods:** The survey included African American, Asian American, Latina, Native American, and Appalachian women with varying familial histories of breast cancer. A total of 49 women were interviewed in person. Descriptive and nonparametric statistical techniques were used to assess ethnic group differences.

**Results:** Overall, interest in testing was high. All groups endorsed more benefits than risks. There were group differences regarding endorsement of specific benefits and risks: testing to “follow doctor recommendations” ( $p=0.017$ ), “concern for effects on family” ( $p=0.044$ ), “distrust of modern medicine” ( $p=0.036$ ), “cost” ( $p=0.025$ ), and “concerns about communication of results to others” ( $p=0.032$ ). There was a significant inverse relationship between interest and genetic testing cost ( $p$

**Conclusion:** Cost may be an important barrier to obtaining genetic testing services, and participants would benefit by genetic counseling that incorporates the unique cultural values and beliefs of each group to create an individualized, culturally competent program. Further research about attitudes toward genetic testing is needed among Asian Americans, Native Americans, and Appalachians for whom data are severely lacking. Future study of the different Latina perceptions toward genetic testing are encouraged.

### Keywords

Breast Cancer; Genetic Testing; Ethnic Attitudes and Interest; Minorities; Special Population Groups

### Cover Page Footnote

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### **ABSTRACT**

**Purpose:** This study examined interest in and attitudes toward genetic testing in 5 different population groups.

**Methods:** The survey included African American, Asian American, Latina, Native American, and Appalachian women with varying familial histories of breast cancer. A total of 49 women were interviewed in person. Descriptive and nonparametric statistical techniques were used to assess ethnic group differences.

**Results:** Overall, interest in testing was high. All groups endorsed more benefits than risks. There were group differences regarding endorsement of specific benefits and risks: testing to “follow doctor recommendations” ( $p=0.017$ ), “concern for effects on family” ( $p=0.044$ ), “distrust of modern medicine” ( $p=0.036$ ), “cost” ( $p=0.025$ ), and “concerns about communication of results to others” ( $p=0.032$ ). There was a significant inverse relationship between interest and genetic testing cost ( $p<0.050$ ), with the exception of Latinas, who showed the highest level of interest regardless of increasing cost.

**Conclusion:** Cost may be an important barrier to obtaining genetic testing services, and participants would benefit by genetic counseling that incorporates the unique cultural values and beliefs of each group to create an individualized, culturally competent program. Further research about attitudes toward genetic testing is needed among Asian Americans, Native Americans, and Appalachians for whom data are severely lacking. Future study of the different Latina perceptions toward genetic testing are encouraged.

**Keywords:** Breast Cancer, Genetic Testing, Ethnic Attitudes and Interest, Minorities, Special Population Groups

## INTRODUCTION

Breast cancer is the most common malignancy in U.S. women; one of eight women in the U.S. will develop breast cancer at some time during their lives (NCI, 2013). Nearly 235,000 cases of breast cancer will be diagnosed in 2013. Breast cancer has a genetic component; 5-10% of all breast cancer cases result from inherited mutations of the BRCA1 and BRCA2 genes (NCI, 2013). Lifetime risk of developing breast cancer greatly increases if a woman inherits a mutation; 60% of women who have a BRCA1 or BRCA2 mutation will develop breast cancer compared to 12% of women in the general population (NCI, 2013). Because tests for these genetic mutations are now available and represent a means to reduce breast cancer morbidity and mortality through primary prevention, the willingness of high-risk women to undergo genetic counseling, if not also genetic testing, is of considerable interest.

Few studies have examined the knowledge and attitudes of women toward cancer genetic testing, particularly among various special populations. Some studies suggest group variation in genetic knowledge, perceived risks, attitudes towards testing, and acceptability of services (Foster, Eisenbraun & Carter, 1997-1998; Hall & Olopade, 2006; Lagos et al., 2005). Basic factors such as health literacy, education, and knowledge of anatomy and disease have been shown to mediate the likelihood of obtaining genetic counseling and/or testing (Burhansstipanov, Bemis, Kaur & Bemis, 2005; Chalela, Pagán, Su, Muñoz & Ramirez, 2012; Kelly, Andrews, Case, Allard & Johnson, 2007).

An understanding of the attitudes of high-risk women toward breast cancer genetic testing is necessary to develop appropriate and culturally sensitive educational materials and programs. In this study, we examine these attitudes among women from five special population groups: African American, Asian American, Latina, Native American, and Appalachians (inhabitants of the Appalachian Region), focusing on the perception of benefits and risks of genetic testing for breast cancer (Abraham & Sheeran, 2005).

## METHODS

### Participants and Procedures

The National Cancer Institute (NCI) Special Populations Networks (SPN) for Cancer Awareness, Research, and Training program and the NCI Cancer Genetics Network partnered with Susan G. Komen for the Cure to investigate attitudes toward and interest in breast cancer genetic testing among five special population groups. The five SPN programs involved in this project were: 1) Redes En Acción: The National Latino Cancer Research Network, 2) Appalachia Community Cancer Network (AACN), 3) Asian American Network for Cancer Awareness, Research, and Training (AANCART), 4) National Black Leadership Initiative on Cancer, and 5) American Indian/Alaskan Native Leadership Initiative on Cancer. This collaboration was supported by a Komen grant and coordinated through the Chronic Disease Prevention and Control Research Center at the Baylor College of Medicine, which granted IRB approval for this study.

A Progress Review Group, consisting of a representative from each of the five national SPN sites, a genetics expert representing each population, an epidemiologist, and advisory members from the NCI and Komen oversaw development of the survey instrument, pretesting and field implementation. Each SPN was responsible for recruiting representative participants,

including “survivors” (women diagnosed with breast cancer), “moderate/high-risk” women (those with a first-degree relative diagnosed with breast cancer age <50), and “low-risk” women (those with no family history of breast cancer). Survivors and moderate/high-risk women were recruited from cancer clinics, advocacy and support groups, cancer registries, and other community clinics and organizations. Low-risk women were recruited from the general community or through referrals. Survey participants were ages 25-64 and self-identified as one of the five population groups; a total of 49 participants completed the survey as part of the pretest phase of the study.

### Measures

The survey instrument was based on items and scales used in previous genetics research surveys among the Caucasian population. The instrument was revised and tested to achieve a 5th to 7th grade reading level and technical terms were explained. The survey instrument, which took about 45 minutes to complete, was administered face-to-face over a period of three months. It included demographic questions and items assessing women’s knowledge, attitudes, and behaviors toward breast cancer and breast cancer genetics, and a culture-specific section for each group.

Perceived benefits and risks of genetic testing (e.g., attitudes) were assessed using a validated questionnaire developed by Lerman and colleagues, evaluating self-efficacy and the reasons “to test” or “not to test” (Lerman et al., 1997). Items related to interest in testing for a breast cancer gene and likelihood of participation in genetic research were scored either as dichotomous (yes, no) or on a Likert scale (higher number = greater level of interest/importance).

### Analysis

To evaluate differences in attitude items between groups, we used the nonparametric Kruskal-Wallis H comparison of mean ranks; Fisher’s Exact Tests were used to assess group differences in proportions of specific attributes. A 2-sided p-value <0.05 was used to test for statistical significance. All analyses were conducted using SPSS 19.0 for Windows (IBM Corporation, 2010).

## **RESULTS**

All participants were born in the US except a portion of Asian and Latina groups (Table 1). The majority of women were high school educated, employed (with the exception of Latinas), and reported that they had some form of health insurance. About half of the sample (44% to 50%) had received a breast cancer diagnosis and the majority had a close blood relative who was diagnosed with cancer. There was a significant group difference in annual household income with fewer Appalachian and Native American women in the above \$50,000 category ( $p=0.020$ ). There were no other significant group differences in socio-demographic factors.

Table 2 shows the group variation in attitudes toward breast cancer genetic testing. Regarding perceived benefits of testing, only one item, “I would want to be tested for a breast cancer gene to follow my doctor’s recommendation,” differed across groups ( $p=0.022$ ) with Latinas placing the greatest importance on a doctor’s recommendation. Regarding reasons not to test (e.g., perceived risks and limitations), 4 items showed statistically significant differences between groups. These were “I am concerned about the effect it would have on my family” ( $p=0.044$ ); “I do not trust modern medicine” ( $p=0.014$ ); “The test costs too much” ( $p=0.041$ ); and “I am concerned the results will be given to others without my permission” ( $p=0.032$ ). Appalachian women, followed by African Americans, had greatest concerns related to effects on their family; Native Americans had the greatest distrust of modern medicine; Appalachians and

African Americans were most concerned about the cost of testing; and finally, Native American and Asian American women had the highest concerns about test results being given to others without their permission. Overall, Latina women were least concerned about any of the perceived risks and limitations to genetic testing.

Summing up the number of benefits that each woman felt was important, there were no significant differences among the groups (mean number of endorsed benefits, Latinas,  $9.2 \pm 1.8$ , African Americans  $8.8 \pm 1.4$ , Appalachians  $8.3 \pm 1.2$ , Native Americans  $7.9 \pm 2.3$ , Asian Americans  $6.0 \pm 3.0$ ). In contrast, the groups varied significantly in the number of risks that were endorsed ( $p=0.002$ ). The mean number of endorsed risks was  $4.2 \pm 2.2$  for Appalachians;  $4.7 \pm 2.9$ , Asian Americans;  $6.6 \pm 2.8$ , Native Americans; and  $7.6 \pm 3.6$ , African Americans. No risk was endorsed by Latinas.

**Table 1. Characteristics by Special Population Group**

	<b>African American (N=9)</b>	<b>Appalachian (N=10)</b>	<b>Asian American (N=10)</b>	<b>Latina (N=10)</b>	<b>Native American (N=10)</b>
<b>Age (mean +- SD years)</b>	46.0 ± 7.2	46.1 ± 18.4	51.6 ± 10.8	41.8 ± 10.6	51.1 ± 3.1
<b>Born in the US (%)</b>	100.0	100.0	60.0	70.0	100.0
<b>Married or Living as Married (%)</b>	33.3	80.0	50.0	80.0	30.0
<b>High School Education or more (%)</b>	100.0	80.0	100.0	100.0	100.0
<b>Employed (%)</b>	85.7	50.0	80.0	40.0	80.0
<b>Annual Household Income &gt;50K</b>	71.4	40.0	80.0	71.4	33.3
<b>Have Children (%)</b>	55.6	90.0	80.0	90.0	70.0
<b>Have Health Insurance (%)</b>	100.0	90.0	100.0	80.0	80.0
<b>Breast Cancer Diagnosis (%)</b>	44.4	50.0	50.0	50.0	50.0
<b>Have Blood Relative w cancer (%)</b>	100.0	100.0	70.0	80.0	90.0

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**Table 2. Attitudes Towards Breast Cancer Genetic Testing Ethnic Group** (Group Median Scores and Significance)

	African American (N=9)	Appalachian (N=10)	Asian American (N=10)	Latina (N=10)	Native American (N=10)	<i>p-value*</i>
<b>Reasons FOR breast cancer genetic testing</b>						
Learn about breast cancer risk	3	3	4	4	3	0.083
Learn about children's risk	3	3	4	4	3	0.499
Provide information for family	3.5	3	2	4	3	0.315
Decide about hormone replacement	4	2	1.5	4	2	0.191
Make decisions about surgery	3	2	3	4	2.5	0.194
Know if I need cancer screening more often	3.5	3	3	4	3	0.276
Plan for the future	4	3	2	3	3	0.384
Make decisions about having kids	2	1	2	4	2	0.129
Follow my doctor's recommendation	3	3	2	4	3	<b>0.022</b>
Follow family's recommendation	2.5	2	2	4	3	0.393
<b>Reasons AGAINST breast cancer genetic testing</b>						
Concerned about effect on family	2	2.5	1	1	1.5	<b>0.044</b>
Do not trust modern medicine	1	1	1	1	2	<b>0.014</b>
Nothing I could do to prevent cancer	2	1	1	1	1	0.115
Concerned could not handle it	1.5	1.5	1	1	1	0.349
Results might not be accurate	2	2	1	1	2	0.109
Worried about losing health insurance	2	1	3	1	2	0.124
Worried about losing life insurance	2	1	2	1	1	0.095
Worried about job discrimination	1	1	1.5	1	1	0.164
Worried about children's health insurance	2	2	1	1	2	0.203
Test costs too much	3	3	2	1	2.5	<b>0.041</b>
Concerned about getting tested without permission	1.5	1	1.5	1	2	0.259
Concerned others will get results without permission	2	1	2.5	1	2.5	<b>0.032</b>
Don't like to give blood for tests	1	1	1	1	1	0.247

Response options: 1=Not at all important; 2=Somewhat important; 3=Very important, 4=Extremely important

\* Two-sided p-value from Kruskal Wallis H comparison of mean ranks



**Table 3. Interest in Genetic Testing and Research by Special Population Group**

	African American (N=9)	Appalachian (N=10)	Asian (N=10)	Latina (N=10)	Native American (N=10)	p-value*
Ever talked with health professional about genetic test (%)	22.2	0.0	33.3	22.2	22.2	0.548
Ever had a blood test to find breast cancer gene (%)	22.2	0.0	0.0	11.1	0.0	0.109
Would Want to know whether you have breast cancer gene (%)	88.9	100.0	100.0	90.0	88.9	0.528
<b>Conditional Interest in breast cancer genetic testing (median scores)</b>						
If cost not issue, interested in testing if family history <sup>a</sup>	3	3	3	3	3	0.642
Interested if it cost \$200 to 500 <sup>b</sup>	3	2.5	2	4	2	0.099
Interested if it cost \$501 to 1000 <sup>b</sup>	2.5	2	1.5	4	1	<b>0.013</b>
Interested if it cost \$1001 to 2000 <sup>b</sup>	1.5	1.5	1	4	1	<b>0.027</b>
Interested if it cost over \$2000 <sup>b</sup>	1	1	1	2	1	<b>0.041</b>
Be in study about genes and breast cancer <sup>b</sup>	3	3	3	4	2	0.618
Give blood so scientists could study cancer <sup>b</sup>	3	3	2	4	1.5	0.355

<sup>a</sup> 1=Not at all interested; 2=Somewhat interested; 3=Very interested

<sup>b</sup> 1=Definitely no; 2=Probably no; 3=Probably yes; 4=Definitely yes

\* Two-sided p-value from Fisher's Exact Test or Kruskal-Wallis H comparison of mean ranks

Table 3 shows the items related to past participation in genetic research and interest in genetic testing. Most women had not talked to a healthcare professional about genetic testing nor had the test (67% to 89%). Nearly all women wanted to know their status regarding the breast cancer gene. For the scenario, “If you had two close relatives with breast cancer, how interested would you be in getting a blood test for a breast cancer gene?”—the groups differed in their responses given specific test costs. Once costs increased to \$501 or more, significant group differences emerged (Table 3). Among the groups, Latinas consistently showed the highest level of interest regardless of increasing cost, while Native Americans and Asian Americans had the least interest in testing. There were no group differences in likelihood of participating in a medical study or providing blood for genetic research.

## DISCUSSION

This study showed some distinct group differences in attitudes toward breast cancer genetic testing. For example, Latinas endorsed the greatest number of benefits of testing and perceived the least number of risks. African American and Native American women endorsed more risks than other groups. On the other hand, there was a generally positive attitude toward genetic testing as each group endorsed more benefits than risks. This corroborates previous research showing that most women rate BRCA genetic testing more beneficial than risky—attitudes that can be enhanced with personalized counseling (Lerman et al., 1997).

Most Latinas endorsed each reason to be tested as “very” or “extremely” important. Research has shown that, despite less knowledge, Latinas have positive attitudes toward testing and find benefits of testing to be greater than associated risks (Chalela et al., 2012; Ramirez, Aparicio-Ting, de Majors & Miller, 2006). Latinas also placed significantly more importance on “following doctors’ recommendations” than other groups. In Latina culture, healthcare providers are seen as authority figures whose opinions are to be respected and trusted (e.g., *respeto*) (Chalela et al., 2012). Thus, physicians can have a strong influence on the uptake of genetic breast cancer testing among high-risk Latino patients. Latina culture values family cohesiveness (*familismo*), collectivism (allocentrism), and positive social exchange (*simpatía*). The desire to have respectful relationships in a collective unit may influence how Latinas respond to queries by healthcare professionals, which may explain the high endorsement of genetic testing observed in this study. Healthcare providers should be cognizant of this cultural aspect (i.e., allocentrism and *simpatía*) so that they can have a balanced perspective of their patient’s health care needs.

Our study showed a tendency for African American women to perceive more risks and barriers, with cost being a large deterrent. Others have characterized this pessimism among African Americans as a tendency to view the vulnerability to outside forces (Purnell & Paulanka, 2005). African Americans may also be less likely to be aware of their family history of cancer and other diseases, which may impact their use of genetic services (Hall & Olopade, 2006). Contrary to the long-held belief of medical disillusionment among the African American community, African American women in this study were no more distrustful of modern medicine than other groups. This contradicts previous studies reporting increased distrust of testing among African American women due to negative historical experiences (Suther & Kiros, 2009; Thompson, Valdimarsdottir, Jandorf & Redd, 2003). Family-related worry and guilt have also been cited as barriers for African American women (Thompson et al., 2005). African American women in our study tended to have greater concerns about the effects of genetic testing on their families than some other groups. It has also been shown that testing intentions increase among

African Americans when given the opportunity to discuss family and personal issues about testing (Lerman et al., 1999).

In our study, Asian American women were less interested in paying for more expensive testing than most other groups. This may be due to the competing demand of providing what is important for their family versus what is important for individual needs. This conflict in prioritizing family versus individual needs is well-documented in many studies focusing on Asian American health issues. This finding is consistent with a study of Hong Kong Chinese adults who placed more value on the wellbeing and reactions of family members than the individual genetic testing (Ho, Ho, Chan, Kwan & Tsui, 2003), and another study reporting that Japanese Americans were less interested than Caucasians in colon cancer genetic testing (Glanz, Grove, Lerman, Gotay & Marchand, 1999). Though Asian Americans endorsed fewer benefits of genetic testing, they also endorsed a small number of risks, suggesting that they may have a more balanced view of the costs and benefits of genetic testing. A study in Singapore showed that while there was initially very high interest in being tested, significant barriers existed that resulted in low uptake: cost, losing control of medical information that may affect future coverage, concern over emotional burden of genetic information, and perception of unchanging medical management (Chieng & Lee, 2012). In our study, Asian American women were most concerned about others getting test results without their permission.

To our knowledge, this is the only study to examine Appalachian women's attitudes toward and interest in breast cancer genetic testing. One study of rural Appalachian adults found that younger age, family history of cancer, and greater worry predicted greater intention to seek genetic testing for hereditary cancer (Kelly et al., 2007). Others have noted that Appalachians face economic challenges including lower income, lack of employment, and poor or limited healthcare resources (Paskett et al., 2011). In our study, Appalachian attitudes toward genetic testing, perceived risks and benefits were mostly in line with other ethnic groups. However, as a group they were more concerned about testing's costs and effects on family. Aside from economic concerns, it is unclear how Appalachian cultural attributes that emphasize religion and self-reliance would affect the uptake of genetic testing.

Native Americans were more likely to distrust modern medicine and had more concerns about the risk of others receiving test results without permission than other groups, reflecting a historical struggle with stigmatization. Native Americans hold a general distrust of healthcare due to a history of research testing with no apparent benefits to individuals (Burhansstipanov et al., 2005; Burhansstipanov, Bemis & Petereit, 2009), and they are reluctant to participate in genetic research and related activities (Burhansstipanov et al., 2009). Earlier research on Native Americans about genetic testing showed that local sociocultural issues were more important than issues such as insurance discrimination and employment (Foster et al., 1997-1998). Native Americans value group membership, connections to the earth, wisdom of elders, and the success and wellbeing of their community. Thus, culturally sensitive group counseling may be more effective than individual counseling, especially with regard to genetic counseling and testing (Calabrese, 2008). This approach may serve to protect not only individual rights but those of the group as well. Because of the importance of community, tribal approval and the demonstration of respect toward tribal values and beliefs are critical to successful genetic research in this population.

A key finding in this study was cost as a barrier to genetic testing. Fewer women claimed interest in genetic testing as the proposed cost of testing increased, with the exception of Latinas who consistently claimed interest at each level of increasing cost. A previous study showed that

Latinas and African Americans did not pursue testing as often as Caucasians, largely due to financial and informational barriers (Singer, Antonucci & Van Hoewyk, 2004). Other studies have reported cost as a barrier to genetic testing uptake among minorities (Peters, Rose & Armstrong, 2004). BRCA genetic testing costs approximately \$3,000 and more if additional testing is required. While many patients have insurance coverage for testing, many cannot afford the out-of-pocket expense (which can be several hundred dollars) and some types of insurance do not cover adult genetic tests such as BRCA1, BRCA2, her2/NEU or triple negative. Many other Americans are under-insured or uninsured, and Hispanics have the highest uninsured rate at 30.7% (DeNavas-Walt, Proctor & Smith, 2012). Thus, genetic testing could be financially out of reach for women of diverse ethnicities.

Though this study was exploratory with limited sample size, it provides new information on the attitudes toward breast cancer genetic testing among five special population groups that face breast cancer health disparities of varying degrees. We note, however, that some of the distinct differences in attitudes may have been due to bias related to social desirability, especially among Latinas who may have been compelled to show more interest in testing than they felt. The small sample size did not allow a more thorough analysis of diversity within each ethnic/racial group, i.e., receptivity by risk status, breast cancer stage at diagnosis, etc., which warrants further research. In addition, income may have contributed to the differences in attitudes toward genetic testing; however the sample was too small for exploration of this issue. Finally, more formal research is needed among the special populations of Asian Americans, Native Americans, and Appalachians, for whom data are severely lacking.

## CONCLUSION

In conclusion, this study found important cultural differences in attitudes about breast cancer genetic testing, and interest in genetic testing and genetic research. An understanding of cultural diversity among different special population groups is necessary for culturally competent and ethnically centered care. Substantial emphasis should be placed on informing participants of different ethno-cultural groups of the costs and benefits of testing. Researchers and healthcare providers should also strive to increase understanding of the legitimate and accurate test costs and opportunities for coverage and reimbursement. In addition, participants would benefit from tailored educational strategies about genetic counseling and testing that incorporate the unique cultural values and beliefs of each group to create an individualized, culturally competent program.

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