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## Breast cancer genetic testing awareness, attitudes and intentions of Latinas living along the US-Mexico border: a qualitative study

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### Abstract

**Background**—Genetic testing for breast cancer may facilitate better-informed decisions regarding cancer prevention, risk reduction, more effective early detection, and better determination of risk for family members. Despite these potential benefits, significant portions of the US population—particularly Latinas—lack awareness of genetic testing for breast cancer susceptibility. Among women who are tested, less than 4% are Latina. To uncover reasons for Latinas' low participation, this study explores awareness, attitudes and behavioral intentions to undergo genetic testing among average-risk Latinas along the Texas-Mexico border.

**Methods**—Eight focus groups were conducted with 58 Latinas aged 19–69 living in Hidalgo County, a largely Latino region of South Texas. Focus group discussions were digitally recorded, transcribed and analyzed using qualitative content analysis to assess, categorize and interpret them. Two experienced study team members analyzed transcripts to identify major concepts grouped into theme categories.

**Results**—Participants mostly had less than a high-school education (43%), spoke primarily Spanish (52%), were of Mexican-American origin (90%) and had a family income of \$30,000 or less (75%). Focus groups found that most participants had positive attitudes and strong interest in genetic testing, yet lacked general awareness and knowledge about genetic testing, its risks, benefits, and limitations. Participants also identified several key cultural-based influencers, such as family, religious beliefs and fear of testing.

**Conclusion**—The delivery of culturally adapted risk information is needed to increase and ensure Latinas' understanding of breast cancer genetic testing during their decision-making processes. Key Latino values—religiosity, importance of family and the influential role of health care providers in health decisions—should also be considered when designing interventions targeting this specific group. Further research is needed to identify effective ways to communicate genetic risk susceptibility information to Latinas to help them make informed testing decisions.

### Keywords

Latinas; Breast Cancer; Genetic Testing; Focus Groups; Attitudes; Intentions; Border

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## INTRODUCTION

Constant advances in genetics, genomics, and molecular science are expected to significantly improve medical care delivery and health outcomes, making personalized medicine for breast cancer possible in the near future. In fact, recent discoveries in breast cancer genetics are bringing personalized treatment for breast cancer closer than ever. In two separate studies, researchers have reclassified breast cancer into at least 10 subtypes grouped by common genetic features, discovered several new breast cancer genes that drive the disease, identified specific cell signaling pathways that control cell growth and division, and identified a “genetic switch” carried by one in five women that doubles their risk of developing breast cancer but could be detected by a blood test years before developing breast cancer symptoms [1,2].

Currently, one of the most important risk factors for the development of breast cancer is having a family history of the disease, particularly in a first-degree relative [3,4]. Hereditary forms of breast and ovarian cancer are associated with germline mutations in BRCA1 and BRCA2 genes, which accounts for about 5 to 10% of all breast cancers and about 10% of all ovarian cancers in the general population [5,6]. Women with these mutations have a 60–78% lifetime risk of developing breast cancer [7]. Breast cancer patients with BRCA1/2 mutations also have a 42 to 47% risk of developing a second breast cancer [7,8].

BRCA mutations have been identified in samples of US Latinas [9,10]. One study found that US Latinas with a personal history of breast cancer have a higher prevalence of BRCA1 mutation than African American and Asian American breast cancer patients [11], and other studies suggest that Latinas have at least comparable levels BRCA1/2 gene mutations as other ethnic groups [6,9,12].

The US Preventive Services Task Force recommends that all high-risk women, based on family history suggestive of hereditary breast/ovarian cancer, should undergo BRCA genetic

counseling to obtain information on their personal and family risk of developing breast and ovarian cancer, the availability of different preventive and surveillance options, and the benefits and risks of getting BRCA1/2 genetic testing [6,13–15]. Genetic counseling helps women make informed decisions about their health care by providing risk management information for prevention and early detection of cancer at its more treatable stages, even if they decide not to undertake genetic testing [6,13–16]. Genetic counseling not only improves women’s knowledge and perception of their absolute risk, but also can often reduce their anxiety. It provides a valuable opportunity for health care providers to recommend appropriate follow-up and emphasize the importance of continuing regular prevention activities [13–16].

Despite this, significant portions of the population do not know about the potential benefits, or even the existence, of genetic counseling and testing for risk of breast or other cancers. Some know about genetic testing, but are dissuaded by misinformation about the tests. Others worry about the effect on their families, feel ashamed about having a genetic variation that puts them and their relatives at risk, and/or worry about ethical and moral threats [17–23].

Latinas, who experience many disparities in genetic counseling and testing, comprise only 1–4% of women undergoing BRCA testing [6,12,24,25]. This low participation rate suggests Latinas have low levels of awareness and knowledge about genetic counseling and testing for breast and other cancers [26,27]. People with basic knowledge about inherited cancer risk and awareness of genetic testing for breast cancer susceptibility mutations can presumably make better-informed decisions about whether to seek these services than people without this basic knowledge [14,15]. However, language barriers, acculturation, lack of health insurance coverage, low education, low income, immigration status and other cultural and socioeconomic factors may influence Latinas’ access to information about genetic testing from health care providers and other sources [26–28].

Only 19% of Latinos were aware of genetic testing for cancer risk, compared to 48% of whites, based on a report by Pagán and colleagues on the 2005 National Health Interview Survey [29]. Mexican Americans had the lowest awareness of all the Latino subgroups (14.3%), dropping to 9.5% among those with low levels of English-language preference [27]. In addition, several studies have shown that Latinos have limited access to genetic counseling and testing [30–32], are more likely to lack health insurance coverage, and often have less information resources [22]. Latinos still are highly interested in cancer genetic testing services, several studies show, and will eventually use them if accessible—but several critical barriers remain, such as fear of genetic testing [6,18,26,33,34].

These disparities in interest in and awareness and use of genetic testing suggest a critical information transmission gap that particularly affects low-income, less acculturated Latinos. Yet little research addresses gaps in US Latinas’ knowledge, attitudes and awareness of the availability of (or interest in) genetic testing for breast cancer susceptibility. Even less is known about these issues among women living along the US-Mexico border [24,26,27,34–36].

Given this paucity in research and the disparities in Latinas' participation in and awareness of breast cancer genetic testing, The University of Texas Health Science Center at San Antonio (UTHSCSA) and The University of Texas Pan American (UTPA) are collaborating, as part of a larger National Cancer Institute-funded program, in a research study to better understand border-region Latinas' decision-making process for breast cancer genetic testing and pave the way for creating and delivering culturally adapted information to address gaps.

## **MATERIALS AND METHODS**

### **Study Design**

This qualitative study conducted eight focus groups to assess Latinas' awareness, attitudes, and behavioral intentions to undergo genetic testing. Focus group results will guide the development of a structured questionnaire and the design of a larger-scale study to further explore genetic testing issues among Latinas living along the US-Mexico border. The qualitative study was approved by the Institutional Review Board of the University of Texas Health Science Center at San Antonio (UTHSCSA) and the University of Texas-Pan American (UTPA).

### **Study Population**

Participants for this study were Latina women aged 18 and older who had not been diagnosed with breast or ovarian cancer and resided in Hidalgo County, a largely Latino region of South Texas. About 84% of the population speaks Spanish at home, 40% do not have a high school diploma, 37% do not have health insurance and 31% of families live under poverty line [37]. With its predominant and rapidly growing Latino population, this area presents a uniquely challenging case in health promotion and health care delivery due to its exceedingly high rates of poverty and uninsurance [38].

### **Process**

The research team conducted eight focus groups with a purposive sample of 58 Latinas in Edinburg in Hidalgo County, Texas, between February and November 2010. Participants were recruited from existing community contacts of The South Texas Border Health Disparities Center at UTPA and by using a snowball technique. In this technique, participants with whom contact has already been made use their social networks to identify and refer other people who could be potential participants [39]. Focus group participants were stratified by language and education, and efforts were made to have a balanced representation of all ages. Four focus groups were conducted with English speakers and four with Spanish speakers. For each language, two groups included participants with less than high-school education and two included participants with high-school education and higher. Each group had at least six but no more than eight participants. All groups were asked the same set of questions using a semi-structured discussion guide with open-ended questions and additional probes when needed (see Table 1). Recruitment took between two and four weeks from initial contact with the recruiter to the date of scheduled focus groups. All groups were held at the South Texas Border Health Disparities Center at UTPA.

## Session Development

In addition to the moderator, two members of the research team sat in each focus group, primarily to handle audio-taping of the sessions, distribute and explain consent, incentives and demographic information forms, and take observational notes. At the beginning of each session, participants were asked to read and sign a consent form and complete a demographic information form. Transportation incentives were provided at the end of the session, once the corresponding forms were distributed and signed. Members who experienced difficulty reading or writing were assisted by one of the research team members. Main discussion themes included awareness of BRCA 1/2 testing, knowledge of BRCA 1/2 testing, perception of gene-behavior-environment relations and other factors that determine health, understanding of genetic risk susceptibility, and intentions to undergo genetic testing.

## Data Analysis

Focus group discussions were digitally recorded, transcribed verbatim and analyzed using qualitative content analysis to assess, categorize and interpret them. Two experienced team members read transcripts to identify major concepts grouped into theme categories with high inter-rater agreement ( $Kappa >0.9$ ). Minor disagreements (fewer than a half-dozen) were reviewed and discussed until consensus was achieved [40–44]. Specific quotations were extracted to give further meaning to each theme. For demographic data, basic descriptive statistical analysis included frequencies using PASW [45].

## RESULTS

Even though focus groups were stratified by education and language, major differences were found only by education but not by language. Therefore, results are presented by education and major differences noted when pertinent. In addition, results are organized by emerging themes identified during data analysis.

### Demographics

Table 2 shows the demographic characteristics of focus group participants. About 43% of all women ( $N=58$ ) had less than a high-school education and 52% were Spanish speakers. About 90% were of Mexican American origin and most were born in the United States. The majority of women were aged 30–49, married, and had an annual family income of \$30,000 or less.

Significant differences were found in country of origin, marital status and family income by education. About 58% of participants in the less-educated category were born in Mexico, compared to only 23% in the more-educated category. More participants who were less educated were divorced, living with a significant other or separated (the “other” category). All less-educated women had a family income of \$30,000 or less per year, compared with 57% of their more-educated counterparts.

Participants reported no personal history of cancer and only seven said they had family members with the disease.

## Themes

Emerging themes from the focus groups data were organized into five categories: (1) knowledge about genetics and genetic testing; (2) attitudes about the interaction between genes and breast cancer; (3) fatalistic attitudes about health and disease; (4) genetic susceptibility; and (5) intentions to undergo genetic testing.

### Knowledge about Genetics and Genetic Testing

In general, most women regardless of education did not have accurate knowledge about genetics and genetic testing. Many equated genetics with physical features passed from parents to children. Only 3% (N=58) of women said that genetics embodies the hereditary risk of developing a disease.

There was a general lack of knowledge about genetic testing and how it is done. None of the women or their relatives ever had a genetic test. Genetic testing was associated with paternity testing and mammography. None of the focus group participants knew what a BRCA1/2 test was, and only a few said that they had heard of genetic testing for breast cancer, but did not know what it meant. Below are some example responses from the participants when they were prompted to describe what they know about genes.

“[Genes are] what your parents give you.”

“[Genes are] something that makes you look similar to somebody else.”

“[Genes are] your hair color, your eye color.”

When asked about what a genetic test is and how it is done, some said:

“I get it [mammography] every year.”

“I have heard that it is to determine paternity.”

“I have no idea but I think it is done with blood.”

### Attitudes about the Interaction between Genes and Breast Cancer

There were some clear differences in attitudes regarding the interaction between genes and disease by education. About 52% (n=25) of participants in the less-educated group believed that having a damaged gene meant that they will inevitably get the disease, while about 70% (n=33) of more-educated women did not believe the statement was true.

“I think if you have the gene you will develop breast cancer eventually...if you carry it.”

“I am not sure but I think you will get the disease if you have the gene.”

The majority of more-educated women agreed that, even if they have a damaged gene, their risk of cancer is influenced by the environment they live in, compared to about half of less-educated women.

“Different types of, like, chemicals and pollution affect people in different ways.”

“I don’t think the environment has anything to do with cancer...I don’t think if you drink water I’m going to have more or less disease.”

### Fatalistic Attitudes about Health and Disease

In general, there were no major differences by education regarding fatalistic attitudes toward cancer. The majority of women (67%) thought they were capable of altering their risk through lifestyle changes, but they needed more information.

“Good nutrition and exercise to keep you healthy and strong to fight disease.”

“I feel I can do something but I don’t have the information, I don’t know what to do to reduce the risk...but I believe if I had the information I could do something to lower my risk.”

It is important to note that, when asked if they believed that God determines a person’s health and no one can alter that, about a third of women (32.8%; 10 in the less-educated group and nine in the more-educated group) responded they did.

“I would say yes because of my faith...even though I know there are many medical advances.”

“Yes, because I think God is the best doctor we have and you pray to Him and ask Him to protect your health.”

### Genetic Susceptibility

Nearly all women, regardless of education, believed that any woman could develop breast cancer even if no gene mutation was present.

“I think even if you do not have the gene you may get breast cancer.”

“I think anyone can get breast cancer because of the environment...their lifestyle, and how often you get check-ups.”

The majority of participants—regardless of education—also believed that a woman with a damaged gene will not always get breast cancer.

“Not necessarily because you have a damaged gene you will get breast cancer... you can do things to prevent it...changing your lifestyle.”

“Yes, like exercise and eating right...attitude and awareness.”

### Intentions to Undergo Genetic Testing

When asked how likely they were to get a genetic test within the next 6 months if it was available in the community, most women—regardless of education—said that they would do it for their children and to be able to prevent it or to act as soon as possible.

“I have three kids, and for me to know...if I carry it and then if they eventually are going to carry it, too...I would like to know so we could prevent it.”

“I would like to know because if caught early...in early stages, it can still be taken care of.”

Most women, especially the less-educated ones, were concerned about cost, as many do not have health insurance coverage. However, most women would get it within the next 6 months if it was free or at low cost.

“I think cost is something that would hold us back.”

“I think is the main reason...I mean a lot of us here, we don't have insurance or we do not have money to pay, and it is very hard for us, you know.”

When asked how likely were they to seek genetic testing if a family member was diagnosed with breast cancer, almost all women—regardless of education—said they would do it.

“If my grandmother has it I would like to know if I also could have it.”

“If I have a sister, there is a possibility between my sister and I of having it. If she has it I want to know if I can have it, too.”

Only two women, one less-educated and one more-educated, said they would not get a genetic test even if it is free, because of fear. They do not want to know if they have the risk.

“No, I don't want to know...because knowing this doesn't necessarily mean that I'm going to get cancer. And I'm a pessimistic person, so knowing this will make feel worried, so I prefer not knowing something like that.”

“I don't know how to explain it...I would like to know but at the same time I don't want to know because then I would be very worried...I would be very, very depressed.”

Most women, regardless of education, said they would ask their health care provider about genetic testing next time they go to the clinic, because they would like to know more (e.g., testing cost, procedure, accuracy).

“I would ask, but what is the cost, you know? I've heard those are very expensive.”

“...there are other factors you need to know...like, how invasive is going to be?”

“Is it with blood... do they check the breasts?”

“How accurate is going to be...I would like to know.”

Participant responses made it evident that the doctor is an influential figure and a trusted source of health advice, as almost all women, regardless of education, said they would get genetic testing if their doctor recommended it. However, they would like to have more information about it (e.g., testing procedure, benefits, frequency).

“Yes I would definitely do it. If the doctor recommends is because he thinks there is a risk a probability.”

“I don't care how it is done, if my doctor recommends it, I will do it.”

“I need more information, like the risk I have by having it done...”

“...Is it going to benefit me, how frequently do I have to do it?”

## DISCUSSION

Given that breast cancer is a leading cause of cancer morbidity and mortality among Latinas, the disparities in their use of genetic services and the important role of BRCA mutations in this ethnic group [3,5,12], this focus group study was conducted to obtain more information



about awareness, knowledge, attitudes, beliefs and behavioral intentions regarding BRCA genetic testing among Latinas along the Texas-Mexico border. This information, as discussed below, is valuable to understand genetic testing awareness of breast cancer risk among Latinas, their unmet needs, as well as their willingness or unwillingness of having genetic testing or counseling for breast cancer risk.

Despite their lack of awareness and knowledge about genetic testing, its risks, benefits, and limitations, Latinas in this group tended to have positive attitudes toward genetic testing. Less-educated Latinas may be less likely to have a clear understanding of the topic, have less access to accurate sources of information, including a health care provider, and have cultural beliefs that may explain the differences found by education among focus group participants. Despite the strong interest in undergoing genetic testing found in this study, less-educated Latinas are more likely to speak Spanish, have low income and no health insurance, which may hinder their use of genetic testing services.

To make informed decisions regarding breast cancer susceptibility tests, women need to be aware of and understand their own breast cancer risk, benefits and limitation of genetic testing. Many women, however, have difficulty understanding these concepts due to low education and poor literacy levels. Participants in our study, for example, preferred the use of words to percentages—a finding that is supported by other studies reporting that low-literacy women were less sure what percentages meant—and suggested that using words to describe risk may be easier to understand than percentages [46]. There is a need to tailor the delivery of risk information to ensure their understanding during the decision-making process. Further research is needed to identify effective ways to communicate genetic risk susceptibility information to Latinas, especially those with low literacy, to help them make informed testing decisions.

Consistent with other studies, health care providers were viewed as influential and trusted sources of health advice. In Latino culture, health care providers are viewed as authority figures and patients respect and trust their advice, guidance and recommendations about their health [28]. Therefore health care providers may play an important role in the uptake of genetic testing for breast cancer susceptibility among this ethnic group.

Religiosity is another key Latina value. For some women, God is viewed as the ultimate protector of health and the only one who can cure cancer, which may affect their preventive and health-related behaviors, in particular their use of genetic testing services. This implies that future health education interventions should be sensitive to religious teachings so that the design and implementation of these interventions will not conflict with the religious beliefs or values of Latinas. It is also important to realize that religion is not necessarily a negative factor in promoting health education. Rather, current or future interventions should consider how to better take advantage of religious platforms, such as local churches, to effectively deliver culturally competent education to improve Latinas' understanding of genetic testing for cancer risk and its associated benefits and risks.

While this study represents an important first step in the understanding of issues related to BRCA genetic testing among Latinas, there are several limitations to consider. The

qualitative nature of the study calls for cautions to generalize our findings to the entire US Latina population. Social desirability may have biased participants' responses and led them to self-censor their actual views. In addition, participants were volunteers who may have more positive attitudes toward testing which may differ from those of average Latinas in the community. Finally, budget limitations did not allow researchers to conduct data triangulation to increase validity of focus groups results.

Still, this study provides important preliminary information about specific areas of knowledge, attitudes, beliefs and behavioral intentions regarding genetic testing for breast cancer susceptibility where additional research is warranted. These details will serve as the foundation for the planning and design of a larger-scale study to further explore genetic testing issues among Latinas living along the US-Mexico border.

## Conclusions

The delivery of culturally adapted risk information is needed to increase and ensure Latinas' understanding of breast cancer genetic testing during their decision-making process. Key Latino values—religiosity, importance of family and the influential role of health care providers in health decisions—should also be considered when designing interventions targeting this specific group. Further research is needed to identify effective ways to communicate genetic risk susceptibility information to Latinas to help them make informed testing decisions.

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**Table 1**

## Sample of Discussion Guide Questions

Questions
<ul style="list-style-type: none"> <li>• Do you have any history of breast and/or ovarian cancer yourself? Your family? If yes, which family members?</li> <li>• Do you know what genes or genetics are? Please tell me what are genes....</li> <li>• Have you ever heard of genetic testing for cancer? What did you hear and where? What about genetic testing for breast cancer? What did you hear and where?</li> <li>• Do you know how the genetic test is done? Please describe...</li> <li>• If you have a “damaged” gene (that’s called gene mutation) that increases your risk of developing breast cancer, do you think you will develop the disease? Why yes or why not?</li> <li>• If you had a “damaged” gene, do you think your risk of developing the disease can be influenced by your lifestyle (e.g., diet, exercise, drinking behaviors)? Why yes or why not?</li> <li>• Do you think God determines a person’s health and no one can alter that? Why yes or why not?</li> <li>• Do you think a person can develop breast cancer, even if she does not have a “damaged” gene? Why yes or why not?</li> <li>• If genetic testing (BRCA) were available to you now, would you be likely to get it the next six months? Why yes or why not?</li> <li>• How likely are you to seek genetic testing (BRCA 1/2) if a family member were diagnosed with breast or ovarian cancer? Why yes or why not?</li> <li>• How likely would you be to agree to genetic testing (BRCA 1/2) for breast cancer risk if your doctor recommended it? Why yes or why not?</li> </ul>

Table 2

## Demographic Characteristics of Participants

Demographic Characteristic	Level of Education						
	Less than HS n=25		HS or Higher n=33		Total N=58		
	n	%	n	%	N	%	
<b>Language</b>	English	10	40.0	18	54.5	28	48.3
	Spanish	15	60.0	15	45.5	30	51.7
<b>Country of Origin</b>	United States	7	41.2	24	77.4	31	64.6
	Mexico	10	58.8	7	22.6	17	35.4
<b>Age</b>	Less than 30	3	13.0	11	33.3	14	25.0
	30–39	8	34.8	6	18.2	14	25.0
	40–49	7	30.4	10	30.3	17	30.3
	50+	5	21.7	6	18.2	11	19.7
<b>Marital status</b>	Married	13	52.0	21	63.6	34	58.6
	Single/Never married	0	0.0	10	30.3	10	17.2
	Other	12	48.0	2	6.1	14	24.1
<b>Family income</b>	Less than \$10,000	10	43.5	3	10.0	13	24.5
	\$10,001–\$30,000	13	56.5	14	46.7	27	50.9
	More than \$30,000	0	0.0	13	43.3	13	24.5

Note: Percentages may not add 100 due to rounding. Ten participants did not respond to country of origin and two did not respond to age and income questions. Three participants did not know their family income.