INTEREST, AWARENESS, AND PERCEPTIONS OF GENETIC TESTING AMONG HISPANIC FAMILY MEMBERS OF BREAST CANCER SURVIVORS

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Objective: To provide a preliminary description of the interest, awareness, and perceptions of genetic testing among Hispanics with a family history of breast cancer

Design: This cross-sectional pilot study used interpersonal structured interviews for data collection.

Participants: We interviewed 48 Hispanics without breast cancer but who had a family member with breast cancer; participants lived in San Antonio and the surrounding area.

Main Outcome: The outcomes were interest in breast cancer genetic testing, awareness about genetic testing, perceived risk of carrying a breast cancer susceptibility gene, and the perceived benefits and risks associated with a genetic test.

Measures: Items previously used in research regarding interest and perceived genetic risk and a previously validated benefits and risks-limitations scale for genetic testing commonly used by other researchers were used to measure the outcomes.

Results: Awareness of genetic testing for breast cancer susceptibility was very low, yet most (82%) participants were interested in a genetic test for breast cancer susceptibility. Participants were more likely to identify with the benefits than the potential risks of genetic testing. The most highly endorsed benefits were to know to take better care of one's self and to undergo more frequent screening.

Conclusions: Hispanics seem to have positive perceptions about genetic testing for breast cancer susceptibility. However, the high level of interest in genetic testing may be driven by a lack of knowledge about genetic testing. Culturally sensitive and appropriate educational programs about breast cancer genetic testing and the surrounding issues are needed for the Hispanic population. (*Ethn Dis*. 2006;16:398–403)

Key Words: Attitudes, Family, Genetic Testing, Genetic Testing Awareness, Hereditary Breast Cancer, Hispanic, Interest in Genetic Testing

INTRODUCTION

While the overall incidence of breast cancer is decreasing, Hispanic women are diagnosed with breast cancer at later stages and have lower survival rates than Caucasian women.[1,2] Several population-based studies have reported that Hispanic women have 1.2- to 1.8- fold greater risk of presenting with stage III or stage IV breast cancer and have a 15% to 30% greater risk of death after a breast cancer diagnosis than Caucasian women.[1–4] Advanced or late stage at diagnosis is a major factor contributing to less favorable survival; therefore, earlier stage at diagnosis of breast cancer in Hispanic women would improve their survival.[1,5] Mammography can detect a lump in the breast up to two years before it is palpable by a clinical breast exam, thus allowing for detection of breast cancer in its earliest stages and improving the opportunity for treatment and survival.[6] However, Hispanic women are less likely to participate in breast cancer screening services.[7,8] Low socioeconomic status, low educational attainment, lack of breast cancer knowledge, access to services, and behavioral factors, such as fear of cancer and low perceived risk of breast cancer, have been established as reasons for low breast cancer screening rates in Hispanic women.[9–13]

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Hispanics' special needs related to unique cultural factors that contribute to their breast cancer prevention behavior have yet to be fully understood. The Health Belief Model (HBM) is one model that may be used to explain why Hispanics are less likely than others to participate in preventive breast cancer screening. This model purports that women will take action to screen for breast cancer if they regard themselves as susceptible to breast cancer and if they believe that breast cancer has potentially serious consequences, that

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a screening for breast cancer would be beneficial in reducing or ameliorating the threat of illness, and that the anticipated barriers to screening are outweighed by its benefits.[14]

We undertook a pilot study to provide a preliminary assessment of the educational and psychosocial needs of Hispanic families affected by breast cancer. This report outlines the pilot study's findings on the current awareness, interest, and perceptions regarding genetic testing for breast cancer susceptibility of Hispanics with a family member afflicted with breast cancer. Examining interest and perceptions in this previously overlooked group will provide insight into the counseling and education needs of Hispanics and their families regarding genetic testing for breast cancer susceptibility and the surrounding issues.

METHODS

The pilot study was designed to assess the experience of Hispanic families as they adjust to a breast cancer diagnosis in the family. This pilot was undertaken to collect preliminary data on breast cancer and genetic testing as well as provide information about the feasibility of conducting a survey study among Hispanics in south Texas. The results of this pilot study were used to inform the design and implementation of a larger study regarding the psychosocial needs of Hispanic breast cancer survivors and their families that included 200 Hispanic participants: 83 family members and 117 breast cancer survivors.

Eligibility requirements for participation included self-identification as Hispanic, Hispanic-American, Latino/Latina, or of some Hispanic origin (Mexican, Puerto Rican, Cuban, South American, etc). In addition, eligible participants were $\geq$18 years of age, had no personal history of breast cancer, and were a family member of a woman who had been clinically diagnosed with breast cancer. Family members included spouses, daughters, sisters, mothers, aunts, and first cousins.

Fifty study participants were recruited through women diagnosed with breast cancer who were identified at various breast cancer clinics in San Antonio, Texas, and through collaboration with local breast cancer organizations and breast cancer support groups. These organizations and groups included the San Antonio affiliate of the Susan G. Komen Breast Cancer Foundation, Alamo Breast Cancer Foundation, and American Cancer Society. These women provided information about the study to their family members and, subsequently, interested individuals contacted the research team. Sixty-two family members were initially interested in the study; of those, 50 were successfully recruited, resulting in an 80% response rate. The institutional review board at the University of Texas Health Science Center at San Antonio and the San Antonio Cancer Institute Protocol Review Committee approved the study protocol.

The women with breast cancer who referred family members to the researchers were mostly recently diagnosed. Thirty-eight (79%) of the breast cancer survivors were diagnosed within four years, six (13%) breast cancer survivors were diagnosed five to seven years prior, and four (8%) breast cancer survivors were diagnosed 8–10 years before their family members were interviewed.

Although 50 Hispanic family members were recruited, this report is limited to 48 participants who had not previously received genetic counseling or genetic testing for breast cancer susceptibility. Two participants reported having undergone genetic counseling for breast cancer susceptibility and were, therefore, excluded. All participants enrolled in the study engaged in structured interviews conducted by two bilingual interviewers that included questions about psychosocial adjustment to a family member's breast cancer diagnosis, genetic testing awareness, attitudes and interest, and satisfaction with the medical care related to their loved one's cancer treatment. The questionnaire used items and scales validated and used in previous research among other populations.[15–19] Most interviews were conducted in person, with $<$5% conducted by telephone, in either English or Spanish, depending on the participant's preference. Interviews, which were approximately one hour in length, were scheduled at a time and location of each participant's choosing.

The current report focuses on the section of the questionnaire pertaining to genetic testing. The outcome variables for this report are: 1) interest in genetic testing; 2) awareness of genetic testing; 3) perceived risk of carrying a breast cancer susceptibility gene; and 4) perceived benefits, risks, and limitations of genetic testing. Survey instruments for both patient and family contain questions used to assess genetic testing knowledge and perceptions, and are available from the lead author (see contact information on title page of this article).

To provide a sociodemographic description of the sample, information was collected regarding typical demographic variables, including age, sex, years in the United States, language spoken, health insurance status, educational attainment, place of birth, Hispanic origin, marital status, and employment status, and annual household income. Participants were also asked about their relation to the family member with breast cancer.

The data analysis for this report was limited to 48 participants who responded to the question about interest in genetic testing. Descriptive statistics were used to compute frequencies of responses for sociodemographic items and interest, awareness, and perception questions. To assess associations of sociodemographic variables with the outcome variables, contingency table

Table 1. Sociodemographic characteristics

Characteristic	*n**	Mean (SD) or Proportion
Age (range: 19–80)	48	44 (14)
Sex		
Female	32	67%
Male	16	33%
Years in the United States		
≤10	6	13%
>10	42	87%
Language		
Spanish only	13	27%
Bilingual	13	27%
English only	22	46%
Health insurance		
Yes	39	81%
No	9	19%
Education		
Less than high school	10	21%
High school graduate	18	37%
Technical college, college, or beyond	20	42%
Employment status		
Employed	33	69%
Unemployed	15	31%
Annual household income		
≤$25,000	18	44%
$25,001–$50,000	13	32%
≥$50,001	10	24%

* Number of respondents.
SD=standard deviation.

analysis with Fisher exact tests were performed for categorical variables, and two-sample *t* tests were performed for continuous variables. Because the sample size of this pilot study was small, responses to individual items assessing the perceptions of benefits and risks/limitations of genetic testing were dichotomized for the analysis.

For the reporting of this pilot study, the statistical level of significance was set at α=.05. Data analysis was conducted using the whole sample, including males, because in the Hispanic culture, males can have a strong influence on decisions that concern the family, as in the case of genetic testing.[20] Additionally, males are also capable of carrying a breast cancer susceptibility gene and passing it on to their children. For this report, data were also analyzed for females alone, since women are the ones who will undergo the genetic testing for breast cancer susceptibility most of the time because of the rarity of male breast cancer. All analysis was performed by using the statistical software package Stata 8.0.[21]

RESULTS

For the most part, immediate family members (92%) were interviewed in this pilot study, with more female than male family members participating. Of the 16 males interviewed, 13 were husbands of breast cancer survivors and 3 were sons. Of the 32 females, 28 were immediate family (4 mothers, 16 daughters, and 8 sisters) and 4 were extended family (1 aunt, 2 first cousins, and 1 niece).

A summary of sample sociodemographic characteristics is presented in Table 1. Notably, 70% of participants in this pilot study were Mexican American, reflecting the predominantly Mexican American population of south Texas. No significant differences in sociodemographic characteristics were seen between male and female family members.

Most participants in this study reported having heard or read almost nothing or relatively little about breast cancer genetic testing (Table 2). Most participants reported a desire to receive more information about hereditary cancer and genetic testing (79%, data not shown).

Participants perceived the benefits of genetic testing to be significantly greater than the risks and limitations (Table 2). The most important perceived benefits of genetic testing for this sample were to take better care of oneself and to get screening tests more often (Table 3). Learning about their child's risk for breast cancer was also a highly rated perceived benefit. The most important risks and limitations of breast cancer genetic testing were the concern over one's own and the family's emotional reaction to the results of the test (Table 3). However, only about one-third of the sample considered these risks to be good reasons not to undergo genetic testing.

Interest, awareness, and perceptions did not vary according to sex or any of the other sociodemographic characteristics listed in Table 1. Fisher exact tests revealed no association between interest, awareness, and perceptions by sex, years in the United States, language spoken, health insurance status, educational attainment, employment status, and annual household income (*P* values >.05), with one exception. Interest in genetic testing for a breast cancer susceptibility gene declined significantly with increasing age (*P*=.0071). The mean age of family members interested in breast cancer genetic testing was 41 (standard deviation=12), compared to a mean age of 55 (standard deviation=12) for

Table 2. Interest, awareness, and perceptions of genetic testing

Variable	Proportion (% [*n*])† or Mean (SD)	
	Whole Sample (*N*=48)	Females Only* (*n*=32)
Interest		
Overall interest		
Yes	81% (39)	90% (29)
No	19% (9)	10% (3)
Interest if covered by insurance		
Yes	79% (38)	78% (25)
No	21% (10)	22% (7)
Interest if self-paid		
Yes	67% (32)	71% (22)
No	33% (16)	29% (9)
Awareness		
Almost nothing	56% (27)	59% (19)
Relatively little	27% (13)	22% (7)
Fair amount/a lot	17% (8)	19% (6)
Perceived risk of being a carrier		
No chance	23% (11)	16% (5)
Small chance	35% (17)	41% (13)
Moderate to high chance	42% (20)	43% (14)
Perceived benefits (range: 0–15)	9.6 (4.4)	10.3 (4.4)
Perceived risks (range: 0–14)	3.4 (2.1)	3.2 (2.3)

† Numbers may not add up to complete sample size because of nonrespondents.
* Fisher exact tests and independent two-sample *t* tests revealed no significant sex difference in any of these variables.
SD=standard deviation.

family members not interested in undergoing a genetic test for a breast cancer susceptibility gene.

DISCUSSION

Given that breast cancer is the leading cause of cancer death among Hispanic women, the receptivity of a screening tool such as genetic testing among women at risk for hereditary breast cancer is of considerable interest.[22] In response, this pilot study was undertaken to provide a description of awareness, interest, and perceptions surrounding genetic testing among Hispanics with a family history of breast cancer so that a preliminary assessment of the receptivity of this population to genetic testing could be made.

Table 3. Perceived benefits, risks, and limitations of breast cancer genetic testing

Perception	Strongly Agree or Agree* (% [*n*])
Benefits	
I could plan for the future	66% (31)
I could make decisions about getting married	21% (8)
To learn if my children are at risk	76% (35)
To take better care of myself	81% (39)
To get screening tests more often	83% (40)
Risks and limitations	
I am concerned about my emotional reaction	31% (15)
I am concerned about my partner's reaction	20% (9)
I am concerned about my family's reaction	31% (15)
I am not sure if the test is accurate	15% (7)
I would worry about how it would affect my insurance	26% (12)

* Data include males and females, *n* may vary because of nonrespondents.

Awareness of a test for genetic susceptibility to breast cancer was low among this sample of Hispanics. These results contrast with findings of studies among Caucasian women, who have reported significantly higher levels of awareness of genetic testing (72%–79%).[44–46,23–25] Although recent efforts have been made to improve genetic education for minority breast cancer patients, these results indicate a need to extend the availability of genetic testing education to Hispanic family members.

Most Hispanics with a family history of breast cancer in this pilot study were interested in genetic testing for breast cancer susceptibility. This finding is consistent with those in studies among Caucasian women at high risk for hereditary breast cancer.[24,26] More family members were interested in genetic testing if the cost of the test was covered by insurance than if they had to pay for it themselves, although interest in genetic testing was not associated with income in this sample. These results suggest that Hispanics at risk for hereditary breast cancer may be open to genetic testing as a breast cancer prevention tool. However, given the fact that most of the sample had received little information about genetic testing, participants did not likely have a realistic perception of the cost of such testing. Therefore, since the price of a genetic test can range from $300 to $2000, cost may become a limitation for individuals for whom the test is not covered by insurance.

Younger family members were more likely to be interested in a genetic test than older family members. This inverse relationship between age and interest in genetic test has also been found in larger studies of Caucasian women with a familial *BRCA1* or *BRCA2* mutation.[27,28] Older family members may feel that they have less to gain from genetic testing than younger family members. Since many women seek genetic testing to

. . . it appears that Hispanic family members of breast cancer survivors may believe that the benefits of genetic testing outweigh the risks

gather information for other family members, such as their children, or to inform decisions about mammography and prophylactic treatment, these reasons may be more salient for younger women than for older women.

The balance between the perceived benefits and the perceived risks may determine the motivation for individuals to undergo genetic testing for a breast cancer susceptibility gene.[29] Hispanics in this sample identified more with the perceived benefits of testing than with the risks, consistent with studies among other populations.[16,30] Similar to studies with Caucasian populations, the most salient benefits to this sample were related to taking steps to reduce one's cancer risk and to learning about their children's risk.[24,30,31] The salience attributed to using the information to take action to reduce one's risk for breast cancer reflects the potential of genetic testing to provide Hispanics with a familial history of breast cancer with a more informed basis for decision-making about preventive strategies.[16,30,32]

Negative psychological consequences, such as emotional distress and anxiety, surround genetic testing decisions.[32] Similar to studies of women at risk for hereditary cancer, this sample of Hispanics identified concerns about their emotional reaction as a potential reason to forgo genetic testing.[15,20,31] These results strengthen support for the provision of psychosocial counseling to anyone undergoing genetic testing. This sample of Hispanics also expressed concern about the emotional effects on their family, as have other study populations. Since the results of a genetic test have repercussions that extend beyond the individual being tested to other members of the family, concern over their reaction may be an especially significant barrier because of the importance of family in the Hispanic culture.[16] These concerns can be addressed by educational approaches that encourage communication with family members about genetic testing.[31]

A concern about the effect of genetic testing on health insurance in this sample echoes similar concerns found in other study groups.[15,20,31,33] These concerns reflect the fact that health insurance coverage and premiums are risk-based in the United States. As such, insurance issues may influence genetic testing decisions among US Hispanics. This concern also points to the ethical and legal issues that surround the confidentiality of genetic test results and highlights the importance of including ethnic minorities in policy discussions and decisions.[34,35]

Overall, it appears that Hispanic family members of breast cancer survivors may believe that the benefits of genetic testing outweigh the risks. Although these results suggest that Hispanics view such testing in a very positive way, these views may be shaped by a lack of knowledge about genetic testing. The results of this pilot study indicate that Hispanics are likely to have heard very little about genetic testing and are, therefore, likely to have low levels of knowledge regarding this topic. The strong possibility also exists that the benefits and risks of genetic testing perceived by the participants may not be based on reliable information. Conversely, more salient risks related to genetic testing may not have been assessed in this study. For example, concerns may be related to the social stigma surrounding breast cancer or being a carrier of a potentially harmful gene. Other research has found that Hispanic women are likely to anticipate feeling ashamed if the results of a genetic test are positive, to an even greater degree than African American and Caucasian women.[20]

The results of this study are limited by the fact that this was a pilot study. The study sample was small and not representative of the national Hispanic population.[36] Interpretations that extend beyond Mexican Americans living in south Texas and with similar sociodemographic characteristics cannot be made from the data presented here. The generalizability of the results is also limited by the characteristics of the study sample. Hispanics that took part in this study were fairly acculturated, more bilingual, and of higher socioeconomic status than the general US Hispanic population.[36] Furthermore, participants were recruited by family members with breast cancer from nonprofit organizations that offer a variety of free support programs to the public. Hispanic women attending these organizations may differ in their perception of genetic testing compared to women paying for support services from other privatized organizations, perceptions that may be shared by their families. Although the recruitment of participants from nonprofit organizations was necessary because of feasibility and resource considerations, the results of this study are limited to Hispanics of similar characteristics.

The results of this study provide a preliminary description of the issues related to breast cancer genetic testing that have not been assessed in this population in previous studies. This pilot study has also been a driving force for the planning and design of a larger-scale study to further explore genetic testing issues in Hispanics.

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