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Awareness, Perceptions, and Provider Recommendation Related to Genetic Testing for Hereditary Breast Cancer Risk among At-Risk Hispanic Women: Similarities and Variations by Sub-Ethnicity

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Abstract

This study explored awareness of risk factors for hereditary breast and ovarian cancer (HBOC), awareness, knowledge and concerns about genetic testing, and preference for how to have genetic testing recommended by a care provider among at-risk Hispanic women. Differences in these factors among Mexican, Cuban, and Puerto Rican women were also examined. Women with a personal or family history of breast or ovarian cancer from the Tampa Bay Area participated in a qualitative interview (*N*=53). Data were analyzed using a combination of open and axial coding with a grounded theory approach. Study participants in all groups reported: being aware that family history was a breast cancer risk factor, limited knowledge of genetic testing, fear of test results, concerns about children's risks, and no physician referral for genetic testing. Noteworthy sub-ethnic differences included preferences for physician recommendation and information about genetic testing. This study provides important preliminary information about areas related to HBOC that require additional education in the Hispanic community as a whole and by sub-ethnicity.

Keywords

Hispanic; *BRCA*; Sub-ethnicity; Genetic testing; Hereditary breast ovarian cancer; Genetic counseling

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Introduction

Mutations in *BRCA1* and *BRCA2* (*BRCA*) genes present a significantly increased risk for Hereditary Breast Ovarian Cancer (HBOC) syndrome. Even though only 10% of cancers are attributable to hereditary cancer predisposition syndromes, women with HBOC have a 55–85% lifetime risk of developing a primary breast cancer and 15–60% risk of developing ovarian cancer (Carter 2001; MacDonald et al. 2002; Robson et al. 2001; Tonin 2000; Verhoog et al. 1998). Additionally, *BRCA* mutation carriers have a 40–60% lifetime risk for a second breast cancer (Ford et al. 1994; Metcalfe et al. 2004; Robson et al. 2005).

Several recent studies have documented the presence of *BRCA* mutations in U.S. based samples of Hispanic women (Mullineaux et al. 2003; Weitzel et al. 2005; Weitzel et al. 2007). A population-based study from the Northern California Cancer Registry reported that Hispanic women with a personal history of breast cancer have the highest prevalence of *BRCA1* mutations when compared to other minority racial/ethnic minority groups (i.e., African American, Asian American) in the U.S. (John et al. 2007). There is a growing body of evidence supporting the efficacy of prophylactic surgery (Hartmann et al. 1999; Hartmann et al. 2001; Meijers-Heijboer et al. 1999; Rebbeck et al. 2004) and chemopreventive agents (Gronwald et al. 2006) in reducing the risk of breast and ovarian cancers in mutation carriers. Consequently, genetic counseling and testing for *BRCA* mutations are important ways to identify those women most likely to benefit from early detection and prevention strategies to minimize cancer-related morbidity and mortality. However, recent data suggest Hispanics are currently under-utilizing cancer genetic services (Chen et al. 2002; Hall et al. 2009; Ricker et al. 2006). In a national study of 46,276 patients who received genetic testing for *BRCA1/2* mutations in community-based (non-academic research) settings between the years of 1996–2006, only 4% (*n*=1,936) were of Hispanic origin (Hall et al. 2009).

Limited evidence suggests low levels of knowledge about genetic counseling and testing for HBOC amongst Hispanics (Ramirez et al. 2006; Vadaparampil et al. 2006). Results from a 2000 National Health Interview survey (NHIS) reported only 20% of Hispanics had heard of genetic testing for cancer risk compared to 49% of non-Hispanic Whites (Wideroff et al. 2003). Furthermore, several recent studies have documented Hispanics have limited access to genetic counseling and testing (Hall and Olopade 2005, 2006; Olopade and Artioli 2004; Sussner et al. 2009; Wideroff et al. 2003), are more likely to be medically uninsured, and often have less health information resources (Cheong 2007). In addition, provider referrals to genetic counseling/testing involve a careful review of family history and are more common among insured patients (Shi 1999). Some studies have documented that socio-cultural mores of Hispanic families often preclude discussions of cancer within the family (Knobf et al. 2007; Lagos et al. 2008). Thus, lack of health insurance and complete knowledge of family history may contribute to limited provider initiated discussions about HBOC syndrome. Furthermore, recent results of a national survey reported minority-serving physicians were significantly less likely to have ever ordered a genetic test to assess cancer risk (Shields et al. 2008).

While review papers and reports emphasize the need for and use of genetic counseling and testing services in the Hispanic community (Doksum et al. 2004; Penchaszadeh 2001; Ramirez 2003), there is less empirical data that may contribute to the development of interventions that can promote risk appropriate utilization of genetic counseling and testing services (Chen et al. 2002; Thompson et al. 2003).

Social Marketing (SM) is described as the application of marketing principles approaches to advance social causes, ideas, or behaviors that provide a framework for public health interventions by which new ideas and issues can be disseminated and ultimately, specific behaviors among target groups can be affected (Lefebvre and Flora 1988). SM has been

successfully used within the Hispanic community to affect knowledge, attitudes, and behaviors for chronic and acute health conditions (Thackeray and Neiger 2003; Wechsler et al. 1998; Williams and Flora 1995). Similar to commercial marketing, the primary focus is on learning about the consumers' wants and needs. Unlike commercial marketing which attempts to persuade consumers to buy a product that has already been developed, in SM the product is adapted to reduce barriers and highlight benefits as seen by the consumer. SM consists of five steps including planning, message and materials development, pretesting, implementation, and evaluation (Lefebvre and Flora 1988).

The planning process focuses on the consumer by addressing the elements of the "marketing mix." This refers to decisions about: 1) the conception of a *product*, 2) *price* 3) distribution (*place*), and 4) *promotion* (4 P's). These issues are identified to discover the consumers' perceptions of the health behavior and their associated needs related to the behaviors, and to determine the factors that may affect whether an individual from the target group(s) contemplates or takes action regarding the health behavior (Lefebvre and Flora 1988). Once information on the 4 P's is collected, it is used to determine whether the audience should be segmented based on Hispanic ethnicity, or if another characteristic (e.g., acculturation, perception of family risk, or fatalistic beliefs) is more salient in determining various audience segments. While the currently available information supports the idea that educational interventions based on ethnicity and/or cultural relevance will be most effective (Glanz 2003; Vadaparampil 2003; Zambrana et al. 1999), other factors such as knowledge and attitudes may also serve as the basis for segmenting the Hispanic population so that the appropriate mix of the 4 P's is designed for each.

The focus of the current study was completing the first step in SM by examining awareness, perceptions, and provider recommendation related to genetic testing for HBOC among at-risk Hispanic women. A secondary aim of the study was to examine if there were differences in these constructs among between the sub-ethnicities of Mexican, Cuban, and Puerto Rican women. The results of this study would ultimately be used to inform the design and implementation of a psychoeducational intervention to increase risk appropriate uptake of genetic counseling for HBOC among Hispanic women.

Methods

Design

A cross-sectional design using sequential mixed qualitative and quantitative research methods was employed. Eligible consenting women participated in a semi-structured, in-depth qualitative interview followed by a brief battery of structured quantitative survey items for descriptive and exploratory purposes. This paper focuses on the results from the qualitative interviews.

Participant Recruitment and Data Collection

The sample size was based on estimates of the number needed for qualitative saturation (Guest et al. 2006; Kvale 1996), rather than on statistical power calculations. Thus, if after a set number of interviews, no new data emerged (i.e., we did not hear new information to the questions in the interview guide) we did not continue recruitment in the sub-groups since the last interviews in these groups yielded no new information. Participants were recruited after the project received institutional review board (IRB) approvals from the University of South Florida and each participant provided written informed consent prior to participation.

Eligible participants were Hispanic women who: a) were between 18 and 65 years of age; b) self-identified as Mexican, Puerto Rican, or Cuban; c) had a personal diagnosis of breast cancer

prior to age 50 or ovarian cancer at any age or had at least one first-degree relative (mother, sister, daughter) diagnosed with breast cancer prior to age 50 or at least one first degree relative with ovarian cancer at any age; and d) had not previously had genetic counseling and/or genetic testing for hereditary cancer. We selected these criteria to reflect basic risk factors cited by leading professional organizations (AMA 2002a; Daly et al. 2009; Hampel et al. 2004; Nelson et al. 2005) that may warrant a referral for a consultation with a genetics professional. Participants were recruited from the Tampa Bay area between May 2006 and September 2008 through various community based and promotional recruitment approaches including posting and in-person distribution of flyers at Hispanic-owned businesses, organizations, health fairs, and food pantries; and press releases of the flyers to local English and Spanish media outlets. Recruitment methods and experiences have been described in detail elsewhere (Vadaparampil et al. 2009). Eligible, consenting women were interviewed in-person at a location selected by the participant and in the language of her choice. The research assistant read all study materials aloud to the respondent to minimize literacy issues. The entire interview (both the qualitative and quantitative portions) took approximately 1 h to complete. The data from the quantitative portion of the study focused on knowledge and attitudes related to HBOC and they are reported elsewhere (Vadaparampil et al. 2009). At the end of the interview participants received a $40 gift card to a local discount store.

Measures

Sociodemographic and Medical Characteristics—The following sociodemographic and medical characteristics were assessed via a self-report questionnaire: age, ethnicity, marital status, number of children, education, employment status, insurance status, religion, income, personal history of breast cancer prior to age 50, personal history of ovarian cancer; first degree relative (i.e., mother, sister or daughter) with breast cancer below the age of 50; and first degree relative (i.e., mother, sister or daughter) with ovarian cancer.

Interview Guide

The interview guide, specifically developed for the current study, went through an extensive process of translation, back translation, and expert panel review that is described in detail elsewhere (Vadaparampil et al. 2009). The interview guide consisted of semi-structured questions centered on the following areas: (1) general knowledge of health and cancer risk; (2) sources of and preferences for health education information (3) women's awareness and perceptions about genetic testing for hereditary cancer; and (4) provider recommendation related to testing for hereditary cancer. A previous report describes the first two areas (Quinn et al. 2010) while the current report focuses on the results from the questions related to genetic testing for hereditary cancer (Table 1). The interviews were conducted by three bilingual and bicultural women who were either first or second-generation immigrants to the United States from a Latin American nation or mainland Puerto Rico. All of the interviewers had undergraduate degrees in a health related field (psychology, public health, and biomedical sciences). Each was provided extensive training on interview techniques by the study PIs.

Data Analysis

For quantitative data, basic descriptive data related to demographic and clinical characteristics were summarized using descriptive statistics.

For the qualitative data, three bi-lingual bi-cultural research assistants transcribed the interviews verbatim. Results were analyzed using the transcripts and a combination of open and axial coding using a constant comparative approach. Lincoln and Guba (1985) describe the constant comparison method: comparing incidents of data applicable to each other; defining a category (or theme) that has common properties; going back to the incidents and applying them to the category; checking the categories still apply to the data (Lincoln and Guba 1985).

Our analysis followed these guidelines closely. The constant comparative method "combines inductive category coding with a simultaneous comparison of all incidents observed" (Goetz and LeCompte 1981). This process undergoes continuous refinement throughout the data collection and analysis process, continuously feeding back into the process of category coding. "As events are constantly compared with previous events, new topological dimension, as well as new relationships, may be discovered" (Goetz and LeCompte 1981). Open and axial coding refers to the process of beginning with codes that have no restrictions or properties and then using the constant comparative method to identify the distinct characteristics of that code. Axial codes are then applied to show relationships between open codes (Strauss and Corbin 1990).

Data were coded independently by at least two researchers, and an inter-rater reliability rate of ≥ 90% was achieved. Through content analysis, key themes regarding perceptions of risk, and psychosocial factors related to consideration of HBOC and genetic counseling and testing were identified. The a priori themes were broadly based on the sub-codes identified in the initial interview guide (perception of general cancer risk, knowledge of genetic testing, fears about the test, prior knowledge, and future needs) and a codebook was developed to operationalize and define each of the themes.

Results

One hundred forty-three women were pre-screened for participation in the parent research study in a period of 16 months. Seventy-six women were ineligible to participate in the study. The most common reasons for ineligibility included being of another Hispanic sub-ethnicity, not knowing the personal or family cancer history type, and being diagnosed with breast cancer after the age of 50. Of the 67 eligible women, 7 were Puerto Rican, but were no longer eligible because we met our recruitment goal of 20 for that group and 7 women scheduled an interview, but did not attend, resulting in a total of 53 study participants.

Demographic, medical and cultural characteristics of the sample are shown in Table 2. There were no significant differences across the majority of demographic and clinical characteristics.

Interview Results

The women were asked what they perceived to be the risk factors for cancer in general. As shown in Table 3, all women in all three sub-groups cited three primary risk factors: family history, lifestyle choices, and sporadic use of health care. However, the order of the importance of these risk factors varied in Puerto Rican women who generally felt lifestyle factors were more important than family history.

> My father had prostate cancer, my grandmother had colon cancer and that makes me very at risk for cancer.
>
> Not having a good diet and eating a lot of fats
>
> Not eating well, lots of stress, probably not exercising, smoking, things like that.
>
> My sister only sees a doctor if she is sick, she does not get regular check-ups.
>
> Not getting your self checked medically, its like a car, you have to make sure you check the oil and the engine to make sure things work, or else it will fail

At least one-third of the women in all groups also mentioned they believed injuries led to cancer.

> I have heard that if you hit your breasts, it could cause cancer—I saw a woman who got cancer after being hit with a bottle on her breast.
>
> My mother hit her stomach and then she got cancer in her uterus.

> The underwires in bras are not good and they harm your breast tissue and cause cancer. I take them out.

Respondents were asked if they knew what a genetic test was and how they would describe it. All women in all groups reported they had limited or no knowledge of genetic testing and would not really know how to explain it.

> I don't know anything about it. I imagine it tells you if there is cancer in your family.
>
> I guess they take blood or a swab and send it to the lab? Or is it an ultrasound?
>
> I don't know for sure… it tests your genes or your DNA?

The women were asked what their greatest worry would be about having the test performed. The majority of all women in all sub-groups were concerned about having a positive test and what this would mean for their emotional and physical health, as well as for their children.

> If I were positive, what would that mean for my daughter? My greatest fear would be to know I gave her something (hereditary).
>
> I would be very stressed out to know that cancer could be ticking away inside me and there is nothing to do.
>
> It's like telling you that you have cancer or could get it…. I would be very upset.

However, a few women in each of the sub-groups were also concerned about the costs associated with the test, and whether or not insurance would pay for the test.

> I would have to make sure it's paid for and I would worry that I would lose my health insurance and not be able to get it in the future if I had the gene.
>
> Is this genetic testing expensive? Because I'm Hispanic and I don't have health insurance.
>
> My concern is I couldn't get genetic testing done at all because I can't afford it

The women were asked if a health care provider had ever recommended a genetic test or genetic counseling to them for HBOC. The majority of women across all groups reported genetic testing had never been suggested to them. Three Cuban women, two Mexican women and one Puerto Rican woman said a healthcare provider had suggested they seek testing, due to their personal and family history. Among the six women who had received a recommendation none of them chose to pursue testing. All of the Cuban women reported they did not due to financial reasons.

> The breast surgeon recommended this to me and my sister after my mother was diagnosed with her second cancer, but insurance did not cover the costs so we could not do it.
>
> It was very hard to find a doctor that would take Medicaid… and they do not cover the test.

All of the Mexican women reported they did not choose testing because there was no follow up discussion by the health care provider.

> Yes the doctor recommended testing after I was diagnosed, but then he did not bring it up again and I did not ask either.
>
> The doctor mentioned it during my last visit but he didn't do anything about it so I didn't do anything.

The Puerto Rican woman who received recommendation did not pursue testing due to fear and uncertainty about the test.

> Yes, he told me to do it, I was scared… and since there were a lot of patients, we changed the topic, but really…I don't even understand. I haven't done it and I'm in doubt.

Respondents were asked to consider four statements and select which one they would prefer to hear from a health care provider about the recommendation for genetic testing. Each statement was designed to reflect either provider recommendation that conveyed a: (a) standard approach: "One of the things you may want to consider is getting a genetic test due to your personal or family history", (b) sense of urgency: "I urge you to get a genetic test based on your personal or family history of cancer", (c) group context to risk: "I tell all my patients, with a history like yours, to get a genetic test to see if they carry the gene mutation for breast or ovarian cancer" or (d) non-directive approach: "Genetic testing is an option, based on your history, but you don't have to if you don't want to."

The majority of Cuban women preferred option B: "I urge you to get a genetic test based on your personal or family history of cancer." The respondents said they liked this statement the best because of the word "urge." They further described physicians who often suggest many things during an appointment and use of the word "urge" would tell them the doctor considered this very important. Of all participants, only two Cuban women chose option D.

The majority of Mexican women preferred option C: "I tell all my patients, with a history like yours, to get a genetic test to see if they carry the gene mutation for breast or ovarian cancer." The women in this group described liking the statement because it explained they were not being singled out as an individual, rather that the test was recommended to all patients who had a history similar to theirs. These women also reported disliking the word "urge" in statement B because it created a sense of emergency and discussions of cancer were "frightening enough."

Among the group of Puerto Rican women, they were equally divided in liking all of the first three statements. More specifically, one-third of the group preferred option A, one-third of the group preferred statement B, and one-third of the group preferred option C. The women reported the same reasons as women in the other two groups for liking options B and C. The women who favored option A said they liked that one because it emphasized they had a choice.

Women were asked what questions they would have if a doctor recommended they have a genetic test for HBOC. These responses varied by sub-ethnicity. Most Cuban women said they would want to learn more about the risks associated with the test and the potential benefits of the test.

> What happens if we do find out that we carry the gene? What type of preventive action do we take to keep the gene from growing or mutating?

> What are the benefits of having this test? If it shows I have a high probability, what can I do about it? Who would have to know the results besides me?

The majority of Mexican women said if a doctor recommends a genetic test to them for HBOC, they would want to know more about the actual procedure, any pain involved and the reason for the recommendation.

> What is it like? A culture? How is it done?

> Does it hurt? How long does it take to get the results back? What do you do while you are waiting?

> Why? I think that if you don't have any symptoms then I really don't need any tests.

> Why? Did he see something? Is there something in my blood that's showing signs of it (cancer)?

The majority of the Puerto Rican women in the study said if a genetic test were recommended to them they would want more information about the risk statistics and the reliability of the test.

> What percent chance does the doctor think I will be positive?
>
> What does the research say about the likelihood that I could have this gene? What chance is there it will be negative?
>
> Is this a reliable test? How often does it tell people they are positive when it is a mistake? How many times do they do the test to be sure?

The women were asked what they would tell a friend whose physician had recommended genetic testing. The majority of Cuban women said they would encourage the friend to pursue genetic testing if her physician had recommended it. They also offered they would tell the friend to carefully look into the financial aspects of the test.

> I would tell her to do it if insurance pays for it.
>
> I would tell her if she has the financial means to definitely do it.

However, a few women were reluctant to encourage a friend, believing there was little point to knowing.

> Is she just going to live with this information and let it eat away at her? What's the point?
>
> Its something she can't help so why get tested?

The majority of Mexican women said they would suggest the friend obtain more information about the test and the process before making a decision. Many of these women also mentioned seeking guidance through prayer.

> I would tell her to consult with her doctor and God to decide what is best for her.
>
> The doctor can answer many questions, but first Our Father will answer you. Then you go to learn more and decide.

The majority of Puerto Rican said they would encourage the friend to have the test done. Their primary reason for encouraging the friend was because a physician had recommended the test, but they also believed the test should not be considered unless the woman was fully aware of the risks.

> I would tell her to take the precautions and do the test right. Her doctor would not have recommended it, if it were not important.
>
> I would say to consider the risks very carefully versus the benefits. The doctor will tell her this but still it must be a choice or the doctor would just do the test?

Discussion

The present study found few differences by sub-ethnicity with respect to knowledge and concerns about testing. Overall, women in our study were aware of family history as a possible risk factor for breast cancer. This is consistent with a previous community-based study of racially/ethnically diverse sample of women residing in the San Francisco area (*N*=184) which found no differences in overall knowledge of risk factors for hereditary or familial breast cancer when comparing Hispanics to Caucasian women (Katapodi and Aouizerat 2005). Interestingly, more Puerto Rican women in the present study cited lifestyle as a risk factor for cancer

compared to the other two groups. This serves as an important difference between these groups, that if replicated in larger studies, may suggest that education about the role of cancer history in breast cancer risk may need to be emphasized (in addition to lifestyle factors) in breast cancer education efforts targeted to Puerto Rican women with a personal and/or family history of breast and/or ovarian cancer. However, consistent with previous literature (Chavez et al. 1995), some Hispanic women from each group in our sample cited factors that are generally not associated with increased breast cancer risk such as breast trauma or use of underwire bras.

Additionally, most women across all three ethnic sub-groups in our study were unable to provide a full or partial explanation of genetic testing. Several studies have evaluated awareness of genetic testing for hereditary cancer. A study of 4,313 Hispanic and 18,316 non Hispanic White respondents to the Year 2000 National Health Interview Survey showed test awareness to be highest among non Hispanic Whites (49.9%) and lowest among Hispanics (20.6%) (Wideroff et al. 2003). Follow up analyses of NHIS data by sub-ethnicity revealed that those who self-identified as Puerto Ricans had the highest levels of awareness (27.3%), followed by Mexican Americans (25.8%), Cuban/Cuban Americans (19.5%), and Mexicans (14.3%) (Vadaparampil et al. 2006). The difference between the present findings and those of previous studies may be because participants in the current study were asked to provide specific information about the test in their own words rather than responding to a close-ended question evaluating awareness or familiarity with genetic testing for cancer (Lacour et al. 2008; Ramirez et al. 2006; Sussner et al. 2009; Thompson et al. 2003; Vadaparampil et al. 2006).

With respect to concerns about testing, most women said their greatest worries were related to their future cancer risk and risks to their children. These results are consistent with those obtained for a multiethnic sample of African American, Hispanic, and Caucasian women (*N*=273). Hispanic women were more likely to strongly agree with overall disadvantages of testing, with over 60% expressing concerns about the effect of test results on their family and close to 40% worried about not being able to emotionally handle test results (Thompson et al. 2003). Additionally, a few women within each of the groups in the present sample mentioned financial concerns about testing. The cost of *BRCA* testing (without any insurance reimbursement) can range between $3,000 to $4,000 (Daly 2004). Similarly, previous studies examining the influence of cost on uptake of genetic testing indicate the majority of patients would not be willing to pay for the entire cost of genetic testing for hereditary cancer (Bosompra et al. 2001;Lacour et al. 2008).

Currently Medicare, Medicaid, and private insurance provide some level of coverage for *BRCA* testing if individuals meet certain criteria such as: (1) having a previously identified *BRCA* mutation in the family; (2) being of Ashkenazi Jewish (Eastern European) ancestry and have or have had breast or ovarian cancer; (3) being diagnosed with breast cancer before age 50; (4) ovarian cancer at any age; or (5) being a male diagnosed with breast cancer (http://www.dnadirect.com/). While many insurance plans do cover the majority of costs associated with genetic testing for HBOC for individuals meeting certain criteria (Kieran et al. 2007), this benefit may not be equally shared by Hispanics who are approximately three times more likely than Whites to be uninsured. Currently, only 17 state Medicaid programs (public insurance for uninsured individuals meeting certain criteria) cover the cost genetic testing (http://www.facingourrisk.org/).

While we explicitly excluded women who had genetic counseling and testing, 11% (*n*=6) of participants reported that a health care provider recommended genetic testing for hereditary cancer, but none chose to pursue testing. In examining the qualitative responses, it appeared Cuban women, cited financial concerns as the primary barrier, and their responses likely reflect the aforementioned cost issues. For Mexican women, lack of provider follow up discussion was the main reason for not pursuing genetic testing. Puerto Rican women described fear and

lack of awareness as their primary barrier. While provider recommendation may be an important first step toward uptake of cancer genetic counseling services, it may be equally critical to provide additional follow up, particularly for Mexican patients, who, based on national prevalence estimates, are least likely to be aware of the availability of genetic testing for hereditary cancer (Vadaparampil et al. 2006). A recent study by Ricker (Ricker et al. 2006) suggested that a combination of provider education as well as increased access to genetic counseling and testing services in a predominantly Mexican low-income Hispanic community resulted more risk appropriate referrals by community providers. Additionally, 88% of patients kept their appointments.

When the participants were asked about their preference for a type of recommendation by their health care provider regarding genetic testing, Mexican women appeared to prefer a message that did not single them out based on their risk, but rather put their risk in the context of a group (e.g., other women like you). Previous data suggest that Hispanic women are more likely to report feeling singled out or feeling ashamed if a genetic test result were to be positive (Thompson et al. 2003). While that study included Mexican women, the researchers did not evaluate differences due to Hispanic ethnicity, making it difficult to determine whether these concerns were expressed more frequently among Mexican women, as in the present study.

In contrast to the Mexican participants, the Cuban participants preferred a message that indicated a sense of urgency. Puerto Rican women appeared not to show a specific preference for any of the messages related to traditional provider recommendation, group context, or urgency. Interestingly, only two of the 53 women preferred a non directive type of recommendation for genetic testing. This finding appears to support the points raised in a review about genetic counseling in the Hispanic population (Penchaszadeh 2001). He suggests that that in the Hispanic culture, health care professionals may be viewed as an authority figure and patients expect advice, guidance, and recommendations about their health.

While no prior studies have explored this issue among Hispanic women in the context of cancer genetic counseling, a previous study of prenatal genetic counseling (Browner et al. 2003) identified the non-directive approach taken to recommend procedures as one source of miscommunication between providers and patients of Mexican origin. Specifically, patients perceived providers' reluctance to make a definitive recommendation as a sign that the procedure was not necessary or part of standard medical care. While there is continued professional debate about the use of a nondirective approach in genetic counseling (Weil 2003; Weil et al. 2006), professionals may need to consider a shift in approach for certain patients. Penchaszadeh (2001) suggests genetic counselors working with Hispanic population may take a more prescriptive approach and cautions that failure to do so may cause confusion and a sense of isolation among patients.

Another area in which differences by ethnicity were identified in the present study concerns preferences for the type of information about genetic testing. Cuban women reported being most concerned with risks and benefits of genetic testing, Mexican women wanted details of the actual test procedures, and Puerto Rican women were more concerned about test characteristics such as accuracy. While previous studies have documented an overall interest in and desire for additional information about genetic testing among diverse groups of Hispanic women (Ramirez et al. 2006; Sussner et al. 2009; Thompson et al. 2003), the present study is the first to identify possible differential preferences for specific information about testing.

Finally, when asked about what they would suggest to a friend whose health care provider recommended genetic testing for them, the Puerto Rican women reinforced the doctor's knowledge and recommendation as the most important consideration. Across the sample, there was some evidence of the influence of religion and fatalism, particularly among Cuban and

Mexican women. A few Cuban women expressed reluctance to encourage a friend to have testing, despite provider recommendation, based on fatalistic attitudes. Fatalism is the belief that death is inevitable when cancer is present based on the philosophic origins and attributes of cancer fatalism: fear, predetermination, pessimism, and inevitable death (Powe 1996). High levels of fatalism have previously been shown to be associated with lower levels of cancer preventive and screening behaviors in studies of Hispanic women (Lopez-McKee et al. 2008; Luquis and Villanueva Cruz 2006). For Mexican women, the role of spirituality/religiosity, and the role of God as equal to or superseding provider recommendation were evident. Similarly, in a qualitative study of seven Mexican women with either a personal or family experience of cancer, concerns about controlling the cancer experience were intertwined with beliefs about God; all seven participants described God as the ultimate healer and thus the only one who can cure cancer (Collins et al. 2008).

Study Limitations

While this study represents an important first step in understanding baseline levels of knowledge among Hispanic women with risk factors for HBOC, there are certain limitations that must be considered. First, the sample was recruited from the Tampa Bay area and may not be representative of Hispanics from other regions of the U.S. However, this study is among the first to include equal representation from three of the major Hispanic sub-ethnic groups in the U.S. Second, as with all qualitative research, these results are not intended to be generalized to the population of interest. The overall sample size for each sub-ethnic group was small, thus, any conclusions related to differences by sub-ethnicity must be replicated in a larger population. Additionally, we relied on self-reported personal and family history of cancer. Some data suggest that self-reported cancer history is accurate (Ziogas and Anton-Culver 2003). It is possible, however, that some women may have participated for the incentive that was offered. Given that for many participants, the reported cancer history pertained to first degree relatives (who were not participants in the study), we felt that medical records confirmation was not feasible. Finally, a small minority of participants had a personal history of cancer which, combined with insurance status/cost of testing, perhaps led to greater testing barriers than if we had interviewed more women with a personal history of cancer.

Conclusion

Recent data suggesting the important role of *BRCA* mutations in breast cancer risk among Hispanic women (John et al. 2007), coupled with the identification of founder mutations in this group (Weitzel et al. 2005; Weitzel et al. 2007), makes it imperative to provide Hispanic women with information related to HBOC in order to promote risk appropriate access to and use of genetic counseling and testing services. The findings of this study indicate that Mexican, Cuban, and Puerto Rican women with a personal or family history of breast cancer are similar in their awareness about the role of family history in breast cancer risk, their knowledge of and concerns about genetic testing, and their receipt of provider recommendation for genetic testing. However, there also appear to be notable differences by sub-ethnicity with respect to preferences for how a genetic testing recommendation is made, as well as for certain questions and beliefs about genetic testing for hereditary cancer. Thus, this study provides important preliminary information about specific areas related to HBOC where additional research and education may be warranted in the Hispanic community as a whole and also by sub-ethnicity.

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Table 1

Semi-structured interview guide

1.	Can you tell me what it means to be “at-risk” for getting cancer? (risk factors)
2.	Are there things a person can do to reduce his or her risk? (Make sure to address each of the factors related to “at-risk” for getting cancer)
3.	Can you tell me how you would describe a genetic test to a friend if she asked you about it?
4.	What would worry you the most about having a genetic test?
5.	Has a doctor ever recommended that you get a genetic test for hereditary cancer?
a.	If yes: Did you decide to have the test?
6.	If a genetic test were recommended to you, which of these statements is likely to make you consider having test?
a.	One of the things you may want to consider is getting a genetic test, due to your family or personal history of cancer
b.	I urge you to get a genetic test, based on your personal or family history of cancer
c.	I tell all my patients, with a history like yours, to get a genetic test to see if they carry the gene for breast or ovarian cancer
d.	Genetic testing is an option, based on your history, but you don’t have to do it if you don’t want to
7.	What other questions would you have for your doctor if he or she recommended you have a genetic test for cancer?
8.	If a friend asked for help deciding about genetic test what would you tell her?

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Table 2

Sociodemographic, medical, and cultural characteristics of study participants (*n*=53) *

	n (%)	Cuban (*n*=17) n (%)	Mexican (*n*=16) n (%)	Puerto Rican (*n*=20) n (%)	X^2statistic & P-value
Sociodemographic Characteristics					
Age					$X^2(4,N=51)=4.10,p=0.39$
<34	13(24.5)	2 (11.8)	5(31.3)	6(30.0)	
35–44	17(32.1)	7(41.1)	5(31.3)	4(20.0)	
45–50	12(22.6)	6(35.3)	3(18.7)	3(15.0)	
51–65	11(20.8)	2(11.8)	3(18.7)	7(35.0)	
Marital Status					$X^2(2,N=53)=2.84,p=0.24$
Married/Living as Married	33(62.3)	8(47.1)	12(75.0)	13(65.0)	
Single/Never Married/Separated/Divorced/Widowed	20(37.7)	9(52.9)	4(25.0)	7(35.0)	
Have Children					$X^2(2,N=53)=0.06,p=0.97$
Yes	47(88.7)	15(88.2)	14(87.5)	18(90.0)	
No	6 (11.3)	2(11.8)	2(12.5)	2(10.0)	
Education					$X^2(6,N=53)=13.04,p=0.04$
<High School	20(37.7)	6(35.3)	11(68.8)	3(15.0)	
High School	5 (9.4)	1(5.9)	0(0.0)	4(20.0)	
Some College	11(20.8)	4(23.5)	2(12.5)	5(25.0)	
College	17(32.1)	6(35.3)	3(18.7)	8(40.0)	
Employment Status					$X^2(2,N=52)=1.58,p=0.45$
Full or part time	29(54.7)	11(64.7)	8(50.0)	10(50.0)	
Retired/disabled/unemployed	23(43.4)	5(29.4)	8(50.0)	10(50.0)	
Missing	1(1.9)	1(5.9)	0(0.0)	0(0.0)	
Health Insurance					$X^2(4,N=50)=8.54,p=0.07$
Public	11(20.8)	5(29.4)	2(12.5)	4(20.0)	
Other	19(35.8)	7(41.2)	3(18.7)	9(45.0)	
No insurance	20(37.7)	4(23.5)	11(68.8)	5(25.0)	
Missing	3(5.7)	1(5.9)	0(0.0)	2(10.0)	
Religion					$X^2(4,N=47)=11.22,p=0.02$

	n (%)	Cuban (*n*=17) n (%)	Mexican (*n*=16) n (%)	Puerto Rican (*n*=20) n (%)	X^2statistic & P-value
Catholic	24(45.3)	3(17.6)	9(56.2)	12(60.0)	
Christian	10(18.9)	7(41.2)	1(6.3)	2(10.0)	
Other	13(24.5)	4(23.6)	4(25.0)	5(25.0)	
Missing	6(11.3)	3(17.6)	2(12.5)	1(5.0)	
Income					$X^2(4,N=47)=7.66,p=0.10$
≤$20,000	19(35.9)	6(35.3)	9(56.2)	4(20.0)	
>$20,000–$40,000	13(24.5)	3(17.6)	5(31.2)	5(25.0)	
>$40,000	15(28.3)	6(35.3)	1(6.3)	8(40.0)	
Missing	6(11.3)	2(11.8)	1(6.3)	3(15.0)	
Medical Characteristics					
Personal History of Breast Cancer < age 50					$X^2(2,N=52)=0.08,p=0.96$
Yes	11(20.8)	4(23.5)	3(18.7)	4(20.0)	
No	41(77.3)	13(76.5)	12(75.0)	16(80.0)	
Missing	1(1.9)	0(0.0)	1(6.3)	0(0.0)	
Personal History of Ovarian Cancer					$X^2(2,N=52)=1.07,p=0.58$
Yes	2(3.8)	0(0)	1(6.3)	1(5.0)	
No	50(94.3)	17(100.0)	14(87.4)	19(95.0)	
Missing	1(1.9)	0(0.0)	1(6.3)	0(0.0)	
First Degree Relative had Breast Cancer < age 50					$X^2(2,N=43)=0.99,p=0.61$
Yes	31(64.6)	3 (17.6)	1 (6.3)	3 (15.0)	
No	17(35.4)	14 (82.4)	15(93.7)	17(85.0)	
First Degree Relative had Ovarian Cancer					$X^2(2,N=40)=7.82,p=0.02$
Yes	25(56.8)	1 (5.9)	5 (31.3)	0 (0.0)	
No	19(43.2)	16 (94.1)	11(68.7)	20(100.0)	
Cultural Characteristics					
Born in Mainland United States					$X^2(2,N=53)=0.03,p=0.99$
Yes	19(35.8)	6(35.3)	6 (37.5)	7 (35.0)	
No	34(64.2)	11(64.7)	10(62.5)	13 (65.0)	
Time in United States					$X^2(4,N=52)=4.30,p=0.37$
<1 year	3(5.6)	2(11.8)	0(0.0)	1(5.0)	

	n (%)	Cuban (*n*=17) n (%)	Mexican (*n*=16) n (%)	Puerto Rican (*n*=20) n (%)	X^2statistic & P-value
1–10 years	15(28.3)	3(17.6)	7(43.8)	5(25.0)	
≥11 years	34(64.2)	12(70.6)	9(56.2)	13(65.0)	
Missing	1(1.9)	0(0.0)	0(0.0)	1(5.0)	
Interview Language Preference					$X^2(2,N=53)=3.76,p=0.15$
English	25(47.2)	11(64.7)	5(31.2)	9(45.0)	
Spanish	28(52.8)	6(35.3)	11(68.8)	11(55.0)	

Table 3

Summary of Qualitative Responses by Sub-ethnicity (*N*=53)*

	Cuban (*n*=17)	Mexican (*n*=16)	Puerto Rican (*n*=20)
Cancer Risk Factors	**1** Family History **2** Lifestyle **3** Irregular Health care	**1** Family History **2** Lifestyle **3** Irregular Health care	**1** Lifestyle **2** Family History **3** Irregular Health Care
Knowledge of GT	Don't know/Could not explain	Don't know/Could not explain	Don't know/Could not explain
Concerns about GT	**1** 1.Positive Results **2** Cost	**1** 1.Positive Results **2** Cost	**1** 1.Positive Results **2** Cost
MD Ever Recommend GT	Majority—No If yes, primary reason: Financial	Majority—No If yes, primary reason: No M.D. follow up	Majority—No If yes, primary reason: Fear and uncertainty
Preferred type of MD recommendation	I urge you to get a genetic test	I tell all my patients with history like yours to get a test	1/3 = Consider a genetic test 1/3 = I urge you to get a test 1/3 = I tell all my patients with history like your to get a test
Questions about GT	Risks and Benefits	Actual process and pain	Risk statistics and reliability of the test
Tell a friend about GT	Would encourage if could afford	Would suggest they get more information	Would encourage if doctor recommended

Responses listed in this table were those most frequently given by the majority of women. *GT* genetic testing; *MD* medical doctor