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BRCA Genetic Counseling Among At-Risk Latinas in New York City: New Beliefs Shape New Generation

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Abstract

Despite the life-saving information that genetic counseling can provide for women at hereditary breast and/or ovarian cancer (HBOC) risk, Latinas disproportionately underuse such services.

Understanding Latinas' beliefs and attitudes about BRCA genetic counseling may be the key to

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Conflict of Interest Author Sussner, Author Edwards, Author Villagra, Author Rodriguez, Author Thompson, Author Jandorf and Author Valdimarsdottir declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Animal Studies No animal studies were carried out by the authors for this article.

better health promotion within this underserved, at-risk group. We conducted 12 focus groups ($N=54$) with at-risk Latina women in New York City, followed by 30 in-depth interviews among a subset of the focus group women. Both were professionally transcribed, translated where applicable and data analysis was completed by two coders trained in qualitative methods. Results revealed personal and community knowledge about BRCA genetic counseling was relatively low, although women felt largely positive about counseling. The main motivator to undergo genetic counseling was concerns about learning family members' cancer status, while the main barrier was competing demands. Generational differences were apparent, with younger women (approximately <55 years) reporting that they were more interested in educating themselves about counseling and other ways to prevent cancer. Younger women were also less likely to ascribe to traditionally Latino-centered cultural beliefs which could serve as barriers (e.g. machismo, fatalismo, destino) to undergoing genetic counseling. Participants were largely enthusiastic about educational efforts to increase awareness of genetic counseling among Latinos. Revealing the beliefs and attitudes of underserved Latinas may help shape culturally appropriate educational materials and promotion programs to increase BRCA genetic counseling uptake within this under-represented community.

Keywords

BRCA; Genetic counseling; Latinas; Breast cancer

Introduction

Latinos represent the fastest growing minority group in the U.S., thus shaping the health needs of the U.S. population in the future (US Census Bureau 2004, 2008). Breast cancer is the most commonly diagnosed cancer and leading cause of cancer death among Latinas (Wideroff et al. 2003). Latinas are 22 % more likely to die of breast cancer during the 5 years after diagnosis and have a later breast cancer stage at time of diagnosis compared to White women (Wideroff et al. 2003; Lantz et al. 2006), even after controlling for equal access to health care services (Watlington et al. 2007).

Genetic tests for at-risk individuals with a family history of hereditary breast and/or ovarian cancer (HBOC) are now a key component to preventive health services, as 5–10 % of all breast cancers and 10 % of all ovarian cancers in the general population are known to be hereditary (Claus et al. 1996). Mutations in *BRCA1/2* genes are associated with a 40–66 % lifetime risk of developing breast cancer, a 13–46 % risk of developing ovarian cancer in unaffected women, and a 52 % risk of developing a second breast cancer in breast cancer patients with a *BRCA1/2* mutation (Chen and Parmigiani 2007; Miki et al. 1994; Wooster et al. 1995). Among Latinas, studies have found that *BRCA1/2* mutation prevalence levels are at least comparable to what is found in other ethnic groups (Frank et al. 2002; Weitzel et al. 2005). In fact, in one of the largest studies of Latino breast cancer patients to date, prevalence levels of BRCA mutations were as high as 25 % (Weitzel et al. 2013).

The U.S. Preventive Task Force (ASCO Policy statement 2003; Nelson et al. 2005) recommends that all at-risk individuals, based on family history suggestive of HBOC,

should undergo BRCA genetic counseling, as a prerequisite to testing (Schneider 1997). Life-saving information provided by BRCA genetic counseling includes: personal and family risk of developing breast and/or ovarian cancer, the availability of different preventive and surveillance options, and the pros and cons of undergoing *BRCA1/2* genetic testing. The end goal of BRCA genetic counseling is to ultimately help individuals make more informed decisions about their health care, providing life-saving cancer risk management information to prevent and/or detect cancer at its earliest, most treatable stage in themselves and their family members (ACS 2006; Schneider 1997).

Despite the known benefits of BRCA genetic counseling and subsequent testing for women at HBOC risk, there remain disparities between those who have access to and knowledge about BRCA genetic counseling and testing and those who do not (Hall and Olopade 2005a, b; Olopade 2004). While numbers are not available for counseling on its own, studies indicate that genetic testing among Latinas is low. Less than 10 % of the first 10,000 individuals undergoing BRCA genetic testing were from traditionally underrepresented racial/ethnic groups in a study conducted by Myriad (Frank et al. 2002; Noll et al. 2007). In a study of genetic testing in community-based setting in the US, only 1 % of patients were Latino (Chen et al. 2002). Finally, a national sample of 14.4 million commercially insured patients from 2004 to 2007 found that Hispanic women were significantly less likely to be tested for *BRCA1/2* mutations compared to non-Jewish white women (Levy et al. 2011).

Understanding the potential factors that may explain the underrepresentation of Latinas in BRCA genetic counseling will be key to successful promotion of these services with Latinas. Despite such disparities and calls for the creation of culturally-appropriate and sensitive health education interventions to increase participation in genetic services among Latinas (Baty et al. 2003; Charles et al. 2006; Ford et al. 2007; Peters et al. 2004; Simon et al. 2006), there is still little known about beliefs and attitudes about BRCA genetic counseling among diverse, at-risk Latinas, or sociocultural factors and their influence on these beliefs and attitudes. Previous research conducted by members of our research team and others has largely identified barriers among “normal” risk Latinas, including lack of knowledge and awareness (Gammon et al. 2011; Kinney et al. 2010; Wideroff et al. 2003), negative beliefs, perceived disadvantages of genetic testing (Singer et al. 2004; Thompson et al. 2003), acculturation level (Heck et al. 2008; Sussner et al. 2009; Vadaparampil et al. 2006), and barriers such as not having enough time for genetic testing, and low priority placed on genetic testing because most women currently felt healthy (Thompson et al. 2003). Despite the need to focus on BRCA genetic counseling as the precursor to testing, there are only a few studies related to BRCA genetic counseling issues within at-risk Latinas. However, some of these studies are limited in that they were conducted among Latinas whom were already referred to and had made appointments for genetic cancer risk assessment (which includes counseling) based on family history (Lagos et al. 2008; MacDonald et al. 2008, 2012). To our knowledge, the only known study conducted with at-risk Latinas who had not previously undergone BRCA genetic counseling was conducted by our research team using telephone quantitative interviews; multivariate analyses indicated competing life concerns were inversely related to intent to undergo BRCA genetic

counseling, while perceived risk and physician referral were positively related to intent (Sussner et al. 2013).

Purpose of the Study

The research presented herein serves as a complement to our recent quantitative work in this area described above (Sussner et al. 2013). Thus it is one of the first studies to determine factors that may explain the under-representation of Latinas in BRCA genetic counseling for HBOC among diverse, at-risk women (both affected and unaffected) who have not previously undergone counseling. Specifically by utilizing qualitative methods, this study allowed us to examine beliefs and attitudes about BRCA genetic counseling and sociocultural factors and their influence on these beliefs and attitudes. To identify these factors, focus groups and in-depth interviews were conducted with a diverse group of Latinas at-risk for HBOC, as recent research underscores the importance of examining heterogeneity within the Latino population, including different countries of origin (Abraido-Lanza et al. 2006).

Conceptual/Theoretical Framework—We adapted the Integrative Model of Behavior Prediction (Fishbein and Yzer 2003), which incorporates key aspects of the Health Belief Model (Janz and Becker 1984; Rosenstock 1974), Social Cognitive Theory (Bandura 1977; 1986; Lev 1997) and Theory of Reasoned Action (Ajzen and Fishbein 1980; Fishbein & Ajzen 1975) in order to guide the conceptual and theoretical framework behind this study. This model recognizes that beliefs and attitudes underlie intention to perform health behaviors. Further, these beliefs and attitudes are a function of many background influences, including social and cultural factors.

Methods

Study Setting and Population: Recruitment

Potential participants completed an IRB-approved family history form for hereditary breast/ovarian cancer (HBOC) risk as part of our recruitment for ongoing studies in breast surgery clinics at Mount Sinai and indicated if they were interested in participating in future research studies. The bilingual Project Investigator (PI) or Research Assistants (RAs) contacted eligible individuals whom had previously given us permission to reach them by telephone to explain the study and confirm they met eligibility criteria including: women self-identifying as Latina, at least 18 years of age, never having undergone BRCA genetic counseling/testing, and having increased risk of breast and/or ovarian cancer, based on personal diagnosis at a young age (<55 years old) and/or family history of breast and/or ovarian cancer, determined by having 1 first degree relative with breast and/or ovarian cancer diagnosed at a young age (<55 years old) or 2 s degree relatives with breast and/or ovarian cancer. Eligible participants were then invited to attend a focus group session. All study procedures were approved by Icahn School of Medicine at Mount Sinai's Institutional Review Board.

Procedures

Focus Group Sessions—Participants could choose to attend either a Spanish or English-language focus group, based on their personal preference. All focus group sessions lasted approximately 1.5–2 h, were held at Mount Sinai and were led by the trained bilingual PI or RAs. Signed consent was obtained at the beginning of the focus group session before the collection of any data. In addition, all participants completed a brief sociodemographic form before the focus group session began. The focus group began by a discussion about what participants had heard or knew about BRCA genetic counseling. Following this discussion, a brief educational presentation including review of an informational packet about BRCA genetic counseling was given to all focus group participants. This educational presentation was used to ensure all participants were on the same page for further questions that followed during the focus group session.

Focus group participants received a \$40 gift card for participation. Following completion of the sessions, all participants were provided information about how to obtain a genetic counseling referral including via: 1) the toll-free telephone number of a confidential referral service provided by New York State (NYS), through the Department of Health and the Cancer Services Program, and 2) contact information about BRCA genetic counseling created by the Clinical Genetics Program at Mount Sinai.

In-depth Individual Interviews—Following the focus group sessions, interested participants were then invited to participate in an in-depth interview to further explore issues raised in the focus group. In-depth interviews lasted approximately 30 min to 1 h and were conducted either in-person at Mount Sinai or over the telephone by the bilingual PI or RA, at a mutually agreed upon time. In-depth interview participants received a \$20 gift card for participation. The rationale for conducting two phases, focus groups followed by in-depth individual interviews was to allow for any further potential exploration of key themes and subthemes that had emerged from the focus group discussions. Before the study was conducted, we aimed to conduct focus groups with approximately 50 women followed by at least half of the women participating in in-depth interviews to allow for saturation of the key themes and subthemes. In fact, we completed focus groups with 54 participants and therefore closed recruitment to the second phase of the study once 30 of the focus group participants had agreed to participate in the follow-up individual in-depth interviews.

Instrumentation

Sociodemographics & Acculturation Measures—Sociodemographic information collected on each participant included: age, marital status, employment, number of children, income, education level, nativity/country of origin, parents' nativity and breast/ovarian cancer personal and family history. In order to measure acculturation, Marin and Gamba's (1996) bidirectional acculturation scale for Hispanics (BAS) was used; this scale explores two major cultural dimensions by including 12 items that measure three language-related areas. Participants responded using a 4-point Likert scale, with responses summed and averaged across 24 questions. The mean acculturation level ranged from a possible 1–4, with higher scores meaning higher acculturation. Reliability of the items in the acculturation scale

was excellent for participants in this study (Cronbach's $\alpha=0.96$). Other measures included interview language, participants' nativity, mothers' nativity and fathers' nativity.

Focus Group Interview Protocol—The focus group guide used in this study was developed based on extant literature and previous experience by our research team (Sussner et al. 2010, 2013) and was organized to explore three over-arching topic areas including: 1) knowledge about genetic counseling for HBOC, 2) personal barriers and facilitators to genetic counseling for HBOC, and 3) Latinas' barriers and facilitators to genetic counseling for HBOC. Within each topic area, there were several themes and subthemes exploring such factors as the role of family, provider referral, language barriers, issues of access, financial/insurance-related barriers, competing life demands, cultural beliefs including fatalismo and destino, as well as medical distrust and social support networks. The topic guide included open-ended questions, with prompts and probes used to delve deeper into informants' responses when necessary.

In-depth Individual Interview Protocol—Preliminary analysis of focus group data revealed key themes and subthemes related to benefits and barriers of BRCA genetic counseling and cultural influences on genetic counseling participation, such as competing demands, the role of family and generational differences. The in-depth interview guide was subsequently developed, following the format used for focus groups but including new questions to obtain more in-depth information related to these themes and subthemes. The structure of the in-depth interview guide was similar to the focus group guide with open-ended questions and prompts included to allow for elaboration by study participants.

Qualitative Data Analysis

Thematic content analysis was used to analyze the qualitative data in this study, which involved identifying recurring themes and subthemes within the data, as well as exploring typologies, variations and relationships between and within these themes and subthemes (Green as cited in Saks and Allsop 2007). The steps were: 1) familiarization with the transcripts via reading and rereading transcripts and listening to tapes to get an overall sense of key issues 2) developing a coding frame within a group or team of researchers who read the transcripts in detail and identify key codes and labels for a codebook; 3) coding based on this coding framework by identifying each segment as a code; and 4) "cut and paste," whereby cases of the same code are then gathered together by using software to examine list of extracts under each code to identify participants' responses.

Research texts included verbatim transcripts from the focus groups and in-depth interviews translated to English by a professional translator, where necessary, with identifiers removed. In order to account for interaction among focus group participants, field notes and speaker order were included in the final transcript. Two coders trained in qualitative methods (KS and TE) were responsible for independently reading, reviewing and manually analyzing the transcripts. A code-book was developed based on agreement between the two analysts and data were then manually coded separately by each coder to identify common themes and subthemes. Following the completion of independent coding, any inconsistencies in coding were discussed and resolved, although no such inconsistencies were found.

Results

Sample Characteristics

Sample characteristics are presented in Table 1, where the total sample size (n), refers to number of participants responding to individual questionnaire items. In the case of participants who did not wish to answer all questions, there are instances of missing data for some participants.

Themes and Subthemes

The following major themes and subthemes from the developed codebook that were extracted from participants' responses in the focus groups and in-depth interviews, are described, and specific example quotations representing each theme and subtheme are presented in Tables 2, 3, 4, 5, 6, 7, and 8. There are a total of 7 main themes and 37 subthemes. As results from the in-depth interviews only served to reinforce key themes that had already been raised in the focus group sessions, we report and group the findings from focus groups and in-depth interviews together. There were also no major differences noted in participant behavior or demeanor based on interview format.

Theme 1: Illness Prevention. See Table 2—At the beginning of the focus group sessions, participants were asked to discuss whether they believed illness and disease could be prevented. Responses given by respondents varied considerably with five subthemes ranging from discussion of belief in a higher power/God (Subtheme 1.1), the importance of natural remedies in preventing disease (Subtheme 1.2), the influence of lifestyle/diet (Subtheme 1.3), generational differences in knowledge about disease prevention (Subtheme 1.4), and personal behavior in relation to family history of disease and genetics (Subtheme 1.5).

Theme 2: Personal and Community Knowledge about BRCA Genetic Counseling. See Table 3—Participants in the focus groups were asked whether they had any knowledge of BRCA genetic counseling for HBOC and if so, to describe the purpose of genetic counseling. Overall, the majority of focus group participants had limited information about BRCA genetic counseling (Subtheme 2.1). Many participants could not decipher the difference between BRCA genetic counseling and testing. For the few participants that were knowledgeable about BRCA genetic counseling, they stated that genetic counseling was useful for the prevention and management of cancer. In addition, for these individuals, personal relevance with cancer, having undergone it themselves or having had a family member affected by cancer appeared to be strong factors influencing their awareness levels about BRCA genetic counseling (Subtheme 2.2).

When asked to speak about knowledge of BRCA genetic counseling for HBOC within the Latino community, most participants reported that they believed knowledge was quite low. Many participants spoke of the generational differences between their parents, grandparents and themselves, saying that the older generations held more “old school” beliefs about cancer and health, in general (Subtheme 2.3). Further, the younger generation (approximately <55 years old) considered themselves more educated and interested in

learning about how to prevent cancer and disease compared to the older generation (approximately 55 years old). Following this discussion, all participants received a brief explanation from the focus group facilitator about BRCA mutations and genetic counseling to ensure that all participants were on the same page for further questions that followed during the focus group session.

At the same time of this initial discussion, the majority of participants expressed that they had never been referred to BRCA genetic counseling by their healthcare provider (Subtheme 2.4); however they reported that having a referral would make them more likely to go for genetic counseling.

Themes 3 and 4: Perceived Benefits and Barriers of BRCA Genetic Counseling and Cultural Influences on Genetic Counseling Participation. See Tables 3 and 4

Subtheme 4.1 Familismo (Central Role of the Family): When asked to describe the benefits of BRCA genetic counseling, almost all participants, in both focus groups and in-depth interviews, spoke about helping their family as one the primary reasons to undergo genetic counseling (Subtheme 3.1). In fact, the central role of the family, known in Spanish as “familismo,” appeared to one of the strongest cultural factors influencing their decisions about health, in general (Subtheme 4.1). Most participants stated that they would be encouraged to undergo BRCA genetic counseling if their family felt it was important for them to do so and if they had family support (Subtheme 4.1.B), although some participants stated that the decision was still ultimately their own personal choice (Subtheme 4.1.C). Specifically, results found that family members having a negative view of genetic counseling would not necessarily deter a participant from pursuing genetic counseling as most participants described themselves as independent, yet having family support would act as a motivating force to pursue counseling. At the same time, the younger participants spoke about generational differences that they perceived made their generation more receptive to BRCA genetic counseling compared to the older generation, such as their parents or grandparents (Subtheme 4.1.D). Although the older participants in this study were still receptive to counseling, the younger participants appeared to be more enthusiastic about actually pursuing counseling compared to older participants, in general. Furthermore, some younger participants discussed how they could serve as role models to encourage older generations to obtain BRCA genetic counseling.

Most participants emphasized the importance of improving communication, information gathering and gaining more knowledge as critical in order to help make the appropriate decision about whether to undergo BRCA genetic counseling (Subtheme 3.2). Finally, other benefits of participating in BRCA genetic counseling included the importance of self-care and individual empowerment (Subtheme 3.3) as well as the possibility of helping finding a cure to cancer (Subtheme 3.4).

Subtheme 4.2. Descuido (Competing Demands): Most participants spoke about competing demands including taking care of their family (children, relatives, grandparents, spouse) as main barriers that would keep them from having the time or energy to get BRCA genetic

counseling at this time. Specifically, participants described how Latina women often prioritized themselves last, with their family needs first, often with this prioritization at the expense of their own health (Subtheme 4.2.A). Participants described how this prioritization of the family was a part of the Latino culture and that it was a fact of life, giving them limited availability to do much for themselves in terms of taking care of their own health. At the same time, some participants described how they believed it was up to them to make their health a priority and that they needed to change this attitude and begin serving as role models to younger women (Subtheme 4.2.B).

Subtheme 4.3. Machismo (Role of Men): Participants were asked to speak about whether machismo beliefs influenced their decisions about BRCA genetic counseling. In response, the majority of participants stated that although machismo still exists in the Latino community, these women, particularly in the younger generation, were proud to consider themselves extremely independent and not needing a man to define themselves (Subtheme 4.3.A). Many discussed that if they had the support of their male partners to undergo BRCA genetic counseling that would give them extra support; however the decision to undergo counseling was ultimately their own choice and they would make the decision they believed was right for them, regardless of what their partner thought.

Many younger participants pointed out how they perceived that older generations of women may have relied more on the men to decide things for the family, but that with the younger generation this was no longer the case. In addition, many older participants echoed this perceived change of rising women's power and independence within Latina families, particularly within the younger generation. Again, the importance of women serving as role models for other younger women was discussed. Furthermore, many participants described how many men in their family and within the Latino community were quite fearful of going to the doctor, in general, describing that many men believed it would be perceived as a sign of weakness to seek help (Subtheme 4.3.B). Participants discussed how these men could benefit from specific encouragement from women in the Latino community to undergo BRCA genetic counseling (Subtheme 4.3.C).

Subtheme 4.4. Fatalismo (God's will): Participants were questioned about the role of "fatalismo," the belief that cancer was God's will and a certain death, influencing their beliefs about BRCA genetic counseling. There were some affected women who reported believing cancer was a death sentence upon first being diagnosed, however their attitudes had changed in stages, as the prognosis of their cancer had improved over time (Subtheme 4.4.A). Further, most participants described generational differences apparent in this belief, in that the older generation of participants were more likely to equate cancer with certain death, whereas those participants in the younger generation were often more hopeful and knowledgeable about ways to prevent and treat cancer (Subtheme 4.4.B). Specifically, many younger participants were more likely to follow the latest scientific information and/or medical advances about cancer compared to older participants. However, some women still spoke about the role of a higher power in impacting their decisions (Subtheme 4.4.C), while a few described the value of self-talk in helping to alleviate their fears about death.

Subtheme 4.5. Destino (Destiny): Participants were also asked to discuss the role of “destino” as a possible influence on their beliefs about BRCA genetic counseling and cancer. The majority of participants did not believe it was their destiny to get cancer, although several were faced with the question of “why me” when they were diagnosed. Participants spoke about the role of other factors such as personal control, chance, as well as education and the development of cancer (Subtheme 4.5.A). The belief in a higher power and/or God appeared as an important factor in most participants’ lives, but was most often cited as a coping mechanism for allowing participants to handle the uncertainty and challenges of a cancer diagnosis (Subtheme 4.5.B). For many affected participants, they reported that their faith had actually been renewed at the time of a cancer diagnosis.

Theme 5: Additional Barriers to Participation in BRCA Genetic Counseling.

See Table 6—Participants cited several barriers to participation in BRCA genetic counseling. One of the most commonly cited barriers was the perceived expense of BRCA genetic counseling, with most participants reporting that they were unaware about how much genetic counseling would cost them (Subtheme 5.1). Another barrier mentioned by participants was fear of finding out that they had a genetic mutation if they pursued testing (Subtheme 5.2).

Theme 6: Influence of Previous Interactions with the Healthcare System. See

Table 7—When asked about their previous interactions with the healthcare system and how it may impact their decision to seek BRCA genetic counseling, some participants discussed having personally received or witnessed differential treatment, either via insurance discrimination and/or interaction with their provider (Subtheme 6.1). Some participants described having poor communication with their physician, either due to language barriers and/or problems understanding medical terminology. Specifically, some participants described having the feeling that they were being treated as though they were not capable of understanding all the information given to them. For those participants who had not received a BRCA genetic counseling referral, they were concerned about whether poor communication had contributed to their lack of a referral, as well as whether such problems impacted their follow-up care. Differential treatment in access to doctors they felt comfortable with was also raised by a few participants (Subtheme 6.2). Some participants mentioned using translators, with a preference for on-site in-person translators versus using a telephone translation service (Subtheme 6.3). A few younger participants mentioned that they themselves had served as translators for older relatives/parents, while some older participants mentioned they often had their children serve as translators, providing support to help navigate the healthcare system and medical facility. A few participants reported feeling a general mistrust of the medical system, such as doctors ordering tests to make money, even if these tests were not necessary (Subtheme 6.4).

Theme 7: Suggestions for Educational Tool about BRCA Genetic Counseling for HBOC. See Table 8—

All participants were enthusiastic about the creation of an educational tool to increase knowledge about BRCA genetic counseling. When asked to provide suggestions for the development of this tool, many participants cited a preference for visual formats, which included a telenovela narrative style or television program format

that was personal and inclusive (Subtheme 7.1) and included simple, easy-to-follow, instructional medical information. It was critical to most women that such programs be bilingual, available in both Spanish and English languages (Subtheme 7.2). Several women mentioned that it was important to them that this information be confidential (Subtheme 7.3). Finally, although participants were interested in the development of this tool, some participants still stressed the importance of human interaction, such as via health fairs or focus groups, to educate women about BRCA genetic counseling (Subtheme 7.4).

Discussion

This study uniquely contributes to the growing literature by qualitatively identifying beliefs and attitudes about BRCA genetic counseling among at risk Latinas. Similar to previous research conducted by members of our team (Sussner et al. 2010; 2013), personal and community level knowledge about BRCA genetic counseling was considered fairly low amongst study participants, although the majority of participants appeared largely enthusiastic about learning more about BRCA genetic counseling. Women appeared motivated to undergo BRCA genetic counseling as it would help their family members, emphasizing the importance of familismo in this community and its impact on health behaviors, previously described in other studies (Penchaszadeh 2001; Perez-Stable 1987; Perez-Stable et al. 1992; Sussner et al. 2013).

However, despite participants' interest and enthusiasm in seeking BRCA genetic counseling, the results of this study are congruent with our recent quantitative work which found that competing demands was the strongest factor influencing intent to undergo genetic counseling (Sussner et al. 2013). Specifically, all women in both focus groups and in-depth interviews described how competing life demands, including childcare and taking care of older relatives, were serious practical constraints which women believed severely limited their perceived ability to find the time and/or energy to seek BRCA genetic counseling at this time. Participants described in detail how as Latina women they often put themselves last, sometimes at the expense of their own health, as has been described in previous health literature with Latinas (Ashing-Giwa et al. 2004; 2006; Shelton et al. 2011; Sussner et al. 2013). In fact, previous research documents a disproportionate burden of caretaking and household duties often held by low-income, minority women (Coltrane 2000; Devault 1991; Sobal and Bisogni 2003).

Other common constraints mentioned by participants included concerns about the cost of BRCA genetic counseling, language barriers which may have impacted their understanding of medical terms and subsequent perceived ability to obtain or receive a referral for genetic counseling, as well as experiencing previous negative encounters with the medical system/mistrust. In fact, an expansive literature review examining barriers to cancer genetic services across minority groups has identified these socioeconomic and psychosocial factors previously (Forman and Hall 2009).

A unique contribution to the growing literature in this area was revealed as generational differences appeared to dominate discussion in the focus group sessions and appeared subsequently in in-depth interviews. Younger women perceived themselves as being more

interested in education and ways to prevent cancer, compared to older women. Older women also acknowledged this apparent difference in level of interest between generations. Further, younger women directly expressed more willingness to go for BRCA genetic counseling compared to older women. Such generational differences were discussed in light of more traditional cultural views often held by Latinas and how traditional views might relate to the likelihood to undergo BRCA genetic counseling as well as responses to interventions to increase BRCA genetic counseling and testing in this population.

In line with our recent quantitative research with at risk Latinas (Sussner et al. 2013), the central role of the family was important to the majority of women, with women describing the ways in which understanding family risk would make them more likely to get counseling and subsequent testing, as well as how encouragement or support from family members would make them more likely to seek counseling. Specifically, some of the younger women described how they could use the emphasis on familismo as a way to describe the benefits of BRCA genetic counseling to the older generation and encourage them to get genetic counseling. In comparison, the man having control of decisions or not showing emotional support to the woman, otherwise known as machismo, appeared not as strong, as previous research may suggest (Lopez-Class et al. 2011), particularly among the younger generation of women. In fact, women in this study, particularly those in the younger generation, identified themselves as being even more independent and stronger compared to their partners, describing how they could use their own strength to encourage men to get counseling when they were not likely to seek it. Similarly, the more traditional beliefs of fatalismo and destino were more common amongst older generations of women in this study, with the younger generation more likely to follow medical studies and advances rather than relying on the belief of God's will or a destiny to have cancer.

Practice Implications

Understanding at risk Latinas' attitudes and beliefs about BRCA genetic counseling as described in this study will ultimately help allow for the creation and development of more culturally appropriate educational materials to increase BRCA genetic counseling in this underrepresented community. As the present participants expressed and as previously found, there is a strong desire for personal, narrative-based or novela style materials that may increase knowledge about BRCA genetic counseling (Sussner et al. 2010). Bilingual media products and materials are particularly needed, as well as both tailored and targeted approaches for communicating cancer genetic information in order to overcome barriers (Kinney et al. 2010). In light of study results presented here, such educational materials and programs should seek to incorporate an understanding of the competing demands and stressors faced by Latinas in this community and directly address ways in which Latinas may overcome such demands in order to prioritize their health. As described in Sussner et al. (2013), one way to achieve this may be to create materials that emphasize the role of the family and the value of BRCA genetic counseling for improving family health. This strategy may be the key to allowing Latina women to realize that by putting their health first they are at the same time putting their entire family's health first, as well. Furthermore, genetic counselors could serve a critical role in not only helping to develop such educational materials and programs, but by also presenting this material to Latino patients and ensuring

that specific discussion of family priorities be fully incorporated into their genetic counseling sessions with this underserved group.

Another critical element of educational programs that could be beneficial would be adopting a community-based navigation model whereby peers and lay health advisors help an individual navigate the healthcare system, as has been successful in increasing breast cancer screening knowledge (Williams et al. 2011), mammography, breast self-examination rates (Erwin et al. 1996; Wells et al. 2011), diagnostic follow-up after mammography (Maxwell et al. 2010), as well as colonoscopy screening among minority women (Jandorf et al. 2013). Specifically, younger peer patient navigation role models could be utilized to help guide older women to understanding the value of educating themselves about BRCA genetic counseling, as well as challenging traditionally held cultural beliefs which could be barriers to older women seeking BRCA genetic counseling. These younger peer navigation role models could also serve as translators to the older generation of women who may have more difficulty in understanding medical jargons/terms or have had negative experiences with the healthcare system due to language related barriers. In addition, this new generation of younger peer navigator role models could also assist men who may appear unwilling to go to counseling, given the concerns raised by participants in this study about their husbands and partners not wanting to be appear weak. Furthermore, additional levels of intervention to overcome the barrier of competing demands and stressors could be created for this underserved population, such as providing genetic counseling in the patient's local community clinics, as well as offering free childcare services in the clinic setting while patients undergo genetic counseling.

Study Limitations and Research Recommendations

There are several limitations of the existing study. First, the generalizability of study results are limited given the nature of qualitative research. For example, the opinions and responses of women participating in the focus group discussions may have been influenced by some of the more vocal women, even though we used experienced and trained facilitators. Women who agreed to participate in this study could also have been those who were more concerned in general about the prevention of cancer and healthy lifestyles. A second limitation could be a biased sample given the fact that women who were recruited were already part of the health care system, being primarily recruited through breast surgery clinics at Icahn School of Medicine at Mount Sinai, with an extremely high proportion of insured individuals. This is critical, as recent research conducted by a member of our team through a breast/ovarian cancer awareness program with diverse Latinas from NYC documents as high as one-third of participants being uninsured (Jandorf et al. 2012).

A third limitation could have been participants' risk levels. Since we were limited in our ability to recruit women at highest risk for genetic mutation, our risk eligibility was expanded, and we use the term *at-risk*, rather than *high-risk*. Fourth, as this study was conducted among Latinas in NYC, representing multiple countries of origin (predominantly Puerto Rican or Dominican), study results may not be generalizable to other groups of Latinas or from other regions or non-metropolitan areas of the USA. However, the multiethnic composition of the 54 respondents strengthens the applicability of findings to

women from several Latino population groups living in the urban Northeast. Finally, in regards to the many differences evident in the results between younger and older participants, this study was limited in that we only inquired about whether the women had children. To examine generational status in more detail, future studies may wish to incorporate specific questions related to grandchildren or even great-grandchildren as part of the demographic information obtained on participants.

Conclusion

In conclusion, this qualitative study complements previous literature by revealing the beliefs and attitudes of at risk underserved Latinas about BRCA genetic counseling. By better understanding such beliefs and attitudes, we may be in a better position to help shape culturally appropriate educational materials and promotion programs to increase BRCA genetic counseling within this underrepresented community.

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Table 1

Sample characteristics

SOCIODEMOGRAPHIC VARIABLES	n(%)	Sample mean	Possible range	Actual range
Language				
Spanish	32(59.3)	n/a	n/a	n/a
English	22(40.7)	n/a	n/a	n/a
Nativity				
Foreign born	41(75.9)	n/a	n/a	n/a
US born	13(24.1)	n/a	n/a	n/a
Country of Origin				
United States	13 (24.1)	n/a	n/a	n/a
Dominican Republic	13 (24.1)	n/a	n/a	n/a
Puerto Rico	10 (18.5)	n/a	n/a	n/a
Ecuador	8(14.8)	n/a	n/a	n/a
Mexico	5 (9.3)	n/a	n/a	n/a
Columbia	2 (5.6)	n/a	n/a	n/a
Peru	2 (1.8)	n/a	n/a	n/a
Cuba	1 (1.8)	n/a	n/a	n/a
Parents' nativity				
Foreign born	51(94.4)	n/a	n/a	n/a
US born	3(5.6)	n/a	n/a	n/a
Personal History Breast/Ovarian Cancer				
Yes	26(60.5)	n/a	n/a	n/a
No	17(39.5)	n/a	n/a	n/a
Family History Breast/Ovarian Cancer				
Yes	20(46.5)	n/a	n/a	n/a
No	23(53.4)	n/a	n/a	n/a
Age		49.9(14.4)	18-n/a	18–79
<40 years old	12 (24.0)			
40–49 years old	11 (22.0)			
50–59 years old	16 (32.0)			
60+ years old	11 (22.0)			
Acculturation (where higher = more acculturated)	54	2.3(0.9)	1–4	1–3.9
Children				
Yes	33(76.7)	2.3(1.1)	1-n/a	1–5
No	10 (23.3)			
Education				
High school	28(51.9)	n/a	n/a	n/a
>High school	26(48.1)	n/a	n/a	n/a
Income				
\$19,999/year	24(60.0)	n/a	n/a	n/a
\$20 K/year	16(40.0)	n/a	n/a	n/a

SOCIODEMOGRAPHIC VARIABLES	<i>n</i>(%)	Sample mean	Possible range	Actual range
Marital Status				
Married/living together	21(38.9)	n/a	n/a	n/a
Not married/living together	33(61.1)	n/a	n/a	n/a
Employment				
Working	18(34.0)	n/a	n/a	n/a
Not working	35(66.0)	n/a	n/a	n/a
Insurance				
Yes	39 (92.9)	n/a	n/a	n/a
No	3 (7.1)	n/a	n/a	n/a

Table 2**Focus groups and in-depth interviews results theme 1: illness prevention**

Subtheme 1.1. Belief in Higher Power

...regardless of science, it is assumed that all human beings are here for someone, a Supreme Being is obviously God...to me, there is no way to prevent it (cancer), but to find out in time, and whether the man can do things...definitely the hand of God must be in the middle...we cannot blame God because we are with this disease, we have to deal with God.

Subtheme 1.2. Natural Remedies

...oh, we got an herb for this. We got a plant for this. We mix that and that in a little bit of water. We got a cure. That's how it is...That's how they (Latinos of older generation) cure the basic cold. Drink a little bit of lime with honey; tomorrow you'll be okay. Everything was home remedy. Doctors, you have to be dying in order for them to go.

Subtheme 1.3. Influence of Lifestyle/Diet

...There are certain things (foods) that are malignant, others that are not malignant. For example we have the grains, we have plants, we have the fruit.

...They almost always ate what the land produced, and there were things that had no chemicals, nothing. But now we buy all things with chemicals, but before our parents, our grandparents ate well. They died, but they did not die of a cancer disease.

Subtheme 1.4. Generational Differences in Knowledge about Disease Prevention

...And cancer, for me, I think the cancer has existed for many generations, but what happened is that we did not know how to detect.

...A lot has to do with education, how long you've been in school, what you're taught because our parents were taught...you only go to the doctor when you're really, really, really sick because you know, during that time they did a lot of herbal medications...you have to fix yourself best way you could and get to work and get to school...in my generation as you go on in your learning hygiene and that type of thing in school...There's a lot of preventive medicine....so your whole thing changes.

Subtheme 1.5. Personal behavior in relation to family history of disease and genetics

...If you have a very high risk it makes you wonder. Hmm...how did my family members take care of themselves and maybe I could stop the curse at myself by taking care of myself better. But there's always that chance that because it's in your genes and it's been passed along the line especially if it's in both ends. There's still that possibility that you could get it and it's scary.

Table 3**Focus groups and in-depth interviews results theme 2: personal and community knowledge about BRCA genetic counseling**

Subtheme 2.1. Limited Information about BRCA Genetic Counseling

...I don't think the average woman knows very much about genetic counseling... only until...you're forced to look into it so to speak.

...I think it's safe to say that not a lot of people probably know about it. It's not something that comes frequently in conversation.

...There is too much information and they (Latinos) do not seek. Yes, if they do not give us information we cannot go get the information. We are always waiting to be opened first to the door...we will not be able to go find information.

Subtheme 2.2. Personal Relevance with Cancer (Themselves or Family Member)

...Other Latinos can speak about genetics...that had breast cancer or had someone in their family and very close to them who have had breast cancer....not to say that anyone else that doesn't have breast cancer is not interested, but to me if it doesn't hit home so to speak, people were not really interested.

...Once you have either a very close family member like your mother or you yourself have cancer that is when the whole world of breast cancer opens up and you learn a lot...it's like a whole a new book in your life.

Subtheme 2.3. Generational Differences

...I don't think the older generation knows very much because usually they find out things from the younger generation or...once you're forced into the situation of being diagnosed, then you get to find out...lot of information that you really didn't even know beforehand.

...The Latino community tends to be very old school and everything is about own remedy. And it's passed on from generations to generations. So yeah, it's hard...when you are talking about cancer and Latino people you get different feedback, oh, you should do this, you should do that, but they really don't read, they don't research, it's all about home remedies...Latino people need to...become more knowledgeable.

...I think unfortunately, there are a lot of ignorant people right now...there are a lot of old school people. And they just, they just feel well, if it's gonna happen, it's gonna happen and there ain't nothing that is going to stop it.

Subtheme 2.4. Lack of BRCA Genetic Counseling Referral-Majority Never Referred

...I really don't think there's that real connection with that doctor anymore. I have a good primary care doctor and I thought she was really great. But in terms of that, the genetic counseling, she never brought that up.

...I think doctors have other priorities, you know, or whether they have so many patients or that is just not their priority, to just send you for genetic counseling...it may be expensive, they may not feel the patient can handle it or would want to, so why bring it up.

Table 4**Focus groups and in-depth interviews results theme 3: perceived benefits to BRCA genetic counseling**

Subtheme 3.1. Helping the Family

...I would do it (GC) for my family and me, because I have a daughter and two children. I would think about my children first and then my family....

...For me the push would be to see ... if I am a carrier of the gene or not... than I can pass, to prevent further, to protect my children.

...I also strongly believe in passing on the information to my family. You know, I have sons. So, I tell them, okay, this one's in the family, this one's in the family, you'll need to make sure that you'd go for check up periodically, look out for this and look out for that. So, if you could pass on into the generation, the more they know your family history about certain disorders and stuff that now they're informed they are, you know, they could get through it a lot quicker. They'll take care of themselves.

...If I'm educated and then I do have that gene and I could've passed it to my daughter, and she didn't probably didn't know, but if she does, I have a better handful of how to advise her and the way to take care stuff like that.

Subtheme 3.2 Improving Communication, Information-Gathering, and Gaining Knowledge to Make Appropriate Decision

...For me it (GC) is important. A plan of knowledge. And avoid much suffering precisely because the suffering and the impact that caused us when we said we had cancer, it just came from the lack of information.

Subtheme 3.3. Self-Care and Individual Empowerment

...To me, it would make me happy because then I'll know where I got it from...it would empower because then I will go head on... and to continue on researching myself...to know that it runs in my family also. Because it educates me more and I get to educate other people. It gives me the power to know that it's not my mistake of not taking care of myself. It was just something that is already in me. So if I will still get genetic counseling, it'll help a lot of women, to ask a lot of questions that I still have about myself...

...It is really a matter of what you know, it helps to know you have it and who does not. When you have it you should be aware of your health and do not have it then you know....

Subtheme 3.4. Helping Finding a Cure to Cancer

...If you're going down the road of finding out what genes are involved and if you get enough women to participate ultimately and get enough information gathered then maybe you could figure out what it is that's happening and try to stop it in it's tracks and ultimately a cure then that would help even more.

Table 5**Focus groups and in-depth interviews results theme 4: cultural influences on genetic counseling participation****Subtheme 4.1. Familismo (Central Role of the Family)****4.1.A. Central Role of the Family**

...I think we, as a group, believe that the family influences a lot. It (the family) has a very important role, because I think the family is like a pillar, is the support, I think the family has a great influence. We are strongly influenced by family support, it strongly influences the support of the couple and I think it has a very, very important, not only important but top priority.

...Of course, it is a priority in all decisions we have to take or what to do, for me family comes first, I think that family is the most important foundation for me and I think for most of my neighbors. To me, the home, the family is the most important thing.

4.1.B. Family Support Can Influence Health Decisions

...I think it's very important for...a family to be involved, especially with support because you may be iffy and very scared on what the results would be especially if you have a very high risk and you're like "whoa, what does that mean for me?"

4.1.C. Personal Choice

...I make my own decisions. Based on, if I am researching about it or I am asking questions. No one influences me. Let's put it that way.

4.1.D. Generational Differences and Role Models

...I feel like my sisters and I are always talking to my mom or my aunts and what was pushing them about certain exams and so the family is important...I think in this way it's the younger generation influencing the older generation thinking we have more information to kindly share with them.

...I remember my grandmother, I asked her about something she would like smack me like "How dare you ask me?" You know that's very personal and that barrier needs to break from here on... 50 years from now...our branch of kids or grandkids or great grandkids can look back and say "Well I can trace all the health issues going back this far." And they know better, and they can break them all at that point so that these things won't get passed on.

...They'll look at me...You're an activist. I'm not an activist. I am just who I am. I don't like losing people...I don't like going to funerals. I don't like going to cemeteries. I don't like none of that and I don't want to see nobody depressed because they lost a loved one over a disease that could have been controlled or taken care of a long time ago. So they leave me alone but I do push especially my sisters. Go get tested, go get tested.

Subtheme 4.2. Descuido (Competing Demands)**4.2.A. Latina Women Prioritize Themselves Last At Expense of Own Health**

...I feel sometimes we feel we have so many...deeds to accomplish in terms of society that we are just as small as anybody's culture that we can try and overdo it and that fills our day with a lot of things of and no space to really attend to our health needs.

...Culturally they teach you...it's family first, second, third, and then maybe you. So you are in that mode already of caring for others and yourself if you have time.

...It's a fact that a lot of the Latinas, they'll wait until the children are able to go to school by themselves or able to stay home by themselves and fix themselves a sandwich, then you will feel comfortable by going to doctor...

...The woman is meant to do everything, take care of the house, take care of this, take care of that, so health does go on the background... That's how we were raised. You last, everybody else first.

...Latinas and Latino culture, we're the last to deal with us. We may know that. We have a conditional disease but we're too busy, we might be taking care of our parents, our elderly parents and you may not have the time to focus on yourself when you're dealing with elderly parents with serious diseases.

4.2.B. Changing Attitudes to Make Health A Priority/Serving as Role Models

...I need to take care. I need to have health to be able to take care of my family. Because if I don't have health, I can't take care of that.

...You have to make time for yourself no matter what or who you're taking care of...make the number one thing, you. Because without you, that first thing can't function according to you. I don't do this because then that person won't function. Well if you don't function, if you're not healthy, that person is not gonna function. He or she is gonna be destroyed without you. So you're gonna think of it, like, "If I'm not here, they're not here."

Subtheme 4.3. Machismo (Role of Men)**4.3.A. More Emphasis on Female Independence Among Younger Generation of Women**

...In terms of that machismo, I feel we have come a long way to achieve and it might still exist a little bit...in general Latinas...have come a long way, we are not often victimized by them, as we now have we go to school, we prepare ourselves and most of us can say is if this is how it will be then I'll go walk off separate ways. Before we didn't have any option and we had to stay at home caring for the children, now it is different.

...If I had a partner who was against me getting tested or...getting counseling, I don't think I'd necessarily listen to them.

4.3.B. Male Pride and Fears of Going to Doctor

...Males in the Latino community, they're very proud...it takes a whole lot to get them to come in (to the doctor) to see...

...It's like they (Latino men) attribute being sick to being weak or something. They really don't want to show even when they're hurt or when they're sick...They don't want to discuss anything... they think they're indestructible or that they have to be strong.

4.3.C. Women to Help Motivate Men to Go to Counseling

...You bump into somebody like me, I'm hard headed and I'm gonna look at you and tell you, "No, you're not right. I'm sorry, you're going to the doctor, I'm going to the doctor. We're gonna check this out because my father had this. And he was the pillar of my family and he's not with me no more. So, guess what? If you're gonna be around me, I want you forever. So, you're gonna be there and do the same thing".

...I feel that they (Latino men) need strong women like us to tell them, "You know what, let's go to the doctor and check that at least once a year... you're gonna get a physical and we're gonna find out what's going. If something's wrong, we'll get on it real quick and get rid of it and that's it".

Subtheme 4.4. Fatalismo (God's Will)

4.4.A. Changing Attitudes of Affected Women At Different Stages of Diagnosis

...I think it's scary. I think when you think of cancer automatically, yes, you think of death and it's scary because at the very beginning once you get the news it's all a matter of well, what day does that person end.

...You know, when you first get that diagnose like that, you go like through different stages. In the beginning you get shocked and then after that, you get like angry a little bit and then after that you feel sorry for yourself because you think you are gonna die. You think, oh, this is it. I'm gone.

...At first the beginning of course I was very negative about it, I think, I thought I was gonna die immediately and then after that, I started working for the treatments, I realized even though it was hard, that there would be a bright side of the end and that I would be able to you know.

4.4.B. Generational Differences, Medical Advances and Education

...I think before I also heard as a child that the person who had cancer was to die, but now science has advanced a lot and here I am also in the final stage, which is the last stage where I am and I have it and I'm fine. Thank God I'm fine.

...Breast cancer is not a death sentence, we have a lot of possibilities for cure of cancer. Just as happened to my mother who was 50years old and is now super healthy (laughs) so no, cancer ... cancer is not a death sentence.

...But now the word cancer is different from before...before people were ashamed, now they believe they will beat it, it was once a taboo.

4.4.C. Belief in God Alleviating Fears about Death/Self-Talk

...I believe that everything in life happens for a reason. Because in my case, I said, well I have cancer, well God, I only want that you'd give me the strength to be better or whatever, take me fast, don't make me suffer, don't make me family suffer, anything. Then later, I realize that everything happens for something, because if I didn't have cancer, I didn't know the people that I knew and I help many people.

...When you are given the news that's something that automatically comes, that cancer is death, but when you get involved and you see the reality and it also indicates the belief when you believe in God you believe he has the control of everything, if I die well that was his will but I think that one should trust him and do what is humanly possible what you have to do.

Subtheme 4.5. Destino (Destiny)

4.5.A. Personal Control and Education

...I don't believe that it is out of my control. I know there are new drugs out there, I know there is treatment. So it's all about going to the right person, the right doctor, the right...counselor and getting information. Asking questions...if I am not sure of anything.

...Because even though cancer is something that you can't control, you can always control what you do about it like going to the doctor, doing what you have to do to even have that small chance of surviving it.

...I think that education is so important, because many women who are either religious, I'm religious too, but think "Oh my God, why you gave this to me?". But it has nothing to do with it.

4.5.B. Belief in Higher Power and/or God as a Coping Mechanism and Renewal of Faith

...I believe that if we pray sincerely, our destiny, it's the destiny that I should be healed, I will be healed. And if I'm not healed completely, but at least I'm able to function and be of help to someone else.

...I pray about it and tell Him how I feel about it. There's the blanket, there's a fatherly-daughter blanket that I feel it covers me and that's Him covering me putting His arms around me, letting me know it'll be okay.

Table 6

Focus groups and in-depth interviews results theme 5: additional barriers to participation in BRCA genetic counseling

Subtheme 5.1. Expense/Insurance Coverage Concerns

...I don't know the process...It's a little scary because you would think genetic testing, all you think about is dollar signs, insurance.... I'm not gonna be broke, do it and my insurance will help out in some way then, you know, it opens a door vault like, wow! Yeah okay, I'm gonna go for it.

...Well I've had two barriers, I was going to do it but the doctor who sent me told me it was not necessary, he said it was possible that insurance will not cover me and I would not insist without insurance, they said it was very expensive, if insurance is not going to cover me because I'm not going to do.

Subtheme 5.2. Fear of Finding Mutation if Pursued Testing

...I think Latino women were raised up with so much fear...they live with distortion of, and I'm gonna get it and I'll get it, and I'll find out when it's there.

Table 7

Focus groups and in-depth interviews results theme 6: influence of previous interactions with the healthcare system

Subtheme 6.1. Differential Treatment by Doctor/Provider: Language Barriers and Medical Terminology

...But if you are let's say Spanish and you don't know the terminology or you don't know, they (the doctors) think the person is ignorant. That's not the case because just because you have a language barrier does not make you ignorant.

...You know, a lot of doctors need to learn that not everyone went to medical school with all this medical terminology, you know. And I'm just like that. I'm not leaving here until I understand exactly and you always need to ask them a lot of questions. If you don't understand, ask a question. And if you don't understand that answer, break it down beyond that, you know, until I get it, until I understand it.

...I feel a lot of them (the doctors) are on a God trip. They feel like God and you know, they're too beyond us, the women, to begin with. Females, and then if you're Hispanic or minority in any way, you're screwed.

...It's one, you're confused, you don't know what's going on. And then, the other person neglects to tell you everything because they know you don't understand.

...When they look at you, it's the way they look at you, she's not gonna know what I'm saying.

Subtheme 6.2. Differential Treatment in Access

...Depending on the type of insurance you have, if you're limited to the type of doctors you have, you have no choice but to take that doctor and therefore, it makes it very hard for you to be able to find one that you truly feel comfortable with and trust. If you have more accessibility... that would be easier for you to find that one doctor that just like, fits you like a glove.

Subtheme 6.3. Use of Translators

...I do not feel comfortable, because the phone (translation) is not the same. When one interacts with people and often then is even a risk, because I once went to a doctor that I was explaining something and he did not understand, it seems that a person who was not fluent in Spanish and what I said he was misunderstood and something else, then that is very risky because it can confuse everyone.

...I can not complain because my son was my ears, my eyes and mouth, our communication is amazing. It is something exaggerated, he knew before what I had to say, then I never had a problem.

Subtheme 6.4. Mistrust of Medical Care/Expenses

...I felt in the past that doctors have sent me for tests just to get money. I feel that I was put through something...really bad, going you know, put fear in me for something...just so the doctor could put the claim in and I would never trust. It was terrible.

Table 8**Focus Groups and In-Depth Interviews Results Theme 7: Suggestions for Education Tool about BRCA Genetic Counseling for HBOC**

Subtheme 7.1. Preference for Visual Formats- Telenovelas/Television Programs

...They watch a lot of novelas...in the same way they watch all these shows like shows on TV and all that, that would be one of best ways to get Latinos interested or educated.

...But first it should come from television. Because everyone watches television, magazines and newspapers more than I think this is the best information to educate us all.

Subtheme 7.2. Importance of Bilingual Programs

...I think in both languages would be very interesting since the Hispanic community is growing a lot and many people who only speak Spanish are left behind because they lack information or do not understand what you're talking about. If we want healthy communities... to prevent illnesses in the United States...that should be covered by these programs in as many different languages as possible.

Subtheme 7.3. Ensuring Confidentiality

...A lot of people worry about privacy...when their information is going to come out of this. So if they know it's confidential, you see information for yourself, you could pass it to family or friends, you know, and there's nothing, is not going to go to anywhere else.

Subtheme 7.4 Education Through Human Interaction

...If you're actually there and people shove it in your face, then you might be more likely to read it and want to educate yourself on it than if it's just sitting there, you know? It becomes more real because then you're like "wow, you know, this woman is taking an interest in me".

...A good way of getting information out there is to have a women's fair...somebody that's out there giving this kind of information so that people can become aware.