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# Interest and Beliefs About BRCA Genetic Counseling Among At-Risk Latinas in New York City

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## Abstract

**Background—**Latinas are less likely to use genetic services (counseling and testing) for hereditary breast and/or ovarian cancer risk compared to other ethnic groups. Meanwhile, little is known about barriers to genetic counseling among Latinas at increased risk of inherited breast cancer.

**Methods—**A two-phase pilot study was conducted to examine interest, barriers and beliefs about BRCA genetic counseling among at-risk Latinas in New York City and explore the potential for developing a culturally-tailored narrative educational tool for use in future studies. Phase 1 included quantitative telephone interviews (*N*=15) with bilingual participants with a personal diagnosis at a young age and/or family history of breast and/or ovarian cancer. Quantitative results informed development of a narrative prototype educational presentation viewed by a subset of participants (*N*=10) in Phase 2 focus groups.

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**Results—**Despite barriers, including lack of awareness/knowledge, concerns related to learning cancer risks of family members, and concerns about cost/health insurance, participants reported positive attitudes, beliefs and interest in learning about BRCA genetic counseling. Further, significant increases in knowledge were demonstrated from pre-post presentation ($p$=0.04).

**Conclusion—**There is an unmet need to educate at-risk Latinas about BRCA genetic counseling. Culturally-tailored educational materials including narratives may increase knowledge about BRCA genetic counseling among this underserved group. The effectiveness of these approaches should be tested in future research with larger samples.

### Keywords

Genetic counseling; BRCA; Breast cancer risk; Latinas/Hispanic women; Cancer genetic services; Access to genetic services; Beliefs; Cross-cultural education; Knowledge

## Introduction

### Hereditary Breast and Ovarian Cancer (HBOC) and BRCA Genetic Counseling

Hereditary forms of breast and ovarian cancer (HBOC), associated with germline mutations in *BRCA1* and *BRCA2* genes, account for 5–10% of all breast cancers and 10% of all ovarian cancers in the general population (Claus et al. 1996; Miki et al. 1994; Wooster et al. 1995). Presence of these mutations is 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). The U.S. Preventive Task Force (Nelson et al. 2005) thus recommends that all high-risk individuals, based on family history suggestive of HBOC, should undergo BRCA genetic counseling. Considered a prerequisite to genetic testing (ASCO Policy Statement Updated 2003), BRCA genetic counseling provides women with information related to their 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. Ultimately, BRCA genetic counseling helps women make informed decisions about their health care, providing potentially life-saving cancer risk management information to prevent and/or detect cancer at its earliest, most treatable stage, even if an individual chooses not to undergo genetic testing (ASCO Policy Statement Updated 2003; Schneider 1997).

### Disparities in Use of BRCA Genetic Counseling and Testing for HBOC in Latinas

Despite the known benefits of BRCA genetic counseling and subsequent testing for HBOC risk, there are great disparities in use of these services (Hall and Olopade 2006; Hall and Olopade 2005; Olopade 2004). Less than 10% of the first 10,000 individuals undergoing BRCA genetic testing (representing the consecutive number of individuals analyzed by Myriad Laboratories over a 3-year period for breast and/or ovarian cancer-related gene mutations) were from traditionally underrepresented racial/ethnic groups, with estimates as low as 1–4% among Latinas (Chen et al. 2002; Frank et al. 2002; Noll et al. 2007). ‘Latino’ is defined in this pilot study as a person of Latin, Central or South American origin, regardless of race; ‘Latina’ therefore refers to women of this classification. Such disparities are especially striking, as breast cancer is the most commonly diagnosed cancer and leading cause of cancer death in Latinas, the fastest growing minority group in the U.S. (U.S. Census Bureau News 2004; U.S. Census Bureau 2008; American Cancer Society 2006). Latinas are also 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 non-Latina White women (American Cancer Society 2006; Lantz et al. 2006), even when controlling for access to health care (Watlington et al. 2007). Furthermore, despite lack of official population estimates, studies suggest that the prevalence levels of *BRCA1/2* gene mutations in Latinas are at least comparable to what is seen in other ethnic groups (Frank et al. 2002; Weitzel et al. 2005).

## Need for Information about BRCA Genetic Counseling in Latinas

Although previous research has examined interest in cancer genetic services in non-clinic Latino populations (Ricker et al. 2007; Ramirez et al. 2006) as well as identified some potential barriers to genetic testing for cancer risk within ‘normal’ risk Latinas (Wideroff et al. 2003; Thompson et al. 2003; Singer et al. 2004; Vadaparampil et al. 2006; Heck et al. 2008; Sussner et al. 2009), such factors have yet to be explored in relation to genetic counseling, particularly among at-risk Latinas. Meanwhile, previous research by members of our research team with African American women suggests there may be unique barriers to counseling, including negative emotional reactivity (such as feelings of fear, despair and hopelessness related to the possibility of having a genetic mutation) and concern about stigmatization, and thus warranting further exploration of BRCA genetic counseling perceptions (Thompson et al. 2002). Despite the obvious need to focus on genetic counseling, to date, there are only two known studies related to genetic counseling issues within high-risk Latinas, with both studies including women who 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). Furthermore, to our knowledge there are no published educational tools designed to educate at-risk Latinas about BRCA genetic counseling. Thus, the goal of this two-phase pilot study was to serve as a critical first step by examining interest and beliefs about BRCA genetic counseling among at-risk Latinas in New York City as well as exploring the potential for developing a culturally-tailored narrative educational tool about BRCA genetic counseling for use in future studies with this underserved population. Phase 1 included quantitative telephone interviews ($N$=15) with bilingual Latina participants with a personal diagnosis at a young age and/or family history of breast and/or ovarian cancer. Quantitative results then informed development of a narrative prototype educational presentation that was viewed by a subset of participants ($N$=10) in two focus groups in Phase 2.

## Conceptual Framework

The conceptual framework informing the quantitative telephone survey used in Phase 1 of this study was the Integrative Model of Behavior Prediction (Fishbein and Yzer 2003) that 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 and Ajzen 1975). This model recognizes that many factors, including perceived barriers and facilitators, underlie health beliefs and intention to perform health behaviors. Further, these factors are a function of many background influences, including social and cultural factors. In this small study, we focused on examining perceived barriers and facilitators to the behavior of BRCA genetic counseling uptake among at-risk Latinas.

Meanwhile, Phase 2 of this study was informed by previous research examining the use of narrative forms of communication for improving health disparities via health behavior change education. The theories underlying narrative forms of communication incorporate both a transportation imagery model whereby real-world judgments are influenced by the integration of knowledge obtained from narrative worlds (Green and Brock 2000), in combination with social cognitive theory (Bandura 1977) in which perceived self-efficacy may be increased as individuals are more likely to perform a behavior if they see it reinforced by a role model performing the desired behavior. Such narrative forms may hold particular relevance and applicability in Latinas, since there may be low health literacy levels, high levels of medical distrust and different preferred sources of lay epidemiological information in this population (Kreuter et al. 2007). For example, in a qualitative study of women offered amniocentesis due to a positive blood screening, Latinas were more likely to consult and rely on extensive networks of resources for information including the experiences of family, friends, neighbors and local lay experts rather than seek information from libraries, self-help books and the internet, as is primarily utilized in middle class European American or White populations (Browner and Preloran 1999). Further, narrative approaches may be particularly suitable for Latinos given these approaches move away from presentation of factual information alone and rather, complement this information by incorporating more culturally appropriate values, beliefs and norms and utilizing role models of similar ethnicity and background through visual formats such as oral traditions or personal narratives (Borrayo 2004; Green 2006). Such formats may be particularly appealing within the context of genetic counseling for Latinos given the collectivist nature of Latino communities and strong value placed on extended family and interdependence (*familismo*) (Penchaszadeh 2001; Perez-Stable 1987; Perez-Stable et al. 1992).

# Methods

## Recruitment

As part of our recruitment for ongoing studies in breast surgery clinics at Mount Sinai, potential participants completed a family history form and indicated if they were interested in participating in future research studies. Using this information, the bilingual Project Investigator (PI) contacted eligible individuals whom had previously given us permission to reach them by telephone to explain the pilot study and to confirm that they met eligibility criteria including: women self-identifying as Hispanic/Latina, at least 18 years of age, never having undergone BRCA genetic counseling, 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, as determined by having at least one first degree relative with breast and/or ovarian cancer. The PI explained to eligible participants that they had the option to participate in both the telephone interview and focus groups, as long as the telephone interview was conducted before the focus group session. This condition was set so as to not have the educational focus group session unduly influence women's beliefs and attitudes that were assessed in the telephone interview. Otherwise, eligible participants could elect to participate in one or the other component alone. If an eligible participant chose to participate in a telephone interview, the PI obtained a waiver of signed consent over the telephone and scheduled a date and time for the telephone interview. If an eligible participant chose to participate in the focus groups, the PI explained that the group would be scheduled by telephone at a later date according to a mutually agreed upon time of the focus group moderator and participants. All participants were asked about their preference for English or Spanish language for conducting of either the telephone interviews or focus groups prior to their participation and told that their preference would be met. Consent was obtained at the beginning of each focus group session prior to starting any study procedures or collection of information in the session. Given that this was a pilot study, the PI aimed to recruit a total of 15 participants for Phase 1, of which all participants were also considered eligible to participate in Phase 2. All study procedures were approved by Mount Sinai's Institutional Review Board.

## Phase 1: Quantitative Telephone Interviews

All telephone interviews were conducted by the bilingual PI and lasted no longer than 30 min. Participants received $20.00 for completing the telephone interview.

**Measures—**Measures queried in the quantitative telephone interviews were selected to capture key components of our conceptual model, the Integrative Model of Behavior Prediction (Fishbein and Yzer 2003).

These measures included:

**Sociodemographic and Health Care Related Information—**Sociodemographic and health care related information included: participants' age, education, number of children, income, marital status, employment, religion/spiritual faith, primary care doctor, and insurance status.

**Family and Personal History Of Cancer—**Information about participants' family and personal history of breast and/or ovarian cancer was included in the form of a family history questionnaire.

**Acculturation Level—**Recognizing that Latinos represent complex, diverse groups of individuals and as such, there is a need to better understand the heterogeneity of Latino experience as it relates to health beliefs (Abraido-Lanza et al. 2006), we included a measure of acculturation level in the Phase 1 questionnaire. Traditionally defined as the degree to which the majority culture is adopted by a minority culture (Suarez 1994), acculturation represents the process of ethnic groups exchanging cultural elements and complexes (Abraido-Lanza et al. 2006). Acculturation has previously been found to be associated with awareness and familiarity about genetic testing for cancer risk among normal risk Latinas (Vadaparampil et al. 2006; Heck et al. 2008; Sussner et al. 2009). The role of language acculturation may be particularly influential in relation to genetic counseling, as counseling by its definition represents a communication process (Penchaszadeh 2001). In this pilot study, acculturation was measured by Marin's 12-item acculturation scale previously validated for use in Latino populations, incorporating language use, media use and ethnic/social relations (Marin et al. 1987). Participants responded using a four point Likert scale. Responses were summed and then averaged across the 12 questions. The mean acculturation level ranged from a possible 1–4, with higher score meaning higher acculturation. Reliability of the items in the acculturation scale was considered good (Cronbach's $\alpha$=0.84). Other indicators of acculturation collected included nativity, interview language and country of origin.

**Medical Mistrust—**Following previous research by members of our research team indicating that medical mistrust medical may be related to concerns about abuses of genetic testing for cancer risk (Thompson et al. 2003), we included the Group-Based Medical Mistrust Scale (GBMMS) in the Phase 1 questionnaire. This 12-item scale includes questions related to suspicion of mainstream health care systems and health care professionals and the kind of treatment provided to individuals of the respondent's ethnic or racial group (Thompson et al. 2004). Participants responded using a Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree), with total medical mistrust score computed by adding all responses (score range=12–60). The internal reliability of this scale was considered good (Cronbach's $\alpha$=0.76).

*Perceived risk of carrying a BRCA mutation* was assessed with one question: “How likely do you think it is that you carry a BRCA1/2 mutation?” rated on a 5-point Likert scale of “not at all” to “extremely likely”.

*Intention to undergo genetic counseling* was assessed with one question: “How likely do you think it is that you will undergo genetic counseling within the next 6 months?” with response options ranging from 1 (not at all likely) to 5 (extremely likely) (Sheeran et al. 2001; Sheeran and Orbell 2000).

*Awareness of genetic counseling for cancer risk* was measured using a 4-item questionnaire (high = more familiarity) that asks participants to assess how much they have heard or read about genetic counseling for inherited disease, cancer and specific cancers (breast and colon). Total awareness score was computed by adding all responses (score range=4–16). Items in this scale had very good internal reliability (Cronbach's $\alpha$=0.94).

*Attitudes about BRCA genetic counseling* were assessed with an 8-item questionnaire measuring participants’ evaluations of genetic counseling along specific adjectives (worthwhile, worrying, reassuring, uncomfortable, wise, healthy, unpleasant, important) (Sheeran and Orbell 2000; Sheeran et al. 2001). Total attitudes score was computed by adding all responses (score range=8–40 where high = more positive attitudes). Internal reliability of scale items was good (Cronbach's $\alpha$=0.75)

*Behavioral beliefs about BRCA genetic counseling* were assessed by a 15-item questionnaire developed by the research team, based on a measure used in our previous study to assess attitudes (both benefits and barriers) about genetic counseling among African-American women (Thompson et al. 2002). Total behavioral beliefs score was computed by adding all responses (score range=15–75 where high = more positive behavioral beliefs). Internal reliability of this scale was adequate (Cronbach's $\alpha$=0.55).

*Familiarity with Computer/DVD formats* was assessed including questions about use and access to computer, internet and DVD sources.

### Phase 2: Explore the Potential for Developing a Culturally-Tailored Narrative Educational Presentation-Focus Groups

Quantitative results obtained in Phase 1 were used to explore the potential for developing a culturally-tailored narrative education tool. As such, following Phase 1 telephone interviews we created an audio-led prototype presentation that was shared with participants in Phase 2 focus groups to obtain feedback regarding interest in development of such a tool. The information included in this prototype presentation was largely influenced by results obtained in Phase 1 telephone interviews (see specific details regarding development process of prototype presentation in Results). The prototype presentation was developed over a 1 month period, following completion of telephone interviews. Two focus groups were then conducted with a subset of participants from Phase 1 ($N$=10; 5 participants per group) in order to pre-test the prototype presentation. The prototype presentation was approximately 20 min in duration (powerpoint screens with accompanying audio) and contained two narrative, yet fictional accounts of Latina women who shared personal accounts of their experiences undergoing genetic counseling for HBOC. The content and key background characteristics of these women and their stories presented was largely influenced by Phase 1 results (description of full development process in Results). In story one, an unaffected, 30 year old, immigrant Latina woman described her decision to undergo genetic counseling due to a strong family history of breast and ovarian cancer including an affected sister who had recently tested positive for the BRCA mutation. In story two, a postmenopausal (60 year old), U.S. born Latina breast cancer survivor who had been diagnosed before 50 years old with no other family history told her story of deciding whether to undergo genetic counseling. Focus groups were moderated by two of the authors (KMS and LJ), researchers with extensive experience and training in qualitative methods. Focus group sessions were digitally-recorded, and lasted approximately 60–90 min, including the 20 min educational prototype presentation and feedback about the presentation. In addition, all focus group participants completed a quantitative baseline sociodemo-graphic form, a general feedback/ evaluation of the presentation questionnaire (including three questions) after viewing the presentation, and a knowledge about BRCA genetic counseling questionnaire using an 8-item scale (scored 1–5; total correct score=40), assessed both before and after viewing the presentation. Responses to the items were summed and mean knowledge score and percentage score before and after the presentation computed. The mean difference in knowledge score (pre-post) and corresponding percentage difference score were also computed. The internal reliability of the knowledge scale was very good (Cronbach's $\alpha$=0.94). For the purpose of quality control, all sessions were digitally-recorded, with the research tapes stored in a locked cabinet in the investigators' file at Mount Sinai following completion of the sessions. Participants received $50.00 as compensation for their time.

### Analyses

Basic descriptive statistics were computed for all measures in the quantitative telephone interview and quantitative measures queried in the focus groups. Fisher's exact tests were performed to compare sociodemographics of women who participated in focus groups to those who did not. SAS software package v.9.1.3 was used to conduct statistical procedures. Although the primary purpose of the focus groups was to pre-test the narrative prototype educational presentation, we also reviewed the audiotapes for emergent themes discussed by participants during the sessions.

## Results

### Sociodemographics

Baseline sociodemographic characteristics of study participants from Phases 1 and 2 are reported in Table 1. Meeting our intended goal for this pilot study, a total of 15 quantitative telephone interviews were completed in Phase 1 and two focus groups were then completed with a subset of participants (*N*=10 with 5 participants per focus group) in Phase 2. There were no statistical differences in socio-demographic characteristics between women who participated in the focus groups (*N*=10) and those who did not participate (*N*=5). For this reason, we summarize results across all participants (*N*=15) here. Of participants in Phase 1, 40% (*N*=6) of participants had a personal diagnosis of breast cancer at a young age (<55 years old) only, 40% (*N*=6) had a family history only defined as at least one first degree relative diagnosed with either breast and/or ovarian cancer, and 20% (*N*=3) had both a personal and family history of breast and/or ovarian cancer. The majority of participants had never been referred to BRCA genetic counseling by their physicians (73.3%, *N*=11). Of those who had been referred to but did not undergo BRCA genetic counseling (*N*=4), half of these women (*N*=2) had both a personal and family history of breast and/or ovarian cancer, one woman had personal history alone and one woman had family history alone. Participants were split between those foreign born (46.7%, *N*=7) and born in the U.S. (53.3%, *N*=8). Of foreign born participants, most were Puerto Rican (62.5%, *N*=5). The mean acculturation level of participants was 3.0 (s.d.=0.6), meaning participants were categorized as above “bicultural” (score=2.5). The majority of telephone interviews were conducted in English (73.3%), although all participants reported being fully bilingual in Spanish and English. Both focus groups were conducted in English in accordance with participant preference. The mean age of participants was 53.4 (s.d.=9.7), with the majority not currently married or living with a partner (80%, *N*=12) and not working (73.3%, *N*=11). The mean number of children was 2.5 (s.d.=1.5), more than half of participants had obtained at least a high school diploma (60%, *N*=9) and made less than $20,000/ year (60%, *N*=9). All participants reported having health insurance, with most having public insurance (Medicare/Medicaid) (66.7%, *N*=10) and all having a primary care doctor they reported seeing regularly. The mean total medical mistrust level was relatively low (*M*=24.2, s.d.=11.5) and most identified themselves as being of Catholic faith and/or religion (60%, *N*=9).

### Phase 1 Results: Quantitative Telephone Interviews

Main results from Phase 1, quantitative telephone interviews are reported in Table 2.

**Awareness of BRCA Genetic Counseling—**The majority of participants reported they had heard or read ‘a fair amount’ or ‘a lot’ about genetic counseling for inherited disease, meanwhile about half of participants said they had heard or read ‘almost nothing’ or ‘relatively little’ about genetic counseling for cancer, in general or for BRCA genetic counseling for breast cancer, specifically. The overall mean awareness about genetic counseling score among participants was 9.9 (s.d=3.8) (scale 4–16, where high = more awareness).

**Perceived Risk of Carrying a BRCA Genetic Mutation, Interest and Intention to Undergo BRCA Genetic Counseling—**After hearing a short description about BRCA mutation risk and counseling, most participants in Phase 1 believed they were ‘likely’ or ‘very likely’ to carry a *BRCA1/2* mutation and reported that they would be ‘very likely’ or ‘extremely likely’ to make an appointment for BRCA genetic counseling in the next 6 months.

**Attitudes About BRCA Genetic Counseling—**Participants in Phase 1 reported largely positive attitudes about genetic counseling for breast cancer risk (mean=33.1, s.d.=5.3 on 8–40 scale), with all participants agreeing that getting genetic counseling for breast cancer would be ‘healthy’ and ‘important’, almost all agreeing it would be ‘worthwhile’ and ‘wise’ and most agreeing that it would be ‘reassuring’. Meanwhile, close to half of participants believed genetic counseling would be ‘worrying’ and a few participants believed genetic counseling would be ‘uncomfortable’ or ‘unpleasant’.

**Behavioral Beliefs About BRCA Genetic Counseling—**Benefits of BRCA genetic counseling included that it would help them initiate discussions with family members about cancer and would help reduce fear and concerns about developing or having a recurrence of breast cancer for themselves. The mean total behavioral beliefs score was fairly high (M=63.5, s.d.=7.3, range=15–75, where high = more positive behavioral beliefs). Barriers to BRCA genetic counseling included distress caused by talking to a genetic counselor and worry related to learning cancer risks of family members, cited by more than half of participants In addition, the majority of participants were concerned that getting genetic counseling could jeopardize their health insurance. All participants desired more information about what genetic counseling could offer them.

**Familiarity with DVD Formats and Information Preferences—**All participants (100%) reported having a DVD player at home, while in comparison only about a half (53.3%) reported having a personal computer at home with internet access. While the majority (80%) of participants reported they would be interested in learning more about genetic counseling for breast cancer using a computer/web-based program, all participants (100%) were interested in learning via a DVD format. In addition, participants reported more use/time spent using a DVD player per week compared to computer/internet use.

### Phase 2 Results: Explore the Potential for Developing a Culturally-Tailored Narrative Educational Tool for BRCA Genetic Counseling through Focus Groups

**Prototype Development—**As outlined in the methods, results from Phase 1 informed development of a narrative educational prototype presentation to be pre-tested in Phase 2 focus groups. This educational tool was intended as a prototype, rather than final product, given the pilot nature of this study.

**Prototype Format—**The prototype presentation was designed to suit a DVD format, given previous literature demonstrating that DVD style formats which can incorporate graphics, pictures and text with voice-overs may be particularly effective for learning among individuals with low health literacy (Hahn et al. 2004; Houts et al. 2006), a widespread problem in the U.S. which is more likely in individuals who belong to racial/ethnic minority groups, such as Latinos (Davis et al. 2002; Williams et al. 2002). Further, literature suggests DVDs are familiar and accessible technology as indicated by the national survey by the Pew Research Center for the People and the Press (2006) reporting that 86% of American households own a DVD player. Our pilot study results from Phase 1 above further supported this point regarding the accessibility of DVD-style formats.

**Prototype Content, Length and Presentation of Narrative Stories—**Following results obtained in Phase 1, the content of the narrative educational prototype presentation was designed to specifically address key areas of concern among participants in our sample, including low awareness and knowledge, potential worry and distress, concern about learning cancer risk of family members and questions about health insurance/cost related to BRCA genetic counseling. Given the need to balance having a presentation which we believed was a manageable length (20 min) along with reflecting the potential diversity of women's experiences who are at increased risk of hereditary breast and/or ovarian cancer, we chose to include two stories in our prototype presentation. This decision was based primarily on our ability to capture what we determined to be key socio-demographic features which differed amongst participants who had completed Phase 1 of the pilot study. First, as all participants were considered at increased risk of breast and/or ovarian cancer, the two stories would be told from women who were also at increased risk. However, as participants in Phase 1 were split over whether their risk of breast/ovarian cancer was based on personal history and/or family history, we chose to include one woman who had a family history alone (story 1) and one woman who was a breast cancer survivor (story 2), with the diagnosis made before she was 50 years old, as with the target women in this pilot study. Further, since participants in Phase 1 were split over whether they were born in the U.S. (70%) versus foreign born (30%), in story 1 the woman was foreign born, while in story 2 the woman was born in the U.S.. Similarly, as the mean acculturation level of participants in Phase 1 was 3.0, reflecting that participants were categorized as above ‘bicultural’ levels, issues related to adapting to life in the U.S. were discussed in story 1. As all participants in Phase 1 telephone interviews had reported a strong religious identification (60% Catholic, 20% Jehovah's Witness and 20% other-Christian), we incorporated discussion of religious influences into both stories.

Main results from Phase 2, focus groups are reported in Table 3.

**General Evaluation and Feedback of Narrative Educational Prototype Presentation—**All focus group participants (100%) reported that they 'liked' the information in the narrative prototype presentation, they found the information 'helpful' (100%), and reported that they would want an educational DVD to share with other at-risk women about this topic (100%). At the completion of each focus group, all participants expressed an interest for information related to how they could obtain BRCA genetic counseling and were provided the telephone number of a free referral service for genetic counseling at Mount Sinai.

**Knowledge About BRCA Genetic Counseling—**Results found that the mean knowledge score among focus group participants before viewing the narrative prototype presentation was 29.4 (s.d.=9.5; min=14, max=38 out of 40 possible points), corresponding to a score of 73.5% correct. After viewing the presentation, the mean knowledge score was 36.1 (s.d.=1.9; min=33, max=38 out of 40 points; score=90.3% correct), resulting in a significant increase in knowledge, from pre-post presentation among participants (mean difference pre-post=6.7; s.d.=0.06; *p*=0.04; difference in score=16.8%).

**Emergent Themes—**Although the main purpose of Phase 2 was to develop and pre-test the narrative educational prototype presentation, there were a few emergent themes that arose from the focus group discussions. First, participants' responses to the narrative approach of the presentation were largely positive, including many who believed that the narrative stories may have allowed participants to easily identify with or relate to the women in the presentation. Second, participants cited many barriers related to BRCA genetic counseling which confirmed findings in Phase 1, including lack of awareness and knowledge, concerns about learning cancer risk of other family members and confusion over whether health insurance would cover the cost of genetic counseling. Related to these barriers, participants expressed much interest in learning more about BRCA genetic counseling, specifically how to address their practical and/or logistical-related concerns. Finally, additional barriers raised in the focus group discussions which were not directly assessed in Phase 1 included whether genetic counseling was consistent with participants' religion and faith, competing priorities and lack of time, including childcare responsibilities and concern about health of other family members above concern for one's own health.

## Discussion

Despite disparities in the use of genetic services for HBOC (Hall and Olopade 2006, 2005; Olopade 2004) and a growing body of literature examining beliefs about genetic testing for cancer risk in Latinas (Wideroff et al. 2003; Thompson et al. 2003; Singer et al. 2004; Heck et al. 2008; Vadaparampil et al. 2006; Sussner et al. 2009), this is the first known study to examine interest and beliefs among at-risk Latinas who have not previously undergone BRCA genetic counseling. Since BRCA genetic counseling is the recommended precursor to genetic testing and can provide women with potentially life-saving information even if an individual never chooses to undergo genetic testing (ASCO Policy Statement Updated 2003; Schneider 1997), it is critical to understand factors related to the use or underuse of genetic counseling. Further, previous research by members of our team conducted with African American women indicates that minority populations may face unique barriers to BRCA genetic counseling (Thompson et al. 2002). Study results presented here further corroborate this research, indicating that at-risk Latinas in NYC face a range of perceived barriers to BRCA genetic counseling, including lack of awareness/knowledge about the benefits of genetic counseling, worry and distress related to learning cancer status of family members, as well concerns about cost/health insurance. Lack of knowledge and awareness have previously been found to be barriers to genetic testing among Latinos (Heck et al. 2008), and previous studies, in African Americans have found that emotional and/or psychological barriers such as worry and distress may hinder use of genetic counseling and testing (Thompson et al. 2002; Donovan and Tucker 2000; Matthews et al. 2000; Hughes et al. 2003). Amongst Latinas, previous research also suggests that they may be more likely to anticipate feeling ashamed if genetic testing results are positive compared to African Americans or non-Latina Whites (Thompson et al. 2003), which may be related to concerns about family members' cancer status. Meanwhile, the findings about insurance and cost concerns related to genetic counseling corroborates previous research which suggests that Latinos may have serious concerns about lack of resources including finances/insurance for genetic testing (Singer et al. 2004).

However, our study results suggest that despite the multitude of apparent perceived barriers which could deter interest in BRCA genetic counseling, among our small sample of at-risk Latinas in NYC, participants held largely positive attitudes and beliefs and were overwhelmingly interested in learning more about the benefits of BRCA genetic counseling. Such results may contrast with previous findings of our research team related to genetic testing, which found that Latinas in a community-based sample reported they did not have enough time for genetic testing and there was low priority placed on genetic testing because most women currently felt healthy (Thompson et al. 2003). However, it is likely that interest level and intent to undergo testing may have been largely driven by the fact that participants in our current study were considered at-risk or relatively high risk, compared to community-based samples previously examined (Thompson et al. 2003). Previous research with Latinas who had undergone genetic risk assessment found that they reported relatively high self-efficacy (Lagos et al. 2008). One of the emergent themes from focus group discussion indicates that participants were most interested in obtaining practical and logistic-related information about how to undergo genetic counseling and how to make sure their insurance would cover the cost or not be jeopardized if they underwent genetic counseling. This finding suggests that while financial barriers do not appear to directly inhibit interest or desire to obtain genetic services, it is possible that such barriers may curtail actual use.

In addition, another emergent theme from qualitative focus group results suggest there may be unique sociocultural influences which may impact use of BRCA genetic counseling within at-risk Latinas in NYC, including questions about compatibility of genetic counseling with participants' religion and faith and competing priorities such as taking care of one's family above taking care of one's own health. Although not previously addressed as these beliefs relate to BRCA genetic counseling, specifically, prior research related to prenatal genetic counseling among Latinas has echoed the importance of cultural beliefs and values, including a strong value placed on the family (both nuclear and extended relatives) in daily life and emphasis of interdependence over independence (*familismo*) (Penchaszadeh 2001;

Perez-Stable 1987; Perez-Stable et al. 1992), consideration of the role of religiosity in health matters, specifically a strong belief in God's will and the belief that the diagnosis of cancer may be equated with a certain death (*fatalismo*) (Perez-Stable 1987) as well as the importance of destiny (*destino*) (Florez et al. 2009). Future research should address the role of these sociocultural factors more specifically as they relate to beliefs and attitudes about BRCA genetic counseling.

Furthermore, study results from focus group sessions where women viewed the narrative prototype presentation about BRCA genetic counseling indicate that at-risk Latinas in NYC may be especially interested in a narrative educational format for learning more about genetic counseling, as participants held overwhelmingly positive attitudes about this narrative style. Knowledge scores from pre-post presentation demonstrated that women's knowledge about BRCA genetic counseling increased as a result of only a brief, 20-minute exposure to these stories. Although this is the first known pilot study to explore the potential for developing a culturally-tailored narrative educational tool for BRCA genetic counseling in Latinas with increased risk of breast and/or ovarian cancer, specifically, our results fall largely in accordance with recent research which underscores the use of narrative forms of communication as tools for cancer prevention treatment and control. Narrative forms may serve as a complement to more traditional didactic styles of health communication which primarily rely on reason, providing factual information and evidence, alone (Kreuter et al. 2007). In line with the transportation imagery model of narrative communication (Green and Brock 2000) and social cognitive theory (Bandura 1977), our study results suggest that the two narrative stories of Latina women describing their personal accounts of experiences undergoing BRCA genetic counseling may have served as such ‘transporting’ narratives complementing the presentation of factual information, as focus group participants expressed that they felt they could relate to and easily identify with the women. These results may reinforce previous research which demonstrates how narratives ultimately can provide direct role models for behavior change, which may be particularly applicable to cancer prevention treatment and control health education efforts, including increasing screening and treatment seeking behavior (Green 2006).

Although there are no known studies to date which evaluate the effectiveness of narrative interventions for increasing BRCA genetic counseling in at-risk Latinas specifically, a recent educational intervention involving a 15-minute storyline using non-scientific images and language for a low-literacy, multi-ethnic, non-high risk population found increases in knowledge about BRCA inheritance, associated risk and risk-reducing options (Lee et al. 2009). Furthermore, there are promising results found from a few narrative interventions which aim to increase breast cancer screening within Latinas. A telenovela story-line to educate Spanish-speaking viewers in the U.S. about breast cancer and behavioral intentions to get screened for breast cancer demonstrated that call attempts to a cancer information hotline significantly increased after 9 pm on the nights a public service announcement (PSA) about breast cancer featuring the number aired during the telenovela. Meanwhile, the telenovela also increased knowledge in relation to some of the main cancer-related messages, specifically in individuals who indicated they identify with characters in Spanish-language television shows (Wilkin et al. 2007). In another study, a culturally tailored interactive soap opera viewed via computer was found to increase breast cancer screening knowledge and beliefs among underserved Spanish-speaking Latinas (Jibaja et al. 2000. These results highlight the need for more in-depth studies in the future, including randomized control trials to assess the relative effectiveness of narrative versus non-narrative educational interventions in Latino groups.

Several limitations to the existing study should be noted, with most concerns related to our relatively small sample size. However, as this was a pilot study with limited funds, by definition, it is important to note that this small sample size was, in fact, deliberate and considered sufficient given our stated goals. Despite potential limitations raised by a small sample, given that Latinas are grossly underrepresented in genetic counseling and there is currently no known information regarding interest and beliefs about BRCA genetic counseling among at-risk Latinas who have not previously undergone genetic counseling, this pilot study was considered a crucial first step.

At the same time, we acknowledge possible limitations as follows: 1) The generalizability of study results may be limited. 2) There remain questions over the external validity of quantitative results. For example, even though there were no statistical differences in sociodemographic characteristics of the participants, such analyses may not be reliable or may be unstable due to the small sample. 3) There may be potential bias introduced by the fact that respondent data from Phase 1 were used to develop the intervention conducted among a subsample of these women in Phase 2. 4) Given that the pilot nature of this study prohibited us from first confirming the findings of Phase 1, before exploring the potential to develop our prototype educational tool in Phase 2, there may be many confounding factors which could influence the efficacy of the educational tool. Future research with larger populations should explore the role of such possible confounding factors, including low literacy, medical mistrust and preferred sources of lay information on efficacy of the model. 5) There may be concerns that intention to undergo genetic counseling was measured in this pilot study over a very brief time, rather than measuring uptake of genetic counseling directly. However, given the intended pilot nature of this study and the fact that typically assessments about screening are measured in this fashion, we recognize the importance of measuring intention, alone. 6) Although study results demonstrated a significant change in knowledge about BRCA genetic counseling, the time frame between pre- and post-test results was brief and it is unknown from this pilot study whether longer term retention of the information occurred. Given this was a pilot study, we had no intention to evaluate the long-term effectiveness of the prototype presentation that was shared with participants in Phase 2 focus groups. However, the previously mentioned Lee et al. study evaluating the use of an educational tool (15 min story presentation) for cancer risk with a non-high risk multi-ethnic population found increased knowledge about breast cancer genetics without increasing anxiety or cancer worry over the long term (Lee et al. 2009), suggesting that larger more long-term studies may find retention of such knowledge. In light of these limitations, we strongly recommend that pilot study results presented here will be used to better inform future studies conducted with larger sample sizes, including development of culturally-appropriate narrative educational tools as well as randomized control trials to test the effectiveness of these much-needed educational tools for this grossly underserved population.

Finally, there may be limitations related to the composition of our sample, which may provide suggestions for how to improve such recommended future studies. For one, the majority of women in the study (80%) considered themselves of Puerto Rican ethnicity. As mentioned earlier, recent research demonstrates the importance of examining the heterogeneity encompassed within the term ‘Latino’ and differences across subgroups in health outcomes (Abraido-Lanza et al. 2006). Furthermore, acculturation level has previously been found to influence beliefs about genetic testing for cancer risk in Latinas (Vadaparampil et al. 2006; Heck et al. 2008; Sussner et al. 2009). It is thus likely that acculturation similarly affects beliefs related to genetic counseling and therefore warrants further examination in future studies. Second, the sample may be strongly biased by the fact that women who were recruited were already a part of the health care system, being primarily recruited through clinics or existing studies and with all reporting some form of health insurance and use of a regular primary care doctor. Finally, as cost and concerns about health insurance appeared as main barriers to genetic counseling even among these women, it is critical that future studies attempt to examine the potentially more severe access-related barriers that other Latina populations may face related to the use of BRCA genetic counseling, including lack of insurance as well as how undocumented or illegal status impacts delivery of genetics services and intention to use such services.

## Conclusions

Ultimately, study results help fill a gap in existing literature by uniquely identifying interest and beliefs about BRCA genetic counseling among at-risk Latinas in NYC as well as pre-testing and receiving critical feedback on a narrative prototype education presentation to inform the development of future educational interventions. By better understanding these factors, public health practitioners will be able to design and test the effectiveness of such culturally-appropriate and sensitive education tools and interventions to increase participation in genetic services among underserved, at-risk Latinas most in need of these services in the future.

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## Table 1

Baseline Sociodemographic Characteristics of Study Participants-telephone Interviews and Focus Groups

| **Sociodemographics-telephone interviews (Focus Groups)** | **N**[a] | **%**[a] | **Sample mean (SD)** [a] |
|---|---|---|---|
| Breast/Ovarian cancer history | | | |
| Personal history only[b] | 6 (4) | 40.0 (40.0) | n/a |
| Family history only[c] | 6 (4) | 40.0 (40.0) | n/a |
| Both personal and family history | 3 (2) | 20.0 (20.0) | n/a |
| Had referral to physician for BRCA genetic counseling | | | |
| Yes | 4 (4) | 26.7 (40.0) | n/a |
| Personal history only | 1 (1) | 25.0 (25.0) | n/a |
| Family history only | 1 (1) | 25.0 (25.0) | n/a |
| Both personal and family history | 2 (2) | 50.0 (50.0) | n/a |
| No | 11 (6) | 73.3 (60.0) | n/a |
| Acculturation level (range= 1–4)[d] | n/a | n/a | 3.0 (0.6); 3.0 (0.8) |
| Interview language | | | |
| English | 11 (10) | 73.3 (100.0) | n/a |
| Spanish | 4 (0) | 26.7 (0) | n/a |
| Nativity | | | |
| Foreign born | 7 (3) | 46.7 (30.0) | n/a |
| U.S. born | 8 (7) | 53.3 (70.0) | n/a |
| Country of origin (Among Foreign born) | | | |
| Puerto Rico | 5 (3) | 62.5 (100.0) | n/a |
| Dominican Republic | 1 (0) | 12.5 (0) | n/a |
| Cuba | 1 (0) | 12.5 (0) | n/a |
| South America | 1 (0) | 12.5 (0) | n/a |
| Age | n/a | n/a | 53.4 (9.7); 49.2 (5.1) |
| Education | | | |
| <High school diploma/GED | 6 (4) | 40.0 (40.0) | n/a |
| ≥High school diploma/GED | 9 (6) | 60.0 (60.0) | n/a |
| Income | | | |
| <$19,999/year | 9 (6) | 60.0 (60.0) | n/a |
| ≥$20,000/year | 6 (4) | 40.0 (40.0) | n/a |
| Marital Status | | | |
| Currently married/living together | 3 (1) | 20.0 (10.0) | n/a |
| Not currently married/living together | 12 (9) | 80.0 (90.0) | n/a |
| Employment | | | |
| Currently working | 4 (3) | 26.7 (30.0) | n/a |
| Not currently working | 11 (7) | 73.3 (70.0) | n/a |
| Number of children | n/a | n/a | 2.5 (1.5); 2.6 (1.5) |
| Primary care doctor | | | |
| Yes | 15 (10) | 100.0 (100.0) | n/a |

| **Sociodemographics-telephone interviews (Focus Groups)** | **N**[a] | **%**[a] | **Sample mean (SD)** [a] |
|---|---|---|---|
| No | 0 (0) | 0 | n/a |
| Insurance status | | | |
| Insured (including public and private) | 15 (10) | 100.0 (100.0) | n/a |
| (Private) | 5 (2) | 33.3 (20.0) | n/a |
| (Public) | 10 (8) | 66.7 (80.0) | n/a |
| Non-insured | 0 | 0 (0) | n/a |
| Medical mistrust (range= 12–60)[d] | n/a | n/a | 24.2 (11.5); 22.6 (13.2) |
| Religious Identification | | | |
| Catholic | 9 (6) | 60.0 (60.0) | n/a |
| Jehovah's Witness | 2 (2) | 13.3 (20.0) | n/a |
| Other-Christian | 4 (2) | 26.7 (20.0) | n/a |

[a] Where the first value corresponds to participants in Phase 1-telephone interviews and the second value in parentheses corresponds to participants in Phase 2-focus groups

[b] Where diagnosed at young age is defined as ≤55 years old

[c] Defined as at least one first degree relative diagnosed with either breast and/or ovarian cancer

[d] Where variable is linear and a high score indicates more of the given variable

## Table 2

Results from Phase 1- Quantitative Telephone Interviews

| **Telephone Interview Results (*N*= 15)** | **Participant Responses N (%)** | | |
|---|---|---|---|
| Awareness of genetic counseling for inherited disease | Almost nothing or relatively little | A fair amount/a lot | |
| How much have you heard/read about genetic counseling for... | | | |
| Inherited disease? | 5 (33.3) | 10 (66.7) | |
| Cancer, in general? | 8 (53.3) | 7 (46.7) | |
| Breast cancer? | 7 (46.7) | 8 (53.3 | |
| Colon cancer? | 9 (60.0) | 6 (40.0) | |
| Mean total awareness score4 (s.d., scale=1–16) | 9.9 (3.8) | | |
| Perceived Risk of carrying BRCA genetic mutation and intention to undergo counseling | Not at all/ somewhat likely | Likely/Very Likely | |
| How likely do you think it is that you carry a BRCA1/2 mutation? | 4 (26.7) | 11 (73.3) | |
| How likely is it that you will make an appointment for genetic counseling within the next 6 months? | 3 (20.0) | 12 (80.0) | |
| Attitudes about BRCA genetic counseling | Disagree or strongly disagree | Unsure neither agree nor disagree | Agree or strongly agree |
| Do you think that getting genetic counseling for breast cancer would be: | | | |
| Worthwhile | 1 (6.7) | 0 | 14 (93.3) |
| Worrying/cause you to worry | 5 (33.3) | 2 (13.3) | 7 (46.7) |
| Reassuring | 0 | 3 (20) | 12 (80.0) |
| Uncomfortable | 14 (93.3) | 0 | 1 (6.7) |
| Wise | 1 (6.7) | 0 | 14 (93.3) |
| Healthy | 0 | 0 | 15 (100) |
| Unpleasant | 11 (73.3) | 1 (6.7) | 3 (20.0) |
| Important | 0 | 0 | 15 (100) |
| Mean total attitudes score[4] (s.d., scale=8–40) | 33.1 (5.3) | | |
| Behavioral beliefs about BRCA genetic counseling benefits: | | | |
| 'Genetic counseling would help initiate discussions with family members about cancer' | 0 | 0 | 15 (100) |
| 'Genetic counseling would reduce my fear and concerns about developing (or having a recurrence) of breast cancer' | 1 (6.7) | 0 | 14 (93.3) |
| Barriers: | | | |
| 'It would be distressing for me to talk to a genetic counselor' | 9 (60.0) | 0 | 6 (40.0) |
| 'Genetic counseling would make me worry about the breast cancer risk of other family members' | 7 (46.7) | 0 | 8 (53.3) |
| 'Undergoing genetic counseling could jeopardize my health insurance' | 3 (20.0) | 1 (6.7) | 11 (73.3) |
| 'I need to get more information about what genetic counseling has to offer' | 0 | 0 | 15 (100) |
| Mean total behavioral beliefs score[a] (s.d., scale= 15–75) | 63.5 (7.3) | | |
| Familiarity with computers/DVD formats and yse | No | Yes | |
| Do you have a personal computer at home with internet access? | 7 (46.7) | 8 (53.3) | |
| Do you have a DVD player at home? | 0 | 15 (100) | |

| **Telephone Interview Results (*N*= 15)** | **Participant Responses N (%)** | |
|---|---|---|
| Would you be interested in learning more about genetic counseling for breast cancer using. . | | |
| Computer/web-based program? | 3 (20.0) | 12 (80.0) |
| DVD? | 0 | 15 (100) |
| On average, how much time each week do you spend using | Don't use/Use less than 2 h use/week | Use at least 2 h /week |
| Computer/internet? | 12 (80.0) | 3 (20.0) |
| DVD player? | 3 (20.0) | 12 (80.0) |

[a] Where variable is linear and a high score indicates more of the given variable (i.e., more awareness, more positive attitudes and behavioral beliefs)

## Table 3

Results Phase 2-Focus Groups

| **Focus group results ($N$=10)**[a] | **Participant responses N (%)** | |
|---|---|---|
| Quantitative Feedback on Narrative Presentation | No | Yes |
| In general, did you like the information in the presentation? | 0 | 10 (100) |
| Did you find the information in the presentation helpful? | 0 | 10 (100) |
| Would you recommend that women at high risk receive this same kind of information through an education DVD? | 0 | 10 (100) |
| Knowledge about BRCA Genetic Counseling | Mean Score (s.d., range) | Percentage Score (Out of 40 total) |
| Mean knowledge score before viewing presentation | 29.4 (9.5; 14–38) | 73.5 |
| Mean knowledge score after viewing presentation | 36.1 (1.9; 33–38) | 90.3 |
| Mean difference knowledge score pre-post presentation | 6.7 (0.06; $p$=0.04*) | 16.8 |
| Specific knowledge statements | Disagree/strongly disagree | Agree/strongly Agree |
| If I meet with a genetic counselor it means that I have to undergo genetic testing | 6 (60) | 4 (40) |
| I need to get more information about what genetic counseling has to offer | 0 | 10 (100) |
| Emergent themes from focus group discussions | | |
| 1) Positive responses to narrative approach of presentation | | |
| Easy to relate/identify with personalized stories of women | | |
| 2) Similar barriers to BRCA genetic counseling as reported in Phase 1 | | |
| Lack of awareness/knowledge | | |
| Concerns about learning cancer risk of other family members | | |
| Concerns about health insurance and/or cost | | |
| 3) High interest in learning more about BRCA genetic counseling | | |
| Practical/logistical concerns including cost and health insurance | | |
| 4) Additional barriers to BRCA genetic counseling not directly assessed in Phase 1 | | |
| Questions about consistency with religion/faith | | |
| Competing priorities/lack of time | | |

[a] Focus groups were completed with a subset of participants who had first completed the quantitative telephone interview

*Significance level $p \leq 0.05$.