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Barriers and Facilitators to BRCA Genetic Counseling Among At-Risk Latinas in New York City

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Abstract

Objective—Despite underuse of genetic services for hereditary breast and/or ovarian cancer risk among Latinas (including counseling and testing for BRCA mutations), there is little known about the barriers and facilitators to BRCA genetic counseling among this group. It is imperative to first understand factors that may impede Latinas seeking BRCA genetic counseling, as it is considered a prerequisite to testing.

Methods—Quantitative telephone interviews (N=120) were conducted with at-risk Latinas in New York City to investigate interest, barriers and beliefs about BRCA genetic counseling. Statistical analyses examined predictors of intention to undergo BRCA genetic counseling.

Results—Despite moderate levels of awareness, Latinas held largely positive beliefs, attitudes and knowledge about BRCA genetic counseling. Perceived barriers included logistic concerns (e.g., where to go, cost/health insurance coverage), emotional concerns (e.g., fear, distress) and competing life concerns (e.g., too many other things to worry about, too busy taking care of children or family members). Multivariate results showed that the strongest predictor of intention to undergo BRCA genetic counseling was competing life concerns; Latinas with more competing life concerns were less likely to intend to undergo BRCA genetic counseling ($p=0.0002$). Other significant predictors of intention included perceived risk of carrying a BRCA mutation ($p=0.01$) and referral by their physician ($p=0.02$).

Conclusion—Educational efforts to promote BRCA genetic counseling among at-risk Latinas and increase referrals by their physicians should **incorporate discussion** of perceived barriers to counseling, such as competing life concerns that Latinas may need to overcome in order to seek genetic counseling.

Keywords

cancer; oncology; genetic counseling; breast; BRCA

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DECLARATION OF CONFLICTING INTERESTS

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INTRODUCTION

Breast cancer is the most common cancer among women in the US. About 1 woman in 8 will develop invasive breast cancer in her lifetime [1]. It is estimated that 5-10% of all breast cancers and 10% of all ovarian cancers are inherited or due to germline mutations in BRCA1/2 genes [2,3]. Mutations in these genes are associated with a 40-66% lifetime risk of developing breast cancer, a 13-46% risk of developing ovarian cancer and a 52% risk of developing a second breast cancer in breast cancer patients [4]. **The U.S. Preventive Services Task Force** [5] recommends that all at-risk individuals undergo BRCA genetic counseling. Considered a prerequisite to genetic testing [6], genetic counseling helps women make 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 [6,7].

Despite the known benefits of BRCA genetic counseling and subsequent testing for hereditary breast and/or ovarian cancer (HBOC) risk, the use and underuse of these services represent one of the most potent examples of health disparities in action, as the gap widens between those who have access to and knowledge about BRCA genetic counseling and testing and those who do not [8-10]. Reports show that less than 10% of the first 10,000 individuals undergoing BRCA genetic testing were from traditionally underrepresented racial/ethnic groups, with approximately 4% Latinas [11]. Similarly, only 1% of patients in a study of genetic testing for cancer risk in community-based settings in the U.S. were Latino [12]. This is of concern as Latinos represent the fastest growing minority group in the U.S., as 15% of the population identify themselves as Hispanic or Latino with 60% U.S. born and 40% foreign-born [13,14]. Breast cancer is the most commonly diagnosed cancer and leading cause of cancer death in Latinas [15]. Latinas are 22% more likely to die during the five years after diagnosis and have a later breast cancer stage at diagnosis compared to Whites [15,16], a differential found when controlling for equal access to health care services [17].

Despite such disparities, there is little known about factors related to the use or non-use of BRCA genetic counseling among at-risk Latinas. Two recent studies were limited in that they only included women who were already referred to and had made appointments for BRCA genetic cancer risk assessment (which includes counseling) based on family history [18,19], thus these studies did not assess barriers to counseling. In a recent study contrasting at-risk Latinas and non-Latinas, among participants who had not previously had genetic counseling/testing, 56.9% of Latinas were unaware of the availability of BRCA1/2 testing, with Latina ethnicity the only significant factor associated with lack of awareness [20]. Further, a qualitative study of at-risk Latinas found that awareness of BRCA genetic risk assessment (including counseling) was low, although participants had favorable attitudes towards counseling services once they were informed about them [21]. Finally, pilot research by our team found that barriers to BRCA genetic counseling included lack of awareness, knowledge, concerns related to learning cancer risk of family members and concerns about the cost of genetic counseling for the uninsured and coverage for those with health insurance; however participants reported largely positive attitudes, beliefs and interest in learning about BRCA genetic counseling [22].

Since BRCA genetic counseling is considered the precursor to testing and can provide women with life-saving information, it is critical to understand factors related to uptake of BRCA genetic counseling. By understanding these factors we will be able to design culturally-appropriate and sensitive interventions to increase participation of Latinas in genetic services for HBOC risk assessment [23-25]. The goal of this study was to examine the barriers and facilitators to BRCA genetic counseling for HBOC among Latinas. Using

our quantitative telephone survey, which was pre-tested and refined based on our pilot results [22], we aimed to conduct 120 quantitative telephone interviews (in English and Spanish) to examine factors related to intention to pursue BRCA genetic counseling among at-risk Latinas, with family histories suggestive of HBOC in New York City (NYC).

The conceptual framework which was broadly used to inform this research was the Integrative Model of Behavior Prediction [26], which incorporates key aspects of the Health Belief Model [27,28], Social Cognitive Theory [29-31] and Theory of Reasoned Action [32,33]. 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 other social and cultural influences. Since the IMPBP was used only to broadly inform this research and not as a comprehensive conceptual model, it is important to note that not all constructs of the IMPBP were included in this study.

METHODS

Study Setting and Population: Recruitment

The majority of potential participants completed a family history form for 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. Either the Principal Investigator (PI) or Research Assistant (RA), both of whom are bilingual, contacted potential participants who had previously given permission for the follow-up call. The PI or RA explained the study and confirmed eligibility. Participants were women who self-identified as Latinas, were 18 years of age or older, had never undergone BRCA genetic counseling and/or testing, and had an increased risk of breast and/or ovarian cancer based on a personal diagnosis at a young age (<55 years old) and/or a family history of breast and/or ovarian cancer (1 or more first degree relatives with breast and/or ovarian cancer diagnosed at a young age [<55 years old] or 2 or more second degree relatives with breast and/or ovarian cancer). If an eligible participant chose to participate in a telephone interview, a waiver of signed consent was obtained over the telephone and date/time for the telephone interview scheduled. In addition to the above recruitment, some potential participants were identified by word-of-mouth contact, in that participants who had completed the telephone interview provided contact information to the interviewer of family members or friends who would potentially be eligible to participate in the study. Some participants were also recruited via outreach to Latina support groups for breast/ovarian cancer in the NYC area. Such potential participants through word-of-mouth and outreach-related channels were contacted by telephone following the same process as described above. All study procedures were approved by Mount Sinai's Institutional Review Board.

Quantitative Telephone Interviews

Telephone interviews were conducted either by the bilingual PI or RA, lasted no longer than 30 minutes, with participants receiving \$20.00 for participation. At the beginning, all participants received a brief explanation from the interviewer about BRCA mutations and genetic counseling. Following completion of the interview, all participants were provided information to obtain a genetic counseling referral: 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. This information was also mailed to participants' homes along with study compensation and copy of waiver of consent.

MEASURES

Measures queried in the quantitative telephone interviews were selected to capture key components of the Integrative Model of Behavior Prediction [23]. Reported internal reliabilities of the instruments used are all based on the sample of Latinas in the current study.

Potential Predictors

Acculturation Level—Five separate measures of acculturation were considered, found to be associated with awareness and familiarity about genetic testing for cancer risk among normal risk Latinas [23-25]. Marin and Gamba's bidirectional acculturation scale for Hispanics (BAS) was used to provide an acculturation score for two major cultural dimensions (Hispanic and non-Hispanic domains) by including 12 items that measure three language-related areas in both domains [34]. 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 score meaning higher acculturation. Reliability of the items in the acculturation scale was excellent (Cronbach's $\alpha=0.96$). Other measures included interview language, participants' nativity, mothers' nativity and fathers' nativity.

Medical Mistrust—Medical mistrust, which has been found to be related to concerns about abuses of BRCA1/2 genetic testing for cancer risk in minorities [35,36], was assessed with the Group-Based Medical Mistrust Scale (GBMMS). This 12-item scale (5-point Likert) 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 [36]. Total medical mistrust score was computed by adding all responses (score range=12-60), with internal reliability considered very good (Cronbach's $\alpha=0.87$).

Perceived Risk of Carrying a BRCA1/2 Mutation was assessed with one question that has been previously used in studies by our research team [37]: "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".

Awareness of Genetic Counseling for Cancer Risk was measured using a 4-item questionnaire (high=more familiarity) previously used in studies by our research team [37] that asks participants to assess how much they have heard or read about genetic counseling for inherited disease, cancer and for breast and ovarian cancer. Total awareness score was computed by adding all responses (score range=4-16). Scale items had very good internal reliability (Cronbach's $\alpha=0.85$).

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) [38,39]. Total attitudes score was computed by adding all responses (score range=8-40 where high=more positive attitudes). Internal reliability of items was good (Cronbach's $\alpha=0.73$).

Beliefs about BRCA Genetic Counseling—Participants were given a list of reasons why some women might or might not decide to undergo BRCA genetic counseling and had to indicate the degree to which they agreed or disagreed with these belief statements (5-point likert). These statements were created by the PI based on previous pilot testing amongst Latinas and adapted from previously published measures created by our research team to assess attitudes about genetic counseling among African-American women [37]. For these

belief scales, we relied on calculation of Cronbach's alpha to measure reliability estimated from the consistency of items in the sum scales. Beliefs included five subcategories, computed as mean scores (specific items detailed in Table 2): 1) Pros of BRCA genetic counseling (N=7 items; Cronbach's $\alpha=0.75$); 2) Cons of BRCA genetic counseling (N=6 items; Cronbach's $\alpha=0.62$); 3) Competing life concerns (N=4 items; Cronbach's $\alpha=0.68$); 4) Cultural concerns (N=3 items; Cronbach's $\alpha=0.62$); and 5) Logistic concerns (N=6 items; Cronbach's $\alpha=0.70$). Participants also responded to three questions about the extent to which they did or did not desire more information about BRCA genetic counseling, however the scale was eliminated as reliability was low ($\alpha=0.37$).

Physician Referral for BRCA Genetic Counseling—Participants responded whether they had ever received a physician referral for BRCA genetic counseling (Yes/No response). However, we did not have information available on record about what guidelines were used by each participants' physician to determine eligibility for a BRCA counseling referral.

Covariates

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

Personal and Family History of Cancer—Information about participants' personal and family history of breast and/or ovarian cancer was included.

OUTCOME

Intention to Undergo BRCA Genetic Counseling

Intention to undergo BRCA genetic counseling was assessed with one question that has previously used in studies by our research team [37]: "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).

ANALYTIC PLAN

We computed basic descriptive statistics, as reported in Tables 1-3. Univariate linear regression analyses examined each potential predictor and covariate individually and determined its association with the study outcome and are reported in Table 4. We also computed individual correlations among study measures, where necessary. Since the questionnaire was administered as an interview there was a minimum amount of missing data. However, in cases of missing data, we omitted those individuals from analysis. We explored all significant variables ($p < 0.10$) in univariate analyses as potential covariates for inclusion in the candidate short list for the multivariate model. We conducted a forward selection test as the automatic statistical procedure of choice to control for potential problems of multicollinearity among variables in the model. Due to a relatively small sample size, we chose a level of significance of $p < 0.10$ as most appropriate for determining initial entry into the forward selection test. We then included variables significant from the forward selection test in the final multivariate model. We added all other covariates independently associated with the outcomes one by one to test for potential confounding. We considered any such covariates producing a change of at least 20% in the **beta weights** of predictors already in the model (from forward selection) as potential confounders and included them in the final model, as well as any theoretically critical sociodemographic variables (i.e., age, personal and family history of breast and/or ovarian cancer). We used a level of $p < 0.05$ to determine overall statistical significance of variables in the final model.

and an R^2 test determined the percentage of variability explained by the final multivariable linear regression model. All statistical procedures used SAS software package v.9.1.3.

RESULTS

Sample characteristics

Table 1 presents sample characteristics. The mean age of participants was 47.5 years, mean number of children 1.8. Approximately half of the sample had completed at least high school education, earned >\$20,000 per year, were not currently married or living with a partner and were currently working. Mean acculturation level was 2.4 (s.d.=7.8, 1-4 scale) and almost half completed the interview in Spanish. Majority of participants reported having a regular family physician and were insured. About half had a personal history of breast and/or ovarian cancer and had a family history of cancer (defined as first degree relative with breast and/or ovarian cancer).

Descriptive Statistics

Table 3 lists the outcome and potential predictors of interest.

Intention to Make Appointment

The majority of participants reported that they would be ‘somewhat likely’-‘extremely likely’ to make an appointment for BRCA genetic counseling within the next 6 months.

Awareness

More than half of participants had heard or read ‘almost nothing’ or ‘relatively little’ about genetic counseling for inherited disease and for cancer. Approximately half had heard or read ‘almost nothing’ or ‘relatively little’ about genetic counseling for breast and ovarian cancer. Mean awareness about genetic counseling was above average, although below average/moderate for BRCA counseling.

Attitudes

Participants had largely positive attitudes about BRCA genetic counseling (‘worthwhile’, ‘healthy’, etc), but also reported counseling would be ‘uncomfortable’, ‘unpleasant’ or ‘worrying/cause them to worry’.

Knowledge

Mean knowledge about BRCA genetic counseling was fairly high.

Medical Mistrust

Mean medical mistrust in this sample was fairly low.

Perceived Pros/benefits

Mean pros/benefits about BRCA genetic counseling was fairly high. As shown in Table 1, almost all participants agreed that BRCA genetic counseling would help them to: better understand the cancer risks of family members, initiate discussions about cancer risk in their family, and decide whether to undergo BRCA1/2 genetic testing. The majority thought that there were important benefits to genetic counseling even if they decided to not get genetic testing and believed that BRCA genetic counseling would reduce their fears/concerns about developing (having recurrence) of breast/ovarian cancer.

Perceived Cons/Disadvantages

Mean cons/disadvantages was moderate/average level. Only a few participants agreed that they would not learn anything new from BRCA genetic counseling. Some were unsure/did not know or were in agreement that talking to a counselor would be distressing. A quarter of participants did not know/were unsure if undergoing BRCA genetic counseling would jeopardize their health insurance. Participants were split over whether BRCA genetic counseling would cause them to worry about breast/ovarian cancer risk in other family members. Most believed that BRCA genetic counseling would help them deal with their fears and uncertainty about development (having recurrence) of breast/ovarian cancer and provide a means to help prevent cancer. Only a few reported that since they had already spoken to their doctor or nurse that they wouldn't learn anything new from BRCA genetic counseling.

Cultural Concerns

Almost all participants did not believe that BRCA genetic counseling was inconsistent with their religious or spiritual beliefs, that if they were diagnosed with cancer they were going to die (fatalismo) and thus there was no reason for genetic counseling. The majority did not agree that if they were diagnosed with breast/ovarian cancer it was their destiny (destino) so there was no purpose to getting genetic counseling. Mean cultural concerns about BRCA genetic counseling was fairly low.

Competing Life Concerns

Mean for competing life concerns with BRCA genetic counseling was moderate/average level. Over a third reported they had too many other things to worry about compared to getting BRCA genetic counseling and considered it low on their priority list. Some believed they were too busy taking care of their own children or family and were too concerned about health of other family compared to their own.

Logistic Concerns

The mean score for logistic concerns about genetic counseling was above average/moderate with the majority believing that getting counseling would take up too much of their time and concern their health insurance would not cover the cost. Before making an appointment for BRCA genetic counseling, most participants wanted to ensure that their health insurance would cover cost and not be jeopardized, critical considering the high proportion of individuals with insurance. The majority did not know/were unsure where to go to get counseling.

Desire for More Information

Mean score for desire for more information about genetic counseling (1-5 scale) was above average/moderate level. Almost all participants believed they needed more information about what BRCA genetic counseling could offer them.

Perceived Risk

A third of participants said they were 'somewhat likely' to carry the BRCA1/2 mutation, while 17.6% and 9.2% said they were 'very likely' or 'extremely likely', respectively, to carry the mutation.

Physician Referral

Most participants had not received physician referral for BRCA genetic counseling.

Univariate Results—Table 4 reports the significant ($p = 0.10$) unadjusted associations in univariate analysis. Independent significant predictors of intention to undergo BRCA genetic counseling for breast and/or ovarian cancer risk included physician referral, pros, competing life concerns which may impede uptake of counseling, positive attitudes, heard/read about BRCA genetic counseling and perceived risk of carrying a BRCA1/2 mutation.

Multivariate Results—Table 5 reports multivariate results. In final models, age, personal and family history of breast cancer were considered theoretically necessary as they have been shown to influence breast cancer risk and screening practices, and beliefs, attitudes and concerns about genetic testing in minority women [40, 41]. Multivariate results showed that the strongest predictor of intention to undergo BRCA genetic counseling was competing life concerns. Specifically, there was an inverse relationship found between competing life concerns and intention to undergo BRCA genetic counseling. Women who had more competing life concerns (e.g., too many other things to worry about, too busy taking care of children or family members, more concern for other family members' health compared to their own) were less likely to intend to undergo BRCA genetic counseling ($p=0.0002$). Other significant predictors of intention to undergo BRCA genetic counseling in multivariate analysis included perceived risk of carrying a BRCA1/2 mutation ($p=0.01$) and referral by their physician ($p=0.02$), with women with higher perceived risk and those who had received a referral for BRCA genetic counseling from their physician more likely to intend to undergo BRCA genetic counseling.

DISCUSSION

Study results contribute to the literature by documenting facilitators and barriers to use of genetic services for HBOC amongst Latinas who had not previously undergone BRCA genetic counseling. Such factors are of interest given research suggests gross disparities in the use of genetic services amongst this underserved group [8-10]. The results showed that despite moderate levels of awareness about BRCA genetic counseling for breast/ovarian cancer risk, participants were largely knowledgeable, held positive attitudes and beliefs about the pros/benefits of BRCA genetic counseling and were interested in learning more about counseling. Main perceived pros/benefits of BRCA genetic counseling cited by participants were related to the family, including helping initiate discussions about cancer risk with other family members and learning cancer risk of other family members. Such findings fall in line with previous literature underscoring the strong value placed on the family (both nuclear and extended relatives) in daily life and emphasis of interdependence over independence (familismo) within Latinos [42-44]. However, despite the largely positive attitudes held by participants, there were many uncertainties related to BRCA genetic counseling; participants were split over whether or not they would find it emotionally distressing to undergo BRCA genetic counseling, whether getting BRCA genetic counseling would cause them to worry about cancer risk of other family members, whether their fears about getting cancer (or cancer recurrence) would be reduced by BRCA genetic counseling, and whether getting BRCA genetic counseling could help them prevent cancer. Such concerns are of importance, as research among African Americans has found that emotional and/or psychological barriers such as worry and distress may hinder actual use of BRCA genetic counseling and testing [39, 45-47].

Although results documented logistic concerns (e.g., time, expense, questions of health insurance coverage, and where to go for genetic counseling) as potential barriers to BRCA genetic counseling for Latinas, it is critical to note that these concerns were not associated with intention to undergo BRCA genetic counseling in the multivariate model. It is possible that although logistic concerns were questions Latinas had about BRCA genetic counseling, these were perceived barriers that they could overcome or find ways to get around.

Alternatively, as discussed in our previous research [22], although financial barriers may not directly inhibit interest or desire to obtain genetic services, such barriers could curtail actual use and uptake of services.

Meanwhile, cultural concerns (spiritual/religious beliefs, fatalismo and destino), debated in the literature as influences for Latinas in relation to their views about cancer or adherence to cancer screening recommendations [43, 48-50], did not appear as relevant to beliefs about BRCA genetic counseling and did not influence intention to undergo BRCA genetic counseling. Rather, competing life concerns (e.g, too many other things to worry about, low priority placed on BRCA genetic counseling, too busy taking care of children or family members, more concern for other family members' health compared to their own) was the only perceived barrier significantly related to the study outcome of intent to undergo BRCA genetic counseling.

Thus, this research uniquely contributes to the literature by uncovering the extent to which competing life concerns may hinder intent to undergo BRCA genetic counseling among at-risk Latinas in NYC. This finding is in line with results from pilot focus groups preceding this study that uncovered unique barriers to BRCA genetic counseling among at-risk Latinas including competing priorities and lack of time, childcare responsibilities and concern about health of other family members above concern for one's own health [22]. Such qualitative results informed development of our quantitative instrument that was subsequently used in this study by incorporating discussion of such competing factors. This finding may also be an extension of previous research by members of our study team documenting that barriers to BRCA1/2 genetic testing for Latinas may include not enough time for genetic testing and low priority placed on testing because women currently felt healthy [35].

Study findings related to competing priorities in minority women coincide with theoretical frameworks incorporating a social contextual approach to understanding of health behaviors [51-53]. Recent qualitative research among low-income Latina and African American women to examine factors that promote or prevent adherence to recommended health behaviors after having an abnormal mammography found that social context of women's experiences was defined by challenges and major life stressors, including competing health issues and demanding caretaking responsibilities and relationships. **The results showed** major life stressors and competing priorities may contribute to women's difficulty in making their own health care a priority in minority groups [54]. This finding supports prior research demonstrating that women take on a disproportionate burden of caretaking and householding duties at the expense of completing recommended health behaviors for themselves [54-60]. Among Latinas, this burden may be amplified, as they are often viewed as responsible for functioning and maintenance of family, both immediate and extended. In fact, dependence on the Latina woman may lead to women avoiding or delaying screening, treatment and care for major health concerns such as cancer to maintain family stability, often prioritized over one's own health [61,62]. Yet, recognizing that a breast cancer diagnosis may lead to significant disruption of family life may provide Latinas the incentive to take action and better manage their health [60]. In light of our findings, we argue that educational efforts to improve use of BRCA genetic counseling for HBOC must directly address and incorporate the competing life priorities Latinas face in relation to seeking BRCA genetic counseling. Specifically, educational messages for this at-risk group and for physicians making referrals to Latinas should utilize known barriers to care in order to actively turn them into facilitators that may motivate Latinas to change and seek counseling. Educational materials should be created to transparently discuss the competing priorities and concerns Latinas face and explain that by prioritizing their own health, Latinas are prioritizing family wellbeing. When describing benefits of BRCA genetic counseling, it may be effective to speak in terms of

improving overall family health and understanding of cancer risk rather than individual risk alone.

Finally, **the results showed** that perceived risk significantly predicted intention to undergo BRCA genetic counseling, in accordance with prior studies among high-risk families where perceived risk of being a BRCA1/2 mutation carrier has been positively associated with interest in testing [63-66]. The finding that physician referral significantly predicted intent to undergo counseling helps contribute to a better understanding of referral patterns for HBOC, as this area has not been well studied. It is of note that almost 40% of participants had been referred and not yet undergone genetic counseling. Although physician referral predicted intention to undergo counseling, these women still had not pursued counseling. In one of the few, albeit small, studies in this area, 7 of 13 women who had been referred to and had actually attended genetic counseling for HBOC reported doing so only after a follow-up call. Women stated that they had fully intended to follow-up with the referral but had forgotten, lost the paperwork, or were waiting to be called [67]. Similarly, research conducted with diverse Latinas suggests that although provider recommendation is an important first step toward uptake of genetic counseling, additional follow up and discussion beyond a one-time referral may be necessary, with specific groups varying in their preferred type of physician recommendation [68]. Future steps may include the development of patient-navigation programs and guided materials that could help Latinas follow-up on physician referral for BRCA genetic counseling.

Study Limits

One main limitation of this study is that the outcome of interest was intention to undergo BRCA genetic counseling, rather than actual uptake or referral. Although there was some concern that intention to undergo BRCA genetic counseling would not have enough variation to serve as the outcome, this did not occur in our sample. There is still some concern however regarding the extent to which intention to undergo BRCA genetic counseling predicts counseling uptake, as some research with testing has shown that intention to have the BRCA1/2 genetic test may not translate into actual uptake [61]. A second limitation of this study was participants' risk level. Although we had initially aimed to include only those at highest risk for genetic mutation, the ability to recruit these highest risk cases proved more challenging than originally expected and for this reason, our risk eligibility was expanded. As a result, we use the term at-risk, rather than high-risk. Third, 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 U.S. Fourth, due to the sampling strategy which included the majority of participants being drawn from breast surgery clinics at MSSM, it is unclear if unaffected participants (those without a personal history of breast or ovarian cancer) had a medical breast-related problem which could introduce some potential bias. Finally, there could be potential bias as women were of fairly high acculturation status, already part of the health care system and recruited through clinics or existing studies, with the majority reporting regular use of a healthcare provider and being insured. In fact, community-based samples of diverse Latinas from NYC through the Esperanza y Vida Program in NYC (a breast/ovarian cancer awareness program) reported as high as a third of participants being uninsured [69]. However, the relatively high proportion of insured women in our sample may have been related to the fact that over half of the women in the study were breast/ovarian cancer survivors. Future research should examine the role of health insurance as a barrier to BRCA genetic counseling in less acculturated, uninsured samples.

CONCLUSION

In order to more effectively promote BRCA genetic counseling among at-risk Latinas, educational efforts should address perceived barriers these women face, particularly incorporating discussion of the competing life concerns which may impede women's intention to seek counseling.

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Table 1
Sociodemographic Information

SOCIODEMOGRAPHIC VARIABLES	N (%)	Sample mean	Possible range	Actual range
Language				
Spanish	53(44.5)	n/a	n/a	n/a
English	66(55.5)	n/a	n/a	n/a
Nativity				
Foreign born	60(56.6)	n/a	n/a	n/a
US born	46(43.4)	n/a	n/a	n/a
Country of Origin (among foreign born)				
Puerto Rico	24 (40.0)	n/a	n/a	n/a
Dominican Republic	23 (38.3)	n/a	n/a	n/a
Central America	3 (5.0)	n/a	n/a	n/a
South America	3 (5.0)	n/a	n/a	n/a
Central America	3 (5.0)	n/a	n/a	n/a
Mexico	2 (3.3)	n/a	n/a	n/a
Cuban	2 (3.3)	n/a	n/a	n/a
Caribbean	1 (1.7)	n/a	n/a	n/a
Other	2 (3.3)	n/a	n/a	n/a
Mothers' nativity				
Foreign born	91(86.7)	n/a	n/a	n/a
US born	14(13.3)	n/a	n/a	n/a
Fathers' nativity				
Foreign born	93(91.2)	n/a	n/a	n/a
US born	9(8.8)	n/a	n/a	n/a
Medical mistrust (higher=more medical mistrust)	119	28.0 (8.9)	12-70	12-49
Age	120	47.5 (13.7)	18-n/a	18-80
Number of children	120	1.8 (1.5)	0-n/a	0-7
Education				
High school	61(50.8)	n/a	n/a	n/a
>High school	59 (49.2)	n/a	n/a	n/a
Household Income				
\$19,999/year	48 (43.6)	n/a	n/a	n/a
\$20K/yr	62 (56.4)	n/a	n/a	n/a
Marital Status				
Married/living together	52 (43.3)	n/a	n/a	n/a

SOCIODEMOGRAPHIC VARIABLES	N (%)	Sample mean	Possible range	Actual range
Not married/not living together	68 (56.7)	n/a	n/a	n/a
Employment				
Working	60 (50.4)	n/a	n/a	n/a
Not working	58 (48.7)	n/a	n/a	n/a
Religious faith				
Not strong	9 (7.7)	n/a	n/a	n/a
A little strong	12 (10.3)	n/a	n/a	n/a
Moderately strong	53 (45.3)	n/a	n/a	n/a
Very strong	43 (36.8)	n/a	n/a	n/a
Family history of breast or ovarian cancer (first degree)				
Yes	56 (46.7)	n/a	n/a	n/a
No	64 (53.3)	n/a	n/a	n/a
Personal history of breast and/or ovarian cancer				
Yes	70 (58.3)	n/a	n/a	n/a
No	50 (41.7)	n/a	n/a	n/a
Primary physician				
Yes	110 (92.4)	n/a	n/a	n/a
No	9 (7.6)	n/a	n/a	n/a
Insurance status				
Insured	86 (88.7)	n/a	n/a	n/a
Not insured	11 (11.3)	n/a	n/a	n/a

Table 2
Description of Behavioral Beliefs about BRCA Genetic Counseling

	<i>Items Included and Agreement (Strongly Disagree=1; Strongly Agree=5)</i>	<i>Strongly Disagree/ Moderately Disagree</i>	<i>Neutral- Neither Agree Nor</i>	<i>Moderately -Strongly Agree</i>	<i>Strongly Agree</i>	<i>α</i>
<i>1) Pros</i>	• Genetic counseling would reduce my fear and concerns about developing (or having a recurrence of) breast or ovarian cancer • Genetic counseling would help me decide whether I should undergo genetic testing for breast and/or ovarian cancer • Genetic counseling would help me initiate discussions about cancer risk in my family • Genetic counseling would help me make important life decisions (e.g., having children) • Genetic counseling would help me better understand cancer risks of other family members • Genetic counseling would help me decide whether to undergo preventive surgery • I believe there are important benefits to getting genetic counseling even if I decide not to undergo genetic testing for breast and/or ovarian cancer	8 (6.7) 4 (3.6) 1 (0.8) 5 (5.2) 0 (0) 12 (10.1) 4 (3.8)	Disagree 6 (5.0) 5 (4.4) 2 (1.7) 9 (7.6) 1 (0.8) 16 (13.4) 1 (1.0)	56 (47.1) 61 (54.0) 57 (47.9) 52 (43.7) 56 (47.1) 66 (55.5) 36 (33.9)	49 (41.2) 43 (38.0) 59 (49.6) 53 (44.5) 62 (52.1) 25 (21.0) 65 (61.3)	0.75
<i>2) Cons</i>	• I feel I already know my chances of getting breast or ovarian cancer, so I wouldn't learn anything more from genetic counseling • It would be distressing for me to talk to a genetic counselor • Undergoing genetic counseling could jeopardize my health insurance • Genetic counseling would make me worry about the breast and/or ovarian cancer risk of other family members (e.g., mother, daughters) • Genetic counseling would not help me deal with my fears and uncertainty about developing (or having a recurrence of) breast and/or ovarian cancer • Genetic counseling would	97 (82.3) 80 (67.2) 73 (62.9) 50 (33.7) 73 (61.3) 68 (57.6)	5 (4.2) 6 (5.0) 30 (25.9) 1 (9.2) 12 (10.1) 17 (14.4)	9 (7.6) 22 (18.5) 7 (6.0) 40 (33.6) 27 (22.7) 27 (22.9)	7 (5.9) 11 (9.3) 6 (5.2) 28 (23.5) 7 (5.9) 6 (5.1)	0.62

	<i>Items Included and Agreement (Strongly Disagree=1; Strongly Agree=5)</i>	<i>Strongly Disagree/ Moderately Disagree</i>	<i>Neutral- Neither Agree Nor</i>	<i>Moderately -Strongly Agree</i>	<i>Strongly Agree</i>	<i>α</i>
	not provide me with any means of preventing breast and/or ovarian cancer • My doctor (or nurse) has spoken with me about my risk of breast and/or ovarian cancer, so I wouldn't learn anything new from genetic counseling	103 (87.3)	5 (4.2)	9 (7.6)	1 (0.9)	
<i>3) Competing Concerns</i>	• I have too many other things to worry about compared to getting genetic counseling	64 (61.3)	9 (8.5)	29 (27.4)	4 (3.8)	0.68
	• Getting genetic counseling is a low priority on my list of things to do	65 (61.3)	13 (12.3)	24 (22.6)	4 (3.8)	
	• I am too busy taking care of my children (or other family members) to get genetic counseling at this time	77 (78.6)	13 (13.3)	6 (6.1)	2 (2.0)	
	• I am more concerned about the health of other family members compared to my own, so getting genetic counseling is not of interest to me right now	83 (78.3)	10 (9.4)	12 (11.3)	1 (1.0)	
<i>4) Cultural Concerns</i>	• Getting genetic counseling is not consistent with my religious or spiritual beliefs	100 (94.3)	4 (3.8)	0 (0)	2 (1.9)	0.62
	• I believe that if I am diagnosed with breast and/or ovarian cancer I will die (fatalismo), so there is no purpose for genetic counseling	88 (83.9)	3 (2.9)	4 (8.6)	5 (4.6)	
	• I believe that if I am diagnosed with breast and/or ovarian cancer it is my destiny (destino), so there is no purpose for getting genetic counseling	97 (91.5)	2 (1.9)	7 (6.6)	0 (0)	
<i>5) Logistic Concerns</i>	• Getting genetic counseling would take up too much of my time	86 (81.2)	11 (10.4)	7 (6.6)	2 (1.8)	0.70
	• Getting genetic counseling would be too expensive for me	49 (46.2)	34 (32.1)	16 (15.1)	7 (6.6)	
	• I worry that my health insurance would not cover the cost of genetic counseling	26 (24.8)	12 (11.4)	49 (46.7)	18 (17.1)	
	• I would be interested in getting genetic counseling, but I am unsure of where to go to get counseling (ex: don't know where to go, who to speak with to make an appointment)	30 (28.8)	4 (3.9)	51 (49.0)	19 (18.3)	
	• I would be interested in	10 (9.7)	4 (3.9)	48 (46.2)	42 (40.4)	

	<i>Items Included and Agreement (Strongly Disagree=1; Strongly Agree=5)</i>	<i>Strongly Disagree/ Moderately Disagree</i>	<i>Neutral- Neither Agree Nor</i>	<i>Moderately -Strongly Agree</i>	<i>Strongly Agree</i>	α
	getting genetic counseling, but I first want to be sure my insurance would cover the cost • I would be interested in getting genetic counseling, but I want to know that my health insurance would not be jeopardized or put in danger	16 (15.5)	6 (5.8)	47 (45.6)	34 (33.1)	
6) <i>Desire for more information about GC</i>	• I need to get more information about what genetic counseling has to offer • To benefit from genetic counseling, I would need to have a better background (more schooling) in science • I feel like I need more information about the ways I could benefit from genetic counseling for breast and/or ovarian cancer	5 (4.2) 73 (61.3) 23 (21.7)	1 (0.8) 7 (5.9) 1 (0.9)	62 (52.1) 30 (25.2) 57 (53.8)	51 (42.9) 9 (7.6) 25 (23.6)	0.36

Table 3

Descriptive Statistics-Outcome and Predictor Variables

Outcome Variable	N (%)	Sample mean	Possible range	Actual range	Alpha
Intention to Make an Appointment for Genetic Counseling for Breast and/or Ovarian Cancer Risk within the Next 6 Months					
Not at all likely	19 (16.0)	n/a	n/a	n/a	n/a
Somewhat likely	41 (34.4)	n/a	n/a	n/a	
Very likely	29 (24.4)	n/a	n/a	n/a	
Extremely likely	30 (25.2)	n/a	n/a	n/a	
Predictor Variables					
Awareness about GC ¹	119	9.1 (3.4)	4-16	4-16	0.85
Heard or read 'almost nothing' or 'relatively little' about genetic counseling...					
For Inherited Disease	69 (57.9)	n/a	n/a	n/a	n/a
For Cancer	63 (52.9)	n/a	n/a	n/a	n/a
For Breast/Ovarian Cancer	59 (49.6)	n/a	n/a	n/a	n/a
For Colon Cancer	89 (74.8)	n/a	n/a	n/a	n/a
Physician referral for GC					
Yes	46(38.7)	n/a	n/a	n/a	
No	73(61.3)	n/a	n/a	n/a	
Pros about GC (see Table 2)	119	4.3 (0.5)	1-5	2.6-5	0.75
Cons about GC (see Table 2)	119	2.4(0.6)	1-5	1-4	0.62
Cultural concerns (see Table 2 list)	106	1.8(0.7)	1-5	1-3.7	0.62
Competing life concerns (see Table 2)	106	2.3(0.8)	1-5	1-4	0.68
Logistic concerns (see Table 2)	106	3.3(0.7)	1-5	1-4.7	0.70
Desire for more information about	119	3.5(0.7)	1-5	1.3-5	0.36

Outcome Variable	N (%)	Sample mean	Possible range	Actual range	Alpha
GC (see Table 2)					
Positive attitudes about GC	119	31.4(4.2)	8-40	17-40	0.73
Examples include:					
Worthwhile (strongly agree/agree)	101 (84.9)	n/a	n/a	n/a	n/a
Healthy (strongly agree/agree)	106 (89.1)	n/a	n/a	n/a	n/a
Uncomfortable	90 (75.6)	n/a	n/a	n/a	n/a
Worrying (strongly agree/agree)	48 (40.3)	n/a	n/a	n/a	n/a
Unpleasant (strongly agree/agree)	91 (76.5)	n/a	n/a	n/a	n/a
Knowledge about GC	112	43.8 (6.2)	11-55	19-55	0.87
Heard/read about GC for breast/ovarian cancer risk	119	2.1(1.5)	0-5	0-5	0.58
Perceived risk (likelihood of carrying a BRCA1/2 mutation)					n/a
Not at all likely	24(20.2)	n/a	n/a	n/a	
Somewhat likely	37(31.1)	n/a	n/a	n/a	
Likely	26(21.9)	n/a	n/a	n/a	
Very likely	21(17.6)	n/a	n/a	n/a	
Extremely likely	11(9.2)	n/a	n/a	n/a	
Medical mistrust (higher=more medical mistrust)	119	28.0 (8.9)	12-70	12-49	0.87

Table 4
Unadjusted Predictor Estimates of Intention to Participate in Genetic Counseling

Outcome: Intention to Make an Appointment for Genetic Counseling for Breast and/or Ovarian Cancer Risk within the Next 6 Months	B Coefficient/ Parameter Estimate (SE)	Significance (p value)
Awareness about GC ^I	0.04 (0.03)	0.20
Physician referral for GC ^I	0.49 (0.19)	0.01 *
Pros about GC ^I	0.63 (0.19)	0.001 *
Cons about GC ^I	-0.09 (0.15)	0.50
Cultural concerns ^I	-0.19 (0.15)	0.22
Competing concerns ^I	-0.66 (0.11)	<0.0001 *
Logistic concerns ^I	-0.04 (0.15)	0.77
Desire for more information about GC ^I	0.09 (0.16)	0.58
Positive attitudes about GC ^I	0.05 (0.02)	0.02 *
Knowledge about GC ^I	0.01 (0.02)	0.40
Heard/read about GC ^I	0.10 (0.06)	0.10 *
Perceived risk (likelihood of carrying a BRCA1/2 mutation)	0.23 (0.07)	0.002 *
Acculturation level ^I	-0.16 (0.13) *	0.20
Language Spanish vs. English	0.24 (0.19)	0.21
Nativity		
Foreign born vs. US born	-0.06 (0.21)	0.77
Mothers' nativity Foreign born vs. US born	0.24 (0.30)	0.42
Fathers' nativity Foreign born vs. US born	0.10 (0.36)	0.77
Age	-0.0008 (0.006)	0.90
Education High school vs. HS	0.27 (0.19)	0.15
Household Income \$19,999/year vs. \$20K/yr	0.27 (0.20)	0.18
Marital Status Married/living together vs. Not married/living together	0.22 (0.19)	0.25
Employment Working vs. not working	0.06 (0.10)	0.56
Medical mistrust ^I	-0.003 (0.01)	0.77
Religious faith	0.005 (0.11)	0.96
Family history of breast cancer (first degree) Yes vs. No	-0.05 (0.22)	0.80
Personal history of breast cancer Yes vs. No	-0.02 (0.19)	0.91

Outcome: Intention to Make an Appointment for Genetic Counseling for Breast and/or Ovarian Cancer Risk within the Next 6 Months	B Coefficient/ Parameter Estimate (SE)	Significance (p value)
Primary physician Yes vs. No	0.40 (0.36)	0.27
Insurance status Insured vs. non-insured	-0.27 (0.33)	0.42

*Significance level $p < 0.10$.

¹Where variable is linear and a high score indicates more of the given variable.

Table 5
Final Multivariable Model-Adjusted Predictors Intention to Make an Appointment for Genetic Counseling within the Next 6 Months

Characteristic	β Coefficient/ Parameter Estimate (SE)	p value
Competing concerns	-0.50 (0.13)	0.0002 ^I
Perceived risk of carrying a BRCA1/2 mutation	0.18 (0.07)	0.01 [*]
Positive attitudes about genetic counseling ^I	0.04 (0.02)	0.14
Physician referral for genetic counseling (yes vs. no)	0.46 (0.19)	0.02 [*]
Age	0.001 (0.01)	0.83
Personal diagnosis breast cancer (yes vs. no)	-0.33 (0.22)	0.13
Family history breast cancer (first degree) (yes vs. no)	-0.29 (0.22)	0.19

* Significance level p < 0.10. n=106; $R^2=0.34$ (adjusted $R^2=0.30$). Final model includes variables significant from forward selection procedure (competing concerns, perceived risk, positive attitudes about genetic counseling, physician referral for genetic counseling) plus confounders (none) and any theoretically relevant covariates (age, personal history breast cancer and family history breast cancer (first degree relatives)).

^I Where variable is linear and a high score indicates more of the given variable.