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Awareness and Preferences Regarding *BRCA1/2* Genetic Counseling and Testing Among Latinas and Non-Latina White Women at Increased Risk for Hereditary Breast and Ovarian Cancer

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Abstract

This study was an investigation of awareness, cognitions, and psychosocial and educational needs related to genetic counseling and testing among Latinas and non-Latina whites at increased risk for having a *BRCA1/2* mutation. Sixty-three Latina and eighty-four non-Latina white women completed telephone surveys employing a mixture of quantitative and qualitative questions assessing awareness, benefits, risks, barriers, and genetic counseling communication preferences regarding *BRCA1/2* testing. Among participants who had not previously had genetic counseling/

testing, 56.9% of Latinas (29/51) and 34.8% of non-Latina white participants (24/69) were unaware of the availability of *BRCA1/2* testing. In multivariate logistic regression analysis, Latina ethnicity was the only statistically significant independent factor associated with lack of awareness (OR=0.42; 95% CI=0.19–0.35). No appreciable differences were noted between ethnic groups regarding perceived benefits of *BRCA1/2* testing or desired genetic counseling topics. These findings underscore the importance of increasing awareness of cancer genetic counseling and genetic testing among both Latina and non-Latina white populations.

Keywords

BRCA1 and *BRCA2*; Genetic counseling; Genetic testing; Latinos; Hereditary breast and ovarian cancer; Awareness; Preferences

The association between mutations in the genes *BRCA1* and *BRCA2* and an increased risk for breast and ovarian cancer has been known for approximately 16 years. Women with deleterious mutations in *BRCA1/2* face a lifetime risk of breast cancer ranging from 49% to 82% and a lifetime risk for ovarian cancer of 18%–54% (Antonioni et al. 2003; Chen et al. 2006; Chen and Parmigiani 2007; Evans et al. 2008; King et al. 2003). The National Comprehensive Cancer Network (NCCN) and American Cancer Society (ACS) provide guidelines/recommendations for early screening and cancer prevention measures for individuals with known *BRCA1/2* mutations (ACS 2009; NCCN 2009). Persons with a suggestive personal/family history of breast and/or ovarian cancer are recommended to have a genetics evaluation where they can discuss the implications of *BRCA1/2* testing for themselves and their family (Force 2005). Through this genetics evaluation, individuals are able to proceed with genetic testing, if desired, supported by genetic counselors or other healthcare professionals trained in the interpretation of genetic test results.

Despite *BRCA1/2* testing being available for many years, data are mixed regarding testing awareness among high-risk women with breast or ovarian cancer (Lacour et al. 2008; Peters et al. 2005). Many studies consistently show low levels of cancer genetics testing awareness in general but especially among minority populations (Benjamin-Garner et al. 2002; Lacour et al. 2008; Meischke et al. 2001; Vadaparampil et al. 2006; Wideroff et al. 2003). The reasons for these disparities are varied; lower levels of genetic testing awareness in minority groups have been associated with low levels of acculturation, low income, minimal completed education, and other factors (Benjamin-Garner et al. 2002; Meischke et al. 2001; Vadaparampil et al. 2006; Wideroff et al. 2003).

An increasing research focus has been devoted to exploring why fewer individuals from minority populations pursue *BRCA1/2* testing and assessing the most effective ways to raise awareness and access (Huo and Olopade 2007). However, initial studies in this sector focused primarily on the differences in awareness and perception of *BRCA1/2* testing in the African American population when compared to non-Latino whites (Ford et al. 2007; Halbert 2006). As Latinos are currently the fastest growing minority population in the United States, there is an increasing interest in Latino perspectives in this area (Sussner et al. 2009; Thompson et al. 2003). Particularly concerning, some studies show that Latinos are less likely to have health insurance than non-Latino whites, have lower incomes and mean

levels of education, and utilize preventative healthcare options such as cancer screening less frequently (Bureau 2004; Hubbell et al. 1996; Monheit and Vistnes 2000; Pearlman et al. 1996; Suther and Kiros 2009). Statistics showing that Latina women with breast cancer are more frequently diagnosed at advanced stages than non-Latina white women also suggest barriers regarding cancer screening usage among Latinas (Bentley et al. 1998; Richardson et al. 1992; Zaverchnik 1993).

The impact of these barriers would be magnified for Latina women with *BRCA1/2* mutations. While men with *BRCA1/2* mutations have slightly increased risks for certain cancers (male breast cancer, prostate cancer, etc.) over the average male, the greatest cancer risks posed by *BRCA1/2* mutations affect women. Recent studies indicate *BRCA1/2* mutations account for as many cases of breast and ovarian cancer in Latino populations as in non-Latino whites (Weitzel et al. 2005). Available data indicate that certain specific *BRCA1/2* mutations are more prevalent in Latino subgroups than in other racial/ethnic populations (Mullineaux et al. 2003; Voelker 2009).

Studies exploring Latino attitudes toward and awareness of cancer genetics testing confirm that barriers to awareness and desire for genetic testing among this diverse ethnic population include both socioeconomic factors (cost, lack of insurance) and personal beliefs (fear) (Bowen et al. 2010; Sussner et al. 2009; Thompson et al. 2003). Many of these studies surveyed a mixture of Latinos, both those who would and those who would not be considered at high risk for a hereditary cancer predisposition (Sussner et al. 2009; Thompson et al. 2003). While interest in genetic testing for cancer predispositions has been found to be high in individuals without a significant personal/family history of cancer, such individuals are often not referred for genetics consultation due to the low likelihood of identifying an underlying mutation. This is reflective of consensus-approved guidelines that *BRCA1/2* testing be done in families with suggestive cancer histories (ACS 2009; NCCN 2009).

Ramirez and colleagues (2006) examined awareness, interest, and perceptions regarding genetic testing for breast cancer predisposition among 48 Hispanics (16 men, 32 women) with a spouse or family member with breast cancer. Awareness of genetic testing for breast cancer risk was quite low, with 83% of participants knowing almost nothing or relatively little about this topic yet interest in genetic testing was high (81% of participants interested) (Ramirez et al. 2006). Testing benefits (taking better care of one's health, frequent cancer screening, knowledge about children's cancer risk) outweighed potential risks/limitations (self and family's emotional reactions). Although the majority of participants had a first-degree relative diagnosed with breast cancer, the age at which the relatives were diagnosed is not reported, nor is the presence of absence of additional family cancer history that may be suggestive of a hereditary predisposition. Thus, it is unclear whether the participants in this study are representative of individuals who would be at increased risk for a hereditary breast cancer predisposition.

Purpose of the Present Study

Data regarding perceptions and awareness of cancer genetics testing among Latinos without a striking personal/family history of cancer may not be reflective of the cognitions of Latinos most likely to be referred for cancer genetics evaluation. Thus there is a need for research centering on beliefs/awareness of cancer genetics testing among Latinos representative of the referral population. Also, while recent studies have highlighted cognitions, barriers, and awareness of genetic testing among Latinos, research is lacking regarding how Latinos desire to receive genetic testing information and what cancer genetic counseling/education would be most helpful to them to facilitate informed decision-making regarding testing.

This study seeks to fill these gaps in knowledge by assessing awareness, cognitions, and psychosocial and educational needs related to genetic counseling and testing among Latinas and non-Latina whites at increased risk for having a *BRCA1/2* mutation. There were three major research questions we wished to explore in our study population: (1) Do levels of *BRCA1/2* testing awareness differ among Latina and non-Latina white women? (2) What are the perceived benefits, risks/limitations, and barriers associated with *BRCA1/2* testing? (3) What are women's preferences regarding what risk information/issues regarding *BRCA1/2* testing are most important to discuss with a genetic counselor? This information will help facilitate the development of effective interventions to increase awareness about hereditary breast and ovarian cancer and enhance informed decision-making about genetic testing.

Methods

Design

Participants were recruited to this cross-sectional study through three population-based sites of the National Cancer Institute's (NCI) Cancer Genetics Network (CGN). In 1998, the NCI established the CGN to develop research infrastructure to conduct systematic empirical multi-site investigations on the genetic basis of human cancer susceptibility, integration of this information into medical practice, and behavioral, ethical, and public health issues associated with human genetic discoveries. Once enrolled in CGN, individuals are eligible to participate in future genetics research studies. The Rocky Mountain Cancer Genetics Coalition (RMCGC) CGN sites are based at the University of Colorado, University of New Mexico and the University of Utah. This study was approved by the Institutional Review Boards (IRB) at the University of Colorado, University of New Mexico and the University of Utah.

Participants and Procedures

Individuals were eligible for participation in this study if they were female, aged 18 years and older, and were either enrolled in CGN or were first-degree relatives of CGN enrollees. Eligibility criteria also included: a personal history of breast cancer under age 50 or ovarian cancer diagnosed at any age; a personal history of breast cancer at any age and a family history of breast and/or ovarian cancer in at least one first-degree relative; or having had a

first-degree relative with breast cancer diagnosed under age 50 or ovarian cancer diagnosed under age 60 years. Participants who had already undergone genetic counseling and/or testing for a hereditary cancer predisposition were not excluded from participation.

Each of the three CGN sites mailed a recruitment letter about the study to potentially eligible women. The letter described the study and informed them that research staff would contact them by mail in 2 weeks if they did not return a response form indicating no further contact in a postage-paid envelope. If no objection was received after 2 weeks, women were sent a letter and informed consent document from the last author. The letter described the study and informed potential participants of an upcoming telephone call to describe the study in more detail, elicit interest in study participation, and answer questions. The initial study recruitment letter, follow-up letter and consent forms were available in both Spanish and English.

A trained study interviewer then contacted each woman for a telephone-screening interview. If a contacted woman was eligible and willing to participate, she was instructed to sign the informed consent document previously mailed to her and return it to the study office in a postage-paid envelope. After written informed consent was obtained, a trained interviewer scheduled and conducted a computer-assisted telephone survey between September 2003 and June 2005. The survey consisted of both closed and open-ended questions that the interviewer read to every participant from a prepared, computerized script. The survey was available in English and Spanish; only one participant elected to complete the survey in Spanish. The analyses reported herein are restricted to those participants who completed the survey in English. The survey took approximately 45 min to complete. The cooperation rate (survey completed/survey completed + all eligible persons contacted that declined participation) was 71% (73% for Latinas and 69% for non-Latina Whites).

Measures

Sociodemographics—Pertinent demographic information obtained from participants included age (years), Latino/Hispanic ethnicity (yes, no), education level (completed high school or less vs. college or technical school graduate, household income (<\$30,000 per year vs. >–\$30,000 per year), health insurance status (private, military, public, vs. none), and presence of a regular source of health care (yes, no).

Genetic Risk Perceptions—Perceived risk of being a carrier of a *BRCA1/2* mutation was assessed by asking participants to indicate their likelihood of carrying such a mutation (0 = very unlikely, 1 = unlikely, 2 = moderate chance, 3 = likely, 4 = very likely). Perceived risk was measured as a continuous variable.

Awareness and Attitudes Regarding *BRCA1/2* Testing—We evaluated participants' awareness of *BRCA1/2* testing after reading the following statement:

BRCA1 and *BRCA2* are genes associated with inherited breast and ovarian cancer. Genetic testing involves taking a sample of blood to identify whether or not someone carries a changed gene for inherited breast and ovarian cancer.” Participants were then asked, “Before receiving information about this study had

you heard of a gene test, that is, a blood test to determine inherited risk of breast and ovarian cancer among families? (yes, no).

In addition to these closed-ended questions, participants were also asked open-ended questions that assessed perceptions about benefits, risks, limitations and barriers to *BRCA* gene testing. Questions included: “In your opinion, what do you think is the most important benefit of having a *BRCA* gene test?”; “Can you think of anything negative that could happen to people who have a *BRCA* gene test?”; and “In your opinion, what difficulties do you think might prevent someone from getting a *BRCA* gene test?” Responding to these questions was optional and participants were prompted to identify additional perspectives with queries such as “Can you think of anything else?” Therefore, some participants listed more than one response and some did not respond to these open-ended questions.

Patient-Provider Communication and Utilization of *BRCA1/2* Counseling and Testing—The following information was read to participants prior to asking them about patient-provider communication and utilization of genetic counseling and testing. “Genetic education and counseling refers to the process of discussing your genetic test results with a doctor, nurse, or genetic counselor. It also can involve talking about genetics, the risks, benefits, and limits of genetic testing, and recommendations for prevention and early detection. Genetic education and counseling is also done to help people make informed decisions about whether to take a gene test.”

Participants were asked the following two questions about past patient-provider communication:

“Has a doctor or other health care provider ever talked to you about gene testing for breast and ovarian cancer? (yes, no)”. Participants were asked if they ever had genetic education and counseling regarding their family history of breast and ovarian cancer and whether or not they had *BRCA1/2* testing (yes, no).

Several questions were asked to assess preferences regarding genetic education, counseling and testing. Participants were asked their preference regarding the type of provider they would like to receive genetic education, counseling and testing from (primary care doctor or cancer genetic specialist). They were also asked how far they would be willing to travel each way to see a genetic specialist (<30 min; 1 h; 1.5–2 h; more than 2 h). An open-ended question was asked to elicit communication needs regarding genetic counseling. “If you were to have genetic education and counseling, what things would you like to talk to them [cancer genetic specialist] about?”

Data Analysis

Statistical analysis of close-ended questions was performed using SPSS Version 17 (SPSS, Inc., Chicago, IL). Descriptive statistics were generated for participant sociodemographics and psychosocial factors. Pearson’s Chi-square tests and t-tests were employed to compare responses by ethnicity. Bivariate analysis was done to examine awareness of *BRCA1/2* testing by demographic (age, education level, income, ethnicity), health care access (regular source of health care and health insurance status), and personal history of breast and/or

ovarian cancer. *P*-values were adjusted using the Benjamini & Hochberg step-up false discovery rate (FDR) controlling procedure (Benjamini and Hochberg 1995). Logistic regression analysis was used to calculate odds ratios (ORs) and 95% confidence intervals (CIs) and determine factors independently associated with lack of awareness of the availability of *BRCA1/2* testing. Any variable having bivariate associations of unadjusted $p < .20$ with testing awareness was a candidate for entry into the logistic model. Backwards elimination procedures were used to determine which variables ($p < .10$) to retain in the final model. Generalized estimating equations were used to fit a random effect to account for potential correlation between observations among family members; these effects were nonsignificant by likelihood ratio testing. In an exploratory manner, we conducted bivariate analyses to determine if informational preferences differed by ethnicity. A *p*-value less than .05 was considered significant.

Responses to open-ended questions were recorded and transcribed by a professional transcriptionist. A qualitative content analysis was then used to analyze the data for each question for all respondents combined, by ethnic subgroup, and by personal cancer status (Crabtree and Miller 1992; Miles and Huberman 1994). A content based analysis was chosen for the analysis of open-ended questions because it provides not only qualitative aspects of the data but also quantitative (Crabtree and Miller 1992). In other qualitative techniques such as interviews or focus groups, the interviewer can probe responses for a richer, more detailed explanation of what is said by the participants. This places more emphasis on the richness of the data rather than the frequency of what is discussed by the participants (Rubin and Rubin 2005). Open-ended questions are more limited in that the interviewer is not probing for additional detail about what is said but is trying to capture information that can be missed with closed-ended questions (Creswell 2009). Therefore, providing quantitative aspects along with the qualitative aspects of the data can allow greater understanding of the most prevalent reported concerns or ideas and also provide some contextual description about them (Bates et al. 2005).

A distinguishing feature of content analytic approaches is the use of a consistent set of codes to designate data segments that contain similar material (Morgan 1993). After coding is complete, the codes are sorted into meaningful categories based on how codes are related and linked along with re-contextualizing of the data to identify patterns (Tesch 1990). Summarizing the codes is the first component; the second component involves further examination of the data to explain why these patterns occur in this manner. The codes were developed by the second author, an experienced behavioral scientist, and the third author, a trained research assistant by reading all data several times to achieve immersion and a deep understanding of the text as a whole and the interpretation of its parts (Tesch 1990). The two coders then independently applied the codes to the data. To verify inter-rater reliability, approximately 20% of the data were coded by both individuals, resulting in an overall .94 intra-class correlation coefficient. Exemplar quotations for selected codes were chosen by the coders to contextualize participants' responses.

Results

Analysis of Close-Ended Questions

Sociodemographics and Clinical Data—Sociodemographic and clinical data for the 147 women ($n=63$ Latinas, $n=84$ non-Latina whites) representing 118 families who completed the telephone survey are summarized in Table 1. Latinas and non-Latinas were similar with regard to education level and insurance status. Latinas reported lower household incomes and were less likely than non-Latinas to have had cancer; these differences approached significance ($p = 0.06$ and $p = 0.05$, respectively). A similar proportion of Latinas and non-Latina whites reported receiving information about the availability of *BRCA1/2* testing from a health care provider. The proportion of Latinas and non-Latina whites that had already received breast/ovarian cancer genetic counseling or *BRCA1/2* testing was also similar. Only about 18% of the total sample reported having had breast / ovarian cancer genetic counseling, and the same proportion reported having *BRCA1/2* testing. Latinas who had not previously received genetic counseling or testing reported lower levels of perceived risk of having a *BRCA1/2* mutation than non-Latina whites (mean=2.94 vs. mean=3.43).

Awareness

Latinas (56.9%) who did not report utilization of breast/ovarian cancer genetic counseling and testing services were less likely to be aware of the availability of *BRCA1/2* testing ($p=0.01$) than their non-Latina counterparts (34.8%). The results of the bivariate analysis of factors associated with testing awareness are provided in Table 2. Factors significantly associated with testing awareness were Latina ethnicity ($p=0.01$) and age ($p=0.001$). Factors meeting the criteria for entry into the logistic regression model were: ethnicity, age and personal history of breast and/or ovarian cancer. Latino ethnicity was the only statistically significant independent factor associated with lack of awareness about testing availability (OR=0.42; 95% CI=0.19–0.85). Age was also retained in the final logistic regression model (OR=1.03; CI=1.00.–1.06) (Table 3).

Genetic Counseling/Education Preferences—As shown in Table 4, responses regarding genetic counseling preferences did not differ by ethnic group. The vast majority of participants (85%) indicated that they preferred to receive information about hereditary cancer risk and *BRCA1/2* testing from a cancer genetic specialist than their regular health care provider. Approximately half of the participants indicated that they would prefer a family member to be present during genetic counseling sessions. Forty-four percent of participants indicated that they would not be willing to drive more than an hour each way for clinical cancer genetic services.

Analysis of Open-Ended Questions

Atlas.ti was used to help analyze the data. This software program allows one to query all coded data and separate the coded data by variables of interest. In this study, the coded data were reviewed overall, by ethnicity and cancer status. The three most commonly reported benefits, risks/limitations, barriers, and topics to discuss with genetic counselor were the same across ethnicity and cancer status.

Benefits of BRCA1/2 Testing—The most commonly reported benefit overall and by ethnicity was informing other family members about their cancer risk (Table 5.). Daughters were the most frequently cited family members that the participant would inform of test results, but other members such as nieces, aunts, sisters, grandchildren and sons were also mentioned. A few quotes that contextualize this perspective include: “Just for protection and awareness for my family”; and “Knowing if something could be passed on to my daughter.” The second most commonly reported benefit was the benefit of enhanced prevention and screening behaviors. Quotes supporting this perspective included: “Maybe help you be more vigilant about mammograms”; and “Preparing for the best preventative methods you can use”. The third most commonly cited testing benefit was personal knowledge and awareness of carrier status (“I guess to see if I could inherit it since my mom died from it”; and “To see if I carried the gene.”).

The most prevalent benefits for women with and without cancer were also informing family members of their cancer risks and prevention/early detection (see Table 6).

Risks/Limitations of BRCA1/2 Testing—Both Latinas’ and non-Latina whites’ two most commonly reported concerns about genetic testing were potential emotional distress and worries about making unnecessary treatment decisions on the basis of positive test results. Emotional distress, the most commonly reported risk/limitation of testing, encompassed worry, anxiety and stress. For example, one participant mentioned, “It drives them [women who seek genetic testing] bananas if they can’t handle knowing that they have that.” Other comments include: “It might scare you to death.”; and “I would think that I would just worry twice as much about it.” Participants’ comments regarding the concern over making unnecessary/unfavorable treatment decisions if the test was positive included: “I think that you could be setting yourself up for something that is not necessarily going to happen in your life”; and “I think having to make decisions about prophylactic surgery is really negative.” Additional cited risks and limitations are listed in Table 5.

Per Table 6, women with and without a personal history of cancer also most commonly cited concerns about possible emotional distress as a risk or limitation of *BRCA1/2* testing.

Barriers to BRCA1/2 Testing—The two most commonly reported barriers to *BRCA1/2* testing were fear and financial concerns by ethnicity and cancer status. Concern about testing availability was the third most commonly cited barrier by both Latinas and non-Latina whites.

Cost (i.e., out-of-pocket expenses) was the most commonly reported barrier overall (38.4% of total). Participants identified that genetic testing for *BRCA1/2* was expensive and that for many of the respondents, their insurance did not cover the costs. The second most frequently cited barrier overall was fear (31.3% of total). Many of the respondents indicated they did not want to know or were fearful that testing would reveal the presence of a deleterious mutation. For example, some participants mentioned: “Fear of the unknown”; and “Be afraid of what the results would be.” The third most frequently cited barrier was availability of the *BRCA1/2* test in terms of access, transportation, and healthcare providers discussing it (16.1% of total). Quotes that supported this perspective include: “Lack of access to hospital,

doctors, oncologists.”; and “The availability, ‘oh we don’t’ do that here, you have to go over here’ and you have to schedule this’.”

Genetic Counseling Preferences—When asked about what information they would most like to discuss with a genetic specialist, family issues (32.4% of Latinas and 39.6% of non-Latina whites) and requests for advice (35.1% of Latinas and 31.3% of non-Latina whites) were the two most commonly cited topics cited for both groups. A desire to learn more specific information about *BRCA1/2* testing was the third most common topic cited by both Latinas and non-Latina whites (21.6% vs. 18.8%).

The impact of a personal cancer diagnosis revealed the most noticeable differences with regard to preferences for discussion topics (Table 6). Women with cancer strongly prioritized a desire to talk about family issues (52.3%) over personal advice (22.7%) or specific information about the *BRCA1/2* test (15.9%). In contrast, women with no personal diagnosis of cancer were more often interested in requesting advice (43.9%) and information about the *BRCA1/2* test (24.4%) from a genetic specialist, than in discussing family issues (19.5%).

Discussion

This is among the first studies to use a mixed methodology to assess awareness of and beliefs about genetic counseling and testing for *BRCA1/2* mutations among Latinas and non-Latina white women at increased risk for hereditary breast and ovarian cancer. By utilizing a combination of open-ended and closed questions in our interviews, we were able to elicit a wide range of responses from participants. We also assessed their preferences regarding the type of genetic cancer risk information that is most important to them and how they would best like to receive cancer genetics education and counseling. Overall, there were more similarities between the surveyed Latina and non-Latina white women’s responses than appreciable differences. However, the level of awareness of *BRCA1/2* testing was significantly different among our Latina and non-Latina white participants, such that 56.9% of Latinas and 34.8% of non-Latina whites were unaware of the availability of genetic testing.

We observed more similarities than differences with regard to Latina and non-Latina white participants’ responses. This may be due to the lack of significant sociodemographic differences between the two groups; Latinas and non-Latina white women had similar levels of education and insurance status. The Latina participants reported a relatively high frequency of insurance coverage and higher annual income level compared to national averages for Latinos (Bureau 2004; Monheit and Vistnes 2000). Only one Latina participant in this study requested to complete the Spanish-language version of the telephone survey (data excluded from analyses). Previous studies examining the awareness of and/or attitudes and beliefs regarding genetic testing for cancer predisposition among Latinos (e.g., Heck et al. 2008; Pagan et al. 2009; Sussner et al. 2009; Thompson et al. 2003) included a higher proportion of participants with Spanish language preference, from lower socioeconomic strata, and/or without health insurance, compared to the present participants. Perhaps the sociodemographic similarities between the two ethnic groups in this study affect different aspects of the genetic counseling/testing experience to varying degrees.

Lower levels of cancer predisposition genetic testing awareness among Latinos when compared to non-Latino whites in the U.S. have been reported in other studies. Pagan et al. (2009) analyzed 2005 National Health Interview Survey (NHIS) data and reported a discrepancy in cancer predisposition genetic testing awareness between Latinos and non-Latino whites similar to the difference observed in this study (Pagan et al. 2009). Pagán et al. found that most of this awareness discrepancy could be attributed to differences in education levels and nativity/length of time lived in the U.S. In their study, higher education levels and being born in the U.S., or having lived there for 15 years or more were both strongly correlated with a higher likelihood of genetic testing awareness. Heck et al. (2008) examined data from both the 2000 and 2005 NHIS, observed similar associations with education level and length of time lived in the U.S.; they also reported higher levels of genetic testing awareness among Hispanics who spoke mostly or only English.

The present sample of Latina and non-Latina white participants had similar education levels, and all participants included in data analyses completed the telephone survey in English. Yet there was still a disparity in genetic testing awareness between Latinas and non-Latina white women. The presence of this continued disparity in genetic testing awareness despite the sociodemographic and survey language preference similarities among our Latina and non-Latina white participants suggests that other factors are playing a role in this ethnic disparity.

There were small differences observed between Latinas' and non-Latina whites' responses to open-ended questions that elicited concerns about testing may also be due to the different proportions of individuals with personal cancer diagnoses in each group. However, overall the top three responses to the open-ended questions were similar across ethnicity.

Research Recommendations

Fear is a common concern associated with *BRCA1/2* testing (Ford et al. 2007; Kinney et al. 2010). Our participants' citing of fear as a barrier may be somewhat interconnected with their reporting of emotional distress as a risk of receiving a positive test result. Their fear may be a desire to avoid this emotional distress.

Some of our participants' statements regarding fear indicate that fear may stem from a lack of knowledge/awareness (i.e. "fear of the unknown") and could be addressed through further *BRCA1/2* education. Genetic counselors are trained to provide anticipatory guidance to individuals considering *BRCA1/2* testing, to help them think through possible outcomes prior to having genetic testing. Encouraging genetic counseling prior to genetic testing may help to address some individuals' fears.

Fear about genetic testing may also be related to fatalistic attitudes about cancer. Such attitudes have been reported to be more prevalent in Latinos than in non-Latino whites. For example a belief in the inability to alter the course of cancer may generate fearful emotions about one's susceptibility to cancer (Vadaparampil et al. 2010). Educational interventions that increase awareness about preventive options (e.g., chemoprevention and prophylactic surgery) for high-risk individuals and improved cancer treatments when cancers are caught early through screening may help to reduce fatalistic attitudes. However, more research is

needed to explore the root causes of these fears regarding *BRCA1/2* testing and learn from women directly what they feel would help them to overcome their fears.

Fear of insurance discrimination has been reported in many studies as a concern surrounding genetic testing and was cited by our participants (Lowstuter et al. 2008; Rose et al. 2005). Some studies have noted reluctance among physicians to refer patients for genetic testing due to concerns their patients will experience genetic discrimination (Lowstuter et al. 2008). This may lead to lower levels of awareness about *BRCA1/2* testing and could be exacerbated in a minority population that is less likely to be insured. The present study was completed prior to the passing of GINA, the Genetic Information Non-Discrimination Act in 2008. GINA provides protection against discrimination by health insurance companies and employers on the basis of genetic test results (Baruch and Hudson 2008). Further studies are needed to assess awareness of GINA's protections both among physicians and the public at large to examine for associated reduction in discriminations fears/increase in referral for/uptake of genetic testing.

Both Latinas and non-Latina whites cited concerns that the financial cost of *BRCA1/2* testing would be prohibitive and that their insurance would not cover the cost. Unfortunately the data preclude determination of whether these women had received this information from their insurance companies or whether it was an assumption based on past coverage experiences and/or knowledge about the cost of the test. As financial concerns have often been cited as barriers to *BRCA1/2* testing, assessing current levels of insurance coverage for *BRCA1/2* testing among various insurance companies would be another avenue for future research (Ford et al. 2007; Kinney et al. 2010).

Practice Implications

When asked what they would most like to discuss with a genetic counselor/specialist, the two most common responses from Latinas and non-Latina whites were family issues and requesting advice. Various types of family information were desired, ranging from risk information for their relatives to how to inform family members about a positive test result and how their relatives could obtain testing. This strong desire for assistance with family communication of cancer genetic test results is supported by prior research (MacDonald et al. 2008). These results also dovetail with the Latina and non-Latina white women participants' most frequently cited benefit of *BRCA1/2* testing: being able to inform other family members about cancer risk after testing. Informing family members has been previously reported as an important factor in women's decision-making regarding *BRCA1/2* testing (Barsevick et al. 2008; MacDonald et al. 2008; Mellon et al. 2006).

The emphasis on informing close female relatives of *BRCA1/2* test results is also congruent with prior studies of *BRCA1/2* results dissemination within families (Barsevick et al. 2008). This communication pattern is consistent with the higher *BRCA1/2*-associated cancer risks in women than men. These findings reflect the need for genetic counselors/healthcare providers to provide information to patients highlighting male transmission of *BRCA1/2* mutations and associated male cancer risks. These aspects of *BRCA1/2* mutations have significant implications, but are potentially less readily apparent to families initially learning about hereditary breast and ovarian cancer.

The range of family risk and communication information desired by our participants also underscores the need for adequate time to address patients' family needs at the time of genetic counseling/genetic test results disclosure. Prior studies have identified barriers to cancer risk communication in families, including secrecy and stigma (Kinney et al. 2010). An increasing body of research is focusing on the issue of how individuals disseminate *BRCA1/2* test results to relatives, with the hope of identifying ways in which health care providers can assist in the process and help overcome barriers (Clarke et al. 2008; Koehly et al. 2009).

Study Strengths and Limitations

A key strength of this study is recruitment of individuals with a personal or family history suggestive of an underlying *BRCA1/2* mutation. All of the women in the sample would have been appropriate to refer for genetic counseling to learn more information about hereditary risk, medical management and *BRCA1/2* testing. Prior studies have included many or a majority of women with no personal or known family history of cancer (Sussner et al. 2009; Thompson et al. 2003). Thus, data from this study are valuable for helping genetics professionals tailor the information they provide to women who stand to benefit the most from *BRCA1/2* testing.

Another study strength was the inclusion of open-ended questions in the telephone survey. Rather than giving participants a list of commonly perceived benefits/risks of *BRCA1/2* testing and asking for their level of agreement/disagreement, we were able to capture a wide range of responses. A potential limitation of this format, however, is that some individuals may not have thought of certain benefits/risks that, had they been given a list, would have ranked as important.

Limitations of our study should be considered when interpreting the findings. Having only "yes" or "no" responses available to the questions regarding awareness of genetic testing (being personally aware and whether or not a healthcare provider had ever discussed genetic testing with the individual) may have limited the responses we received. Some individuals may have been unsure whether or not they had previously heard of genetic testing for cancer predisposition, but had to make a definitive answer in order to complete the question. Incorporating an option for participants to answer "not sure" to these questions may have altered our testing awareness data and provided a more nuanced understanding of the topic.

It is both a study strength and limitation that Latinas and non-Latinas showed no striking sociodemographic differences. As aforementioned, prior national surveys and smaller regional studies targeting Latinos included a higher proportion of participants in lower socioeconomic strata and without health insurance than the participants in this study (DeNavas-Walt et al. 2009; Heck et al. 2008; Pagan et al. 2009; Thompson et al. 2003; Wagner et al. 2001). Thus the present findings may not be representative of the U.S. population of high-risk Latinas. However, they do begin to fill a gap in the literature by providing more detailed information about the awareness/attitudes/beliefs of Latinas whose health insurance, education levels, and language preferences are similar to non-Latina white women, rather than focusing on underserved Latina populations. Future research should seek to recruit Latinas at increased risk for hereditary cancer predisposition from disparate areas

of the U.S. encompassing both rural and densely populated urban populations to obtain the widest range of the socioeconomic spectrum.

This study did not directly examine effects of acculturation on perceptions of *BRCA1/2* testing or preferences for provision of genetic counseling. As discussed previously, the similarities in participants' sociodemographic characteristics and language preferences point toward a higher level of acculturation among the Latina population compared to those studied in other research (cf. Sussner et al. 2009). Acculturation is a complex concept encompassing multiple factors, some of which were not assessed in this study (such as nativity/length of U.S. residency).

The sampling frame used in this study may have resulted in enrollment of Latinas with high levels of acculturation. While all printed materials for this study (letters/consent forms) were available in both Spanish and English, all study participants were recruited from CGN. The three CGN sites from which study participants were recruited (Utah, Colorado, New Mexico) were not uniform in whether or not the initial CGN enrollment materials were available in both Spanish and English or if translators were available to facilitate bilingual enrollment by telephone. The differences in CGN recruitment may have thus played a role in attracting Latina participants who overwhelmingly expressed an English language preference for the study's survey. This may limit the applicability of the results to Latinas who have more recently arrived in the United States and/or who lack fluency in English. However, bias was probably minimized by the use of three CGN sites that employed population-based recruitment and had some capacity for facilitating Spanish-speaking recruitment.

Conclusions

The results of this study suggest Latinas and non-Latina white women at increased risk for hereditary breast and ovarian cancer have many similar beliefs and perceptions regarding *BRCA1/2* testing. Both Latinas and non-Latina whites frequently mentioned potential family benefits from *BRCA1/2* testing and most were interested in receiving more information about family cancer risk and how to effectively disseminate genetic test results and risk information to relatives. Some of the similarities between the two groups may stem from shared sociodemographic factors (education level, insurance status, language preference).

Some differences emerged when stratifying individuals based on personal cancer history rather than ethnicity with regard to genetic counseling information preferences. Women who have completed cancer treatment (or have metastatic disease) may feel their families will reap the most benefit from *BRCA1/2* test results (Brandt et al. 2002; Vadaparampil et al. 2008). Our results support the observation that high-risk women with no personal history of cancer prioritize different information relating to cancer genetics risk assessment and *BRCA1/2* testing than women who have had cancer themselves (Brandt et al. 2002). The informational needs of unaffected women may change over time as they learn and act upon appropriate screening/risk-reducing recommendations based on their *BRCA1/2* test results. The data support tailoring genetic cancer risk information provided to women based on their personal cancer status.

A disparity in awareness about *BRCA1/2* testing emerged between Latinas and non-Latina-whites in this study. These results are consistent with prior studies demonstrating lower levels of *BRCA1/2* testing awareness among minority groups compared to non-Latina whites in the USA (Ford et al. 2007; Halbert 2006; Thompson et al. 2003). Results from this study underscore the importance of clinicians' and health care organizations' utilization of community engagement strategies with local minority populations to determine optimal ways to increase awareness of family history and cancer risk, genetic counseling and testing availability (Kinney et al. 2010), and to implement culturally acceptable clinical and public health genomic programs. However, the present data also support findings from prior studies illustrating the problem of cancer predisposition genetic testing awareness in the U.S. is not confined to minority populations (Heck et al. 2008; Pagan et al. 2009). It is noteworthy that approximately one-third of the surveyed non-Latina white women at increased risk for hereditary breast and ovarian cancer were unaware of *BRCA1/2* testing. These findings emphasize the need for all at-risk individuals to be better informed about the availability of genetic counseling and testing for hereditary cancer predispositions.

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Table 1

Distribution of sociodemographic, psychosocial and health care characteristics and bivariate relationships by ethnicity^a

Variable	Total sample (N=147) n (%)		Latinas (n=63)		Non-Latina Whites (n=84)		p value	Adjusted p value ^c
Personal history of breast and/or ovarian cancer								
Yes	86 (58.5)		29 (46.0)		57 (67.9)			
No	61 (41.5)		34 (54.0)		27 (32.1)		0.01	0.05
Education								
HS grad or less	47 (31.97)		23 (38.33)		24 (27.59)			
More than HS grad	100 (68.03)		37 (61.67)		63 (72.41)		0.17	0.34
Household income								
<30 K	31 (21.5)		17 (29.3)		14 (16.3)			
30 K	113 (78.5)		41 (70.7)		72 (83.7)		0.06	0.15
Health insurance								
Yes	139 (95.1)		56 (94.9)		83 (95.4)			
No	7 (4.79)		3 (5.0)		4 (4.60)		1.00	1.00
Health care provider informed participant about the availability of <i>BRCA1/2</i> testing								
Yes	30 (20.4)		11 (17.5)		19 (22.6)			
No	117 (79.6)		52 (82.5)		65 (77.4)		0.44	0.63
Awareness of the availability of <i>BRCA1/2</i> testing ^b								
Yes	67 (55.8)		22 (43.1)		45 (65.2)			
No	53 (44.2)		29 (56.9)		24 (34.8)		0.01	0.05
Prior hereditary breast cancer genetic counseling								
Yes	27 (18.4)		12 (19.0)		15 (17.9)			
No	120 (81.6)		51 (81.0)		69 (82.1)		0.51	0.64
Had <i>BRCA1/2</i> testing								
Yes	27 (18.4)		12 (19.0)		15 (17.9)			
No	120 (81.6)		51 (81.0)		69 (82.1)		0.22	0.37
Mean (SD)								
Age (years)	54.5 (12.4)		52.7 (11.1)		55.9 (13.3)		0.62	0.69

Variable	Total sample (N=147) n (%)	Latinas (n=63)	Non-Latina Whites (n=84)	p value	Adjusted p value ^c
Perceived likelihood of having a <i>BRCA1/2</i> mutation (1 = very unlikely to 5 = very likely) ^b	3.29 (1.26)	2.94 (1.21)	3.43 (1.14)	0.03	0.10

^aNumbers are smaller for those variables with missing values

^bExcludes women who have had *BRCA1/2* genetic counseling and/or testing

^cAdjusted for multiple significance testing

Bivariate associations between genetic testing awareness and sociodemographic, psychosocial and clinical characteristics^{a, b}

Table 2

Variable	Not aware of <i>BRCA</i> testing (n=53) n %	Aware of <i>BRCA</i> testing (n=67) n %	p value	Adjusted p value ^c
Ethnicity				
Latina	29 (54.7)	22 (32.8)		
Non Latina White	24 (45.3)	45 (67.2)	0.01	0.04
Personal history of breast and/or ovarian cancer				
Yes	24 (45.3)	41 (61.2)		
No	26 (54.7)	26 (38.8)	0.06	0.16
Education				
HS grad or less	18 (34.0)	21 (31.3)		
More than HS grad	35 (66.0)	46 (68.7)	0.46	0.53
Household income				
<30 K	11 (19.6)	15 (22.4)		
>=30 K	41 (80.4)	52 (77.6)	0.48	0.53
Health insurance				
Yes	46 (86.8)	59 (88.1)		
No	7 (5.08)	8 (10.9)	0.52	0.53
Health care provider informed participant about the availability of <i>BRCA</i> /2 testing				
Yes	15 (28.3)	18 (27.3)		
No	38 (71.7)	48 (72.7)	0.53	0.53
Age (years)	57.2 (11.1)	54.5 (12.9)	0.001	0.008
Perceived likelihood of having a <i>BRCA</i> /2 mutation (1 = very unlikely to 5 = very likely)	3.27 (1.24)	3.05 (1.20)	0.33	0.53

^aNumbers are smaller for those variables with missing values^bExcludes women who have had *BRCA*/2 genetic counseling and/or testing^cAdjusted for multiple significance testing

Table 3

Final logistic regression model for factors associated with BRCA1/2 testing awareness

Factors independently associated with genetic testing awareness	Odds Ratio (OR)	95% Confidence Interval (CI)
Latina Ethnicity	0.42	0.19–0.85
Age	1.03	1.00–1.06

Table 4
Distribution of genetic risk communication preferences and bivariate relationships with ethnicity

Variable	Total sample (N=147) n (%)	Latinas (n=60)	Non-Latina Whites (n=87)	p value
Prefer to have family members present during genetic counseling sessions				
Yes	76 (52.8)	36 (60.0)	40 (47.6)	0.14
No	68 (47.2)	24 (40.0)	44 (52.4)	
Clinician preference for genetic counseling & testing				
Primary care provider	22 (14.9)	11 (18.3)	11 (12.7)	0.15
Genetic specialist	125 (85.1)	49 (81.7)	76 (87.3)	
Maximum distance willing to drive (one way) to a Cancer Genetic Specialist for education, counseling and testing				
<30 min	38 (25.8)	14 (16.2)	24 (28.6)	0.79
31–60 min	27 (18.4)	12 (19.0)	15 (17.9)	
61–120 min	28(19.0)	14 (22.2)	14 (16.7)	
>120 min	54 (36.7)	23 (36.5)	31 (36.9)	

Table 5

Results of content analysis of open-ended questions^{a,b}

Variable and coded responses	Non-Latina Whites n (%)	Latinas n (%)	Total N (%)
Perceived benefits of <i>BRCA1/2</i> testing			
Inform family members	61 (33.0)	40 (37.7)	101 (34.7)
Prevention/early detection	61 (33.0)	33 (31.1)	94 (32.3)
Knowledge/awareness	27 (14.6)	18 (17.0)	45 (15.5)
Contribute to research	9 (4.9)	5 (4.8)	14 (4.8)
Uncertain/don't know	10 (5.4)	3 (2.8)	13 (4.5)
Make healthy lifestyle changes	7 (3.8)	2 (1.9)	9 (3.1)
Peace of mind	5 (2.7)	3 (2.8)	8 (2.7)
Perceived risks and limitations of <i>BRCA1/2</i> testing			
Emotional distress if the test was positive	37 (42.5)	21 (55.3)	58 (46.4)
Unnecessary treatment decisions	15 (17.2)	4 (10.5)	19 (15.2)
Insurance discrimination	15 (17.2)	3 (7.9)	18 (14.4)
Becoming fatalistic	7 (8.0)	3 (7.9)	10 (8.0)
Guilt from passing it on	3 (3.4)	3 (7.9)	6 (4.8)
Inaccurate results	3 (3.4)	1 (2.6)	4 (3.2)
Barriers to <i>BRCA1/2</i> testing			
Financial burden to pay for test	59 (41.3)	22 (32.4)	81 (38.4)
Fear	41 (28.7)	25 (36.8)	66 (31.3)
Lack of availability	24 (16.8)	10 (14.7)	34 (16.1)
Lack of awareness	18 (12.6)	9 (13.2)	27 (12.8)
Don't know	1 (0.7)	1 (1.5)	2 (0.9)
Cultural barriers	0 (0.0)	1 (1.5)	1 (0.5)
Desired topics to discuss with a genetic specialist			
Family issues (i.e. risks and sharing of results)	19 (39.6)	12 (32.4)	31 (36.5)
Advice	15 (31.3)	13 (35.1)	28 (32.9)
Specific information about <i>BRCA1/2</i> test	9 (18.8)	8 (21.6)	17 (20.0)
Personal risk estimates	3 (6.3)	3 (8.1)	6 (7.1)
I don't know	1 (2.1)	1 (2.7)	2 (2.4)

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Variable and coded responses	Non-Latina Whites <i>n</i> (%)	Latinas <i>n</i> (%)	Total <i>N</i> (%)
Lifestyle changes	1 (2.1)	0 (0.0)	1 (1.2)

Percentages refer to total responses received. Some infrequent responses not included in this table
a *n*'s total > sample size because participants' responses could be coded into multiple codes
b

Table 6

Content analysis of open-ended questions stratified by cancer status^{a,b}

Variable and coded responses	Affected <i>n</i> (%)	Unaffected <i>n</i> (%)	Total <i>N</i> (%)
Perceived benefits of <i>BRCA1/2</i> testing			
Inform family members	66 (39.1)	35 (28.7)	101 (34.7)
Prevention/early detection	49 (29.0)	45 (36.9)	94 (32.3)
Knowledge/awareness	29 (17.2)	16 (13.1)	45 (15.5)
Contribute to research	11 (6.5)	3 (2.5)	14 (4.8)
Not sure about any benefits	4 (2.4)	9 (7.4)	13 (4.5)
Improved lifestyle	1 (0.6)	8 (6.6)	9 (3.1)
Peace of mind	5 (3.0)	3 (2.5)	8 (2.7)
Limitations and risks of testing			
Emotional distress	36 (42.9)	22 (53.7)	58 (46.4)
Unnecessary treatment decisions	14 (16.7)	5 (12.2)	19 (15.2)
Insurance discrimination	14 (16.7)	4 (9.8)	18 (14.4)
Becoming fatalistic	9 (10.7)	1 (2.4)	10 (8.0)
Guilt from passing it on	4 (4.8)	2 (4.9)	6 (4.8)
Inaccurate results	3 (3.6)	1 (2.4)	4 (3.2)
Barriers			
Financial	45 (37.8)	36 (39.1)	81 (38.4)
Fear	39 (32.8)	27 (29.3)	66 (31.3)
Availability	21 (17.6)	13 (14.1)	34 (16.1)
Lack of awareness	13 (10.9)	14 (15.2)	27 (12.8)
Don't know	1 (0.8)	1 (1.1)	2 (0.9)
Cultural barriers	0 (0.0)	1 (1.1)	1 (0.5)
Desired topics to discuss with a genetic specialist			
Family issues (i.e. risks and sharing of results)	23 (52.3)	8 (19.5)	31 (36.5)
Advice	10 (22.7)	18 (43.9)	28 (32.9)
Specific information about <i>BRCA1/2</i> test	7 (15.9)	10 (24.4)	17 (20.0)
Personal risk estimates	3 (6.8)	3 (7.3)	6 (7.1)

Affected = personal diagnosis of cancer

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Unaffected = no personal diagnosis of cancer

Percentages are of total responses received. Some infrequent responses not included in this table

b_i n_i 's total > sample size because participants' responses could be coded into multiple codes