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## Genetic Counseling for Hereditary Breast and Ovarian Cancer Among Puerto Rican Women Living in the United States

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### Abstract

**Background**—Little is known about barriers to Hereditary Breast and Ovarian Cancer (HBOC) genetic counseling among Puerto Rican women.

**Objective**—This study reviews existing literature to identify individual, interpersonal, and systems level factors that may impact the use of HBOC genetic services among Puerto Rican women living in the United States.

**Methods**—A systematic search of articles published between the years 1995–2014 was performed in PubMed and ISI Web of Science. Additionally, the bibliography of relevant articles was reviewed for additional potential articles.

**Results**—Individual level barriers most frequently identified included: a lack of knowledge or awareness about HBOC or genetic counseling and testing, and facilitators included high levels of interest in genetic counseling/genetic testing. Interpersonal level barriers included worry about knowing a family member’s risk, and conversely, a facilitator was the ability to help family members. Systems level barriers included concerns about the cost, having competing life demands, whereas facilitators included holding private insurance.

**Conclusion**—Puerto Rican women are a unique ethnic minority group with specific perceptions, beliefs and levels of education about genetic counseling and testing for HBOC. Addressing individual, interpersonal and systems level factors unique to this group may improve knowledge and awareness. Policy and structural changes may be needed to improve system level barriers.

### Keywords

Cultural factors; genetic counseling; genetic testing; hereditary breast cancer; hereditary ovarian cancer; latinos; puerto ricans

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#### CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

#### PATIENT CONSENT

Declared none.

## INTRODUCTION

According to estimates from the United States (US) Census Bureau, [1] approximately 54 million Latinos live in the US as of 2013, accounting for 17% of the total US population. Current estimates suggest the Latino population will reach 31% by 2060, [2] making Latinos the fastest-growing and largest US minority population. However, Latinos are an ethnically and racially diverse group with origins in Mexico, the Caribbean, Central or South America, and Spain [2]. Although data on these groups is often presented in the aggregate, each differ with regard to demographic, cultural, and clinical factors [3–5]. For example, Puerto Ricans are the second largest Latino resident population in the US, [6] and in the past three years, more Puerto Ricans left the island of Puerto Rico for the US than in the previous three decades combined [7]. Puerto Ricans are more likely than other Latino populations in the US to be proficient in English and achieve higher levels of education, but have a lower overall median household income [7]. Related to health disparities, Puerto Ricans reported the poorest health status and highest prevalence of several acute and chronic medical conditions, compared to non-Latino whites and other Latino subgroups [8].

Breast cancer is the most commonly diagnosed cancer among all women in the US, including Latinas, and is the leading cause of cancer death among Latina women [9]. Although ovarian cancer accounts for only 3% of cancers in all women, the mortality rate (~70%) of ovarian cancer is higher than for any other cancer of the female reproductive system [10]. After Black women and White women, women of Latina origin have the third highest ovarian cancer incidence and mortality rates [10]. Despite relatively lower incidence rates, Latinas tend to be diagnosed at later stages of cancer resulting in poorer prognosis and survival [11].

While multiple genes may confer inherited cancer risk [12], *BRCA* mutations (genes linked to Hereditary Breast and Ovarian Cancer [HBOC] syndrome) are the most prevalent and penetrant mutations, accounting for the majority of hereditary breast cancers [13]. Carrying a *BRCA* mutation results in an increased lifetime risk of breast cancer of up to approximately 60 – 70% [14–16] and lifetime ovarian cancer risk of up to 40% [14, 16]. A recent study by Weitzel and colleagues indicated a high prevalence (25%) of *BRCA* mutations in Latinas based on a large study of U.S. Latino breast/ovarian cancer families, primarily of Mexican origin [17]. Another study showed prevalence of *BRCA* also may be high in Puerto Rican women. Among female breast cancer patients who underwent genetic testing for *BRCA* in Puerto Rico, 11 out of 23 participants were identified as carrying a *BRCA1* or *BRCA2* deleterious mutation [18]. Results of these studies suggest Puerto Rican women may be at least near or higher than the same risk for carrying mutations in the *BRCA1* and *BRCA2* genes as Caucasian women.

Those identified as carriers of a genetic mutation causing HBOC may undergo additional screenings, take medications, or have surgeries to significantly reduce their risk of cancer. As such, the US Preventive Services Task Force [19] recommends at-risk individuals who meet certain family and/or personal cancer history criteria undergo genetic counseling for HBOC risk to help women make informed health care decisions. Despite the utility of genetic counseling to evaluate HBOC risk, available data show racial and ethnic minority

groups represent a small proportion of those tested, [20] and Latinas in particular, underutilize cancer genetic services [21–23].

Given the differences between Puerto Rican and other US Latino populations with respect to education, language proficiency and income, all of which have been previously associated with awareness and/or utilization of genetic counseling and/or genetic testing, [24–26] it is important to explore the specific issues that may be relevant to the Puerto Rican population. In addition to individual level factors, interpersonal, and systems level factors are known to influence health behaviors [27]. Therefore, the purpose of this review article is to consider key individual, interpersonal and systems level factors that may impact use of HBOC genetic services in Puerto Rican women living in the United States.

## METHODS

Two researchers independently searched two electronic databases to identify studies published from 1995 (*i.e.*, the year *BRCA* testing became clinically available) to 2014 that addressed potential barriers and facilitators to cancer genetic counseling for HBOC among Puerto Rican women living in the US. The following Medical Subject Headings (MeSH) terms were used for PubMed: genetic counseling, genetic testing, genetic testing/utilization, *BRCA1* gene, *BRCA2* gene, cancer genes, Latinas, Puerto Rico, Hispanic, Hispanic American, genetic testing, knowledge, and awareness. Using the ISI Web of Science database, the search was restricted to the same search terms as in PubMed, with the additional criteria of peer-reviewed articles, written in English. Bibliographies of publications from both searches were examined for additional eligible studies not identified in Pubmed or ISI.

The authors reviewed the articles for data that may impact the uptake of genetic counseling and/or testing among Puerto Rican women. Two authors independently extracted data from each of the studies included in the review; the extracted data included purpose, methods, overall sample size, number of Puerto Ricans included in the sample, individual, interpersonal, and systemic barriers, and facilitators. A review matrix was created to structure information abstracted from each study (see Table 1).

## RESULTS

Initially, search results yielded 12 papers, 8 were excluded because they did not refer to HBOC genetic counseling, did not clearly indicate whether Puerto Ricans were included in their Hispanic or Latino sample, and 1 reference was excluded because it was a published conference abstract with no corresponding manuscript. By checking the reference list of the 3 remaining papers, 6 additional papers were identified addressing the main topic of this paper. As shown in Table 1, a total of 9 papers were included in the current review.

The papers contained in this review were published from 2006 – 2014. The purpose of the papers included: exploring awareness, knowledge, and/or beliefs and attitudes about genetic counseling and testing, and the impact of acculturation on awareness/knowledge of genetic counseling and testing. Five papers used quantitative methods, 3 used a mixed methods approach, and 1 used qualitative methods only. The total study sample ranged from 10 –

10,883 and the number of Puerto Ricans included in the samples ranged from 3 – 2655 (10.1% – 41.7% of the overall sample within each paper). Of the 9 papers, 7 aggregated the findings as part of a study of Latinos from various ethnicities, while 2 reported results of Puerto Ricans in contrast with other Latino ethnicities.

## INDIVIDUAL LEVEL BARRIERS AND FACILITATORS

### Awareness

Specific to awareness about genetic testing, results from the 2000 National Health Interview survey (NHIS) indicated that overall, 20.6% of Latinos had heard of genetic testing for increased cancer risk, with levels of awareness highest among Puerto Ricans (27.3%) and lowest among Mexicans (14.3%) [28]. As indicated in a study of barriers and facilitators to *BRCA* genetic counseling among at-risk Latinas in New York City, including foreign born Puerto Rican women, most had heard or read “almost nothing” or “relatively little” about genetic counseling for inherited disease and for cancer [29]. A more recent mixed methods study examined differences in awareness of genetic counseling and testing between Latino ethnicities and found Puerto Ricans had higher levels of awareness of cancer genetic counseling and testing compared with Mexicans and Cubans [30]. Although Puerto Ricans were more aware of genetic counseling, and were aware of family history as risk for breast cancer, they also were the least likely sub-ethnic group to attribute their breast cancer risk to personal history of cancer; most often citing lifestyle factors as the primary cause of breast cancer [30]. Interestingly, a study examining awareness of genetic testing among Latinos using NHIS data from 2000 and 2005, found those with a higher perceived future cancer risk were, in fact, more likely to be aware of genetic testing [31]. Based on the results of these studies, it would seem that personal cancer history is more often attributed to lifestyle factors, but that future cancer risk may be more likely to be associated with family history.

### Knowledge

In addition to a lack of awareness, low levels of knowledge about genetic counseling and testing were also identified in several studies [30, 32, 33]. Studies about knowledge of genetic counseling and testing found Latinos in general, had low levels of knowledge about *BRCA* genetic counseling, [34] and Puerto Rican women, in particular, correctly answered fewer than 50% of questions about HBOC [30, 33]. These low levels of knowledge were hypothesized to function as barriers to obtaining genetic counseling and/or testing among a sample of Latino participants in a mixed methods study [34].

Research to identify reasons for low rates of participation in genetic counseling for HBOC among Latinos found most participants had limited information about this topic, and many were not able to articulate the difference between genetic counseling and testing [32]. However, higher levels of knowledge about HBOC were found among Puerto Ricans who had experienced cancer in the family, [32] and a majority of participants in another study were able to correctly answer questions about patterns of inheritance and cancer risk associated with HBOC [33]. Similar to findings of awareness, it seems Puerto Ricans may be more likely than other sub-ethnicities to understand the hereditary nature of cancer, but are not knowledgeable about genetic testing and counseling.

### Concerns and Worry

Participants in several studies reported concerns related to the potential for emotional distress to be caused by genetic counseling from learning one's own or family members' cancer risks [29, 30, 34]. Additionally, the possibility for results from genetic testing to remove control from God and discriminate against others has been identified as a concern among some Latinas in previous studies [35]. One study in this review found age was positively associated with concerns about potential abuses that may result from genetic testing such that older Latina women had greater concern about potential abuses as a result of genetic testing compared to younger women [36].

### Interest in Learning More

Despite a general lack of awareness and knowledge, and indicating concern about negative affect associated with the process of cancer genetic counseling and testing, studies indicated that Latinas in general, [29, 32] and Puerto Ricans in particular, [37] are highly interested in learning more about the benefits of genetic counseling. In fact, many held generally positive attitudes about genetic counseling and testing and perceived a benefit was the potential for genetic counseling to help facilitate discussions in their families about cancer risk [29]. In a study exploring the influence of acculturation on attitudes, beliefs, and familiarity with genetic testing, higher levels of acculturation were associated with familiarity with genetic testing as well as more perceived benefits and less barriers to genetic testing [36].

## INTERPERSONAL LEVEL: CULTURAL FACTORS

An analysis of the 2000 NHIS identified a correlation between acculturation and awareness of genetic testing among Hispanic immigrants such that those higher in acculturation, as measured by English language preference, were more aware of genetic testing than those lower in acculturation [28]. Results from other studies examining awareness and acculturation found lower levels of acculturation (*i.e.*, Spanish language preference and fewer years living in the US) to be predictive of lower levels of awareness of genetic counseling and testing [31, 34, 36]. Another study among Latino immigrants, including Puerto Ricans, used additional measures of acculturation and found higher levels of acculturation to correlate with higher perceived benefits and lower perceived barriers to genetic testing, a relation that remained even when adjusting for potential confounding factors [36].

Life concerns, such as taking care of children or other family members, were perceived as barriers and were significantly related with the intent to obtain genetic counseling among at-risk Latinas in New York City; over a third of participants in the study considered genetic counseling to be a low priority [29]. Similarly, by utilizing qualitative methods with at-risk Latinas in New York City, a subtheme called "Descuido," referring to competing demands, emerged [32]. Most participants in that study described the need to take care of their family as the main barrier to having the time or energy to attend genetic counseling. Women in this study also described how the Latino culture prioritized family first, often at the expense of their own health [32].

Conversely, in that same study, “Familismo,” or the central role of the family, was one of the cited benefits of HBOC genetic counseling in Puerto Ricans among a sample of Latinas; [32] other studies confirm that helping their families was one of the main reasons Latinos in general, and Puerto Ricans in particular, provided for intending to undergo genetic counseling [28, 32]. In 2013, Sussner and colleagues found almost all Latina participants agreed that HBOC genetic counseling would help them better understand family member’s risk, have discussions about cancer in their families, reduce their fears and concerns about developing the disease, and finally decide to undergo genetic testing [29].

## SYSTEMS LEVEL: INSURANCE/FINANCES

Vadaparampil and colleagues identified the cost of genetic testing as one of the primary barriers to undergoing genetic testing among Puerto Rican women in the US as well as those in Puerto Rico [30]. Although participants in a study by Sussner and colleagues were unaware of the actual costs associated with genetic counseling and testing, the perceived expense was the most commonly cited barrier to attending genetic counseling in that study, as well [32]. Similarly, other studies found whether or not an individual had health insurance was related to familiarity with genetic testing for cancer risk assessment; those with insurance were more likely to be aware and knowledgeable of cancer risk assessment [28, 31, 36]. Latinas also were concerned about the possibility for genetic test results to jeopardize their health insurance coverage [34]. Participants in one study discussed experience with or witnessing a differential treatment based on insurance discrimination and/or interaction with their health care provider, which may prevent them from seeking out genetic counseling or testing [32].

The role of provider referral also was identified as an important system level factor associated with genetic counseling/genetic testing. In a study examining preferences for educational information about HBOC, Puerto Ricans were interested in discussing HBOC with their provider [37]. Although one study identified receipt of physician referral for genetic counseling as a facilitator of Latinas’ intention to attend genetic counseling, participants in that study had yet to attend [29]. Similarly in a qualitative study, Latinas who received a referral from a physician had yet to attend genetic counseling, and the sole Puerto Rican participant who received a referral cited fear and uncertainty as barriers to comply with the referral [30]. It may be that Latinas in general, and Puerto Ricans in particular, need more information in addition to a referral to help reduce some of the affective barriers associated with attending genetic counseling.

## DISCUSSION

Our review summarizes key factors that may impact uptake and use of genetic counseling and/or testing for HBOC among Puerto Rican women living in the US. Importantly, we identified modifiable barriers at multiple levels: individual, interpersonal and health care system. First, we found strong evidence for a lack of basic awareness/knowledge about genetic counseling and testing as well as the potential contribution of genetic factors to breast cancer risk in these studies. While increasing awareness and knowledge is a critical first step, it is important to consider the optimal channels and message content when delivering this information to specific sub-populations within a larger group that may have



different preferences and beliefs. Recent studies indicate face-to-face interactions are the most revered and preferred communication style for delivery of health messages among Latino audiences more broadly [38, 39] and Puerto Rican populations, in specific [37]. A study exploring information preferences for HBOC among at risk Mexican, Cuban and Puerto Rican women found that Puerto Rican women, wanted to receive written material followed-up by additional information provided through discussions viewed on television (*i.e.*, telenovelas) or through in-person discussions (*i.e.*, provider discussion or health outreach education events - “charlas”) [37]. The preferences for Puerto Rican women were distinct from Cubans and Mexicans who preferred to hear the information from a provider or participate in a discussion.

Importantly, the studies reviewed concluded communication of health information to a Hispanic audience must incorporate the larger interpersonal cultural context in which information is presented and received. Previous work suggested a strategy to achieve this would be to include four key principles of Hispanic communication—sympathy (*simpatía*), personalization (*personalismo*), confidence (*confianza*), and affection (*cariño*) in the delivery of information. Doing so has the potential for the message to be better received than *via* traditional health communication methods [40, 41]. Our review also suggests incorporating the concept of better managing competing demands (*descuido*) may be of particular importance with respect to improving the utilization of HBOC genetic counseling and testing services.

An important consideration for less acculturated individuals is the limited availability of genetic counseling services by bi-cultural, bilingual genetics professionals [42]. According to the recent data from the Pew Research Hispanic Trends Project [43], a national survey of U.S. Latinos found ~60% of respondents older than age 18, ~40% of all respondents, and 68% of those who were foreign-born, rated their English speaking ability in categories below “very well.” Thus, for complex health information, it is likely Latinos prefer to receive this information in Spanish. While access issues related to bilingual genetics professionals for Spanish speaking/Spanish preferring patients has been a longstanding barrier for Latinos, [42] a recent study demonstrated genetic counseling can be effectively and efficiently delivered *via* telephone [44]. Specifically, participants in both the telephone and face-to-face group had equivalent knowledge gains and similar levels of satisfaction and decisional conflict, distress, and quality of life. While these results appear promising to reduce geographical, linguistic, and logistic access barriers to genetic counseling, the prior study did not include any Latino participants. Therefore, it is unknown whether this approach would be feasible and acceptable to Puerto Rican women, particularly those who are Spanish speaking/Spanish preferring.

Additionally, addressing systems level barriers such as the costs of testing and provider referral/recommendation are critical. Latinos in the US are approximately three times more likely than whites to be uninsured, [45] and have the highest number of uninsured individuals compared to other racial/ethnic groups in the US. Lack of insurance may therefore be a barrier to obtaining cancer genetic counseling and testing for Puerto Ricans in the mainland. However, the Affordable Care Act (ACA) may reduce some cost related barriers. Specifically, as part of its preventive health service benefits, the ACA has

provisions for genetic counseling and testing with no out-of-pocket expense for *BRCA1* and *BRCA2* mutation testing for HBOC in women who have not yet had cancer [38]. However, one limitation of the ACA relative to the studies we reviewed is that many participants who expressed interest in genetic counseling and/or testing were diagnosed with breast cancer. Generally, these are the individuals in whom testing should begin in a family concerned about cancer risk. Unfortunately, the ACA benefits do not extend to breast cancer survivors. Thus, even for those with insurance, the out of pocket costs of deductibles or co-payments of several hundred dollars may put genetic counseling and testing services out of reach [38].

Finally, our findings suggest Puerto Rican women feel provider recommendation AND discussion is a critical component of increasing appropriate uptake of genetic counseling and testing services. Although primarily focused on Latinos of Mexican origin, there has been a substantial amount of work from Weitzel and colleagues suggesting that the provision of education to those health care providers most likely to deliver care to Latino populations increased the number of referrals and completed genetic counseling appointments in Latinas [39]. However, it is important to note that this provider education took place in the context of culturally competent, low or no cost services offered to at-risk Latinas [39].

To our knowledge, this review is one of the first to focus exclusively on issues related to utilization of genetic counseling and testing for HBOC specifically in the Puerto Rican population. However, it is important to consider our review in light of certain key limitations. First, we examined issues specific to Puerto Rican women residing in the U.S. This group may have higher levels of acculturation compared to those who live exclusively on the island of Puerto Rico. In addition, there is a difference with respect to the insurance system and access to genetics services between those living in the U.S. versus on the island of Puerto Rico. Thus, the findings of this review cannot be directly applied to Puerto Rican populations living on the island of Puerto Rico.

Genetic counseling and testing for HBOC has been clinically available for almost two decades. Unfortunately, we continue to see disparities in awareness, knowledge, access to, and uptake of genetic counseling and testing services. This is particularly true in Latino communities, despite documented rates of *BRCA* mutations similar to Caucasian populations [17, 18]. One approach to addressing this disparity is to work within these communities to address unique factors that may impact utilization of services. By considering Puerto Ricans as a unique ethnic minority group, we may have greater success in educating them about benefits of HBOC genetic testing and increase rates of counseling among affected individuals and their families.

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## References

1. United States Census Bureau. State & County QuickFacts USA. [website]. 2014. [cited: 03 January 2015]. Available from: <http://quickfacts.census.gov/qfd/states/00000.html>
2. United States Census Bureau. Population Division: Annual estimates of the resident population by sex, age, race alone or in combination, and hispanic origin for the United States and States: April 1, 2010 to July 1, 2013. 2014. [cited: 5 October 2014]. [website]. Available from: <https://www.census.gov/popest/data/datasets.html>
3. Buki LP, Feigal BM, Carrillo IY. Are all Latinas the same? Perceived breast cancer screening barriers and facilitative conditions. *Psychol Women Q.* 2004; 28:400–11.
4. Hunt LM, Schneider S, Comer B. Should “acculturation” be a variable in health research? A critical review of research on US Hispanics. *Soc Sci Med.* 2004; 59(5):973–86. [PubMed: 15186898]
5. Brodie, M.; Valdez, J.; Levin, R.; Suro, R. National survey of Latinos: summary of findings. Menlo Park CA and Washington DC: Henry JKaiser Family Foundation and Pew Hispanic Center; 2002. Available from: <http://pewhispanic.org/files/reports/15.pdf>
6. Motel, S.; Patten, E. Statistical portrait of the foreign-born population in the United States, 2011. Washington, DC: Pew Research Center: Hispanic Trends; 2013. Available from: <http://www.pewhispanic.org/2013/01/29/statistical-portrait-of-the-foreign-born-population-in-the-united-states-2011>
7. Cohn, Dv; Patten, E.; Lopez, MH. Puerto Rican Population Declines on Island, Grows on U.S. Mainland. Washington, DC: Pew Research Center; 2014. Available from: <http://www.pewhispanic.org/2014/08/11/puerto-rican-population-declines-on-island-grows-on-u-s-mainland/>
8. Hispanic health in the United States. Council on Scientific Affairs. *JAMA.* 1991; 265(2):248–52. [PubMed: 1984156]
9. Division of Cancer Prevention and Control. Cancer among women. Centers for Disease Control. 2014 Sep 2. [cited: 25 September 2014]. [website]. Available from: <http://www.cdc.gov/cancer/dcpc/data/women.htm>
10. Division of Cancer Prevention and Control. Ovarian Cancer Statistics. 2014 Sep 2. [cited: 15 September 2014]. [website]. Available from: <http://www.cdc.gov/cancer/ovarian/statistics/index.htm>
11. Bentley JR, Delfino RJ, Taylor TH, Howe S, Anton-Culver H. Differences in breast cancer stage at diagnosis between non-Hispanic White and Hispanic populations, San Diego county 1988–1993. *Breast Cancer Res Treat.* 1998; 50(1):1–9. [PubMed: 9802615]
12. Lindor, NM.; McMaster, ML.; Lindor, CJ.; Greene, MH. *J Natl Cancer Inst Monogr.* 2. 2008. Concise handbook of familial cancer susceptibility syndromes; p. 1-93.
13. Euhus DM, Robinson L. Genetic predisposition syndromes and their management. *Surg Clin North Am.* 2013; 93(2):341–62. [PubMed: 23464690]
14. Antoniou A, Pharoah P, Narod S, et al. Average risks of breast and ovarian cancer associated with *BRCA1* or *BRCA2* mutations detected in case series unselected for family history: A combined analysis of 22 studies. *Am J Hum Genet.* 2003; 72(5):1117–30. [PubMed: 12677558]
15. Litton JK, Ready K, Chen H, et al. Earlier age of onset of *BRCA* mutation-related cancers in subsequent generations. *Cancer.* 2012; 118(2):321–5. [PubMed: 21913181]
16. Chen S, Parmigiani G. Meta-analysis of *BRCA1* and *BRCA2* penetrance. *J Clin Oncol.* 2007; 25(11):1329–33. [PubMed: 17416853]
17. Weitzel JN, Clague J, Martir-Negron A, et al. Prevalence and type of *BRCA* mutations in Hispanics undergoing genetic cancer risk assessment in the Southwestern United States: A report from the Clinical Cancer Genetics Community Research Network. *J Clin Oncol.* 2013; 31(2):210–6. [PubMed: 23233716]
18. Dutil J, Colon-Colon JL, Matta JL, Sutphen R, Echenique M. Identification of the prevalent *BRCA1* and *BRCA2* mutations in the female population of Puerto Rico. *Cancer Genet.* 2012; 205(5):242–8. [PubMed: 22682623]

19. Nelson HD, Huffman LH, Fu R, Harris EL. Force USPST. Genetic risk assessment and *BRCA* mutation testing for breast and ovarian cancer susceptibility: Systematic evidence review for the U.S. Preventive Services Task Force. *Ann Intern Med.* 2005; 143(5):362–79. [PubMed: 16144895]
20. Frank TS, Deffenbaugh AM, Reid JE, et al. Clinical characteristics of individuals with germline mutations in *BRCA1* and *BRCA2*: Analysis of 10,000 individuals. *J Clin Oncol.* 2002; 20(6):1480–90. [PubMed: 11896095]
21. Ricker C, Lagos V, Feldman N, et al. If we build it ..will they come?--Establishing a cancer genetics services clinic for an underserved predominantly Latina cohort. *J Genet Couns.* 2006; 15(6):505–14. [PubMed: 17106633]
22. Chen WY, Garber JE, Higham S, et al. *BRCA1/2* genetic testing in the community setting. *J Clin Oncol.* 2002; 20(22):4485–92. [PubMed: 12431973]
23. Hall MJ, Reid JE, Burbidge LA, et al. *BRCA1* and *BRCA2* mutations in women of different ethnicities undergoing testing for hereditary breast-ovarian cancer. *Cancer.* 2009; 115(10):2222–33. [PubMed: 19241424]
24. Levy DE, Byfield SD, Comstock CB, et al. Underutilization of *BRCA1/2* testing to guide breast cancer treatment: Black and Hispanic women particularly at risk. *Genet Med.* 2011; 13(4):349–55. [PubMed: 21358336]
25. Mai PL, Vadaparampil ST, Breen N, McNeel TS, Wideroff L, Graubard BI. Awareness of cancer susceptibility genetic testing: The 2000, 2005, and 2010 National Health Interview Surveys. *Am J Prev Med.* 2014; 46(5):440–8. [PubMed: 24745633]
26. Wideroff L, Vadaparampil ST, Breen N, Croyle RT, Freedman AN. Awareness of genetic testing for increased cancer risk in the year 2000 National Health Interview Survey. *Community Genet.* 2003; 6(3):147–56. [PubMed: 15237199]
27. McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. *Health Educ Q.* 1988; 15(4):351–77. [PubMed: 3068205]
28. Vadaparampil ST, Wideroff L, Breen N, Trapido E. The impact of acculturation on awareness of genetic testing for increased cancer risk among Hispanics in the year 2000 National Health Interview Survey. *Cancer Epidemiol Biomarkers Prev.* 2006; 15(4):618–23. [PubMed: 16614100]
29. Sussner KM, Jandorf L, Thompson HS, Valdimarsdottir HB. Barriers and facilitators to *BRCA* genetic counseling among at-risk Latinas in New York City. *Psychooncology.* 2013; 22(7):1594–604. [PubMed: 22987526]
30. Vadaparampil ST, McIntyre J, Quinn GP. Awareness, perceptions, and provider recommendation related to genetic testing for hereditary breast cancer risk among at-risk Hispanic women: Similarities and variations by sub-ethnicity. *J Genet Couns.* 2010; 19(6):618–29. [PubMed: 20798982]
31. Heck JE, Franco R, Jurkowski JM, Sheinfeld Gorin S. Awareness of genetic testing for cancer among United States Hispanics: The role of acculturation. *Community Genet.* 2008; 11(1):36–42. [PubMed: 18196916]
32. Sussner KM, Edwards T, Villagra C, et al. *BRCA* genetic counseling among at-risk Latinas in New York City: New beliefs shape new generation. *J Genet Couns.* 2015; 24(1):134–48. [PubMed: 25120034]
33. Vadaparampil ST, Quinn GP, Small BJ, et al. A pilot study of hereditary breast and ovarian knowledge among a multiethnic group of Hispanic women with a personal or family history of cancer. *Genet Test Mol Biomarkers.* 2010; 14(1):99–106. [PubMed: 19929403]
34. Sussner KM, Jandorf L, Thompson HS, Valdimarsdottir HB. Interest and beliefs about *BRCA* genetic counseling among at-risk Latinas in New York City. *J Genet Couns.* 2010; 19(3):255–68. [PubMed: 20151317]
35. Thompson HS, Valdimarsdottir HB, Jandorf L, Redd W. Perceived disadvantages and concerns about abuses of genetic testing for cancer risk: Differences across African American, Latina and Caucasian women. *Patient Education and Counseling.* 2003; 51(3):217–27. [PubMed: 14630378]
36. Sussner KM, Thompson HS, Valdimarsdottir HB, Redd WH, Jandorf L. Acculturation and familiarity with, attitudes towards and beliefs about genetic testing for cancer risk within Latinas in East Harlem, New York City. *J Genet Couns.* 2009; 18(1):60–71. [PubMed: 18686019]

37. Quinn GP, McIntyre J, Vadaparampil ST. Preferences for hereditary breast and ovarian cancer information among Mexican, Cuban and Puerto Rican women at risk. *Public Health Genomics*. 2011; 14(4–5):248–58. [PubMed: 20150724]
38. Walcott FL, Dunn BK, DeShields M, Baquet C. The affordable care act and genetic testing for inheritable cancer syndromes: Impact on high-risk underserved minorities. *J Health Care Poor Underserved*. 2014; 25(1):46–62. [PubMed: 24583487]
39. Ricker CN, Hiyama S, Fuentes S, et al. Beliefs and interest in cancer risk in an underserved Latino cohort. *Preventive medicine*. 2007; 44(3):241–5. [PubMed: 17027932]
40. Torres JB. Communication patterns and direct social work practice with Latinos in the US. *J hum behav social environ*. 2000; 3(2):23–42.
41. Purnell, LD. *Transcultural health care: A culturally competent approach*. 4. Philadelphia, PA: F.A. Davis Company; 2012.
42. Penchaszadeh VB. Genetic counseling issues in Latinos. *Genet Test*. 2001; 5(3):193–200. [PubMed: 11788084]
43. Motel, Seth; Patten, Eileen. *A statistical portrait of US Hispanics*. Washington D.C: 2013 Feb 15. Available from: <http://www.pewhispanic.org/2013/02/15/statistical-portrait-of-hispanics-in-the-united-states-2011/>
44. Schwartz MD, Valdimarsdottir HB, Peshkin BN, et al. Randomized noninferiority trial of telephone versus in-person genetic counseling for hereditary breast and ovarian cancer. *J Clin Oncol*. 2014; 32(7):618–26. [PubMed: 24449235]
45. De Jesus M, Xiao C. Cross-border health care utilization among the Hispanic population in the United States: Implications for closing the health care access gap. *Ethn Health*. 2013; 18(3):297–314. [PubMed: 23043379]

**Table 1**  
Review of Genetic Counseling and Testing Studies Involving Puerto Rican Populations in the U.S.

| Year | Authors  | Purpose   | Methods   | Total Sample Size and Population  | Puerto Ricans in the Sample             | Individual  | Interpersonal  | Systems   |
|------|--|---|---|---|---|---|--|---|
| 2008 | Heck JE, Franco R, Jurkowski JM, Sheinfeld Gorin S [31]              | Awareness of genetic testing  | Quantitative Using HINTS Data                                 | Latino or Hispanic Living in the United States (N = 10,883)                         | 24.4% (weighted percentage)             | <b>Facilitators</b><br>Higher perceived future cancer risk = more awareness   | <b>Barriers</b><br>Low acculturation levels = less awareness   | <b>Barriers</b><br>Holding public health insurance = less awareness<br><b>Facilitators</b><br>Holding private insurance = more awareness<br>Physician appointment in previous year = more awareness |
| 2009 | Sussner KM, Thompson HS, Valdimarsdottir HB, Redd WH, Jandorf L [36] | Influence of acculturation on attitudes, beliefs and familiarity with genetic testing | Secondary Quantitative Analysis                               | Latinas living in northern Manhattan, NY (N = 103)                                  | n = 43                                  | <b>Barriers</b><br>Older age = positively associated with concerns about abuses of genetic testing  | <b>Facilitators</b><br>High acculturation levels = familiar with genetic testing, more benefits, less barriers | <b>Barriers</b><br>Higher medical mistrust = less benefits, more barriers<br><b>Facilitators</b><br>Holding insurance = more familiar with genetic testing  |
| 2010 | Sussner KM, Jandorf L, Thompson HS, Valdimarsdottir HB [34]          | Interests and beliefs about BRCA genetic counseling                                   | Two phase study: 1) Quantitative interviews & 2) Focus groups | High-risk Latinas in New York City<br>Interviews: (N = 15)<br>Focus group: (N = 10) | Interviews: n = 5<br>Focus group: n = 3 | <b>Barriers</b><br>A lack of awareness of cancer genetic counseling and testing<br>A lack of knowledge about cancer genetic counseling<br>Concern about distress caused by genetic counseling<br>Worry related to learning about family members' cancer risk<br><b>Facilitators</b><br>Overall held positive attitudes about genetic counseling<br>Wanted more information about benefits of genetic counseling | <b>Barriers</b><br>Concern about compatibility with religious beliefs<br>Competing demands of everyday life    | <b>Barriers</b><br>Concern about health insurance coverage loss based on genetic counseling<br>Concern about insurance coverage and cost of testing   |

| Year | Authors  | Purpose  | Methods  | Total Sample Size and Population   | Puerto Ricans in the Sample                       | Individual   | Interpersonal   | Systems   |
|------|--|--|--|--|---|--|---|---|
| 2013 | Sussner KM, Jandorf L, Thompson HS, Valdimarsdottir HB [29]                                      | Barriers and facilitators to intend to attend BRCA genetic counseling for HBOC   | Quantitative phone surveys                           | At risk Latinas in New York City (N = not reported)  | n = 24  | <p><b>Barriers</b><br/>Were concerned about distress caused by genetic counseling. Worry about distress caused by knowing family members' cancer risk.</p> <p><b>Facilitators</b><br/>Largely knowledgeable and positive attitudes and beliefs about genetic counseling. Wanted to learn more about genetic counseling. Higher perceived risk predicted intention to undergo counseling. Genetic counseling could promote discussion of hereditary risk in their family.</p> | <p><b>Barrier</b><br/>Competing concerns; too many other things to worry about, reduces intention to attend genetic counseling.</p> <p><b>Facilitators</b><br/>Did not perceive that genetic counseling was inconsistent with religious or spiritual beliefs.</p> | <p><b>Facilitators</b><br/>Receiving a physician referral for genetic counseling increased intention to attend genetic counseling.</p>                |
| 2014 | Sussner KM, Edwards T, Villagra C, Rodriguez MC, Thompson HS, Jandorf L, Valdimarsdottir HB [32] | Examine beliefs and attitudes about BRCA genetic counseling. Estimate the  | Focus groups and interviews                          | At risk Latinas in New York City Focus groups: (N = 54) Interviews: (N=30) – drawn from focus group sample | Focus groups: n = 10 Interviews: n = not reported | <p><b>Barriers</b><br/>Low levels of knowledge about BRCA genetic counseling.</p> <p><b>Facilitators</b><br/>Overall interest in learning more about BRCA genetic counseling.</p>  | <p><b>Barriers</b><br/>Competing life demands.</p> <p><b>Facilitators</b><br/>Information could help their family members (familismo).</p>  | <p><b>Barriers</b><br/>Concern about cost of genetic counseling. Language barriers. Previous negative encounters with healthcare system/mistrust.</p> |
| 2006 | Vadaparampil ST, Wideroff L, Breen N, Trapido E [28]   | percentage of Hispanic adults in the US population who have heard of genetic testing for inherited cancer susceptibility | Quantitative analyses of Hispanic responses to HINTS | Latinos living in the US (N = 4,313)   | n = 437   | <p><b>Barriers</b><br/>Not taking vitamins = low awareness.</p> <p><b>Facilitators</b><br/>High levels of routine physical activity =</p>  | <p><b>Barriers</b><br/>Low levels of acculturation = less awareness of genetic testing.</p>   | <p><b>Barriers</b><br/>Low levels of educational achievement = low awareness of genetic testing. Having public or no insurance = low awareness.</p>   |

| Year | Authors   | Purpose  | Methods  | Total Sample Size and Population         | Puerto Ricans in the Sample | Individual  | Interpersonal  | Systems   |
|------|---|--|--|--|-----------------------------|---|--|---|
| 2010 | Vadaparampil ST, McIntyre J, Quinn GP [30]  | Exploring awareness, perceptions, and provider recommendation related to genetic testing for HBOC among high-risk Hispanic women | Qualitative interview and quantitative survey                            | Latinos living in US (N = 53)            | n = 20                      | <p>increased awareness</p> <p><b>Barriers</b><br/>                     Low awareness about genetic testing (although PR had highest levels of awareness) * Lack of awareness about the role of personal breast cancer history with cancer risk (compared to lifestyle risks) * Worry/fear about knowing personal risk * Worry about children's risk</p> <p><b>Facilitators</b><br/>                     Provider recommendation *</p> |  | <p><b>Barriers</b><br/>                     Concerns about cost<br/>                     Questioned the reliability of the test *</p> <p><b>Facilitators</b><br/>                     Provider recommendation *</p> |
| 2010 | Vadaparampil ST, Quinn GP, Small BJ, McIntyre J, Loi CA, Closser Z, Gwede CK [33] | Examine knowledge about hereditary breast and ovarian cancer among Hispanic women  | Quantitative survey  | Hispanic women living in the US (N = 53) | n = 20                      | <p><b>Barriers</b><br/>                     Overall low levels of knowledge about hereditary breast and ovarian cancer across all sub-ethnicities * Women with a history of breast cancer had lower knowledge about HBOC than those without a history.</p> <p><b>Facilitators</b><br/>                     The majority answered questions correctly about patterns of inheritance and cancer risks associated with HBOC</p>          |  |   |
| 2011 | Quinn GP, McIntyre J, Vadaparampil ST [37]  | Assess preferences of Hispanic women for health education  | Semi-structured in depth qualitative interview and a quantitative survey | Hispanic women living in the US (N = 53) | n = 20                      |   | <p><b>Facilitators</b><br/>                     Majority discussed cancer in their families once a</p> | <p><b>Barriers</b><br/>                     Written material is not their first preference Majority indicated primary</p>   |



| Year | Authors | Purpose  | Methods | Total Sample Size and Population | Puerto Ricans in the Sample | Individual | Interpersonal               | Systems  |
|------|---------|--|---------|----------------------------------|-----------------------------|------------|-----------------------------|--|
|      |         | information about HBOC<br>information about HBOC |         |                                  |                             |            | family member was diagnosed | source of health information was print materials*<br><b>Facilitators</b><br>The majority reported discussing family history of cancer with a provider* Majority wanted to discuss HBOC with their provider Prefer to learn about HBOC through discussions, <i>i.e.</i> 'charla' following the receipt of a brochure or pamphlet mailed to their home * |

\* Indicates results specific to Puerto Rican participants