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Perceptions of Breast Cancer-Related Stigma and Genetic Knowledge Among Latina Women: El Mejor Entendimiento Del Miedo.

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el mejor entendimiento del miedo.

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Dedication

This thesis is dedicated to my family – my wonderful Italian family who nonetheless supports my love and interest for all things Spanish.

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Abstract

Purpose: Breast cancer is the leading cause of cancer death among Latina women, with *BRCA1/2* gene mutations accounting for a commensurate proportion of breast/ovarian cancer in Latina women as compared to non-Latina women. Despite this statistic, it has been shown that Latino populations exhibit low awareness and use of genetic services and that they hold culturally-related beliefs which stigmatize cancer. We hypothesized that a simple, culturally-tailored educational flier would improve genetics knowledge as well as decrease breast cancer-related stigma among Latina women in our sample. **Method:** Two groups of Latina women (N = 19) were provided with a pre-survey, educational flier, and then post-survey to assess their knowledge of breast cancer-related genetics and their emotional status. Qualitative responses regarding cancer-related perceptions were also gathered post-flier. Participants included women both affected and unaffected by breast cancer and were surveyed from either a Spanish-language breast cancer support group in Orlando, FL or a Hispanic community health education seminar in Charleston, SC. The Wilcoxon signed-rank test was employed to analyze pre- and post-flier results. The Repeated Measures ANOVA was used to assess emotional status as a function of cancer diagnosis. Qualitative data was coded and analyzed using grounded theory methods. **Results:** None of the women showed significant gains in knowledge related to breast cancer after viewing the educational flier. All women demonstrated significant increases in anxiety between baseline emotional status and emotional status related to either a real or hypothetical diagnosis of cancer. Unaffected

participants showed higher anxiety means overall. Qualitative analysis identified four major themes: (1) cancer means fear, death, and family isolation; (2) cancer is difficult to explain; (3) perceived causes of cancer; and (4) attitudes of hope. **Conclusions:** We showed that either a real or hypothetical diagnosis of breast cancer increases anxiety above that of baseline emotional status among our sample population of Latina women who attend health-focused support groups. We theorize that a refined version of the flier may be more effective as part of a larger educational platform, in which participants are provided with expanded information and encouraged to participate in cancer and genetics-centered conversation. We hope future research endeavors will build upon the utility of effective educational materials to improve genetic counseling referrals and genetic-medicine healthcare among this growing population.

Keywords: Cancer genetics, breast cancer, *BRCA1*, *BRCA2*, genetic testing, stigma, Latina, Spanish

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List of Abbreviations

BES .....Baseline Emotional States

CRES-pre .....Cancer-Related Emotional Status, Pre-Educational Flier

CRES-post..... Cancer-Related Emotional Status, Post-Educational Flier

HHI ..... Hispanic Health Initiative

STAI.....State-Trait Anxiety Inventory

Chapter 1: Background

1.1.The Current State of Breast Cancer and Availability of *BRCA* Gene Testing

In 2010, cancer became the leading cause of death worldwide (Neal, Beckjord, Rechis, Schaeffer, Berno, & Duchover, 2011). Moreover, breast cancer is the most commonly diagnosed cancer among women in the world according to Phillips and Cohen (2011). The authors maintain that breast cancer is the leading cause of cancer-related deaths among women 20-59 years of age in high-income countries, and it is the second leading cause of cancer death for women in the United States. In perspective, the authors claim that despite the mortality rates due to breast cancer in the United States, half of all breast cancer cases occur in economically developing countries.

Guidelines in the United States advise women age 40 and above to receive yearly mammograms, which is the prevailing method for early breast cancer detection. Although multiple organizations have put forth respective screening protocols, those released by the American Cancer Society (ACS) are frequently cited. The ACS recommends that average-risk asymptomatic women age 40 and above receive annual clinical breast examinations and engage in optional monthly self-breast examinations (Phillips & Cohen, 2011). The authors expand on screening rationale: "To date, no established preventative measures exist for breast cancer; therefore, the greatest hope for reducing breast cancer mortality and improving breast cancer survival lies in early detection and prompt follow-up treatment" (p. 239).

According to Gold and Carbone (2010), scientists estimate that between 5% and 10% of breast cancers are hereditary, meaning that the cancer is caused by a defective gene in the body that can be passed down through generations. The authors categorize hereditary breast cancer as being suspected in individuals with a positive family history for breast and ovarian cancer, families in which males present with breast cancer, breast cancer appearing before the age of 40, and/or bilateral or multifocal breast cancer. The remaining 90% to 95% of cases of breast cancer is considered sporadic or familial, suggesting an association with environmental influences and/or unknown genetic determinants (Yeomans Kinney, Gammon, Coxworth, Simonson, & Arce-Laretta, 2010).

Competition among institutions around the world led to the discovery and sequencing of the *BRCA1* and *BRCA2* genes in the early 1990s. Mutations within the *BRCA1* and *BRCA2* genes are estimated to contribute to up to 50% of the hereditary breast cancer category (van der Groep, van der Wall, & van Diest, 2011; Walsh & King, 2007; Meindl, Ditsch, Kast, Rhiem, & Schmutzler, 2011). Research on these genes showed how their products, when working correctly, act as tumor suppressing proteins. Conversely, mutations, or changes in the chemical sequence of these genes, can confer an increased lifetime risk of 40% to 85% to develop breast cancer and a lifetime risk of 16% to 40% to develop ovarian cancer. The risk is 12.7% and 1.4%, respectively, for the general population (Antoniou et al., 2003; Hopper et al., 1999; Chen & Parmigiani, 2007; Gold & Carbone, 2010).

Gold and Carbone (2010) recounted how with better understanding of the location and sequence of the *BRCA1/2* genes, laboratories were able to develop diagnostic testing, thus capitalizing on the opportunity for preventive management of hereditary breast

cancer. Myriad Genetics, Inc., and its subsidiary, Myriad Genetics Laboratories, Inc., were granted a United States patent in 1997 covering 47 *BRCA1* gene mutations. *BRCA2* mutation patents were granted to Myriad Genetics in 1998 and 2000. The Utah-based company currently has prominence over the commercialization of genetic testing for mutations in these hereditary breast cancer genes, and diagnostic testing in the United States is thus ordered through their laboratory. As of 2010, Myriad Genetics has curated a database of the results of over 400,000 samples, including known deleterious mutations and numerous polymorphisms.

The American Society of Clinical Oncology (ASCO) recommends that cancer predisposition testing be offered only when (1) the person has a strong family history of cancer (or diagnoses at very early ages), (2) the test can be adequately interpreted, and (3) the results will influence the medical management of the patient and family (Gold & Carbone, 2010). Evidence suggests that surveillance, chemoprevention, and prophylactic surgical interventions are all beneficial options for individuals with a deleterious *BRCA1/2* mutation. The ACS advises that women at an increased risk due to family history talk with their physicians about the benefits and limitations of starting mammography screening earlier (before the age of 40), as well as the benefits of additional examinations such as magnetic resonance imaging (MRI) and ultrasonography. The ACS also acknowledges the utility of genetic testing ("Genetic Testing: What You Need to Know," 2013) and includes online references to guide individuals who may be good candidates for the test.

1.2. The Genetic Counseling Profession: Support in Navigating the Genetic Testing Process

According to a 2006 task report by Resta, Biesecker, Bennett, Blum, Hahn, Strecker, and Williams, genetic counselors are appropriate referrals in order to facilitate the genetic and psychosocial implications of familial disease. The authors describe genetic counselors as healthcare experts with specialized graduate degrees and experience in the areas of medical genetics and counseling. The process of genetic counseling involves helping people understand and adapt to the medical, psychological, and hereditary implications of genetic contributions to disease. According to Rolnick et al. (2011), identification of high risk individuals by family history may indicate an inherited genetic susceptibility, and through genetic counseling, patients can become more aware of the use of effective strategies for disease prevention and early detection.

A subset of genetic counselors specialize in the role of cancer genetic counseling. The primary goal of this field is to manage patient concerns regarding the occurrence or risk of a genetically inherited cancer in the family and to assist in the genetic testing process if desired by the patient (Resta et al., 2006; "Cancer Genetics," n.d.). The National Comprehensive Cancer Network (NCCN) states that "women at high risk would benefit from genetic counseling that helps patients or family members make informed decisions about genetic testing and enhances selection of early cancer detection or risk-reduction strategies" (Kinney et al., 2010, p.2).

Genetic counselors are able to provide patients with a professional evaluation of genetic test results as well as discussion regarding health and management implications (Gammon et al., 2011). According to Glenn, Chawla, and Bastani (2012), genetic

counseling is advised prior to testing for *BRCA1/2* in order to "asses risk-level, explain the risks and benefits of testing, and provide psychological support and assistance in decision-making" (p. 267). The authors also described the influence of counseling in terms of follow-up care, including providing support to navigate options of surgery, chemoprevention, and increased screening. Importantly, identification of the gene change in one family member is often informative for other family members who might be at risk. These at-risk individuals might then decide to pursue genetic testing for their own benefit. In effect, genetic counseling is sometimes able to provide risk reduction strategies for an entire, multi-generational family (Glenn, Chawla, & Bastani, 2012). Moreover, Rolnick et al. (2011) showed that genetic counseling with high risk individuals has been reported to increase knowledge and decrease anxiety regarding the genetic testing process.

Myriad Genetics also acknowledges that "genetic testing indicates the probability rather than the certainty of having a disease, and the results of the tests can be difficult not only for the average patient but also for the average doctor to interpret" (Gold & Carbone, 2010, p. 14). Vos et al. (2010) supported this notion in their explanation of how a pathogenic mutation, or positive result, implies increased risk to develop cancer. They described that this increased risk then presumes increased options for risk-reducing strategies, but also for potential feelings of distress. The authors continued to explain how an uninformative, or negative, result implies that "no mutation was found but that the counselee's pedigree suggests that cancer is [still] likely to be heritable in this family" (p. 240). In other words, although no known *BRCA1/2* mutation was found, the individual remains at an increased risk for breast cancer. The authors concluded by explaining the

potential to find a variant of uncertain clinical significance (VUS). This type of result implies that a genetic mutation *has* been found; however, its current clinical significance is unknown, such that the variant could be either pathogenic (disease-causing) or benign (not disease-causing). Vos et al. (2010) remarked that a VUS result often confers high levels of uncertainty and relatively high distress in the patient.

Psychological implications of genetic testing must also be considered. Carriers of a mutated gene may grapple with the burden of guilt in regard to passing on the mutation and potentially being the cause of his or her children and grandchildren to be at increased risk of developing disease (Weil, 2000). Gibbon (2007) and Hallowell (1999) expanded on this concept by acknowledging the significance of tension that can result between an individual's investment in "what is perceived as preventative health" and the consequential "predictive information for the family" (as cited in Gibbon, 2011, p. 1784). Gibbon also cited Konrad (2005) to explain that genetic knowledge can unfold unevenly in families and encroach upon kin's 'rights to know' or 'not to know,' meaning that the results of one family member's test could potentially provide health information for other family members, whether or not those individuals are interested in knowing.

The genetic counseling process also guides mutation-positive patients through inquiries about potential health insurance discrimination and financial implications, including coverage for preventive measures. Conversely, patients who receive a negative test result run the risk of psychological harm due to false reassurances (the belief that he or she is now immune from the disease) (Gold & Carbone, 2010). This occasionally complex topic of false reassurance can also be clarified through the counseling process. In this way, genetic counseling is opportune in order to navigate the logistic, educational,

and emotional adjustments that may be caused by the results of genetic testing (Resta et al., 2006).

1.3 The United States Latino Population and Their Awareness of Genetic Testing

Latino is the Latin word for "Spanish," and is also used as a prefix for the South American continent, or Latin America (Fisher, 1996). The term Latinos/Latinas is often reported as a single category, although it is representative of "multiple subgroups from various countries and cultural backgrounds" (Sudarsan, Jandorf, & Erwin, 2010, p. 194). This ethnically and racially diverse group of people have roots in Central or South America, the Caribbean, and Spain (Yeomans Kinney et al., 2010). Fisher (1996) reflected that while some consider *Latino* to be a better representation of Spanish, indigenous, and African cultures that are now part of Latin America, the term is also applied as a generic ethnic label by the American Public Health Association (Fisher, 1996). Latinos (noting the –os suffix) refers to both males and females as a group, whereas Latinas is reserved for only female representation.

Importantly, Latinos are currently the fastest growing minority population in the United States (Gammon et al., 2011). According to Yeomans Kinney et al. (2010), more than 37 million Latinos are currently living in the United States, and Latinos are predicted to comprise 25% of the United States population by the year 2050. Although ancestry varies, Mexicans represent the largest percentage of the Latino population (54.1% in 2010), followed by Puerto Ricans, Cubans, Central Americans (other than Mexicans), South Americans, Dominicans, Spaniards, and those who consider themselves of "general Hispanic ancestry" (Cokkinides, Bandi, Siegel, & Jamal, 2012; U.S. Census Bureau, 2010).

According to Yeomans Kinney et al. (2010), Latino individuals exhibit low awareness and use of genetic services. The low uptake is especially concerning as breast cancer is the most frequently diagnosed cancer and leading cause of cancer death among Latina women, according to the same authors. Although overall incidence rates of breast cancer have been shown to be lower among Latina populations than among white women, Latinas are 22% more likely to die of breast cancer within five years after diagnosis (Sussner, Thompson, Valdimarsdottir, Redd, & Jandorf, 2008). Moreover, Yeoman Kinney et al. (2010) showed that these women are more likely to be diagnosed at younger ages and with the disease having already progressed to later stages. Sussner et al. (2008) found that these factors still hold true even when controlling for income, education, and method of detection.

Literature has similarly suggested that Latina women are less likely to use preventive services such as mammograms and self-breast exams (Yeomans Kinney et al., 2010). Studies from 2005 found that only 59.6% of Latina women aged 40 and above had undergone a mammography exam within the past 2 years, as compared to 68.1% of non-Latina whites. Part of the lower incidence of breast-cancer among Latinas, as well as higher mortality rates, might simply relate to absence of diagnosis due to low mammography utilization (Sudarsan, Jandorf, & Erwin, 2010).

Reports from Myriad Genetics have shown that of all women who opted for *BRCA* testing between 1996 and 2007, only 4% were Latina (Sussner et al., 2008). Despite this statistic, evidence has suggested that *BRCA1/2* mutations account for as many incidences of breast and ovarian cancer in Latina women as compared to non-Latina women. A study by Myriad Genetic Laboratories, Inc. analyzed over 17,000

women at high-risk for breast cancer. Results found that 31.3% of Latin American/Caribbean women tested positive for a *BRCA* mutation as compared to 23.3% of women of Western/Northern Europe descent ("Myriad Genetic Laboratories," 2013). More recent data has reported a subset of *BRCA* mutations that is more prevalent among the Latinos, including a higher prevalence of 'large rearrangement mutations' within the *BRCA* genes. (Mullineaux et al, 2003; Voelker, 2009; Myriad Genetic Laboratories, 2013; Gammon et al., 2011).

A 2012 study by Glenn, Chawla, and Bastani (2012) investigated barriers to genetic testing for breast cancer risk among ethnic minority women. The authors attributed underuse of genetic testing among these women to lack of knowledge and awareness, as well as other nuanced cultural and language factors. They further explained that low levels of awareness for genetic testing were generally observed across all minority women, including those of Latina ethnicity. Additionally, a 2000 analysis performed by the National Health Information Survey (NHIS) in East Harlem (New York City) found that only 20.6% of Latinos reported having heard of genetic testing for cancer risk, as compared to 32.9% of African Americans and 49.9% of whites (Sussner et al., 2008).

1.4 Latino Cultural Influences regarding Healthcare and Genetics

According to Fisher (1996), the Latino term *curanderismo* is derived from the Spanish word *curar*, meaning 'to heal.' The term applies to the treatment of a variety of illnesses using a combination of psychosocial interventions, herbs, potions, and religion. In more modern times, *curanderismo* incorporates modern psychology and scientific medicine. The belief system commonly links disease state to one of three causes: natural

and supernatural forces; imbalances of heat and cold; and emotion. Given this backdrop of beliefs, Fisher remarks that many Latino families might even consult a folk healer before considering an appointment with a medical doctor, adding that the impersonality of Western medical practice can present an additional deterrent.

Gibbon (2011) studied the understanding of predictive genetics regarding breast cancer among Cuban women. She noted that many women described the cause of the disease as a 'physical blow' or *golpe* that was significant enough to cause cancer. It was implied among the women that the breast was a *zona delicada* (delicate, sensitive body area) that was therefore more susceptible to injury. The author proposed that this concept arose from a sense that the disease strikes *to* or *against* the body from *outside* the body (pollution, dietary deficit, etc.), rather than being generated *within* the body (Gibbon, 2011). This notion of *golpe* – or outside influence triggering breast cancer – is also not uncommon among Latinos in the United States or Mexico, and in fact, might be similarly perceived as the English equivalent to stress. Finkler (1991) has suggested that the *golpe*/stress creates connection between disorder in the body and state of disease and concurrently points to a source of illness within one's life history (as cited in Gibbon, 2011).

According to a study by Gibbon (2011), a relative unavailability of predictive genetics (including *BRCA* testing) exists in Cuba. Lack of media coverage and discussion regarding the genetics of breast cancer, as well as general lack of breast cancer activism, has been observed in this population. The effect is that few women in Cuba have heard of the *BRCA* genes, and women in the study therefore had no point of reference to discuss genes or genetic factors. Those who had heard of *los genes* were still

unable to engage in meaningful discussion, and instead used vague concepts such as 'something being transmitted in the blood' (Gibbon, 2011).

A chapter from Race, Ethnicity, and Health (LaVeist & Isaac, 2013), examined the interplay between acculturation and Latino health status in the United States. The authors loosely defined acculturation as "Westernization," "urbanization," "Americanization," and "modernization," among more formal definitions such as the "phenomenon that results as groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original cultural patterns of either or both groups" (Redfield,' Linton, & Herskovits, 1936, p.149 as cited in LaVesit & Isaac, 2013).

Interestingly, the authors found that health outcomes among Latinos in the United States showed substantial heterogeneity as well as variations across country of origin. Negative effects of acculturation (poorer health) were shown in domains of nutrition, exercise, drug use, and smoking. However, they found positive effects (improved health) in domains of general health care use, use of preventive strategies, insurance acquisition, and cervical/breast screening. The authors concluded that health outcomes as a function of acculturation are "very complex and not well understood" (LaVeist & Isaac, 2012, p. 225).

Cokkinides et al. (2012) similarly investigated health domains of United States Latino adults. Authors showed that these individuals have lower levels of mammography use, colorectal screening, and Pap tests compared to non-Hispanic/Latino whites in the United States. However, the authors also showed differences in risk factors according to

country of origin and age group, and therefore cautioned that these variables be considered in cancer control planning.

A 2012 study by Sussner, Jandorf, Thompson, Heiddis, and Valdimarsdottir more closely examined the result of acculturation on both barriers and facilitators to *BRCA* genetic counseling among at-risk Latinas in New York City. Participants in their sample population showed a mean acculturation level of 2.4 on a 1-4 scale using Marin and Gamba's bidirectional acculturation scale for Hispanics. Using this number and demographic data, researchers described their sample group of women as being of fairly high acculturation status. Results showed that "more than half of participants had heard or read 'almost nothing' or 'relatively little' about genetic counseling for inherited disease and for cancer" (p. 6).

Glenn, Chawla, and Bastani (2012) provided another context for understanding low uptake for genetic services among Latinos. The authors showed that Latina women were especially inclined to prioritize family health needs above their own personal healthcare demands. Latina study participants described the traditional female role as the reason for delaying her own health care in favor of the overarching needs of the family. In turn, this hierarchy has rendered the women less aware and accepting of preventive health services, including awareness and knowledge of genetic testing and genetic counseling (Glenn, Chawla, & Bastani, 2012). One woman provided this illustration:

> I think we [Latinas] tend to be more concerned about…family loyalty [vs personal health care needs]…we become martyrs and we will take the pain and suffering…culturally this is what women do, it is something ingrained in your

culture in your upbringing…You [women] don't burden the family unnecessary. (p. 270)

1.5 Unique Barriers Affecting United States Latinos in their Access to Genetics Healthcare Services

As evidenced by Rolnick et al. (2011), the genetic counseling community recognizes that there are particular obstacles that confront their patients regarding use of and access to cancer genetic services. The study found that genetic professionals considered the top "perceived patient barriers to seeking genetic counseling after referral" (p. 314) to include any of the following factors: risk evaluation viewed as a non-priority, concerns about impact on insurability, distance to appointments, lack of insurance, lack of patient/provider knowledge about the value of genetic counseling, discouragement by family members, and fear.

In regard to Latino-specific barriers in the United States, a study by White, Garces, Bandura, McGuire, & Scarinci (2012) identified obstacles that included lack of health insurance, limited English proficiency, recent immigration status, and perceptions such as procrastination, embarrassment, and fear. Results of a research study by Walton, Brandt, & Hilfinger Messias ("Latina Initiative Against Cancer," 2012) has suggested that the most common regional barriers to breast/cervical cancer screening for Latina women in the state of South Carolina include lack of access to cancer screening services, fear of not having an interpreter, and miscommunications with the clinic. The combined effect of these deterrents has resulted in that Latinos engage in less frequent use of preventive services, engage in increased use of hospital emergency rooms, and exhibit less satisfaction with their healthcare (Hispanic Health Initiative [HHI], n.d.).

It has been demonstrated that a substantial proportion of the Latino population in the United States tends to lack a regular healthcare provider, a specific place of care, or a dependable form of transportation to access healthcare services (Sudarsan, Jandorf, & Erwin, 2010). Lack of quality medical care is exacerbated by the fact that nearly one-third of American Latinos lack health insurance (Yeomans Kinney et al., 2010). According to Chandler et al. (2012), "Latina immigrants, and undocumented Latinas […] are more likely to be uninsured than their documented counterparts" (p.E24). In effect, this group of women who lack insurance are at heightened risk for poor health outcomes and increased burden from chronic disease. These women are also more likely to express "a great deal of dissatisfaction" with the care that they do receive (Chandler et al., 2012, p. E25).

In addition to not having insurance, a 2012 study by Glenn, Chawla, and Bastani described issues confronting Latina women in regard to insurance discrimination. One woman stated, "I am already worried about it. I can't get insurance…I have tried to get insurance…I have been looking for ten years…It's already a concern…and yeah! You are discriminated [against!]. The people [who] need it the most can't get it" (p. 271). The authors concluded that this form of discrimination functions as a barrier to genetic testing and additionally influences decision-making options after testing.

To understand the effect of managing breast cancer without insurance coverage (or without adequate insurance coverage), a 2011 study by Phllips and Cohen explored the healthcare implications for African American women, another minority population at high risk for breast cancer mortality. One woman described the high cost of surveillance care for high-risk status in this way, "I've had two MRIs, which one was $5,000 and one

was $2,000. My insurance doesn't pay it at all…They don't pay it unless you have been diagnosed with cancer…so that's why I haven't had another one" (p. 243).

Chandler et al. (2012) theorized that United States discrimination of Mexican immigrant women creates a unique form of stigmatization. The authors argued that as "women lack recognition of their essential humanity [due to their undocumented status]" (p. E33), power inequalities are worsened between patients and healthcare providers. This may be exacerbated by disparities in communication skills. In this regard, women feel stigmatized primarily as immigrants and secondarily as cancer patients; they are therefore increasingly reluctant to seek appropriate care (Chandler et al., 2012).

According to Escarce and Kapur (2006), language proficiencies exert substantial influences on patients' experiences with healthcare providers, and information provision has been shown to be preferred in patients' favored language and with access to qualified, professional interpreters (U.S. Department of Health and Human Services, 2001). When language barriers exist between patient and provider, patients have been more inclined to decrease their use of primary care, increase use of emergency department care, and receive inadequate follow-up. This phenomenon is exacerbated by the fact that the United States healthcare system is largely geared toward serving English speakers and there is yet to be a corresponding increase in Latino healthcare workers to match the rapidly increasing Latino population (Escarce & Kapur, 2006; Timmins, 2002; Peterson-Iyer, 2008).

1.6 Stigmatization of Cancer: Shame, Fear, and Silence

In addition to the discussed influences in the decision to engage in genetic testing and counseling among Latina women, a particularly striking barrier is the emotions of

fear or shame. In fact, the literature has documented that cancer-associated stigma is prevalent among Latinos. 'Stigma' is described by the LIVESTRONG Foundation (The Lance Armstrong Foundation) as "the perception of the person affected by cancer as differing from the norm in a negative or undesirable way" (Neal et al., 2011, p. 3). This definition of stigma therefore cultivates risk for self-induced inequity of medical care, loss of status, rejection, isolation, and failure to adopt risk-reducing strategies such as screening.

Gibbon (2011) noted the inherent link between understanding of disease and the "cultural meanings that may be linked to it" (p. 1785). This author theorized that the concept of personhood (or identity) is associated with multiple variables, such as kin, family, and/or citizenship. These variables extend to an individual's sense of moral values, spirituality, and religion, which are then further interwoven into the larger context of institutional cultures or state provisions. In total, these varying "pulls" on personhood can affect healthcare and may "influence, facilitate, or impede" biological understanding or uptake of new technologies (Gibbon, 2011, p. 1785).

According to Gregg's 2011 investigation of the stigmatization of cervical cancer among Brazilian women, the term stigma is a "discrediting attribute, an undesired differentness from social expectations" (p. 73). In effect, stigmatized women – or cancer-burdened women – may encounter anxiety relevant to their "deformed bodies" as well as "exclusion from moral community" (p. 73). Gregg (2011) merged these descriptions into what she considers a relatively ignored interplay between power roles and being stigmatized. She stated that recent theorists have implied that "for stigmatization to occur, power must be exercised" (p. 73). Although the result is often discrimination

resistance, Gregg found the opposite effect within this population of Brazilian women, which was actually to perpetuate and maintain the stigma in order to preserve the continuity of community order and values. This example demonstrates that one effect of stigmatization may actually be the acceptance of discrimination in order to concede to condemning values in one's society and not create turmoil (Gregg, 2011).

Yeoman Kinney et al. (2011) found that the word cancer evoked the following descriptors among Latinos: *pain*, *suffering*, *sadness*, *death*, *worry*, *fear*, *anger*, and *agony*. Participants assumed that cancer was synonymous with death and that there was "nothing that one can do about it" (p. 107) or that it was simply "God's will" (p. 111). The same study noted that participants described cancer as a "cultural taboo" (p. 112), something that might be contagious or shameful. Other participants expressed embarrassment and modesty as significant barriers to detection and risk-reduction services. Gregg (2011) noted that the Brazilian women in her population would not talk openly about their disease with friends or neighbors. Community doctors in Brazil commonly referred to the disease only as 'inflammation' or 'wound,' which were applied as euphemisms for death. In Cuba, the indirect terms *el cangrejo*, 'the crab, is sometimes used to describe the disease, as well as simply "*problemas con las mamas* (problems of the breast)" (Gibbon, 2011, p. 1790).

It is noteworthy that many Latino countries of origin do not have similar concepts of "biological citizenship" as those in the United States/United Kingdom where communities and cultures are tied to strong breast cancer activism movements with emphasis on detection, prevention, and awareness (Gibbon, 2011, p. 1790). In 2007, LIVESTRONG launched a global cancer research study to empower individuals affected

by cancer and to address the pervasive problem of stigma in communities worldwide. Latin American countries that were included in the study were Mexico and Argentina. Information was gathered through a global media audit, public opinion research, and semi-structured interviews. Recurrent sentiments emerged such as little or no control over risk, lack of a cure, fear of death from cancer, and lack of knowledge about how and where to screen for cancer. Results showed that stigma produced a silencing effect that opposed cancer risk-reducing behaviors or the likelihood to seek out supportive services. They found that cancer continues to "carry a significant amount of stigma; however, there are opportunities to capitalize upon shifting perceptions and positive change" (Neal et al., 2011, p. 1). They further concluded that many people still feel uninformed, that people want information, and that communication is critical in efforts to reduce cancer-related stigma and associated burden of disease.

Due to the cultural silence of the disease, Latinos may be more reluctant to share family history of cancer. This concept that "not telling a relative [about a diagnosis] is the best course of action" confers an additional deterrent to genetic counseling services (Yeomans Kinney et al., 2010; Gibbon, 2011, p. 1791). Depending on country and culture of origin, traditions of non-disclosure and paternalism render it particularly difficult for genetic healthcare providers to elicit complete and accurate family histories, navigate family relationships, or provide appropriate care-giving or preventive suggestions (Gibbon, 2011). The discontinuity in family pedigrees, as well as the silence and perceived stigmatization, prevents open discussion, meaningful interpretation of genetic risk, and possible interventions to increase awareness and decrease morbidity.

1.7 The Importance of Culturally and Linguistically Tailored Health Interventions

Importantly, the growing United States Latino population is uncovering the reality that "cultural norms and health beliefs of the Spanish-speaking population are not well understood by healthcare providers" ("PASOs," n.d.). To manage this circumstance, research has suggested the importance of tailored interventions to reflect community priorities and cultures (Sudarsan, Jandorf, & Erwin, 2010). Walton, Brandt, and Messias (2009) maintained that health education materials should be "culture and language appropriate" with information presented in a culturally precise framework, and with context at "no higher than a fifth grade reading level." In addition, Latino-specific risk factors – including lower screening usage – should be recognized and considered in clinical settings and "for cancer control planning" (Cokkinides et al., 2012, p. 353).

Yeomans Kinney et al. (2010) explored effective education methods and preferences among first or second generation Latinos living in the United States. Participant suggestions included reduction in the "level of technical detail" (p. 112) with technical information presented "clearly and succinctly" (p. 112), as well as easy-to-interpret materials with simple words. Other suggestions included use of entertainment forms of education (such as through *telenovelas*) or direct dissemination of materials through schools and churches (Yeomans Kinney et al., 2010). Cokkinides et al. (2012) bolstered this suggestion by adding that "educational campaigns [to prevent cancer] should consider using multiple media, including television, radio, and newspapers and magazines, in both English and Spanish, to expand their reach to diverse Hispanic/Latino communities" (p. 361).

To add merit to the suggestion for decreased technical and scientific jargon, Saley et al. (2010) explored genetic perceptions of hereditary causes of cancer and illness among Arabic-Australians. This population similarly contends with fears of stigmatization and fatalistic beliefs related to cancer. Study results showed that participants were less likely to use the more scientific word *gene*, and more likely to describe genetics as *inherited blood, in the family, get it through a parent,* and *strong or weak blood*. In similar fashion, Gibbon's study (2011) investigating Cuban women with breast cancer found that there was better understanding when genetic risk was re-phrased in terms of hereditary factors, such as *la herencia,* (family history) and *la salud or las enfermedades de los antecedents/ancestros* (health or illness of family members).

Rosal et al. (2004) explored education preferences of Latinos with low-literacy levels regarding diabetes education. When presented with a one-page brochure and small educational poster, participants seemed to like the straightforwardness of the educational message and of the simplicity of the brochure. They also showed enthusiasm for graphic representation of significant concepts. The authors recommended the use of repetitive messages to solidify main points and to encourage information digestion.

White et al. (2012) investigated the promotion and effectiveness of breast and cervical cancer screening for Latina immigrants. Results demonstrated that educational approaches were most effective when tailored to address the cultural concerns surrounding screening and suggested that efforts should involve trusted social connections within the community. The authors also recommended that outreach include Spanish-language announcements to call women to action regarding screening appointments. However, they concluded that further research is necessary in order to

better understand barriers [to screening] and to more appropriately develop educational messages. Walton, Brandt, and Messias (2009) suggested similar proposals, maintaining that "interaction with lay health workers [such as *promotoras*, the Spanish term for 'lay health workers']" is a crucial element in increasing adherence to cancer screening guidelines.

1.8 Latinos Show High Level of Interest in Genetic Testing, Despite Barriers

Published literature suggests that Latinos maintain a high level of interest in genetic testing for breast cancer susceptibility, despite apparent barriers to services and the need for improved educational interventions. Gammon et al. (2010) observed that although 83% of Latino participants knew "almost nothing or relatively little [about genetic testing for breast cancer risk]" (p. 626), 81% of participants were interested in the topic. An article by Sussner et al. (2008) suggested that "lack of knowledge may, in effect, drive interest level" (p. 69).

According to Glenn, Chawla, and Bastani (2012), minority women in the United States have expressed interest in pursuing counseling and testing for three overarching reasons: to provide information to their families, to inform their own health, and for the benefit of society and scientific research. One Hispanic woman from this same 2012 study expressed her interest in genetic testing: "…for prevention and to know what to do in case it would happen to me or…to any of my relatives or future generations" (p. 271). Another Hispanic woman reported that her biggest obstacle in receiving genetic testing was simply a lack of information available, despite her being "diligent in keeping up with [her] health" (Glenn, Chawla, & Bastani, 2012, p. 271).

1.9 Implications for Improved Knowledge and Health

The importance of this study is in its recognition for enhanced and informed decision making among Latinas with familial breast cancer. While studies have implicated educational preferences for Latino populations, we currently do not know of any research conducted that has examined the effectiveness of a simple educational module with regard to breast cancer genetics.

We hypothesize that a straightforward, targeted educational flier will significantly improve genetics knowledge and understanding among Latina women in our sample as well as reduce breast cancer-related stigma. Our data will therefore measure pre- and post-flier trends in knowledge/understanding and perceptions of stigmatization among this population. We secondarily believe that these outcomes will help to improve current educational materials for these women as well as increase the current dissemination of such materials. We recognize that an effective paper flier may become one fundamental element in a larger and more encompassing educational campaign that includes muti-media outlets.

The objectives of this study include the following:

- Assess the effectiveness of a simple educational flier on the understanding of genetics knowledge among Latina women.
- Analyze immediate emotional responses regarding breast cancer stigma.
- Improve educational materials about the genetics of breast cancer intended for use with Latino populations.
- Promote improved health through enhanced understanding and empowerment regarding hereditary breast cancer.

We hope to find increased understanding of genetics in concert with reduction of cancer-related stigma among our sample population of Latina women in Florida and South Carolina. We expect these results to stem directly from an educational flier tailored to the educational preferences of this cultural group.

Chapter 2: Manuscript

Perceptions of Breast Cancer-related Stigma and Genetic Knowledge among Latina Women:
el mejor entendimiento del miedo.[1]

[1] Cognetti, J.M., Walker, P., Ordonez, J., & Smithwick-Leone, J. To be submitted to *Journal of Genetic Counseling.*

2.1 Abstract

Purpose: Breast cancer is the leading cause of cancer death among Latina women, with *BRCA1/2* gene mutations accounting for a commensurate proportion of breast/ovarian cancer in Latina women as compared to non-Latina women. Despite this statistic, it has been shown that Latino populations exhibit low awareness and use of genetic services and that they hold culturally-related beliefs which stigmatize cancer. We hypothesized that a simple, culturally-tailored educational flier would improve genetics knowledge as well as decrease breast cancer-related stigma among Latina women in our sample. **Method:** Two groups of Latina women (N = 19) were provided with a pre-survey, educational flier, and then post-survey to assess their knowledge of breast cancer-related genetics and their emotional status. Qualitative responses regarding cancer-related perceptions were also gathered post-flier. Participants included women both affected and unaffected by breast cancer and were surveyed from either a Spanish-language breast cancer support group in Orlando, FL or a Hispanic community health education seminar in Charleston, SC. The Wilcoxon signed-rank test was employed to analyze pre- and post-flier results. The Repeated Measures ANOVA was used to assess emotional status as a function of cancer diagnosis. Qualitative data was coded and analyzed using grounded theory methods. **Results:** None of the women showed significant gains in knowledge related to breast cancer after viewing the educational flier. All women demonstrated significant increases in anxiety between baseline emotional status and emotional status related to either a real or hypothetical diagnosis of cancer. Unaffected participants showed higher anxiety means overall. Qualitative analysis identified four major themes: (1) cancer means fear, death, and family isolation; (2) cancer is difficult to

explain; (3) perceived causes of cancer; and (4) attitudes of hope. **Conclusions:** We showed that either a real or hypothetical diagnosis of breast cancer increases anxiety above that of baseline emotional status among our sample population of Latina women who attend health-focused support groups. We theorize that a refined version of the flier may be more effective as part of a larger educational platform, in which participants are provided with expanded information and encouraged to participate in cancer and genetics-centered conversation. We hope future research endeavors will build upon the utility of effective educational materials to improve genetic counseling referrals and genetic-medicine healthcare among this growing population.

2.2 Introduction

In 2010, cancer became the leading cause of death worldwide, with breast cancer ranked as the most commonly diagnosed cancer among women (Neal et al., 2011; Phillips & Cohen, 2011). Scientists estimate that between 5-10% of breast cancer is hereditary, implying that the cause of the cancer is a defective gene in the germline of an individual which can be passed through family generations. Mutations within the *BRCA1* and *BRCA2* genes are estimated to contribute to up to 50% of this hereditary breast cancer category (van der Groep, van der Wall, & van Diest, 2011; Walsh & King, 2007; Meindl, Ditsch, Kast, Rhiem, & Schmutzler, 2011). For individuals carrying a *BRCA1/2* mutation, the average lifetime risk to develop breast cancer may be up to 85%, with additional increased risks for other cancers, including ovarian cancer (Yeomans Kinney et al., 2010).

Evidence suggests that surveillance, chemoprevention, and prophylactic surgical interventions are all beneficial and potentially life-saving options for individuals with

BRCA1/2 mutations. The National Comprehensive Cancer Network (NCCN) states that high risk women would benefit from consultation with genetic counseling professionals in an effort to guide patient education and informed decision-making about genetic testing (Gammon et al., 2011). A subset of genetic counselors specialize in the role of cancer genetic counseling and employ their knowledge to specifically identify those individuals and families at increased risk of cancer in order to promote awareness, early detection, and prevention (NSGC, 2013).

Despite the recognized benefit of genetic counseling, Latino populations exhibit low awareness and use of genetic services. This shortcoming is striking in light of the fact that breast cancer is the most frequently diagnosed cancer and leading cause of cancer death among Latina women (Yeomans Kinney at al., 2010). It has also been found that Latinas are 22% more likely to die from breast cancer within five years after diagnosis as compared to white women and are also more likely to be diagnosed at younger ages and with the disease having already progressed to later stages (Sussner et al, 2008; Yeomans Kinney et al., 2010).

Importantly, Latinos are currently the fastest growing minority population in the United States and are predicted to comprise at least 25% of the United States population by the year 2050 (Yeomans Kinney et al., 2010). At large, members of this population tend to confront unique cultural barriers in their access to quality medical care, including lack of health insurance and non-familiarity with the English language and/or Western medicine (Fisher, 1996; Sudarsan, Jandorf, & Erwin, 2010). With explicit regard to genetics, Latinos are less likely to have heard of genetic testing for cancer risk and are more likely to agree with perceived disadvantages of genetic testing (Sussner et al.,

2008). This is in spite of research that suggests that *BRCA1/2* mutations account for a commensurate proportion of breast and ovarian cancer in these women as compared to non-Latina women (Gammon et al., 2011).

Literature has also demonstrated prevalent cancer-associated stigma among Latino populations. Results from a global cancer research study conducted by the LIVESTRONG foundation state that stigma is described as the "perception of the person affected by cancer as differing from the norm in a negative or undesirable way" (Neal et al., 2011, p. 3). Such sentiments may subject an individual to potential discrimination, loss of status, rejection, and isolation (Neal et al., 2011). The same report also showed that refrain from cancer-related discussions – or keeping a diagnosis secret— consequently blocks individuals from taking risk-reducing behaviors or seeking out supportive services.

Despite aforementioned healthcare barriers and cancer-related stigma, recent literature has suggested that Latinos maintain a high level of interest in genetic testing for breast cancer susceptibility (Sussner et al., 2008). Moreover, there are demonstrated opportunities to capitalize upon shifting perceptions of stigmatization, in which communication and the dissemination of educational materials will be crucial (Neal et al., 2011).

Research has demonstrated the efficacy and utility of healthcare education materials that directly reflect cultural priorities and preferences of Latino populations (Sudarsan, Jandorf, & Erwin, 2010). However, we noted an absence of data to describe the effect of a Latino-targeted educational module tailored specifically to genetic knowledge. In order for genetic information to be meaningful and appropriately

disseminated, it must first be shown to effectively inform the proposed consumers. We hypothesized that a simple, culturally tailored educational flier would improve genetics knowledge as well as decrease breast cancer-related stigma among Latina women in our sample. Our data measured pre- and post-flier trends in knowledge, understanding, and perceptions of stigmatization among this population. We believe there is extraordinary value and life-saving potential in the delivery of genetic information that addresses the negative and undesirable perceptions of the disease.

2.3 Materials and Methods

2.3.1 Participants. The first group of participants was invited to participate from the Hispanic Health Initiative (HHI) Breast Cancer Support Group in Orlando, FL. The meeting was conducted solely in Spanish language and assembled at MD Anderson hospital. The principal investigator (PI) attended the group, introduced the project, and disseminated/collected the materials.

The following was used as inclusion criteria for the HHI Orlando group:

- Women self-described as Latina
- Native Spanish-speakers

The following was used as exclusion criteria for the HHI Orlando group:

- Males
- Non-native Spanish-speakers
- Women who were blind (due to the nature of the materials)

We originally intended to use "Women who had received a diagnosis of breast cancer during some point in their lifetime" as part of the inclusion criteria. However, one

woman from HHI Orlando was found to not have been affected. The decision was made to include her responses in data analysis in order to increase sample size.

A second group of women was invited to participate from HHI's PASOs program in Charleston, SC. The PASOs program is conducted through the Medical University of South Carolina and serves to optimize health among Hispanic populations through support and education. These women were invited to participate in order to realize greater survey response and improve data analysis after all willing individuals from HHI Orlando were surveyed.

Due to travel barriers, the PI was not present during the PASOs meeting. Detailed instructions were provided to the support group leader via phone, email, and written letter so that she might conduct the session in similar fashion. All survey materials were mailed to the group leader; survey responses were collected and returned to the PI. The leader of this group was a native Spanish-speaker.

Due to the nature of this support group, survey materials were altered to reflect the possibility that members of the PASOs support group had not received a personal diagnosis of breast cancer (see Appendices C and D). Inclusion criteria remained the same.

2.3.2 Research Methods. All disseminated materials and instructions were provided in Spanish language. We presented the women with a pre-survey which included six questions designed to assess understanding of breast cancer genetics. Responses to the questions were marked as either *True*, *False*, or *I Don't Know*. The pre-survey also included an adapted 20-item version of the State-Trait Anxiety Inventory (STAI) to measure baseline emotional status; the women were asked to respond to the

scale by reflecting on *How They Feel during Most Days of the Week*. The same scale was presented once more on the pre-survey in order to investigate perceptions of cancer-related anxiety/stigmatization. The women from HHI Orlando were asked to reflect on *How They Feel When They Think about Their Breast Cancer Diagnosis*. The women from PASOs Charleston were asked to reflect on *How They Would Feel if they Were to Receive a Diagnosis of Breast Cancer*.

We then presented the women with an educational flier (one page, front-and-back) that served as an educational module to explain basic genetics, the genetics of breast cancer, and the profession of genetic counseling (see Appendix B). The women were given between three to five minutes to read through the flier. The flier was also read aloud by the support group leaders in order to assist participants with lower literacy levels.

A post-survey was then administered. The six questions regarding breast cancer genetics were re-asked in the same phrasing and order. The same set of STAI questions regarding emotional status was again presented in the context of having had an actual diagnosis of breast cancer, or considering a hypothetical diagnosis of breast cancer. Generalized questions (*How Do You Feel During Most Days of the Week*) were excluded, and baseline emotional status was considered to be consistent with answers from the pre-survey.

We obtained qualitative data from the three open-ended questions at the end of the post-survey (see Appendix D). A semi-structured interview method (see Appendix E) was used to collect qualitative data from those participants from Orlando willing to share their contact information. Women from Charleston were not invited for follow-up phone

interviews due to timing of data collection. Two follow-up interviews were conducted by the PI via Google Voice and recorded using Audacity software and assisted by a Spanish-language medical interpreter.

Pre-surveys and post-surveys were appropriately coded in order to compare and contrast each individual's responses as a set. Coding of the surveys did not include any of the participants' identifying information. All data was kept private and confidential in a password protected laptop.

Those who included contact information from HHI Orlando were entered into a raffle to win a $25 gift card to a local restaurant or store. All participants from PASOs Charleston were entered into a raffle to win 1 of 3 gift cards totaling $50. The research study was approved by the Institutional Review Board of the University of South Carolina at Columbia, SC, in July, 2012.

2.3.3. Statistical Analysis. Quantitative data was analyzed using SPSS (Statistical Package for the Social Sciences), version 21.0; data responses were grouped according to whether participants had been affected or unaffected by breast cancer due to the potential confounding influence of cancer diagnosis on answer selection. The Wilcoxon signed-rank test was employed in place of the dependent t-test as a nonparame tric analysis due to the small sample size. The six factual questions were analyzed both pre- and post-educational flier to investigate changes in scores. Emotional status responses (Baseline, Cancer-Related Emotional Status Pre-Educational Flier, and Cancer-Related Emotional Status Post-Educational Flier) were analyzed against one another to investigate potential differences. Positive-emotional statements in the questionnaire were reverse coded during analysis to ensure consistent ranking.

The Repeated Measures ANOVA test was carried out on all three emotional status measures to assess whether affected or unaffected group membership significantly affected resulting anxiety levels.

Qualitative data was coded and analyzed using grounded-theory methods to investigate themes from the open-ended responses and follow-up phone interviews. Translation was performed by both the PI and a Spanish-English medical interpreter who provides services to the University of South Carolina Genetic Counseling department. Select quotes were included in the results section in both translated English and the original Spanish counterpart.

2.4. Results

2.4.1 Participant Demographics. Total participants from HHI Orlando and PASOs Charleston equaled19 (N = 19). Seven of eight participants from Orlando had received a diagnosis of breast cancer at some point during their lifetimes (affected), and none of the 11 participants from Charleston had received a diagnosis of breast cancer (unaffected). In total, 37% (n = 7) of participants were affected and 63% (n = 12) were unaffected. The unaffected group ranged in ages from 25-96, and age was not assessed in the Orlando group due to logistic limitations. For those individuals with a history of breast cancer, year of diagnosis ranged from 1980 to 2011. All participants identified themselves as being Hispanic with Spanish being their native language. Respondent demographics are summarized in Table 2.1 and Figure 2.1.

Table 2.1 Participants' Country of Origin (*N* = 19)		
	HHI Orlando	PASOs Charleston
Mexico	0	9
Colombia	3	0
Puerto Rico	3	0
Dominican Republic	2	0
Peru	0	1
Spain	0	1

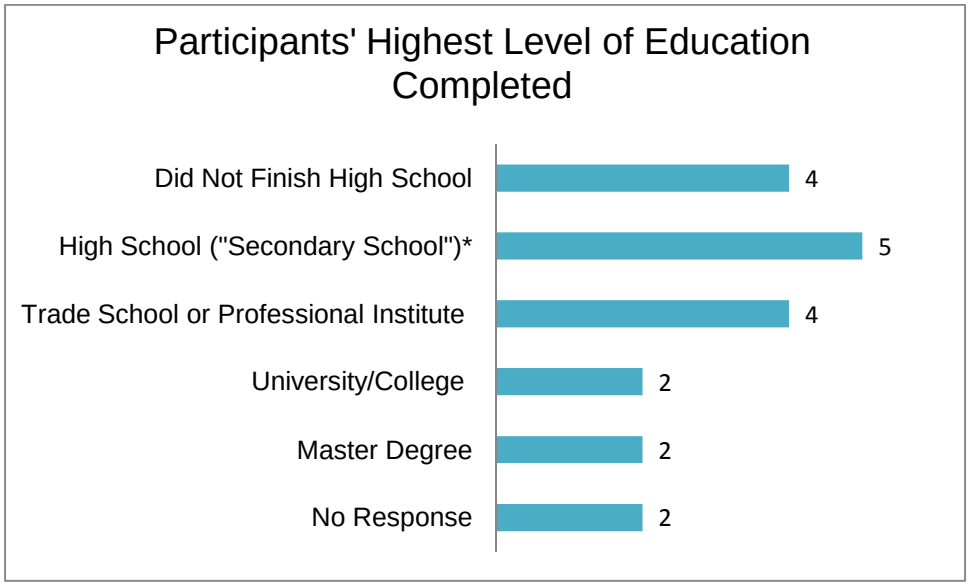

Figure 2.1 Participants' Highest Level of Education Completed (*N* = 19)

*The term "Secondary School" implies education following Elementary School. It cannot be assumed to be synonymous with the United States version of High School due to substantial heterogeneity between countries' educational systems.

2.4. 2 Changes in Knowledge Related to the Genetics of Breast Cancer:

Pre- vs. Post-Educational Flier. Participants were asked to respond to six factual questions before and after reviewing an educational flier. The Wilcoxon signed-rank test was carried out on the responses from the group of Latina women affected by breast cancer (n = 7). The results showed that genetic knowledge scores did not elicit a statistically significant change between pre- and post-educational flier. Results are shown in Table 2.2.

Table 2.2. Genetic Knowledge among Latina Women Affected by Breast Cancer, Measured Pre- and Post- Educational Flier (n = 7)

	Q1: About half of all breast cancers are hereditary.	Q2: There is more than one gene that can increase the risk of breast cancer.	Q3: All women who have a mutation in the breast cancer gene will get cancer.	Q4: A woman without a breast cancer gene mutation can still develop breast cancer.	Q5: A woman may be at increased risk of breast cancer if she has several close relatives with breast cancer.	Q6: It's possible to have several relatives with breast cancer by chance alone.
Z	-.966[a]	-1.342[a]	-.272[a]	.000[b]	-1.134[a]	-1.289[a]
Asymp. Sig. (2-tailed)	.334	.180	.785	1.000	.257	.197

a. Based on positive ranks.
b. The sum of negative ranks equals the sum of positive ranks.
c. Wilcoxon Signed Ranks Test; p = < .05

The Wilcoxon signed-rank test was also carried out on the responses of Latina women unaffected by breast cancer (n = 12). The results showed that genetic knowledge scores did not elicit a statistically significant change between pre- and post-educational flier. Question #2 showed a positive trend (Z = -1.913, p = .056), but was not statistically significant. Results are shown in Table 2.3.

Table 2.3. Genetic Knowledge among Latina Women Unaffected by Breast Cancer, Measured Pre- and Post- Educational Flier (n = 12)

	Q1: About half of all breast cancers are hereditary.	Q2: There is more than one gene that can increase the risk of breast cancer.	Q3: All women who have a mutation in the breast cancer gene will get cancer.	Q4: A woman without a breast cancer gene mutation can still develop breast cancer.	Q5: A woman may be at increased risk of breast cancer if she has several close relatives with breast cancer.	Q6: It's possible to have several relatives with breast cancer by chance alone.
Z	-.333[a]	-1.913[b]	-.812[b]	-1.222[a]	-.812 [a]	-.433[b]
Asymp. Sig. (2-tailed)	.739	.056	.417	.222	.417	.665

a. Based on negative ranks.
b. Based on positive ranks.
c. Wilcoxon Signed Ranks Test; p = < .05

2.4.3 Quantitative Analysis of Cancer-Related Anxiety. Participants were asked to respond to a Likert scale questionnaire that assessed Baseline Emotional Status (BES), Cancer-Related Emotional Status before the educational flier (CRES-pre), and Cancer-Related Emotional Status after the educational flier (CRES-post).

The Wilcoxon signed-rank test was carried out on responses from Latina women affected by breast cancer. The results showed a statistically significant increase in anxiety between the women's BES and CRES-pre (Z = -2.032, p = .042). Anxiety levels did not show statistically significant differences between BES and CRES-post or between CRES-pre and CRES-post. Results are shown in Table 2.4.

Table 2.4. Difference in Baseline Emotional Status and Cancer-Related Emotional Status (Pre- and Post- Educational Flier) Among Latina Women Affected by Breast Cancer (n = 7)

	CRES-pre vs. BES	CRES-post vs. BES	CRES-post vs. CRES-pre
Z	-2.032[a]	-1.000[a]	-.535[b]
Asymp. Sig. (2-tailed)	.042	.317	.593

a. Based on negative ranks.
b. Based on positive ranks.
c. Wilcoxon Signed Ranks Test; p = < .05

The Wilcoxon signed-rank test was also carried out on responses from Latina women unaffected by breast cancer (n = 12). The results showed a statistically significant increase in anxiety between the women's BES and CRES-pre (Z = -2.021, p = .028). Results also showed a statistically significant increased anxiety between BES and

CRES-post, meaning post-flier anxiety remained statistically higher than that of baseline anxiety (Z = -2.383, p = .017). Anxiety levels did not show a statistically significant difference between CRES-pre and CRES-post. Results are shown in Table 2.5.

Table 2.5. Difference in Baseline Emotional Status and Cancer-Related Emotional Status (Pre- and Post- Educational Flier) Among Latina Women Unaffected by Breast Cancer (n = 12)

	CRES-pre vs. BES	CRES-post vs. BES	CRES-post vs. CRES-pre
Z	-2.201[a]	-2.383[a]	-.210[a]
Asymp. Sig. (2-tailed)	.028	.017	.833

a. Based on negative ranks.
b. Wilcoxon Signed Ranks Test; p = < .05

The Repeated Measures ANOVA was carried out in order to analyze affected vs. unaffected women across all three emotional factors (BES, CRES-pre, and CRES-post). Results showed that levels of anxiety were dependent on whether the women were part of the affected or unaffected group. There was a statistically significant difference between the groups, F (2,7) = 4.923, p = .046. A marginal means plot analysis demonstrates visually meaningful trends, including decreasing anxiety tendencies among both groups between CRES-pre and CRES-post as well as overall higher anxiety levels among unaffected participants across all three factors. Estimated marginal means among the affected women also shows a *clinically* significant decline in CRES-post below a

standardized mean of *36.5* (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Results of the Repeated Measures ANOVA are shown in Figure 2.2.

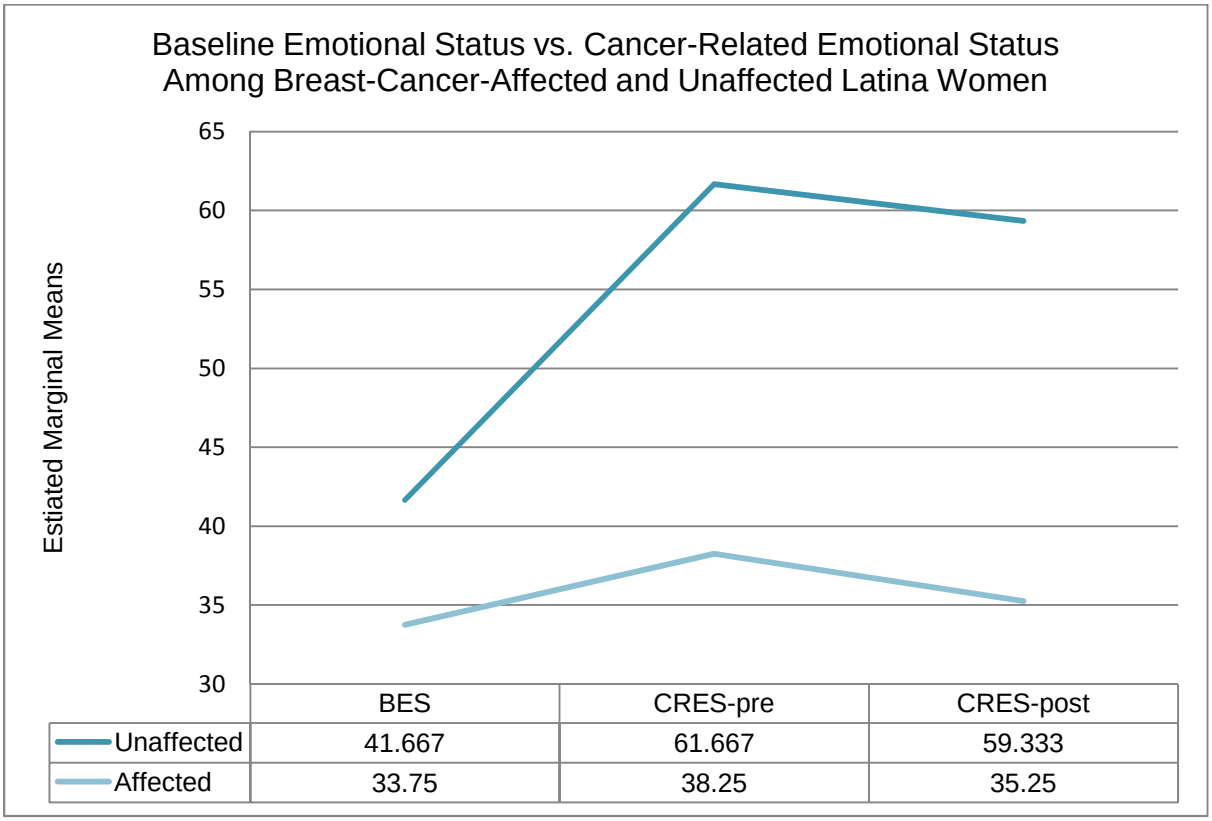

Figure 2.2 Baseline Emotional Status vs. Cancer-Related Emotional Status Among Breast-Cancer-Affected and Unaffected Latina Women.

2.4.4 Qualitative Review of Cancer-Related Perceptions Post- Educational Flier.

We collected qualitative results from both written-in responses on post-surveys as well as phone-interview transcripts. All women completed at least part of the written response section in Spanish language, and two women were able to be reached for follow-up phone interviews in Spanish language. After translation into English language by the PI and interpreter, grounded theory methods revealed four major qualitative

themes: (1) cancer means fear, death, and family isolation; (2) cancer is difficult to explain *("No sé"*); (3) perceived causes of cancer; and (4) attitudes of hope. Examples are presented first in the translated English counterpart, followed by the original Spanish quotation. All themes include a mixture of written-in and phone-interview responses.

Theme 1: Cancer means fear, death, and family isolation.

The women were asked to describe "What is the first thing that comes to mind when you think of the word cancer?" (*¿Qué es lo primero que viene a la mente cuando se piensa en la palabra cáncer?*) The majority of women related cancer to the following words: death (*muerte*), fear (*miedo*), and nerves (*nervios*). Three respondents expanded on their initial impression of cancer by writing, "That I am going to die," ("*Que me voy a morir"*). These three women were from Charleston and had not been previously diagnosed with breast cancer.

A few respondents remarked on sentiments of "being the only one diagnosed with cancer," in conjunction with feelings of loneliness and/or suffering. One respondent explained, "I cannot give an explanation of cancer to my family because I am the only one [in my family] who has suffered this sickness," ("*No puedo dar una explicación de cáncer en mi familia, porque yo soy la única que he sufrido esta enfermedad"*). When asked via phone-interview whether a participant had other family members diagnosed with cancer, she responded, "No…no…no…no. Only me," ("*No…no…no…no. Yo solamente"*).

Notably, many women expressed concern over dying and leaving their children without a parent, "[I think of] death and of your children who would probably be left alone," ("*En la muerte. Y tus hijos que probablemente queden solos"*) and, "[Cancer

makes me think] I am going to die and that I would leave my children alone," ("*Me voy a morir; voy a dejar a mis hijos solos"*).

Theme 2: Cancer is difficult to explain ("No sé").

Results showed a majority of written-in responses that claimed, "I don't know" (*No sé*). This answer was cited as a response for any of the three post-survey questions that were presented to the women; it was sometimes provided as an answer to all three. However, *No sé* was provided more often as an answer to the following questions (1) What do you think are medical causes of breast cancer? (*¿Cuál cree usted que son las causas médicas de cáncer de mama?*) and (2) How do you explain cancer in your family? *(¿Cómo explica usted el cáncer a su familia?*). *No sé* was shown more often among the Charleston women who had not been affected by breast cancer.

Related to *No sé,* women also illustrated feelings of general confusion and being overwhelmed. One woman expressed her difficulty in understanding/explaining cancer by claiming, "It's difficult to explain it [cancer], given that cancer confuses everyone," ("*Es difícil explicarlo; puesto que todo el mundo se confudir mucho"*).

Theme 3: Perceived causes of cancer.

Participants discussed a number of perceived causes of cancer. Causes were more often expressed in response to the question: What do you believe are non-medical causes of breast cancer? *(¿Cuáles son las causas no-médicas de cáncer de mama?*). Causes that were cited most frequently included lifestyle, stress, and environment; these were often cited in combination. One woman wrote: "[Breast cancer] could be influenced by poor nutrition, by stress or suffering," *("Puede influir mala alimentación, por stress o sufrimiento"*).

Of all mentioned causes, food/nutrition was cited most frequently. Women expounded on this category to include concepts of overweight and overconsumption of processed foods: "The environment and some (or all) processed foods," ["*El medio ambiente y algunos alimentos (o todos) procesados"*]. Another participant explained how she cautioned her family members by stating, "I have told my children that they need to watch their nutrition, because we can all get [be affected by] cancer," ("*Yo les he dicho a mis hijos que se cuiden en su alimentación, porque el cáncer nos puede llegar a todos"*).

A few women referenced "*golpes,*" or hits, as causative factors. This term was referenced by Finkler (1991) and Gibbon (2011) as corresponding to a general English understanding of stress, or more specifically, a 'physical blow' that is perceived to be strong enough to cause cancer.

Genes/Genetics were referenced as being cancer-causing by about one-quarter of participants, always under the category of non-medical causes of cancer. Participants did not expand on this answer, and left responses solely as "genes" or, "changes in genes." One woman wrote, "The degeneration of genes," ("*degeneración de los genes"*).

One woman whom we interviewed via phone expressed strong tones of religiosity. She was the only participant to reference God and/or Christianity during the study.

"I am very religious and believe very much in God [*el Señor*]… I do not use vices, ever. I have always been a very conservative person in everything…in my eating and everything. If God gave this [cancer] to me, well it's a sign that he chose me. Only me. And of five sisters, this was given to me. God chose me."

("Porque yo soy muy cristiana, y creo mucho en el Señor … yo no uso vicios, nunca. Y yo siempre he sido una persona muy conservada en todo… para comer y para todo. Si el Señor me mandó eso, pues es seña que él me escogió. Yo solamente. Y de cinco hermanas que éramos, a la que me dio fue a mí. El Señor me escogió.")

Theme 4: Attitudes of hope.

In contrast to responses of fear and/or death, a number of participants nonetheless expressed sentiments of positivity. Some of these attitudes seemed to stem from internal predispositions to hope.

"I think that a Good mental attitude in the face of cancer helps with curing (healing). I think that a large percentage (80%) of the cure depends on us."

["Pienso que con Buena actitud mental frente a la enfermidad de cancer ayuda a la curación ("healing"), creo que porcentaje grande (80%) de curar depende de nosotros."]

Other women credited external factors such as modern scientific medicine and the continuing search for treatment and cures: "Science has greatly improved and some cancers can be successfully treated," ('*Que la ciencia ha adelantado mucho y algunos*

canceres se pueden tratar con éxito'). Positive sentiments were shown more frequently among the Orlando group (affected) than the Charleston group (unaffected).

Positive sentiments were shown more frequently among the HHI Orlando group (affected) than the PASOs Charleston group (unaffected). It is also noteworthy that one woman from Orlando was the only woman to have gone through a genetic counseling process. She has a known *BRCA2* family mutation. She also expressed notable optimism, perhaps beyond that of the other women: "Years before, it was 'I am already dead.' Now, with medical advances, I had more hope than that of my mother, aunts, and family members," *("Muchos años atras fue:"estoy muerta ya." Ahora con los adelantos medicos, yo tuve mas esperanza que mi mama, tías, y familias").*

2.5 Discussion

Our study demonstrated that there is significant anxiety associated with breast cancer among our sample population and that an educational flier may provide an effective tool to reduce this anxiety. Our study purports that by measuring anxiety we were simultaneously assessing emotions of stigma at some level. We believe that the word anxiety suggests an umbrella of stigma-related terms including "undesirable and negative feelings" (Neal et al., 2011, p. 3) and connotations of guilt and shame that therefore increase stress and cause "psychological and social morbidity" (Chapple, Ziebland, & McPherson, 2004, p.1). In the publication by Chapple, Ziebland, & McPherson (2004), the authors interviewed 45 patients in the U.K. with lung cancer, many of whom remarked on the stigma associated with that disease. We believe that while those respondents experienced external stigma-related reactions from other people in many cases, the women in our study may feel stigma, including guilt and shame,

internally, due to their cultural norms and barriers that may prevent them from receiving adequate education about the true medical causes of breast cancer.

We did show steeper increases in means anxiety among our sample of unaffected women (BES to CRES-pre; *41.4* to *61.7*) compared with the affected group (*33.8* to *38.25*). This may have been in part due to the idea that a hypothetical diagnosis of cancer led to greater initial anxiety, which may have caused the steeper initial rise in anxiety. In other words, these women had not already contended with and accustomed themselves to cancer-associated stress. We also acknowledge that their health seminar was not tied directly to breast cancer and that the survey theme was therefore a surprising – and potentially anxiety-producing – topic. This idea of an unannounced cancer survey may also account for their higher levels of anxiety overall, including baseline status.

We recognize that that not all variables could be controlled for during the study, including those that may have contributed to declining means in anxiety post-educational flier, therefore falsely inflating the weight of the educational intervention. Other mechanisms for decreases in anxiety could have included general alleviation of anxiety over the course of the group session, greater sense of comfort after talking and interacting with other group members, or heightened positive emotions related to finishing the survey.

We did not show significant gains in knowledge of genetics related to breast cancer. It is possible that this could simply be a function of small sample size or of insufficient time to absorb the flier's information. However, we also consider that the study design likely underestimated the complexity of the questions and the validity of the answers in the context of the lower literacy levels among at least some of the women. In future

studies, we would propose that the questions be back-translated and validated via a pilot study to assess participant comprehension of the statements. We additionally consider that the women may have experienced survey fatigue after reviewing the flier and were therefore less motivated to answer the questions correctly.

We point out that Question #2 demonstrated a positive trend among the unaffected women, meaning that although it was not statistically significant, a larger sample size may have achieved statistical significance for increased level of genetic knowledge. Question #2 stated that *There is more than one gene that can increase the risk of breast cancer*, and the answer is true. The educational flier was specifically designed to communicate that both the *BRCA1* and *BRCA2* genes can contribute to hereditary breast cancer. There are, of course, other known genes but they were not mentioned as part of the study. We suggest that this question was more easily answerable due to the repetition of *BRCA1* and *BRCA2* (written twice) and the plurality of the word 'genes' on the educational flier. This aligned with conclusions from the 2004 study by Rosal et al. which found that educational preferences of Latinos included repetitive and succinct messages.

Analysis of qualitative data cannot be framed against pre-educational flier sentiments, as this information was only gathered from the post-survey and follow-up phone interviews. Nonetheless, the voices provide context for further education and interaction among Latina women regarding breast cancer. While the educational flier seemed to have decreased anxiety means in our sample population, we recommend that its implementation may be more effective as part of a larger educational platform. For instance, the flier might be disseminated as part of an invitation for a health education

seminar where actual seminar conversations could include expanded education along with talking-points that address qualitative findings.

We found that more positive and optimistic statements were provided among the affected HHI Orlando group than the unaffected PASOs Charleston group. These positive statements included the hopefulness conveyed by the *BRCA*+ participant. Regarding this group as a whole, it is not unlikely that having survived breast cancer rendered these women less likely to remark on the absoluteness of death from cancer.

The unaffected PASOs Charleston group also provided more responses of *I don't know* to the open-ended questions at the end of the survey. This demonstrates that confusion and not-knowing persisted beyond distribution of the educational flier and reinforces our finding that women did not improve knowledge scores related to breast cancer genetics. Because the majority of *I don't know* responses were provided by unaffected participants, we suggest that the women affected with breast cancer had received at least some helpful medical or psychological information during their diagnosis and/or treatment. Given this supposition, we suggest that breast cancer related materials could be especially useful as educational tools for preventive interventions during educational seminars directed towards all Latina women, not just those who have been affected by cancer.

We theorize that affected women were less likely to have responded *I don't know* due to having gone through a personal diagnosis of breast cancer. However, they were certainly not immune from emotions of confusion and/or devastation. Support groups and educational interventions might be able to target more detailed subjects among these

women, such as deeper understanding of emotions of grief and shame as well as better understanding of perceived barriers to genetic counseling (Sussner et al., 2012).

Only about one-quarter of participants referenced genes/genetics as cancer-causing variables. This finding seems to be consistent with literature showing that minority populations have limited knowledge about genetics (Gammon et al., 2010; Gibbon, 2011; Catz et al., 2005). We also noted that genetics was referenced as a non-medical cause of cancer, while food/nutrition/stress was cited more frequently as being a medical cause of cancer. We similarly propose that genetics was provided under the umbrella of non-medical causes of cancer as a result of participants being less familiar with genetics, therefore perceiving it as "less medical." In addition, as described by Peterson-Iyer (2008), Latinos who are more inclined to rely on non-Western doctors are more likely to approach illness as form of *sickness*, rather than a *disease* in a purely biomedical sense.

Importantly, we did not measure the women's understanding of the availability of genetic testing. Gammon et al. (2011) discussed that lower levels of *BRCA1/2* testing awareness among minority groups in the United States demonstrates a need for all at-risk individuals to be better informed about its availability. In our sample population, only one woman had gone through genetic counseling and was known to be a *BRCA* mutation carrier. This woman was opportunely prompted by the nature of the study to speak up and share her experience with the other support group members. It is plausible that her experience spread awareness and shed favorable light on the opportunity and availability of genetic counseling and testing. This case attests to a potential outlet for willing Latina women who have already gone through the genetic counseling/testing process to conduct personal community outreach and story-telling. This concept builds upon the research by

Sudarsan, Jandorf, & Erwin (2010) who maintained that determinants of health be addressed through "social networks, neighborhoods, and communities" (p. 194).

2.5.1. Limitations. Our study analyzed the data of a relatively small sample population from two United States locations, representing six countries of origin. All materials were developed by the PI who is not Latina and for whom Spanish is not her native language. It is conceivable that participants from HHI Orlando were less motivated to participate in the study with knowledge that the PI was not of Latina ancestry. In addition, the PI has no way of knowing the exact details of data collection from PASOs Charleston, as she was not present.

2.5.2 Areas for future research. As of result of small sample size, we were unable to tease out significant variables that have been shown to affect health strategies among Latinos. Future studies might investigate how country of origin, age, and level of acculturation alters improvements in genetics knowledge and levels of anxiety/stigma (Cokkinides et al., 2012). We also acknowledge that our demonstrated increases in anxiety related to cancer (BES to CRES-pre) may not be unique to Latina women. Indeed, heighted anxiety may likely represent a universal and general response to the idea of cancer. However, follow-up studies could investigate the degree of heightened anxiety related to cancer as compared between different ethnicities.

Our study did not originally intend to survey women unaffected by breast cancer; however our results showed statistically significant differences in anxiety between our affected and unaffected groups of participants. Future endeavors might explore how to better stratify educational materials for Latina women according to diagnosis status in order to achieve more significant decreases in post-flier anxiety.

In addition, we chose to create our educational intervention using a simple paper flier due to its cost-effectiveness, efficiency, and ability to reach larger populations, particularly those without multi-media access. However, we recognize that illiteracy and disinterest in reading "educational material" limits the potential effectiveness of our tool and we would therefore be interested in the influence of other modalities that have shown to be effective and preferred among Latino populations. These modalities might include entertainment forms of education such as *telenovelas*, radio, and magazine (Yeomans Kinney et al., 2010; Cokkinides et al., 2012).

It might also be worthwhile for genetic counselors to propagate information by attending meetings and giving presentations to oncologists, surgeons, primary care physicians, and gynecologists who are Spanish-speaking and involved in serving the Latino community. This concept was initially proposed by Rolnick et al. (2011) to reduce patient barriers to genetic testing, and was also addressed in literature by Escarce & Kapur (2006), stating that Latinos are hindered in their ability to obtain healthcare services due to their own limited English proficiency and the limited Spanish proficiency of healthcare providers. This vehicle of information distribution (via Spanish-speaking doctors or nurses) also prioritizes and emphasizes the need to add more Spanish-speaking medical providers to the Unites States healthcare system as the Latino population grows.

2.6 Conclusions

We believe that the potential to reduce cancer-related stigma combined with enhanced knowledge of genetics among Latinas is an important step in closing in on genetic health service gaps. It is well documented that there is value in providing both genetics education as well as education that addresses the negative and undesirable

perceptions of disease. These combined factors can therefore empower Latina women to overcome fear and combat cancer-associated morbidity, as well as share valuable and life-saving information with family members.

The participants in our study represented Latina women who were both affected and unaffected by breast cancer. The sample size was small, but we showed significant increases in anxiety (above baseline emotional status) in response to either a real or hypothetical diagnosis of breast cancer among our participants. Unaffected participants demonstrated higher anxiety means overall, and both unaffected and affected participants demonstrated some decrease in mean anxiety between pre- and post-educational flier, when analyzed as distinct groups.

Participants in our study did not show improvements in genetic knowledge related to breast cancer after the educational flier intervention. This may have been a function of small sample size, complexity of information, poor English to Spanish translation, or inadequate time to process the information in the flier. This study chose to use a simple paper flier due to its cost-effectiveness, efficiency, and ability to reach larger populations, particularly those without multi-media access. However, further refinement of the flier and its presentation of delivery may be necessary in order to improve its effect. We also acknowledge that there is room to explore alternative methods of flier distribution along with other outlets of education, including television and radio. However, we remind future researchers that many members of this population do not have access to multi-media equipment, and are consequently limited in where and how they receive genetic health information (Livingston, 2010).

Our hope is that future research endeavors will build upon the utility of effective educational tools that address genetics education among Latino populations, with the intention to achieve an equitable balance between genetic medicine, identity, and health status. Such endeavors thus align with the United States Department of Health and Humans Service's overall health objectives for the year 2020 which includes the goal to "Improve health and prevent harm through valid and useful genomic tools in clinical and public health practices" (Healthy People, 2012). To move forward in this sense – specifically with regard to health goals among Latino populations in the United States– culturally tailored information must be provided that addresses their most compelling barriers and enhances access to healthcare services, including genetic counseling.

Chapter 3. Conclusions

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Appendices

Appendix A: Survey Invitation

HHI Orlando Participants (English and Spanish Versions)

Dear Potential Participant:

You are invited to participate in a graduate research study focusing on breast cancer among Latina women. I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research investigates the perceptions of cancer and of genetic knowledge of Latina women diagnosed with breast cancer. The research involves reviewing an associated flier about breast cancer and genetics, and completing two surveys.

The surveys attempt to interpret your understanding of genetics information and viewpoints regarding cancer before and after having looked at the flier. If you do not wish to answer a certain question, please skip that question and continue with the rest of the survey.

All responses gathered from the surveys will be kept anonymous and confidential. We only ask for your name and phone number in the event that you are interested in providing more information at a later date over the phone. It is not necessary that you provide this information. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

Participants who include contact information will also be entered into a raffle to win a $25 gift card to a local restaurant or store. If you are chosen, this prize will be sent to you at a later date, after having collected all data. Your contact information will not be used for any other purposes beyond a follow-up phone interview or to send you the raffle prize if you have won.

Your participation in this research is voluntary. By completing the survey, you are consenting that you have read and understand this information. At any time, you may withdraw from the study by not completing the survey.

Thank you for your time and consideration to participate in this survey. Your responses may help genetic counselors create more helpful education materials for Latina women. If you have any questions regarding this research, you may contact either myself or my faculty adviser, Peggy Walker, MS, CGC, using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803)777-7095.

Sincerely,

Jade Cognetti, B.S., B.A.
Genetic Counselor Candidate
University of South Carolina School of Medicine
USC Genetic Counseling Program
Jade.cognetti@gmail.com
(321)662-6889

Peggy Walker, MS, CGC
Faculty Adviser
University of South Carolina School of Medicine
USC Genetic Counseling Program
Two Medical Park, Suite 208
Columbia, SC 29203
Peggy.Walker@uscmed.sc.edu
(803) 545-5746

Estimado Participante Potencial:

Usted está invitada a participar en un estudio de investigación de posgrado centrado en el cáncer de mama en las mujeres latinas. Soy un estudiante de posgrado en el programa de consejo genético en la Universidad de South Carolina, Facultad de Medicina. Mi investigación se trata de las percepciones de cáncer y del conocimiento genético de las mujeres latinas diagnosticadas con cáncer de mama. Esta investigación involucre un folleto sobre el cáncer de mama y la genética, y responder dos encuestas al respect.

Hay dos encuestas que tratan de interpretar su comprensión de la información genética y puntos de vista sobre el cáncer antes y después de haber mirado el folleto. Si usted no desea responder a una pregunta determinada, por favor salte esa pregunta y continúe con el resto de la encuesta.

Todas las respuestas obtenidas de las encuestas serán anónimas y confidenciales. Sólo le pedimos su nombre y número de teléfono en el caso de que usted esté interesada en proporcionar más información en una fecha posterior a través del teléfono. No es necesario que proporcione esta información. Los resultados de este estudio podrían ser publicados o presentados en congresos académicos, sin embargo, las participantes no serán identificadas.

Los participantes que incluyen información de contacto también serán entradas en una rifa para ganar una tarjeta de regalo de $ 25 a un restaurante o tienda local. Si usted es elegida, este premio será enviado a usted en una fecha posterior, después de haber recogido todos los datos. Su información de contacto no será utilizada para ningún otro propósito más allá de una entrevista telefónica o para enviarle el premio de la rifa si ha ganado.

Su participación en esta investigación es voluntaria. El completar la encuesta implica que usted ha leído y comprendido esta información. En cualquier momento, usted puede retirarse del estudio al no completar la encuesta.

Gracias por su tiempo y consideración a participar en esta encuesta. Sus respuestas pueden ayudar a los consejeros genéticos a crear materiales educativos más útiles para las mujeres latinas. Si usted tiene alguna pregunta relacionada con esta investigación, puede ponerse en contacto conmigo o con mi asesor académico, Peggy Walker, M.S.G.C, utilizando la información de contacto a continuación. Si usted tiene alguna pregunta acerca de sus derechos como participante en la investigación, puede comunicarse con la Oficina de Cumplimiento de Investigación de la Universidad de South Carolina al (803) 777-7095.

Gracias,

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PASOS Charleston Participants (English and Spanish Versions)

Dear Potential Participant:

You are invited to participate in a graduate research study focusing on breast cancer among Latina women. I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research investigates the perceptions of cancer and of genetic knowledge of Latina women. The research involves reviewing an associated flier about breast cancer and genetics, and completing two surveys.

The surveys attempt to interpret your understanding of genetics information and viewpoints regarding cancer before and after having looked at the flier. If you do not wish to answer a certain question, please skip that question and continue with the rest of the survey.

All responses gathered from the surveys will be kept anonymous and confidential. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

As incentive, participants will be entered into a raffle to win a $20-$30 gift card to Wal-Mart. If you are chosen, this prize will be given to you on this date.

Your participation in this research is voluntary. By completing the survey, you are consenting that you have read and understand this information. At any time, you may withdraw from the study by not completing the survey.

Thank you for your time and consideration to participate in this survey. Your responses may help genetic counselors create more helpful education materials for Latina women. If you have any questions regarding this research, you may contact either myself or my faculty adviser, Peggy Walker, MS, CGC, using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803)777-7095.

Sincerely,

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Hay dos encuestas que tratan de interpretar su comprensión de la información genética y puntos de vista sobre el cáncer antes y después de haber mirado el folleto. Si usted no desea responder a una pregunta determinada, por favor salte esa pregunta y continúe con el resto de la encuesta.

Todas las respuestas obtenidas de las encuestas serán anónimas y confidenciales. Los resultados de este estudio podrían ser publicados o presentados en congresos académicos, sin embargo, las participantes no serán identificadas.

Como incentivo, las participantes entrarán en un sorteo para ganar una tarjeta de regalo para Wal-Mart, en el valor de $20-$30. Si usted es elegida, este premio será entregado a usted en esta fecha.

Su participación en esta investigación es voluntaria. El completar la encuesta implica que usted ha leído y comprendido esta información. En cualquier momento, usted puede retirarse del estudio al no completar la encuesta.

Gracias por su tiempo y consideración a participar en esta encuesta. Sus respuestas pueden ayudar a los consejeros genéticos a crear materiales educativos más útiles para las mujeres latinas. Si usted tiene alguna pregunta relacionada con esta investigación, puede ponerse en contacto conmigo o con mi asesor académico, Peggy Walker, M.S.G.C, utilizando la información de contacto a continuación. Si usted tiene alguna pregunta acerca de sus derechos como participante en la investigación, puede comunicarse con la Oficina de Cumplimiento de Investigación de la Universidad de South Carolina al (803) 777-7095.

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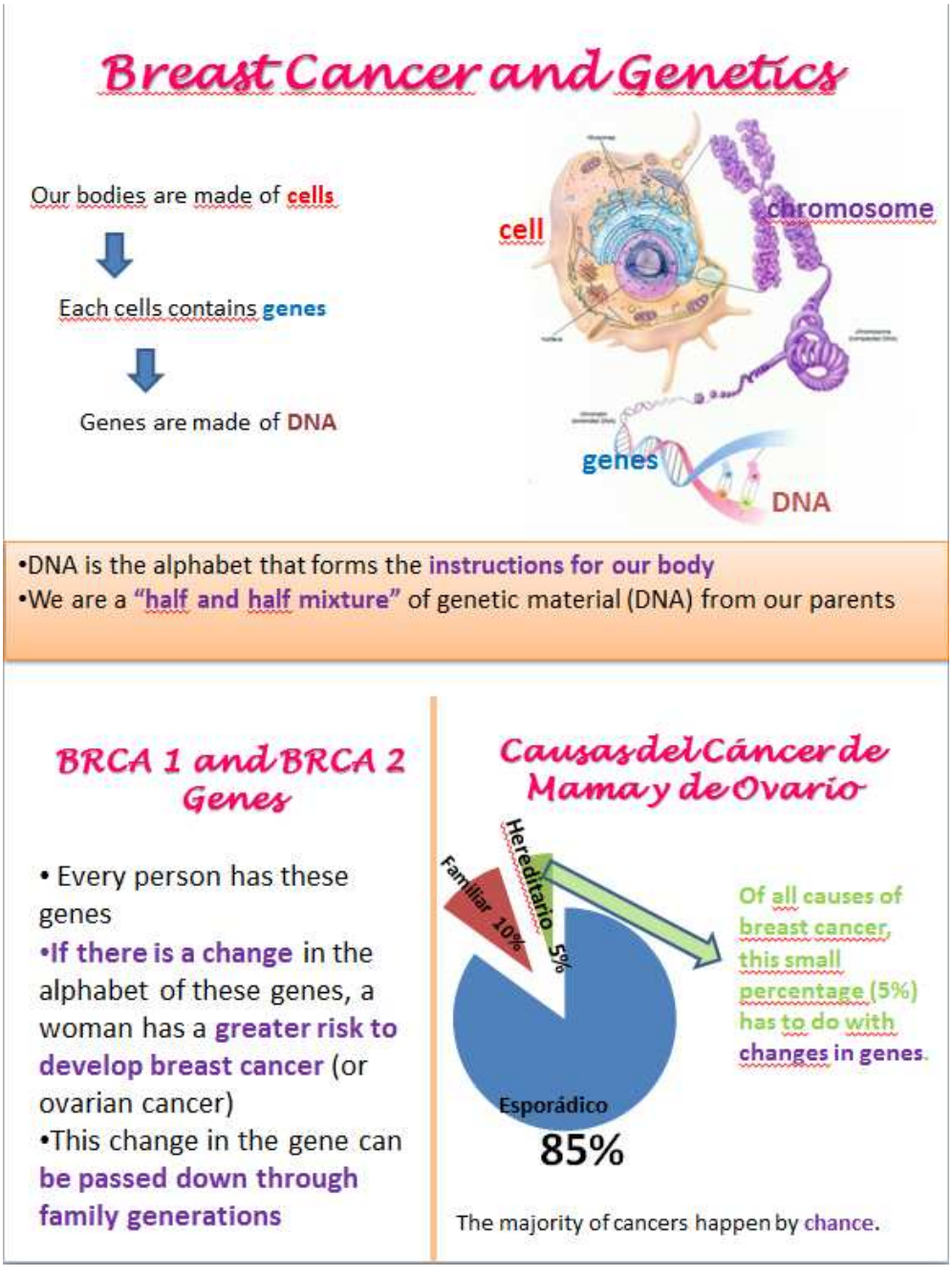
Appendix B: Educational Flier

(English Version; front and back)



Genetic Testing

The genes related to breast cancer are called BRCA 1 and BRCA 2.

Evidence of a change in BRCA :

- The appearance of breast or ovarian cancer before 50 years of age
- Many incidences of breast or ovarian cancer within only a few family generations

Genetic testing can tell us for certain whether there is a change in the gene.

Genetic testing consists of a simple blood anaylsis. It is sent to the lab and analyzed for changes in the DNA.

If there is a change=
Positive Result:

- Personalized treatment plan
- Appropriate treatment and medical intervention can be life-saving for you and your family members

If there is not a change=
Negative Result:

- If you already have cancer, this significantly reduces the risk that this gene change is passing through your family

Result Without a Certain Category:

- There is a change in the gene, however it is still unknown if this gene is benign or cancer-causing

Support

National Society of Genetic Counselors
http://www.nsgc.org/FindaGeneticCounselor

Susan G Komen Foundation
http://ww5.komen.org/Espanol/Enespanol.html

Latinas Contra Cancer
http://www.latinascontracancer.org

LIVESTRONG Spanish
http://livestrong.org//?lang=es-ES

Bright Pink (English only)
http://www.brightpink.org/

Genetic Counseling

Genetic counselors are health professionals specialized in genetic medicine.

They are responsible for communicating genetic health risks to families and for presenting options to manage those conditions and risks.

Sessions generally last between 30 minutes and one hour.

All of this information can be discussed in more detail and specific to your family.

Image credit: brightpink.org

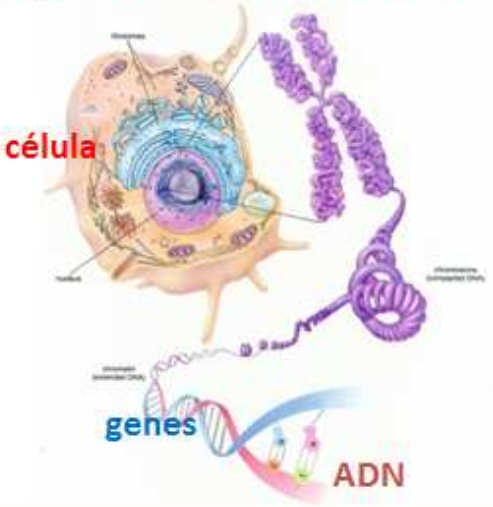
(Spanish Version; front and back)

Cáncer de Mama y la Genética

Nuestros cuerpos están hechos de **células**

Cada célula contiene **genes**

Los genes son hechos de **ADN**



•El ADN es como en alfabeto que forma las **instrucciones para nuestro cuerpo**
•Somos una **"mezcla de mitad y mitad"** de material genético (el ADN) de nuestros padres

Los Genes BRCA 1 y BRCA 2

• Cada persona tiene estos genes
•**Si hay un cambio** en el alfabeto de estes genes, una mujer tiene un **mayor riesgo de desarrollar** al cáncer de mama (o de ovario)
•Este cambio genético puede ser **pasado a través de diferentes generaciones**

Causas del Cáncer de Mama y de Ovario

De todas causas del cáncer de mama, este pequeño porcentaje (5%) tiene que ver con **cambios en los genes.**

La mayoría de los cánceres occuren **de al azar.**

Prueba Genética

Los genes relacionados con cáncer de mama se llaman **BRCA 1 y BRCA 2.**

Evidencia de un cambio de BRCA :

- La aparición de cáncer de mama o de ovario **antes de los 50 años**
- Muchas incidencias de cáncer de mama (o de ovario) **dentro de unas pocas generaciones de la familia**

Las **pruebas genéticas** pueden decirnos **de seguro si hay un cambio en el gen.**

La prueba genética se trata de un simple **análisis de sangre.** Se envía al laboratorio y se analizaron los cambios en el ADN.

Si Hay un Cambio = Resultado Positivo:

- **Plan de tratamiento personalizado**
- **Tratamiento adecuado y la intervención médica puede salvar la vida de usted y sus familiares**

Si No Hay un Cambio= Resultado Negativo:

- **Si usted ya tenga al cáncer, se elimina considerablemente el riesgo de cáncer de mama pasando a través de la familia en estes genes**

Resultado Sin una Determinada Categoría

- **Hay un cambio en el gen, pero todavía no se sabe si es causante de cáncer o benigno**

Apoyo

National Society of Genetic Counselors
http://www.nsgc.org/FindaGeneticCounselor

Latinas Contra Cancer
http://www.latinascontracancer.org

Susan G Komen Foundation
http://ww5.komen.org/Espanol/Enespanol.html

LIVESTRONG español
http://livestrong.org//?lang=es-ES

Bright Pink (English only)
http://www.brightpink.org/

El Consejero Genético

Los Consejeros Genéticos son **profesionales de la salud especializados en Genética Médica.**

Son responsables de **comunicar a las familias sobre riesgos de enfermedades genéticas** y de **presentar opciones** para lidiar con ellos.

Las sesiones de consejeria pueden durar **entre 30 minutos y una a hora,** generalmente.

Toda esta información puede ser discutida con **más detalle en relación con su familia.**

Image credit: brightpink.org

Appendix C: Participant Pre-Surveys

HHI Orlando (Pre-Survey, English)

Code____

You are being asked to take part in this survey because you are a Hispanic woman who has received a diagnosis of breast cancer. We are studying the feelings of Latina women diagnosed with breast cancer and their knowledge about the genetics of breast cancer. The study is voluntary and confidential and should not take more than 15 minutes of your time. This study is conducted by Jade Cognetti, a graduate student at the University of South Carolina. No one who knows you will see your answers. Jade will collect all of the surveys and keep them private and will not tell anyone your name. Please return all surveys to Jade before you leave the support group. Thank you for your answers.

Jade Cognetti, B.S., B.A
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University of South Carolina School of Medicine
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Two Medical Park, Suite 208
Columbia, SC 29203
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(803) 545-5746

Please try to answer all questions, even if you are unsure of an answer.

	True	False	I don't know
About half of all breast cancers are hereditary.			
There is more than one gene that can increase the risk of breast cancer.			
All women who have a mutation in the breast cancer gene will get cancer.			
A woman without a breast cancer gene mutation can still develop breast cancer.			
A woman may be at increased risk of breast cancer if she has several close relatives with breast cancer.			
It's possible to have several relatives with breast cancer by chance alone.			

Please continue to the back of the page!

Code____

Please mark how you generally feel about your life on most days of the week.

	Never	Sometimes	Often	Always
I feel calm				
I feel secure				
I feel angry				
I feel I am suffering				
I feel at ease				
I feel sad				
I am worrying over possible problems				
I feel satisfied				
I feel frightened				
I feel comfortable				
I feel self-confident				
I feel nervous				
I feel in pain				
I feel indecisive				
I feel relaxed				
I feel content				
I feel ashamed				
I feel confused				
I feel steady				
I feel pleasant				

Please mark how you feel when you think about your breast cancer diagnosis.

	Never	Sometimes	Often	Always
I feel calm				
I feel secure				
I feel angry				
I feel I am suffering				
I feel at ease				
I feel sad				
I am worrying over possible problems				
I feel satisfied				
I feel frightened				
I feel comfortable				
I feel self-confident				
I feel nervous				
I feel in pain				
I feel indecisive				
I feel relaxed				
I feel content				
I feel ashamed				
I feel confused				
I feel steady				
I feel pleasant				

HHI Orlando (Pre-Survey, Spanish)

Code____

Se le pide a participar en esta encuesta porque eres una mujer hispana que ha recibido un diagnóstico de cáncer de mama. Estamos estudiando los sentimientos de las mujeres latinas diagnosticadas con cáncer de mama y sus conocimientos sobre la genética del cáncer de mama. El estudio es voluntaria y confidencial y no debe tardar más de 15 minutos de su tiempo. Este estudio es realizado por Jade Cognetti, una estudiante graduada en la Universidad de South Carolina. Nadie que le conozca podrá ver sus respuestas. Jade va a recoger todas las encuestas y mantenerlas privadas. Ella no va a distribuir su información a nadie. Por favor, devuelva todas las encuestas a Jade antes de salir del grupo de apoyo. Gracias por sus respuestas.

Jade Cognetti, B.S., B.A
Genetic Counselor Candidate
University of South Carolina School of Medicine
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(803) 545-5746

Code _____

Por favor trate de contestar todas las preguntas, incluso si no esté seguro de una respuesta.

	Verdad	Falso	No sé
Aproximadamente la mitad de todos los cánceres de mama son hereditarios.			
Existe más de un gen que puede aumentar el riesgo de cáncer de mama.			
Todas las mujeres que tienen una mutación en el gen del cáncer de mama ya a tener cáncer.			
Una mujer sin una mutación del gen del cáncer de mama puede desarrollar el cáncer de mama.			
Una mujer puede estar en mayor riesgo de cáncer de mama si tenga varios parientes cercanos con cáncer de mama.			
Es posible tener varios familiares con cáncer de mama únicamente debido al azar.			

Por favor, Continúa al dorso!

Code _____

Por favor, marque cómo se siente en general sobre su vida durante la mayoría de los días de la semana.

	Nunca	A veces	A menudo	Siempre
Me siento tranquila				
Me siento segura				
Me siento enojada				
Siento que estoy sufriendo				
Me siento a gusto				
Me siento triste				
Me preocupo por los posibles problemas				
Me siento satisfecha				
Tengo miedo				
Me siento cómoda				
Me siento segura de mí misma				
Me siento nerviosa				
Me siento adolorida				
Me siento indecisa				
Me siento relajada				
Me siento contenta				
Me siento avergonzada				
Me siento confundida				
Me siento estable				
Me siento agradable				

Por favor, marque cómo se siente cuando se piensa en su diagnóstico de cáncer de mama.

	Nunca	A veces	A menudo	Siempre
Me siento tranquila				
Me siento segura				
Me siento enojada				
Siento que estoy sufriendo				
Me siento a gusto				
Me siento triste				
Me preocupo por los posibles problemas				
Me siento satisfecha				
Tengo miedo				
Me siento cómoda				
Me siento segura de sí misma				
Me siento nerviosa				
Me siento adolorida				
Me siento indecisa				
Me siento relajada				
Me siento contenta				
Me siento avergonzada				
Me siento confundida				
Me siento estable				
Me siento agradable				

PASOs Charleston (Pre-Survey, English)

Code____

You are being asked to take part in this survey because you are a Hispanic woman who has received a diagnosis of breast cancer. We are studying the feelings of Latina women diagnosed with breast cancer and their knowledge about the genetics of breast cancer. The survey is voluntary and confidential and should not take more than 15 minutes of your time. This study is conducted by Jade Cognetti, a graduate student at the University of South Carolina. No one who knows you will see your answers. Please return all surveys for the group leader. Thank you for your answers.

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Please try to answer all questions, even if you are unsure of an answer.

	True	False	I don't know
About half of all breast cancers are hereditary.			
There is more than one gene that can increase the risk of breast cancer.			
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A woman without a breast cancer gene mutation can still develop breast cancer.			
A woman may be at increased risk of breast cancer if she has several close relatives with breast cancer.			
It's possible to have several relatives with breast cancer by chance alone.			

Please continue to the back of the page!

Code____

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I feel nervous				
I feel in pain				
I feel indecisive				
I feel relaxed				
I feel content				
I feel ashamed				
I feel confused				
I feel steady				
I feel pleasant				

Please mark how you think you would feel if you were to receive a breast cancer diagnosis.

	Never	Sometimes	Often	Always
I feel calm				
I feel secure				
I feel angry				
I feel I am suffering				
I feel at ease				
I feel sad				
I am worrying over possible problems				
I feel satisfied				
I feel frightened				
I feel comfortable				
I feel self-confident				
I feel nervous				
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I feel relaxed				
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I feel ashamed				
I feel confused				
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PASOs Charleston (Pre-Survey, Spanish)

Code____

Se le pide a participar en esta encuesta porque estamos estudiando los sentimientos de las mujeres latinas sobre el cáncer de mama y sus conocimientos sobre la genética del cáncer de mama. El estudio es voluntaria y confidencial y no debe tardar más de 15 minutos de su tiempo. Este estudio es realizado por Jade Cognetti, una estudiante graduada en la Universidad de South Carolina. Nadie que le conozca podrá ver sus respuestas. Por favor, devuelva todas las encuestas para la líder del grupo. Gracias por sus respuestas.

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Code _____

Por favor trate de contestar todas las preguntas, incluso si no esté seguro de una respuesta.

	Verdad	Falso	No sé
Aproximadamente la mitad de todos los cánceres de mama son hereditarios.			
Existe más de un gen que puede aumentar el riesgo de cáncer de mama.			
Todas las mujeres que tienen una mutación en el gen del cáncer de mama ya a tener cáncer.			
Una mujer sin una mutación del gen del cáncer de mama puede desarrollar el cáncer de mama.			
Una mujer puede estar en mayor riesgo de cáncer de mama si tenga varios parientes cercanos con cáncer de mama.			
Es posible tener varios familiares con cáncer de mama únicamente debido al azar.			

Por favor, Continúa al dorso!

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	Nunca	A veces	A menudo	Siempre
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Me siento segura				
Me siento enojada				
Siento que estoy sufriendo				
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Me siento satisfecha				
Tengo miedo				
Me siento cómoda				
Me siento segura de mí misma				
Me siento nerviosa				
Me siento adolorida				
Me siento indecisa				
Me siento relajada				
Me siento contenta				
Me siento avergonzada				
Me siento confundida				
Me siento estable				
Me siento agradable				

Por favor marca qué crees que se sentiría si usted fuera a recibir un diagnóstico de cáncer de mama.

	Nunca	A veces	A menudo	Siempre
Me sentiría tranquila				
Me sentiría segura				
Me sentiría enojada				
Me sentiría como si estuviera sufrienda				
Me sentiría a gusto				
Me sentiría triste				
Me preocuparía por los posibles problemas				
Me sentiría satisfecha				
Tendría miedo				
Me sentiría cómoda				
Me sentiría segura de sí misma				
Me sentiría nerviosa				
Me sentiría adolorida				
Me sentiría indecisa				
Me sentiría relajada				
Me sentiría contenta				
Me sentiría avergonzada				
Me sentiría confundida				
Me sentiría estable				
Me sentiría agradable				

Appendix D: Participant Post-Surveys

HHI Orlando (Post-Survey, English)

Code____

This is Part 2 of the same research study by Jade Cognetti. We are studying the feelings of Latina women diagnosed with breast cancer and their knowledge about the genetics of breast cancer. The study is voluntary and confidential and should not take more than 15 minutes of your time. This part of the study has three questions where you can write in answers in your own words. No one who knows you will see your answers. If you want to talk more about your experiences with breast cancer to Jade on the telephone, please print your name and phone number at the bottom of the survey. Jade will collect all of the surveys and keep them private and will not tell anyone your name. Please return all surveys to Jade before you leave the support group. Thank you for your time.

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Code___

Please try to answer all questions, even if you are unsure of an answer.

	True	False	I don't know
About half of all breast cancers are hereditary.			
There is more than one gene that can increase the risk of breast cancer.			
All women who have a mutation in the breast cancer gene will get cancer.			
A woman without a breast cancer gene mutation can still develop breast cancer.			
A woman may be at increased risk of breast cancer if she has several close relatives with breast cancer.			
It's possible to have several relatives with breast cancer by chance alone.			

Please mark how you feel when you think about your breast cancer diagnosis.

	Never	Sometimes	Often	Always
I feel calm				
I feel secure				
I feel angry				
I feel I am suffering				
I feel at ease				
I feel sad				
I am worrying over possible problems				
I feel satisfied				
I feel frightened				
I feel comfortable				
I feel self-confident				
I feel nervous				
I feel in pain				
I feel indecisive				
I feel relaxed				
I feel content				
I feel ashamed				
I feel confused				
I feel steady				
I feel pleasant				

Please continue to the back of the page

Code___

What first comes to mind when you think of the word cancer?

What do you think are medical causes of breast cancer? What are non-medical causes of breast cancer?

How do you explain cancer to your family?

Would you describe yourself as Latina? Yes No

What is your country of origin? _____

Is Spanish your native language? Yes No

When did you receive a diagnosis of breast cancer? The year _____

What is your highest level of education? No high school degree___ High school degree___ Trade school ___

College degree ____ Master's degree ___ Other (please explain)_____

Have you ever seen a genetic counselor? Yes No

Thank you very much for participating! If you would like the opportunity to **discuss more of your views on cancer** AND be **entered in a raffle to win a $25 gift card**, please include your name and phone number below. If you do not wish to add more information or be entered in the raffle, we do not need your contact information.

Name:_____

Phone:_____

HHI Orlando (Post-Survey, Spanish)

Code____

Esta es la parte 2 de la misma investigación por Jade Cognetti. Estamos estudiando los sentimientos de las mujeres latinas diagnosticadas con cáncer de mama y sus conocimientos sobre la genética del cáncer de mama. El estudio es voluntaria y confidencial y no debe tardar más de 15 minutos de su tiempo. Esta parte del estudio incluye tres preguntas donde usted puede escribir respuestas en sus propias palabras. Nadie que le conozca podrá ver sus respuestas. Si desea hablar más sobre sus experiencias con el cáncer de mama a Jade por teléfono, por favor escriba su nombre y número de teléfono en la parte inferior de la encuesta. Jade va a recoger todas las encuestas y mantenerlas privadas. Ella no va a distribuir su información a nadie. Por favor, devuelva todas las encuestas a Jade antes de salir del grupo de apoyo. Gracias por sus respuestas.

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Code____

Por favor trate de contestar todas las preguntas, incluso si no esté seguro de una respuesta.

	Verdad	Falso	No sé
Aproximadamente la mitad de todos los cánceres de mama son hereditarios.			
Existe más de un gen que puede aumentar el riesgo de cáncer de mama.			
Todas las mujeres que tienen una mutación en el gen del cáncer de mama ya a tener cáncer.			
Una mujer sin una mutación del gen del cáncer de mama puede desarrollar el cáncer de mama.			
Una mujer puede estar en mayor riesgo de cáncer de mama si tenga varios parientes cercanos con cáncer de mama.			
Es posible tener varios familiares con cáncer de mama únicamente debido al azar.			

Por favor, marque cómo se siente cuando se piensa en su diagnóstico de cáncer de mama.

	Nunca	A veces	A menudo	Siempre
Me siento tranquila				
Me siento segura				
Me siento enojada				
Siento que estoy sufriendo				
Me siento a gusto				
Me siento triste				
Me preocupo por los posibles problemas				
Me siento satisfecha				
Tengo miedo				
Me siento cómoda				
Me siento segura de mí misma				
Me siento nerviosa				
Me siento adolorida				
Me siento indecisa				
Me siento relajada				
Me siento contenta				
Me siento avergonzada				
Me siento confundida				
Me siento estable				
Me siento agradable				

Por favor, Continúa al dorso!

Code____

¿Qué es lo primero que viene a la mente cuando se piensa en la palabra cáncer?

¿Cuál cree usted que son las causas médicas de cáncer de mama? ¿Cuáles son las causas no-médicas de cáncer de mama?

¿Cómo explica usted el cáncer a su familia?

¿Se describiría usted como latina? Sí No

¿Cuál es su país de origen? _____

¿Es el español su lengua materna? Sí No

¿Cuándo recibió un diagnóstico de cáncer de mama? El año _____

¿Cuál es su nivel más alto de educación? Ningún grado de secundaria __ Diploma de escuela secundaria ___ Instituto profesional (no universidad) ___Diploma universitario ____ Diploma "Master's" ___
Otro (por favor explique) _____

¿Alguna vez ha ido a un consejero genético? Sí No

Muchas gracias por participar! Si a usted le gustaría tener la oportunidad de **discutir más de sus puntos de vista sobre el cáncer** Y **ser entrada en una rifa para ganar una tarjeta de regalo de $ 25**, por favor incluya su nombre y número de teléfono a continuación. Si no desea agregar más información o tener parte en la rifa, no necesitamos su información de contacto.

Nombre:_____

Teléfono:_____

PASOs Charleston (Post-Survey, English)

Code____

This is Part 2 of the same research study by Jade Cognetti. We are studying the feelings of Latina women diagnosed with breast cancer and their knowledge about the genetics of breast cancer. The study is voluntary and confidential and should not take more than 15 minutes of your time. This part of the study has three questions where you can write in answers in your own words. No one who knows you will see your answers. The group leader will collect all the surveys and keep them private. Please return all surveys the group leader before leaving. Thanks for your time.

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Code___

Please try to answer all questions, even if you are unsure of an answer.

	True	False	I don't know
About half of all breast cancers are hereditary.			
There is more than one gene that can increase the risk of breast cancer.			
All women who have a mutation in the breast cancer gene will get cancer.			
A woman without a breast cancer gene mutation can still develop breast cancer.			
A woman may be at increased risk of breast cancer if she has several close relatives with breast cancer.			
It's possible to have several relatives with breast cancer by chance alone.			

Please mark how you think you would feel if you were to receive a breast cancer diagnosis.

	Never	Sometimes	Often	Always
I feel calm				
I feel secure				
I feel angry				
I feel I am suffering				
I feel at ease				
I feel sad				
I am worrying over possible problems				
I feel satisfied				
I feel frightened				
I feel comfortable				
I feel self-confident				
I feel nervous				
I feel in pain				
I feel indecisive				
I feel relaxed				
I feel content				
I feel ashamed				
I feel confused				
I feel steady				
I feel pleasant				

Please continue to the back of the page

Code___

What first comes to mind when you think of the word cancer?

What do you think are medical causes of breast cancer? What are non-medical causes of breast cancer?

How is cancer explained in your family?

Would you describe yourself as Latina? Yes No

What is your country of origin? _____

Is Spanish your native language? Yes No

Age: _____

Have you ever received a diagnosis of breast cancer? In the year: _____

What is your highest level of education? No high school degree___ High school degree___ Trade school ___

College degree ____ Master's degree ___ Other (please explain)_____

Have you ever seen a genetic counselor? Yes No

PASOs Charleston (Post-Survey, Spanish)

Code____

Esta es la parte 2 de la misma investigación por Jade Cognetti. Estamos estudiando los sentimientos de las mujeres latinas sobre el cáncer de mama y sus conocimientos sobre la genética del cáncer de mama. El estudio es voluntaria y confidencial y no debe tardar más de 15 minutos de su tiempo. Esta parte del estudio incluye tres preguntas donde usted puede escribir respuestas en sus propias palabras. Nadie que le conozca podrá ver sus respuestas. La líder del grupo se recogen todas las encuestas y mantenerlas privadas. Por favor, devuelva todas las encuestas a la líder del grupo antes de salir. Gracias por su tiempo.

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Code____

Por favor trate de contestar todas las preguntas, incluso si no esté seguro de una respuesta.

	Verdad	Falso	No sé
Aproximadamente la mitad de todos los cánceres de mama son hereditarios.			
Existe más de un gen que puede aumentar el riesgo de cáncer de mama.			
Todas las mujeres que tienen una mutación en el gen del cáncer de mama ya a tener cáncer.			
Una mujer sin una mutación del gen del cáncer de mama puede desarrollar el cáncer de mama.			
Una mujer puede estar en mayor riesgo de cáncer de mama si tenga varios parientes cercanos con cáncer de mama.			
Es posible tener varios familiares con cáncer de mama únicamente debido al azar.			

Por favor marca qué crees que se sentiría si usted fuera a recibir un diagnóstico de cáncer de mama.

	Nunca	A veces	A menudo	Siempre
Me sentiría tranquila				
Me sentiría segura				
Me sentiría enojada				
Me sentiría como si estuviera sufrienda				
Me sentiría a gusto				
Me sentiría triste				
Me preocuparía por los posibles problemas				
Me sentiría satisfecha				
Tendría miedo				
Me sentiría cómoda				
Me sentiría segura de sí misma				
Me sentiría nerviosa				
Me sentiría adolorida				
Me sentiría indecisa				
Me sentiría relajada				
Me sentiría contenta				
Me sentiría avergonzada				
Me sentiría confundida				
Me sentiría estable				
Me sentiría agradable				

Por favor, Continúa al dorso!

Code____

¿Qué es lo primero que viene a la mente cuando se piensa en la palabra cáncer?

¿Cuál cree usted que son las causas médicas de cáncer de mama? ¿Cuáles son las causas no-médicas de cáncer de mama?

¿Cómo explica usted el cáncer en su familia?

¿Se describiría usted como latina? Sí No

¿Cuál es su país de origen? _____

¿Es el español su lengua materna? Sí No

Edad: _____

¿Usted ha recibido un diagnóstico de cáncer de mama? El año: _____

¿Cuál es su nivel más alto de educación? Ningún grado de secundaria __ Diploma de escuela secundaria ___ Instituto profesional (no universidad) ___Diploma universitario ____ Diploma "Master's" ___
Otro (por favor explique) _____

¿Alguna vez ha ido a un consejero genético? Sí No

Appendix E: Semi-Structured Interview Questions

English:

You are being asked to participate in this phone interview because you filled in your contact information on the post-survey that investigated perceptions of cancer and of genetic knowledge of Latina women diagnosed with breast cancer. This survey was conducted on ___ date at ___ support group. This phone interview aims to investigate those perceptions in more depth. This interview is voluntary and should not take more than 30 minutes. The study is conducted by Jade Cognetti, a graduate student in genetic counseling at the University of South Carolina. Please note that this interview will be recorded. All of your responses will be anonymous, and your personal information will not be given out. If you have any questions, please contact Jade Cognetti or her faculty adviser, Peggy Walker, MS, CGC.

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On the survey, you described cancer as [….]. What else you would like to add to that description?

On the survey, you described medical causes of cancer as […]. What else you would like to add?

What are your reasons for believing that? Where did you first hear that information?

On the survey, you described non-medical causes of cancer as […]. What else you would like to add?

What are your reasons for believing that?? Where did you first hear that information?

On the survey, you wrote how you explained your diagnosis to your family as […]. What else you would like to add?

What was your family's response?

Did you feel strongly supported? Why or why not?

What opinions did your family have about the cause of the diagnosis? **How** were these opinions different than yours?

Did you find the educational flier helpful?

Why or why not?

What was confusing about the flier?

What information was the most useful?

What improvements would you recommend?

What else you would like us to know about your perceptions of breast cancer or your experience with this research?

Thank you for your time.

Spanish:
Usted está invitada a participar en esta entrevista telefónica debido al hecho de que usted ha dado su información de contacto en el post-encuesta que investigó las percepciones de cáncer y del conocimiento genético de las mujeres latinas diagnosticadas con cáncer de mama. Esta encuesta tomó lugar en ____ por la fecha _____. Esta entrevista telefónica tiene como objetivo investigar las percepciones en más profundidad. Esta entrevista es voluntaria y no debe tardar más de 30 minutos. El estudio es realizado por Jade Cognetti, una estudiante graduada en el Consejero Genético en la Universidad de South Carolina. Por favor, tenga en cuenta que esta entrevista será grabada. Todas sus respuestas serán anónimas, y su información personal no será compartida. Si usted tiene alguna pregunta, póngase en contacto con Jade Cognetti o su asesor académico, Peggy Walker, MS, CGC.

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En la encuesta, usted ha descrito el cáncer como [....]. ¿Qué más le gustaría añadir a esta descripción?

En la encuesta, usted ha descrito las causas médicas de cáncer como [...]. ¿Qué más le gustaría agregar?

¿Cuáles son sus razones para creer eso? Cuando se enteró de esta información?

En la encuesta, usted ha descrito las causas no médicas de cáncer como [...]. ¿Qué más le gustaría agregar?

¿Cuáles son sus razones para creer eso? Cuando se enteró de esta información?

En la encuesta, escribió cómo se explica su diagnóstico a su familia [...]. ¿Qué más le gustaría agregar?

¿cómo reacciona su familia?

¿Se sintió que tenía bastante apoyo (emocional)? ¿Por qué o por qué no?

¿Qué opiniones le tienen a su familia acerca de la causa del diagnóstico? ¿Cómo fueron esas opiniones diferentes a la suya?

¿Le ha resultado útil el folleto educativo?

¿Por qué o por qué no?

¿Lo que se presta a confusión sobre el folleto?

¿Qué información es la más útil?

¿Qué mejoras recomendaría usted?

¿Qué más le gustaría que sepamos acerca de sus percepciones de cáncer de mama o de su experiencia con esta investigación?

Gracias por su tiempo.