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ABSTRACT

Breast cancer is the most frequently occurring cancer and the leading cause of cancer deaths among Latina women in the US. Studies have not traditionally considered all of the intersecting factors affecting women’s health. In particular, the experiences of Latina breast cancer survivors have not been systematically explored from a feminist ecological perspective. Therefore, this study considered contextual identities, relational, institutional, global, historical and political forces (Ballou, Matsumoto, & Wagner, 2002) that are part of the breast cancer experience of Latina women. The purpose of this study was to give voice to, and gain an understanding of, the lived experiences of Latina breast cancer survivors as they navigate the health care system and face their realities as women of a minority group in the US. Individual interviews were conducted within a feminist qualitative methodology of inquiry. The IPA (Interpretative Phenomenological Analysis) (Smith, 1996) method guided the analysis and interpretation of the interviews expanded by the feminist ecological model. Further, the study critically examined these results in relation to existing literature and theory. The results illuminated the diverse lived experiences of Latina breast cancer survivors which were influenced by a number of individual and contextual factors. The areas of inquiry included: the meaning of identity changes, the family’s perspective on the illness, support systems as well as resistance and strengths shown by these women in facing systemic barriers. Finally, major themes revealed the importance of cultural values, family, children, social connection and support groups in the community. The implications of these findings from a feminist ecological perspective suggest the need for systemic changes and the relevance of culturally sensitive interventions to support Latina women diagnosed with breast cancer.
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Chapter I: Introduction

Breast cancer is the most frequently occurring cancer and the leading cause of cancer deaths among Latinas (Siegel, Naishadham, & Jemal, 2012). In 2010, the estimated incidence was 90.2 per 100,000 Hispanic/Latina women and the mortality rate was 15.5 per 100,000 women (National Cancer Institute, 2009, p.5). Breast cancer incidence is lower for Latinas. However, mortality for Latinas is higher than for any other ethnic group. Latina women, compared to other groups, present cancer health disparities such as lack of adequate cancer care and treatment as well as disparities in screening, incidence, and mortality (Barton-Burke, Barreto Jr, & Archibald, 2008). These disparities seem to be mediated by factors such as treatment barriers, lower socio-economic status, cultural beliefs, and decreased access to health insurance (Kouri, He, Winer, & Keating, 2010).

This study, on the lived experiences of Latina breast cancer survivors, sought to capture the different realities of Latina women from their own perspective, while considering these different realities within a feminist ecological framework. Furthermore, this study aimed to understand how these women defined their identities as cancer survivors and made meaning of their illness within their cultural universe and ecological realities. This study used Interpretative Phenomenological Analysis (IPA), (Smith, 1996) embedded in a feminist ecological framework of inquiry (Ballou et al., 2002). This qualitative methodology facilitated the compilation of the narratives of Latina cancer survivors. The overall purpose of this study was to illuminate what these women have to say about their own experiences as breast cancer survivors and contextualize those within a feminist ecological perspective, including other ecological variables that may affect their breast cancer experiences. Furthermore, this knowledge could potentially be used to inform professionals across multiple health care disciplines. Finally, these contributions
might also help to develop culturally sensitive treatments and interventions in working with Latina women.

Demographics of Latinas

There are 30.1 million Latino adults in the United States and 14.4 million (48%) of them are Latina women (Gonzales, 2008). Latinas can differ in the language of preference, migratory and socioeconomic status, amount of social support as well as educational access (Zsembik & Fennell, 2005). Most of the Latinas (52%) were born in countries other than the US and 57% of them have arrived since 1990. Six-in-ten Latina immigrants were born in Mexico. In terms of language of preference, seven-in-ten (73%) immigrant Latinas report not speaking English in their home. Educational attainment among Latinas shows that nearly half (49%) of all Latina immigrants have less than a high school education while a similar share (46%) of native-born Latinas have at least some college education. Finally, Latinas are younger than non-Latinas; their median age is 41, compared with a median age of 47 for non-Latina (Gonzales, 2008).

These demographic characteristics are relevant as an increase in breast cancer diagnoses occurs after the age of 40 and, therefore, the overall lower breast cancer rates of Latinas might be due to their overall lower median age. Another possible explanation of the overall lower breast cancer rates of Latinas may be related to the so-called “immigrant paradox,” which shows that there is an unexpected “immigrant advantage” with regards to health and mental health outcomes for some Latina groups. The immigrant advantage seems to be related to culturally meaningful protective factors such as better family cohesion and belief in a sense of purpose for immigration. These advantages often begin to deteriorate for immigrants in the first and second generation (Alegría et al., 2008; Schwartz, Unger, Zamboanga, & Szapocznik, 2010). It is
unclear exactly how this immigrant advantage impacts cancer rates and how other factors might contribute to the overall lower breast cancer rates of Latinas.

Latinas are 20% more likely to die from breast cancer than non-Latina white women diagnosed at a similar age and stage. They are also more likely to present with a less favorable disease stage compared to non-Latinas. These findings are attributed to the fact that Latinas are diagnosed later because they are less likely to receive clinical breast exams and screening mammograms than non-Latina Whites and African Americans (Warren, Londoño, Wessel, & Warren, 2006). In particular, recent immigrants seem to have more difficulties in accessing health services due to unfamiliarity with the health system and language of preference (Alegria et al., 2008). This is important because lower acculturated Latinas may be at particular risk due to limited access to culturally and linguistically appropriate services as well cancer care support (Janz et al., 2009). Of the three major U.S. Latino subgroups (Mexican-American, Puerto Rican, and Cuban), Mexican Americans, the largest Latina group in the US, are the least likely to use preventative services for cancer screening (Suarez, 1994). Latina women of Central/South American, Cuban, and Mexican origin had twice the risk of never receiving breast cancer screening. As with mammography, higher levels of education, income, and insurance coverage (both private and public plans) decreased the relative risks of reporting not having used breast cancer screenings (Miranda, Tarraf, & González, 2011).

In conclusion, Latinas may present more unique expressions of their realities in surviving breast cancer depending on their insurance coverage, economic situation, linguistic barriers, country of origin, and time since arrival in the US. Their narratives are likely shaped by immigration issues, experiences of discrimination and other potential barriers. This study aimed to understand the lived experiences of these women from a feminist ecological model.
Interpretative Phenomenological Analysis was employed, grounded within a feminist ecological model in order to give voice to these narratives of survivorship.
Chapter II: Literature Review

Breast Cancer among Latinas

The purpose of this review is first to explore the current literature addressing the main areas of research of breast cancer. In particular, this study endeavored to discuss existing research on Latina breast cancer survivors. The areas of this review will focus on: detection of breast cancer, quality of life among breast cancer survivors, coping, qualitative studies addressing breast cancer life experiences among Latina women, and finally, a review of the current ecological feminist literature on cancer within the Latina community.

Literature addressing the causes of current breast cancer health disparities among Latina women suggests that Latinas face contextual and psychological factors that impact them more than other groups in the US (Shavers & Brown, 2002). A literature review of studies addressing the quality of life of Latina breast cancer survivors in the US found that Latinas appear to be at risk for poor quality of treatment following breast cancer diagnosis relative to non-Latinas (Yanez, Thompson, & Stanton, 2011). Results from multi-ethnic studies have shown that Latinas, as compared with the non-Latino white population, present with later-stage cancer, receive differential treatment judged less than the standard of care, and have a higher risk of breast cancer mortality (Shavers & Brown, 2002).

Studies on quality of life among Latinas from an ecological contextual model show the importance of health care access, impacted by legal and immigration factors, physical and built environments, as well health care affordability. This review comes to the conclusion that Latinas are underrepresented within longitudinal and intervention studies. It also highlighted the need for clear documentation of the comprehensive care needs of underserved cancer survivors and interventions within integrated systems of care to address the medical and ecological factors
known to impact these breast cancer survivors (Lopez-Class, Gomez-Duarte, Graves, & Ashing-Giwa, 2012). Another comparative quantitative study of Latina and Asian-American breast cancer survivors addressed the differences in health beliefs among these two groups. Asian-Americans were more likely to believe that their family situation and cultural background play a role in their health. They also were more likely to indicate that their doctor, their partner and themselves influenced their cancer treatment decisions. On the other hand, Latinas were more likely to believe that God, luck, and health professionals play a role in their health. These studies concluded that for Latina-Americans, a positive doctor/patient relationship was related to more healthy life styles. This positive doctor/patient relationship overall seemed to have a positive influence on their physical and emotional well-being. For instance, it was associated with an increase in physical exercise. For Asian Americans, treatment decisions with their doctors and the “socio-cultural factor,” for instance, their family situation and cultural background, plays a role in their health and it was significantly related to stress management. This study presented evidence that Latinas and Asian Americans varied in the patterns of cultural factors influencing health behaviors and health related quality of life. Conclusions from these types of studies might lead to the development of culturally sensitive breast cancer interventions for promoting positive health behaviors and ultimately increasing quality of life (Lim, Gonzalez, Wang-Letzkus, & Ashing-Giwa, 2009).

In a review of cancer coping and support (Alfano & Rowland, 2006), the authors concluded that patients who receive psychosocial support services fare better than those who do not, and that areas of functioning that were positively influenced by intervention include stress levels, mood, physical functioning health-related quality of life, and self-efficacy, among others. Literature shows that support groups represent an important coping strategy that help women
manage the distress associated with a breast cancer diagnosis, for example, dealing with issues of depression, anxiety and fear of recurrence (Alfano & Rowland, 2006; Ashing-Giwa et al., 2004). Thus, as would be expected, perceived social support among Latina breast cancer survivors seems to be associated with lower distress levels (Alferi, Carver, Antoni, Weiss, & Durán, 2001). Support networks help Latinas cope with the feelings of fear, worry, denial, and concerns that arise as a result of disruption of their caregiver role in their family systems (Ashing-Giwa, et al., 2004; Galván, Buki, & Garcés, 2009).

Additionally, research shows that access to support groups contributes to the psychological benefits experienced by Latinas: emotional support, validation, help with learning how to express their feelings, information related to survivorship, ability to express in Spanish their condition, empowerment and greater self-efficacy (Galván, et al., 2009; Nápoles-Springer, Ortíz, O’Brien, Díaz-Méndez, & Pérez-Stable, 2007). In fact, support groups appear to be an especially appropriate intervention for Latina breast cancer survivors, as they have reported feeling more comfortable speaking with their peers than with family members who may believe that cancer is fatal or may not fully understand women’s experiences (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006). Finally, a relevant study comparing the narratives of African-American, Latina, and European American women, found important ethnic differences in the meanings assigned to faith and spirituality, empowerment through the migration experience, and becoming a better person through the journey of recovery. These findings suggest distinctive recovery narratives that are embedded within the groups’ cultural models of illness (Coreil, Corvin, Nupp, Dyer, & Noble, 2012).

However, little is known about these women’s perspectives. Their individual stories of oppression, and of resilience in navigating the health care system, are important themselves and
for what we can learn from those lived experiences. Some Latinas may have limited support resources or networks in the US due to limitations imposed by immigration, such as lack of access to needed services. Some Latinas may experience less systemic limitations due to their socioeconomic characteristics and/or acculturation. These differences could be understood within a feminist ecological framework that explores how ecological dimensions shape and give meaning to their survivorship.

Cultural Beliefs about Breast Cancer

Another area of research in the current literature addresses cultural beliefs about breast cancer. These beliefs and cultural characteristics that influence the meaning of the illness also seem to contribute to barriers in accessing health care, getting screenings, and effectively communicating with providers. Possible attitudes and beliefs about cancer that limit Latinas in being proactive include religious beliefs (leaving everything in God’s hands) and the fact that talking about cancer is taboo in the Latino culture (Davis, Diaz-Mendez, & Garcia, 2009). Furthermore, other studies suggest that Latinas tend to trust the medical remedies of their native countries more than those used by mainstream providers in the US. They seem to place more value on traditional methods because they are less invasive and/or less expensive (Ashing-Giwa, et al., 2006). From a feminist ecological model, these cultural beliefs and traditional methods are considered and valued in order to gain a better understanding of women’s realities.

On the contrary, biomedicine tends to emphasize the individual’s responsibility in seeking help and caring for themselves. It is relevant from a feminist approach to consider the socio-political constraints, discrimination, and oppression that women from a minority group may encounter or experience that could limit their access to medical care. Furthermore, at an individual level, it is important to consider that women may not believe in medical practices and
rely more on traditional remedies in treating illnesses. This could be a potential barrier in seeking or trusting established medical treatments. The feminist ecological model aims to integrate these systemic barriers and cultural views on illness. The inclusion of these traditional practices and beliefs has implications for informing culturally sensitive treatments that can decrease the barriers that women may experience such as not being understood or listened to.

In reviewing some of the individual characteristics embedded in Latina cultural characteristics, literature shows a great interest in the concept of fatalismo (fatalism), which refers to the general belief that all events in people’s lives are determined by fate (Abraído-Lanza, 2007). When applied to health, fatalism is often operationalized as negative or pessimistic attitudes regarding preventive health practices and disease outcomes. Fatalism has therefore been identified as a potential barrier to cancer prevention and early detection efforts (Abraído-Lanza, 2007). However, the relevance of fatalism in explaining Latinas’ screening behavior in the context of social and environmental constraints is unclear (Espinosa de los Monteros & Gallo, 2011). Many scientists expressed great caution against identifying fatalism as an impediment to Latino health without considering the numerous material barriers that these women may experience (e.g., low education, poor access to health care, poverty, racism, and discrimination), (Abraído-Lanza, 2007). In expanding upon the understanding of cultural beliefs, another study (Flórez et al., 2009) focused on exploring Dominican women’s views on breast cancer and screening within a cultural framework of destino (destiny), the notion that both personal agency and external forces can influence health and life events. In contrast to simplistic notions of “fatalism,” their study suggested complex strategies and beliefs regarding breast cancer and cancer screening. This study aimed to understand how personal agency and external forces, in conjunction, can influence health and life events. Rather than agreeing with a static concept of
fate (fatalism), which tends to represent women as passive targets of disease, these authors suggested that these women endorse a belief system where early action and religious faith serve as empowerment tools to both prevent and cope with illness. The authors conducted twenty-five semi-structured interviews with women from the Dominican Republic. They found that women actively participated in screening because they believed that cancer could become a death sentence if diagnosed late or left untreated. In this study, women’s narratives suggested that beliefs regarding breast cancer and cancer screening spoke of resilience. These results seem to contradict the literature on fatalism where most of the studies seem to characterize these beliefs as based on hopelessness. This study with Dominican women argued that, rather than cultural beliefs, lack of insurance, lack of access to services and information seems to more greatly determine accessibility to early screening (Flórez, et al., 2009).

Finally, the literature reveals a limited number of studies comparing how cultural beliefs about breast cancer for Latino women are different from other groups. A quantitative, ethnographic study conducted in Orange County (Hubbell, Chavez, Mishra, & Valdez, 1996), focused on the importance of understanding culturally based beliefs and how those may affect the way breast cancer disease is seen. It included a total of 803 Latinas and 422 Anglo women. Results indicated that Latinas were more likely than Anglo women to believe that factors such as breast trauma (71% versus 39%) and breast fondling (27% versus 6%) increased the risk of breast cancer. Latinas were less likely to know that symptoms such as breast lumps (89% versus 98%) and bloody breast discharge (69% versus 88%) could indicate breast cancer, while they were more likely to believe that mammograms were necessary only to evaluate breast lumps (35% versus 11%). The authors concluded that Latinas' beliefs about cancer differ in important ways from those of Anglo women and that these beliefs may reflect the cultural framework
within which Latinas interpret diseases. For instance, beliefs that breast cancer was a punishment from God or the attribution that the illness was due to improper behaviors. The authors also indicated that access to information about the disease for Latina women was different than for non-Latina women, thus affecting what they knew about the disease. These findings are relevant for the development of culturally sensitive breast cancer control programs and for practicing physicians in understanding different belief systems about the illness (Hubbell, et al., 1996). In conclusion, these type of studies need to consider other demographic characteristics that may limit the access to health care and information related to breast cancer.

**Body Image in Latina Women**

Breast cancer has particular physical consequences for women, transforming their definitions of femininity and sense of body control. The negative physical side effects are increased distress, social disruption, alienation from self, and fear of future adverse outcomes (Petronis, Carver, Antoni, & Weiss, 2003). Qualitative studies conducted with women survivors of cancer, including Latinas, reported the importance of capturing and understanding the breast cancer experience and the different dimensions that this includes, for example, changes in their bodies and the impact of cancer on their relationships. These are issues which were not fully captured by quantitative studies.

A longitudinal study looked at the outcome variables of: sexual dysfunction, depression, and body image concerns. The study included a large sample of Hispanic and non-Hispanic women. Results indicated that, after controlling for covariates 18 months after surgery, Hispanic women were more likely than non-Hispanic women to have reported feeling unattractive, less feminine, and having a decreased libido (Christie, Meyerowitz, & Maly, 2010). Other studies have concluded that Latina breast cancer survivors have reported embarrassment, feelings of
inadequacy, lack of self-worth, and feelings of frustration concerning weight gain, and other body issues resulting in not recognizing themselves as the women they used to be (Ashing-Giwa et al., 2006). In a quantitative cross-sectional study conducted with Latinas, African American, Asian and non-Latina White women, using different measures to assess well-being after breast cancer diagnosis, the authors concluded that Latina women seem to report more physical symptoms than women of other ethnicities without speculating on why these differences among groups occurred. However, the authors indicated that survivorship adjustment was possibly mediated by cognitive processes and therefore differences were found (Giedzinska, Meyerowitz, Ganz, & Rowland, 2004). Overall, these studies show how cancer affects different domains in women’s health as well as their sense of femininity. The above studies contribute to our understanding of the multiple aspects of breast cancer survivorship, but were not conceptualized from a feminist ecological model that could provide further understanding on how gender realities of oppression, sexism and internalized messages of beauty and femininity are transformed when becoming a breast cancer survivor. The IPA method, grounded in a feminist ecological model, would facilitate the articulation of how women make meaning of their experiences as contextualized within external realities: sociopolitical, institutional, legal, and historical. These subjective experiences and the person-in-context was interpreted together with the interviewer (Todorova, 2011). The feminist ecological model will help the interviewer to contextualize the phenomenon including the socio-cultural context (Ballou, et al., 2002).

In conclusion, the literature suggests that little is known about how cultural beliefs and characteristics affect the lived experiences of Latina breast cancer survivors. Furthermore, few studies have been done on how these women navigate and survive systemic barriers within their cultural frameworks. This study aimed to expand upon the existing literature on Latina breast
cancer survivors by accessing personal life experiences and interpreting those personal meanings within their socio-cultural and political realities.

**The Feminist Ecological Model**

This study was conceptualized from a feminist ecological model that recognizes multiple dimensions influencing individuals’ experiences. The feminist ecological model describes the principles of ecological theory, feminist therapy theory, multicultural psychology, liberation psychology, and critical psychology (Ballou, et al., 2002). The model suggests that experiences and changes have to be acknowledged and enacted not only at an individual level, but systemically as well. This model considers: valuing all experiences, valuing individual differences, contextualizing the causes of emotional distress, questioning norms and standards of traditional mental health and recognizing the imperative of social change (Ballou, et al., 2002). Feminist theory further recognizes that in traditional mental health research and treatment, individuals’ lived experiences can be neglected within a research paradigm that emphasizes empirical validation, experimental “control,” and outcome measures stressing symptom reduction. Feminist models attempt to redistribute power in all relationships between participants and researchers, oppressed groups and dominant forces. This integrated analysis of oppression acknowledges that gender is intertwined with other forms of oppression, and that the experiences of women are shaped differently within a system where power and privilege are unequally distributed, causing various intersecting levels of oppression. Feminist research is guided by feminist theory that seeks social change by increasing awareness of inequalities and providing knowledge on different ways in which individuals cope with their distress (Hill & Ballou, 1998).

The feminist ecological model is an alternative to medical models in how it attempts to understand health issues affecting women. Medical models locate the problem within the woman
by concentrating on diagnosis and treatment of pathology and internal disorders (Ballou, et al., 2002). Therefore, the understanding of illness and the survivor of a disease such as breast cancer is limited by models that do not consider the multidimensionality of lived experiences of breast cancer survivors and how women make meaning of those experiences. From a feminist perspective, women’s experiences are embedded in their ecological contexts. The assumption from a feminist/ecological model is to consider Latina women as experts on their own experiences rather than imposing objective empirical assumptions on health and disease outcomes. In reviewing some of the work done from a feminist approach, which analyzes the intersections of different realities on women’s experiences, some authors have focused on the intersection of race, class, and culture with sex and gender (Greene, 1996) while few have focused on women’s lived experiences of immigration, in particular, with Latina women. Those authors addressed cultural values and identities, language barriers as well as resilience (Comas-Díaz, 2000; Espin, 1999). For this theoretical conceptualization of Latina women’s experiences, the ecological feminist model considered: contextual identities of the individual, relational, institutional, global, historical and political forces (Ballou, et al., 2002). Furthermore, the model would integrate main aspects of the individual’s identity, biological, emotional, cognitive, and all within a relational context. In particular, relational identity involves the integration of multiple views of oneself in relation to the illness and in relationship to others (Barret & Ballou, 2007).

Breast cancer forces women to define a new identity as survivors and to relate to this new identity on different levels: emotional, physical, and in relation to the world around them. Those new dimensions and meanings in women’s realities need to be explored from their own perspective. Additionally, female breast cancer survivors also have to make meaning of their lived experiences in an ecological context. The lived experience of Latina survivors, and how
they make meaning of the illness, resonates with a model that considers women’s experience as central to informing research. The figure below illustrates the inclusion of all these different dimensions in the feminist ecological model.

Figure 1. Contextual feminist ecological model (Ballou, Matsumoto, & Wagner, 2002, p. 44)
Breast Cancer from a Feminist Ecological Perspective

Breast cancer remained a hidden disease among women in the United States until the 20th century (Osuch et al., 2012). It was initially brought into the open with public revelations from individual women, which was followed by the development of support groups and, ultimately, the formation of political activist groups with various priorities. For example, those concerned with toxic environmental exposures as a potential cause of breast cancer, organized, demonstrated, and lobbied for research funding and eventually became partners in the research that arose from their efforts (Osuch, et al., 2012). Traditionally, breast cancer was considered a women’s health issue, relegated to the private lives of women. However, it has been placed, through social activism, as a public, political issue. This has become crucial in thinking about the sociopolitical structures of local communities, and in particular, more recently, for immigrant women (Erwin et al., 2010).

Literature from more traditional approaches addressed factors which impede or facilitate women's participation in mammography screening including ways to involve women in treatment decision-making, and women's ability to cope with breast cancer diagnoses. However, few of those studies examined breast cancer from the perspective of women with the disease (Anglin, 1997). One study, with white middle class female survivors, addressed the experience of breast cancer from a feminist perspective, in examining women’s narratives on breast cancer mutilating treatments in producing problems associated with feminine identity: body image and sexuality. The phenomenological analysis of the breast cancer narratives resulted in four interrelated clusters of meanings: the medicalized breast, the functional breast, the gendered breast, and the sexualized breast. These findings were relevant to understanding the different meanings that were attributed to the breast and how women perceived themselves in relation to
breast cancer. The conclusions from this study indicated the need for further research with minority groups (Langellier & Sullivan, 1998). Finally, another phenomenological study on breast cancer suggested that the narratives of survivors were culturally constructed. The author used a phenomenological study of embodiment after breast cancer, using data collected through one focus group discussion and two in-depth interviews each with 12 women who had experienced breast cancer. The study concluded how important it was to pay attention to structure as well as to the construction of the stories within the cultural context of each woman (Thomas-MacLean, 2004).

These few studies show that contextual factors, media, societal messages, women’s identities and culture are all part of women’s lived experiences of cancer. Based on the literature review, we can conclude that the lived experiences of Latina women as cancer survivors have not been studied from a feminist ecological perspective. The feminist ecological model would require the inclusion of many intersecting factors that Latina women have to experience compared to other groups of women in the US. Those may include cultural beliefs about breast cancer, the experiences of illness within their culture, the importance of their families, potential discrimination, socioeconomic barriers, and lack of insurance coverage, from a feminist ecological perspective as potential discrimination and oppression. Furthermore, new Latina immigrants present unique realities such as added linguistic and cultural barriers. The intersection of previous experiences of immigration along with some common realities of many other women in the U.S., and around the world, is validated in this study that aimed to hear the voices of these real survivors.
Cultural Meanings from a Feminist Ecological Perspective

Within traditional Latino culture, certain values have to be considered in order to frame the context of Latina women. The concept of marianismo (marianism) is a cultural value that defines the role of Latina women and is heavily influenced by Catholicism. The message behind marianismo is to consider the Virgin Mary as a role model of the ideal woman. Thus, Latinas are encouraged to be spiritually strong, morally superior, nurturing, and self-sacrificing (Arredondo, 2002). This cultural value might, to some degree, be present in Latinas’ lives depending on their level of acculturation, religious views or individual cultural identification. Breast cancer survivors navigate among different realities at the individual, familial and societal levels. The feminist ecological model postulates that these cultural messages and beliefs potentially influence women’s experiences and meanings.

Another important aspect to consider in understanding Latinas from the perspective of their cultural values is the concept of familismo (familism). This cultural value refers to the importance of strong family loyalty, closeness, and getting along with other members in the family as well as contributing to the wellbeing of the nuclear family, extended family, and kinship networks (Ayón, Marsiglia, & Bermudez-Parsai, 2010). According to the literature, family ties and roles are very important to the identity of most Latinas, with these cultural connections affecting their choices and decisions in life. Research on how breast cancer survivors negotiate these family ties and their own health issues seems to indicate that, when a Latina woman suffers from an illness, the entire family is affected due to the heavy dependence on the woman’s role in the family. Many Latinas seem to ignore their own health concerns in order to avoid creating distress in the family (Ashing-Giwa, et al., 2006). However, some studies suggest that familismo is a protective factor for Latino families, and, in particular, for women...
struggling with cancer, as this cultural value increased the likelihood of seeking out mammogram exams (Suarez, 1994).

Finally, another Latina cultural characteristic is the significance of *personalismo* (personalism) which is the valuing and building of interpersonal relationships. *Personalismo* encourages the development of warm and friendly relationships, as opposed to impersonal or overly formal relationships (Santiago-Rivera, 1995). The importance of these cultural characteristics and how these cultural values protect and interfere with women’s experiences in surviving cancer has not been extensively studied in the literature. The personal narratives of these women could help to clarify the roles these cultural values have in making meaning of their experiences. The feminist ecological model acknowledges the importance of considering cultural values in validating women’s experiences and this study sought to integrate and make meaning of these values from and within the Latina narratives. The role as interviewer will also have an impact on their narratives as a critical element of these shared experiences.

**Purpose of the Study**

The purpose of this study was to explore the lived experiences of Latina breast cancer survivors as they navigate the health care system and face their realities as women of a minority group in the US. The analysis was grounded in the feminist ecological model which acknowledged individual perspectives and the sociopolitical context of which they are a part (Ballou et al., 2002). This qualitative study analyzed data using the Interpretative Phenomenological Analysis (IPA) grounded within a feminist ecological perspective. The purpose of this research was to provide information that can facilitate the improvement of health services for Latina breast cancer survivors. The results of this work will have implications for clinical practice, policy, training, and research efforts.
This study addressed the following inquiry questions:

1) Does Latina women’s sense of identity change after surviving cancer? If so, how does it change and how do they make sense of this change?

2) What does it mean for the family of a Latina woman surviving breast cancer?

3) What are the strengths demonstrated by Latinas in overcoming their illness and surviving?

4) What are the experiences of misunderstanding, insensitivity, and oppression that these women may have experienced?
Chapter III: Methodology

Feminist Inquiry

The feminist ecological perspective, which informed the framework of this project, was also reflected in the methodology. There are different approaches to inquiry which can be conducted from a feminist perspective. These methods of analyzing phenomena in health psychology are informed by theoretical and epistemological assumptions within feminist theory. According to Wilkinson (2000) feminist traditions of inquiry are divided into: positivist empiricism, feminist experiential research, and feminist discursive research. The feminist experiential method of inquiry focuses on challenging preconceptions about how people make sense of their experiences. Furthermore, it aims to develop new insights into understanding the individual’s interpretation of phenomena and to hear their own lived experiences. Feminist experiential research thus focuses on individual experience, assuming that individuals are experts on their own lives. Furthermore, feminist experiential methods of inquiry are particularly interested in honoring those voices that have traditionally not been heard. The goals are not only to understand, in this case, women, but also to present women’s lives from their perspective (Wilkinson, 2000).

The work with breast cancer based on experiential feminist approaches to inquiry has used different qualitative methods. Some of the qualitative methods used include one-to-one interviews, focus groups, life histories, ethnography and narrative/storytelling approaches (Wilkinson, 2000). The use of different qualitative methods is illustrated by the work done by Anne Kasper (1994) interviewing women with breast cancer. In this study, the author points out the importance of working on new studies that contribute to expanding feminist methodologies using an array of qualitative methods. Another example is the phenomenological work done by
Frank (1995) where he also expands upon the idea of using feminist methods of inquiry to understand women’s experiences with breast cancer. Finally, Kahane (1995) presents perspectives on the lived experiences of Asian-American, lesbian and very young women with breast cancer. All of this qualitative work, from an experiential feminist tradition of inquiry, illustrates the expansion and deepening of work through the inclusion of different qualitative methods of inquiry in order to illuminate the diversity of women’s breast cancer experiences. The nature of the feminist research, as argued by Kasper (1994), has to be open to integrating different methods to enrich the understanding of the experience. In summary, research from a feminist perspective can integrate different qualitative methods, so as to understand women’s experiences and situate the findings in social and political contexts.

The current study employed experiential methods of inquiry within the feminist ecological framework (Ballou, Matsumoto, & Wagner, 2002). Our experiential approach to inquiry was informed by feminist experiential methods and by Interpretative Phenomenological Analysis (IPA) (Smith, 1996). The IPA method does not deny the existence of an external reality but focuses more on subjective experience and on people’s interpretations of their own experience (Smith, 1996). As Todorova (2011) indicated, personal meanings need to be contextualized as contexts shape individual’s meanings and individual interpretations of their own realities. The response to the consideration of external reality was acknowledged by Smith (2011) adding that individual experience is central but there is openness for discussion of critical social and political influences. In conclusion, feminist experiential methodology of inquiry informed this project, and is supported by IPA, which was grounded within the feminist ecological model in order to expand the interpretation of the individual narratives in context.
Method: Interpretative Phenomenological Analysis (IPA)

IPA (Smith, 1996) is an approach to qualitative, experiential and psychological research which has been informed by concepts and debates from three key areas of the philosophy of knowledge: phenomenology, hermeneutics, and ideography (Smith, Flowers, & Larkin, 2009). This method was chosen since its theoretical framework supposes a possibility of achieving an understanding of participants’ subjective experiences in interaction with the interviewer’s interpretations (Smith & Osborn, 2003). The focus is on personal meaning and sense-making, that can be extended to understand experiences in a particular context (Todorova, 2011). Furthermore, this methodology allows research to specifically access the individual experiences of these women within a context that looks at their realities as grounded within a feminist ecological perspective.

The qualities required of the IPA researcher are: open-mindedness, flexibility, patience, empathy and a willingness to enter into, and respond to, the participant’s world (Smith et al., 2009). The role of the interviewer is in validating and supporting these women in sharing what they have experienced. The questions have to be open-ended and should be exploratory not explanatory. They may reflect process rather than outcome and they will focus on the meaning, rather than the concrete causes or consequences of events. The researcher is aware of systemic issues and socio-political contexts that shape women’s realities, discussing the identified meanings through the critical, multileveled feminist ecological model. The inclusion of this awareness in the research process expanded our knowledge in providing support to these women in meeting their therapeutic needs, and addressed systemic issues for future interventions. Further, the inclusion of relational aspects, such as empathy, to connect with these women, was crucial in establishing trust and sharing lived experiences.
Data Collection Procedures

At the beginning of each interview participants were provided with a written informed consent form that was approved by the human subjects review board of Northeastern University. The consent form was written in English and Spanish to meet the linguistic preferences of the participants. The participants were guided through its contents by the interviewer, in order to avoid the possibility of women being uncomfortable in the case of literacy difficulties. During this overview, the interviewer highlighted that interviews would be audio recorded and transcribed, emphasizing anonymity. Participants were also explicitly informed of their right to discontinue their participation at any time and to refuse to answer any question. No participants chose to exercise these rights. Following this overview, participants were given the opportunity to ask questions. Only after all questions were answered, and the consent form signed, did the interview begin. In the case of Skype interviews, the same procedure was followed, however, the consent form was sent via regular mail and returned by mail as well. Several precautions were taken to ensure participant confidentiality: each participant was assigned a pseudonym, which was used in all transcripts and text citations. In no instance were participant names included in interview recordings or transcripts. Audio recordings were erased once transcription was completed. Further, consent forms and tapes were kept in a locked filing cabinet containing no identifiable data.

Interviews were both exploratory and open-ended, while similar areas of inquiry were addressed across interviews. This allowed participants to generate contextualized, process-oriented and detailed narratives, therefore, following feminist approaches of inquiry. When necessary, follow-up questions were asked regarding particular emerging themes; some questions were helpful to clarify or explore particular themes allowing for more detailed
responses. Finally, participants were once again reminded that all information was confidential and were thanked for their participation in the study.

**Recruitment of Participants**

The recruitment procedure for this study was designed to invite women who were interested in speaking about their experiences as breast cancer survivors. Following Northeastern University Institutional Review Board approval in September of 2013, recruitment of participants occurred by using flyers, emails, and word of mouth. Participation was voluntary and took place in confidential settings. I contacted Latino community organizations in order to utilize already established natural groups or settings within the Latino community. One Latino community organization in East Boston responded by allowing potential candidates to be interviewed. Further, other organizations posted the flyers and shared information with their community members. The final sample was derived mainly from *La Esperanza*, a Latino breast cancer organization in Holyoke, Massachusetts, and one participant from Arbour Health System, in Jamaica Plain, Massachusetts. Three participants who indicated interest to be part of this study were contacted through friends and relatives of the researcher. I conducted three interviews via Skype since these women lived outside of Massachusetts.

**Recruitment and Lived Experiences at La Esperanza**

The nature of the relationship established with the only agency that provides specific breast cancer services for Latina women in Massachusetts, La Esperanza, deserves special attention in this study. This special attention is informed by feminist methodology of inquiry that stresses a participatory research experience. After the initial phone contact with La Esperanza, the director of this organization was willing to meet, talk about their organization, and my research project. During this initial informal meeting, the director, a community
advocate with Puerto Rican roots who grew up in the Bronx, extensively described the activities taking place at La Esperanza, their history and the systemic issues affecting their organization. After her approval, I was invited to conduct interviews at La Esperanza and a wonderful learning experience took place. La Esperanza is the only organization in Massachusetts that addresses the needs and quality of life of Latinas with cancer in the Pioneer Valley of Western Massachusetts. This culturally and linguistically sensitive organization has been supporting Latina women for more than 20 years. The demographics of the Latina women served at this organization range from 30 years of age to seniors; this constitutes a developmental constellation of women who, being at different life stages, provide an invaluable wisdom by sharing their experiences. The women attending or involved as mentors at La Esperanza come from Puerto Rico, Colombia, Honduras, The Dominican Republic, and El Salvador. Most women identify as having a strong faith under different Christian denominations. The support groups and activities taking place at La Esperanza rely on the experience of survivor mentors: women in remission who have the interest, energy, and inspiration to help others like themselves. Women share their experiences and their stories, encouraging women to comply with early detection screenings. Further, these mentors provide support to women diagnosed with cancer as part of ongoing groups, home visits, and hospital accompaniment ("La Esperanza", 2014). The role of this organization in the Latina community is an example of political resistance as this is the only Latino-centered organization in the Mass area that strives to provide culturally-informed and culturally-relevant care for its participants. Leaders of the organization have fought to maintain funding throughout the years as it does not directly abide by the medical model. Additionally, this organization demonstrates that other treatment models can also be efficient and effective in the care of women with breast cancer.
Participants

The size of the sample for this study was determined by recommendations from feminist inquiry and IPA methods. The recommended number of subjects for an IPA analysis is a minimum of 6 participants, in order to be able to conduct in-depth analysis. IPA is an ideographic approach, concerned with understanding phenomena in particular contexts; the homogeneity of the sample is defined by the variation contained within the analysis of the particular phenomena “breast cancer survivorship.” The sample should provide meaningful points of similarity and difference between participants of a study (Smith et al., 2009).

Participants in this study consisted of ten bilingual and monolingual Latina breast cancer survivors. They shared a common experience as breast cancer survivors and self identified within a cultural framework as Latina or Hispanic. The purpose of the interviews was to gain in-depth knowledge about breast cancer survivors’ experiences within social and cultural contexts. Inclusion criteria were: self-identifying as Latina or Hispanic and a diagnosis of breast cancer at least 5 years ago. These criteria were based on the literature consideration and definition of breast cancer survivorship. However, one woman who identified as a survivor was receiving treatment at the time she was interviewed. She was included as a participant and her identification as a survivor was given priority. Lifespan issues and age of diagnosis was considered for interpretation but not as inclusion criteria. The youngest woman was 46 years old and the oldest 78. Participants were mainly living in Massachusetts; three participants live in other states: Michigan, Virginia, and California. Immigration was a common experience to all of them. All participants were born outside of the US: Puerto Rico, Honduras, Costa Rica, Cuba, Mexico, and The Dominican Republic. The women had lived for more than ten years in the US. All of them were mothers and most of them grandmothers as well. Two of them were also great-
grandmothers. The majority of them were married, two were widows, and two of them were divorced. One of them had a Master’s degree, one a bachelor’s degree, and the rest had a high school diploma or less.

Role of the Researcher

My role in this research varied depending on the group of women interviewed. At the La Esperanza organization in Holyoke, I was not only an interviewer but also a participant in their group experience. I observed the participants in their group activities and interactions. The connection with the director of the agency greatly facilitated this initial contact and the development of trust and openness with the women that I ended up interviewing. I visited this agency on two occasions. On the first visit, an art group was taking place. We had dinner together and I had the honor of being part of their group, which allowed me to talk to the women and get to know them. On the second occasion, another type of support group was taking place while I was doing the interviews. There were also a couple of children there. On this occasion, we had dinner together again, they had Latin music playing, and I had another chance to spontaneously talk with all of them. By the end, they invited me to visit them in the near future and a formal goodbye closing took place.

During the interviews, women asked me about my country of origin or other personal questions such as if I had children. It seemed that there was a need for a sense of familiarity and connection which is consistent with the cultural norm of personalismo (personalism). The interviews were frequently very intense emotional experiences for both the participants and for myself. We said goodbye by kissing and hugging or with very affectionate goodbyes in the case of the Skype interviews. This involvement was congruent with the feminist inquiry used in this research and the cultural communication patterns of women who self identified as Latina or
Hispanic. The use of the Spanish language facilitated the exchange of jokes and connection among us. I come from Spain and our accent is distinctive from other Spanish speaking countries, which could be a potential barrier to establishing rapport and trust. Further, I was aware that within the Latino or Hispanic culture, Spain’s historical background as a European country which colonized America and other parts of the Caribbean, could potentially interfere with their trust in me. I was aware of this, but it did not seem to negatively interfere with the interview process or our interactions before or after the interview. What seemed more relevant was who I was as a person rather than my country of origin, the way I looked, or my accent. One participant explicitly expressed how much she liked me, “usted me gusta,” and the oldest lady that I interviewed, before leaving, came to me and said: “usted es muy buena” 1. “ Being valued at this personal level has a very deep meaning in our culture and I felt honored. The personal connection, personalismo, was present and the use of “mi hija,” was frequent across Puerto Rican participants in addressing me.

**Interviews**

One interview was conducted with each woman. Sessions varied in length from 45 to almost 90 minutes. The interview guide was developed, using open-ended queries relevant to the research questions regarding personal experiences of surviving breast cancer, and informed by the feminist ecological perspective. These semi-structured interviews were conducted in English or Spanish depending on the preferences of the participants. One interview was done in both languages as the participant’s linguistic preferences changed throughout the interview. Further, the interview schedule was used flexibly and the participant played an important role in the topics that were covered (Smith et al., 2009). The themes emerged freely from the women, and

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1Translation: “I like you;” “you are a very good person.”
the intent of the interview process was to allow women to freely express themselves. The interviews were conducted using a relational feminist approach, paying attention to the emotional content and the phenomenological nature of the interviews including my own impact on the women’s discourse. Women were informed that I was interested in their experiences and in learning from them. Consistent with this study’s feminist inquiry, interviews followed the participant’s narrative. Areas of inquiry were therefore pursued with each participant based on their individual responses. Once the interviews began, most women proceeded to talk about their experiences and feelings.

A feminist inquiry approach was used to build rapport, create a safe environment, as well as enact attentive listening to what the participant had to say, using her own words. In cases in which the participants were more reluctant to talk, open questions were helpful to guide the interview, backing away from the issues that felt more uncomfortable to participants. Further, ethical considerations for safety and the emotional wellness of the participants were considered. The focus was to provide a safe setting, using clinical skills when necessary and other elements, for instance, humor, physical contact, and including all the familiar greetings that felt culturally appropriate. As a relational participant in the interview, I was acknowledging personal characteristics of participants, content during interviews, and fluctuations in affect in order to provide attuned responses. Most of the interviews started with questions about the time when they were diagnosed with breast cancer. From there, I chose participants’ themes to expand the experience and introduce some specific questions to gather more specific information. In addition, some themes were not present in particular women’s experiences or they did not bring it up. Although I did explore most of the same themes with all of the women, certain themes did not apply to their experience. The questions covered the following areas of inquiry: body image
issues; psychological impact; the meaning of surviving breast cancer; identity changes; the
meaning of the illness in the context of their culture, family, and children; and support systems.
Further, questions about faith, immigration, and systemic barriers were also part of the interview
content.

After the interviews, I asked participants how they felt and if they experienced any
emotional discomfort. I addressed this by giving them some time to process and feel
comfortable. In one particular case, a clinical referral for a community based organization was
made, and a follow-up was done, contacting this participant by phone a few weeks after the
interview.

Data Recording Procedures

All interviews were tape recorded and transcribed verbatim first in Spanish and then
translated into English. Interview audio recordings were transcribed by the investigator,
resulting in a transcript showing all the words that were spoken by everyone who is present.
Afterwards, each translated interview was reviewed and compared to original transcripts; the
revisions ensured a consistent translation. However, to capture the meaning of certain words
and expressions when translating from Spanish into English was at times challenging. For
example, it was difficult to capture particular nuances of the Spanish language that also reflect
emotional states, closeness, metaphors, and implicit meanings.

Once these interviews were transcribed and verified, the audio recording was
permanently erased. Transcriptions were then assigned a pseudonym and de-identified for
participant protection. After the interviews, notes in a “diary” were made reflecting upon
impressions of the interviews, the woman interviewed, and my own feelings about the
interaction, content and process of each interview. This material was helpful for contextualizing certain phenomena for further interpretations in the results section.

**Analysis Procedures: Sequence of Analysis**

In this study, analysis procedures were based on the feminist method of inquiry and IPA method. Transcripts of interviews were analyzed through systematic qualitative analysis, organized using the IPA guidelines. The study also used an inductive approach, allowing themes to emerge from the narratives, rather than being derived in a pre-conceived way from the existing literature or hypotheses on breast cancer among Latina women. In addition, consistent with the feminist ecological model, this analysis conceptualized breast cancer survivorship in broad terms that include both individual experience and lived experiences in their ecological realities. The focus is on participants’ attempts to make sense of their experiences.

IPA analysis follows different steps: abstraction or identification of patterns between emergent themes, contextualizing or looking at the connections between emergent themes, identifying recurrent themes and the interpretation and meaning of those themes. This analysis allowed for patterns to emerge from the voices of participants. The idea is to avoid researcher imposed themes and allow participants to express freely their life experiences and to interpret those realities with them (Smith et al., 2009). The sequence of analysis follows these suggested steps:

1. **Step I: Reading**
2. **Step II: Initial noting.** Attention to language they use, abstract level and the patterns of meanings; conceptual comments with a more interrogative level;
3. **Step III: Developing emergent themes;**
Step IV: Searching for connections across emergent themes;
Step V: Next case; and
Step VI: Looking for patterns across cases, themes that were more potent, ways in which they were different and why.

The process continued with comparisons across cases and identifying recurrent themes. Afterwards, the process of interpretation was based on the analysis of the described patterns and themes from the perspective of the individual Latina breast cancer survivor. A major component of this phase was to code the themes and patterns found after they were organized categorically and compared across cases. To achieve this goal, open and selective coding of the transcripts was utilized, which led to a classification of the more abstract themes and subthemes. Finally, a narrative account was developed, which includes the researcher’s analytic interpretation in detail and was supported by the verbatim extracts from the participants (Smith et al., 2009).

The sequential analysis helped to interpret the individual’s lived experience and how each woman made sense of breast cancer survivorship. Further, the analysis across cases facilitated connections among common themes experienced by women and whether these themes were experienced similarly or differently. Finally, the implications of these individual and collective experiences or themes were analyzed in the frame of a feminist ecological reality. This process was supported and supervised by committee members who provided feedback, reviewed interviews, codes, and themes. The phase of interpretation was discussed including different levels of interpretation and abstraction considering the metaphors present in the interviews. The multiple perspectives used in looking at the material helped to expand the levels of interpretation of the particular phenomena. In addition, it helped to contextualize the results within the feminist ecological model, with the intention of giving voice to the experiences of each woman.
Chapter IV: Results

This chapter will present the results of this study, which attempted to understand the individual experiences of each Latina breast cancer survivor who participated. The narratives were organized into themes in a way that avoided presenting a single homogeneous account of the experiences of being a Latina breast cancer survivor. The purpose was to preserve the unique aspects of each participant’s experiences within the context of their realities.

Overview of Emergent Themes and Super Ordinate Themes

The IPA method helped to identify major emergent themes from participant interviews. First, the initial detailed coding of each interview led to the identification and selection of the more potent emerging themes in each individual’s narrative. Second, after comparing all the emergent themes across cases, super ordinate themes were identified. The final classification of super ordinate themes required a more abstract level of analysis, illuminating individual experiences in the context of each interview, as well as in connection with other women’s experiences and their ecological realities.

This detailed analysis of the codes yielded 15 emergent themes and 5 super ordinate themes. The final themes were selected since they were more potent among cases and appeared to have more significant meaning for participants. The super ordinate themes are the following:

1. Meaning of Survivorship
2. Femininity
3. Faith
4. Responsibility to others
5. Systemic Barriers and Resources
1. MEANING OF SURVIVORSHIP
   - Self-blaming
   - Confronting death
   - Appreciation for life
2. FEMININITY
   - Body changes
   - Identity changes
   - Connection to self and others
3. FAITH
   - Acceptance
   - “Fatalism”
   - Source of spiritual strength
4. RESPONSIBILITY TO OTHERS
   - “Marianism”
   - “Familism”
   - Children
5. SYSTEMIC BARRIERS AND RESOURCES
   - The experiences of navigating the medical system
   - Linguistic barriers
   - Support groups

Figure 2: Major super ordinate and emergent themes

The Meaning of Survivorship

Survivorship was reflected in how women made meaning of their experience once they were confronted with the breast cancer diagnosis. All of the women were faced with the realization of death, as many women mentioned: “cancer significa la muerte” (cancer means death), “cuando uno oye la palabra cáncer, piensa en la muerte” (when one hears the word cancer, one thinks of death). The trauma after receiving the news was interpreted and managed differently by the women. Some expressed that they had to be strong and fight it in order to be there for others, while some blamed themselves. Survivorship implies a new sense of identity; it means a new relationship with their social systems and with their environment, bringing a new existential meaning and purpose in life. Furthermore, it is a transformative experience that takes place at an individual level in their particular contextual realities. Throughout the women’s narratives, cultural elements were embedded in their experiences.
Herminia was 39 years old when she found out that she had breast cancer six years ago. In Herminia’s narrative, she talked about her immigration experience when she and her parents obtained the work permit to come to the US. Herminia had to give up her academic aspirations and start working in two different jobs to provide for her brothers and sisters in the Dominican Republic. Herminia’s life journey reflected the confrontation with the diagnosis of cancer at an early age:

The news really shocked me, I thought about death. It was something very traumatic. For the first time, I felt aimless and without direction. It was a shock. I did not expect it, being so young, not so young, I was about to be 40 years old when I was diagnosed. Then, I started to feel really bad, that was news that I did not expect. I am resentful with life. I started thinking: “I haven’t done anything wrong to anyone, what would I have done?” Maybe I did something and maybe I do not remember. I don’t know. I have a lot of resentment with myself. Maybe, I did not pay attention to myself because nobody in the family had cancer but how could I possibly think about it?

Herminia blames herself for being diagnosed with breast cancer. The causality of the diagnosis is internalized as her own responsibility and as something that she has done wrong. However, throughout her life, Herminia was a good sister, a good daughter, and a good mother. She can’t make meaning of this diagnosis and she questions if she did something that she is unaware of. The self-blaming within Latino culture could be attributed to Catholicism as God’s punishment which is connected to “fatalism” and to the uncertainty of life events that are not under our control, but are attributed to God’s will. Furthermore, it can be contextualized by society blaming women for being responsible for their health issues rather than considering illness as being caused by multiple factors.
The theme of self-blaming is also illustrated in Miranda’s narrative. Miranda, as a 76 year-old survivor, is experiencing life at a very different stage. Miranda got divorced when her two daughters were very young and worked hard to provide for them. The children grew up in NYC and when one of them got involved with gangs, they moved out of the city to find a better environment for them. Miranda looks back and tries to make sense of the illness, first by blaming herself and second by adding the life circumstances that affected her well-being:

When I had the second cancer, I think it was because I neglected my health, I think that was what happened. I did not eat well, I cried often. My daughters were 14 and 16 years old and gave me a hard time. I used to cry a lot and I did not eat well and then I got breast cancer, but I think I did not take good care of myself. I did not eat well, I neglected myself.

Her explanation for the diagnosis is based on neglecting her health which also implies the significance of gaining some sense of control and agency to survive by changing life style patterns. Miranda’s narrative illustrates a transformative experience with an existential learning component. Miranda became aware that being there for others caused her health issues. She learned through her illness to pay attention to her needs.

The need for emotional support and connection when facing the idea of death is further illustrated in Almudena’s case. Almudena, a 49 year-old, immigrated to the US from Central America as a young adult. Currently, Almudena is a six year survivor and has two children. The day that Almudena got the diagnosis, the event was emotionally intense, denial took place, and she needed emotional support to face it:

That day for me was so hard, I cried and cried. But you always have friends that give you emotional support. I never imagined that I could have cancer. I felt like I was about to die
and I thought I’ve got until here. I began to cry and cry and cry. I remember my friend got there to give me the emotional support that you most need. When you are dealing with this disease having a lot of emotional support, it is so important. If someone does not have it, you feel like you are falling. It is so hard.

For Almudena the “death sentence” of cancer was processed by connecting with her amiga (friend) who gave her emotional support. Knowing that she was not alone encouraged her to face the diagnosis and helped her to continue the transformative experience of survivorship. In Almudena’s narrative, she mentions the importance of amigas but amigas de verdad (real friends) adding that breast cancer showed her who her real friends were. The sense of a connection to others is a fundamental part of her survivorship.

In another example of how the diagnosis was received, Virginia, a 64 year-old mother of two children (one diagnosed with autism), explains how she viewed the illness as a final death sentence:

At the time I was diagnosed, the doctor told me I had a 40% chance of survival. I had like five years to live so I had to organize my house and throw away the things that were unnecessary. Then my life happened to be very different, it was very different. My life was about to be gone so I wanted to be ready to die and relax. So even to this day I only live a month at the time, I don’t make plans for next year. I don’t have plans for next year. I have plans for the month of July, anything further than that I don’t because I am terrified with the possibility that my cancer will come back.

Virginia lives with the fear of recurrence, but she changed her outlook on life by enjoying every moment. The fear of recurrence is present, but instead of taking a passive approach, she redefines the priorities in her life; the fear does not paralyze her, it helps her to live life
differently. In her narrative, Virginia talked about her life changes and her proactive approach to live life day by day. There is no room for self-pity, but rather, a more meaningful way of looking at life as precious rather than taking it for granted. This also demonstrates another existential lesson of making meaning of her experience as a survivor.

In summary, the theme of the meaning of survivorship reflects a process. First, it shows how the diagnosis had a deep psychological impact and how women confronted the idea of death. Second, it shows how they tried to find an explanation for the diagnosis by bringing up self-blaming, which is associated with Latino cultural meanings related to “fatalismo” (fatalism). Self-blaming also reflects women’s internalizing messages as being responsible for their own health. Third, it shows how they survive while living with the fear of recurrence, manifesting appreciation for life and valuing the emotional connection with “amigas” (friends). Finally, celebrating survivorship gives them a sense of achievement and existential growth, making meaning of their experiences as survivors.

**Femininity**

The theme of femininity has different levels of interpretation; for the purpose of presenting the results, three emergent themes were considered: body changes, identity changes, and connection to self and others. The interviews reflected the construct of femininity from each woman’s narratives. However, the individual experiences and meanings seem to be different depending on their age, motherhood, intimate partnerships, as well as their sense of connection with other women. The theme of femininity will be further expanded upon in other result sections. For instance, when talking about “being there for others” and the role of Latina women in their families. Finally, femininity is constructed in the context of their ecological realities and the messages received from society.
In this passage, Virginia, currently a 19-year survivor, talks about how, through her physical changes, her views on femininity were defined by her role as a care giver and as a mother. In the beginning of her survivorship journey, she attended a group offered to English speakers at the hospital where she was receiving services:

I realized that my experience was very different from other people. For example, many women spoke of plastic surgery, or that they did not have a breast. It was something for them like, as they say vanity. However, for me it was survival. During my surgery, my vanity died (laughs) and then it was survival (laughs). There were two ladies, they did not attack me but they told me: “you never say anything”, then, I said: “well, I come here and I listen, for me what you talk about is very interesting. I do not say anything because I live in a very different world than the one you live in. Then I told them: “we are living in very different worlds. Yes, I have no breasts, but I do not care, do not mind that I lost all my hair, I do not mind having to wear glasses, I do not care if I have to use crutches but for me the most important it’s to be alive. I want to be alive in any way. If I wake up in the morning and I can breathe that's enough for me. My husband does not mind about my breasts, I do not care either because I have a disabled child. All those things that you have to deal with, I have all of them, but my life is very different than yours.”

Virginia considered body changes as secondary because she prioritized the need of being alive to take care of her child. Virginia’s body and identity changes were occurring within her family context and it seemed secondary because her priority was her child. She made meaning of her body changes differently from the other women around her and her voice was different. Virginia claimed a different femininity from others in the group and this constituted a learning experience for other women.
Miranda’s passage also illustrates how body changes were interpreted. She uses her sense of humor to minimize the impact of those changes. In Miranda’s narrative, she talks about the need of having a sense of humor to confront reality and how this helped her through her life to face illness:

I lost my hair, I was very thin, and I could not gain weight. The tumor was large and it was my decision, I did not want to take any risk and I told them to remove everything. Yes, I'm older, I'm alone. If I had a husband, he could manage with one breast, men only have one mouth. The doctor said that I had a sense of humor; it helped me because it gave me strength to face the illness. When they removed it, I could not look at myself in the mirror. When I took a bath, I did not look at myself, I used a sponge to bathe so I did not notice that it was not there and then I got used to it.

Miranda’s physical changes are not experienced within the context of an intimate relationship. However, she reclaims her body ownership and how those changes would have to be accepted by a potential partner. Nevertheless, Miranda goes through a transition, a process of accepting the loss of her breast, by adjusting to her new body, to her new self. Miranda develops a new sense of identity through her body changes; this new self becomes part of who she is and she voices that others would have to accept her.

On the other hand, Herminia faced how physical changes affected her sense of femininity and how this has an impact on her intimate relationship:

I gained weight when I had the chemo, your body swells and then I could not get into my clothes. I was a size 16 since and I no longer wanted to go to the street. It was depressing when I was trying to go for a walk or outside. It was something degrading; I do not wish it to any woman. It was a bad experience. My husband initially supported me, but now it
is not the same, by not having breasts, it is not the same. I feel that he is not the same, it is
not the same relationship because you already know how men are, he tries to help, to be
there, as far as he can. I do not want to have sex, I do not feel comfortable. I told him:
“Go, go find another woman, maybe it's good for you but he says: “no”. I say: “you need
something that I cannot give you.”

Herminia’s sense of femininity in relation to her husband seems to be impacted by her
loss of breasts and the physical changes experienced. She seems unable to accept her new self
and this affected her relationship with her husband. Herminia’s rejection of her own body
changes as well as her lack of sexual drive makes her feel guilty, to the point that she was willing
to let her husband have sexual relations with other women, or perhaps, this was a way to see if
her husband was going to be there for her despite all the physical changes. So far, her husband
supports her and seems to be there for her. When talking about reconstruction, Herminia
indicated that she declined the procedure because of the physical implications and the long
surgical and recovery process involved.

Almudena talks about her body changes in the context of her family and, specifically,
in relation to her children. She describes the impact of those changes within her family. The body
changes had implications on how others perceived her:

That was so hard because I lost all my hair. I lost my eyelashes, eyebrows, I had swollen
hands, and I was turning yellow. One changes, so many, many things. Sometimes, one
does not know how to deal with these changes when you have small children. At that
time, I had my child of seven and my child of six years old. When I lost my hair my
youngest child looked at me and he liked it, but my older son did not like it. He did not
want me to go out with him, he felt embarrassed of seeing me without hair. When I went to school meetings I had to tie a scarf.

Almudena’s narrative explains how the body changes she experienced interfered with her ability to function and relate to others by having to adjust to others’ expectations. The visibility of breast cancer is hard to assimilate, especially for young children such as Almudena’s older child. He can’t accept these physical changes; he can’t accept that his mother is sick. Furthermore, it also reflects how women experience pressure to look in a particular way that is socially more acceptable or common.

Marta, a 50 year-old school teacher, talked about this and how her body changes were a collective experience and how, instead of covering herself and hiding her illness, she “educates” others. Marta is a school teacher and her students also witnessed her body changes:

I sent an email to all the other teachers in the building: “there are gonna be times I am not going to have anything on my head. I want the kids to know I have no problems, explaining, coming to your classroom, whatever.” I really feel like, especially women with cancer they have enough to deal with. If your head is hot or scratchy or uncomfortable, do you have to deal with that too?

Marta also talked about the social pressure for women to meet certain standards and how she is resisting this pressure through her own experience, as a teacher:

So for me, I love that line “I am not my hair” more than this and more than that stuff on my head. I feel like women are defined by that too much, for what they wear. I have fun with fashion, I love jewelry but it should be something fun not something that you feel you need to do.
Another emergent theme associated with femininity is related to connections to other women through their group experiences. The meaning of being part of a group helped women to value their experience and relate to others in similar situations. Some of the women that were interviewed are members of the group for Latino breast cancer survivors at La Esperanza. The sense of connection experienced in this group reflects femininity.

Almudena talked about how meaningful the group experience at the support group for Latina women has been:

I am very thankful, and I would do anything, do volunteer work in return for all the help. When I come here and G. asks me to do something I am very glad to do it, and help the ladies who are older than me. Because, for me, it is a way to pay back for all the things they have given us here.

Miranda described the group experience and connection to other women as very significant in her life.

Therefore I'm happy because I have received much support from the group I have met many women who are always supporting each other, when we go to the hospital they come to visit us. I'm happy about that because I have many friends and I've met many people. I went to very important places such as Boston, as well as other important sites. I went to the walks, to the nutrition class, painting class. We have many other classes and I am thankful for this, for having these opportunities. I'm happy and one always feels good here. It's like a family.

The fact that Miranda belongs to this support group is part of a transformative experience; these women are accepting who they are in connection to others. As Latina women, some of them experienced economic deprivation, linguistic barriers and the group offered opportunities in their
lives to travel, do activities, and be informed. Finally, Latina women seem to value these collective experiences of “being there for others” and “with others,” where connection is a mutual experience which provides support.

In summary, the theme of femininity among these Latina women is reflected through different emergent themes that talk about body and identity changes, as well as the impact of those changes in relation to others: partners, children, and the world around them. For some women, the transformations in their bodies implied a process of acceptance of a new self within their particular realities. In addition, some women experienced these physical and psychological changes in their femininity as interfering with their sexuality and capacity to connect with their partners on a physical level. Furthermore, the element of humor was used by some women to minimize the impact of those changes. Moreover, some women reclaimed their identity by accepting their physical changes, questioning societal impositions for looking in a particular way, or hiding the physical impact of the illness. Finally, Latina women value connection, mentorship, and support given to and received by other women. This was reflected in their narratives in references to the importance of the support group as a means for women to build strong bonds of solidarity and redefine femininity.

Faith

All the women in this study, except for one, identified believing in God. The women expressed that faith and that being part of religious groups was a very important part of their lives. The meaning of faith was different among women and it also was different in terms of their involvement in community churches. The use in Spanish of references to God was present through all the interviews: gracias a Dios (thank to God), que sea lo que Dios quiera (God’s will), Dios mío (My God). These references help to express emotional states. Furthermore, the
implicit meanings of these invocations to God evoke the inevitable uncertainty in life. Therefore, these expressions are revealing “fatalismo,” or, in some cases, an existential acceptance of life events that are not under one’s control.

When interviewing Felisa, a 78 year-old survivor, her faith and active role as a member of a Christian church was described. Felisa has been suffering from several medical conditions throughout her life and, after losing her husband, she moved to a nursing home where her family visits her often. Felisa has always shown strength by not complaining and by suffering pain in silence. A few days after our interview, Felisa suffered a stroke and she recovered from it. In her narrative Felisa expresses her experience with breast cancer in the context of her strong faith:

I believe the Lord is the one who gives the strength to all. I trust in God. He is the only one who can help us, to save us, because He gives strength to us. In the hospital, I saw women crying, others were very worried and I feel sorry for them because I think, they need more faith. I accept the things that God wants to send me, things that happen. I don’t let things bother me. I don’t have any complaints, I'm happy with what I've done, with what they have done with me, thanks to God I am alive. Yes, it has affected me, but those are things that happen to anyone, I'm neither the first nor the last one going through this. It is God’s will.

Felisa’s faith gives her strength and determination to face life events with acceptance and resignation but also with a sense of agency to overcome difficulties. She is now at a later stage in her life and she has gained a sense of endurance and confidence, and has shown strength in many different domains in her life as an immigrant woman. Finally, Felisa minimizes her experience by saying that she is not the only one who suffered from cancer, as if the illness was a test that God is giving to test faith, strength and acceptance.
Miranda experienced her faith differently at different stages in her life. Nevertheless, she also sees God as the one that gives people tests in life that need to be overcome:

Look at all the challenges that we have to go through with all the diseases, no matter which one. But these are tests and we have to accept what God gives us. And thanks to God, He always supplies all our needs and one of them is the need to heal. Science is really advanced; therefore there is not much to fear. You know, the one who knows how to progress, progresses, but what happens in life, it is the fate of every person.

Miranda is describing that uncertainty in life is part of our existential experience; it is our destiny to face and overcome illness thanks to God’s help. There is no control over life events, only God knows. The theme of fatalismo (fatalism) is expressed in the uncertainty of life events that are not under control, where the fate or destino (destiny) of each person is implicitly under God’s control or will. The importance of faith is also reflected in how it helps Miranda to survive and appreciate what she has.

Virginia describes the importance of faith as a source of strength in her survivorship:

You have to realize something that my faith it is very important. I pray to God every night before I go to bed, I pray to God and ask for another beautiful day. I say: “this was a great day and I am looking forward to another one tomorrow.”

She prays and asks to continue living, expressing her appreciation for life. The uncertainty is present in her life, but she also holds hope for continuing to live through her strong faith. The process of surviving is a daily awareness and appreciation of God for being able to continue living.

In summary, the super ordinate theme of faith is reflected through the emergent themes representing faith as a source of strength and a spiritual support to face and accept the existential
confrontation with breast cancer. Faith helps these women to make meaning of the illness by proving their strength through God’s tests in life. Moreover, it also brings hope and appreciation for life. These women transform their realities into meaningful experiences, with faith helping to achieve this, to move on, rather than contemplate how life passes by.

**Responsibility to Others**

The theme of responsibility to others helps to build upon the super ordinate theme of femininity and, specifically, women’s role within the Latino culture as being there for others. The super ordinate theme of responsibility to others reflects the most salient emergent theme associated with the construct of *marianismo*, or attributed women’s roles, within the Latino culture. Furthermore, it is also associated with *familismo* and the importance of *familia* (family) in the Latino culture and, in particular, is manifested through the importance of children. In addition, the super ordinate theme illustrates how these women identify with those cultural meanings in their experiences of surviving breast cancer. Through their narratives, women voiced their sense of responsibility as mothers, to other family members, as well as their experiences of self-sacrificing for others. Finally, they talked about the importance of having a physical and emotional connection to their families and loved ones, especially with their children.

Miranda’s narrative illustrates how being there for others meant neglecting her own care. She makes reference to her cultural background as imposing the role of being there for others first:

*We neglect ourselves, because of the kids, the house, the family, always others, always being there for others. I think it's a cultural thing: the children, the husband, the mother.*

*My mother always lived with me. I suffered a lot, because of all of that, the illness came*
to me. I felt lonely but in the end my family came to me and they showed me that they loved me. I could have died.

Miranda finds an explanation for why she suffered from cancer. She sees it as a consequence of always being there for others, taking care of others’ needs and by neglecting her own. After all the suffering, she is able to continue living and realizing that the others, in this case her family was also there for her. Miranda’s survivorship demonstrates her strength and how the cultural meanings are associated with marianismo helped develop and strengthen relationships in the family, who, in the end, were there for her as well.

Teresa’s passage also illustrates characteristics of marianismo, through her trying to avoid suffering for her children by showing strength. In Teresa’s interview she talked about her life experience as the oldest daughter of a family of nine siblings. After her father died, Teresa, as the oldest daughter, had to help her mother who always considered Teresa “a very strong person.” Teresa talks in her narrative how, to this day, her brothers and sisters listen to her and show “respeto” (respect):

I don’t want my girls to be weak. I want them to be strong but at the same time when I went through this, I did not want to show the emotions that I had many times. I did not want them to see me; you know like that, I wanted to be strong for them. I did not want them to worry. You know, I didn’t want to cause pain.

The need to avoid having others suffer shows the nature of her self-sacrifice. She feels the need to be strong for others and a sense of survival and legacy for her children and, in this case, women in particular. It is relevant that Teresa wants her female daughters to be strong as part of her legacy as a mother who also is strong. When Teresa is emotionally struggling and her daughters want to help, she forces herself to show strength to avoid being a burden for them.
In Almudena’s experience, she talks about the importance of being alive for her children that needed her and the responsibility of being there for others. This also has an existential meaning of surviving for others, in this case, for her younger children:

And because my children need me, that's the biggest motivation that one has. When you have cancer and you have family and small children you have to fight more because I want to see them grow and that they get an education, that they learn something, that they have something on their own. Then, if I die someday they know something and they can face life.

Almudena is describing the values of “familism” and the importance of being there for her children by surviving breast cancer. Almudena wants to see her children grow up and become educated to face life as well. The need for survival is part of a bigger purpose in life: providing a future for her children and the legacy that she wants to leave behind for her children.

Similarly, Herminia also talks about how the diagnosis had a huge impact on her family and especially on one of her daughters who feared losing her mother. Her story reflects how Latino children are part of the family reality. The children are brought to the doctor’s office to receive the news. However, Herminia’s daughter could not process the news well and Herminia had to find support for her:

When the doctor told me that I had cancer she told me: “you have to come with your family.” That was the biggest mistake I made, to take them, I shouldn’t have done that. I should have gone with my mom, my sister. There, it was when she started to cry and got into a depression because she started cutting herself. I told her to calm down that everything was fine. I took her to a therapist, the therapist helped her quite a lot, now she
is in college and thanks to God she is doing well. Now she is doing well, now she is not worried.

The children experienced breast cancer as part of their growing up. Children inevitably witnessed, experienced, suffered and survived breast cancer as well. In Herminia’s situation, she struggled with the reality of how the impact of this diagnosis had psychological consequences for her daughter. The meaning of breast cancer is also processed as a family illness; it is a collective experience and there is also a collective meaning. It transforms family roles, family history, and family development. Children worry and carry this psychological impact for the rest of their lives.

In summary, the theme of being there for others is related to the cultural values associated with marinismo, which is connected to the importance of nurturing as part of women’s femininity. Latina mothers in this study show values of familismo and their will to protect children and avoid having them suffer from the stressful psychological impact of breast cancer. Nevertheless, the diagnosis of breast cancer becomes a family illness and the family suffers and struggles with all the changes that this diagnosis implies, especially the children who were confronted with the diagnosis at an early age. Moreover, the narratives also reflected the importance of children in Latino families as a source of hope for continuing to live, and, ultimately, for survivorship. Finally, Latino families in these narratives show unity; they care and support each other and women’s roles are fundamental for this cohesion. The Latina women in this study seemed to be a fundamental pillar for their families. These immigrant women had an active role in family survival, which included cohesion, adaptation, and economic functioning in the US. However, when women get diagnosed with breast cancer, the family, in a reciprocal
manner, has to adapt and provide instrumental and emotional support to the women. This means a huge transformation in family dynamics.

**Systemic Barriers and Resources**

The super ordinate theme of systemic barriers and resources reflects women’s lived experiences and their interactions with the medical system, their experiences of resistance, and supports they received. Their experiences with the medical system reflected the most potent emergent themes identified in the transcripts. Some of these emergent themes included: delivering the diagnosis, linguistic barriers, access to information, and personal experiences showing resistance against medical decisions. Those encounters shaped their survivorship journey, the meanings attributed to the illness, and, ultimately, their identities as survivors. Finally, this super ordinate theme also includes themes about what women consider relevant and meaningful for their recovery, for instance, culturally and linguistically sensitive support groups and other culturally competent resources.

Marta spoke about receiving the diagnosis over the phone and how this event was a very intense emotional experience. She discussed how this occurred and what she would have preferred to have happened:

My primary physician got the news and he told me over the phone. So then I cried. I think I cried for two days. If the doctor would have said OK you need to come for an appointment I would have known. But at least, I would have known then and maybe process it better in the doctor’s office. I think I would have preferred in person even if I would know when they said come in and say that I had cancer. I would have preferred in person.
Marta’s narrative illustrates how diagnosis, in some cases, is delivered and how this initial event is experienced as distant, especially from the Latino’s perspective of *personalismo*, which is highly valued.

Other women, primarily Spanish speakers, faced systemic barriers that affected not only their individual experience, but also their families, in particular their children. For instance, Jimena, a Puerto Rican woman, expressed her concerns about the linguistic systemic barriers experienced by her and how her children were traumatized by this experience:

> At that time, I had no interpreter. The interpreter was my 10 year old son. It was something very hard. I was suffering and my baby was suffering because he had to translate and had to be there for me. Then when they used to come, I had to tell my child to not go to school because they sent an American nurse and I don’t speak English. I would like to say that when things like this happen and people do not know the language, they should send someone who knows the language because the children suffer when they see the mother suffering. He had to see what they were doing to me and translate. My baby was crying seeing me going through that.

The reality of children translating for parents seems to be faced by many immigrant parents including those with legal status in the US or even citizenship holders as Puerto Ricans. Experiencing systemic barriers, as part of the reality of immigrant women, has a psychological impact; in the case of women suffering from breast cancer, the consequences are more profound. When women, suffering from a physical condition that interferes with their capacity to take care of their children, also face these types of systemic barriers, their sense of identity as mothers, as women, as human beings, is deeply affected; it impacts their sense of dignity.
Almudena, also a primary Spanish speaker, talked about her experience and the importance of having culturally sensitive groups that help women to recover, feel connected and gain a sense of belonging:

I have a big regret and I feel frustrated that I was not able to learn English. Sometimes I feel uncomfortable, out of place. This is one of my goals: I want to try to learn some English this year and do things that I like. When we come here to this group, it helps me a lot because I can speak the Spanish language. This is the only Hispanic group that's here. It feels good to speak your own language. When you come here to talk with all the women, you see the different situations and sometimes you see that your problem is a small one. There are women that have bigger situations than mine and that helps me, it gives me more strength. And the truth is that we needed this Hispanic group.

For Almudena, being part of a group where she can speak her language not only helps her to connect with other women, but also helps her with her sense of self, her cultural identity, and self-esteem. Attending this support group is a powerful experience on multiple levels. It reflects different meanings for her and it shows that survivorship is not only a physical process where women get medical treatments; it is also a psychological process and involves connecting with others on both a personal and emotional level.

Finally, another theme that Teresa’s narrative illustrates is her experience of resisting and questioning medical decisions. Teresa talks about how she questioned the doctor’s decisions:

I told him “it makes me sick,” he said: “you need to stay on this until your body gets used to it.” I asked him: “how long is it going to take my body to get use to? I don’t want to take this medicine,” and he said, basically he said: “you are gonna die if you don’t want to follow all my treatments, you are going to die.” I said Doctor, you know, I can’t take
this medicine: “if you want me to take this medicine for all these years and if I am going to feel so sick I’d rather die” I am responsible, I am responsible for whatever happens to me.” Yes, he told me: “you are going to die” and like I said I tried to make appointments with him a couple of times after and they didn’t take me. I made him mad (laughing), but, as I said, there are some doctors that only see black and white. They don’t know any kind of gray between those two colors.

Teresa’s narrative describes a Latina woman who has an active role in her medical treatment. Teresa’s experience brings up considerations of systemic issues in the medical system where women are seen as passive receptors of medical treatments, rather than experts in their own experience. The male dominated field of breast cancer presents an interesting dichotomy on women’s experience: women own their bodies, but others make decisions for them. Teresa shows how she owns her body by questioning these medical decisions. Even though she is an immigrant woman, she has a voice and she expressed it.

In summary, the themes covered in this section explored the individual experiences of survivorship in the context of their interactions within the medical system. First, the relevance of cultural meanings such as personalismo is reflected in delivering the news of the diagnosis. Second, women talked about their experiences, voicing concerns about the linguistic barriers experienced in their interactions with medical providers and, specifically, on how these deeply affected their families, in particular, their children. Furthermore, women talked about the importance of support groups for Latina women as an invaluable resource that provides a sense of belonging, cultural identity and connection with other women. Finally, a woman questioned medical decisions, which is a very powerful illustration of resistance and how an immigrant woman from Mexico also has a voice in the US.
CHAPTER V: Discussion within the Feminist Ecological Model

This chapter will expand upon the interpretation and analysis of the individual narratives using the feminist ecological model (Ballou, et al., 2002). In addition, the discussion will describe the coherence between the theoretical framework, the methodology and the method used within a feminist approach to inquiry. Further, the results and findings will be expanded within the feminist ecological model, adding different levels of interpretation and contextualizing the individual narratives. Finally, findings and implications, as well as limitations and contributions, of this study will be presented.

**Feminist Inquiry**

This study employed a feminist methodology, hence the lens for understanding the lived experiences are based on feminist principles. The current study used a phenomenological method to illustrate the lived experiences, subjectivities, emotions, interpretations, and embodiment of women’s experiences, [elements historically associated with females and excluded from mainstream positivist research (Whitmore, 2014); as well as situating these in their socio-cultural and political context.

From the perspective of feminist inquiry, a variety of methods can be chosen within the general feminist ecological methodology (Whitmore, 2014). In this case, IPA was chosen as a powerful approach to access sources of knowledge not previously valued by traditional research, voicing the lived experiences of Latina breast cancer survivors. The use of phenomenology, within a feminist theoretical framework, aims to extend the limited literature in this area as well as to expand our knowledge of breast cancer experiences among Latina women within a feminist ecological model.
Method: Interpretative Phenomenological Analysis (IPA)

IPA has its theoretical origins in existential phenomenology and hermeneutics, with an idiographic focus (Smith, 1996). Hermeneutic phenomenology focuses upon the context, intention, and meaning surrounding a text or representation (Smith, 1996). Existentialist phenomenology conceptualizes the centrality of being-in-the-world, arguing that our experience of the world is through our bodies (Merleau-Ponty, 1962). Breast cancer, thus, can be viewed as an embodied experience; it is elaborated as such in the interpretation of the narratives.

The early connection of existential and feminist theory is exemplified in the work of Simone de Beauvoir on gender analysis (Beauvoir, 1972), which represents a nexus of existentialism and phenomenology from a feminist lens. Yet her work was criticized by feminist phenomenologists for not considering the individual experience within complex, and, generally, oppressive social structures. These considerations are fundamental in understanding the “personal,” and how the individual body experience is linked to the “political.” Therefore, women’s lived experience is located within social, political, and ideological structures (Allen-Collinson, 2011). It is the capacity to bring to the surface, both the opportunities and the oppressive elements of these structures that a critical feminist perspective strives to give voice to.

The commonalities between phenomenology and feminist theory have been further developed by other authors, establishing how existential phenomenology can support important feminist values. This current study emphasized those values and was guided by them in seeking to accomplish this connection. The main considerations in making this connection are the following: both consider lived experiences as central in gathering knowledge of the phenomenon; both value the content of individual experiences, giving women the opportunity to talk about their experiences in their own voices; and both are exploratory and not explanatory.
Moreover, feminist research is committed to openness, description, and understanding, as well as awareness and consciousness, qualities that characterize existential phenomenology as well (Garko, 1999).

Further, the limited studies conducted on lived experiences within feminist theory revealed the importance of expanding these types of studies. For instance, the studies on women’s health issues (Boughton, 2002); social lived experiences (Langellier & Sullivan, 1998); women’s bodies and sports (Allen-Collinson, 2011); and the work on political narratives of breast cancer in Spain (Porroche-Escudero, 2012); are good examples of these connections. Consequently, these studies have shown how lived experiences, interpreted from the perspective of feminist theory, contribute to gaining a deeper knowledge of women’s subjective experiences within their ecological realities. The current study on Latina breast cancer survivors is broadening this area of knowledge, articulating as well the connection of phenomenology and feminist theory.

Subsequently, this study has contextualized lived experiences in socio political and cultural contexts using the feminist ecological model. As Todorova (2011) indicated, contexts shape individual’s meanings and individual interpretations of their own realities. The consideration of this external reality was acknowledged by Smith (2011), adding that individual experience is central, and there is openness for discussion of social and political influences. Ultimately, this has been the methodological and theoretical purpose of this study: to expand and inform our knowledge of breast cancer among Latina women in the US.

**Discussion of the Results within a Feminist Ecological Model**

The results as presented in Chapter 4 illuminate women’s subjective interpretations of their individual experiences as defined by them and shaped by contextual realities. The
interpretation of these subjective narratives by the researcher was based on the interview contents, interactions, and the dialogue with these women. In this relational interaction, women are considered the experts in their own experience. The analysis of the results describes individual phenomena within the different layers of the feminist ecological model, adding my own understanding of their experiences.

Due to the lack of qualitative research from a feminist ecological perspective, the study was initially guided by questions based on gaps in the literature on breast cancer among Latina women. These preliminary guiding questions were meant to illustrate how Latina women’s sense of identity changes after surviving breast cancer and how they made sense of these changes. Furthermore, this study intended to voice what it meant for the families of these Latina women surviving breast cancer. Finally, the guiding questions explored the strength and resistance demonstrated by Latinas in overcoming their illness, as well as their experiences of misunderstanding, insensitivity, and oppression.

**Summary of the Results**

The major findings show that survivorship is a process that evokes a new sense of identity for these women. The meaning of survivorship is embedded in their ecological realities. Overall, the narratives showed that the age of diagnosis and their family situation, such as having an intimate partner, and having young children at the time of the diagnosis, shaped the impact of the breast cancer diagnosis. The narratives also revealed that making meaning of all the physical, psychological, and emotional changes was done in connection to others. Additionally, the support received from their families and other support systems added different meanings to the lived experiences of the illness. The findings supported the emergent themes associated with femininity that are experienced by these women through their roles as mothers, which are
embedded in the cultural values associated with *marianismo* (maniranism) and *familismo* (familism). This role as caregiver was also a source of strength and provided a purpose in life: “surviving for their children.” Simultaneously, they also received support from family members. Additionally, support groups for Latina women, and their strong commitment to their faith, were important sources of strength in this process of survivorship.

Moreover, the results showed that the assumptions about Latina women as being fatalistic and passive were not reflected in the narratives of these women. On the contrary, women expressed the importance of information and education about breast cancer. They expressed the ways they challenged institutional structures, for instance, social impositions about feminine body image, or how they resisted medical decisions by voicing their needs. Furthermore, these women showed the importance of helping other women either through mentoring, supporting them with their sense of humor, and solidarity. Finally, results demonstrated that women were in general appreciative of the help received from support systems. Nevertheless, some women experienced linguistic barriers and talked about their negative experiences in navigating the medical system. Women described the importance of the cultural value of *personalismo* (personalism) in their interactions with medical providers.

**Learning from these Women’s Experiences: Implications for Intervention and Research**

A more detailed explanation of the findings and what can be learned from these women is presented next, as well as the systemic implications of these findings and how those could inform interventions to increase support for Latina women.

**Lessons on Survivorship**

At an individual level, the meaning of survivorship illustrated how the illness had an impact on their identity. Women experienced a state of denial and a tendency to self-blame when
facing the diagnosis and the idea of death. The self-blaming within Latino culture could be attributed to the construct of fatalismo and as God’s punishment. However, women in this study transformed the meaning of this existential confrontation with death into changes that implied taking care of their needs and making more time for self-care. Women didn’t give up for several reasons, one of them specifically being their need to be there for others, especially their children. This initial “fatalismo” is transformed by finding new ways of making meaning of their lives.

These findings on why women tend to blame themselves rather than finding other possible explanations for their suffering, is systemically contextualized. The dominant epidemiological discourse about illness emphasizes the importance of individuals as being responsible for their own health. This medical discourse neglects to consider the systemic issues that contribute to women’s health and, specifically, to Latina breast cancer survivors. For instance, in these discourses, information about industries that produce carcinogens is not included (Klawiter, 1999). The awareness of multiple social, cultural, and other system-wide factors that affect breast cancer should be considered in treating women diagnosed with breast cancer. Therefore, interventions could decrease the impact of the diagnosis by providing information that includes awareness of the complexity of breast cancer. Ultimately, women could make self-enhancing meaning of the illness by feeling less guilty about the diagnosis of breast cancer.

**Lessons on Femininity**

The women in this study reflected their sense of femininity in relation to others through motherhood, their roles in their families, as well as through the connection with other women and their intimate partners. The acceptance and valuing of others helped these women to also accept their new bodies and changes in the meaning of their sexuality. These results seem
consistent with other phenomenological studies on femininity among Latina women (Greer, Neville, Ford, & Gonzalez, 2013). Women in this study, rather than feeling pressured to keep a “feminine” identity based on imperative social norms such as intact breasts, hair, and other physical attributes, developed a new sense of self and learned to live with those changes.

Moreover, some women in this study voiced resistance against social impositions on femininity and demanded to be accepted with their mutilated bodies and new identities. In some cases, women even questioned societal messages associated with femininity: “I am not my hair,” or not considering breast reconstruction as would be expected by society at large. Furthermore, the women interviewed that belonged to the La Esperanza support group, expressed how this connection with other women was a transformative experience: women felt accepted and supported in their physical transformations; their new sense of self was validated in a safe environment of acceptance, support, and care. This revealed the value of environments where women don’t feel pressured to meet the societal standards of femininity.

Finally, in considering possible interventions to decrease the pressure on women to look a particular way and feel accepted, it is essential to reflect on what one of the women in this study referred to as “educating” people about the realities of breast cancer. The “visibility” of breast cancer implies educating others about the physical changes experienced by women. Furthermore, this also includes children, with special attention to developing programs targeted to support children of women going through this process of multiple changes. We have to think critically about a dominant culture of breast cancer showing images of intact bodies based on an industry that promotes reconstructions (Ehrenreich, 2001) and how this affects the “visibility” of breast cancer. Organizations that challenge the dominant survivor image do exist, for instance, The Bay Area Women and Cancer Walk, which shows women's bodies following mastectomy (Klawiter,
Public awareness of the reality of the illness could help women feel more confident with their new identities and normalize, rather than stigmatize, changes following breast cancer.

**Lessons on the Meaning of Familia**

In considering other areas of inquiry, Latina mothers in this study demonstrated elements of the value of “familism” and the importance of their caregiver roles, protecting their children, and the wellness of the family. The diagnosis of breast cancer becomes a family illness. Latinas’ families suffer and struggle with all the changes that this implies, specifically the children who are also an active part of survivorship. In this study, women expressed how concerned they were about their families and how the illness affected them; they also expressed their need to continue caring for them and being supportive figures. These relationships give them a strong sense of connection and serve as their primary support in times of need and despair, specifically for immigrant families who already faced systemic barriers associated with their immigrant lived experiences.

Latina women are connected to their families and children, with their identities being significantly defined by those bonds that give meaning to their existence. All of the women in this study had children and all of them considered family the most important factor in their lives. Therefore, breast cancer is not an individual experience, but rather a “family experience.” The importance of surviving cancer for their children was found across all cases and this finding was consistent with other research findings about the importance of children for Latinas (Nedjat-Haiem, Carrion, Ell, & Palinkas, 2012). Models that do not consider families as central in people’s lives could be neglecting the importance of incorporating families and children in this process of survivorship. In immigrant families, strength comes from adapting as a family. As some authors have suggested, family and children should be included in treatment programs
tailed to Latina women (Buki et al., 2008). Therefore, more inclusive treatments could help women to experience their illness not as a burden to their families, but as the source of strength.

**Lessons on Fatalismo**

Faith was an important source of strength for this group of Latina women which is consistent with literature findings (Abraído-Lanza, 2007). In further describing this theme, we found that “fatalism,” needs to be qualitatively studied in order to expand the cultural meanings of this complex worldview element. In some quantitative studies on breast cancer among Latina women, *fatalismo* is considered to be a predictor that impeded women from proactive behaviors (Pérez-Stable, Sabogal, Otero-Sabogal, Hiatt, & McPhee, 1992). As women expressed in this study, uncertainty in life is part of our existential experience, our capacity to face and overcome illness happens thanks to God’s help. There is no control over life events, only God knows. The women in this study expressed, through fatalistic expressions in Spanish, their experience of lack of control over certain events. However, they all demonstrated very proactive attitudes to overcome their illness and emphasized the need to inform and educate others. Further, it is essential to contextualize fatalism within US culture. North American culture emphasizes the need to think positively and show happiness, values which are also reflected in the breast cancer culture full of pink colors and happy women fighting cancer (Ehrenreich, 2001). On the contrary, within the cultural meaning of fatalism, expressions of anger, sadness, or hopelessness are culturally accepted. Latino culture responds to a different interpretation of the phenomena of breast cancer within their cultural values that are also represented in different artistic forms and expressions. As mentioned in the literature review, new paradigms examining health outcomes need to be explored, specifically with minority groups, where considering the intersectionality of socioeconomic factors as well as how discrimination may interfere with health outcomes, are
further integrated into our prevention/intervention strategies (Viruell-Fuentes, Miranda, & Abdulrahim, 2012). Therefore, it is beneficial to also consider systemic barriers that Latina breast cancer survivors may experience when exploring narratives of their lived experiences. Such systemic barriers include inadequate health care and coverage, socioeconomic disparities, discrimination, language barriers, access to education, isolation, immigration, and institutionalized racism. These systemic barriers can be potentially hidden in the mainstream literature, which emphasizes cultural differences and different world views as causes of the high mortality rates of breast cancer among Latinas in the US. Further, mainstream literature may potentially neglect to acknowledge the oppression of dominant forces that control not only economic resources but also “knowledge,” that imposes dominant cancer discourses that do not consider women’s individual lived experiences.

**Lessons on Systemic Barriers and Supports**

The lessons learned from these women in navigating the medical system as well as additional barriers experienced by them, illustrates how those experiences gave different meanings to their survivorship. Some women talked about the significance of “personalism” in their interactions with medical providers and how this was missing from their interactions in going through medical treatments. From a feminist perspective, using more relational approaches in treatments could benefit those interactions. For example, delivering diagnosis over the phone could be substituted for more personal interactions. Further, considering how the results of the diagnosis should be delivered, for example, in a sensitive manner in front of children, while being attuned to their developmental stages, and, most importantly, to avoid using them as translators as this is not only an insensitive practice in working with immigrants but also a culturally disrespectful and unethical practice.
Despite the barriers they experienced, many women expressed gratitude for all the support received, especially the ones attending the Latina support group at La Esperanza. The results indicate that women experienced support and connection through groups offered for Latina women. Being part of a group where women can speak their primary language not only helps them to connect with other women, but also helps them with their sense of self, their cultural identity, and the process of survivorship. These findings on the importance of groups for Latina women are consistent with the literature (Ashing-Giwa, et al., 2006). However, the literature also shows that Latina breast cancer survivors are not being adequately served and that few programs are available for this population (Buki, Hinestrosa, & Grupski, 2007). The current study reflects this reality, given the limited number of groups for Latina women in Massachusetts. Currently, in Boston, groups for Latina survivors are offered in hospital settings. However, women report receiving invasive treatments in these hospitals. In considering the lived experiences from a feminist ecological model, an alternative would be offering groups and services for these women in settings that are easily accessible for them. Further, offering services located within their communities where other support systems are in place would facilitate a shift in the distribution of resources and create support for political action within traditionally oppressed communities.

**Limitations of this Study**

At an individual level, talking about breast cancer is not an easy topic and people prefer to keep these experiences private. Therefore, the very nature of the topic limited access to women. Further, at a systemic level, the lack of specific agencies in the Boston metropolitan area that specifically serve Latina breast cancer survivors made the initial connection with women very challenging. Hospitals in Boston run groups for Latina women, but access to those women
is protected by the hospital’s IRB restrictions. Furthermore, other challenges were added to this process, such as, geographical limitations, and women who, after being identified as potential candidates, were reluctant to talk because of several systemic barriers such as being undocumented. Finally, arrangements were at times challenging due to weather conditions and participants’ health or work schedule limitations.

Although this study reflected the narratives of ten women and their experiences with breast cancer, it is not meant to deny the existence of many other realities among Latina women. The study is also limited by the researcher’s interpretations of these realities. Therefore, another researcher with different gender characteristics, personality, country of origin, and world views, could have influenced the process differently. One might ask whether, for example, a male interviewer would be able to make the type of connections made in this current study.

**Contributions of this Study**

The main contribution of this study was to illustrate women’s experiences by honoring their stories and bringing them to life. The study attempted to increase the number of studies, from a feminist ecological perspective, voicing the lived experiences of Latina breast cancer survivors. We learn from the reality of these ten Latina breast cancer survivors by bringing awareness of their experiences. In addition, this study has contributed to the limited research on the phenomenology of illness informed by feminist theory and questioning some of the dominant discourses on breast cancer, specifically with Latina women. The study was guided by the feminist ecological model: valuing all experiences, valuing individual differences, contextualizing the causes of emotional distress, questioning norms and standards of traditional health and mental health, and recognizing the imperative of social change (Ballou, et al., 2002). Further, this study’s use of feminist theory recognizes that, in traditional mental health research
and treatment, individuals’ lived experiences can be neglected; feminist models attempt to redistribute power in all relationships between participants and researchers, oppressed groups and dominant forces (Hill & Ballou, 1998). Therefore, the individual narratives were connected to contextual forces, with critical analysis meant to promote change and help other women in similar situations. The aim of this study was to find ways for multiplicity, collaboration, dialogue, and care for women by engaging different voices.

The current study also proposes the consideration of treatments that utilize community based resources and local agencies by supporting them with funding. The relevance of biomedical research is acknowledged; however, breast cancer includes a biopsychosocial component and treatments should reflect these at multilevel interventions and in multiple contexts. Therefore, it is important to consider integrated treatments within communities and not exclusively centralizing those in hospitals. Consequently, this would imply the diversification of interventions and a more equalitarian distribution of resources. However, the health care system in the US does not function on universal medical principles as in other countries and the distribution of wealth in society follows the same unequal distribution. Therefore, being aware of this contextual reality demands that we consider other alternative models to the existing medical corporations. One such alternative model is exemplified by La Esperanza. By helping these women in their communities, the work at La Esperanza demonstrates the resistance and dedication of supporting women in the community with very limited resources. This study further reveals that changes are required by society at large so that the reality of breast cancer, including its ugly side, can be voiced and seen. This could normalize the lives of these women that may feel pressured to hide the inevitable changes of their bodies.
Finally, future research, as mentioned in the literature, should focus on shifting paradigms from individual culture-based frameworks to perspectives that consider the role of structural factors in producing health inequalities among immigrants (Viruell-Fuentes, et al., 2012). This shift also implies expanding the discussion of illness within the exo and macro level encompassed by the feminist ecological model. Therefore, considering the structural oppression within those systems and, at the institutional level, in particular, on how those affect immigrant women. This discussion should also consider the intersection of systemic oppression with gender, culture, ethnicity, education, and socioeconomic status and how breast cancer is experienced and lived differently by women depending on those individual characteristics. Further, other considerations are crucial: how historical and economic influences have determined the current breast cancer discourse and how political action is needed to resist and shift this medicalized dominant culture, which is supported by corporations and industries, that consider breast cancer as an individual issue rather than a social problem. Finally, as previously mentioned, breast cancer is an illness that includes different domains: the biological, the personal, societal, and the environmental. Breast cancer campaigns should include these multiple realities. In particular, considerations of environmental concerns and use of chemicals in products that can damage women’s health as well the need for regulation of those chemicals and clear information about them.

The importance of international dialogues on women’s health issues also needs to be part of a more liberating discourse. Breast cancer continues to be a large problem among women, especially in so-called developed countries. The discussion should include multiple voices and perspectives. In conclusion, Latinas may present more unique expressions of their realities in surviving breast cancer depending on their insurance coverage, economic situation, linguistic
barriers, country of origin, and time since arrival in the US. Their narratives are likely shaped by immigration issues, experiences of discrimination, social inequality and other potential barriers. This study aimed to understand the lived experiences of these women utilizing a feminist ecological model. By giving voice to these narratives of survivorship, we make the individual political within their socio-political and cultural realities. We expand knowledge from the embodied experiences of these women within their ecological realities. Ultimately, these women are the experts on breast cancer and we need to continue listening to them.
REFERENCES


Medicine, 58(9), 1647-1657. doi: http://dx.doi.org/10.1016/S0277-9536(03)00372-1


## APPENDIX A:
### TABLE I: PARTICIPANTS

<table>
<thead>
<tr>
<th>Coded name</th>
<th>Age</th>
<th>Survivorship</th>
<th>Country of origin</th>
<th>Language of preference for interview</th>
<th>Years in the US</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Celia</td>
<td>60</td>
<td>More than 5 years</td>
<td>Puerto Rico</td>
<td>Spanish</td>
<td>More than 20 years in the US</td>
<td>Mother and grandmother</td>
</tr>
<tr>
<td>Felisa</td>
<td>78</td>
<td>More than 10 years</td>
<td>Puerto Rico</td>
<td>Spanish</td>
<td>More than 60 years in the US</td>
<td>Mother and grandmother</td>
</tr>
<tr>
<td>Almudena</td>
<td>49</td>
<td>More than 6 years</td>
<td>Honduras</td>
<td>Spanish</td>
<td>More than 20 years in the US</td>
<td>Mother</td>
</tr>
<tr>
<td>Jimena</td>
<td>50</td>
<td>More than 10 years</td>
<td>Puerto Rico</td>
<td>Spanish</td>
<td>More than 20 years in the US</td>
<td>Mother and grandmother</td>
</tr>
<tr>
<td>Teresa</td>
<td>60</td>
<td>More than 13 years</td>
<td>Mexico</td>
<td>English</td>
<td>More than 40 years in the US</td>
<td>Mother and grandmother</td>
</tr>
<tr>
<td>Marta</td>
<td>50</td>
<td>More than 5 years</td>
<td>Cuba</td>
<td>English</td>
<td>More than 40 years in the US</td>
<td>Mother</td>
</tr>
<tr>
<td>Virginia</td>
<td>64</td>
<td>More than 16 years</td>
<td>Costa Rica</td>
<td>Spanish/English</td>
<td>More than 30 years in the US</td>
<td>Mother</td>
</tr>
<tr>
<td>Miranda</td>
<td>76</td>
<td>More than 10 years</td>
<td>Puerto Rico</td>
<td>Spanish</td>
<td>More than 40 years in the US</td>
<td>Mother and grandmother</td>
</tr>
<tr>
<td>Linda</td>
<td>77</td>
<td>More than 20 years</td>
<td>Puerto Rico</td>
<td>Spanish</td>
<td>More than 40 years in the US</td>
<td>Mother, grandmother and great-grandmother</td>
</tr>
<tr>
<td>Herminia</td>
<td>46</td>
<td>More than 5 years</td>
<td>Dominican Republic</td>
<td>Spanish</td>
<td>More than 20 years in the US</td>
<td>Mother</td>
</tr>
</tbody>
</table>
APPENDIX B:
AREAS OF INQUIRY

• When were you diagnosed with breast cancer?
• What did you know about the illness before being diagnosed?
• How would you describe who you are now after surviving the illness?
• What did breast cancer mean for your family?
• How did you feel about the changes in your body as a result of the breast cancer?
• What do you think has been helpful in overcoming breast cancer?
• What have you learned from your experience of breast cancer?
• Do you see any transformations in your life?
• How was your experience with the medical system?
• How do you think what you have gone through could help others going through a similar condition?
Notification of IRB Action

Date: September 24, 2013  IRB #: 13-06-14

Principal Investigator(s): William Sanchez
Monica Torreiro-Casal

Department: Counseling and Applied Educational Psychology

Address: 404 International Village
Northeastern University

Title of Project: The Lived Experiences of Latinas: Contextualizing Breast Cancer within a Feminist/Ecological Model

Participating Sites: N/A

Informed Consent: One (1) signed consent form

DHHS Review Category: Expedited #6, #7

Monitoring Interval: 12 months

Approval Expiration Date: SEPTEMBER 23, 2014

Investigator’s Responsibilities:

1. Informed consent form bearing the IRB approval stamp must be used when recruiting participants into the study.
2. The investigator must notify IRB immediately of unexpected adverse reactions, or new information that may alter our perception of the benefit-risk ratio.
3. Study procedures and files are subject to audit any time.
4. Any modifications of the protocol or the informed consent as the study progresses must be reviewed and approved by this committee prior to being instituted.
5. Continuing Review Approval for the proposal should be requested at least one month prior to the expiration date above.
6. This approval applies to the protection of human subjects only. It does not apply to any other university approvals that may be necessary.

C. Randall Colvin, Ph.D., Chair
Northeastern University Institutional Review Board

Nan C. Regina
Director, Research Integrity

Northeastern University FWA #: 4630
May 31, 2013

(Name of Organization or Agency)

Dear Sir/Madam:

My name is Monica Torreiro-Casal and I am a Ph.D. candidate in Counseling Psychology in the Department of Counseling and Applied Educational Psychology, at Northeastern University. I am contacting your organization to potentially invite Latina women who would be willing to take part in a research study entitled: *The Lived Experiences of Latinas: Contextualizing Breast Cancer within a Feminist/Ecological Model*. The purpose of my dissertation study is to understand the experiences of Latina breast cancer survivors as they navigate the health care system. I am interested in this topic because in my clinical practice I had the opportunity to work with women who survived cancer; their stories had a huge impact on our work, as they are the experts in determining what is helpful and what is challenging in their surviving breast cancer. I became very interested in this topic and want to learn more from the voices of these experts. I hope that this knowledge will help to inform other professionals and help other women in similar situations, specifically within the Latino community.

The study will consist of two individual interviews. Participation in the study is voluntary and interviews will be confidential. The interviews will be conducted at a location that it is convenient to the participants. I have been trained as a clinician and I have been providing therapy for several years. Furthermore, I am supervised by Dr. William Sanchez who is the chair of my thesis committee. Dr. Sanchez is a licensed psychologist with extensive clinical experience. I am willing to give a brief presentation of my study to your organization in person. Thank you for your consideration in allowing me to speak to Latina breast cancer survivors associated with you agency/organization. I look forward to hearing from you soon.

Sincerely,

Monica Torreiro-Casal, M.A.
PhD Candidate in Counseling Psychology
Latina Breast Cancer Survivors Needed to Talk about Their Experiences

Northeastern University, Department of Counseling and Applied Educational Psychology

Seeking Latina women who survived breast cancer and are willing to share and contribute with their knowledge to help improve health services for breast cancer survivors.

- Participation in this study is voluntary and confidential.
- Two interviews, conducted in either Spanish or English, will be conducted by a PhD candidate with clinical experience in counseling psychology.
- Your expertise will contribute to the knowledge of surviving breast cancer.

If you are interested please contact: torreiro-casal.m@husky.edu.neu or call (617) 501-1203

Approved

NU IRB
VALID THROUGH 1/3/14
1/24/13
1/24/14
Northeastern University, Department of Counseling and Applied Educational Psychology
Investigators: William Sanchez, Monica Torreiro-Casal
The Lived Experiences of Latinas: Contextualizing Breast Cancer within a
Feminist/Ecological Model

I am inviting you to take part in a research study on “The lived experiences of Latina breast
cancer survivors.” The purpose of this study is to understand the experiences of breast cancer
survivors as they interact with the health care system. I am interested in this topic because in my
clinical practice I had the opportunity to work with women who survived cancer; their stories
had a huge impact on me. I became very interested in this topic and how to learn more from the
voices of the experts, in this case, women breast cancer survivors.

I am a PhD candidate in Counseling Psychology at the Department of Counseling and Applied
Educational Psychology at Northeastern University. I am conducting this research project as part
of my PhD in Counseling Psychology requirements. I am inviting you to participate in this study
because your invaluable experiences in surviving breast cancer would be a great help in
developing a better understanding of the meaning of being a breast cancer survivor.

If you decide to take part in this study, I will ask you some questions and tape record our
conversation. You may also ask me any questions that you might have. Participation in the study
is voluntary and you can stop the interview at any time.

The interviews will be conducted at a location that is convenient to you on two different
occasions and it will take approximately 1 hour for each occasion.

The interview is confidential and your identity will not be disclosed anywhere. Once the
interview has ended, the tape recording will be securely kept and will only be accessible to me
and my professor, until transcribed by me. Once I have transcribed it, the tape recording will be
destroyed and the transcript will not contain any identifying information.

Risks/Discomforts: Although the interview has minimal risks, the nature of the discussion may
be emotionally difficult. You can stop at any time and as a trained clinician, I will assist in
processing the discussion and, if needed, assist with contacting appropriate service providers.

It is hoped this knowledge can contribute to informing other professionals on how to best
provide care and help other women in similar situations better understand their experiences.

In case you have any questions about this study please contact me at:

Monica Torreiro-Casal: torreiro-casal.m@husky.edu.neu. You can also contact my advisor, Dr.
William Sanchez at w.sanchez@neu.edu; tel.: 617-373-2404.

If you have any questions about your rights in this research project you may contact:
Nan C. Regina Director, Human Subject Research Protection, 960 Renaissance Park,
Northeastern University, Boston, MA 02115, Tel: (617) 373 4588 email:n.regina@neu.edu. You
may call anonymously if you wish.
I agree to take part in this research

Signature of person

Date

Printed name of person above

Signature of the person who explained the study to the participant above and obtained consent

Date

Printed name of the person above