The social context of stress and social support among immigrant Latinas diagnosed with breast cancer

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The Social Context of Stress and Social Support among Immigrant Latinas
Diagnosed with Breast Cancer

By

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
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Dedication

This dissertation would not have been possible without the encouragement, support, friendship and love I received from my husband, Will Tyson. I thank him for quelling my academic insecurities, and always believing in me. I sincerely appreciate the many delicious dinners he cooked that nourished and energized me to continue writing. He was and is my inspiration. I would also like to thank my parents for showing me that with love, dedication and perseverance you can accomplish anything and the Tyson family for their prayers. I have been blessed to have many friends who have in one way or another made a difference in my life. I am especially grateful to Janelle Mernard, my friend and colleague for her advice and willing ear. It is an honor and pleasure to graduate along side her. I would also like to recognize, Adria Jensen, Pradeep Vanguri, Hossana Soler Vila, Marlene Rivera. Alma Flores and Antoinette Powell for their counsel and encouragement. My dissertation research would not have been possible without the support, friendship and assistance from Melba Martinez. Her personal story and dedication to improving the lives of Latinas diagnosed with cancer deeply motivated me. Gracias. Last, but not least I will forever be indebted to the many Latina cancer survivors who participated in this study. I have learned immensely from them; their experiences, stories and friendship have humbled me and enlightened me. They have taught me to never underestimate the power of being positive and the significance of hope and faith. I sincerely want to thank each of them for their patience and for allowing me to be a part of their life. I would like to dedicate my dissertation to them and to the memory of Amparo and Liliana who lived fully and fought a valiantly but in the end lost their fight against cancer.
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The Social Context of Stress and Social Support among Immigrant Latinas Diagnosed with Breast Cancer

Dinorah Martinez Tyson

ABSTRACT

Social support plays a crucial role in both the physical and mental adjustment to the diagnosis of breast cancer and its treatment. However, the mediating effects of social support are embedded within the larger, social and cultural contexts in which support given and received. Due to language, culture and economic issues, immigrants may find themselves without the social support and networks that had previously enabled them to cope with illness and disease. This research grounds our understanding of social support and breast cancer within that larger context that includes the social environment and the experience of health disparities.

Ethnographic methods were used to explore the cultural domains of social support and to examine cultural and structural factors that influence this multifaceted construct. Participant observation, key informant interviews and 28 in-depth interviews with Latina immigrants diagnosed with breast cancer were conducted in Phase I. The qualitative data gathered in Phase 1 informed the development of the structured questionnaire that was administered in Phase II to 60 Latina immigrants in West Central Florida who had been diagnosed with breast cancer.

Breast cancer not only affects individuals, it impacts their social relationships, finances, work, and social roles. The analysis provides a rich and in-depth understanding of social support and contextualizes the breast cancer experience of Latina immigrants. Results suggest that cultural expectations about gender roles shape what kinds of support and assistance is provided by men and women. Spirituality and prayer were identified as non verbal sources of support. Beliefs about not burdening the family with personal concerns and beliefs that family needs should come before one’s own were negatively associated with social support. English proficiency and length of time in the United States were not associated with social support. Regardless of length of time in the US there appears to be strong ties with family in their native country. While family both in the US and in their native country were identified as sources of support, they were also identified as a source of stress. Recommendations for clinicians, practitioners and community-based organizations that provide supportive services and programs to Latinos are included.
Chapter 1: Introduction

Introduction

People experience many possible emotions after a diagnosis of cancer, including shock, disbelief, despair, anger, fear, sorrow, and uncertainty (Bloom 2002; Courtens et al. 1996; Lewis et al. 2001). Breast cancer affects every aspect of an individual’s life. Both the serious psychosocial and emotional side-effects of cancer and its treatment increase the need for social support (Ashiping-Giwa et al. 2004b; Mathews et al. 1994a). Social support plays a crucial role in both the physical and mental adjustment to the diagnosis of cancer and its treatment (Cassileth et al. 1985; Holland & Holahan 2003; Schroevers et al. 2003). However, the mediating effects of social support are embedded within the larger, social and cultural contexts in which support is perceived, mobilized, given, and taken (Pearlin 1985). This study seeks to understand how cultural and structural factors combine to shape the assumptions, beliefs, and values that constitute social support among Latin American immigrant women diagnosed with breast cancer.

Research rationale

Hispanics/Latinos are now the largest and fastest growing ethnic minority group in the United States (Pew Hispanic Center 2008). In addition, Latinas tend to be diagnosed with breast cancer at younger ages, at more advanced stages of disease, have lower cancer survival rates, and are more likely to receive poorer quality care/treatment and follow-up after a cancer diagnosis when compared to other ethnic groups (Li et al. 2003a). Possible explanations for these disparities include low rate of medical insurance coverage, lack of knowledge about services, limited access to screening programs, and poverty (Chavez 1999; Haynes & Smedley 1999; Huerta 1999;
Huerta 2003a). These issues may even be more of a problem for first generation immigrants who may fear the unknown and are unfamiliar with the US health care system (Haynes & Smedley 1999; Huerta 2003a).

Hardships associated with immigration to the United States are often confounded by problems associated with lack of employment, inadequate health insurance coverage, poor housing and working conditions, discrimination, acculturative stress, legal problems, limited English proficiency and multiple other challenges, which all occur at a time when family and other traditional support systems are minimal, or even non-existent (Chavez et al 1997b; Cuellar et al 2004; Kramer et al 1999; Leclere et al 1994). Add the diagnosis of breast cancer to this picture, and it becomes much more complex. Not only is the diagnosis of breast cancer a stressful experience, but there are many long term psychological and physical effects that can potentially and frequently pose still heavier burdens to immigrant women.

The experience of immigrating and adjusting to the United States and its healthcare system is especially relevant to researchers working with immigrant populations and women’s health issues. Grounding our understanding of social support and breast cancer within a larger context that includes the social environment, social change, and healthcare inequalities will enable us to see how these phenomena are integrated, thereby enabling researchers to develop better programs and interventions that address everyday realities. In addition, because many social support instruments are quantitative, usually involving a checklist or scale, and narrowly focused, researchers may not learn about the coping behaviors, resources, or women’s histories and beliefs and how these in turn effect social support.

Social support requires interpersonal relationships, which are influenced by cultural norms, beliefs and behaviors (Dressler 1985; Hamilton & Sandelowski 2004b;
Jacobson 1987; Makabe & Hull 2000). However, very few studies among cancer survivors have explored the application of this concept from a cross-cultural perspective (Moore 1999). Mutran, Reed and Sudha point out that differences in definitions of social support constructs are seldom considered and pose obstacles to research in this area (2001). Few studies have explored social support and its relation to health outcomes among Hispanic women diagnosed with breast cancer (Alferi et al 2001; Katapodi et al 2002), and none of them have explored the underlying cultural assumptions that lend meaning and insight to social support among Latinas. Nor have these studies examined the influence that social change and migration have on Latinas’ well-being and ability to adapt to and cope with breast cancer.

The theoretical orientation guiding the research presented here is that of critical biocultural anthropology. The critical biocultural perspective is holistic and integrative (Singer 2007). It focuses on the processes and sociocultural contexts of health and disease, while simultaneously addressing larger, political economic structures that influence the social environment and may mediate opportunities for social support, as well as access to healthcare and resources. More detail is provided in Chapter 2 Literature Review.

**Research questions and objectives**

This dissertation research addresses the following research questions:

**Q1:** How do cultural and structural factors combine to shape the assumptions, beliefs, and values that constitute social support among Latinas diagnosed with breast cancer?

**Q2:** What are the cultural and structural factors that influence social support among Latina immigrants diagnosed with breast cancer?

The specific objectives of the research are:

**O1:** Contextualize the cancer experience of Latina immigrants diagnosed with breast cancer.

**O2:** Explore the sociocultural domains of social support.
O3: Identify the cultural and structural factors that influence social support among immigrant Latinas diagnosed with breast cancer.

O4: Identify the information and support needs of Latina immigrant breast cancer survivors.

O5: Provide recommendations for community-based organizations, clinical practice and psycho-oncology

Research Hypothesis

Personal observations, along with the literature guide the following hypotheses that were tested through the dissertation research:

H1. Cultural expectations about gender roles will influence social support:

H1.a., Compared to women, a higher proportion of men will likely provide instrumental/tangible support, and a higher proportion of women will likely provide emotional support, compared to men.

H1.b., Cultural expectations that women should not burden family and friends with personal concerns/worries will negatively influence social support.

H1.c, Cultural expectations to be strong (aguantar/tolerant) will negatively influence social support.

H2. Language (English proficiency) will be positively associated with social support.

H2.a, Women with limited English proficiency will be less likely to have informational than those that who are English proficient.

H3. Chronic stress (poverty, family problems, economic/financial problems, immigration status) will be negatively associated with social support.

H4. Length of time in the United States will influence social support.

H4.a., Women who have been in the US a shorter period of time will likely rely on family and friends in their native county for emotional support.

H4.b., Women who have been in the US for a shorter period of time will likely have less informational support than those who have resided here longer.

The following section offers brief definitions of key terms and concepts used in this study.
Definitions of key terms

**Breast cancer survivor/survivorship**: Currently, a person is considered a cancer survivor from the time of cancer diagnosis “through the balance of his or her life” (Farmer & Smith 2002). Family members, friends, and caregivers are affected by the survivorship experience and are therefore included in this definition (Farmer & Smith 2002). Herein it is acknowledged that the use of the term survivor/survivorship stems from the western biomedical model, which emphasizes autonomy and individuality (Mathews 2000; Mathews et al 1994a). Because describing women simply as having been diagnosed with breast cancer negates the long term psychological and physical effects of cancer and its treatment, this term may be used.

**Breast cancer**: The uncontrolled growth of malignant breast tissue. It is currently the most common cancer in women in the US. After diagnosis, one of the most important things to determine is the “stage” or the extent to which the cancer has spread. This also helps determine the woman’s chances for survival (Love & Lindsey 2000) (See Table 1.1). Stage I represents an early cancer that is localized and has not spread to the lymph nodes. In stages II and III, the cancer is increasingly more advanced. In Stage IV, the disease has spread to other parts of the body (metastasized). Breast cancer treatment is complex because the different types of breast cancer vary greatly in their growth rates, tendency to spread and response to treatment (Berkow et al 1997). Treatment may include surgery, radiation therapy, chemotherapy, and/or hormone blocking drugs. Surgery and radiation therapy are localized and only target the affected area, while chemotherapy and hormone therapy are systemic (Olivotto & Levine 2001).
Table 1.1. Stage Definitions of Breast Cancer

<table>
<thead>
<tr>
<th>Stage</th>
<th>Definition</th>
<th>Average five-year survival</th>
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<tr>
<td>Stage I</td>
<td>Tumor less than 2 cm, no metastases, no cancer in lymph nodes</td>
<td>80-95%</td>
</tr>
<tr>
<td>Stage II</td>
<td>Tumor 2-5 cm but not involving skin and chest wall, if lymph nodes are involved they must be movable.</td>
<td>50-75%</td>
</tr>
<tr>
<td>Stage III</td>
<td>Advanced local tumor, fixed to the skin or chest wall, or presence of lymph nodes attached to structures in the axilla</td>
<td>30-60%</td>
</tr>
<tr>
<td>Stage IV</td>
<td>Cancer spread beyond breast and axilla to lymph nodes above the collar bone, or to distant organs</td>
<td>5-20%</td>
</tr>
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**Social support**: Social support is a mediating pathway by which networks might influence health status (Berkman & Glass 2000c; Berkman et al 2000). Social support is typically divided into domains that include:

1) Emotional (love, caring, sympathy, understanding),
2) Instrumental (help, aid, assistance with tangible needs),
3) Appraisal (help with decision making), and
4) Informational support (providing information or advice)

**Social networks**: Social networks can be described as the web of social relationships that surround an individual and the characteristics of those ties (Berkman & Glass 2000c). Network characteristics include: size, homogeneity, density, frequency of contact, multiplexity, duration, and reciprocity (Michael et al 2002; Suarez et al 2000),

The informal social network comprises relationships with family, friends, and peers, whereas connections with service providers constitute formal networks (Berkman 1984).

**Latinas/Hispanics**: It is important to place the term and use of the word Hispanic within the context of the United States society. In this study, the findings concerning this group is meaningful within the U.S. context (Oboler 1995). This term is socially and
politically constructed. It was created by the U.S. Office of Management and Budget in the 1970s and was used in the census for the first time in 1980 (Hayes-Bautista 1992; Hayes-Bautista & Chapa 1987). The term Hispanic has given a political solidarity to Mexicans, Cubans, and Puerto Ricans in the U.S., which has in turn given them the power to collectively advance political and economic causes and the “political might” to influence state and national policies. For this reason, the leaders of these groups lobbied for the adoption of the term “Hispanic” (Sommers 1991; Trueba 1998). Herein, I include women who share a common heritage in the Spanish-speaking Caribbean, as well as Central and South America. I will use the terms Latina and Hispanic interchangeably.

**Latin American immigrant women:** This study explores the breast cancer experience of Latin American immigrant women who have been diagnosed with breast cancer. Broadly defined, this term includes both recent arrivals and long term residents of the United States who are foreign-born, who emigrated from countries in the Spanish-speaking Caribbean, including Puerto Rico Mexico, Central and South America. Latin American immigrant women may also be referred to as Latina immigrants, foreign born Latinas and Hispanic immigrant women in this study.

**Psychosocial:** The term is used to emphasize the close relationship between psychological and social effects of a patient’s illness. It also refers to mental health and social conditions, or factors that affect psychological or social well-being (http://www.merriam-webster.com/dictionary/psychosocial).

**Psycho-oncology:** The field of oncology that includes the psychosocial and the psychobiological aspects of oncology. It is concerned with aspects of cancer that go beyond treatment. It is an area that is concerned with the social factors that may affect disease progress and with the effects of cancer on patients’ psychological well-being (http://www.ipos-society.org).
**Chronic stress:** Chronic stressors are difficulties, problems, and challenges that people may experience over time during their daily lives, for instance unemployment, racism, poverty, work and work overload (Israel et al 2002; Schulz et al 2001).

**Organization of dissertation**

The dissertation manuscript is organized into six chapters. This chapter includes the research rationale, followed by the research questions, objectives, and hypothesis. Key terms are then defined. This is followed by a description of the organization of the dissertation.

Chapter 2 Literature Review provides a summary of the literature relevant to the dissertation topics of medical anthropology, social support and breast cancer and is divided into four prospective sections. Section 1 of Chapter 2 begins with a discussion of medical anthropology’s contribution to our understanding of the cancer experience. Many of the themes that emerge illustrate the gap between biomedical discourse and the patients’ lived experiences and suffering. Subsequently, anthropological perspectives on the study of cancer among Hispanics are presented. This is followed by section 2 that includes a description of the guiding theoretical framework used for this dissertation. Section 3 of the literature review concentrates on social support as it relates to cancer survival and psychological adaptation. This is followed by a description of cross-cultural perceptions of social support. Thereafter, the literature on social support and immigration is discussed. Next, studies that explore social support among Latinas within the health context are examined. Section 4 of this chapter provides a summary of the epidemiology of breast cancer. It describes the detection, prognosis, and treatment of breast cancer. Subsequently, trends in the incidence, mortality, and prevalence of breast cancer are discussed. This is followed by a discussion of breast cancer risk
factors. Finally, a brief summary is provided with special attention given to the current gaps in the epidemiological data.

Chapter 3 Methodology details the research methodology. This chapter begins by describing the recruitment of study participants and inclusion criteria. This is followed by an overview of the research design. The qualitative and quantitative data collection techniques used in this study are discussed in detail. The mixed methods include participant observation, key informant interviews with support and health providers, in-depth interviews and structured interviews with Latin American immigrants diagnosed with breast cancer. Participant observation processes are presented first followed by a description of the sampling techniques, data collection, and data analysis processes for each method. The last part of this chapter includes informed consent.

Chapter 4 Results presents the research findings. This chapter is divided into three sections. The first section describes the research setting and provides a brief demographic overview of the Hispanic population in West Central Florida and Latin American immigrant women. This section also includes a discussion of the research experience. Section 2 contains the results from the key informant and in-depth interviews. The data describe the sociocultural context of the breast cancer and provides an emic perspective of social support. Section 3 illustrates the results from the structured questionnaires. Findings identify the cultural and structural factors that influence social support.

Chapter 5 Discussion begins with a review of the hypotheses. Thereafter, the research findings are thematically discussed. Discussions of the findings are presented in the following order, key informant, and in-depth interview, followed by structured questionnaire. Then findings are related back to the literature. This is followed by the description of study strengths and limitations of this study.
Chapter 6 Recommendations and Conclusion provides an overview and summary of research findings. Then, suggestions for future research are discussed. Recommendations for community-based organizations, clinical practice, and psycho-oncology are provided. This is followed by a description of how the information and knowledge gained through this research was applied at the local level. Finally, the anthropological underpinnings of this study as well as this study’s contributions to anthropology are discussed.

**Summary: situating the research**

For the last few years I have intimately worked with a grassroots community-based organization that serves Latina breast cancer survivors in the Tampa Bay area (See Chapter 3 Setting). My first hand experience with the vital role social support plays in the recovery process and the stress and personal struggles many of the women have encountered has fueled my interest in the topic of stress and social support. The knowledge and insights I have gained through these experiences have guided my choice in dissertation topic and informed the research questions. While this dissertation provides an anthropological analysis of social support among Latina breast cancer survivors it also provides an in-depth and intimate understanding of the lived experience and personal struggles Latinas face in dealing with and overcoming this disease. Included in this dissertation are personal stories of survival and resiliency that are powerful and emotionally evocative.

In summary, although breast cancer occurs in the context of individual experience, to understand it fully requires linking such experiences with in a system of social relations and social change. Further, by examining women’s position in the social fabric and cultural expectations that may render them more vulnerable to economic and
family stressors during cancer treatment, we have a better understanding of Latina cancer survivors’ support needs.
Chapter 2: Literature Review

Introduction

This chapter includes a review of the pertinent literature divided into four sections. Section 1 examines the contributions of medical anthropology toward our understanding of the cancer experience and provides an overview of conceptual frameworks that have guided anthropological research on cancer. Special attention is given to the work of Chavez, Hunt, Erwin and other anthropologists who have specifically studied cancer among Hispanics. Section 2 examines the guiding theoretical framework of critical biocultural anthropology. This is followed by the description of a conceptual model of social support that includes how structural conditions influence the psychobiological processes by which social integration and support affects health. Section 3 examines the social support literature as it relates to cancer outcomes and describes the relationship between social support, health and disease. A review of cross-cultural studies of social support is provided with special attention to the literature on the influence of migration on social support. Section 4 provides an overview breast cancer which includes a description of the diagnosis, prognosis and treatment of breast cancer as well as disease-related risk factors.

Section 1: Medical anthropology’s contribution to our understanding of cancer

Medical anthropology is concerned with the cultural, social and biological factors that contribute to health and disease (Castro & Farmer 2007; Whiteford & Bennett 2005). It is a discipline that centers on anthropology’s holistic perspective which considers the larger social and cultural context (Whiteford & Bennett 2005). Medical anthropologists have explored the understanding and negotiating power between the physician and the

**Anthropological relevance: Theoretical and methodological contributions**

Various theoretical and conceptual frameworks have been employed by anthropologists to better our understanding of the cancer experience. Early on medical anthropology adopted a more hermeneutic approach, while in recent years there has been a gradual shift to more critical perspectives. Anthropology’s contribution to the field of cancer has been especially dominant in the area of cultural models of disease (Adler 1999; Chavez et al 1993b; Coreil & Behal 1999; Coreil et al 2004; Gregg & Curry 1994; Hunt 1993; Mathews et al 1994b) and in describing ideas about cancer and its prevention to help explain participation in screening and prevention programs (Bailey et al 2000; Chavez et al 1995; Chrisman et al 1999; Erwin et al 1999; Erwin et al 1996).

Cultural anthropologists have studied the cancer experience primarily through the examination of the discourse of cancer and through the lens of interpretive anthropology.
(Del Vecchio Good et al 1994; Gifford 1986; Gordon 1990; Langellier & Sullivan 1998; Manderson 1999a; b). Much of this research employs the cultural hermeneutic approach put forth by Good and Del Vecchio Good (1981) and has tended to focus on a particular theme (e.g., metaphors used to describe cancer). Some studies used illness narratives to examine the cultural construction and meaning of cancer (Del Vecchio Good et al 1994; Gifford 1986; Gordon & Paci 1997; Hunter 2004; Mathews et al 1994a).

Another area of anthropological interest stems from the anthropology of the body, or the embodiment of cancer (Boonmongkon et al 1999; Gifford 1986; 1994; Lock 1998; Saillant 1990). This research has also illuminates cultural models of cancer and their relations to medical practice, political power and gender relations (Gifford 1986; Gregg & Curry 1994; Lock 1998; Manderson 1999a; Weiss 1997). Much of this literature has been influenced by the seminal work of Sontag (1978), which provides the earliest semantic exploration into the popular knowledge of cancer and the body (Saillant 1990: 82).

More recently, medical anthropologists have examined the political structure of health and medical practice using the case study of cancer. Studies by Balshem, Kaufert, Anglin and Weiss have helped contextualize the experience of cancer within the political economic structures using examples from the US and Israel (Anglin 1997; Balshem 1990; 1991; 1995; Kaufert 1998; Weiss 1997). Chavez (1995) and Hunt (2002) also address the influence of structural factors (e.g., limited resources, lack of health insurance, limited health care access) on cancer related behaviors and beliefs among Hispanics.

Medical anthropologists have contributed much to our understanding of the cancer experience. However, most studies have either focused on an interpretive, hermeneutic approach or on a structural/political economic perspective. Few have used
an integrative approach (Hahn 1995) that embraces both an individual’s personal experience and the structural/ political economic processes that both shape, and are shaped by, the individual experience (Gifford 1994). Thus, this dissertation research seeks to add to this literature and use an integrative approach to contextualize the breast cancer experience of Latina immigrants and understand how cultural and structural factors combine to shape social support. In the following paragraphs, anthropology’s contributions to our understanding of cancer are briefly discussed in more detail.

**Narratives**

Anthropologists use narratives to contextualize and understand the meaning of disease and illness - this has contributed to our understanding of the individual illness experience. According to Mathews (1994), narratives provide an important window into the process involved when individuals attempt to adapt personal experience to pre-existing cultural models, modifying such models in light of new information and content conflicts in their own interpretation and meaning of illness. Through this approach, important metaphors used by cancer survivors in conceptualizing and understanding breast cancer (Mathews 2000) have been illuminated. Metaphors are an important part of the social construction of the body, healthy or ill (Scheper-Hughes & Lock 1987). Metaphors describing images of cancer are found throughout cancer and illness narratives and studies about people’s understanding of their illness experiences (e.g., (Ashing et al 2003; Gordon et al 1991; Hunt 1994; Langellier & Sullivan 1998; Weiss 1998).

**Understanding of culture**

The cancer experience cannot easily be separated from its cultural context. While many domains relating to the cancer experience are universal, e.g.,
communication, spirituality or decision-making patterns, people experience them differently depending on their “worldview” (Kagawa-Singer et al 1997). Thus, clinical realities are culturally constituted and vary cross-culturally and across the domains of health care. One of the most important contributions medical anthropologists have made to the field of cancer is that culture matters, that culture is adaptive and dynamic. Kagawa-Singer notes that in the medical and public health literature “cultural factors are probably the least understood and most misused of all the influencing factors in health care …commonly in cancer studies, lifestyle, ethnicity, culture and race are used synonymously” (Kagawa-Singer 1995b: 113). Furthermore, Hunt states that “problems of unequal access to health posed by more material barriers, such as insurance, transportation, education, and language are pushed from the foreground, and ethnic culture is made culpable for health inequalities” (Hunt et al 2004: 982). In this respect, culture can be equated with social injustice and poverty as the cause of health disparities (Freeman 2003). DiGiacomo (1999) states that one of the assumptions made in this arena is that the values, beliefs, or attitudes of a particular group, identified in ethnic, class or behavioral terms, are reified, and classified as homogeneous and represented as problematic, and more often than not are characterized as a “risk factors” (DiGiacomo 1999: 7). It is also important to recall that the explanations developed to account for disease are not static; they evolve and are reinterpreted as new information is presented and evaluated (Harris et al 2003b: 911).

The value of community perspectives

Anthropologists have long been interested in community organization and community development (Chrisman et al 1999). Anthropologists have emphasized the importance and value of gaining an insider’s view and of involving the community in the design and implementation of cancer prevention and education programs (Chrisman et
al 1999; Erwin 2002; Gregg 2000; Strickland et al 1996; Strickland et al 1999). These contributions have also informed our understanding of cancer from a holistic, cross-cultural perspective to enable the design of more culturally relevant interventions that build on the strengths and assets of the community and the issues that are important and meaningful to them.

**Culture of biomedicine**

Anthropologists have contributed to our understanding of and acknowledgment of the culture of biomedicine and how power is negotiated and contested within this culture. The negotiation of power has been described in various cultures and settings between physicians, patients, community and medical systems (Good 1995; Good et al 1990). Kleinman describes health care systems as forms of social reality, in which everyday life is enacted, social roles are defined and performed and in which people negotiate with each other the established status relationships under a system of cultural rules (Kleinman 1995). Anthropologists have also examined how physicians working in the cancer arena maintain their position of authority (Anglin 1998; Gordon & Paci 1997; Lock 1998; McMullin et al 2002; McMullin et al 1996) and how they communicate the diagnosis and prognosis of cancer through non-disclosure and truth telling cultural practices (Bennett 1999; Gordon 1990; Harris et al 2003b; Kaufert 1999; Long & Long 1982).

Medical anthropologists who have studied biomedicine as a cultural system have explored how biomedicine is socially, culturally, and historically constructed (Anglin 1997; Balshem 1999; Digiacomo 2003; Good et al 1990; Kaufert 1998). Biomedicine reflects the worldview of western industrialized societies, in which emphasis is placed on the individual and where facts and truth are guided by science and technology (Baer & Nichols 1998). According to Moore, in no arena has the scientific and objective paradigm
of biomedicine gained more primacy than in the area of breast cancer research (Moore 1999). Biomedicine views illness as a biological entity (Gregg & Curry 1994). Under the biomedical rubric, health professionals (e.g., oncologists) tend to separate the body and the mind and exclude the human/illness experience (Kleinman & Kleinman 1991). In contrast, anthropologists who have explored cancer have focused on the illness experience and acknowledge the difference between illness, disease and sickness (Hahn & Harris 1999).

**Anthropological perspectives on the study of cancer among Hispanics**

The anthropological literature on the topic of cancer among Hispanics/Latinos in the United States is primarily comprised of the work done by Leo Chavez and colleagues (Chavez et al 1993a; Chavez et al 1995; Chavez et al 1993b; Chavez et al 1997a; b; Chavez et al 2001; Hubbell et al 1996a; Hubbell et al 1996b; Hubbell et al 1997) Linda Hunt (Hunt 1993; Hunt 1994; Hunt 1998) and more recently Debbie Erwin (Erwin et al 2005; Erwin et al 2007). To briefly summarize Hunt (Hunt 1993; Hunt 1994; Hunt 1998) explored the meaning of cancer and the causal explanations of patients and oncologists in Santo Domingo, Mexico using in-depth interviews and participant observation. While, Chavez et al. (Chavez et al 1993a; Chavez et al 1995; Chavez et al 1993b; Chavez et al 1997a; b; Chavez et al 2001) used a combination of ethnographic and survey research techniques and cultural consensus analysis to examine the influence of cultural beliefs about breast and cervical cancer risk and the use of cancer screening tests (pap smears and mammograms) among Latina immigrants (Mexican and Salvadorian), US born Chicanas, and European American women in Los Angeles, California. More recently, other anthropologists have explored and written about this topic (Hunter 2004) and (Weiner 1999), who includes a couple chapters on Hispanics and cancer in an edited volume on cross-cultural cancer perspectives). The majority of this work focuses on
breast and female reproductive cancers. Hunt’s study in Mexico and Hunter’s work in Peru provides an international perspective, while Chavez’s study in Orange, County California provides national/local cross-cultural perspective. Hunt interviewed patients who had been diagnosed with cancer, while Chavez et al. interviewed women who had not been diagnosed with cancer and were part of the general population. Erwin’s work has focused on tailoring a breast and cervical cancer prevention education intervention modeled after the Witness Project® among Latinas (Erwin et al 2005; Erwin et al 2007).

Kleinman’s exploratory models of illness have conceptually guided most of the published anthropological studies on the topic of cancer and Hispanics (Chavez et al 1993a; Chavez et al 1995; Chavez et al 1993b; Chavez et al 1997a; b; Chavez et al 2001; Hunt 1993; Hunt 1994; Hunt 1998). Explanatory models of illness, as described by Kleinman (1978), have been used to gain a better understanding of the individual’s understanding of the cause of illness, symptoms, pathophysiology, severity and sick role, and treatment (Kleinman et al 1978). According to Young, Kleinman’s exploratory models are similar to Geertz’s belief that cultures provide people with ways of thinking that are models of reality (Young 1980).

Latinas’ views of cancer causality and risk are derived from a subjective, lived experience, which is concerned with cultural norms and social order (Gifford 1986). They explain and interpret breast and cervical cancer within the context of social relationships (Martinez et al 1997) and their everyday lives. Hispanic/Latina beliefs about cancer causality can be classified along two broad themes: 1) beliefs related to immoral or improper behavior that emphasized lifestyle/personal choices often related to sexuality and 2) reproductive behaviors and beliefs related to heredity and other biomedical factors (Chavez et al 1993a; Chavez et al 1995; Chavez et al 1993b; Chavez et al 1997a; Chavez et al 2001; Erwin et al 2005; Hunt 1993; Hunt 1994; Hunt 1998).
Particular emphasis is placed on the following: physical trauma and/or personal aggression (Chavez et al. 1993a; Chavez et al. 1993b; Goldman & Risica 2004; Hunt 1994; Hunt 1998; Martinez et al 1997); failure to reproduce or excessive reproduction (Hunt 1998); husband infidelity and promiscuity (Hubbell et al. 1996b; Hunt 1998); heavy work (Hunt 1993; 1998); lack of prenatal care and improper breast feeding (Chavez et al. 1995; Hunt 1993; Hunt 1994); and lack of medical attention (Chavez et al. 1995; Chavez et al. 2001).

Both Chavez and Hunt report integration or blending of both traditional and biomedical models of cancer (Chavez et al. 1995; Chavez et al. 2001; Hunt 1994). Traditional illness models are incorporated with biomedical models because they address specific emotional, psychological, social and political economic issues important to the patient’s experience of illness (Hunt 1993; 1998). Hunt found that even though patients receiving biomedical treatment for cancer relied primarily on biomedicine for diagnosis and treatment, their illness explanations showed that they often incorporated traditional illness concepts of witchcraft or susto into the biomedically based explanatory models of cancer. For example, when asked about what might have caused a particular type of cancer, respondents mentioned conventional concepts such as heredity or physiology. But when she asked "why do you think this particular person got sick," respondents gave answers that had a moral tone and spoke of flawed behavior, interpersonal aggression and reproductive related behaviors (Hunt 1998 p. 301).

Chavez (1995) identifies a two separate causality models for breast cancer: a lay Latina model and a biomedical model. Further he reports Chicanas (US born Latinas) had a biocultural view of cancer in which they exhibited beliefs shared by both Latina immigrants and European American women that blended both traditional and biomedical beliefs about cancer. Baer et al. (2008) posit that these models can more accurately be
described not as distinct models but as a continuum (Baer et al 2008). Chavez et al. (2001) also contend that Latina immigrants arriving in the US have to negotiate their cultural knowledge about disease and prevention they arrive with, with the predominant cultural knowledge and physicians’ knowledge of disease (2001). The blending of biomedical and traditional/indigenous beliefs about cancer has also been reported among other ethnic groups (Gregg & Curry 1994; Mathews et al 1994b).

Both Chavez and Hunt explored physician beliefs about cancer. Hunt found that Mexican physicians also emphasized behavior that was deemed improper or immoral as the ultimate cause of the illness (Hunt 1998). Class issues also emerged, with physicians placing additional blame on lower-class patients who were diagnosed at a later stage of disease for not seeking care earlier when the disease was more treatable. Similarly, Martinez, Chavez and Hubbell (1997) also found that physicians in Orange County, California sometimes crossed the boundary into a moral interpretation of sex-based risks in cervical cancer. For example, the use of value laden terms like “promiscuous” or “promiscuity” to define risk behaviors related to cervical cancer among Hispanic/Latina women were often used (Martinez et al 1997).

All patients have culturally embedded ideas about why they become sick. However, these ideas may differ greatly from biomedical etiologies, especially in the case of recent immigrants (Eisenbruch & Handelman 1990: 1295). Immigrant women from Latin America bring with them a set of general cultural beliefs about gender relations, patriarchy, sexuality and morality (Dorrington 1995, Hondagneu-Sotelo 1994, Martinez, Chavez and Hubbell 1997) that can be traced back to the historical and social context of Spanish colonization of Latin American and the Caribbean are pervasive enough that they provide an important framework for understanding Latina’s beliefs about cancer. Chavez (2001), found that the main differences between Latinas,
European American and physicians in their study were primarily driven by immigration. In other words, Latina immigrants, who were from Mexico and El Salvador, often had different beliefs about breast cancer than US bornLatinas and European-American women (Chavez et al 1993b; Hubbell et al 1996a; Hubbell et al 1997). Regardless of country of origin, Latina immigrants shared many more beliefs about breast cancer than their American-born Latina counterparts. In addition, Hubbell, Chavez, Shiraz, Mishra and Valdez (1996) found beliefs that reflect a moral framework were more prevalent among Latina immigrants than they were among US born Latinas. Chavez and Hubbell also report that Latina immigrants were more likely than U.S. born Latinas or European American women to have fatalistic beliefs.

**Hispanic cultural beliefs: Looking beyond fatalism**

The literature on Hispanic beliefs about cancer is growing in the wider public health arena. Most of the non-anthropological literature on the influence of Hispanic/Latino culture on cancer beliefs has characterized culture in the following ways: 1) culture is seen as knowledge and this knowledge is interpreted negatively; 2) cancer researchers use culture to explain the existence of "misconceptions"; and 3) through broader cultural themes like *familismo*, *fatalism*, *respeto*, *simpatia*, *personalismo*, *collectivism* etc. (Chavez et al 1995). Chavez laments "Culture is rarely examined "as part of a coherent system of beliefs" (Chavez et al 1995: 43). For example, Perez-Stable states, Latinos are more likely than Anglos to believe that having cancer is like getting a death sentence, and that they would prefer not to know if they had incurable cancer or that 'destiny cannot be changed' (Perez-Stable et al 1992). The authors di not elaborate any further.

According to Hunt (Hunt et al 2004) public health efforts to objectively model cultural influences on health tend to operationalize ethnic culture as a level of
acculturation, which is usually measured with acculturation scales commonly used in Hispanic or Latino health studies (p. 974). In a systematic literature review on the use of acculturation in Hispanic health studies, she found that most of the studies reviewed consistently characterized Hispanic culture either as a “source of dysfunction” or as a “therapeutic panacea” (p. 980). According to Hunt (Hunt et al 2004), in this model culture is “understood as ‘primitive’ and natural, either disruptive and degenerate, or pristine and harmonious, but always instinctive and inherent rather than rational and intentional” (Lucas & Barrett 1995).

Two themes that often emerge in the Hispanic literature on cancer are “fatalism” (Chavez et al 1997a) and “misconceptions” (Perez-Stable et al 1992). Fatalism is described as “a general outlook on life founded on the beliefs that life events are inevitable and that one’s destiny is not in one’s own hands” (Davison, Frankel and Smith 1992 cited in Chavez and Hubbell 1997). According to Balshem, by labeling beliefs as fatalistic, there is no need to look further into the community’s or individual’s etiology - they are dismissed as illogical or misconceptions (1991). The process of medicalization makes the health beliefs that are incongruent with the biomedical model the “material for the construction of a negative other and are part of what makes the ‘hard to reach’ population inscrutable” (1991 p. 164). This is often seen in the public health/medical literature related to Hispanic’s cancer beliefs where this population is presented as being noncompliant and fatalistic, where researchers deemed to place an overemphasis on either faith or folk models of illness that are “incorrect”. For the most part, these arguments are informed by the cultural, symbolic and political context of biomedicine that has served to disconnect health professionals from understanding these patients’ realities and everyday lives (Moore 1999).
Even though Chavez states that cultural beliefs such as “fatalism” were used in the 1950’s and 1960’s as a simple way of explaining health behavior by blaming the victim (2001), he co-authors an article titled “The Influence of Fatalism on Self-Reported Use of Papanicolaou Smears” in a medical journal. To examine fatalistic beliefs, the authors asked a series of questions. For example, they asked the interviewees if they agreed with the following statements: “Having cancer is like a death sentence” and “There is very little I can do to prevent cervical cancer.” They conclude that “fatalistic beliefs are among the factors that negatively influence Latinas’ use of Pap smears and that it is important for health care professionals to address those beliefs” (1997 p. 418). This article does not frame the women’s responses within the larger social context. Perhaps, because of their life experience with cancer e.g., everyone they ever knew of who had cancer in their own country died, or they lacked the resources to get proper treatment and follow-up care. It made complete sense for them to see cancer “fatalistically.” However, simply recommending that “it is important for health professionals to address those beliefs” does little, and if anything contributes to the construction of the “negative other” (Balshem 1991). In this article, Chavez et al. fail to address the social context and shared cultural understandings that inform such beliefs. As Mathews et al. eloquently state, “…efforts to eradicate "fatalism" by providing them with educational materials obviates the need for professionals to understand patients’ beliefs within the broader social context” (Mathews et al 1994a).

Of the anthropological studies on Hispanics/Latinos and cancer, none have examined Hispanic women’s cancer experience after cancer diagnosis in the United States. The work by Chavez et al. (1995) primarily focuses on cancer prevention; the authors interviewed healthy women about their cancer beliefs and use of cancer screening programs. While Hunt addressed issues related to diagnosis and treatment
among women in Mexico, her findings may not be generalizable to Latina women living in the United States who are undergoing, or have undergone, cancer treatment as the health care infrastructure here is different and the immigration process undoubtedly will influence their cancer experience (Hunt 1993; Hunt 1994).

In the public health arena, there have been an increasing number of published studies on Hispanic/Latinas and life after cancer focusing on diagnosis, treatment and survivorship, but, very few have included an anthropological perspective. In addition, although the literature on Hispanics/Latinos and cancer is increasing, it is surprisingly small compared to the literature published on cancer in other ethnic groups such as African Americans. In summary, anthropological research has a role to play across the cancer continuum, from prevention to survivorship and palliative care and can great contribute to our understanding of cancer (Manderson 1999b: 317).

Section 2: Theoretical framework: Critical biocultural anthropology

Medical anthropology has sought to integrate the biological and physiological with the cultural (Whiteford & Bennett 2005). Studies based on a biocultural framework build on tenets of human biology, political economy and medical ecology. They include social, cultural and/or behavioral variables in the study design (Goodman & Leatherman 2001; McElroy & Townsend 1996; Singer 2007) and offer valuable models for studying the interface between physiological, psychological and cultural factors that have an effect on human well-being (Baer 1996; Singer 2007). The strength of this approach is its potential for holism and integration. It establishes a context for human action (agency) within the interaction of biological, physical, and social environments (Leatherman 1996).

Adaptation has been a core feature of the biocultural framework and has also been a concept that has caused much debate in medical anthropology (Singer 2001a; b; Wiley 1993). Medical anthropologists have extended this concept to behavioral and
cultural domains. McElroy and Townsend define adaptation as changes or modifications that enable a person or group to survive in a given environment, which includes both the social and physical environment (McElroy & Townsend 1996). Furthermore, they identify four types of adaptive mechanisms: genetic change, physiological and developmental adjustments, cultural responses, and individual coping (McElroy 1990 p. 249).

Components of this model are appropriate for organizing data on human responses to disease (e.g., breast cancer), disability, loss, and life transition and include a range of cultural, social, cognitive, hormonal, and immunologic systems (ibid). However, the medical ecology model proposed by McElroy has been criticized for overlooking the political economic aspects that influence health and disease (Brown et al 1996). Thomas (2001) states that the expanded scope of human adaptability “attempts to understand the dynamics of how people adjust to constraints around them using their biology, behavior, social organization, and ideology…” (Thomas 2001: 70). Singer goes on to say that we need to develop a dialectical, biocultural anthropology that incorporates political economy and that “adaptations” might be better analyzed as social adjustments to oppressive sociopolitical relationships (Singer 2001a: 115) that include the analysis of how processes of inequality and social change interact with human biology (Goodman & Leatherman 2001).

According to Goodman and Leatherman, the political economic perspective brings the following contributions to biocultural anthropology: 1) the examination of social relations, which are essential to resource production and distribution, and points to the need to look at social processes; 2) the importance of the links between the local and global; 3) that history is critical to understanding the direction of social change; 4) that humans are active agents in constructing their environments; and 5) ideology and
knowledge of researchers and study participants are key to understanding human action (Goodman & Leatherman 2001).

A biocultural model is helpful for organizing factors related to health and disease, especially among immigrant populations (Janes & Pawson 1986). Janes, who has examined the social consequences of migration and the mediating role of social support, posits that this model embraces both the local cultural system of which that individual is a member and the wider social environment in which they live (Janes 1990). In addition, a critical biocultural framework allows one to address the coping responses of human agents (Leatherman 1996). Further, this is a fitting approach since the researcher is interested in: 1) immigrant women’s health (specifically from Latin America and the Spanish-speaking Caribbean) within the context of the US health care system, specifically oncology; 2) the impact of migration on women’s social support networks and how these changes may or may not influence their well-being, quality of life and adjustment to breast cancer; and 3) how the social support resources used by Latinas can serve to mediate some of the structural factors that affect access to information, access to care and ultimately survival.

**Contextualizing social support**

Researchers in anthropology, psycho-oncology, sociology, social epidemiology, and psychology have explored how social support, social integration and social relationships influence health and disease. Social relationships and coping resources influence both psychological and physical health (Berkman & Glass 2000c; Berkman et al 2000; Cohen 2004b; Cohen & Syme 1985b; Wortman & Conway 1985). Several anthropologists have examined the concept of social support from an ecological, biocultural perspective (Berges et al 2006; Dressler 1991; 1992; 1998; 2004; Dressler et
Dressler states that social support systems are highly variable across cultures. In Mexico he found that for men the strongest effect of social support on blood pressure was for the level of perceived support from compadres, and for women it was the level of perceived support from family members (Dressler 1996). In a southern African American community in the United States, the most important forms of social support were organized within the context of intracultural diversity. Older individuals saw extended kin as the most important source of social support, while younger individuals saw non-kin systems of social support as most relevant (Dressler 1985; 1993). In St. Lucia, Dressler observed social support systems developed through the household unit (Dressler 1984). The cultural construction of access to social support in relation to blood pressure and psychological distress was investigated by Dressler in Brazil (Dressler et al 1997; Dressler et al 1996). Janes’ study of Samoans who had migrated to California during the time period of the 1960’s to the 1980’s presents the following social organization of support. He found that Samoans extended kin group is a vital source of mutual support (Janes 1990). Kagawa-Singer observed differences in the support systems used by Asian and Euro-American women diagnosed with cancer. Japanese Americans provided more tangible support than emotional support, the networks were significantly smaller, and the members of the networks primarily consisted of immediate, female family members (Kagawa-Singer et al 1997).

Jacobson states that the study of social support opens a window into the structures of meaning that constitute culture (Jacobson 1987). In most studies of social support there is little consideration given to the ways in which appropriate social relationships are socially and culturally constructed and to the ways in which
sociocultural systems may construct choice in social relationships (Dressler 1996). According to Dressler, many of the studies on social support and health are based on a narrowly focused model that is mainly concerned with the amount and quantity of social support.

What is missing from current formulations regarding social support is the recognition that within specific societies the sorts of emotional and instrumental transactions that make up social support are not appropriate for just any category of social relationship. Rather different kinds of relationships are culturally defined as having different kinds of reciprocal rights and obligations. To seek supportive transactions outside of the relationship is to transgress cultural norms, which in turn may interfere with the social and psychological processes that are conducive to better health” (Dressler et al 1997: 306).

Further, Janes and Dressler discuss resistance resources, which include social support and personal coping resources (Dressler 1996; Dressler et al 1997; Janes 1990). Dressler has attempted to understand the coping styles and emotional health among African Americans in the Southern United States. He posits stress is a result of an individual being faced with environmental demands and having few resources to cope with those demands. Resistance resources include extended kin and friends, churches, clubs, personal self-reliance, and an active coping style rather than passive responses. People with low resistance resources are more likely to experience health problems (Dressler & Bindon 2000). From a biocultural perspective, resistance resources consist of those factors or processes that facilitate the fit of humans to their social environment or in a psychological sense assist with tension management (Janes 1990 p. 130).

**Social environment, social relationships and health**

Cohen differentiate studies that examine the structural measures of social support (i.e., describing the existence or quantity of relationships) and functional measures of social support that assess whether interpersonal relationships serve particular functions (e.g., describing kinds of support - provide affection, feelings of belonging or material aid) (Cohen 2004a). Social integration is a multidimensional
construct defined as participation in a broad range of social relationships that include active engagement in a variety of social activities or relationships, identification with one’s social roles and a sense of communality (Brissette et al 2002). This concept stems from Durkheim’s influential work on suicide and social conditions. Theoretically, the sense of social solidarity, mutual support and aid within a social group, is an essential aspect of social interaction that contributes to better functioning and health (Dressler 1996). Cohen (2004) states that social integration influences one’s sense of self and that role concepts are shared among a group of people, and I would argue are guided by cultural norms and values that provide a common set of expectations about how people should act in different roles. In meeting these role expectations, individuals develop a sense of predictability, stability, identity, purpose, belonging, and self worth (Berkman et al 2000; Cohen 2004b; Thoits 1986). Further, Berkman and Glass (2000) hypothesize that social integration or connectedness has been a strong predictor of mortality because these ties give meaning to an individual’s life by virtue of enabling him/her to participate in it fully - to be obligated and connected to one’s community (p. 147).

Figure 2.1. Conceptual Model of Social Environment and Social Support

![Figure 2.1. Conceptual Model of Social Environment and Social Support](image)

Adapted from Berkman and Glass 2000:.143
Berkman and Glass (2000) illustrate a conceptual model of how social relationships influence health. They begin with broader macro level conditions and end with the psychobiological processes by which social integration affects health (Figure 2.1). The model proposed by Berman and Glass embeds social networks and social support within the larger social and cultural context in which macro social forces related to political economy mediate opportunities for social support. This framework enables researchers to examine how culture, social change, migration, and urbanization affect the structure of social networks and social support (Berkman and Glass 2000 p. 144).

Cohen and Syme (1985) argued for a contextual understanding of social support and suggested that the social environment in which support occurs substantially influences the nature of support and its effects on health (Dressler et al 1986). This perspective is holistic and integrative in that it focuses on the process and cultural context of health and disease, while addressing the larger social environment. This model fits in with the tenets of a political-economic biocultural anthropology.

**Stress and social support**

The influence of social and cultural stressors on health is ultimately dependant on the psychological and social resources individuals possess that enable them to cope (Janes 1990). The most widely used stress-related model of social support is the buffering model (Lehto-Jarnstedt et al 2004). According to the model, social support is beneficial because it decreases the negative effects of stress on both physical and mental health (Cohen 2004a; Cohen et al 2000; Cohen & Syme 1985b) and serves as an intervening variable that modify the health outcomes of exposure to a variety of stressors. According to Uchino (2004), this model suggests that life events (e.g., migration, cancer diagnosis) and daily challenges ultimately have their influence on well-being by what is called the appraisal process (pg. 36). This is a psychological process in
which information from the environment is processed in reference to our perceived coping abilities (Turner-Cobb et al 2004; Uchino 2004). The stress buffering model of social support posits that even when an individual is faced with an extremely stressful event, having individuals who can provide a person with support can help reduce the intensity of the stress response and facilitate coping over the long term (Cohen & Syme 1985b).

Chronic stressors are challenges, problems and difficulties people encounter in their daily life (Israel et al 2002; Schulz et al 2001). Chronic stress is the result of sociocultural and structural pressures or stressors that are imposed on individuals on an ongoing bases (McElroy & Townsend 1996). Janes’ found that social inconsistency, the inability to meet behavioral or social expectations associated with status, were sociocultural stressors for Samoan migrants in California (Janes 1990). Examples of structural stressors include poverty, lack of insurance, employment, and finances. Stress is an individual’s response to any kind of challenge whether positive (e.g. moving to a new country) or negative (e.g., cancer diagnosis) and how an individual copes and adapts to the situation (Israel et al 2002).

An adequate model of the relationship between stress, social support and well-being must consider individual differences in need or desire such support, as well as the social and environmental context in which support is perceived, mobilized, given, and taken (Cohen & Syme 1985b). The emphasis is on the buffering model, in which support serves as a resource in response to stressful events (Berkman & Glass 2000c; Cohen 2004b; Cohen & Syme 1985b; Dressler 1996). The stress-buffering model asserts that social connections benefit health by providing material and psychological resources necessary to cope with stress (e.g., diagnosis of cancer is a stressful event). Additionally, this model of social support predicts that social support is beneficial for
those suffering adversity, but does not play as significant a role for those without highly stressful demands (Cohen 2004b). Thomas (2001) states special attention should be given to the efficacy of social support systems in buffering the effects of psychological stress and disease. This is especially relevant to studies of social support among the poor and underserved who may be the most vulnerable to political economic stressors. Further, by examining how social support may shift from facilitating adjustment to the system to reformation and transformation may provide insights into health by combining ethnomedical and biomedical perspectives (Thomas 2001: 69).

**Social support, health and disease**

The majority of the research on the topic of social support and cancer-related health outcomes stems from the area of psycho-oncology. The concept of social support is multifaceted and relates to many aspects of cancer survivorship (e.g., adjustment, well-being and other cancer-related health outcomes).

Social support is a multidimensional construct and is transactional in nature, involving both giving and receiving guided by cultural norms of interdependence, solidarity and reciprocity (Berkman & Glass 2000b). It is a mediating pathway by which networks might influence health status (Berkman & Glass 2000c; Berkman et al 2000). Social support is typically divided into subtypes that include: 1) emotional (love, caring, sympathy, understanding), 2) instrumental (help, aid, assistance with tangible needs), 3) appraisal (help in decision making), and 4) informational support (provision of information or advice) (Berkman & Glass 2000c; Bloom et al 2001; Cohen 2004a).

Definitions of emotional support are broad; the most frequently cited type of support is the individual's ability to confide in other members of their social network about health related problems (Bloom et al 2001; Helgeson 2003). Appraisal support has been defined as an agreement with ideas or feedback that leads to self validation
Instrumental support is generally defined as assistance with material or financial aid, tasks, goods and services (Berkman & Glass 2000c; Bloom et al 2004; Bloom et al 2001), being able to call on someone for assistance (Koopman et al 1998) and assisting with chores and other household tasks (Gotay & Wilson 1998; Lugton 1997). Informational support is less frequently studied than the other types of support (Helgeson 2003). When this type of support has been studied, the researchers usually focused on information available from formal educational programs, health professionals, and/or support groups (Cope 1995; Coreil et al 2004; Samarel et al 1998b; Samarel et al 2002).

Social support is transactional in nature, involving both giving and receiving guided by cultural norms of interdependence, solidarity and reciprocity (Berkman and Glass 2000 citing George 1986). According to Cohen and Syme, determinants of the availability of support include community size and resources, socioeconomic status, customs, cultural norms, values and beliefs about when it is appropriate to ask others for help (1985). Results from studies in the area of cardiovascular disease, stroke and other chronic conditions suggest that social support may have the greatest impact on determining the prognosis and survival of disease, not the onset (Berkman and Glass 2000).

The strongest associations between social support (particularly emotional support) and a health outcome are seen in relation to psychological well-being (Cohen 2000; Uchino 2004). Many believe that the perception of the availability of support is more important than its actual use (Cohen 2004a; Cohen & Syme 1985b). Perceived social support leads individuals to believe they are cared for and that they belong to a network of mutual obligation (Sammarco 2001a; b). The feeling of being supported
comes from the sense that one’s individual suffering and pain are important to someone whom the cancer survivor sees as central to their support network (Spencer et al 1999).

Section 3: Social support and breast cancer: Survival and psychosocial adaptation

In the next few paragraphs, the concept of social support as it relates to cancer survival and psychological adaptation is discussed. Social isolation increases mortality risk from cancer (Fawzy et al 1993; Funch & Marshall 1983; Spiegel 1993). Several studies have illustrated the importance of social support in the length of survival from cancer (Ell et al 1992; Kelly 1998; Maunsell et al 1995; Spiegel 2001; 2002). Researchers have reported that a higher level of social support or social integration is associated with better survival outcomes among women diagnosed with breast cancer (Kroenke et al 2006; Maunsell et al 1995; Reynolds & Kaplan 1990). Women diagnosed with breast cancer and living beyond initial treatment continue to experience physical and emotional symptoms. Information and support needs persist well past the initial diagnosis (Cappiello et al 2007). Instrumental support after a breast cancer diagnosis may assist women by taking them to doctor appointments, nutrition and mobility, thus protecting against disability (Kroenke et al 2006). On the other hand emotional support may reduce stress, which might improve immunosurveillance against cancer recurrence (Turner-Cobb et al 2000). Thus, some research suggests that emotional support be more critical for breast cancer survival than emotional support. Following treatment women have reported having less social support from family, friends and providers; however, the need for resources and support through the transition to survivorship may be just as critical as during the initial diagnosis and treatment (Davis et al 2004; Ganz et al 2004; Institute of Medicine 2006; Lethborg et al 2003). The literature states that long
term cancer survivors continue to have physical and psychosocial support needs years after treatment (Institute of Medicine 2006).

A study of stressful life events, social integration and survival from breast cancer found that stressful life events were associated with lower rates of survival and social integration was associated with higher survival rates (Funch & Marshall 1983). One study that examined the relationship between social support and cancer incidence, mortality and prognosis during a 17 year follow-up period found that socially isolated women had a considerably elevated risk of dying from cancer (Reynolds & Kaplan 1990). Interestingly, a similar study (Ell et al 1992) compared survival among women who had been diagnosed with either breast, colorectal or lung cancer. They found that marital status and perceived adequacy of emotional support approach significance (p=.08) only for those diagnosed with breast cancer, and only with breast cancer was social support a protective factor predicting survival (p.535). However, it is important to note that some studies that have explored this relationship have been inconclusive (Blanchard et al 1995). Cassileth, reported no relationship between social integration and survival, or time to recurrence of disease among patients with advanced-stage cancer and concluded that the inherent biology of the disease alone determines the outcome (Cassileth et al 1985).

During the last two decades, much attention has been paid to the psychological well-being of cancer survivors (Ashing-Giwa et al 2004a; Ashing-Giwa et al 2004b). Numerous studies report the beneficial impact of social support on women’s psychological well-being and coping ability through every stage of breast cancer illness - from diagnosis to treatment and beyond (Hoskins et al 1996; Lugton 1997; Maunsell et al 1995).

The negative aspects of social support on women diagnosed with cancer are discussed less frequently (Schroevers et al 2003). As an example, a negative impact can occur when there is a mismatch between desired support and support that is received (e.g., when friends and neighbors withdraw from contact) (Reynolds & Perrin 2004). Researchers should understand that intended support may be perceived as helpful by some and negative by others. For example, in a study of breast cancer patients (Peters-Golden 1982) researchers found that approximately 75% of the participants agreed that people treated them differently after learning they had cancer, and of these 72% reported that they were misunderstood by others and over 50% felt they were being avoided or feared. Another example of a negative impact is when there is a perceived lack of social support that is expected (this would only be substantively
different from the first case if it isn’t the support itself that is lacking, but the perception thereof). This was illustrated in a study by Landmark (2002) in which participants reported that the perceived lack of social support from the hospital where they received their cancer treatment was a huge strain and psychological burden to them (Landmark & Wahl 2002).

Changes in social support after the diagnosis of cancer have also been noted (Davis et al 2004). Researchers have found an increasing need of social support over time since diagnosis among breast cancer survivors, thus implying the need for support lasts well beyond the initial acute period of diagnosis and treatment (Hoskins et al 1996). However, several studies report that the frequency of social support since time of diagnosis actually decreases over time since diagnosis - creating a possible disconnect between support needed and support received (Bloom et al 2004; Courtens et al 1996; Neuling & Winefield 1988).

**Multicultural perceptions of social support**

The benefits of social support as a resource for people with cancer have been investigated, as described previously; however, most of the studies conducted among women diagnosed with breast cancer on the topic of social support have tended to focus on Euro-American women (Ashing-Giwa et al 2004b; Makabe & Hull 2000). In recent years, few researchers have explored, in-depth, the concept and use of social support among diverse ethnic groups (Ashing-Giwa et al 2004b; Hamilton & Sandelowski 2004b; Kagawa-Singer & Wellisch 2003; Makabe & Hull 2000; Moore 1999; Moore 2001; Wellisch et al 1999). Interestingly, when African American patients, for example, have been included in research, the discovery of lower amounts of social support have lead investigators to conclude that African Americans are socially isolated and lack social support (Rodrigue 1997). Similar conclusions have been made about social support

Culture affects the social support experiences of patients with cancer (Ashing-Giwa et al 2004b; Aziz & Rowland 2002; Erwin et al 2007; Hamilton & Sandelowski 2004b; Kagawa-Singer & Wellisch 2003; Makabe & Hull 2000; Moore 1999; Moore 2001; Wellisch et al 1999). However, according to Hamilton and Sandelowski, most studies of social support do not clearly address whether lower amounts of social support actually result from a lack of resources or if it is the failure of researchers to identify them due to cultural differences in social support that might not fit the biomedical paradigm (Hamilton & Sandelowski 2004a). Interestingly, non-verbal support, as described by Kagawa-Singer (1997; 2003) and Hamilton et al. (2004), is rarely considered and most social support questionnaires do not ask about this type of support (Wellisch 1999). This omission may be due to the fact that in biomedical and mainstream American culture much more value is placed in verbal communication than in non-verbal communication.

Another form of support not usually addressed in the literature is the use of distracting activities as a type of social support (Moore 1999). Hamilton et al. (2004) found that participants felt supported when their social networks provided opportunities for distraction. Thoits has argued that behaviors used to assist individuals to change the meaning of stressful situations are forms of social support. In addition, offers of prayers and assistance to maintain valued social roles in the family and in the church are rarely discussed. Another form of support left out of most of the literature on social support and breast cancer is the influence of the church and offering of prayer as a form of instrumental support (Thoits 1986; 1995). Hamilton et al. (2004) found that among the African American participants in their study the most frequent type of emotional support
was the presence of others, which was described as the non-verbal expression of love and caring.

We need to expand our understanding of the types of emotional and informational support used by ethnic, minority groups who may have fewer opportunities to interact or access health care professionals and may rely more on informal networks (Burhansstipanov et al 1998; Guidry et al 1997a; Hamilton & Sandelowski 2004b).

Learning about and understanding the informal networks and types of support used by members of these groups can be an invaluable tool for developing interventions that build on the strength and support resources of these communities (Gotay & Wilson 1998).

**Immigration, social support and health**

Studies on the health advantages of foreign-born Hispanics/Latinos have suggested that one of the favorable health advantage of the foreign-born is the cultural value that emphasize family cohesion and social support (Palloni & Arias 2004; Zambrana et al 1997). Suarez, suggests that family members and friends often encourage health promoting behaviors (Suarez 1994) that the social support provided by family reduces stress (Landale & Oropesa 2001; Vega & Amaro 1994).

Studies have found that chronic disease mortality patterns for immigrants and the US-born vary considerably and in many cases are more favorable for immigrants (Singh and Miller 2004). For example, Singh and Miller (2004) relay that black male and female immigrants had a least a 35% lower total cancer mortality than US Born blacks. They suggest one of the reasons for this may be that immigrants may have a higher level of social support and social integration compared to the US Born (p.17). Some have suggested that high levels of social support among Mexican immigrants in the United States has in part contributed to their favorable health status (Finch & Vega 2003).
Assessing the meaning of support for those who experience it is also important if we want to better understand its protective function, especially for immigrants (Simich 2003).

In contrast, other scholars have argued that the process of migration disrupts social ties (Portes 1998), which are rebuilt only after an extensive period of time of residence in the destination area (Goodwin et al 1991). This disruption weakens social support, causing immigrants to lose a major source of social capital, the network of social relations that entail reciprocal commitment, social support, and social control (Zhou 1997). Within this rubric, migration has a negative impact on psychological and social functioning (deSnyder 1996) that involves major changes in the physical, cultural and social context within which individuals and families have learned to function and cope with illness and disease (Ebaugh & Curry 2000; Hanline & Daley 1992; Kramer et al 1999; McNeece et al 2002).

Immigration is a major life event (Alegria et al 2004; Foroughi et al 2001; Janes 1990). It is a process that may bring particular stresses that may influence peoples social support resources and social environment (Zuniga et al 1999) and its effects can persist for years after migration (Dressler 1996; Goodwin et al 1991). Several scholars have explored the concept of social support among immigrant populations (Holroyd et al 2001; Katapodi et al 2002; Landale & Oropesa 2001; Markovic et al 2002; Matsudaira 2003; Meana et al 2001; Neufeld et al 2002; Simich et al 2003) and suggest that the disruption of social ties associated with immigration can remove culturally expected sources of assistance and diminish available social support (Neufeld et al 2002; Suarez-Orozco & Palaez 2002; Triandis 1995). The immigration experience typically implies that some family and friends will be left behind in the country of origin (Berry 1997; Neufeld et
al 2002; Suarez-Orozco & Pañez 2002; Triandis 1995), thus the separation from family and friends ruptures the support system many immigrants were accustomed to.

Due to language, culture and economic issues, immigrants will often find themselves without the social support and networks that had enabled them to cope and function (Zuniga 2002) and isolation may become an issue, especially for those who may have already suffered familial, resource, and network loss (ibid). Similarly, researchers in psycho-oncology have reported changes in the social support systems of women diagnosed with breast cancer, where changes in appearance and decreased physical and social functioning may affect their ability to carry out social roles and responsibilities, which may lead to changes often resulting in decreased social support (e.g., friends and family withdraw) and increased isolation (Landmark et al 2002; Luoma & Hakamies-Blomqvist 2004; Manne et al 2004; Michael et al 2002). Furthermore, gender role is of special importance, because it dictates the kinds of support deemed appropriate (Kagawa-Singer & Wellisch 2003; Kagawa-Singer et al 1997; Moore 2001). For example, in a study comparing social support among Asian and Euro-American women, researchers found that cultural beliefs regarding family role and women’s roles affected social support (Wellisch et al 1999).

Although migration challenges people’s adaptive capacity, its impact on health is a product not only of those stressors resulting from these experiences but also of the contingencies surrounding them (Simich et al 2003). Social support from family and like ethnic community members is one of the most powerful of these contingencies (ibid). Living close to others from your own country or of the same ethnicity also provides a supportive social environment (Zuniga 2002). Often members of such ethnic communities serve as cultural brokers sharing their experiences and providing information about available resources, provide linkages to social activities, religious
organizations, and local health care providers. Family, extended family, and ethnic communities provide immigrants with significant social supports, both emotionally and economically (Kramer et al 1999; Vega & Amaro 1994; Zambrana et al 1997). The use of these informal and formal networks is crucial, and for many immigrants they serve as a screening and referral agent for community resources and health care related services (Neufeld et al 2002). Reports indicate that informal social networks offer vital assistance to Latinos who are coping with stressful situations (Guidry et al 1997a; Kramer et al 1999) and that Latino immigrants are more vulnerable to stress precisely because they may lack extended-family supports (Gomez et al 2004; Sluzki 1992; Suarez-Orozco & Palaæz 2002).

**Social support and Latinas within the health context**

Several researchers have examined the role and use of social support and social networks among Hispanic/Latina women within the health context, (AbraidoLanza et al 1996; Alferi et al 2001; Cortina 2004; Martinez-Schallmoser et al 2003; Scarinci et al 2003; Suarez et al 2000). From this literature the following themes emerge; 1) differences in social support are related to language (Spanish vs. English) (Katapodi et al 2002; Martinez-Schallmoser et al 2003), and to acculturation/length of time in the US (Finch et al 2003; Flaskerud & Uman 1996; Hovey et al 2000; Smart & Smart 1995), and 2) there are cultural and social norms guiding support interactions that mediate the buffering effects of social support (Abraido-Lanza 2004a; Abraido-Lanza et al 2005; Abraido-Lanza et al 1996; Alferi et al 2001; Cortina 2004; Gotay & Wilson 1998; Suarez et al 2000). Interestingly, both Alfreri et al (2001) and Suarez (1994) found that although family has been identified as a key resource of support for Hispanics their study findings did not fit this picture. Katapodi et al (2002), examined women’s reported social support and their adherence to cancer screening guidelines. Overall foreign-born Latinas
reported significantly lower mean social support scores compared with the Euro-American and African American women in the study. Interestingly, the Latina women born in the United States had a significantly higher social support score compared to those that were foreign-born. Also mean social support scores differed significantly by spoken language, those who answered the survey in Spanish had lower scores (Katapodi et al 2002). Latina immigrants may be more comfortable with accessing coping resources that are more compatible with their cultural belief system (Kramer et al 1999).

Abriado-Lanza (1996) investigated psychosocial adjustment to chronic disease in among Latinas with arthritis. Her findings reflect social and cultural norms related to available and appropriate types of support, where tangible support was related to less psychological distress and emotional support predicted greater psychological well-being. Qualitative data revealed that women expressed ambivalent or negative feelings about receiving housework support, which they identified as being integral to their role as homemakers. Reports indicate that informal social networks offer vital assistance to Latinos who are coping with stressful situations (Guidry et al 1997b) and that Latino immigrants are more vulnerable to stress precisely because they may lack extended-family supports (Camino 1994).

Past research suggest that support-provider characteristics also influence social support perceptions and access (Hoskins et al 1996; Thoits 1986). Thoits states that empathetic understanding is one of the components of social support and those individuals who share sociocultural characteristics with the person in need of social support are better able to empathize and therefore offer more effective and appropriate support (Thoits 1995). Cortina (2004) suggests that Hispanic women are most likely to
perceive supportive social relations from family and close friends, who often share their background (Cortina 2004).

In summary, determinants of the availability of support include community size and resources, socioeconomic status, customs, cultural norms, values and beliefs about when it is appropriate to ask others for help (Cohen & Syme 1985a). Culture influences individual health and lifestyle behaviors, family, structure and social networks (Dressler et al 1997; Dressler & Bindon 1997; Palloni & Arias 2004). Culture also shapes the nature of the social environment and operates through norms and beliefs about family relationships and obligations. Such norms and beliefs may influence the propensity to live alone of or in extended families, the density of social networks, and the amount of social support exchanged (Palloni & Arias 2004).

**Restating research hypothesis**

Thus, personal observations, participant observation and the literature guide the following hypotheses that are tested through the dissertation research:

**H1. Cultural expectations about gender roles will influence social support:**

H1.a., Compared to women, a higher proportion of men will likely provide instrumental/tangible support, and a higher proportion of women will likely provide emotional support, compared to men.

H1.b., Cultural expectations that women should not burden family and friends with personal concerns/worries will negatively influence social support.

H1.c, Cultural expectations to be strong (aguantar/tolerant) will negatively influence social support.

**H2. Language (English proficiency) will be positively associated with social support.**

H2.a, Women with limited English proficiency will be less likely to have informational support than those that who are English proficient.

**H3. Chronic stress (poverty, family problems, economic/financial problems, immigration status) will be negatively associated with social support.**
H4. Length of time in the United States will influence social support.

H4.a., Women who have been in the US a shorter period of time will likely rely on family and friends in their native county for emotional support.

H4.b., Women who have been in the US for a shorter period of time will likely have less informational support than those who have resided here longer.

Figure 2.2 illustrates the conceptual model of social support I propose to explore through the dissertation research. Cultural beliefs and expectations, length of time in the US, English proficiency and chronic stress are explored in relation to social support. The dotted lines represent expected associations. It is also noted that the influence of these variables on social support and the individual (micro) with breast cancer occur within a larger context that includes structural forces (macro) and social environment.

Figure 2.2 Conceptual Model Immigration Experience and Social Support

Adopted from McElroy & Jezewski, 2000
Section 4: Breast cancer

This section provides a brief review of the epidemiology of breast cancer and is used to describe the diagnosis and treatment process and situate the disease experience within the biomedical context. The first part of this section describes the disease of breast cancer (screening and detection; diagnosis, staging and prognosis; and treatment). Second, trends in the incidence, mortality and prevalence of breast cancer are discussed. Breast cancer risk factors are discussed in part three, and factors associated with poorer survival are delineated in part four. Finally, a summary is provided with special attention given to the current gaps in the epidemiological data.

Breast cancer is the most common type of cancer diagnosed in women in the United States (American Cancer Society 2003). While most breast tumors are benign, breast cancer is the uncontrolled growth of malignant breast tissue/cells. In situ cancer in the breast occur when the malignant cells are within the milk ducts, ductal carcinoma in situ, or glands, lobular carcinoma in situ, where the cancer is localized - it has not spread or invaded other parts of the breast. These cancers are most often detected through mammograms, since most are too small to be felt. If left untreated, ductal carcinoma in situ may grow and become an invasive cancer with the potential to spread to other parts of the body (Berkow 1997). Lobular carcinoma in situ usually occurs in women experiencing menopause. There is a high risk it will develop in both breasts, therefore both breasts are treated.

Cancer becomes invasive when the cancer breaks through the wall of the ducts or glands. Invasive cancers can be localized, i.e., confined to the breast, or metastatic, where it spreads to other parts of the body. The most common type is ductal carcinoma, which occurs in about 75% of the women with invasive cancers (Olivotto et al 2001). Lobular carcinomas, which account for 15% of invasive cases, are estrogen receptor
positive, which means they are likely to respond to hormonal treatments (Love & Lindsey 2000). Inflammatory carcinomas are much less common. The breast becomes swollen and the skin turns red. It is an aggressive cancer that usually spreads to the lymph nodes.

**Detection, prognosis and treatment**

The first stage of cancer is when the tumor is small and most treatable. Usually, the first sign of possible breast cancer is a lump or a change in the breast(s) (e.g., changes in shape/swelling, puckering/dimpling of the skin that does not go away, and/or scaly skin around the nipple). In more than 80% of breast cancer cases, the woman finds the lump herself (Berkow et al 1997). The size of the cancer can vary. Screening is especially important because early stage breast cancer exhibits few symptoms. The earlier the cancer is detected, the less radical the treatment and the better chances for survival (Love & Lindsey 2000). Currently, there are three screening techniques for detecting breast cancer: breast self exams (BSE), breast clinical exams (BCE) and mammography.

When a potentially cancerous lump is found, a biopsy is performed. Then, if cancerous cells are found, more tests are performed to determine the characteristics of the cancerous tumor (e.g., size, type, grade - degree of aggressiveness, biomarkers, growth rate, estrogen and progesterone receptors and lymph nodes affected). The characteristics affect prognosis and determine the treatment (e.g., surgery, radiation, chemotherapy, etc.) the woman will receive. There are three general types of breast cancer surgery: lumpectomy and quadrantectomy, which are breast-conserving, and mastectomy, which removes the entire breast. Breast-conserving surgery attempts to leave as much of the breast as possible, only removing the tumor and a small amount of surrounding tissue. The major reason for having breast-conserving surgery is cosmetic -
to preserve body image. However, the treated breast often shrinks and may change in contour (Love & Lindsey 2000). In a simple mastectomy, the entire breast is removed; however, the muscle beneath is left intact. The lymph nodes may be removed to determine if the cancer has spread, this procedure is called node dissection/sentinel node biopsy. In a radical mastectomy, in addition to the breast tissue, the underlying chest muscle, some nerves, the skin, and all of the lymph nodes in the armpit are removed (NationalCancerInstitute 2003). Survival rates for women who have an entire breast removed and for those who have breast conserving therapy followed by radiation therapy appear to be similar for at least 20 years following the surgery (Berkow et al 1997).

Breast reconstruction is an option for some women; this is dependant on the women’s desire/ beliefs about reconstructive surgery, the type of surgery (e.g., simple vs. radical mastectomy), the extent of deformity, her financial status, and/or insurance status/policy (Martinez 2004). There are several techniques that can be used; for example, silicone or saline implants, tissue expanders or tissue taken from another part of the body (Le et al 2005). If reconstructive surgery is not a viable option, breast prostheses, which can be inserted into a special bra, are available and can be obtained through various cancer organizations.

Supplemental treatments are administered as a preventive measure after surgery. This is called adjuvant therapy, which includes radiation therapy, chemotherapy, and/or hormone therapy. Depending upon the cancer characteristics (e.g., stage, growth rate, etc.), a combination of treatments may also be administered. For advanced or high risk cancers, chemotherapy and/radiation is sometimes administered before surgery to reduce the size of the tumor.
Radiation therapy uses high energy rays to kill cancer cells. Without radiation therapy, the likelihood of developing cancer in the same breast is as high as 40% over 10 years (Olivotto et al 2001). Radiation treatment is administered over a period of time. Treatments are usually given daily, for example, Monday through Friday for the duration of the treatment which can range from weeks to months. Which may pose a burden to those who have difficulty with transportation (e.g., they do not drive or don not have someone to take them to/from the treatment facility). Radiation therapy may also be used to improve the quality of life of patients who have recurrent cancer or suffer symptoms from metastasized cancer. However, there are side effects to consider. The skin around the treated area becomes pinkish red, like a sun burn and sometimes peels after radiation therapy. Additional side effects include breast firmness, where the treated breast can become enlarged, tender and heavy with fluids. This can last 6-18 months post treatment (Love & Lindsey 2000) and/or the women may have feelings of sharp electric shocks and fleeting pain that result from damaged nerves. Red ‘burst blood vessels’ may also appear 18-24 months after treatment (Olivotto & Levine 2001). Other major side effects are tiredness, fatigue during treatment and depression (Love & Lindsey 2000). Other organs and parts of the body are also affected by radiation therapy, including the heart and lungs. The lungs may become inflamed a few weeks to several months after the treatment is complete; this condition is called radiation pneumonitis. Some studies have shown that women who receive radiation on the left-sided breast have an increased chance of developing heart disease (ibid). If the lymph nodes near the collar bone are treated, the throat may feel scratchy. There may also be scarring under the arm and on the chest wall.

Chemotherapy and hormonal therapy are systemic treatments that affect the whole body and travel through the blood stream (NationalCancerInstitute 2003). The
agents used in chemotherapy target the cell division/reproduction processes. Unfortunately, this treatment is not selective and attacks all cells that are rapidly dividing, including hair and bone marrow cells in addition to cancer cells. Treatment with several chemotherapy agents given together are sometimes better at preventing recurrences and are more effective than one agent alone (Berkow et al 1997). Chemotherapy drugs may be given intravenously or orally. The duration of the treatment regimen can last from three to six months. It may take several hours to administer the chemotherapy intravenously. During each session, the patient can spend up to 6-8 hours at the treatment facility. Each treatment is followed by a rest period, which allows the maximum cancer killing effects of the chemical agents to work while permitting the body’s blood cell count to return to normal (usually a 21 day period) (Olivotto & Levine 2001).

Chemotherapy has severe side effects which vary according to the agents used. Hair loss (over the entire body), nausea, loss of appetite, and vomiting are common side effects. According to (Olivotto et al 2001), hair loss is one of the most upsetting side effects because it is a public symbol that the woman has cancer (2001:178). Because many chemotherapy drugs reduce white blood cell counts, patients undergoing treatment are more susceptible to infections. Additional side effects include anemia, abnormal bleeding and bruising, diarrhea and constipation, joint and muscle aches and pains, loss of muscle strength, and sore mouth (mucositis). Chemotherapy also disrupts menstruation. It may bring early and abrupt menopause in women due to the effects it has on the ovaries, which will impact fertility (Love & Lindsey 2000). Sexual side effects include: decreased libido due to stress, hormones, self-confidence, and body image; vaginal dryness; and infections. There are also cognitive side effects such as temporary memory loss and depression.
Hormone therapies are generally easier to take and have fewer side effects (Cancer. 1996). Hormone blocking drugs interfere with hormones that support cancer cell growth and are usually started right after surgery and are continued for months or years. These treatments are designed to reduce the level of female hormones (e.g., estrogen and progesterone) in the body and can include the use of drugs (e.g., tamoxifen) and/or removal of the ovaries (through surgery or radiation). The side effects of hormone therapy depend on the drug, dose and treatment duration. They may include hot flashes, vaginal discharge, weight gain, facial hair, headaches, fatigue, and hypercalcemia (increased calcium levels in the blood) (Love & Lindsey 2000).

Complementary and alternative therapies are also used to complement regular treatments. These include diet, vitamins, herbs/teas, meditation and visualization, spiritual healing, prayer, acupuncture, homeopathy, and bioelectromagnetics. There is agreement as to what constitutes optimal breast cancer treatment and follow-up care. The two areas where consensus is greatest are, 1) the use of radiation therapy following breast conserving surgery or a total mastectomy for early stage cancer (Li et al 2002; 2003b) and 2) the use of adjuvant chemotherapy for lymph node positive breast cancer (AmericanCancerSociety 2003).

**Breast cancer trends: An epidemiologic overview**

Breast cancer incidence and mortality vary widely among women of different racial/ethnic backgrounds (Moore 1999) and are mediated by individual experience of health and illness, gender, class, culture and socioeconomic status. In the next few sections, Hispanic/Latina breast cancer incidence, mortality, survival rates and cancer-related behaviors will be compared with those of non-Hispanic Americans (Figure 2.3). Overall, Hispanics have lower cancer incidence and mortality from the four major cancers, including breast cancer; however, they have higher incidence and mortality
from cancers in which infectious agents play a significant etiologic role (e.g., cervical cancer) (American Cancer Society 2007; Huerta 2003b).

Incidence and mortality rates from breast cancer are generally lower among Hispanic women compared to white and African American women (See Figure 2.3). The average annual age-adjusted incidence rates from 2000-2004 were 132.5/100,000 among white women, 118.3/100,000 among African Americans, 89/100,000 among Asian/Pacific Islanders, 89.3/100,000 among Hispanics, and 69.8/100,000 in Native American/Alaska Natives (American Cancer Society 2007).

Figure 2.3. Breast Cancer Incidence and Mortality

![Female Breast Cancer Incidence and Mortality Rates by Race and Ethnicity, US, 2000-2004](image)


There has been a steady increase in the incidence of breast cancer in the United States since the 1940’s (Wingo et al 1998) due to changes in women’s lifestyles (e.g., nutrition) and reproductive patterns (e.g., menstruation at an early age, having fewer children and at a later age). The changes in reproductive patterns increase the exposure
of the breast to estrogens that are associated with cancer (American Cancer Society 2007). In addition, advances in early detection and the use of mammography have also influenced the increased number of new cases diagnosed since the 1980's. From 1975 to 2000, the greatest increase in invasive cancers was seen in women 50 years of age and older. For the same period, the incidence in ductal carcinoma in situ breast cancers increased five times faster than the rates for invasive cancers. This increase is a direct result of mammography's ability to detect cancer at an early stage of development (ibid).

Breast cancer is the leading cause of cancer deaths in Hispanic women - compared to white non-Hispanic women for whom lung cancer is the most common (O'Brien et al 2003). According to the American Cancer society, breast cancer death rates have declined in recent years. The biggest decrease occurred in women below the age of 50 (3.7% per year from 1991-2000). For women 50 years of age and older, the decrease was more subtle (2.0% per year from 1991-2000) (AmericanCancerSociety 2003). The decrease in breast cancer death rates can be attributed to advancements in treatment and early detection. However, African American women and women from other ethnic groups have benefited less from the decrease in breast cancer. Among Hispanic women, breast cancer mortality rates dropped 1.8% from 1992 to 1999, a smaller decrease than the one seen in white non-Hispanic women - 2.6% (O'Brien et al 2003). Among African American and Asian and Pacific Islanders, death rates dropped 1.1% per year from 1992-2000 (AmericanCancerSociety 2003).

Survival is the best indicator for progress in cancer treatment (Pecorelli et al 2003). Increases in breast cancer survival are the result of earlier diagnoses through increased screening, more effective treatment, prevention of cancer recurrence and of secondary diseases, and decrease in mortality form other causes (MMWR June 25, 2004). Survival after breast cancer recurrence has also improved, suggesting that new
therapies are helping women with recurrent cancer live longer; however, rates have improved more slowly for non-white populations (Giordano 2003). It is important to note that higher survival rates do not necessarily result in lower mortality rates, living longer with cancer might reflect an earlier diagnosis rather than an improved outcome (Li et al 2003b; MMWR June 25, 2004).

The relative survival rates for women diagnosed with breast cancer are: 87% at five years after diagnosis, 77% after 10 years, 63% after 15 years, and 52% after 20 years (AmericanCancerSociety 2003). However, it is lower for women diagnosed at younger ages, perhaps due to having more aggressive cancers and poorer response to hormonal treatments (Boyapati et al 2004; Boyer-Chammard et al 1999; Love & Lindsey 2000).

Differences in survival patterns exist between racial/ethnic groups (Boyer-Chammard et al 1999; Haynes 1999; Joslyn 2002). African American, Hispanic, and American Indian women are more likely to be diagnosed with advanced-stage breast cancer and to have poorer outcomes after diagnosis compared to non-Hispanic whites (Li et al 2003b). Several studies have reported lower survival rates for Hispanics and African Americans/Blacks compared to non-Hispanic whites (Joslyn 2002; O'Malley et al 2003a; O'Malley et al 2003b).

Breast cancer risk and factors associated with poorer survival

Breast cancer is a complex, multifactorial disease where there is a strong interplay among genetic/biological, environmental and lifestyle factors (Gerber et al 2003; Martin & Weber 2000). In recent years, the largest increases in breast cancer have been seen among women with the lowest risk, which has lead researchers to investigate changes in reproductive patterns, lifestyle and nutrition (Bernstein 2002).
In addition to being female, age is the strongest risk factor for developing breast cancer (NationalCancerInstitute 2003). For example, women who are 50 years of age have double the risk of developing breast cancer than women who are 40, and the risk doubles again at age 70 (Olivotto et al 2001). Genetics and certain hormone levels (e.g., estrogens) are also strong risk factors. A previous diagnosis of breast cancer, a family history of breast cancer (a first degree relative, e.g., mother, sister and/or daughter) and being a carrier of the BRCA1 and 2 gene (American Cancer Society 2007; Love & Lindsey 2000; Martin & Weber 2000) are also strong risk factors. Moderate risk factors include later pregnancy (after age 30), previous non-cancerous breast disease, and post-menopausal obesity. Weak risk factors include hormone replacement therapy, menstruation before 12 years of age, diet (e.g., more than 1 alcoholic drink a day and high fat intake), and body weight (e.g., obesity) as well as environmental factors such as radiation exposure (Kelsey et al 1993; Olivotto & Levine 2001).

Significant differences in have been reported across racial/ethnic groups at diagnosis, stage at diagnosis, histology and treatment (Boyer-Chammard et al 1999; Hausauer et al 2007), which may contribute to the survival disparities that exist between whites and other ethnic groups (American Cancer Society 2007; Joslyn 2002).

Advanced-stage cancer diagnosis (Stage III or IV) is one of the key factors associated with lower breast cancer survival and mortality rates (Boyer-Chammard et al 1999; Ghafoor et al 2003; Hausauer et al 2007). Multiple factors, ranging from biologic (at the cellular and molecular level), sociocultural and behavioral (beliefs, screening practices), to structural (access to care and socioeconomic status), are associated with later-stage diagnosis in multicultural populations (Hunter 2000). Women diagnosed with cancer from low-income backgrounds are more likely to be diagnosed at a later stage of the disease and are more likely to have lower 5-year survival rates than are women of
higher socioeconomic status (Baquet & Commiskey 2000; Miller et al 2002; O’Malley et al 2003b).

Several studies have explored factors related to late-stage diagnosis in multicultural populations. Lannin, Mathews, Mitchell, Swanson, Swanson, and Edwards (1998) examined the influence of cultural factors and socioeconomic status in racial differences in breast cancer stage at diagnosis in a matched case control study (Lannin et al 1998). They found that lacking transportation, having no private health insurance, being Black/African American, having lower income, and never having been married were 2.0-3.7 times more likely to be predictive of late-stage diagnosis. Certain cultural and psychological factors were also found to be predictive of late stage diagnosis; these include perceptions that the air causes cancer to spread, the devil causes cancer, that having breast surgery makes women less attractive, and that chiropractics are an effective treatment for breast cancer. Women with these perceptions were 1.9-2.8 times more likely to be diagnosed with advanced cancer. Combined socioeconomic and cultural belief factors largely accounted for the effects of race on late-stage diagnosis, illustrating that socioeconomic factors alone do not account for all differences in stage at diagnosis.

Access to medical care is an important factor contributing to stage and survival differences among multicultural populations (Hunter 2000). Lack of health insurance is associated with lower survival rates and less access to optimal breast cancer treatment (Baquet & Commiskey 2000; Haynes 1999; Richardson 2004a; Richardson 2004b). Women at risk for being undertreated include women from lower socioeconomic backgrounds and women without health insurance or those insured by Medicaid (Richardson 2004b). According to Bickell and Chassin (2000), women with no insurance or with Medicaid insurance were at higher risk of not receiving radiation therapy after
breast conserving surgery or not receiving adjuvant chemotherapy and were less likely
to receive these treatments than were women with private insurance (Bickell et al 2000).
In addition to health insurance, having a usual provider of care increases access to
cancer treatment (Breen et al 1999).

Studies have shown that younger women diagnosed with breast cancer tend to have poorer prognosis than older women regardless of race/ethnicity (Boyer-Chammard et al. 1999). Hispanics and African Americans appear to be diagnosed at a younger age than white women are (Bentley et al 1998; Wojcik et al 2003; Zaloznik 1997). The presence of the cancer at an earlier age would indicate that it is a more aggressive form of cancer (Hunter 2000). Similarly, Boyer-Chammard et al (1999) found that non-Hispanic whites were diagnosed with breast cancer at a significantly older age than were the other racial/ethnic groups in their study. The median age at diagnosis for non-Hispanic white women was 64 years of age, compared to 55 years of age in Hispanic, 52 years in African American/Black and 50 years in Asian women. In the study, more Hispanics and African American/Blacks than non-Hispanic whites were diagnosed under the age of 50. The researchers state that this can be explained by differences in the age distribution of selected racial/ethnic populations. There are smaller proportions of African American and Hispanic populations older than 70 years of age and they have a younger median age. Also, older African American and Hispanic women may be less likely than younger African Americans and Hispanics, who are at higher risk, to seek medical care (Boyer-Chammard et al 1999).

According to Hunter 2000, a number of studies suggest that certain tumors may have a more aggressive phenotype and show changes in the distribution of tumor markers in some population subgroups (Hunter 2000). Differences in tumor marker expressions could explain some of the differences, as African American and Hispanic
women are more likely to have tumors that are hormone receptor negative as well as other biologic characteristics that are known to have a poorer prognosis (Elledge et al 1994). Some researchers suggest that cancer tumors in African American/Black women are known to be more aggressive and have certain tumor characteristics that have less favorable outcomes (Trock 1996). Chen, Correa, Kurman, Wu, Eley, Austin et al. (1994) conducted a hospital-based study to evaluate tumor characteristics in African American and white women diagnosed with breast cancer(Chen et al 1994). They report that African Americans were more likely to have a poorly differentiated tumor, high grade nuclear atypia, tumors that are estrogen receptor negative, and other biomarker characteristics associated with a poorer prognosis when adjusting for tumor stage, age, geographic location, BMI, SES, reproductive factors, and health care access.

There is evidence that treatment choices may vary by race and ethnicity (Li et al 2003b). A study conducted by Lazovich, Solomon et al. (1999) found that non-white women were less likely to receive breast-conserving therapy (Lazovich et al 1999). Survival differences seen between African American and Hispanic may reflect differences in breast cancer treatment. Boyer-Chammard (1999) reported that African American and Hispanic women received more adjuvant chemotherapy than did whites in their study and suggest this maybe due to African American and Hispanics having more advanced disease and needing more aggressive treatment (Boyer-Chammard et al 1999). They also found that hormonal therapy was prescribed less for African Americans and Hispanics than it was for non-Hispanic whites. This may be due to a higher percentage of African American and Hispanic women having estrogen-receptor-negative (meaning they may not respond to hormonal therapy) breast cancers compared to non-Hispanic whites (Gapstur et al 1996). Another population-based study, examined racial differences in the treatment of women with early-stage breast cancer. The results
indicate that African American women in the study who received breast-conserving therapy were significantly less likely to receive follow-up radiation therapy. Regardless of whether the treatment they received was optimal or sub-optimal, African American women had lower survival rates; however, when both groups received optimal treatments, differences in survival were significantly less (Joslyn 2002). According to Li, Malone and Daling (2003), African American, American Indian and Hispanic women were more likely to have breast cancer surgery not recommended or to refuse surgery, and were also less likely to be treated with radiation than whites. Among women with early-stage breast cancer, African Americans, Asian and Pacific Islanders, Mexicans, and Puerto Ricans were 20% to 50% more likely to receive inappropriate treatment (Li et al 2002; 2003b).

**Summary and gaps in the epidemiologic data**

Overall, Hispanic/Latina women tend to have a more favorable epidemiological outlook. They have lower breast cancer mortality and incidence rates than do white or African American/black women. However, while mortality rates have decreased for Euro-American women, they have increased for Hispanic/Latina women. Hispanic/Latina women, like African American/black women, also tend to be diagnosed with a breast cancer at a more advanced stage, making it more difficult to treat successfully. These differences often reflect socioeconomic differences between groups (Glanz et al 2003) as well as unequal access to quality care (AmericanCancerSociety 2003), patient/physician interactions or knowledge (Li et al 2003b). According to Kagawa-Singer, “the overwhelming importance of socioeconomic factors in explaining racial/ethnic differences in incidence and mortality rates for cancer go beyond variables of personal risk factors or medical care services, and suggest the influence of a broad range of other factors associated with poverty. These include differential exposure to
crowding, inadequate education, unemployment or underemployment, substandard housing, chronic malnutrition, higher smoking rates, psychosocial stress and noxious environmental agents.” (Kagawa-Singer 1995a: 111)

Some of the gaps and issues related to the available epidemiological data on breast cancer among Hispanics relate to the following. First, many studies reporting incidence data rely on Surveillance Epidemiology and End Results (SEER) data. Interestingly, SEER only collects information from 11 states and Florida, one of the states with the highest number of Hispanics/Latinos, is not one of them. So, much of the incidence data reported nationally may not be generalizable to Hispanics in Florida, which I would argue considerably vary in country of origin and other variables (historical, economic, immigration status etc) from Hispanics in California and New Mexico (two of the states included in the SEER registry). Compared to New Mexico and California, Florida has a much larger proportion of Hispanics/Latinos who are foreign born, including those born in Puerto Rico. For example, foreign born Latinos, including persons born in Puerto Rico make up 12% of the Latino/Hispanic population in New Mexico and 33% of the Hispanic/Latino population in California. In contrast, foreign born Latinos/Hispanics, including persons born in Puerto Rico make up 64% of the Latino/Hispanic population in Florida. In addition, New Mexico and California have a much higher proportion of Mexicans, 45% and 78% respectively, compared to Florida where just 13% of the Latino/Hispanic population is Mexican. Puerto Ricans make up 18% of the Latino/Hispanic population in Florida compared to 1% of the Latino/Hispanic population both in New Mexico and California. While Cubans make up 32% of the Latino/Hispanic population in Florida and 1% of the Hispanic/Latino population in California and 0% in New Mexico. Second, there are no standard requirements for reporting race and ethnicity information in cancer registries across states. Though there
has been a general move towards consensus, to date, at least in the state of Florida, there are no standard data collection requirements for race and ethnicity. Each hospital reporting a cancer diagnosis to the state registry has its own race/ethnicity classification system; this could lead to an under representation of the number of cancer cases among Hispanics. Also, less than 50% of the Hispanic cases reported provide information on nationality or country of origin, making it nearly impossible to disaggregate (e.g., Cuban, Mexican, Puerto Rican etc…) cancer incidence and prevalence/survival data from state cancer registries. The case is different for mortality statistics, where nationality/country of origin is recorded, for the most part, on all death certificates and this information is available from the National Center for Health Statistics. This brings us to the third gap/issue, which is that most of the data that are available, both at the state level and nationally, report cancer statistics for all Hispanics as an aggregate group (O'Brien et al 2003), which masks any potential differences in cancer mortality among the diverse groups that fall under the Hispanic label. For example, Martinez-Tyson, et al (2008) provide a population-based overview of cancer mortality among Hispanics in Florida that explored cancer mortality rate differentials between Cubans, Mexicans, Puerto Ricans and all other Hispanics. The authors report cancer death rates of the Hispanic subgroups compared favorably with those of white non-Hispanics and that cancer rates often presented for all Hispanics mask important differences between the different ethnic subgroups that fall under the Hispanic umbrella (Martinez-Tyson et al 2008).

In addition to an epidemiologic overview of breast cancer, this section provides information on the actual disease of breast cancer, its diagnosis and treatment, as well as factors contributing to survival. Perhaps it is more information than needed, but this information is important in order to understand the breadth and impact of what the diagnosis of breast cancer entails (emotionally, physically and mentally) and the many
factors that may contribute to the differences seen between Hispanic women and women from other ethnic groups.

In summary, this chapter provides a review of the literature related to the medical anthropology, social support and breast cancer. The guiding theoretical frameworks of critical biocultural anthropology as well as the stress buffering model of social support were discussed. The following chapter details the research methodology, which includes recruitment of study participants, the research design, sampling strategy, data collection and analysis.
Chapter 3: Methodology

Introduction
This chapter outlines the research methods employed in the current study, analysis and interpretation of research findings. The chapter begins with a description of recruitment of study participants and the inclusion criteria for participation. This is followed by the research design and methodology. The ethnographic approaches used allowed me to assess the socio-cultural factors that may mediate social support among immigrant Latina breast cancer survivors in a contextually based manner, that provides a rich and in-depth understanding of social support.

Recruitment of study participants
Latinas immigrants diagnosed with breast cancer were recruited from the community, local support groups and grass roots organizations that serve this population. Thus, it was a community-based sample. I regularly attended and participated in local activities and got to learn about the women and they in turn got to learn about me. When I had the opportunity I shared my research idea with the Latina immigrant breast cancer survivors I met. The Latina immigrant breast cancer survivors recruited for this study where also asked if they knew other breast cancer survivors who might be interested in participating in this project. I gave everyone a little card with my cell phone number and told the women they could call me anytime (e.g., evening or weekend). The importance of this simple gesture was made clear to me during my first interview, in which the participant said that she followed-up with me because I gave her my personal contact information not some flyer with an office phone number to call. This underscores the importance of building relationships when doing research in the
community, especially when working with vulnerable populations such as possibly undocumented or non English speakers. Establishing trust and building relationship is crucial in community-based research.

Key informants included support group leaders, nurses, educators, and advocates who worked locally with Latinas who had been diagnosed with cancer. Key informants also assisted with recruitment of study participants.

**Inclusion criteria**

The criteria for participant inclusion in the in-depth and structured interview were that the women: a) self-identified as Hispanic/Latina, b) had been diagnosed with breast cancer within the last five years, c) were 18 years of age and older and d) had been born outside the mainland United States (i.e., Latin American immigrant women). The reason for selecting a five year range from diagnosis is because a woman is considered cancer “free” after five years with out a recurrence (Love & Lindsey 2000). Also, the first five years after diagnosis are some of the most psychologically and physically challenging because of the diagnosis it self, the treatments and follow-up care. It has been suggested that this is a particularly stressful time and a crucial adaptation period (Zebrack 2000b), thus a period where social support would be needed the most.

**Research design**

An ethnographic approach that combined both qualitative and quantitative data collection/analysis methods (Bernard 2002) was used. Interviews were situated contextually into a background of several years’ participant observation of various aspects of the Latino community in Tampa, FL, and more recently participant observation of breast cancer awareness activities and work with LUNA, Inc. a Hispanic cancer support group. In phase I, I conducted key informant interviews with individuals who provided cancer care and/or supportive services to Latina cancer survivors and in-
depth interviews with immigrant Latina breast cancer survivors (See Figure 3.1 for an overview).

The first phase laid the groundwork for the second, so that data from the health/support providers, in-depth interviews and free lists informed the development of the structured questionnaire that was administered in Phase II. Within the ethnographic context of this study, combining qualitative and quantitative methods helped address the complexity of domains such as social support in a way that quantitative instruments alone could not, thus integrating epidemiological and anthropological approaches.

Figure 3.1. Overview Diagram

Ethnography is a process based on direct observation in which data are typically gathered and interpreted qualitatively in an attempt to construct a holistic description of a culture or socio-cultural phenomena (Janes 1984). The methods used included participant observation, in-depth interviews and free listing, key informant interviews
and structured interviews. After each data collection phase, data was analyzed to identify patterns, themes and inconsistencies among the data, thus the analysis was iterative (Bernard 2002). Furthermore, the combination of methods allows for data triangulation and provides a richer understanding of the cultural and social context of social support further improving the internal validity of the findings. All participants were informed about the nature of the study that their participation was voluntary and that information will be kept confidential.

**Participant observation**

Participant observation is one of anthropology’s most important research tools. It involves the presence and participation of the researcher in the social life of the people and in the study setting (Hahn 1999). Participant observation enables the researcher to become immersed in the community and build rapport, and trust, enabled a deeper understanding of the breast cancer experience and what it meant to have breast cancer if you did not have family in Florida, did not have insurance or speak English. I attended birthday parties, celebrations, made hospital visits, attended funerals and participated in cancer walks/races. My involvement with local cancer organizations gave me the opportunity to 1) establish rapport with leaders in Latino communities, local cancer organizations, physicians, and Latina support groups; 2) take part in community and cancer-related activities; and 3) gain entry into this community. As a participant observer I continued to participate in such activities. I took field notes on interactions, observations, and informal conversations and specifically focused on the topics/issues discussed by the women, their friends’, family and other activity participants. During the interviews notes on non-verbal cues, voice tone, body language and other nuances were recorded. Participant observation helped contextualize and improved the validity of the
research findings and helped determine additional questions to ask in the open-ended and structured interviews.

**Key Informant interviews (N=5)**

**Sampling techniques: Key informant interviews**

Nonprobability sampling techniques (Bernard 2002) such as purposive and snowball sampling were used to recruit support service providers. Key informants were selected based on their: 1) experience working with Latina cancer patients, 2) knowledge of Hispanic culture, and 3) intimate knowledge of cancer patient needs.

**Data collection: Key informant interviews**

Interviews were conducted with a breast cancer support group leader, an oncology nurse, a community cancer survivor advocate and two social workers from local organizations and hospitals/clinics that work with Latina cancer survivors. The initial interviews were conducted face to face April 2007 through May 2007. The interviews were done at the participant’s office or home. Key informants were consulted over the course of the project and were contacted via phone and email as needed. Key informants served as guides and assisted with recruitment. They also provided feedback and reviewed the structured questionnaire administered in Phase II and were consulted throughout the project. The five key informants interviewed were native Spanish speakers and fluent in both English and Spanish. An interview guide that included open-ended questions regarding the social support services available to and used by Latinas as well as community resources and/or gaps in supportive services/programs and the support needs of Latinas diagnosed with breast cancer was developed. The data collected was used to complete/verify field notes and to inform the questions for the structured interviews and the in-depth interviews. The key informant interviews also provided another point of view that further contextualized the experience of Latina
immigrants diagnosed with breast cancer. See Appendix A for the key informant
interview guide.

**Data analysis: Key informant interviews**

Data from the primary interview were analyzed thematically. A code book based
on the interview guide and research questions was created. The data were sorted,
organized and coded iteratively by hand and response frequencies were calculated.
Field notes taken during conversations with key informants were also reviewed and
coded.

**In-depth interviews and free lists (N=28)**

**Sampling techniques: In-depth interviews:**

Nonprobability sampling techniques (Bernard 2002) such as purposive and
snowball sampling were used to recruit Latin American immigrant women diagnosed
with breast cancer for Phase I of this study. A sample size of 20-30 is usually sufficient
for most domains (Guest et al 2006). The interviews were conducted with a range of
informants in order to capture variation (e.g., range of possible items) and improve
external validity (Bernard 1996; Bernard 2002). The sampling procedures used are
appropriate due to the exploratory and ethnographic nature of this study and are
selected for the following reasons. First, participants needed to have a breast cancer
diagnosis, thus I could not recruit from the general Latina population. Second,
immigration is a sensitive topic and therefore a referral from a trusted source may
reassure the study participant that I am trustworthy. Third, the population parameter of
Latinas who have been diagnosed with breast cancer in West Central Florida is relatively
small. For example, 1,409 Latina women were diagnosed with breast cancer in West
Central Florida compared to 21,403 white/Caucasian women from 2000-2005 (FCDS
2006). Fourth, the state cancer registry does not collect race/ethnicity data from
hospitals/oncologists in a standardized fashion, thus making it difficult to recruit participants from the cancer registry and the data reported for the county where the cancer was diagnosed, not guaranteeing that the individual diagnosed actually lives in that county.

**Data collection: In-depth interviews**

The face-to-face in-depth interviews and freelists were conducted with 28 Latina cancer survivors. The in-depth interviews were completed from April 2007 through October 2007. The interviews ranged from 30 to 150 minutes, with the average interview taking 70 minutes to complete. In-depth interviews were done at the participant's home or at another place (e.g., coffee shop) that was convenient to the participant. The interviews were digitally audio taped with the participants consent. Participants were also asked to complete a brief demographic form. The in-depth interview guide included freelists and open-ended questions about immigration experience, cancer diagnosis and treatment, and social support.

Free lists are often used to identify items in a cultural domain and to calculate each item’s relative cultural salience (i.e., prominence, importance, familiarity, and representativeness) (Bernard 2002; Ryan et al 2000). Free listing is an effective method for defining the contents and boundaries of a cultural domain using the language, concepts, and categories that are meaningful to informants (Gravlee 2005; Ryan et al 2000). For coherent domains, samples of 20–30 informants are generally adequate; additional informants add few new items (Borgatti 1998). The freelisting exercise was conducted at the beginning of each interview. It was used to elicit the types of social support resources that are used and meaningful to Latinas diagnosed with cancer and examine the four types of social support. For example, participants were asked to list all
the ways a person could show someone who was sick or recovering from illness (e.g. breast cancer) that they loved or cared about them (emotional support). Participants were also asked to list all the things a person with breast cancer needed assistance with (Instrumental support). Items that were listed earlier or more frequently were assumed to be more salient in a given domain. I used nonspecific prompting and read back the list of free listed items to participants to elicit the items as completely as possible (Brewer 2002).

The data derived from the in-depth interviews was, in part, used to develop the structured questionnaire administered in Phase II. See Appendix B for the in-depth interview guide. The interview guide was written in Spanish. The open-ended questions allowed unanticipated issues and topics to emerge and yielded an emic perspective on the sources, types, and use of social support. Sample questions included:

- Thinking back to your childhood, what were some of the things you learned about when people were sick or ill?
- How do you usually manage hard times or stressful events in your life?
- Can you tell me in your own words what support means to you? What makes someone supportive?
- What was it like when you came to this country? Who came with you/ who stayed behind?
- What are the things that caused you the most stress during the diagnosis and treatment for breast cancer?
- How did your social relationships change? Did people behave differently towards you?
Tell me about you breast cancer experience? What has been helpful since your diagnosis and why was that important to you? Who or what are the things that have made this process difficult?

Who was/is involved with helping you to manage your breast cancer diagnosis and treatment?

Was there any one you wanted to involve but could not? Why?

The information collected from the interviews provided a rich understanding from an individual perspective (Bernard 2002) and allowed for greater probing of specific experiences or perspectives. Data collection stopped when data saturation was reached (Guest et al 2006). In total, 28 interviews were completed from April 2007 through October 2007. The Interviews were done in person and conducted in Spanish. However, some of the participants interviewed were bilingual and code switching occurred. Where the interview began in Spanish but intermittently we would switch to English and then back to Spanish.

Data analysis: In-depth interviews

I created a code book based on the interview guide and research questions. Then I created a data spread sheet in excel that included both the interview questions and codes. The audio taped data was transcribed in the Spanish into the excel spreadsheet. The data were sorted, organized and coded iteratively by hand. Coding is the identification of recurrent themes and is used to identify common understandings, terminology and/or context of the topic from the interviewee’s point of view (de Alba Garcia et al 2007). Drawing from content analysis techniques the data were analyzed for: 1) frequency (how often the comment--similar comments--was mentioned); 2) extensivity (how many participants made the comment or similar comment); and 3) specificity (how clearly focused the comment or similar comments were). Additionally,
coding the text in this fashion allowed the qualitative data to be analyzed statistically (Bernard 1996) such as calculating frequency scores (Jehn & Doucet 1996). Each theme was then assessed in terms of its implications for the study research questions and hypothesis as well as domains to be included in the structured interviews in Phase II. Spanish quotes from the in-depth interviews were translated to English by the researcher.

To discern cultural salience and categorization patterns of domains freelist data were analyzed through univariate analysis of the items listed under each category/question. Each item’s frequency of occurrence and the order of occurrence were calculated using Anthropac (Borgatti 1996). Items that occur more often were assumed to be more salient (Bernard 2002; Ryan et al 2000).

**Structured interviews (N=60):**

**Sampling techniques: Structured interviews**

Purposive, snowball and quota sampling techniques were also used for the structured interviews in Phase II of this study. According to Bernard, a sample size of at least 30 is appropriate (Bernard 2002; Fink 2003) and is generally robust enough for statistical analysis (Madrigal 2003). Further, Ragin et al (2003) state that intensive research typically focuses on a small to moderate number of cases and examines them in depth (Ragin et al 2003). For the structured interviews a moderate sample size of 60 will accommodate univariate and bivariate statistical analysis and still allow the researcher to establish a measure of empirical intimacy (Green 2001). Strategies suggested by Werner and Bernard (1994) were used to guide the quota sampling strategies I developed a variable matrix with the demographic parameters and variables of interest, then I developed a contact tree/participant record table that provided an overview of the population sampled.
Data collection: Structured interviews

The questions for the structured interviews were derived from the literature, review of existing questionnaires and Phase I findings. When developing a questionnaire, it is necessary that researchers ask questions that are conceptually relevant and reflective of the issues that are important (Roche et al 1998). Bilingual/bicultural terms and phrases also need to be taken into consideration according to people’s daily lives and everyday vocabulary (Weidmer et al 1999). Data derived from qualitative methods are very useful for developing questions for interviews schedules and questionnaires by identifying appropriate questions, proper question wording and content domains as well as to help reveal the range of variation in response alternatives (Bernard 2002). Thus, I incorporated findings from the in-depth interviews and Freelists from Phase I as items in the structured questionnaire that was administered in Phase II. The structured questionnaire included the following domains: demographics, chronic stress, immigration experience, social support, provider communication, and cancer experience. See Appendix C for the Structured Questionnaire. Because the structured questionnaire is designed to explore multiple domains of the participants experience testing for psychometric properties of the entire questionnaire would not be appropriate (Wellisch et al 1999).

Demographics: These questions covered participant characteristics such as age, education, household income, insurance status, employment, English proficiency, chronic stress and marital status. An English proficiency index that included measures of each respondent’s perceived ability to understand, speak, read and write English (N=60). This index is considered to be a reliable measure with a Cronbach’s Alpha of .945.
Chronic stress: Chronic stress was used to assess the influence of structural factors that might influence social support (Gottlieb 1997). Chronic stressors are difficulties, problems, and challenges that people may experience in their daily life over a period of time, for instance unemployment, poverty, neighborhood, and work (Israel et al 2002; Schulz et al 2001). Data from the in-depth interviews were used to create twelve items to assess chronic stress. Reliability tests showed that only seven of these items could be effectively grouped together to form a chronic stress scale (See Appendix D for the list of items). A sample size of 23 respondents for whom all seven items were applicable were used to calculate an acceptable Cronbach’s Alpha of .748.

Immigration experience: The questions on migration/immigration experience were adapted from Jane’s Social Support and Migration questionnaire (Janes 1990) and from the literature (Marikovic 2002) as well as Phase I findings. Likewise some items such as length of time in U.S., country of origin etc. and frequency of communication with family in native country were also included.

Social support: A social support scale was created by the researcher. The items included in this scale were created from free list results collected in Phase I, data from the in-depth interviews, key informant interviews and participant observation. I also drew from items in the social support literature (Holroyd et al 2001; Katapodi et al 2002; Landale & Oropesa 2001; Markovic et al 2002; Matsudaira 2003; Meana et al 2001; Neufeld et al 2002; Simich et al 2003). The existing social support scales that were reviewed (e.g., MOS Social Support Survey) served as a guide (Sherbourne & Stewart 1991).

The social support scale created for this study included 21 dichotomously scored (yes = 1/no = 0) items (eight assessed emotional support; eight assessed instrumental/tangible support; and four assessed informational support). It is referred to
in the analysis as overall social support. Since the social support scale was composed of
dichotomously scored items the Kuder-Richardson formula number 20 (KR20) was used
to assess the scales reliability (Carmines & Zeller 1979). Reliability tests calculated
through SPSS showed that all 21 items could be effectively grouped together to form a
social support scale (See Appendix D for the list of items). A sample size of 18
respondents for whom all 21 items were applicable were used to calculate an acceptable
KR20 alpha of .854. Some participants stated that some of the items were not applicable
to them (e.g., help with childcare if they did not have children) thus they did not answer
“yes” or “no” for that given item. Their responses for the items that were not applicable
were recorded as missing. The overall social support score for each participant was
calculated by adding up the ‘yes’ responses and then dividing that by the total number of
responses. Since some of my hypotheses specifically related to emotional support, I
used the eight items used to assess emotional support to create an 8 item emotional
support scale Reliability test showed that all eight items could be grouped together to
form an emotional support scale that has a sample size of 58 respondents for whom all
eight items were applicable were used to calculate an acceptable KR20 alpha of .796.

Provider communication: A five item scale to assess patient/provider
communication was created as another way of gauging informational support as the
literature states that support from health professionals (physician, surgeon, nurse, etc.)
is important to individuals diagnosed with cancer (Gray et al 2000), and that information
provided by doctors is vital to understanding one’s treatment and survivorship trajectory
(Gray et al 2000; Neuling & Winefield 1988; Thewes et al 2004). Reliability test showed
that four items could be grouped together to form an provider communication scale that
has a sample size of 60 respondents for whom the four items were applicable was used
to calculate an acceptable Cronbach’s Alpha of .880. (See Appendix D for the list of items).

**Cancer experience:** Questions on breast cancer diagnosis, treatment, follow-up care, support program participation, and health care system navigation were adapted from existing questionnaires and informed by the findings from Phase I. Questions about cancer’s impact on their role as women and on disease-related stress/problems were created from data derived from the in-depth interviews.

The questionnaire was developed iteratively in both Spanish and English as the researcher is bilingual and fluent in both languages. The questions that were derived from the literature and were originally written in English were translated by the researcher into Spanish. The questions that were informed by the Phase I findings were created in Spanish. Once a solid draft of the questionnaire was developed, both a copy in English and Spanish was created. Back translation techniques were not used. However, to make sure that the Spanish questions, concepts and terms used were meaningful, understandable and grammatically correct the questionnaire was sent to the bilingual key informants for their review. They made a few suggestions which were incorporated into the final draft. Once a solid draft of the questionnaire was constructed, but before the questionnaire was administered, it was pilot tested among five women from various nationalities for clarity, ease of understanding and administration, and acceptability (Vazquez-Montilla 2000). Regional differences in the use of Spanish idiomatic expressions and different words were considered. For example, *mamas, senos, pechos* are all Spanish words for breast. Minor revisions and modifications were made as necessary. Thus, certain words and terms were changed to make the questionnaire more relevant and meaningful.
**Administering the structured questionnaire**

Bernard states that phone interviews are not intimidating, like self administered surveys, but allow interviewers to probe or to answer questions (Bernard 2002). While phone interviews have the impersonal quality of self administered questionnaires they were used because they also have the personal quality of face to face interviews. The structured questionnaire was administered over the phone March-July 2008. On average, the interviews took 45 minutes, ranging from 30 minutes to 90 minutes. Participants were recruited as described in the Recruitment of Study Participants section in Chapter 3 Setting. The majority of the interviews (N=58) were done in Spanish. The interviews were done at a time that was convenient to the participant, typically evening or weekend. Each participant was read the informed consent verbal script. If they were agreeable each question was read over the phone and their answers were manually recorded by the interviewer. Women were given an opportunity to share their thoughts and given time to elaborate. To promote efficiency and reduce error associated with data entry the structured questionnaires were created as scannable forms. The hard-copy completed questionnaires were then read by an optical scanner using Teleform (Verity Software), a high-accuracy content capture system for automatically processing paper-based forms. This is a more efficient way to enter data and is compatible with field research (Weller & Baer 2001). The data was compiled into one Excel database suitable for exporting into SPSS, a statistical software package.

**Data analysis: Structured questionnaire**

The data from the structured interviews were coded, tabulated and input into SPSS (SPSS 1999) for analysis. Descriptive statistics were performed to understand the data and to determine a representation of the responses obtained. Nonprobability sampling techniques used in Phase II require nonparametric statistical tests because
samples are not randomly selected from the larger population. Nonparametric bivariate statistical analysis explored relationships among respondents. This sample of 60 is sufficient for this level of analysis (Bernard 2002; Fink 2003). These analyses were performed to examine the independent variables: cultural beliefs, English proficiency, socioeconomic status, chronic stress and disease-related stressors, and length of time in the US in relation social support and to determine if a relationship exists among these variables (Bernard 2002; Kuzma 1998).

The following nonparametric tests were used to analyze the quantitative data. The Mann Whitney Test was used to compare two independent samples. Spearman’s rho was used to determine if there was an association between two variables. Chi-square was used to see if there was a significant difference between the effect of two categorical independent variables and an independent categorical variable. Kruskal Wallis was used to compare three or more groups. Specifically, descriptive statistics were used to compare support provided by men and women (H1). Mann Whitney Test was used to compare overall social support of those who agreed with the statement 1) women should not burden family and friends with personal concerns, and the statement 2) the needs of the family should come before your own to those who did not agree with these statements (H1a). Spearman’s rho was used to see of there was an association between having to keep a strong happy face and overall social support (H1a). Mann Whitney Test was used to compare overall social support of those who agreed with the statement: 1) we have to accept suffering and the statement 2) we have to resign ourselves to what life brings to those who did not agree with these statements (H1c). Spearman’s rho was used to explore the relationship between English proficiency and overall social support (H2). Spearman’s rho was used to determine if there was an association between English proficiency and provider communication (informational
support) (H2a). Chi-square tests were used to see if there was a significant difference in social support among participants with low, moderate or high English proficiency and informational support (H2a). Spearman’s rho was used to see if there was a relationship between chronic stress and overall social support (H3). Spearman’s rho was used to explore the association between length of time in the US and overall social support (H4). Descriptive statistics were used to compare emotional support from someone in participant’s native country vs. someone in the US by length of time in the US (H4a). Chi-square tests were used to see if there was a significant difference in informational support among participants who had been in the US 10 years or less to those who had been in the US over 10 years (H4b).

To conduct some of the analysis and allow for comparisons between groups, I recoded some continuous variables into categorical variables. For example, each participant received an English proficiency score ranging from 0 to 2. For some of the analysis I create a new English proficiency variable that included: low (0-.75), moderate (.75-1.75) and high English proficiency (2). I also created a new dichotomous variable for years in the US that included those that have been in the US 10 years or less and those that had been in the US over 10 years (Abraido-Lanza et al 2005). For some of the analysis that explored differences by ethnicity, I only used the ethnic groups that had five or more respondents. A dichotomous variable was also created for age that included women younger than 50 and women 50 and older. For some of the analysis income was converted to a dichotomous variable that included those that had a household income of $10,000 or less to those that had a household income of $10,000 or more. Similarly, I created a variable that included women who were married and not married. Items that were reported as not applicable were recoded as missing data.
Informed consent and Institutional Review Board

This study was approved by the USF Institutional Review Board (IRB) (See Appendix E) and informed consent was obtained from all participants following USF IRB guidelines. The researcher explained the purpose of the study to each participant and informed consent was obtained. Participants were told their participation was voluntary. While there are no direct benefits to the participant who participated in this study, researchers have reported that survivors participating in qualitative research found therapeutic value and expressed appreciation as a result of doing so (Ferrell et al 1997; Zebrack 2000a). There were no known risks for participating in this study; however, participants may have experienced discomfort with answering questions. In an attempt to avoid this, the researcher assured the participant that they could stop at any time for a break if she wished. This research was unfunded and thus participants did not receive and incentive/honorarium for their participation. However, participants who participated in the face to face in-depth interviews received a thank you card and small gift (e.g., small ceramic vase or picture frame) as a token of appreciation.

In summary, this chapter detailed the methodology used in this study. The previous paragraphs illustrate how qualitative and quantitative data collection techniques can be used to contextualize social support. The following chapter describes the results and begins with a description of the research setting and places the researcher and study within the context of doing local applied medical anthropology in West Central Florida. The second section of this chapter presents data from the key informant and in-depth interviews. The data describe the sociocultural context of breast cancer and social support. This section is followed by the data from the structured interviews that identify the cultural and structural factors that influence social support among Latina immigrant cancer survivors.
Chapter 4: Results

Introduction

This chapter situates the researcher within the study context and presents the research setting and study findings. For ease of understanding findings have been divided into three sections. Section 1 describes the research setting and places the researcher in context. This section also includes a discussion of the research experience and the multiple roles the researcher had to negotiate. Section 2 illustrates results from the key informant and in-depth interviews conducted in Phase I. Cultural beliefs, values and expectations about what constitutes social support are discussed. Qualitative data reveal some of the culturally mediated beliefs and expectations that influence social support. Participants’ lived experience as Latina immigrant women diagnosed with breast cancer also shape their worldview and provide an intimate look at Latina cancer survivorship. Findings from Phase I informed the development of the structured questionnaire administered in Phase II. Results from the structured questionnaire are presented in Section 3 of this chapter. Findings from the structured questionnaire identify the cultural and structural factors that influence social support.

Section 1: Research setting

Fieldwork took place in West Central Florida (WCF), primarily in the Tampa Bay and Orlando area. For this study West Central Florida, is defined as the following Hillsborough, Manatee, Orange, Osceola, Pasco, Pinellas, and Polk. This area of Florida is also known as the I-4 corridor, as Interstate 4 is a major thorough fare that crosses the state east to west. Hispanics/Latinos are the largest and fastest growing ethnic group in West Central Florida (Census 2008). According to 2007 population estimates, Hispanics
make up 22% (n=263,156) of the population in Hillsborough County, 13% (n=41,392) of the population in Manatee County, 24% (n=259,240) of the population in Orange County, 41% (103,608) of the population in Osceola County, 10% (n=46,245) of the population in Pasco County, 7% (n=63,787) of the population in Pinellas County and 16% (n=89,507) of the population in Polk County (Census 2008). Among Latinas in these counties the largest ethnic groups are Puerto Ricans (41%), Mexican (17%), Cuban (11%), Colombian (4%) and Dominican (3%) (Census 2008).

The majority of Latinos in WCF live in or near the large metropolitan/urban centers of Orlando and Tampa Bay area. WCF is also known for its agricultural crops of orange, tomato, strawberry and peppers, which are harvested in the rural parts of the counties (e.g., southeastern Hillsborough County). Latinos in the living in rural areas of WCF are more likely to work in agriculture and be of Mexican decent. Tourism is an important industry in the area, with the beaches on the coast and several large theme parks along the I-4 corridor, hotels and restaurants provide service level employment opportunities.

Regarding cancer services, WCF has the only comprehensive cancer center in the state. In addition to private oncologists there are several cancer institutes, and treatment centers in the area. In Florida, the proportion of breast cancer deaths among Cuban (18.2%), Puerto Rican (18.3%), and Mexican women (20.5%) and other Hispanics (17.7%) is about the same compared to 15.1% of white non-Hispanic women (Martinez-Tyson et al 2008). From the year 2000 to 2005, 1,409 Hispanic women were diagnosed with breast cancer in WCF, compared to 21,403 white non-Hispanic women. The age adjusted incidence rate for this five year period was 99.95 for Hispanic women and 150.21 for white non-Hispanic women (FCDS).

**Latina immigrants: Description of study population**
In WCF Latinas born outside the US (including those who are foreign-born and those who are born in Puerto Rico) in WCF make up from 53% (n=138,987) of the Hispanic female population (U.S. Census Bureau 2002). Osceola County has the highest percentage of Latinas born outside the mainland United States of 64% (n=16,220) compared to 40% in Pasco County (n=3,823). Fifty-four percent (n=56,980) of Puerto Rican women in WCF were born outside the mainland United States, compared to 60% (n=17,350) of Cuban women, 45% (n=21,906) of Mexican women and to 54% (n=42,751) of women classified as other Hispanic. The majority (58%) of foreign born Latinas from Latina America, Central America and Mexico in WCF immigrated to the US between 1990-2000 (U.S. Census Bureau 2002). In addition, according to the 2000 census, 93% (n=157,979) of Latina’s born out side the United States that reside in WCF speak Spanish. In Florida 61% of Hispanic native-born women have health insurance with a mean family income of $61,321. In comparison 39% of Hispanic foreign born women are uninsured and have a mean family income of $38,476 (U.S. Census Bureau 2008). Please note these figures do not factor in a possible undercount of Latinos, a problem experienced when enumerating immigrant or undocumented persons (Guzmán & McConnell 2002).

Latinos count for half the population growth since 2000 (Gonzales 2008). While there has been a decline in the number of undocumented immigrants, the number of legal immigrants has been steadily increasing (Larsen 2004). Latina immigrants may be very different from their US born counterparts. For example, Latina immigrants have had different environmental exposures, diet and lifestyle in their native country that could either serve to protect against or increase the risk of disease. Immigrant Latinas tend to be older than US born Latinas (Gonzales 2008). Latina immigrants may also have more difficulty accessing health care services, especially if they are undocumented and/or do
not qualify for assistance programs. They may also be less familiar with the US health care system and biomedical culture compared to US born Latinas who might have a better understanding of the health care system and culture of health care in the US. Not to mention US born Latinas are more likely to be English proficient and thus better able to communicate with their health care providers. In addition, Latina immigrants may adhere to difference cultural models of illness where there is less focus on prevention.

According to the Pew Hispanic Center, foreign born Hispanic women are less likely to be naturalized citizens than non-Hispanic foreign born women. Where as 55% of non-Latina immigrants are naturalized citizens, only 31% of Latina immigrants are. Other differences between US born Latinas and Latina immigrants include marital status, education and employment. For example, foreign born Hispanic women (63%) are much more likely to be married than native-born Hispanic women (44%). Regarding education, Almost half (49%) of all Hispanic women immigrants have not completed high school, compared with only 22% of the native-born Hispanic women. Women from South America have the highest educational levels, with 50% having attended at least some college. A larger proportion of native-born Hispanic women (64%) participate in the Labor force compared to 54% of immigrant Hispanic women (Gonzales 2008).

Negotiating and navigating multiple roles: Research in context

Over the last ten years, I have acquired a strong education in anthropology and public health as well as real life work experience in the health and cancer care arena. I have worked at cancer center and research hospital for the last seven years. My involvement with the Latina cancer survivor community began in Tampa in 2003. Since then I have worked closely with LUNA: Latinos Unidos por Un Nuevo Amanecer, Inc. (Latinos United for a New Beginning) (LUNA, Inc.,) a support group for Latinas diagnosed with cancer. LUNA Inc. is a grassroots community based organizations. This
work has had both personal and professional significance. It has been personally significant due to the significant amount of volunteer time that has gone into helping plan meetings, coordinate educational and survivorship activities, like Camp Alegria in 2005 and 2008 (Martinez et al. 2008), write grants for specific projects, find resources that include cancer treatment, low cost medications, and other types of assistance. Professional significance stems from my work at a major cancer center where my responsibilities include creating community partnerships, and developing cancer educational programs and materials for Latinas that are culturally and linguistically relevant. I have also participated in several Spanish educational TV and radio programs about breast cancer.

As an applied anthropologist I have had to navigate multiple roles, the researcher, the advocate, the coordinator, the social worker, the student and fellow Latina. I have participated and observed the complexity of cancer care and survivorship from multiple perspectives. These roles have also caused me some level of frustration and to some degree affected my objectivity as I have been personally and emotionally invested both in my job and in the lives of the women I have met. The emic and the etic perspectives at times became blurred as I seemed to straddle both endpoints of the continuum. Women came to see me as a resource and called me for assistance with obtaining low cost medications, making medical appointments, translation, obtaining prosthesis, and finding a doctor or treatment facility. I have seen the difficulty women encounter when navigating the health care system, especially if they did not speak English, lacked insurance or were undocumented. There are two cases that I discuss in the results section that illustrate the difficult scenarios I sometimes encountered which furthered my understanding of health disparities and of the every day realities of Latinas diagnosed with cancer.
There has been some debate in recent years about the role of advocacy and the special challenges ethnographic research with vulnerable populations can bring (Whiteford & Trotter 2008). I faced several challenges during the course of the research. First of all I was working with a vulnerable population which had both personal and professional implications. Personally, I could not just interview the women and move on. After hearing about their personal struggles, I felt obligated to advocate for them and made an extra effort to connect them to local resources and find information for them. On a few occasions, women called me to serve as an interpreter. I got to know a few of the women and developed a personal relationship with them and their family outside of my work and research. Personally, the interviews were emotionally draining, especially when two of the women I interviewed passed away a couple of months after our conversation. Not to mention the subject matter made me ultra sensitive to my own health. Meaning I found my self, sometimes unconsciously, checking to make sure I did not have cancer, as I knew so many people with this disease.

Professionally, I sometimes found myself between a rock and a hard place. Latina women from the community called me for assistance, some had found a lump and needed a mammogram others had been diagnosed with breast cancer and had no insurance and thus were looking for an oncologists, surgeon and treatment facility. Imagine the fear and desperation women must have felt knowing they had cancer and then having to wait weeks to find a doctor or facility that would treat them. I can remember nine such cases. What made this extremely frustrating for me was that I worked at a major cancer center and yet was unable to help them obtain the cancer care they needed. For what ever reason, none of these nine women qualified or were eligible for care at the cancer center where I worked. Here, I was working at a major cancer
center and found myself calling community-based clinics, local hospitals and private oncologists I knew to get women the service and care they so desperately needed. From an anthropological perspective, anthropologists have an obligation to the people they study and must protect the physical, social and psychological well being of their study participants (American Anthropological Association 1986).

I have learned much about the language and culture of biomedicine, specifically related to cancer care. I have worked on several projects where I have been responsible for overall coordination, protocol and proposal development; literature synthesis; qualitative/quantitative data collection; evaluation and data analysis. Currently, I am the co-investigator on two projects that specifically address the cancer communication, information and educational needs of Latinos, but neither of these projects explores the cultural and social context of social support.

My position as a researcher at a cancer center and as a LUNA, Inc., volunteer and support group facilitator has given me entry into a community of Latina cancer survivors and to the biomedical community made up of oncologists, nurses and social workers. I have developed trust and established relationships with several cancer organizations, health professionals and specifically with Latinas diagnosed with cancer. Through the years I have build rapport and trust in the community by attending support group meetings, participating in activities, and being there when someone needs assistance. People know who I am and what I do. Working with organizations like LUNA Inc and at a major cancer center gave me credibility. I believe my dissertation research would not have been possible with out the level of trust and rapport I have with the women. As Bernard states, rapport is what makes it possible for anthropologists to the kinds of research they do (Bernard 2002).
Relevance of community-based organizations

Community based organizations like LUNA Inc are vital to the community and fill an important information gap. Grass roots organizations are attuned to the needs of their respective communities and are trusted sources of information and assistance. LUNA’s mission is to provide support and offer culturally, linguistically relevant education to Hispanic breast cancer survivors, their families, friends and caregivers. The group was founded in August 2002 by a Latina cancer survivor, the first Latina support group in the Tampa Bay area. The first LUNA support group started with five members and then grew to have a network of over seventy members. The group held monthly meetings and coordinated social and recreational activities. Currently, LUNA has two support groups in the Tampa Bay area: LUNA de Pinellas is which meets at a hospital in Pinellas County. LUNA de Pinellas was modeled after the first support group; however, it is open to both Latino men and women diagnosed with cancer. The second LUNA support group meets at a local cancer center and is open to Latina women diagnosed with cancer, their family and friends. LUNA, Inc. has also partnered and collaborated with local Latina groups and grass root organizations in Orlando and Kissimmee. LUNA’s signature event is Camp Alegria, activity dates May 2005 and April 2008 (Martinez et al 2008). Camp Alegria is a three day retreat for Latinas diagnosed with cancer. The goal of this activity is to offer Latinas diagnosed with cancer a positive and memorable experience through a variety of culturally and linguistically relevant educational, social and recreational activities. In 2005, 56 Latina cancer survivors attended the camp and this number grew to 91 participants in 2008.

The research setting provides the background for the research results that are presented in the following paragraphs. Results from key informant and in-depth
interviews are included in Section 2. Section 3 details the results from the structured questionnaire administered in Phase II.

**Section 2: Key informant and in-depth interview results**

**Key informant interview findings**

Key informants (N=5) were interviewed at the beginning of the project. They include two social workers, an oncology nurse, a breast cancer support group leader, and a Latina community advocate. All five key informants were bilingual (English/Spanish) and intimately work and care for Latina cancer patients. On an average, the key informants had 7.8 years (range 6-12 years) experience working with Latina cancer patients, (range 6-12 years). Their insights inform the questions asked in the in-depth and structured interview and situate the breast cancer experience of Latina immigrants with in context. Findings are presented thematically.

**Political economic factors and sociocultural stressors that negatively impact Latina immigrants**

According to key informants the biggest problems Latinos faced in the United States were related to 1) health care access (5/5, 100%), 2) lack of health insurance (3/5, 60%), 3) language barrier (3/5, 60%), 4) financial and economic issues (3/5, 60%), 5) immigration status (3/5, 60%), 6) lack of continuity of health care (2/5, 40%), and lack of transportation (2/5, 40%).

Regarding Latino immigrants they report that the problems mentioned above were magnified and that in addition they also had to contend with additional challenges of adjusting to a different system and way of doing things. Four key informants (80%) mentioned navigating the health care system (4/5, 80%), the cost of living (3/5, 60%) adjusting to different family roles (3/5, 60%), stresses and worries about family in their native country (3/5, 60%) and not having family and other traditional support networks
(2/5, 40%), adjusting to minority status (1/5, 20%) and developing trust (1/5, 20%). This comment describes the impact of not having family in the US on Latina immigrants diagnosed with cancer and describes the added burden that places on them. She says,

“Not having family here is a big impact, really affects Latino immigrants. The social structure of the Latino is so strong and is grounded in the family. It is very rare that we do not help each other. What happens when you come here and you are diagnosed with cancer and your whole family is in another country? Because what I have scene in some cases, unfortunately is that some women wind up alone once they discover they have this problem [cancer] and have no one.”

Community Advocate

Changing family roles, the need to fulfill social roles and not being able to, was listed by 60% of key informants (3/5) as a source of stress.

“hmm… within their own family or married couple and children the stressors are unbelievable, a lot of the people have multiple generations in their home, they are still trying to keep to the tradition of a man working because they have to. There is an elderly person they [women] are taking care of or they have children they are taking care of. There is frustration from the man because he feels he can not support his family and he can't do what he needs to do, women have to go out to work which may cause stress within the family...”

Oncology Nurse

Regarding the adjustment to shifting family roles one of the key informants shared a story about a patient she encountered.

“I remember very clearly this very lovely breast cancer patient who had recently arrived from Cuba and she was integrated into her family here [her sister’s home] who had been here for many years. Her sister was part of the first wave of Cubans that came to this country twenty-five years ago if not more; and so this family was very traditional, Catholic, middle-class Cuban family… For the sister, who is newly diagnosed and just arrived into this country, the adjustment into her sister’s family who were all Cuban was very stressful for her. Very stressful. It wasn't easy. Because things were done differently. This family that was accepting her had made adjustments, had assimilated in some ways. And so that was stressful in many ways; roles between her sister and her mother were more blurred and less defined than they were for this sister who was coming from Cuba recently. The burden on the sister who had taken her in when she was ill, having to take her to everything because the language was such a problem and the lack of her catching up, not even having a driver’s license; she couldn't drive. It was tremendous. There was a lot of stress and strain and both of them were really extraordinary women and very sensitive to each other, you know, very mindful of each other’s burdens and stresses and what not but it was very difficult.”

Social Worker #1
Key informants also discussed the stress and anxiety Latina immigrants with breast cancer experienced (4/5, 80%). One of the stressors described was that many Latina immigrants could not afford not to work during cancer treatment and thus endured the side effects of chemotherapy on the job. For example, one key informant observes:

“They try to go on with life. You know, they do not stop working. If they do not go to work they lose their jobs. Latina immigrants go through the cancer, um, the chemotherapy, the radiation and they do not stop working. They have to go to work. Many of them, most of them do not have the luxury of taking time off because they do not have that benefit.”

Social Worker #2

The following quote provides a summary of the stressors Latina immigrants confront.

“I have worked with women from Mexico, Cuba, all over Latin America; they have a lot more anxiety and stress. Cancer is not the only problem for Latina immigrants diagnosed with breast cancer. The majority of them have other problems that affect them. Family or financial problems, immigration… all this and on top of it they have cancer that makes them even more stressed. They have less access to community resources or public assistance, social security or welfare. This causes them more worry”

Support Group Leader

They also discussed the difference immigration status had on access to cancer care. For example, one key informant states

“…I see a big difference in some of the women that come and they have no legal documentation from the women that have a visa or have political asylum in this country. They get Medicaid right away therefore they have access to much more services than a woman that comes from Mexico or El Salvador or Perú that are working… you know, they’re not on the books and they’re paying them two dollars an hour which is much more than what they would make back home but still not enough for them to… survive”

Social Worker #2

Similarly, another informant points to the limitations of the Medicaid system as she describes the challenges Latina immigrants face and says,

“It is challenging because some segments of our Latina population come to us with multiple psychosocial issues. Financial issues, transportation issues, childcare issues. Some of our Hispanics or Latinas come with issues of not being documented. Their legal status in this country is compromised and that’s a whole set of problems and issues. Also patients who come with Medicaid insurance which we all know in some ways are very limited in terms of what is
covered for them. I can almost say there is a punitive aspect to the Medicaid system because of great limitations in services.”

Social Worker #2

**Need for patient navigators**

Four key informants (80%) mentioned the need for patient navigators that could assist patients with resources and navigate Latina immigrants through the maze of cancer care and serve as a trusted source of information. For example, the support group leader relates, “I think women need to have a personal contact with someone when they go for treatment, for the chemo, to have someone they feel they can trust to make sure they get the care and assistance they need”

**Cross cultural similarities and difference**

I asked key informants to describe some of the differences they observed between Latina immigrants from various countries. Two key informants (40%) said Mexicans were more quiet and reserved compared to Latinas from other parts of Latin America and one said that Mexican women were more likely to consult traditional healers. Four of the key informants (80%) said distinctions were regional such as between women from the Caribbean, Central and South America and Mexico. However, they went on to add that within the context of breast cancer that being immigrants made more of a difference than what country they were from. The following quote summarizes the thoughts expressed:

“I can’t tell you that, can’t give you concrete differences, they are more nuances. I can not think of any examples… when we come here we are immigrants, when it comes to cancer the experiences are the same; there are more similarities than differences. There are so many issues that are going on that relate to everyone, worry about taking care of kids, am I going to be mutilated, the same fear, and part of it is fear of the unknown, we do not know that much about the disease until it affects us then we are fighting emotions as we are trying to learn more about what happens… We have the same concerns regarding breast cancer; we all face similar challenges…”

Community Advocate
**English proficiency, informational support and communication**

Key informants (4/5, 80%) discussed the impact not speaking English had on provider communication, understanding and information access. One informant also shares the story of how some of her Latina patients who are coming in for treatment do not know they had breast cancer. They are told they have BCIS which stands for breast carcinoma in situ. And since the word “cancer” is not used they do not know it is cancer.

She says:

“There is a type of breast cancer called BCIS and they [Latina patients] will talk about it like it is not really cancer and they will say BCIS (pronounced “bisihayes” in Spanish) and they are not saying the word cancer and it is not till I am sitting there and they tell me ‘I had un tumorsito (a little tumor) and they took it out and it is not a big deal and I do not know why I am here.’ I will tell them they have breast cancer and they will go ‘what?’ They will repeat BCIS… They have never been told they had cancer”

Oncology Nurse

Three key informants (60%) specifically mentioned how English proficiency affects Latina breast cancer patients understanding of their disease and treatment. For example, a social worker observes:

“The ones that have some command of English have a little better understanding of what is going on, they are kind of more able to access information, or read information, more informed and on top of it. The ones that do not speak English are completely lost. They do not know what is going on. It is a very scary thing. They will tell me, they are very nice and smile a lot but do not have a clue what is going on or what their doctor is saying.…. “

Support Group Leader

Similarly, the oncology nurse explains:

“I have also noticed that those that speak a little English can actually get in trouble because the doctor assumes they understand everything they say...I will have a couple where one speaks English and the other is clueless and I will ask them if they want me to be there with them when the doctor comes so that I can translate and they will tell me I want you to stay because I can understand some things, I can pick up a few words and then I am totally loss... that is why they are totally loss...”
She goes on to say how some of her Latina patients do not understand why they received this treatment versus that treatment. As she continues you can sense the frustration building in her voice.

“They will ask me why does she get a pill and I do not know... they will think not taking the pill is a bad thing when it is a good thing... they also hear the word “positive” but positive is usually not good in cancer and it makes it hazy. It does not matter if they can speak a little English, they do not understand. The doctors want to get through and do an assessment but they are not getting a good assessment. You take the time, get someone that can translate, get someone on the phone... the person may be in pain and the doctor just wants to get out of there to the next patient. They are not getting across, so it is frustrating to me. I have explained to the doctors that they [Latina patients] will smile and nod and I tell them you are not getting true information from these people they will tell you “fine, fine, fine” “oh little pain” but it is not anywhere near when I get in there and ask the same question in Spanish because they do not want to sound stupid or say the wrong word. We need to tell the doctors that is going to take a little longer but you need patience, got to be able... to ask the right question... the doctors lecture and tell the patient what they need to and then at the end they ask the question “Did you understand, do you have any questions?” Instead of beginning the visit with a question... by then they [the patients] are lost.”

Oncology Nurse

Another point brought up by two key informants (40%) is that, in their opinion, Latina patients are not always given treatment options or even know there might be other options available. For example, one key informant states:

“Oftentimes women are not even aware that there are options available. I do not know how much explanation takes place, quite frankly with Hispanic women by healthcare providers if there is an option. Maybe sometimes, I do not know. I’m just talking in general. I think maybe because of the indigence or because they are perceived to be indigent the options are not even discussed.”

Social Worker #1

**Frustrations with a broken system and lack of psychosocial programs for Latinas**

Several key informants (3/5, 60%) also voiced their frustration with the health care system over how difficult it was for Latinas to access quality care if they did not have insurance or did not have good insurance coverage. They also shared the personal struggles they encountered in trying to connect Latina immigrant patients with
assistance, follow-up and treatment. Such as the following quote from one of the key informants:

“I feel frustration over the system - over a system that treats them [Latinas] as second class citizens. They are not getting the care they deserve um... they are not given choices. They do not fully understand, no one takes the time to understand what is really going on... they do not follow-up with patients that have mammogram that come back questionable. No one ever follows up with them to come back and do another one and so then a year goes by and by then we have an issue that could have been solved and now we are looking at a metastasis issue. Just pure negligence of the system. That is the hardest thing and lack of information about where to go, where to send them.”

Oncology Nurse

One of the social workers interviewed states that one of the greatest challenges for Latina immigrants “has been to access services in their language in a culturally-sensitive and relevant context.... It is an added stressor for Latinas coming into a system that is perceived by them as being very Anglo, very foreign and this is discomforting and stressful....”

The five key informants interviewed (100%) stated that psychosocial and mental health services were not readily available to Latina immigrants diagnosed with cancer. For example, one key informant states,

“These programs are generally not available for Latinas because there are not that many providers that are prepared in the area to provide the services. Number one because many of the Latina cancer survivors and cancer patients do not have insurance, therefore they have no access to counseling services. There is not that many counseling services that are provided, you know, free or in Spanish.”

She goes on to say

“...some people fall through the cracks because there are not enough bilingual people. There are not many Latinos that are providing counseling... There’s not that many counseling services for Hispanics that are available.”

Social Worker #2
Sources of Support: Family, Faith and Spirituality

Three key informants (60%) talked about faith and spirituality and how spirituality and faith provided support and help Latinas cope with breast cancer. Family was also identified as a source of support by four key informants (80%). For example, “I think number one is religion or faith. I think that one coping mechanism is escaping to watching the novelas or you know, trying to focus on what is important to your family and putting yourself last on the list of priorities.” Similarly another key informant relates, “I think most Hispanics have turned to their families for emotional support and for distraction. They draw on their faith position, praying and attending religious services, talking to their priest or reverend.”

Gender roles, social relationships and breast cancer

Key informants (4/5, 80%) also discussed the influence gender roles had on support and the impact breast cancer had on social relationships. The following quote from one of the key informant summarizes some of the sentiments expressed.

“I think that in many instances the Latino culture defines roles much more; not rigidly but much more definitively. Very specifically males do this and the females do that. Again, not as stereotypical but in very general terms, it really varies according to education and background. With breast cancer, roles in some way begin to blur, not as blurred as in their American counterparts but more subtly.”

Oncology Nurse

Key informants (3/5, 60%) also talked about culturally defined social roles stated that changes is social roles were also a source of stress for Latinas with breast cancer.

“I think that in many instances the culture defines roles much more; not rigidly but much more definitively. Very specifically males do this and the females do that. Again, not as stereotypical but in very general terms, it varies according to education and background. With breast cancer, roles in some way begin to blur, not as blurred as in their American counterparts but more subtly.”

Social Worker #1

Another key informant relates,

“Yeah, the men, when they have cancer the women are there they want to know what they can cook for them, how they can help, what they can do, what are the
things... They are very involved in making sure they [men] can get better... When the women have cancer there is no one looking out for them unless they have a daughter, unless they have somebody that will come with them, usually they do not. They are lucky if their husband is there but they sure as heck aren’t saying what can I cook for them, what can I do.”

She goes on to say:

“Women [diagnosed with cancer] want to continue to do the stuff around the house like clean and cook and they feel guilty when they can not. It is one of the things they say, I am not doing anything; I can not do the laundry; I can not cook anymore; I do not do anything... They get home and are tired and say my husband is complaining and the kids want my attention. There is not that give and take and their whole thing is that he [husband] is out there he is working he is doing what he has to do I do not want him to feel like he has to come home and take care of me...”

Social Worker #2

The topic of divorce was brought up by 3/5 key informants (60%). Two (40%) reported they saw an increase in divorce and/or in Latino men leaving their wives during or after cancer treatment. While one (20%) reported that she had actually seen very few Latino men leave their wives and that this phenomenon happened across the board regardless of ethnicity. All three key informants said this happened where relationship problems existed before the diagnosis and that you did have men that were very supportive. Sixty percent of key informants (3/5) also mentioned they observed that Latina women tended to go to the doctor appointments alone or with other female relatives. One key informant specifically talked about the differences she saw if it was a Latino man with cancer or a Latina woman with cancer. She says,

“A lot of Latina women go through breast cancer by themselves... If it is a Latino man that has cancer a woman is by his side at every appointment at everything, if it is a woman that is going through it [cancer] either they try and hide it from the person they are with or they do it alone. I mean there are countless husbands and partners that I have never met. The husband may be involved but they are just not there, and I am not really sure if it is the wife that is doing it to protect them or if they just do not want to deal with it. But Latinas go through it alone a lot of times. In comparison to women from other cultures... as far as Caucasian American it is definitely different; a lot of the spouses are with them both men and women.”

Oncology Nurse
One of the key informants went on to add that Latino men get a bad rap, when they may be doing things that are supportive even if you do not see them at the doctor appointments with their wives. She states:

“But you know I want to say that Hispanic men, with the exception of those men who for whatever reasons do not have the wherewithal or the psychological resources... you know, are going to be there for their wives. They are going to be very concerned and very caring. You may not see them at the meetings or doctor appointments but they’re there for their women... I think across the board Latino men care about their wives, their women. They’re scared, they’re stumbling, and they want help. They feel powerless; they may not know what to say. Often times they’re afraid even to approach their woman intimately because they think they are going to hurt her; having irrational fears across the board. American and Hispanic men perhaps feel they contributed to this cancer in some way, by some sexual practices and what not. It’s irrational but it’s there. I would say that it is quite a profound experience for the men as it is for the women and requires quite a bit of adjustment. It’s a tremendous learning opportunity for both because now they have to learn to talk to each other in a different sort of way, ask for things that they’ve never had to ask before and come out of their comfort zone. And so roles are beginning to be re-defined in ways that are different. I do not want to be a part of people, any profession that bad-mouths Hispanic males. They’ve been given a bad rap for so long. I have seen very good marriages and very good supportive husbands.”

Social Worker #1

She went on to say that perhaps a reason you see men less is because breast cancer is a feminine disease.

“Particularly when you are referring to anything that is of a feminine nature and certainly breast cancer is a very feminine thing... it involves the female gender for the most part.... And the women have to support each other, like bond around this issue....This is a very gender-specific female disease and that the women have certain sensitivity and understanding for the disease that is not present with their spouses or significant others.”

Social Worker #1

**Sexuality and intimacy**

Three key informants (60%) mentioned the impact breast cancer has on sexuality and intimacy and stated this was an area that needed more attention. One described the biological changes that occur after treatment and illustrates the impact this might have on sexuality and marital relationships. She says:
“Especially women that have been through chemo, there are changes in vaginal secretions, changes in libido... especially younger who women are going into early menopause after treatment... they experience dryness, painful intercourse. They need to talk about it... But it is difficult because there is no where to send them.... There is stuff they can do. But you have to be careful because there are estrogen creams that might not be good or they can try different lubes. The dryness does not go away. Tons of Latina women do not know about these things.”

Oncology Nurse

Another key informant relates how these changes affect the marital relationship.

“The men are like ‘I have been beside you through breast cancer and chemo and radiation and now it has been a year and a half. It is a long process and now it is time, let’s get back to our usual stuff’ and in reality it is not and that is what the women are thinking. They think ‘who am I, the men have put up with this and now I can’t say I am not in the mood etc...”

Support Group Leader

Disclosure and the burden of cancer

Three (60%) of key informants explained Latinas feel they must protect their family and children and thus do not communicate their diagnosis or how they feel emotionally and physically. They went on to say that women especially wanted to protect their children regardless of their age (e.g., including both adult and minors). Two out of the three key informants who brought up this issue stated that compared to women from other ethnic groups, communicating with family seemed to be more of an issue for Latinas. The following quote illustrates this point well.

“And then issues around communicating to their kin about cancer... There is a very pervasive orientation among the Hispanic population that women are very protective of their children and family and they feel that they have to guard and protect their children’s innocence and they struggle about telling parents or their children of their cancer situation. In some ways they do not want to puncture that innocence, to rob them of that and cause them suffering. So to break through that barrier sometimes can become, can be a challenge. I do not want to say, I do not want to generalize but you see a tendency in that direction. But when you work with them as a group and you educate, and you inform as to what the benefits are in sharing... they come around. When you give them actual tools and skills and a dialogue how to tell them, what to say to them, they’re very appreciative that you’ve given them, equipped them with the tools and skills which empowers them.”

Social Worker #1
Support groups:

Peer support and support groups were mentioned as important sources of support for Latinas with cancer by 60 (3/5) key informants. Such as the following comment illustrates:

“So because of the value of family and it’s multi-generational, Latinas feel comfortable as a group. So culturally relevant self-help groups or group discussions and support groups are very important and very relevant and effective means of providing Latinas the kind of social support that’s critical for people to get through cancer experience in coping and adjusting… They are also a very effective way of getting information and resources to women. And I think it’s very empowering for women. It helps them restore the control.”

Social Worker #1

In-depth interview results: Sociocultural context of social support and breast cancer

The data gathered from these interviews provides rich information further contextualizing the experience of immigrant Latinas diagnosed with breast cancer. Participants were given pseudo names to protect their identity and preserve their privacy. Quotes are identified as follows: name, age, nationality, cancer stage at diagnosis. Each interview began by asking the women to list the most important things in their lives. The top three responses were family (71%), health (64%) and children (43%).

Participant demographics (N=28)

Participants ranged in age from 35 to 68 years, with 57.1% under 50 years of age. Participants represented nine different nationalities: 24% were Puerto Rican, 24% Colombian, 11% Venezuelan, 11% Ecuadorian, 14% Cuban, 4% Argentinean, 4% Mexican, 4% Peruvian, and 4% Panamanian (See Figure 4.1.).
Almost 30% of participants were monolingual Spanish speakers and 17.9% had not obtained a high school degree, 28.6% were high school graduates and 53.6% at least some college. The following table (Table 4.1) summarizes the demographic characteristics of in-depth interview participants.

**Table 4.1. In-depth Interview Demographics (N=28)**

<table>
<thead>
<tr>
<th>Item</th>
<th>Response</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Language spoken</strong></td>
<td>Spanish only</td>
<td>28.6</td>
</tr>
<tr>
<td></td>
<td>Spanish/non-fluent English</td>
<td>32.1</td>
</tr>
<tr>
<td></td>
<td>Bilingual</td>
<td>39.3</td>
</tr>
<tr>
<td><strong>Educational attainment</strong></td>
<td>Less than High School</td>
<td>17.9</td>
</tr>
<tr>
<td></td>
<td>High School Graduate</td>
<td>28.6</td>
</tr>
<tr>
<td></td>
<td>Some college or College Graduate</td>
<td>53.6</td>
</tr>
<tr>
<td><strong>Current employment</strong></td>
<td>Home maker</td>
<td>32.0</td>
</tr>
<tr>
<td></td>
<td>Half time</td>
<td>25.0</td>
</tr>
<tr>
<td></td>
<td>Full time</td>
<td>28.6</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>7.1</td>
</tr>
<tr>
<td></td>
<td>Disability</td>
<td>3.6</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>3.6</td>
</tr>
<tr>
<td><strong>Current household income</strong></td>
<td>10,000 or less</td>
<td>29.6</td>
</tr>
<tr>
<td></td>
<td>10,001-30,000</td>
<td>44.4</td>
</tr>
<tr>
<td></td>
<td>30,000-50,000</td>
<td>18.5</td>
</tr>
<tr>
<td></td>
<td>50,000+</td>
<td>7.4</td>
</tr>
</tbody>
</table>
At the time of the interview, 32% of the women were homemakers, and 28.6% were employed full time. Interestingly, prior to their cancer diagnosis, only 14.3% were homemakers. Overall, 39.4% reported having a negative change in employment status (e.g., full time to part time or full time to disabled).

Currently, 74% have a household income of less than $30,000, and 25.9% have an income above $30,000. Prior to their cancer diagnosis, fewer women (51.8%) reportedly had an income of less than $30,000 and more women (48.1%) reportedly had a household income above $30,000. Overall, 32.1% had a negative change in income (e.g., had a lower household income after the cancer diagnosis).
At the time of the interview, 67.9% of the women were married. When asked about duration of time spent in the United States, just over 20% of the women had been in the county five years or less, 14.3% of the women had been in the country for 6-10 years, 17.9% of the women had been in the country for 11-20 years, 35.7% of the women had been in the country for 21-30 years, and 10.8% had been in the country for over 30 years.

All the women who participated in the in-depth interviews were diagnosed from 2002 to 2007, meaning they were within five years of their diagnosis. The participants displayed varying stages of cancer at diagnosis; with 21.4% of the women diagnosed with stage I breast cancer, 32.1% with stage II, 35% with stage III and 7.1% with stage IV. In order to treat the cancer, the majority of women had a mastectomy (57.1%), while 39.3% had a lumpectomy. A majority also received chemotherapy (78.6%), ranging from 4-100 sessions, and radiation (75%), ranging from 1-60 sessions to date.

Currently, 60.7% of the women have some type of health insurance, compared to the 53.6% who had insurance before the cancer diagnosis. 17.9% of the participants obtained insurance after being diagnosed, while 3.6% lost their health insurance after the cancer diagnosis. Some of the women who were not insured prior to diagnosis were treated under charity care at some of the local hospitals or cancer centers or were enrolled into the county health care plan; if they met program qualifications (Additional demographic information is available in Appendix F). At the time of the interview, 57% of participants had attended LUNA, Inc. support group meetings.

The next several pages detail the results from the free lists and the open-ended portion of the in-depth interviews. The percentage of participants who gave certain responses have been included, where applicable. The data are presented thematically.
The immigration experience: Coming to America

In order to situate the breast cancer experience within the immigration context, participants were asked to describe their immigration experience and what it was like coming to America. Almost half the women interviewed describe the experience of coming to the United States as positive (13/28, 46%), and almost half described the experience as negative (13/28, 46%). A couple (2/28, 7%) of the women said it was “ni mala, ni buena,” meaning neither good nor bad. Women who described the experience as positive talked about coming to the US to get married or be with family, children and grandchildren (15/28, 54%), finding employment (30%) or finding a church that helped them get settled (6/28, 21%). Women who had an overall negative experience coming to the US talked about coming here alone (11/28, 39%) and leaving their family behind and about not being able to communicate in English (8/28, 29%). Some (6/28, 21%) shared they were fleeing abusive relationships or oppressive situations back in their native country.

One participant, who had a particularly trying time acclimating herself to American culture, recalled her experience:

“Oh my Lord, my God, I thought I came to hell. I left my family, my sister, my two bothers... I cried and cried. We [mom and I] did not know anyone here; we came to stay with a friend of a friend of a friend.... We had $5 in our pockets. We met a couple that took us to church, and they helped us... I did not know English and was very lonely. Finally, we brought my family over, and they did not like it here, so they went back. My mom did not want to go back....I am grateful because I met my husband here. No one told me about the different culture. No one helped me but the church. They told me what to do, how not to honk the car, not have radio too loud, no music loud in the apartment. In our country, it is different. It was lonely. I did not know the language or the laws; it was very hard. But now I am an American citizen.”

[Blanca, 46, from Ecuador, Stage II]

Thirty nine percent (11/28) of the women interviewed came to the US alone, 18% came with their husbands, 32% (9/28) came with their children or family, and 11% (3/28) came with one of their parents. Eighty nine (25/28) percent said that most of their family
stayed behind in their native country when they immigrated to the US, and 96% (27/28) said they currently had family and friends in their native country. Laila, a 63 year old Colombian, with Stage II breast cancer described her experience leaving family and friends to come to the United States:

“At the beginning it was very good. I came to see my son. I did not want to stay, but he convinced us to. Then it was very hard; we were here with out our family. I felt like I was missing something. I had left my daughter. In our country, there is more community. You can take a bus or taxi easily and go buy what you need, and here you need to drive. Over there, we have a lot of family and friends. Here you are alone, and here is where I got sick.”

The participants interviewed also shared some of the immigration-related difficulties and stresses they encountered when they came to the US. Some women cited the risks associated with crossing the border illegally (2/28, 7%), discrimination (3/28, 10%), and not knowing the language nor understanding the culture here (11/28, 39%). Some of the women (8/28, 28%), who were professionals back in their native country, also talked about the adjustment and stress caused by not being able to work in their fields here in the US and having to work service level jobs (e.g., house cleaning) or at jobs unrelated to their profession back in their native country:

“It was horrible, horrible. I came here and started working. I had a social security card and an open visa; I came here to work and have had a very difficult life here. I do not know how it would have been in my country. I have a degree in child psychology. But here I work at an insurance company. I do not do anything related to my field. Things have been horrible for me; I have had immigration problems, and I have had a lot of bad luck.” [Isis, 44, Venezuelan, Stage I]

When asked why they came to the US, the majority (24/28, 85%) said they came in search of a better life for themselves or for their children and family. Some (6/28, 21%) came to find work and after facing difficulty finding jobs in their native country. For example, Kati, a 50 year old Ecuadorian with Stage II breast cancer, cited employment opportunities and the betterment of her family as her reasons for coming to the United States:
States: “I came to this country to work and support my mother and to support my son’s studies [son is studying in Ecuador]. My mom died the same day I finished chemo. All I have left is my son. You leave everything, and I could not go see her”

When asked how often they spoke to their friends and family in their home country, the majority (21/28, 75%) of the women said they spoke with them at least 2-3 times a week. Most of the communication occurred by phone alone (17/28, 61%), although some (9/28, 32%) used both phone and the Internet to communicate. Forty-six percent of participants stated their family in their native country depended on them for remittances. Half the women (14/28, 50%) stated that the majority of their close family and friends lived in their native country, not in the US.

Cultural expectations and gender roles: What happens when someone is sick?

Cultural norms about gender roles effect who provides support to someone that is ill and what he/she should do to assist someone who is sick. According to participant responses, men were expected to: be responsible for the paper work, “manejar los papeles,” and assist with insurance issues and other medical related documents (14/18, 50%), drive the sick person to/from the doctor appointments (6/28, 21%), work (10/28, 36%), and take care of the bills and help financially with such things as buying medications (11/28, 39%). Some women (6/28, 21%) said men do only what is necessary and only help if they are needed (e.g., might help clean or might visit).

Participants related that women are expected to: nurture and care for the sick person (13/28, 46%), assist them with their personal needs (e.g., bathing and feeding) (7/28, 25%), give love and affection (7/28, 25%), cook and/or deliver food and home remedies (such as teas) (15/28, 53%), clean and maintain the house (18%) and take care of children (5/28, 18%).
When asked what men typically do when someone is sick, Maria, a 40 year old Stage III breast cancer survivor from Colombia, responded:

"More the paperwork stuff, talk to the insurance agent, this paper, that paper. They are in charge of the bills and accounts, how things are going to get paid, what documents we need, and women are more focused on taking care of the patient. That division is very marked."

To further understand gender roles in relation to caretaking during illness, participants were asked to describe what happened when a female member of the household got sick in their native country. The response most frequently given was that the family would come together and help the ill female care for her household (15/28, 53%). If the patient was unable to fulfill her daily household duties, her mother or mother in law would come and assist her in managing her illness and her household, including assisting her in taking care of her husband’s needs. If the patient had a daughter, the daughter would take her mother’s duties, while she was ill. If the patient did not have a daughter, but had a sister, her sister would step in. Neighbors also played an important role and were called upon for assistance (4/28, 14%). It was important that female relatives and/or neighbors bring food or soups (8/28, 29%) and remedios caseros (home remedies), namely cosimientos (teas) that were made for the sick person (12/28, 43%).

When asked what female family members and/or neighbors might do to help a woman who had fallen ill, Raquel, a 47 year old Puerto Rican woman with Stage unknown breast cancer, answered, “They would make home remedies, buy medicines, if they brought food, they might stay and help clean and do the chores, take her to the doctor, stay at the hospital, and bring chicken soup”

Some of the participants (7/28, 25%) also mentioned that it is important that females offering assistance to the ill woman not tell others or young children that she was sick. Leonor, a 39 year old, Puerto Rican, Stage III breast cancer patient, noted,
“Latinos are more closed about this. Talking about being sick is a taboo… you never told anyone when someone was ill. It is very private; you do not talk about it.” And 18% (5/28) mentioned it was important the family maintain un ambiente tranquilo (tranquil environment).

Several participants (10/28, 36%) also shared that women who were sick were usually accompanied to the doctor by other women (e.g., a sister or friend). Men, on the other hand, went to the doctor accompanied by their wives and/or children. Some of the participants (3/28, 11%) mentioned that middle class families sometimes had a household helper/maid to help clean and cook, which would relieve the sick woman from her household duties.

Several women (10/28, 36%) discussed how different it was to be ill here, in the US, compared to being ill in their native country. For example, as immigrants, women in the States have to continue to work through their illness and do not have the extended family support they had in their native country. Some (8/28, 29%) also mentioned how the lack of the extended family support networks in the US also effect the role of men; in the US, men had to play a more active role in caring for their wives when they were sick and had to learn to do some of the things that were traditionally done by women (cook, clean, care for children, attend to personal needs, etc.) in their native country.

**Women’s role**

Through participant observation (at support group meetings, cancer events) I noticed that women talked about how cancer had affected their ability to do certain things that they as women were suppose to do and be, like a good mother or a good wife and how this caused them additional stress and worry as well as put a strain on personal relationships and affected the support they received from their husband or children. For example, I remember a woman saying how she was expected to still have
dinner ready for her husband and to have the house kept even though she was in treatment. Or that it was her wifely duty to perform (sexually) and keep her husband satisfied. Women also expressed the importance of keeping the peace and tranquility at home and sometimes felt they could not reveal how they felt as to not disrupt the lives of those around them and to keep order and harmony within the household. Thus I felt it was important to include a free list question on women’s role and then later use some of the freelist responses in the structured questionnaire. Results are listed below. The roles or things that a woman should be that were most frequently listed were *ama de casa* (homemaker), to be a wife, to care for the family, to work, and to be a mother (Table 4.2).

<table>
<thead>
<tr>
<th>Items mentioned</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>To be a homemaker/<em>Ama de casa</em></td>
<td>16</td>
<td>57</td>
</tr>
<tr>
<td>To be a wife</td>
<td>15</td>
<td>54</td>
</tr>
<tr>
<td>To care for family</td>
<td>14</td>
<td>50</td>
</tr>
<tr>
<td>To work</td>
<td>13</td>
<td>46</td>
</tr>
<tr>
<td>To be a mother</td>
<td>13</td>
<td>46</td>
</tr>
<tr>
<td>To be a good daughter</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>To educate herself</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>To educate children</td>
<td>7</td>
<td>25</td>
</tr>
<tr>
<td><em>To Actualisarse</em></td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>To have faith</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>To love self</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>To be a good friend</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>To respect her body</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>To be a good lover</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>To be honest</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>To take care of herself</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>To be responsible</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>To be courageous</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>To be compassionate</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>To be a good citizen</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>To love God</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>To give love</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

Participants also discussed the reaction of men and women when facing illness, Leslie, a 52 year old Argentinean suffering from State III breast cancer, stated:
“It depends on the economic situation... but women are stronger, a woman has to be very ill to stop working and stop her role as mother, wife, and the housework. It is expected that the woman continue. If it is a man and it is not serious, he may continue to work, but he is weaker and you need to take more care of him more than you do women.”

A common sentiment expressed among the participants was that women were still expected to be strong and tolerant (75%, 21/28), even if they were sick. This especially held true once the women were living in the United States (10/28, 36%). As a result of these expectations, 52% (11/21) of participants also shared that getting sick was even more stressful because they were not able to fulfill their obligations as a mother, wife, homemaker and worker (trabajadora). Unless she was very sick, a woman was still expected to continue these roles and to continue to work. The respondents went on to add that when a woman was so sick that she was not able to fulfill these roles, there was havoc in the household. Since she was usually the one that maintained order in the house, the men were at a loss regarding what to do. The following quote summarizes the sentiments expressed by the respondents regarding a woman’s role in the household and in the family:

“Women are more conscious and knowledgeable. We take better care, a woman gets more involved. Women are stronger than men. The woman is the one that does everything. If something happens to me everything changes, everything stops, and the kitchen and cooking go haywire. When it is the woman who is sick a lot of things change. As a woman, certain things are expected from you ... because you are a woman and this causes more stress, you always think if something happens to me what is going to happen to my family, you have to be strong and tolerate... men expect you to be strong.”
[Manila, 54, Cuba, Stage I]

**Delicate balance between telling and protecting: communicating with family about breast cancer**

When asked how they had communicated their diagnosis to their families, 79% (22/28) of the respondents said they told their family right away; 7% (2/28) said they had not told their family, and 14% (4/28) said they waited until after their surgery or after they
started the treatment to tell their family. Some of the women (5/28, 18%) shared that this was one of the most stressful parts of their cancer experience, especially if their parents were elderly or lived in their native country. I observed that participants were especially protective of their elderly parents and tended not to communicate their pain, feelings of anguish or go into detail about negative aspects of their treatment with them. They feared the negative news might cause additional stress and worry for their parents and affect their health and well being. Carmen, a 49 year old Colombian with Stage III breast cancer, relayed the difficulty she faced telling her mother about her cancer diagnosis:

“I waited over a month to tell her, my mom has diabetes and I did not want to scare her. We lost our house because of the cancer treatments and stayed with nothing… We had to sell the house to pay for the treatment and medical bills… even though I have insurance… I did not tell her that. I told her I lost my hair and then I went home to my country to visit her for a week so she saw that I was ok”.

I did not specifically ask participants who, specifically, in their family they told. However, A few participants (5/28, 18%) delineated they told their siblings first and then waited to tell their parents. Some waited to tell them after the diagnosis and others waited until they were done with treatment. Sara, a 55 year old Puerto Rican told her siblings first, so they might help prepare her mother for the news. She says, “I told by brothers and sisters first (they live out of state and in Puerto Rico) so they would be prepared when I told mom (mom lives in Puerto Rico). I told her a week alter the diagnosis. “

A majority of the women (20/28, 71%) stated that their family’s reaction to their diagnosis caused them additional stress. Women wanted to protect their families by not burdening them or causing them worry, so many (14/28, 50%) did not share all the details of their treatment or tell their families when they were not feeling well, were in pain, and/or were upset or distressed. Laila, a 63 year old Colombian with Stage II breast cancer, described the emotional toll of protecting her family from her diagnosis: “I devote myself to my children, grandchildren, but no one knows the changes inside of
me, what I really feel, sometimes I feel like I am going to implode trying not to
demonstrate to my children how I feel inside (crying).”

To further illustrate this point I will us the case of Maria a 58 year old Colombian woman, who I interviewed in Phase II. As background, Maria was recently diagnosed with breast cancer and has just finished her radiation treatment. She lives with her elderly mother and has a daughter who lives out of state; she does not drive and depends on public transportation. She is frightened and frustrated. For the last few months she endured excruciating abdominal pain. Maria just found out the cancer had spread to her intestines. The doctor told her the situation did not look good and that she needed to talk to her family. Maria simply nodded yes. The doctor did not understand why she was not calling her family. When the doctor left the room she cried and shared with me how stressful it was for her to conceal the intolerable pain she felt from her family. She wanted to protect her mother and her daughter from her agony and thus carried the weight of her pain alone. She related that it was her duty to maintain the peace and tranquility.

Access, insurance and English proficiency: Does being an immigrant affect Cancer treatment?

When asked if they thought that being an immigrant affected the cancer treatment they received, several women (7/28, 25%) began by stating that the treatment that they are receiving here is better than what they would have received in their native country; they said it was a blessing that they were in the US when they were diagnosed with cancer.

Laila, a 63 year old Colombian with Stage II breast cancer, recalled her reaction to her diagnosis:

“I fainted when they told me I had cancer; I thought I was going to die at that moment. That is what happens in our country. Thank God there is a lot of
medicine here. I am OK now; they had to remove my breast and I have an implant now. That hospital gave me life. If I had been in Colombia, I might not have lived; they do not have what we have here.”

In contrast, some women (8/28, 29%) also revealed that they had debated going back to their native country for treatment, fearing they would not have the support they needed if they stayed in the US for treatment. However, none of them went back for treatment. Melania, from Colombia who is married to an American man explains why she thought of going back to Colombia for treatment.

“I thought about going back for treatment… because here in the US when you go to a hospital room you see people alone, by themselves. In my country the person is never by themselves… I do not have family here, I am alone. I have my husband, but if this had happened in my country I would have been surrounded with love and someone would have always been there with me and they would be attuned to my needs”

[Melania, 43, Colombia, Stage I]

Of the 28 women interviewed, 46% (13/28) stated that being an immigrant did not affect the treatment and care one received for cancer in the US, 11% stated that it did have an effect, and 43% (12/28) said it sometimes had an effect. Of those that reported it had an effect or sometimes had an effect, 53% (8/15) said the sub-standard treatment was due to lack of insurance, and the other 46% (7/15) said sub-standard treatment was due to lack of English proficiency on the part of the patient. The following summarizes the sentiments of most of the participants regarding the impact that not speaking English, or not speaking English well, had on their cancer treatment:

“If you do not know English, then yes, it makes a lot of difference in the treatment. You do not know how to ask questions about treatment. You do not know what is going on. Even though my English is not greatest sometimes, I did not know what they meant. Even if you know the language, if you do not know medical terms, then you do not understand. Even though you are educated, you do not understand. Add to that if you did not know the language. After every treatment, they say how do you feel, and it is hard to express yourself, especially when someone is interpreting. They are not feeling the pain and cannot express it in the same way. It is hard to translate, so I can not imagine not knowing the language. That is a big gap.”

[Blanca, 46, from Ecuador, Stage II]
Sixty-four percent (18/28) of women received the majority of cancer and treatment information in English. However, 82% (23/28) preferred the information in Spanish. Women who were noninsured or underinsured (11/28, 39%) encountered many difficulties navigating a seemingly disjointed health care system and had to go from hospital to clinic and back, piecing together the treatment services they needed. As an example of the disjointed nature of the health care system, mammograms are done in one place; diagnostic tests (sonogram or biopsy) may be done in another. If the results indicate that cancer is present, then the patient needs to find an oncologist and a surgeon who will do the mastectomy or lumpectomy, who is different from the oncologist, then there is the chemotherapy, which is separate from radiation therapy. This list of medical professionals specializing in very specific cancer-related fields does not include mental health professionals or psychosocial counselors. If the patient is uninsured or, for whatever reason, is not able to be seen at a comprehensive cancer center, where all the professionals can be found in one location, then obtaining treatment becomes much more daunting and difficult to navigate. Add not speaking the language (not being English proficient) to this picture, and the cancer care system becomes that much more intimidating.

There are two cases that stand out as examples of the disparities some Latina immigrants encounter in accessing cancer care. One of the women interviewed was in the United States legally, from Cuba, and had just moved to the area, and the other was undocumented from Colombia and had lived in the United States for years. Both lacked health insurance, and neither spoke English. One is alive today and doing well; the other passed away a few months after our interview. Dafna is a 56 year old Cuban woman, diagnosed with Stage II breast cancer, who legally immigrated to the US. She recently moved to the area. She recalls her diagnosis and treatment in the following excerpt:
“I had a car accident and hit my breast in the accident…My breast looked a little funny/ugly, and I told the doctor who was seeing me for the accident. He sent me to get a mammogram. I did not have health insurance, but I paid for the mammogram that was $99.

When I took the results back to him, he said he saw something he did not like. I asked him if it was cancer, but he said he could not give me a diagnosis, just that it did not look right. He said I should do another mammogram and a sonogram. Again, I had no health insurance, but since it might be related to the accident the auto insurance covered the exam. There they diagnosed me with cancer. The doctor told me he could not see me anymore because he was not an oncologist, and I had to find a surgeon and a hospital.

It was like the sky closed in on me. I had just moved to the area and did not know anyone; I had no friends here. A lady I ran into gave me a little paper with your [the researcher’s] number on it. I called and explained my situation and you [the researcher] helped me a lot. I was connected to St. Joseph’s (sobbing)... I am a little depressed because this has been hard for me; I have gone through some very difficult times.

The biopsy they did came back positive. And then I asked how am I going to pay for it [treatment]? How will I do this or get that? ... Then, with the help of the nurse [a nurse at the community clinic] and someone else from the hospital between everyone they were able to help me find a place that would give me the treatment I needed. Thank God I have had my surgery. I have an oncologist and a doctor. I am grateful to the free clinic; they approved my care. Thank you for going with me, also because of the language. Even though I have been here for a few years in this country, I could not study English well, and I can’t get by on the English I know...

I started my first chemotherapy. I applied for Medicaid, and I was denied. I applied to the county insurance program, and they finally approved me. I have the insurance for six months. A free clinic helped me. I feel like I am still going through this entire trauma. When I go to the doctor or to the hospital, I am terrified that they are going to deny my care. I pray they do not reject me, you know.”

Dafna was able to finish her chemotherapy treatments. While she eventually received some assistance for the cancer treatments she still does not have health or dental insurance. Every six months she has to reapply and hope that she does not get denied. Dafna recently shared with me that she is desperate looking for a dentist as her teeth have gotten loose, loose to the point that they affect her ability to chew and her gums bleed easily. These are all side effects related to the chemotherapy. She can not
afford the dentist and fears she is going to lose all her teeth. Oral health care is usually not covered under the cancer treatment assistance programs.

Agustina, a 54 year old single mother from Colombia, had a similar experience, though her cancer was at an advanced stage [Stage IV] by the time she got the treatment she needed. I met her at a community health fair. At the time, she was given six months to live. I interviewed her two years later. Interestingly, she lived less than a mile from a comprehensive cancer center. Agustina had an amazing outlook on life and positive attitude. The following illustrates struggle she went through to find the care she needed:

“Well, I did my mammogram, and they found some abnormalities, and they sent me to do a sonogram and an MRI, but they were charging me $2500 for those tests. I called the cancer center, but they said they could not see me until I had a cancer diagnosis. I tried calling all these places, but no one could help me. Then the time passed, and it was about a year later when I fell on the stairs and got a bad back pain for like three months. My cousin took me to the hospital. They gave me some pills for the pain, and they gave me some pills for the kidneys; they thought it was my kidneys.

Then another three months went by, and I still had a lot of pain, and my cousin took me to another hospital, and they were going to give me pain pills again, but my cousin talked to the doctor, and he came back to see me and did a more thorough exam and tests, and then he told her I had cancer. It had spread to my spine, skull and... And she explained to him all that I had been through because I did not have insurance.

They kept me at the hospital for a few weeks and did more tests. The cancer was everywhere... they said I had six months to live. I stayed at the hospital for another two weeks; they put me in hospice. The pains were terrible. I could hardly tolerate the pain. I had to wear a back brace...

Well, it has been two years, and I am still here. I am fighting, and one day they are going to tell me you do not have cancer.”

I also observed that immigration status, beyond being undocumented, had an impact on access to cancer care. For example, Latina immigrants diagnosed with breast cancer who are in the US legally and are in the process of applying for residency or asylum are caught in the middle as they are neither undocumented or US citizens and
thus may not qualify for certain assistance programs. For example, Laila a 63 year old Colombian explained the difficulties she had obtaining follow-up care after she finished her cancer treatment. Laila was in the process of applying for residency when she was diagnosed with breast cancer. Initially, she qualified for charity care at a local cancer center however; she had to reapply for the program every six months. The last time she went in for her follow-up appointment she was denied and no longer qualified for charity care. Laila expressed her frustration and concern. She did not know how she would be able to purchase the medications she has to take on a daily basis for five years, which cost $400 for 60 pills or how she was going to afford the follow-up visits with an oncologists every six months that averaged $350 just to see the doctor and did not include any test that might be needed. She shared with me she was debating returning to Colombia to continue her follow-up care there. However, this would negatively affect her residency process and her husband and family who had immigrated to the United States with her.

Cruz Maria, who was diagnosed with breast cancer in 2008, had a similar experience. One of the social workers called me several months ago asking if I could help her find a treatment facility for Cruz Maria. Cruz Maria was, in a sense, caught in the middle, while she was here legally, she did not have residency yet. She arrived from Cuba in 2007 and had only been in the US a few months before she was diagnosed. While she received political asylum, she had to wait a year to have the paperwork needed to qualify for assistance. After a couple months and several phone calls she qualified for charity care at a local hospital. Cruz Maria, her son and daughter-in-law did not know where to go and neither of them spoke English. That in combination with being new to the area made it even more difficult to find resources. Dafna’s, Laila’s and Cruz
Maria’s story illustrate some of the political economic immigration related challenges Latina immigrants encounter accessing cancer care in the United States.

**Social support from an emic perspective**

Freelist were used to elicit the different domains of social support and the types of assistance or support that someone who is sick might need (Table 4.3). Women were asked to “List all the ways you should help someone who is sick or recovering from an illness” Participant’s responses help gauge the types of assistance that was most important and were used to explore the construct of support from a different perspective. Women listed a total of 24 ways you should help someone who is sick or recovering from an illness. Results are presented in the table below. Interestingly, the term “support” was mentioned 11 times, even though all the things mentioned were types of support. A majority of them address instrumental/tangible needs.

<table>
<thead>
<tr>
<th>Items mentioned</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit</td>
<td>13</td>
<td>46</td>
</tr>
<tr>
<td>Help with housework</td>
<td>13</td>
<td>46</td>
</tr>
<tr>
<td>Support</td>
<td>11</td>
<td>39</td>
</tr>
<tr>
<td>Take to the doctor</td>
<td>9</td>
<td>32</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>9</td>
<td>32</td>
</tr>
<tr>
<td>Help run errands</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>Listen to them</td>
<td>7</td>
<td>25</td>
</tr>
<tr>
<td>Cook for them</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Help them find information</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Physical assistance</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Economical assistance</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Encourage them</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Call them</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Bring them flowers</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Talk to them</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Help with childcare</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Pray for them</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Interpret/Translate</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Ask them what they need</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Understand them</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Help them find resources</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Confianza</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>
Women were also asked to list all the things you should do to show someone who is sick that they are loved and cared for (Table 4.4). A total of 24 items were mentioned by participants. There was some overlap in their responses for this question and responses for the ways to help someone who is sick.

<table>
<thead>
<tr>
<th>Items mentioned</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give encouragement</td>
<td>13</td>
<td>46</td>
</tr>
<tr>
<td>Give affection</td>
<td>10</td>
<td>36</td>
</tr>
<tr>
<td>Listen to them</td>
<td>10</td>
<td>36</td>
</tr>
<tr>
<td>Cook for them</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>Go to the doctor with them</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>Be there</td>
<td>7</td>
<td>25</td>
</tr>
<tr>
<td>Visit them</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Give support</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Clean</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Consentiendolo</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Be patient</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Precencia (being present)</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Show concern through your actions</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Call them</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Economic assistance</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Give them information</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Show tenderness</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Pray for them</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Not give up on them</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Attend to physical needs (e.g., bathing)</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Take care of children</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Understand them</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Give advice</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Translate for them</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

Open-ended responses reveal a majority of the women interviewed (20/28, 71%) described social support primarily as emotional support (e.g., listening (15/20), understanding (14/20), encouragement (12/20), visiting (12/20), and bringing soup (10/20). They also described support as help with things around the house, such as housework (15/28), cooking (15/28), and finances (15/28, 54%). Some women also mentioned assistance with finding resources and information (7/28, 25%) as a type of
support. Prayer and having someone pray for them or with them were also described as support (8/28, 29%). A few women (6/28, 21%) also described support as being assistance with something that they need without having to ask for it: “…compassion, being able to put yourself in someone else’s shoes. Support is not waiting until they tell you they need something. Support is showing up with a soup, or whatever they like, if you’re her friend you know what she likes, to visit” [Mirta, 57, from Puerto Rico, Stage III].

I did not specifically ask women how their support needs were different now from when they were first diagnosed with breast cancer. However, from personal observations and from talking with women over time I have noticed that when women first learn about their breast cancer diagnosis there is an increased need for emotional and moral support. The need for instrumental support increases during treatment (surgery, chemotherapy, radiation), when women may have limited mobility, nausea, fatigue, aches and pains and thus not be able to perform their daily routine, maintain the home, work, drive etc. However, treatment side effects can last or emerge long after the actual treatment is complete, thus some women continue to need instrumental support.

The concept of “presencia,” of being present or having someone in mind was also discussed as a type of support by 36% (10/28) of the women. Some of the other ways that women characterized support pertained to feeling secure (4/28, 14%) and being able to have “confianza” or trust in/with someone (5/28, 18%). Some women also said that the act of seeing other women like themselves going through a similar experience was also a support and provided comfort. Having a positive attitude around someone who was ill was also seen as support (7/28, 25%).
Women define support differently, based on their personal preferences and needs. The following quotes illustrate how various Latina breast cancer patients have defined support:

“Someone to listen to you. Especially in the beginning, you want someone to listen to you. You want to let go everything you are feeling, to listen... that is what they did at the clinic. Someone that listens to what you say and someone that is helping me psychologically.” [Maria, 40, from Colombia, Stage III]

“I think it is feeling secure. For me, support is a lot of things, but, most importantly, it is the security you feel around someone else” [Berta, 41, Mexico, Stage II].

“Information about where one needs to go, where they can go for help, what information they need to have, moral support, and to be there physically close to the person, gives them company; tell them not to be afraid” [Kati, 50, Ecuador, Stage II].

“Being present in the person’s difficult times, not just in the social but the physical, financial, emotional” [Anita, 47, from Panama, Stage II].

When the women were asked to share who or what had been the most helpful and supportive through their cancer experience, the majority (26/28, 93%) mentioned their family. Husbands were mentioned by 58% (14/24) of the women. Some women had very supportive husbands while others did not. For example, Sara, who was diagnosed in 2006 with breast cancer, has, as she describes, a very supportive husband who cooked and cleaned the house with out her having to ask. They pray together and he accompanies her to most of her doctor appointments and the cancer survivorship activities she attends. Her husband is also Puerto Rican and is retired. On the other hand, Margarita, who was diagnosed in 2003 shared with me that her marriage fell a part and that her husband left her after she finished the cancer treatment. Female family members (sisters, female cousins, mothers, mothers-in-law and daughters) were each mentioned by 54% (14/26) of the women. A few participants (3/26, 12%) mentioned their sons and nephews; other than that, no other male relatives were mentioned. Female
friends were also mentioned as being important sources of support by 12/28, 43% of the women. A few (6/28, 21%) of the women mentioned health professionals (e.g., support group facilitators, social workers, nurses and their doctors) who gave them information and connected them to resources in the community (e.g., financial and medical), as being most helpful. People that provided transportation to doctor appointments also were mentioned. Maria, a 40 year old Colombian with Stage III breast cancer, adequately summarized many of the sentiments expressed by the women interviewed regarding the importance of family and community support:

“Well, my family has been everything. We were hand in hand, my husband, my mom. She came from Colombia for five months to be with me. Really, my whole family. I miss them a lot. My whole family is in Colombia. Flor [a social worker] has connected me with others… it is like a chain of support”

A majority of the women (20/28, 71%) stated that spirituality, or the belief in God, was central to their coping process. Women talked about God and the importance of God in their recovery. Forty-six (13/28) percent talked about the peace and comfort they got reading the Bible and books of religious psalms. Women also talked about the importance of prayer, though not necessarily in a church setting, and about having someone to pray with them or for them. This relates back to the concept of “presencia” mentioned previously; the women felt supported when someone had them present/in mind in their prayers. Though not all the women attended church, those that mentioned they did (8/28, 29%) talked about the important role the church had in their recovery. Yamira, a 59 year old Cuban with Stage II breast cancer, describes how her faith has helped her cope with her illness:

“I believe a lot in God and in my Virgin, and I grew up Catholic. I believe in God, but one day at home during one of the toughest times during treatment I saw a commercial about a church called “Para de sufrir” (Stop Suffering), and they were announcing a healing service for those that had cancer and other diseases to go to a healing service.
I remember I still had the bandages from the mastectomy. I felt so good; the church was full of people. There were people with crutches. The pastor talked and they put their hands on the sick people and I got goose bumps, and I know something happened to me that day. That is the church I go to now. I was Catholic, my family was catholic. I love the Virgen de la Caridad; she is the patron of my country... but that church gave me a lot of support with my illness."

However, not everyone received the support they expected from the church or from their church family. One participant, Sara who was diagnosed with breast cancer in 2006, specifically mentioned how she had been let down by members of her congregation, who she expected would be more supportive than they were. She describes her experience with people from her church.

"First they told me, how sorry they felt and to let them know what I needed, but it was all “de boca” (just words)... I told people at church right away when I was diagnosed. Some people close up, but I opened up. I thought that by telling them right away I was going to receive a lot of support from them but that was not the case. Since I do not have family here I thought they were going to be my family. My husband has been alone through all this, he also needs tranquility and support. He did everything. I have two daughters but they both work and have a family and children of their own to take care of. No one (from church) came and offered to help clean my house or cook for me, I did not receive that type of support from them (church family), Weeks would pass and they did not even call then at church they see you and say ‘oh, I love you’ and I would leave the service right after it was over because I did not want to offend anyone, I did tell two or three people, if you love me so much why do not you at least call...”

Several of the women (4/28, 14%) indicated that they felt closer to God after the illness and mentioned the importance of God’s unconditional love and support, especially when they felt alone. Anita, a 47 year old Panamanian with Stage II breast cancer, identified her relationship with God as a sustaining force during her illness:

"Knowing that I was in God’s care, and he was in charge of everything gave me hope, gave me hope not to quit and not to despair. It is spiritual support; that is the most important thing for me... when I am alone and depressed and crazy thoughts come to my head, I start to pray, talk to God, read the Word. When I am done, I have more hope and a little more peace.”
Finding the good in the bad, in the pain and in the ugly

Women described their cancer experience in a myriad of ways; however, their descriptions can be divided into two general categories: the positive and the negative side of cancer. Interestingly, almost 40% (11/28) saw their overall cancer experience as positive. Participants also mentioned the role cancer had in reaffirming of their beliefs and in establishing a connection with God/spirituality (20/28, 81%), having a new outlook on life (20/28, 71%), receiving support from family (20/28, 71%), going to support groups and meeting new people and/or other women like themselves (13/28, 46%). As one woman shared, cancer changed her outlook on her life and the world around her:

“It [cancer] changed my values and outlook. I appreciate things much more now; it showed me the value of other people, not materials things... but I want to help others. I talk about my illness, if it is going to help others. I got closer to my family. I value things more than before; you live day to day... I do not remember the day I was diagnosed. I left it behind me. You go through things for a reason.”

[Luli, 37, from Colombia, Stage III].

Similarly, Isis, a 44 year old Venezuelan woman with Stage I breast cancer, discussed meeting other women with cancer and the influence that had on her outlook:

“I met other people with cancer. I met people younger than me that had cancer, and I saw that life goes on. I am taking better care of me now. I think being stressed can make your body more susceptible to diseases like cancer. I met new people that want to help and that together we can overcome things.”

Raquel, a 47 year old Puerto Rican woman, identified her renewed interest in social interaction as a positive outcome of her cancer diagnosis:

“I saw how important I was to other people; people asked me how I was. I value life more. I was in touch with the world more. Before, it was just work, work, work; now I am more social. I talk to people now, tell them to care for themselves, to give people advice.”

Participants were also asked to describe the ways cancer had changed their life. The positive responses were similar to the ones reported above. The positive changes women most frequently mentioned were taking better care of themselves (e.g., by eating better and putting themselves first) (15/28, 54%) and spending more time with
their families and the family closeness that resulted (8/28, 29%). Participants (8/28, 29%) also mentioned that cancer made them revaluate their priorities and that they made a conscious effort not to allow themselves to be affected by stress:

“...before I would worry about the things in the house, that it was clean, that dinner was ready, and now I worry more about me. If I cannot clean the floor today, I will clean it tomorrow. This was hard for me, because I would always do everything, but now I say that stuff is not that important”

[Luli, 37, from Colombia, Stage III]

Kati, a 50 year old Ecuadorian with Stage II breast cancer, feels that cancer made her conscious of her own well-being:

“I try to take better care of myself now, what I eat. I keep thinking I am alone and need to take care of myself. Before, I would worry more about my family, and now I see I need to take care of me. I need to stick it in my head that I am alone, but I am not abandoned because of my illness. My son will get married any day [in Ecuador], and I do not want to be a burden for anyone.”

Stress and cancer

The most common term used by the women interviewed to describe stress was “estar preocupada” (being worried or worrying all the time); they also described feeling a loss of control. Stress was also described as presión (pressure) o estar presionada (being pressured). One woman described stress in the following manner:

“It is anguish, desperation, anxiety. Not knowing which ways to go, what to do. You feel corralled. For me, it is like a person being corralled; they feel pressure around them, because they are like in a pressure cooker. You do not know how to get out of it; you can’t find the means to do so… That is what stress is to me. It is anguish, desperation. It is everything that causes emotional unbalance.”

[Mariana, 48, from Puerto Rico, Stage IV]

The stress, problems and duress women described through out the interview can be grouped into three categories: 1) social (e.g., familial), 2) structural and socio-economic, and 3) disease –related, which can be subdivided into physical (e.g., bodily) and psychosocial. Many of the sources of stress identified by the women overlap and act synergistically and are not mutually exclusive (See table 4.5). When asked to list all the
factors that can cause cancer, the women interviewed listed a total of 23 causal factors. Stress was second on the list.

<table>
<thead>
<tr>
<th>Items mentioned</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor nutrition</td>
<td>18</td>
<td>67</td>
</tr>
<tr>
<td>Stress</td>
<td>15</td>
<td>56</td>
</tr>
<tr>
<td>Heredity</td>
<td>12</td>
<td>44</td>
</tr>
<tr>
<td>Smoking</td>
<td>8</td>
<td>30</td>
</tr>
<tr>
<td>Pollution</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Environment where you live</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Chemicals in food</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td>No exercising</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td>Sadness</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Alcohol</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Sun</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Family problems</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Getting hit</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Disorderly lifestyle</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Plastics</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Toothpaste</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Microwave</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Being too strict with self</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Punishment</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Hormones</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Medications</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

The effects of stress on family, work and their own health were discussed through out the interviews. One woman identified stress as a reason she had to stop working: “the stress did not let work... I worked in a school kitchen; it is so stressful there, and I could just not be that stressed. And, you know, I think it was the stress that caused my cancer, but p’alante” (keep moving forward). [Raquel, 47, from Puerto Rico, Stage unknown].

**Social/familial stressors**

Even though family was seen as a source of support, it was also listed as a source of stress (15/28, 54%). Participants talked about strained relationships with their sons and/or daughters (6/28, 21%), and about not having the level of support that they
expected from family and friends (3/28, 11%). Other family-related sources of stress and duress were also discussed, including being far away from their family who had remained in their native country (5/28, 18%), having to keep a strong/happy face to avoid burdening their family (14/28, 50%), and worrying over what would happen to their family/children if something happened to them (15/28, 54%). Others (2/28, 7%) shared that, while having family come and visit them from their native country was comforting, it was also a sort of stress, because they felt as if they had to attend to their guests and be a good host, even though they were sick.

Anita, a 47 year old Panamanian with Stage II breast cancer, illustrates the frustration that some patients feel about not receiving the support they need:

“I am alone; I have fought this alone. My son does not give me support. My daughter does not give me support, because she is disabled. I have not received any support from friends here. For me it’s been... (sigh)... I feel full of sadness. In these times of need, I have not had the physical support or emotional support from my friends... From my family, but they are far away [in Panama]. You know, sometimes you need help, and you do not have it. I am like ‘Wow, I am learning to survive and not fall.’ I do not have the luxury to just lay there... this has caused me a lot of stress.”

Blanca, a 46 year old Ecuadorian with Stage II breast cancer, describes the difficulty of being separated from family in their native country during her illness: “Family cried. The hardest part was for us not to be together. Emotionally, by phone [family lives in Ecuador], they gave a lot of support. I talked more to my sister than my brother; it is a guy thing or they are not into the calling thing”

Women were also faced with dealing with their illness, while trying not to burden their families: “… I went to try and get financial assistance, and they denied me. I did not want my family [both her adult sons have young children] who has children to help me. I did not want to burden them.” [Yamira, 59, from Cuba, Stage II]

Similarly, Reina, a 35 year old Peruvian with Stage III breast cancer, was conscious about not burdening her family with her illness: “My family is in Peru, but I did
not want them to suffer. We talked everyday, and I would just tell them everything was fine.”

Women delineated how stressful and different it was to be ill in the US compared to being ill in their native country (13/28, 26%). Further, participants went on to describe (10/13, 77%) how immigrating to the US ruptured social ties and support networks that would traditionally provide support in a time of need.

Luli, age 37, from Colombia, observe:

“When you are far away from your country it is hard, if you were diagnosed and were in your country you have more help, if you are far away you have that many more obligations and more stress… you have obligations to your family there and obligations here. If I was in my country and I needed something from the store I could call my mom, my sister, I could tell them I need this… Here it does not matter how close I feel to someone, it is not the same… you are not with your own.”

However, not all participants perceived being far away from family in their native country as stressful for they felt they received the support they needed from them regardless of the distance. Melania, who is from Colombia states:

“You need to look for support from other members of your family. You know, it did not cause me that much stress not having my family here… They called and were present through the phone and through their prayers.”

[Melania, Colombia, Stage I]

The participants were asked if there was someone they wish they could have leaned on for support but could not, for whatever reason. Participants specifically mentioned their mothers (9/28, 32%) or family back in their native country (10/28, 36%). Ten percent mentioned their husband or partners, who traveled frequently for work or did not live in Florida. When asked who she would like to be able to lean on for support, one participant said, “…my family and my mom who are in NJ and Puerto Rico. My friend too, if she had been here [lives in Puerto Rico]. She would have taken me out and made me laugh. My emotional situation would have been a lot better” [Sara, 55, from Puerto Rico, Stage II].
**Structural and socioeconomic stressors**

The socioeconomic stressors and problems women mentioned were primarily financial (i.e., paying bills, medicine and medical bills) (15/28, 54%) and insurance-related (6/18, 33%), as well as the increased economic burden on their family and household because of the financial and insurance issues directly related to cancer care (10/28, 36%). Maria, a 40 year old Colombian with Stage III breast cancer, reflected on the economic burden of cancer:

“Economically, the first three chemos we had to pay out of pocket; we do not have insurance. Then we had to run and try to find assistance, someone to help us. We do not like to ask the government for help, but we had to. I got community care, but that is stressing me out a lot. I still have to pay for the chemo and now more and more bills have started coming in… The economic part is super stressful… In the five years I have been here, I have never worried like this about our finances.

Yamira, a 59 year old Cuban with Stage II breast cancer, also suffered the economic toll of a cancer diagnosis: “… it was two years of treatment. It affected my home; I lost my house, spent all our savings during the two years of treatment. We filed for bankruptcy. It affected us financially; we lost the car. It was a process, but I am alive.” The costs of treatment, and the effect on the family, are a primary concern for many women (15/28, 54%): “What worries me the most is our finances. How am I going to provide for my family?” [Mariana, 48, from Puerto Rico, Stage IV].

With regard to employment, 33% (5/15) said their supervisor and co-workers had, for the most part, been understanding and supportive. However, several women (6/15, 40%), who primarily worked in service level jobs (e.g., restaurant, cleaning, factory), said working was difficult at times, and they would have preferred not to work during treatment but that they had to, to sustain themselves and/or family.

Fifty percent (14/28) said they worked during their treatment, and 43% (6/14) said they had to quit their job during treatment. Such was the case with Gloria, who was...
diagnosed with breast cancer in 2007. She worked at a glass-making factory and lived in an unsafe area and mobile home park. Gloria spoke some English and had emigrated from Panama. She had a double mastectomy and was prescribed chemotherapy; her treatment regimen would have lasted several months. Her job provided insurance, but if she did not work she would not only lose her insurance but have no money to pay for bills and medications. She experienced severe side effects from the chemotherapy (e.g., nausea, fatigue) for days on end and still had to work. Her job required her to lift and break heavy sheets of glass. I remember she showed me how she would put tube socks beneath the rubber gloves she used that went up to her arm pits to protect her arms from accidental cuts. She was putting herself at risk for infection and lymphedema but felt she had no choice. She ended up losing her job because her productivity fell, and she had missed too many days. Gloria mentioned that she was going to stop the chemotherapy because she felt cured and she had read somewhere that it would do more harm than good. She later revealed to me that the truth was that the doctor told her could not treat her if she did not pay, so she stopped the treatment. I did not get to interview her for this project, for she moved out of state before I had the opportunity. I know her story well and it illustrates the plight of many hard-working Latina immigrants who endure the burden of cancer under unbearable circumstances. She was not “noncompliant” with her treatment; she simply felt she had no choice.

The psychosocial impact of cancer

The following disease-related stresses and concerns emerged from the interviews. They can be subdivided into two broad categories: physical, which includes physical changes (e.g., appearance, side-effects, physical limitations), and psychosocial, which include emotional changes, changes in sexuality/intimacy, and changes in perceived femininity. The physical and the psychosocial are interrelated. For example,
changes in appearance might affect women’s sexual/intimate relationship with their spouses.

Several participants (10/28, 36%) talked about the stress and pain they endured managing the side effects of treatment. Side effects like nausea, fatigue, hair loss and worry about what other organs the chemotherapy would affect were mentioned:

“I said whatever I have to go through, I will do whatever I can to stay alive. We have the idea that you go to the doctor, you take a medicine and get better. With cancer, it is not like that. Sometimes, with cancer, you feel great, and then you get the treatment, and the treatment makes you feel sick. It is the opposite… then I was worried about how the treatment would affect me, like the skinny people who look like walking dead people. I was afraid of the sores in the mouth, too.”

[Leonor, 39, from Puerto Rico, Stage III]

Participants (12/28, 43%) also discussed the physical limitations brought on by cancer (e.g., not being able to move or pick up heavy things and limited mobility on the treatment side of the body, either due to scaring or lymph node removal). Women (10/12, 83%) talked about how this affected their ability to complete tasks around the house or at work (e.g., clean). Fourteen percent (4/28) also mentioned being less active after their treatment and dancing less. Nena, a 42 year old Puerto Rican with Stage III breast cancer, reflected on the changes she has endured since her treatment: “Well, before I was happier, more active. Now, I get depressed a lot and am less active. That side of the body is not the same. I can not do the same things any more, and it is not as strong as before”.

The breast is a symbol of womanhood and motherhood; too many of the women (9/16, 56%), the removal of the breast was very traumatic and deeply affected them. Only 38% (6/16) had breast reconstruction at the time of the interview. Isis, a 44 year old Venezuelan with Stage I breast cancer, discussed her feelings and concerns regarding breast reconstruction:
“I was worried about how my breast was going to look. They did a lumpectomy; I have scar. I need to ask the doctor if I can do reconstruction. I have ‘un undido’ (spot that is sunken in). I have not asked the doctor. I think what if because I am being vain because I am vain they do a surgery that moves stuff around and spreads the cancer, if it is there... I am unsure; I have those doubts.”

One woman describes why she wants to get reconstruction, even though she is over 50.

Her response illustrates the importance of the breast as part of a woman’s feminine identity:

“I look in the mirror, and I do not see a feminine woman. I may be over 50, but I am still a woman. They [church friends] have told me, ‘Why do you need those breasts anymore?’, but, as a Christian, I have to shut my mouth. I just do not feel sexy. To leave the house, I put on my wig, my prosthesis, and, when I get back home, I start removing all the stuff that is fake [wig, prosthesis], one by one... All that makes me a woman comes off, and then I feel like I am no longer a woman.”

[Sara, 55, from Puerto Rico, Stage II]

Women also talked about how the scars and removal of the breast affected how they dressed (4/28, 14%) and their overall appearance:

“I used to love to tan. I would be in my bikini and lay out all day, and I would walk on the beach in my bikini...well... I did have to change what I wore... that changed a lot, and that has been hard. I was very ‘coquetica’ (sexy) with my husband. I would wear sexy pajamas with thin shoulder strips and stuff, but now... I feel like a little grandma... with the ones I use now... cover my whole body. My body has changed.”

[Maria, 40, from Colombia, Stage III,]

Similarly, another participant relates her diminished sense of femininity and sexuality, as a result of her surgery:

“Look, I thank God I was widowed. I do not know how I would have reacted if I had a husband. In my culture, breasts are important. You dress nice to accentuate them. I am glad that I do not need to worry about sex. Before I had the prosthesis, people would stare at my chest. I was embarrassed to go out. I felt like I lost something. If you can go to heaven without an eye, you can go to heaven without two breasts.”

[Mirta, 57, from Puerto Rico, Stage III]

Participants shared how breast cancer affected their femininity and self esteem (15/28, 54%) and diminished their sex drive/libido (10/28, 36%).

“It has affected me a lot as a woman. It has diminished my sex drive immensely...When you are in the moment, and then you look down and then...
there is a part of your womanliness missing…. I have talked with other women who have gone through this. They all say the same thing…. It is not like before… I did not tell this to anyone, just to other women who have gone through it like me, not even my husband. I have not told him how I feel. It has affected my relationship with him… when it is time to do it, I think we, as women, can handle the situation. We know what to do to make him feel good (laughs a little) and not let them know we have no desire. This is an area that we need a lot of information about; we need more education. This is not something that is discussed openly, for it affects all of us that have gone through cancer. It is a taboo, maybe, where we do not talk about it openly.

[Yamira, 59, from Cuba, Stage II, 2002]

Weight gain (5/28, 18%) and hair loss (6/28, 21%) were also mentioned as factors that negatively impacted the participants’ self-esteem. The women interviewed talked about feeling less sexy and less attractive after their treatment: For example, one participant said, “It has affected me so much, especially because I am the mom and the dad here, and I feel like I have failed my family. As a woman, I do not feel feminine. I feel fat and ugly... Emotionally, it has affected me a lot, too” [Anita, 47, from Panama, Stage II].

Regardless whether women had a lumpectomy or mastectomy, the procedure still had an impact on how women saw themselves. Leonor, a 39 year old Puerto Rican with Stage III breast cancer, reflected on the impact that her lumpectomy had on her psyche:

“Even though it has been three years, I am embarrassed in front of my husband. I have scars and discoloring of the skin... that is always on the back of your mind. He says he loves me just like that, but, as a woman, your body is everything... and I only did a lumpectomy; it is a small scar. It is in my subconscious”

Thirty-seven percent of the women interviewed reported negative changes in their spousal relationship (7/19). For example, some women talked about how supportive their husbands had been during the treatment but noted that, afterwards, their husbands expected things to go back to normal, yet the women did not feel normal, because they felt that they were not the same emotionally and physically:

“It affects the spousal relationship. My husband sometimes comes to me and says ‘Can’t we do it? Can’t we do it?’ And I tell him I am sick, even though I am
not dying. Sometimes I think, ‘Does he pity me?’ Sometimes I tell him I can... I would feel bad when I had to get undressed in front of him. I would cover myself and hold back a little, and our intimate relationship has changed; you lose all your desire. An even now, after the treatment is over, it continues to be this way. Sometimes men are not too patient about that kind of thing.

[Nena, 42, from Puerto Rico, Stage III]

The women who had strong spousal support seemed less affected and did not report feeling a loss of their womanhood because of the treatment. Some participants (8/28, 29%) also discussed the hormonal changes they experienced, including the early onset of menopause caused by some of the treatments and how this might affect their fertility and ability to have children in the future. Some women (15/28, 54%) also discussed the emotional changes that they experienced, due to cancer treatment. For example, 28% (8/28) reported being more sensitive and feeling depressed. Some (3/28, 11%) felt they worried more and feared having a recurrence.

**Information needs and provider communication**

Towards the beginning of the interview, the participants were asked to freelist the kinds of information that they felt were most important to someone diagnosed with breast cancer. A total of 18 items were listed (See Table 4.6, next page). The two items most frequently listed were information about the disease (e.g., cancer type, stage) and treatment options).

During the interviews, a topic that came up several times was the lack of information available and the difficulty Latina women encountered in getting information about their disease, treatment options, and available resources. The women also discussed the lack of information available to help them cope with the negative psychosocial aspects cancer and its treatment, such as the lack of counseling and mental services readily available.
Table 4.6 Freelist Result: Things someone with breast cancer should know

<table>
<thead>
<tr>
<th>Items mentioned</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>About disease</td>
<td>22</td>
<td>81</td>
</tr>
<tr>
<td>Treatment</td>
<td>15</td>
<td>56</td>
</tr>
<tr>
<td>Side effects of treatment</td>
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<td>30</td>
</tr>
<tr>
<td>How to take care of self</td>
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<td>22</td>
</tr>
<tr>
<td>The assistance that is available</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Their options</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td>Survival/If there is hope</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td>How to get family support</td>
<td>3</td>
<td>11</td>
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<tr>
<td>What to eat</td>
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<td>7</td>
</tr>
<tr>
<td>When to get mammograms</td>
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<td>7</td>
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<td>What exercises to do</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>How to change lifestyle</td>
<td>2</td>
<td>7</td>
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<tr>
<td>Not to be afraid</td>
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<tr>
<td>That they are not alone</td>
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<td>4</td>
</tr>
<tr>
<td>Know their limits</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>To be honest with their partner</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>To reduce stress</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Not all women are the same</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

Throughout this research, it has been noted that women say that they did not ask their doctor questions because they did not want to question his/her authority or they did not want to bother the doctor when he/she had already done so much for them. Women in the study have shared that they did not even know what to ask. Many doctors’ offices do post some literature in the waiting areas, but it is not always readily available or in Spanish. Some participants (11/28, 39%) shared that some of their doctors gave them brochures and information; some even drew pictures of what was happening to them. However, not all received the same breadth and depth of information from their doctor.

One woman discussed her lack of knowledge and information about treatment options and her lack of information about the test they had done. Her frustration becomes evident throughout the excerpt:

“I saw someone who had chemo, who did not have a port scar on her chest. She said, ‘They gave me chemo through my vein.’ And she said the doctor gave her
the option to put it through the vein or chest, but I did not know. They said go this day, and I did, and I did not know I had options. Now I do not wear shirts that show the top of my chest, because I have a big scar. They have had to open it [scar] like three times; they had to put the port in 3 times. They did not give me the option.”

She goes on to say:

“I did not know how many nodules they had taken out or what kind of chemo I got or the name of the cancer I had or what stage. And, after meeting some ladies, I went back to the doctor. I asked him to write everything down for me. I did not know why they did not give me the pill you take for 5 years, and later I found out it was because all my lymph nodes came back negative. All I knew was that I had breast cancer, which I had radiation and chemo, but that is it. I did not know anything. I think you need to inform yourself. Know what kinds of medicines are available. My health insurance is the Hillsborough County health care plan. I asked my doctor if he knew a doctor that spoke Spanish, and he said one of the nurses did but she was not always there I did not know who to ask or who I could ask.”
[Nena, 42, from Puerto Rico, Stage III]

Another participant also noted the lack of information available to Latina women seeking cancer treatment:

“I’ll tell you why I know this, because a lot of Latinos are not very well-educated… They are not educated about chemotherapy. What are the side effects? What can I do? Why the doctor chose a certain kind of, um, the amount of chemo, um, how a tumor works… You know, educate us about it, you know. Educate us about the different kinds of chemo. What are their side effects? What can I do? Educate us about the different kinds of cancer, why a doctor chose this type of chemo for you, the amount of chemotherapy you should go through.
[Elizabeth, 67, from Puerto Rico, Stage I]

When women were asked where they got the majority of their cancer information, the majority (20/28, 71%) indicated that they obtained information from their doctor’s office and/or from a social worker at the hospital:

“The doctor gave me a book and highlighted pages about my treatment. I went to library and got books about cancer. When I went to the doctor, I wrote all the questions we had. I told the doctor I wanted them to just cut them off, but first they wanted to give me treatment, and I said, ‘Why, if I am going to cut them both off?’ And she said, ‘Because the cancer is big, and we do not want it to spread.’ She gave me a good reason why they did treatment, then surgery.”
[Blanca, 46, from Ecuador, Stage II]
Several (7/28, 25%) women said they did not know where to go or who they could call. A few (4/28, 14%) got the most useful information from other cancer survivors, who referred them to the American Cancer Society and to local support groups. A couple participants (2/28, 7%) had older daughters that looked up information for them. Some (4/28, 14%), however, reported not getting enough information from their doctors. Anita, a 47 year old Panamanian with Stage II breast cancer, recalled how she obtained information regarding her cancer treatment: “When I went to the oncology office, I met a woman who had gone through this, and she gave me information. My doctors just skimmed over information; they did not explain things thoroughly”

Even though there are organizations that support cancer patients and their friends and families and many websites about cancer (e.g., American Cancer Society, Susan G. Komen for the Cure and the National Cancer Institute), information and literature is not always easily accessible or available to the community: “I got everything from the library. I did not know about the American Cancer Society. I learned about it at the end of my treatment” [Blanca, 46, from Ecuador, Stage II, 2005]. More recently many of the organizations mentioned above have translated their online literature to Spanish; however, Internet access is required to access the information.

A few women (4/28, 14%) also mentioned said that there should be a centralized source of information and/or a person that could help them navigate the maze of cancer care and explain the various treatments. For example Leslie, from Argentina relates:

“I do not know if I am selfish or what, but I would call places, and they would refer me to more places. I ask myself, ‘Why can’t there be a person to help me, like a nurse or something’...For me, if there was are representative that I could call and then we can both try and get information, we can work together. You may get some information, and you call but then you get referred to more places, and it gets to a point that you burn out. Someone that is there to help you, then you could probably get more.
[Leslie, 52, from Argentina, Stage III]
In addition to a lack of accessible information about cancer treatment, participants felt that there was also a lack of information regarding nutrition (10/28, 36%) and sexuality and intimacy (7/28, 25%). The women also cited a need for information and support for the families and spouses of cancer patients (7/25, 25%), in order to help them understand the changes (physically, mentally and emotionally) that the patients are going through: “Everyone worries about the patient but no one thinks of the family member who suffers just as much. That is an area where we have a need. They have to deal with the change in character. Support groups are good for that.” [Luli, 37, from Colombia, Stage III]

A few participants (5/28, 18%) also discussed the lack of counseling and mental health services available to Latinas that could help them cope and work through some of the these issues, especially those related to sexuality and intimacy and how to communicate with family:

“The relationship with my husband changed 100%, because they never think about what you feel... when you have that treatment, you do not feel like doing that [intercourse]. It is not because you do not love them, it is because you can’t; you do not have the desire. I totally lost my sexual desire. He would come to me, and I could not. You are dry, and then they get mad and think you do not love them. There is little information about this side effect of cancer treatment, and it causes a lot of problems... From the day you are diagnosed, they should have something, a counselor for that...they should at least give you a book on it. [Margarita, 54, from Colombia, Stage III]

In summary, this section provides a vivid snapshot of the lived experience of Latina’s diagnosed with breast cancer. Findings bring to light the need for information and the struggles women have endured accessing care and or at home in their personal and familial relationships. Further, information collected through the in-depth interviews was used to inform the questions used in the structured questionnaire. For example, the stressors mentioned by participants informed the items that were included in the chronic stress scale. Data from the structured questionnaire are presented in the next section.
Section 3: Structured interview results: Cultural and structural factors that influence social support

This section includes the results from the structured questionnaire, administered in Phase II, and results focus on the cultural and structural factors associated with social support. A total of 60 Latinas participated in these interviews.

**Participant Demographics (N=60)**

Participants represented 10 Latin American countries (Figure 4.2.). The largest group of participants was Puerto Rican (33.3%), followed by Colombian (16.7%), Cuban (11.7%), Mexican (8.3%), Dominican (8.3%), Ecuadorian (6.7%), Peruvian (6.7%), Venezuelan (3.3%), Honduran (3.3) and Guatemalan (1.7%).

Figure 4.2. Ethnicity of Structured Interview Participants N=60

Table 4.7 (next page) provides a brief snap shot participant demographics. A summary table of all participant demographics is included in Appendix G.
The age range of study participants was 30 to 85 years of age, with 45% of the women being under 50 years of age. The women interviewed were diagnosed with breast cancer between 2003-2008, with 58.3% diagnosed in 2006 and 2007. Stage of cancer at diagnosis varied, with 33.3% of women being diagnosed with Stage I, 25% with Stage II, 21.7% at Stage III, and 1.7% at Stage IV, while 18.3% did not know what stage they were in when diagnosed. Seventy percent of the women had a mastectomy, and 75% received chemotherapy as a treatment modality. Just over a quarter of the women (26.7%) had undergone breast reconstruction at the time of the interview. Eighty percent of the women interviewed stated that they currently had insurance. However,
this includes a number of women that were under charity care at local hospitals and cancer centers. They considered charity care a form of insurance. Forty-seven percent stated that they did not have access to a therapist or mental health professional, if they needed it. Fifty percent of the participants reported that they had not attended a cancer support group.

The next several pages detail the findings from the structured questionnaire. For the statistical tests, I looked for levels of association or significant differences at the .05 level.

**Age and ethnicity and social support**

Before presenting the results that address the proposed hypothesis, I investigated the relationship between the demographic factors of interest: age, ethnicity, as well as marital status and overall social support.

- A correlation analysis (Spearman's rho) between age and overall social support \( r = -.192(58) \), \( p > .05 \) was performed to see if there was a correlation between age and overall social support. The relationship was not significant.
- A Mann Whitney Test was used to compare overall social support between women who were less than 50 years of age and women who were over 50 years of age. There was no significant difference \( z = -1.436 \), \( p > .05 \).
- A Kruskal-Wallis analysis to see if there was a difference in overall social support among women from different ethnic groups (Colombia, Cuba, Dominican Republic, Mexico, and Puerto Rico) was performed. Results show there was no significant difference \( X^2 = 4.294 (4, N=47) \), \( p > .05 \). I selected the ethnic groups where I had five or more cases.

Income, length of time in the US, and English proficiency are explored in more detail in the following paragraphs, as they are directly related to the proposed hypothesis.
Cultural Beliefs, Norms and Expectations about Gender Roles and Social Support (Hypothesis 1)

The next few paragraphs describe results related to Hypothesis H1, H.1.a, H.1, b., H.1.c.

H1. Cultural expectations about gender roles will influence social support

Each the participant was asked if she had that particular type of support. If she responded “yes,” that she had that type of support, she was then asked to list up to three people that could provide that support, if she needed it. Table 2 illustrates the proportion of men vs. women listed as sources of support by the participants.

Figures 4.3.a, 4.3.b., and 4.3.c. illustrate the percentages listed in Table 4.8, broken down by support category (e.g., emotional, tangible, etc.) It also indicates the percentage that did not have that type of support. This table and figures show that a higher proportion of emotional supports were provided by women compared to men. For example, 50% (n=29) of participants listed only women as someone who understands their problems compared to the 8.3% (n=5) who listed only men. Similar trends can be seen for the other types of emotional support, such as someone to visit you if you were not feeling well with 55% (n=33) stating they received support from only women and 8.3% (n=5) from only men. Interestingly, a slightly higher proportion of men provide support items included under tangible support compared to the proportion of men who provide support items listed under emotional support. For example, 46.7% (n=28) of participants listed only men as someone who went to the pharmacy to get prescriptions compared to the 25% (n=15) of participants who listed only women. A similar trend is seen in support from someone to help with household bills, where again we see a higher proportion of support being provided by men. In general, it was surprising to see the percentage of women who reported not having certain kinds of support.
Table 4.8. Social Support from Men vs. Women

<table>
<thead>
<tr>
<th>Do you have the following kinds of support available if you need it</th>
<th>No support %</th>
<th>Have support from</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men only %</td>
<td>Women only %</td>
</tr>
<tr>
<td>Someone who listens to you when you need to talk N=60</td>
<td>28.3</td>
<td>5.0</td>
</tr>
<tr>
<td>Someone to confide in or talk to about your problems N=59</td>
<td>25.0</td>
<td>5.0</td>
</tr>
<tr>
<td>Someone who is patient with you N=59</td>
<td>21.7</td>
<td>21.7</td>
</tr>
<tr>
<td>Someone who encourages you N=60</td>
<td>8.3</td>
<td>13.3</td>
</tr>
<tr>
<td>Someone who understands your problems N=59</td>
<td>26.7</td>
<td>8.3</td>
</tr>
<tr>
<td>Someone who shows you love and affection N=60</td>
<td>15.0</td>
<td>11.7</td>
</tr>
<tr>
<td>Someone to do something enjoyable with N=59</td>
<td>30.0</td>
<td>18.3</td>
</tr>
<tr>
<td>Someone to visit you at home or in the hospital, if you were not feeling well N=60</td>
<td>10.0</td>
<td>8.3</td>
</tr>
<tr>
<td>Someone to look over your pets, if you were if you were hospitalized N=40</td>
<td>60.0</td>
<td>20.0</td>
</tr>
<tr>
<td>Someone to help you, if you were confined to bed N=60</td>
<td>13.3</td>
<td>10.0</td>
</tr>
<tr>
<td>Someone to drive you to the doctor N=59</td>
<td>25.0</td>
<td>26.7</td>
</tr>
<tr>
<td>Someone to go to the pharmacy and get your medications/prescriptions N=59</td>
<td>18.3</td>
<td>46.7</td>
</tr>
<tr>
<td>Someone to help you with your household bills N=58</td>
<td>30.0</td>
<td>51.7</td>
</tr>
<tr>
<td>Someone to help you cook, if you were unable to cook N=60</td>
<td>15.0</td>
<td>16.7</td>
</tr>
<tr>
<td>Someone to help with daily chores, if you were not feeling well N=60</td>
<td>18.3</td>
<td>16.7</td>
</tr>
<tr>
<td>Someone to help you with childcare, if you were not feeling well N=26</td>
<td>81.7</td>
<td>5.0</td>
</tr>
<tr>
<td>Someone to bring you soup/food, if you were not feeling well N=60</td>
<td>13.3</td>
<td>3.3</td>
</tr>
<tr>
<td>Someone to help you fill out medical-related paperwork N=52</td>
<td>50.0</td>
<td>10.0</td>
</tr>
<tr>
<td>Someone to help you figure out insurance issues N=50</td>
<td>68.3</td>
<td>8.3</td>
</tr>
<tr>
<td>Someone to help you find resources N=54</td>
<td>71.7</td>
<td>1.7</td>
</tr>
<tr>
<td>Someone to interpret / translate for you N=49</td>
<td>48.3</td>
<td>6.7</td>
</tr>
</tbody>
</table>
For example, 28.3 (n=17) reported not having someone who listened to them when they needed to talk. Similarly, 26.7% reported not having someone to understand their problems. Seventy-one percent (n=38) report not having someone to help them find resources. And 81% (n=21) of women with children report not having someone to help with childcare.

H1.a. Compared to women, a higher proportion of men will likely provide instrumental/tangible support, and a higher proportion of women will likely provide emotional support, compared to men.

The largest percentage of men were reported as offering assistance by driving to the doctor (26.7%), going to the pharmacy to get medications (46.7%), and paying household bills (51.7%). On the other hand, a higher percentage of women were reported as offering assistance by cooking (61.7%), helping with household chores (53.3%), and understanding the patient’s problems (50%).
Figure 4.3.a. Emotional Support from Men vs. Women

Emotional Support

- Someone who listens to you when you need to talk
- Someone to confide in or talk to about your problems
- Someone who is patient with you
- Someone who encourages you
- Someone who understands your problems
- Someone who shows you love and affection
- Someone to do something enjoyable with
- Someone to visit you at home or in the hospital if you were not feeling well

[Bar chart showing data for men, women, and both]
Instrumental/Tangible Support

Figure 4.3.b Instrumental/Tangible Support from Men vs. Women
Figure 4.3.c Informational Support from Men vs. Women

Figure 4.4. Marital Status and Support from Men

Informational Support

- Someone to help you fill out medical-related paperwork
- Someone to help you figure out insurance issues
- Someone to help you find resources
- Someone to interpret / translate for you

Legend:
- None
- Men
- Women
- Both men and women
Thus, findings support hypothesis H.1.a. Data from the structured questionnaires illustrate a similar trend regarding who provides support or assistance, if needed, by gender. The findings show that men were more likely to provide support by addressing necessities outside the home, like going to the pharmacy, driving to the doctor, and paying bills. Women were more likely provide emotional support, such as listening, talking, encouraging, understanding, and visiting. However, a large percentage of the participants listed both men and women for love and affection. Regarding informational support, women seemed to encounter logistical barriers, saying they did not have someone to help them with paperwork, insurance issues, community resources and interpretation/translation. Among those that did have someone to help with informational support, a larger percentage listed women as providers of support. Cooking, housework, and assisting the patient, if she was confined to a bed are categorized under instrumental/tangible support. It was hypothesized that these types of assistance would more likely be provided by men; however, research indicates that they were more likely to be provided by women.
H1.b., Cultural expectations that women should not burden family and friends with personal concerns/worries will negatively influence social support.

Beliefs and concerns about protecting the family and not burdening them with personal concerns were mentioned frequently by participants interviewed in Phase I. Participants were asked if they agreed or disagreed with the following two statements: a) “It is best not to burden family and friends with personal concerns/worries,” and b) “The needs of the family should come before your own.” Table 4.9 illustrates the percentage of participants who agreed with each statement. For example, 55% agreed that it was best not to burden family and friends with personal concerns, and 41.7% agreed that “the needs of the family should come before your own.”

Table 4.9 Cultural Beliefs and Expectations N=60

<table>
<thead>
<tr>
<th>Statement</th>
<th>Percent Agree</th>
<th>Percent Disagree</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is best not to burden family and friends with personal concerns/worries.</td>
<td>55.0</td>
<td>45.0</td>
<td>.001</td>
</tr>
<tr>
<td>The needs of the family should come before your own</td>
<td>41.7</td>
<td>58.3</td>
<td>.014</td>
</tr>
<tr>
<td>We have to accept suffering</td>
<td>76.3</td>
<td>23.7</td>
<td>.134</td>
</tr>
<tr>
<td>We have to resign ourselves to what life brings, we can not change what</td>
<td>75.0</td>
<td>25.0</td>
<td>.432</td>
</tr>
<tr>
<td>is going to happen</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

A Mann-Whitney Test was used to compare the overall social support score of those who agreed with the statement that “It was best not to burden family and friends…” with the overall social support score of those that disagreed with the statement. This test was found to be statistically significant, z = -3.236, p < .01. This indicates that women who agreed that it is best not to burden family and friends with personal concerns also report less overall social support.

A Mann-Whitney Test was also performed to compare the mean overall social support score of those who agreed with the statement that “The needs of the family should come before your own” with the mean overall social support score of those that disagreed with the statement. This test was found to be statistically significant, z= -
2.448, \( p < .05 \). This indicates that women who agreed that the needs of the family should come first also report less overall social support.

To assess beliefs and expectations regarding being strong/tolerant about pain and accept suffering, participants were asked if they agreed or disagreed with the following two statements: “We have to accept suffering,” and “We have to resign ourselves to what life brings; we can not change what is going to happen.” A Mann-Whitney Test was used to compare the mean overall social support score of those who agreed with the statement that “We have to accept suffering” with the mean overall social support score of those that disagreed with the statement. This test was found not to be statistically significant, \( z = -1.49, p > .05 \).

The same statistical test was done to compare the mean overall social support score of those who agreed with the statement that “We have to resign ourselves to what life brings, we can not change what is going to happen” with the mean overall social support score of those that disagreed with the statement. This test was found not to be statistically significant, \( z = -.786, p > .05 \).

Participants were also asked if they told their family about their diagnosis right away, if they waited to tell them, or if they had not told their family (See Table 5). The majority of participants (65%) did tell their family right away, while 33% waited to tell their family about their diagnosis. Correlation analysis (Spearman’s rho) was used to discern if there was a relationship between when the patients told their family about their diagnosis and the overall social support they received. There was no significant correlation, \( r = -.191(58), p > .05 \).

Participants were also asked if they ever felt they needed to maintain a happy/strong face during their cancer treatment (See Table 4.10). A large percentage of participants (48.3%) felt that they did. A correlation analysis (Spearman’s rho) was done to see if there was a relationship between having to keep a happy/strong face and the
overall social support the patient received; however, there was no significant correlation, \( r = -0.057(58), p > 0.05 \).

Table 4.10. Communication with Family N=60

<table>
<thead>
<tr>
<th>Did you tell your family about your diagnosis?</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, right away</td>
<td>65.0</td>
</tr>
<tr>
<td>Yes, but I waited to tell them</td>
<td>33.3</td>
</tr>
<tr>
<td>No, I have not told them about my diagnosis</td>
<td>1.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Have you ever felt you needed to keep a happy/strong face during your cancer treatment?</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>28.3</td>
</tr>
<tr>
<td>Sometimes</td>
<td>23.3</td>
</tr>
<tr>
<td>Yes</td>
<td>48.3</td>
</tr>
</tbody>
</table>

Chi-square and Mann Whitney Test were used to further explore possible differences between the demographic factors of interest: age (under 50/over 50), ethnicity (Colombia, Cuba, Dominican Republic, Mexico and Puerto Rico), length of time in the US (10 years or less/more than 10 years), English proficiency, marital status (married or not), and the selected beliefs and cultural expectations discussed above.

Table 4.11 shows there was only a significant difference being between younger and older women who agreed with the statement “The needs of the family should come before your own.” \( \chi^2 = 10.823(1, N=60), p < 0.01 \). This indicates that older women were more likely to agree with the statement than younger women. There was no significant difference between younger and older women regarding when they told their family about their diagnosis and whether they believed they needed to maintain a strong/happy face during treatment. There was no significant difference between ethnicity and the selected beliefs and cultural expectations.
Table 4.11. Comparing Cultural Beliefs and Expectations between Older and Younger Women

<table>
<thead>
<tr>
<th>Belief</th>
<th>50 and younger (n=27) % Agree</th>
<th>Older than 50 (n=33) % Agree</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is best not to burden family and friends with personal concerns/worries.</td>
<td>52.0</td>
<td>58.0</td>
<td>.795</td>
</tr>
<tr>
<td>The needs of the family should come before your own</td>
<td>18.5</td>
<td>60.6</td>
<td>.001</td>
</tr>
<tr>
<td>We have to accept suffering</td>
<td>69.2</td>
<td>81.8</td>
<td>.358</td>
</tr>
<tr>
<td>We have to resign ourselves to what life brings; we can not change what is going to happen</td>
<td>63.0</td>
<td>84.8</td>
<td>.073</td>
</tr>
</tbody>
</table>

Table 4.12 shows that women who have been in the US more than 10 years feel that one must accept suffering, $\chi^2 = 5.229(1, N=60), p < .05$. There were no other significant effects. There was no significant difference between women who have been in the US 10 years or less and women who have been in the US 10 or more years regarding when they told their family about their diagnosis and whether they believed they needed to maintain a strong/happy face during treatment.

Table 4.12. Comparing Cultural Beliefs and Expectations between Women Who Have Been in the US $\leq 10$ Years and $>10$ Years

<table>
<thead>
<tr>
<th>Belief</th>
<th>$\leq 10$ years (n=20) % Agree</th>
<th>$&gt; 10$ years (n=40) % Agree</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is best not to burden family and friends with personal concerns/worries.</td>
<td>45.0</td>
<td>60.0</td>
<td>.288</td>
</tr>
<tr>
<td>The needs of the family should come before your own</td>
<td>35.0</td>
<td>45.0</td>
<td>.581</td>
</tr>
<tr>
<td>We have to accept suffering</td>
<td>57.9</td>
<td>85.0</td>
<td>.046</td>
</tr>
<tr>
<td>We have to resign ourselves to what life brings; we can not change what is going to happen</td>
<td>65.0</td>
<td>89.0</td>
<td>.223</td>
</tr>
</tbody>
</table>

Table 4.13 shows that just over half of the women who have high English proficiency agree with the statement “We have to accept suffering,” as compared to 80% of women with moderate English proficiency, and 90% of women with low English.
proficiency. The difference was significant, $\chi^2 = 7.871(2, N=60), p < .05$. This indicates that women with low English proficiency were more likely to agree with the statement “We have to accept suffering.” There was no significant difference between women who have low, moderate or high English proficiency regarding when they told their family about their diagnosis and whether they believed they needed to maintain a strong/happy face during treatment.

Table 4.13. Comparing Cultural Beliefs and Expectations among Women Who Have Low, Moderate and High English Proficiency

<table>
<thead>
<tr>
<th></th>
<th>Low EP (n=22) % Agree</th>
<th>Moderate EP (n=20) % Agree</th>
<th>High EP (n=18) % Agree</th>
<th>$p$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is best not to burden family and friends with personal concerns/worries</td>
<td>68.2</td>
<td>50.0</td>
<td>44.4</td>
<td>.278</td>
</tr>
<tr>
<td>The needs of the family should come before your own</td>
<td>54.5</td>
<td>35.0</td>
<td>33.3</td>
<td>.304</td>
</tr>
<tr>
<td>We have to accept suffering</td>
<td>90.9</td>
<td>80.0</td>
<td>52.9</td>
<td>.020</td>
</tr>
<tr>
<td>We have to resign ourselves to what life brings; we can not change what is going to happen</td>
<td>86.4</td>
<td>75.0</td>
<td>61.1</td>
<td>.186</td>
</tr>
</tbody>
</table>

There was no significant relationship between marital status and the selected cultural beliefs and expectations (Table 4.14, See next page). There was also no significant difference between women who were married and those that were not in their responses to when they told their family about their diagnosis.

There was a significant difference between women who were married and those that were not in their response to the question “Have you ever felt you needed to keep a happy/strong face during your cancer treatment?” Twice as many married women (20 of 31) felt they had to keep a strong face, as compared to unmarried women (9 of 29), $\chi^2 = 6.727(2, N=60), p < .05$. 
Table 4.14. Comparing Cultural Beliefs and Expectations between Women Who Are Married And Not Married

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not Married (n=29) % Agree</th>
<th>Married (n=31) % Agree</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is best not to burden family and friends with personal concerns/worries.</td>
<td>54.5</td>
<td>45.5</td>
<td>.211</td>
</tr>
<tr>
<td>The needs of the family should come before your own</td>
<td>48</td>
<td>52</td>
<td>.586</td>
</tr>
<tr>
<td>We have to accept suffering</td>
<td>46.7</td>
<td>53.3</td>
<td>.534</td>
</tr>
<tr>
<td>We have to resign ourselves to what life brings; we can not change what is going to happen</td>
<td>46.7</td>
<td>53.3</td>
<td>.440</td>
</tr>
</tbody>
</table>

Table 4.15 illustrates the percentage of women who agree with the selected cultural beliefs and expectation statements by ethnicity. There was no significant difference.

Table 4.15. Comparing Cultural Beliefs and Expectations among Colombian, Cuban, Dominican, Mexican and Puerto Rican Women

<table>
<thead>
<tr>
<th>Statement</th>
<th>Colombia (n=10) % Agree</th>
<th>Cuba (n=7) % Agree</th>
<th>Dominican Republic (n=5) % Agree</th>
<th>Mexico (n=5) % Agree</th>
<th>Puerto Rico (n=20) % Agree</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is best not to burden family and friends with personal concerns/worries.</td>
<td>29.2</td>
<td>8.3</td>
<td>16.7</td>
<td>8.3</td>
<td>37.5</td>
<td>.281</td>
</tr>
<tr>
<td>The needs of the family should come before your own</td>
<td>26.3</td>
<td>15.8</td>
<td>15.8</td>
<td>10.5</td>
<td>31.6</td>
<td>.718</td>
</tr>
<tr>
<td>We have to accept suffering</td>
<td>20.6</td>
<td>14.7</td>
<td>14.7</td>
<td>8.8</td>
<td>41.2</td>
<td>.668</td>
</tr>
<tr>
<td>We have to resign ourselves to what life brings; we can not change what is going to happen</td>
<td>19.4</td>
<td>19.4</td>
<td>8.3</td>
<td>11.0</td>
<td>41.7</td>
<td>.523</td>
</tr>
</tbody>
</table>
Language (English proficiency), provider communication and social support

(Hypothesis 2)

The next few paragraphs describe results related to Hypothesis H2 and H.2.a.

H2. Language (English proficiency) will be positively associated with social support.

Correlation analysis (Spearman’s rho) was used to explore the relationship between English proficiency and overall social support, \( r = .023(58), p > .05 \). The correlation analysis indicates that there was no significant relationship between English proficiency and overall social support. Findings do not provide evidence for this hypothesis.

H2.a Women with limited English proficiency will be less likely to have informational support than those that who are English proficient.

Health providers, namely physicians, are a source of informational support, specifically information related to disease and treatment information, which women in the in-depth interviews listed as the most important information that a woman with cancer needed to know. A majority of the women interviewed (58.3-63.3%) reported that, “yes,” they were able to communicate with their health provider (Table 4.16, next page). Correlation analysis (Spearman’s rho) was used to determine if there was a relationship between English proficiency and provider communication, which was assessed using a four item provider communication scale (See Chapter 4 Methodology). Results show that there is a moderate correlation between English proficiency and provider communication, \( r = .366(58), p < .05 \). Those with higher English proficiency also report better provider communication.
Table 4.16  Provider Communication N=60

<table>
<thead>
<tr>
<th></th>
<th>No %</th>
<th>Sometimes %</th>
<th>Yes %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you understand all the explanations and instructions you received from your doctor?</td>
<td>6.7</td>
<td>33.3</td>
<td>60.0</td>
</tr>
<tr>
<td>Did you receive sufficient information about the treatment you received?</td>
<td>16.7</td>
<td>25.0</td>
<td>58.3</td>
</tr>
<tr>
<td>Where you able to communicate your worries and concerns to your doctors?</td>
<td>15.0</td>
<td>25.0</td>
<td>60.0</td>
</tr>
<tr>
<td>Did you feel your doctor listened to your concerns?</td>
<td>16.7</td>
<td>20.0</td>
<td>63.3</td>
</tr>
</tbody>
</table>

Results in Table 4.17 show that women with low English proficiency are more likely to have someone help them with paperwork (90.5%) than women with high English proficiency (25%), χ²=14.836(2), N=60, p<.01. Similarly, women with low English proficiency and moderate English proficiency are also more likely to have someone to interpret/translate for them than women with high English proficiency, χ²=20.913(2), N=60, p<.01.

Table 4.17. English Proficiency and Informational Support

<table>
<thead>
<tr>
<th></th>
<th>Low EP (n=22)</th>
<th>Moderate EP (n=20)</th>
<th>High EP (n=18)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Someone to help you fill out medical-related paperwork</td>
<td>90.5% Yes</td>
<td>52.6% Yes</td>
<td>25.0% Yes</td>
<td>.001</td>
</tr>
<tr>
<td>Someone to help you figure out insurance issues</td>
<td>40.0% Yes</td>
<td>38.9% Yes</td>
<td>25.0% Yes</td>
<td>.659</td>
</tr>
<tr>
<td>Someone to interpret / translate for you</td>
<td>77.3% Yes</td>
<td>83.3% Yes</td>
<td>0.0% Yes</td>
<td>.000</td>
</tr>
<tr>
<td>Someone to help you find resources</td>
<td>40.9% Yes</td>
<td>31.6% Yes</td>
<td>31.5% Yes</td>
<td>.297</td>
</tr>
</tbody>
</table>

To determine if there was a difference in the rate of English proficiency (low, moderate, high) between younger and older women, a Chi-square test was run. Results show no significant difference, χ²=5.048 (2, N=60), p >.05. A Kruskal Wallis test was used to determine if there was a difference in English proficiency (score) between women of different ethnicities (There was no significant difference in English proficiency among the different ethnicities, χ²=4.648 (4, N=47), p >.05. Informational support
measures assume that all women need help with paperwork, insurance issues, translation and resources.

A Mann Whitney Test was done to determine if there was a difference in English proficiency (score) between women who had been in the US 10 years or less compared to those who had been in the US more than 10 years. Results show there was a significant difference, \( z=-3.036, p < .01 \). It indicates that women who have been in the US a longer period of time are more English proficient. There was no significant difference in English proficiency between women who were married and those who were unmarried, \( z= -.784, p >.05 \).

**Chronic stress, psychosocial distress and social support (Hypothesis 3)**

The next few paragraphs detail results related to H3 and psychosocial distress and social support.

**H3. Chronic stress (poverty, family problems, economic/financial problems, immigration status) will be negatively associated with social support.**

Findings from the in-depth interviews revealed two main categories of stressors: social/socioeconomic factors and disease-related factors. The results related to chronic stress, social/socioeconomic factors and social support will be presented first. Then the data on disease-related stressors and their association with social support will be offered.

A majority of women who had children (54%) said that the relationship with their children was not a problem and/or was not stressful for them. However, almost 38% said that providing for their family was a problem or proved to be stressful. Paying household bills was a problem or was stressful for 40.7% of the participants. Immigration status was not a problem for 75% of the women (See Table 4.18, next page).
Using the seven-item chronic stress scale (See Chapter 3 Methodology), a correlation analysis was used to determine if there was a relationship between chronic stress and overall social support. Results show that there was a moderate significant negative correlation, $r = -.431(58)$, $p < .01$, between overall social support and chronic stress. That indicates that women who reported higher chronic stress also reported lower overall social support.

Chronic stress reported by women who were less than 50 yrs of age was compared to chronic stress reported by those who were 50 years and older. There was no significant difference, $z = -.268$, $p > .05$. A Kruskal Wallis Test was used to compare chronic stress among the different ethnic groups. Results show that there was a significant difference between Colombian, Cuban, Dominican, Mexican and Puerto Rican, $\chi^2 = 9.802 (4, N=47)$, $p < .05$.

Chronic stress reported by women who had been in the US less than 10 years was compared to chronic stress reported by women who had been in the US for 10 years or more. There was no significant difference, $z = -.126$, $p > .05$. There was also no significant difference in chronic stress between participants who were married and those who were unmarried, $z = -1.633$, $p > .05$. A correlation analysis was used to determine if there was a relationship between chronic stress and English proficiency. Results show

<table>
<thead>
<tr>
<th>Are any of the following a problem or stressful for you?</th>
<th>No</th>
<th>Sometimes</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship with my children (n=48)</td>
<td>54.0</td>
<td>20.8</td>
<td>25.0</td>
</tr>
<tr>
<td>Providing for my family (n=48)</td>
<td>45.8</td>
<td>16.7</td>
<td>37.5</td>
</tr>
<tr>
<td>Not being able to pay for medications (n=58)</td>
<td>44.8</td>
<td>20.7</td>
<td>34.5</td>
</tr>
<tr>
<td>Paying household bills (rent, electricity, water etc) (n=59)</td>
<td>40.7</td>
<td>18.6</td>
<td>40.7</td>
</tr>
<tr>
<td>Immigrations status (n=52)</td>
<td>75.0</td>
<td>3.8</td>
<td>21.2</td>
</tr>
<tr>
<td>The type of work you do (n=34)</td>
<td>58.8</td>
<td>20.6</td>
<td>20.6</td>
</tr>
<tr>
<td>Work environment (n=34)</td>
<td>64.7</td>
<td>14.7</td>
<td>20.6</td>
</tr>
</tbody>
</table>
that there was a moderate significant correlation, $r = -0.358(58)$, $p < 0.01$, between English proficiency and chronic stress. This indicates that women with higher English proficiency also reported less chronic stress.

**Socioeconomic factors that influence social support**

Household income and employment are important socioeconomic factors. Thus, a Kruskal-Wallis Test was run to determine if there was a relationship between household income (See Table 4.19 for income breakdown) and overall social support. No significant difference was found, $\chi^2 = 7.019(4, \text{ N}=60)$, $p > 0.05$.

<table>
<thead>
<tr>
<th>Table 4.19. Household Income N=60</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Household income</strong></td>
</tr>
<tr>
<td>10,000 or less</td>
</tr>
<tr>
<td>10,001-30,000</td>
</tr>
<tr>
<td>30,001-50,000</td>
</tr>
<tr>
<td>More than 50,000</td>
</tr>
<tr>
<td>Do not know</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source of Income</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own/ Spouse Salary</td>
<td>63.3</td>
</tr>
<tr>
<td>Social Security</td>
<td>28.3</td>
</tr>
<tr>
<td>Economic Assistance from Children</td>
<td>18.3</td>
</tr>
<tr>
<td>Economic Assistance from Family</td>
<td>20.0</td>
</tr>
<tr>
<td>Rent from Other Properties</td>
<td>3.3</td>
</tr>
<tr>
<td>Own Business</td>
<td>3.3</td>
</tr>
<tr>
<td>Other</td>
<td>20.0</td>
</tr>
</tbody>
</table>

Mann-Whitney test results comparing social support between those who had a household income of $10,000 or less (28.3%) to those with a household income of more than $10,000 proved to be statistically significant, $z = -2.431$, $p < 0.05$. This indicates that women who have a household income of $10,000 or less report lower overall social support.

The participants’ responses to the statement “It is best not to burden family and friends with personal concerns/worries” were compared between those whose household income was $10,000 or less (28.3%) and those that had a household income greater that $10,000. Results show there was a significant difference, $\chi^2 = 4.418$
(1, N=60), p < .05, with a higher percentage of participants who had a household income less that $10,000 agreeing with the statement.

A Kruskal-Wallis Test was run to determine if there was a relationship between current employment (See Table 4.20) and overall social support. No significant relationship was found, $\chi^2 = 6.566$ (5, N=60), p > .05. Current employment was divided into two categories: those that worked (part time and full time) (43.4%) and those that did not work (homemakers, retired, disabled). Mann-Whitney Test results comparing those who worked with those who did not work were found to be statistically significant, z = -2.204, p < .05. This indicates that women who did not work reported lower overall social support.

Table 4.20. Employment Status N=60

<table>
<thead>
<tr>
<th>Current Employment</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fulltime</td>
<td>36.7</td>
</tr>
<tr>
<td>Half time</td>
<td>6.7</td>
</tr>
<tr>
<td>Retired</td>
<td>13.3</td>
</tr>
<tr>
<td>Ama de casa (homemaker)</td>
<td>13.3</td>
</tr>
<tr>
<td>Unemployed looking for work</td>
<td>5.0</td>
</tr>
<tr>
<td>Unemployed due to disability/illness</td>
<td>25.0</td>
</tr>
</tbody>
</table>

The responses to the statement “The needs of the family should come before your own” were compared from participants who worked and from participants who did not work. Findings show there was a significant difference, $\chi^2 = 13.039$ (1, N=60), p < .01, with a higher percentage of those who did not work stating they agree with the statement.

**Disease-related distress and social support**

Data from the in-depth interviews also revealed important disease-related stressors, thus the relationship between these stressors and social support was also investigated. Table 4.21 provides a snapshot of women’s distress associated with their illness/treatment. Fifty percent of women report that their illness was very distressing to their family. When asked if their sexual/intimate relationship with their spouse had been negatively impacted by their illness, 43.6% responded “yes, a lot”. A majority of the
women (58.7%) who worked said that their illness and treatment had interfered with their employment. Forty-five percent said their illness had interfered with their activities at home. About a third of the women (33.3%) said they felt isolated because of their illness/treatment.

Table 4.21. Distress Associated with Illness/Treatment

<table>
<thead>
<tr>
<th>Question</th>
<th>No, not at all %</th>
<th>A little %</th>
<th>Yes, a lot %</th>
</tr>
</thead>
<tbody>
<tr>
<td>How distressing has your illness been for your family? (n=60)</td>
<td>20.0</td>
<td>30.0</td>
<td>50.0</td>
</tr>
<tr>
<td>Has your sexual/intimate relationship with your spouse/partner been negatively impacted by your illness? (n=39)</td>
<td>43.6</td>
<td>12.8</td>
<td>43.6</td>
</tr>
<tr>
<td>Has your illness and treatment interfered with your employment? (n=46)</td>
<td>37.0</td>
<td>4.3</td>
<td>58.7</td>
</tr>
<tr>
<td>Has your illness and treatment interfered with your activities at home? (n=60)</td>
<td>20.0</td>
<td>35.0</td>
<td>45.0</td>
</tr>
<tr>
<td>Do you ever feel isolated because of your illness or treatment? (n=60)</td>
<td>40.0</td>
<td>26.7</td>
<td>33.3</td>
</tr>
<tr>
<td>Have you ever felt you had to make a choice between working to support your family and following your treatment? (n=60)</td>
<td>No 71.7</td>
<td>Sometimes 3.3</td>
<td>Yes 25.0</td>
</tr>
</tbody>
</table>

Correlation analysis was done to determine if there was a relationship between family distress and overall social support. Results found no significant relationship, r=.066, p >.05. Similarly, there was no significant association between the sexual/intimate relationship and overall social support, r=-.038, p>.05, nor between employment interference and overall social support, r=-.046, p>.05, nor between interference with household activities and overall social support, r=.193, p>.05. However, there was a moderate significant correlation, of r = -.467, p<.01, between women who report feeling isolated because of their illness or treatment and overall social support. This indicates that women who report feeling more isolated also report less overall social support. There was no correlation between having to choose between working and receiving treatment and overall social support, r=-.60, p>.05.
**Immigration, Length of Time in the US and Social Support (Hypothesis 4)**

The following paragraphs details the results related to H4, H4.a, and H4.b.

**H4. Length of time in the US will influence social support.**

Table 4.22 details data related to length of time in the US and ties to the participant’s native country. Almost half of the women (46.7%) had been in the US for 20 years or longer. The average number of years in the US was 21.6. Almost 17% had lived in the US five years or less. Thirty-five percent came to the United States alone. Mean age at emigration was 30. Colombian participants had been in the US the shortest amount of time, and Puerto Rican participants had been in the US for the longest amount of time.

Table 4.22. Length of Time in the US and Ties to Family in Native Country (N=60)

<table>
<thead>
<tr>
<th>Length of time in the US</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lived in the US 5 yrs or less</td>
<td>16.7</td>
</tr>
<tr>
<td>Lived in the US Between 6-10 yrs</td>
<td>20.0</td>
</tr>
<tr>
<td>Lived in the US Between 11-15 yrs</td>
<td>10.0</td>
</tr>
<tr>
<td>Lived in the US Between 16-20 yrs</td>
<td>6.7</td>
</tr>
<tr>
<td>Lived in the US more than 21 years</td>
<td>46.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Who came with you to the USA?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>35.0</td>
</tr>
<tr>
<td>With husband and or family members</td>
<td>65.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How Often Communicate with Family in Native Country?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>3.3</td>
</tr>
<tr>
<td>Every Once in a While</td>
<td>15.0</td>
</tr>
<tr>
<td>Once a Month</td>
<td>10.0</td>
</tr>
<tr>
<td>Once a Week</td>
<td>45.0</td>
</tr>
<tr>
<td>More than Once a Week</td>
<td>25.0</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>1.7</td>
</tr>
</tbody>
</table>

| Sent Remittances Back Home Before Diagnosis | 54.2 |
| Did Diagnosis Affect Ability to Send Remittances Home? | |
| Could No Longer Send Remittances                | 37.5 |
| A Little, Could Not Send as Much as Before       | 43.8 |
| Not at all                                       | 18.8 |

Over 50% sent remittances to their family before they were diagnosed with cancer; however, after the cancer diagnosis, 37.5% of those who sent remittances reported no longer being able to send money to their family in their native country.
A correlation analysis (Spearman’s rho) was done to assess if there was a relationship between the length of time the participant had been in the US and overall social support. Results found no significant relationship, \( r = -0.022(58), p > .05 \). Years spent in the US was collapsed into two categories and a Mann-Whitney Test was then used to determine if there was a difference in overall social support between women who had been in the US less than 10 years and those who had been in the US more than 10 years. There was no significant difference, \( z = -0.840, p > .05 \). A Mann-Whitney Test was used to see if there was a difference in the length of time women had been in the US before they were diagnosed and overall social support. Women who had been in the US 10 years or less before they were diagnosed were compared to women who had been in the US more than 10 years before they were diagnosed with breast cancer. There was no significant difference between the length of time women had been in the US before the cancer diagnosis and overall social support, \( z = -0.136, p > .05 \).

Findings show that 35% of women immigrated to the US alone. A Mann-Whitney Test was performed to determine if there was a relationship between overall social support and coming to the US alone. Results show that there is a significant difference in overall social support between those that came to the US alone and those that came with family, \( z = -3.058, p < .01 \). Thus, women who came to the US with family report higher overall social support than those that came to the US alone.

_H4. a.,_ Women who have been in the US a shorter period of time will likely rely on family and friends in their native county for emotional support.

Each participant was asked if she had a particular type of emotional support. If she responded “yes,” then she was asked to list up to three people that provided that type of support. Then, she was asked to identify if they lived in the US or in their native country. Table 4.23 (next page) and Figure 5.5 illustrate the percentage of people who provided support to the participant by where they lived (i.e., if they lived in their native county...
country or if they lived in the US) and by the length of time the participant had been in the US. A slightly higher percentage of participants who lived in the US over 10 years (32.5%, n=13) reported not having someone who understands their problems compared to participants who had been in the US 10 years or less (20%, n=4). Data also illustrate that a higher proportion of participants who had been in the US 10 years or less report receiving emotional support from someone in their native country compared to participants who had been in the US more than 10 years. For example, 20% (n=4) of participants who lived in the US 10 years or less report only having someone who understands their problems in the their native country compared to 0% of participants who had been in the US 10 or more years. Interestingly though, across all the types of emotional support listed, a higher proportion of support was provided by someone in the United States regardless of the length of time the participant had lived in the United States.

Figure 4.5 visually illustrates the percentage of women who reported having a particular type of emotional support from someone in their native country, in the US or both in the US and their native country by length of time the participant has spent in the US (10 years or less compared to more that 10 years). To determine if there was a relationship between the numbers of years the participant has spent in the US and emotional support (See Methods Section) from someone in their native country, a correlation analysis was done. Results found no correlation, r=-.216, p >.05. This indicates that there is no significant relationship between the length of time the participants have been in the US and the emotional support received from someone their native country.
### Table 4.23. Comparing Emotional Support from Someone in Native Country vs. Someone in US by Length of Time Participant has Spent in the US

<table>
<thead>
<tr>
<th>Length of time in the US</th>
<th>Have support from</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No Support</td>
<td>Someone in their native country</td>
<td>Someone in the USA</td>
<td>Both someone in native country and in USA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;= 10 (n=20) %</td>
<td>&gt; 10 (n=40) %</td>
<td>&lt;= 10 (n=20) %</td>
<td>&gt; 10 (n=40) %</td>
<td>&lt;= 10 (n=20) %</td>
<td>&gt; 10 (n=40) %</td>
<td></td>
</tr>
<tr>
<td>Someone who listens to you when you need to talk N=60</td>
<td>30.0</td>
<td>25.0</td>
<td>15.0</td>
<td>5.0</td>
<td>40.0</td>
<td>57.5</td>
</tr>
<tr>
<td>Someone to confide in or talk to about your problems N=59</td>
<td>20.0</td>
<td>27.5</td>
<td>5.0</td>
<td>5.0</td>
<td>50.0</td>
<td>60.0</td>
</tr>
<tr>
<td>Someone who is patient with you N=59</td>
<td>30.0</td>
<td>17.5</td>
<td>5.0</td>
<td>2.5</td>
<td>50.0</td>
<td>80.0</td>
</tr>
<tr>
<td>Someone who encourages you N=60</td>
<td>5.0</td>
<td>12.5</td>
<td>10.0</td>
<td>2.5</td>
<td>75.0</td>
<td>80.0</td>
</tr>
<tr>
<td>Someone who understands your problems N=59</td>
<td>20.0</td>
<td>32.5</td>
<td>20.0</td>
<td>0.0</td>
<td>55.0</td>
<td>65.0</td>
</tr>
<tr>
<td>Someone who shows you love and affection N=60</td>
<td>20.0</td>
<td>12.5</td>
<td>10.0</td>
<td>0.0</td>
<td>50.0</td>
<td>80.0</td>
</tr>
<tr>
<td>Someone to do something enjoyable with N=59</td>
<td>25.0</td>
<td>32.5</td>
<td>5.0</td>
<td>0.0</td>
<td>65.0</td>
<td>60.0</td>
</tr>
<tr>
<td>Someone to visit you at home or in the hospital, if you were not feeling well N=60</td>
<td>10.0</td>
<td>10.0</td>
<td>5.0</td>
<td>0.0</td>
<td>80.0</td>
<td>87.5</td>
</tr>
</tbody>
</table>
Figure 4.5. Comparison of Emotional Support from Someone in Native Country or Someone in the USA by Length of Time the Participants have been in the US

[Diagram showing comparison of emotional support from different sources based on length of time in the US.]

Key:
- No Support
- Someone from native country
- Someone from USA
- Someone from both native country and USA
Even though many of the women have been in the US for several years, there still appear to be strong ties with family that remained in their native country. Table 4.24 and Figure 4.6 illustrate the frequency of communication with friends and family in the participants’ native countries via phone or email. A higher percentage (85%) of women who had been in the US 10 or fewer years were in contact with family in their native country at least once a week, as compared to women who had been in the US over 10 years (62.5%).

Table 4.24. Communication with Friends and Family in Native Country

<table>
<thead>
<tr>
<th>Frequency of communication with friends and family in native country via phone or email</th>
<th>10 or fewer years (n=20)</th>
<th>Over 10 years (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>0.0</td>
<td>5.0</td>
</tr>
<tr>
<td>Every once in a while</td>
<td>5.0</td>
<td>20.0</td>
</tr>
<tr>
<td>Once a month</td>
<td>10.0</td>
<td>10.0</td>
</tr>
<tr>
<td>Once a week</td>
<td>55.0</td>
<td>40.0</td>
</tr>
<tr>
<td>More than once a week</td>
<td>30.0</td>
<td>22.5</td>
</tr>
<tr>
<td>Not applicable</td>
<td>0.0</td>
<td>2.5</td>
</tr>
</tbody>
</table>

Figure 4.6 Communications with Friends/ Family in Native Country

H4.b. Women who have been in the US for a shorter period of time will likely have less informational support than those who have been here a longer period of time.
Table 4.25 compares the percentage of participants that reported “yes” to having the selected types of informational support by length of time the participants had been in the US (those who have been here 10 years or less compared to those who have been here more than 10 years).

Table 4.25 Comparing Informational Support between Women Who Have Been in the US =/< 10 Years and >10 Years

<table>
<thead>
<tr>
<th></th>
<th>10 or fewer years (n=20)</th>
<th>Over 10 years (n=40)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Someone to help you fill out medical-related paperwork</td>
<td>70</td>
<td>56</td>
<td>.389</td>
</tr>
<tr>
<td>Someone to help you figure out insurance issues</td>
<td>36.8</td>
<td>35.5</td>
<td>.923</td>
</tr>
<tr>
<td>Someone to help you find resources</td>
<td>36.8</td>
<td>28.6</td>
<td>.554</td>
</tr>
<tr>
<td>Someone to interpret / translate</td>
<td>75</td>
<td>58.6</td>
<td>.236</td>
</tr>
</tbody>
</table>

Results in Table 4.25 show that women who have been in the US for 10 years or less are not more likely to have someone help them with paperwork than those who have been in the US more than 10 years, $\chi^2 = .983(1)$, $N=52)$, $p>.05$.

Women who have been in the US for 10 years or less are not more likely to have someone help them figure out insurance issues than those who have been in the US more than 10 years, $\chi^2 = .009(1)$, $N=50)$, $p>.05$.

Women who have been in the US 10 years or less are not more likely to have someone help them find resources than those who have been in the US more than 10 years, $\chi^2 = .391(1)$, $N=54)$, $p>.05$.

Women who have been in the US 10 years or less are not more likely to have to interpret/translate for them than those who have been in the US more than 10 years, $\chi^2 = 1.402(1)$, $N=49)$, $p>.05$. 

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A Mann Whitney Test was performed to compare the mean provider communication score, which was assessed using a four item provider communication scale (See Table 9), comparing responses of participants that had been in the US 10 years or less to responses of participants that had been in the US for more than 10 years. Results show there was a significant relationship, $z=-1.976, p<.05$. This indicates that women who have been in the US for a longer period of time also report better provider communication.

There was no difference between marital status and length of time in the US, $\chi^2 = .843(1), N=60$, $p>.05$. A Kruskal Wallis test was done to determine if there was a difference between ethnicity and length of time in the US. There was a significant difference, $\chi^2 = 12.193 (4, N=47), p <.05$. Colombian participants had been in the US the shortest amount of time, and Puerto Rican participants had been in the US for the longest amount of time. There was a significant difference in length of time participants has spent in the US (10 years or less vs. more than 10 years) and age, $\chi^2 = .4.84(1), N=60$, $p <.05$. Seventy nine percent of women over 50 had been in the US for more than 10 years compared to 48% of younger women.

In summary, findings from the in-depth interviews and structured questionnaires provide a contextual understanding of social support and suggest that cultural beliefs and the social environment in which support is given and received influences social support. Furthermore, the data presented in this chapter call attention to the support and psychosocial needs of Latina immigrant breast cancer survivors. The next chapter includes a discussion of the research findings as they relate to the research objectives and hypotheses. Please note, while the data provides an abundance of information the discussion will focus on the findings that relate back to the research hypothesis.
Chapter 5: Discussion

Introduction

The first part of this chapter provides a brief review of the hypotheses as an organization technique for the ensuing discussion. Then the discussion of the findings and their relationship to the literature are presented. The discussion is organized thematically. This section is followed by a description of the study limitations. The combination of qualitative and quantitative methods used in this dissertation allows for data triangulation and improves the internal validity of the findings.

Overview of study findings

The qualitative findings address, in part, the first research question of this study. Which was “how do cultural and structural factors combine to shape the assumptions, beliefs, and values that constitute social support among Latinas diagnosed with breast cancer?” Quantitative findings address, in part, the second research question of this study, “what are the cultural and structural factors that influence social support among Latina immigrants diagnosed with breast cancer? Furthermore, results illustrate how cultural and social environmental factors shape the assumptions, beliefs, and values that constitute social support and help identify some of the sociocultural factors that are associated with this construct. As described in Chapter 4 Methods, content analysis techniques were used to analyze qualitative data and nonparametric tests (e.g. Mann Whitney Test, Chi-Square, Kruskal Wallis and Spearman’s correlation) were used to analyze the quantitative data derived from the structured interviews. While the interview guide and structured questionnaire generated rich and abundant data, the discussion in this chapter will primarily focus on the findings that are directly related to the project’s
research objectives and hypothesis. Table 5.1 provides a brief overview of the findings as they relate to the research objectives and hypothesis.

Table 5.1. Research Objectives and Hypothesis as Supported by Findings

<table>
<thead>
<tr>
<th>Research objectives</th>
<th>Met by…</th>
</tr>
</thead>
<tbody>
<tr>
<td>O1: Contextualize the cancer experience of Latina immigrants diagnosed with breast cancer.</td>
<td>Met through qualitative data</td>
</tr>
<tr>
<td>O2: Explore the sociocultural domains of social support.</td>
<td>Met through qualitative and quantitative data</td>
</tr>
<tr>
<td>O3: Identify the cultural and structural factors that influence social support among immigrant Latinas diagnosed with breast cancer.</td>
<td>Met through qualitative and quantitative data</td>
</tr>
<tr>
<td>O4: Identify the information and support needs of Latina immigrant breast cancer survivors</td>
<td>Met through qualitative data</td>
</tr>
<tr>
<td>O5: Provide recommendations for community-based organizations, clinical practice and psycho-oncology</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Support by…</th>
</tr>
</thead>
<tbody>
<tr>
<td>H1. Cultural expectations about gender roles will influence social support</td>
<td>Supported by qualitative data</td>
</tr>
<tr>
<td>H1.a. Compared to women, a higher proportion of men will likely provide instrumental/tangible support, and a higher proportion of women will likely provide emotional/personal support, compared to men.</td>
<td>Supported by quantitative data</td>
</tr>
<tr>
<td>H1.b. Cultural expectations that women should not burden family and friends with personal concerns/worries will negatively influence social support.</td>
<td>Supported by qualitative data and quantitative data</td>
</tr>
<tr>
<td>H1. c. Cultural expectations to be strong (aguantar/tolerant) will negatively influence social support.</td>
<td>Supported by qualitative data</td>
</tr>
<tr>
<td>H2. Language (English proficiency) will be positively associated with social support.</td>
<td>Unsupported by quantitative data</td>
</tr>
<tr>
<td>H2.a. Women with limited English proficiency will be less likely to have informational support than those that who are English proficient.</td>
<td>Supported by qualitative data and partially supported by quantitative data</td>
</tr>
</tbody>
</table>
Table 5.1 continued from previous page

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Description</th>
<th>Data Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>H3. Chronic stress (family problems, economic/financial problems, immigration status) will be negatively associated with social support.</td>
<td></td>
<td>Supported by qualitative and quantitative data</td>
</tr>
<tr>
<td>H4. Length of time in the US will influence social support. Either these all need periods, or none do.</td>
<td></td>
<td>Unsupported by quantitative data</td>
</tr>
<tr>
<td>H4. a., Women who have been in the US a shorter period of time than whom? will likely rely on family and friends in their native country for emotional support.</td>
<td></td>
<td>Partially supported by qualitative and quantitative data</td>
</tr>
<tr>
<td>H4.b., Women who have been in the US for a shorter period of time will likely have less informational support than those who have been here a longer period of time.</td>
<td></td>
<td>Unsupported by quantitative data</td>
</tr>
</tbody>
</table>

**Gender roles and support**

“Men may visit you but their visits are much shorter, women will talk more, men may talk briefly about the illness but that is it, they take you to the doctor. Women always bring something, and talk more.”

[Leslie, Argentina, Stage III]

In order to contextualize the breast cancer experience and understand the cultural beliefs and expectations that mediate social support it was important to explore the influence culturally ascribed gender roles might have on social support. Key informants relate that culturally defined gender roles influenced the support Latino male and female cancer patients received and who the receive it from. They observe that women tend to go to doctor appointments by themselves while their Latino male counterparts usually go to oncology appointments accompanied by their wives. Data from the in-depth interviews also show cultural norms about gender roles and the influence these have on the kinds of assistance provided by men and women when someone was sick. When asked to describe what men and women did when someone was sick, participants clearly articulated the things that were done by men and the things that were done by women. Women’s ideas about who should provide different types of
support reflect principles of gender and were clearly defined, as there was little overlap regarding what participants said was expected of women when someone was sick and what was expected of men. Men appeared to be more likely to provide tangible/instrumental assistance (e.g., manage paperwork, drive to the doctor) while women were more likely to provide emotional support, nurture, and care for the patient. For example, key informants related that from their personal observations, Latina women, unlike their American counterparts, tended to go to oncology appointments alone or with other female relatives/friends more often than with their husbands or other male relatives/friends. They also commented that Latina patients tended to get dropped off by their husbands, who later came to pick them up after their appointments.

Building on the results from the key informant and in-depth interviews results from the structured questionnaire illustrate a similar pattern and for the most part verify the findings from Phase I. Men were listed more frequently in helping with things outside the home like going to the pharmacy, driving to the doctor, and paying bills. Women were listed more frequently with providing emotional support such as listening, talking, encouraging, understanding, and visiting. I had hypothesized that men would provide instrumental/tangible support, like help if confined to a bed, cooking and housework, but that support was more frequently provided by women.

Overall, it appears that a larger proportion of support was provided by women (e.g., mothers, daughters, and girl friends) and fellow cancer survivors, who were identified as trusted information sources. The types of support that are available from men are consistent with men’s culturally defined roles as described by participants in the in-depth interviews. These findings are consistent with the literature, which reports that women diagnosed with cancer need and seek support from other women (Campbell et al 2004; Erwin et al 2007; Ferrell et al 2003; Isaksen et al 2003; Wellisch et al 1999). Studies also report that Latinas are more likely to get support from other female relatives
and *comadres* (Jones et al 1999) than from their husbands/partners (Martinez-Schallmoser et al 2003). However, while these findings may suggest that women give more support than men, it might be worth considering that husbands and male relatives may be just as supportive but in modes that are culturally prescribed, such as working to financially support the family and purchasing medications. According to Erwin et al, Latinos have a patriarchal system where sources of power and authority favor the man in male/female relationships and define certain roles and relationships for women. Latino men may be more likely to drive and control access to health care due to their privileged economic status (Erwin et al 2005); women are also often financially depend upon men.

Another consideration is that many Hispanic immigrant men work in low-wage service jobs (Flores-Ortiz 2000) that usually have limited employment benefits (i.e., may or may not include vacation and/or sick days). Thus, they may not be able to take time off of work to accompany their ailing wives, especially in the case of cancer where there are so many follow-up and treatment appointments. In sum, the data supports the observations that gender roles mediate support since they shape the kinds of support available to women and deemed appropriate for them to expect/seek (Erwin et al 2005; Kagawa-Singer & Wellisch 2003; Kagawa-Singer et al 1997).

**Delicate balance between telling and protecting: Internal turmoil and external calm**

“At first they [parents in Peru] wanted me to return to Peru, but I stayed. I did not want to worry them, I had to be strong. I did not tell them when they were doing the test. I did not tell them because I did not want to alarm them.”

[Reina, Peru, Stage III]

Key informant interviews revealed the culturally mediated beliefs and practices related to protecting family and communicating with family, specifically parents and children, about the cancer diagnosis negatively affected Latina immigrants diagnosed with breast cancer. The discussion regarding this topic was emerged within the context of stress, specifically in response to the questions asking key informants to describe the
things that stressors Latina immigrants diagnosed with breast cancer might encounter. This topic was further explored with in-depth interview participants. Key informants also discussed how cancer changed social roles and affected women’s ability to fulfill their family and household obligations. They went on to say that this disconnect was also an additional source of stress for Latina women diagnosed with breast cancer.

Data from the in-depth interviews are consistent with the findings from the key informant interviews regarding women’s role and the delicate balance women seemed to navigate between telling and protecting. In-depth interview participants discussed the stress communicating their diagnosis to their families caused them and described how they waited to tell or told their family they were alright when in reality they were in physical or emotional discomfort and pain.

In-depth interview findings also suggest Latina women’s roles center around homemaking duties *ama de casa* (this includes cooking, cleaning), being a wife, caring for the family, working, nurturing and providing strength. Participants discussed how cancer had affected their abilities to fulfill these social roles. Another related theme emerged from the in-depth interviews was that participants felt women needed to *aceptar* to be *fuerte y aguantar* (to accept, be strong and tolerant) and *resignarse* (resign) themselves to what life brings. Participants also emphasized how in the U.S. Latina women had to be especially strong and continue to work (in and outside the home) when they were ill because they did not have the extended family support they had in their native countries. In addition, participants suggested that women had to be strong and *mantener la tranquilidad* (keep the peace/calm) for their families. Participants related how, in order to protect their families, they sometimes had to disguise and hide how they felt (emotionally and physically).

Themes that emerged from the key informant and in-depth interviews were further explored in Phase II. The structured questionnaire included items to assess if
culturally mediated beliefs about women’s role and protecting the family influenced social support. The results suggest that cultural beliefs that “It is best not to burden family and friends with personal concerns/worries” and that “Family needs should come before one’s own” appear to negatively influence social support. Two items “We have to resign ourselves to what life brings, we can not change what is going to happen” and “We have to accept suffering” were included in the structured questionnaire to quantitatively explore how these cultural beliefs and expectations might influence social support. However, findings from the structured interviews did not reveal a relationship. There was also no significant relationship between having to keep a strong/happy facade and social support. A possible explanation is that perhaps the items were ineffectively worded and failed to convey the questions’ precise intended meaning. Another reason may be that accepting suffering, as well as the situation, may be perceived by participants as dealing with it and asking for help. Ashing-Giwa and colleagues made a similar observation in which they relate that Hispanic participants reported distress about sharing their diagnoses and burdening their families with their disease which lead to some women to act as if they were not as ill in order to reduce their families’ concerns and continue caretaking and professional activities as expected (Ashing-Giwa et al 2004c). One can see how this might likely affect the social support system. If one does not want to burden others, s/he is less likely to ask for assistance with things they might need. This ties into what some of the participants mentioned, regarding the meaning of social support; for them, social support is when those close to them know what patients need without needing to ask. In contrast, a recent study among mostly European American women found that the majority of women in their study were able to talk openly with their families about their breast cancer, and open communication was associated with better mental health outcomes (Mallinger et al 2006).
Disclosure practices of not telling are culturally embedded. Gordon and Paci (1997) report similar findings among cancer patients in Italy and note that non-disclosure is situated within the larger traditional practice of social unity and of protection from or adaptation to the inevitable necessities of life (Gordon & Paci 1997). Study results suggest that women’s non-disclosure of their treatment, emotional and physical status to their family is culturally embedded. Not telling serves to protect the family and maintain social order. The sociocultural stress of not wanting to burden their family with their personal concerns may stem from what Janes (1990) calls social inconsistency. The social inconsistency or the inability to meet behavioral or social expectations of non-disclosure associated with women’s role of protecting and caring for the family and the personal need for support and assistance may elucidate the stress described by women in the interviews. Perhaps this may also explain why Latinas, in comparison to European American women, have less social support as reported in the literature (Alferi et al 2001; Katapodi et al 2002) and point to the need to understand the underlying cultural norms that guide communication and support interactions. Findings suggest the need to respect women’s non-disclosure but at the same illustrate the need to find ways to support Latina women who might be under such duress.

**Moral and spiritual support**

“Being spiritual and my intimate relationship with God has helped me because in the moments where I have felt alone I read the bible and the Lord talks to me…” [Sara, Puerto Rico, Stage II]

Key informants delineated spirituality and faith in God were important sources of support and helped Latina immigrants diagnosed with breast cancer cope with the fear and uncertainty of a cancer diagnosis. Similarly, faith and and prayer were also identified as forms of non-verbal support by participants in the in-depth interviews. Participants also mentioned reading psalms and their faith in God’s will, “si Dios quiere,” as forms of
moral support. This finding suggests that prayer and individual faith as sources of power may help individuals deal and cope with consequences that occur from the illness. Spirituality and prayer have been described as forms of non-verbal support among African American breast cancer patients (Ashing-Giwa et al. 2004c; Erwin 2002; Farmer & Smith 2002; Hamilton & Sandelowski 2004a). For example, Hamilton et al. found that African American women were more likely to receive support from prayers, which also allowed them to continue religious practices (Hamilton & Sandelowski 2004a). Another study by Lopez et al. reports that the African American women sought support from sources (e.g., the church) they perceived to be “safe” because seeking support put them at risk of being stigmatized, discriminated against, or rejected (Lopez et al. 2005). This suggests that spirituality and prayer are important sources of support and should be considered in assessing social support (Ashing-Giwa et al. 2006a; Benavente 2001; Erwin et al. 2007).

**Te tengo presente (I am thinking of you)**

“You visit the sick, bring gifts, food, fruits, you bring prayer too. You have to call, that is what we do, and family and friends are attuned and have you in mind.”

[Carmen, Colombia, Stage III]

Another nuance/concept that emerged from observations and in-depth interview data was the salience of *precencia* (presence) in social support. This concept was not discussed by key informants and was not included in the structured questionnaire. This is different from the actual, physical presence of others; it’s what we, in American culture, may describe as “being there”, as in “I’ll be there.” In this case the concept to which women are referring subtly yet distinctly differs from the American interpretation of the phrase. *Precencia* is the notion that others have you present in their thoughts as in “I am thinking about you” or “I have you in my prayers”. This [*precencia*] could be demonstrated nonverbally (e.g., by praying for someone) or *fisicamente* (physically).
(e.g., with a small gift, token, and/or gesture, like bringing soup). Hamilton et al. (2004) also identify the presence of others (e.g., being there) as an important type of support among the African American participants. In their study, it was described as a non-verbal expression of love and caring (Hamilton & Sandelowski 2004a). When I first started attending the LUNA support group meetings in 2003 I remember the founder and facilitator would always bring little gifts for each of the members, especially during celebrations or holidays. It was very important to her that each person have a little token/gift. Now I understand why the little gifts (which may seem trivial) were an important part of what made the support group culturally relevant.

**La familia: Source of support, source of stress**

“In the beginning they [family] could not believe it [had cancer] but then they gave me a lot of encouragement. We would talk almost everyday. Having them far away caused me a lot of stress.” 
[Berta, Mexico, Stage II]

Key informants observe the importance of the family as a source of social support for Latina immigrants diagnosed with breast cancer. Findings illustrate saliency of family and social cohesion in woman’s lives. However, the data also suggests that family can be a source of stress, in part, due to Latina immigrants worrying about family back in their native country and concern over not being able to provide for their family both stateside and abroad.

Results from the in-depth interviews confirm the relevance of family, which women felt was one of the most important sources of social support. Similar to the findings reported by key informants, women also identified family as a source of stress. Family-related stressors delineated by participants include strained relationships, disappointment with low level of familial support, being far away from family, disclosing the cancer diagnosis, social role limitations, and having to keep a strong/happy face to avoid worrying or burdening family members. Findings also relate to the negative effect
of social support, when it is expected and you do not receive it. Women were vital to the sustainability of their family in the United States and some to the livelihood of family back in their native country through remittances. Having breast cancer affected their ability to provide for family and this was another source of stress for many of the women.

Regarding support from family, similar findings have also been reported by Ferrell, et al. (2003) and Landmark, et al (2002). They relate that support from family and close relatives as the most important source of support for women diagnosed with breast cancer (Ferrell et al 2003; Landmark et al 2002). Ashing-Giwa and colleagues, who investigated the relationship between support and distress among cancer survivors, made a similar observation. In their study Latina participants revealed that family was considered a source of both stress and support (Ashing-Giwa et al 2004c). Similar themes emerged in another study by Ashing-Giwa and colleagues in which they state that Latinas reported higher levels of role limitations due to emotional and physical problems that may increase their stress regarding family roles and caregiver duties (Ashing-Giwa et al 2007).

**Provider communication and information needs: Does speaking English make a difference?**

“You are limited because you do not know the language, sometimes you want privacy with the doctor, but you have an interpreter there and he may not tell the doctor what you want.”

[Luli, Colombia, Stage III]

Findings from the key informant interviews illustrate the negative influence lack of English proficiency had on patient/provider communication and on the informational support Latina immigrants received. Latina immigrants that do not speak English and can not clearly communicate with their doctors have a difficult time understanding their disease trajectory and treatment. Findings from the in-depth interviews also corroborate that limited English proficiency has a negative impact on participants’ respective abilities
to obtain information about their treatment and their ability to effectively communicate with their providers. Latina immigrants had poor health literacy that includes difficulty understanding and acting upon health information, from insurance forms to medications. Several women related they did not know why they got this treatment vs. that treatment or the stage of their breast cancer. From ongoing conversations with key informants and through participant observation, I came to understand that English proficiency can be a tricky thing. Women who knew a little bit of English or enough English to get by were most at risk to misunderstand information given by their doctors. Conversely, women who were monolingual Spanish speakers and relied on a translator better understood the doctors’ report.

Contrary to expectations, results from the structured questionnaire show that English language proficiency was not associated with overall social support. It appears this finding is not consistent with the literature that found that language (e.g., speaking or answering questionnaire in Spanish) was associated with lower levels social support (Abraido-Lanza 2004a; Katapodi et al 2002). Perhaps the relationship between English proficiency and social support was not significant in this study because the entire sample was made up of immigrants who spoke Spanish and there was no comparison group.

While data from the structured questionnaire did not show a significant relationship between English proficiency and social support, data do suggest that English proficiency was associated with provider communication and women’s ability to effectively communicate with their cancer care providers. Similar findings have been reported in the literature which states that provider communication is sometimes inadequate and is an issue to individuals diagnosed with cancer, especially those whose English proficiency is limited (Landmark et al 2002; Lopez et al 2005; Moore 1999).

When Latinos, especially recent immigrants, seek medical care, they bring expectations; have communication preferences and limited familiarity with navigating the
health care system (Livingston et al 2008). Our health care system is often poorly set up to address health literacy barriers, placing great language and fluency demands on patients and their families. Limited health literacy and the difficulties in understanding health information as described by key informants and participants is this study is not unique to Latina immigrants (Merriman et al 2002; Sharp et al 2002). Health literacy, which is defined as the extent that individuals can understand, process and obtain health services and information to make appropriate health decisions (Nielsen-Bohlman. et al 2004).

Recent review articles point to the high prevalence of limited health literacy and the need for high-level health navigation skills and techniques for self-management of acute and chronic disease and promotion of health (Dewalt et al 2004; Institute of Medicine 2004). Further, for a significant portion of the Hispanic population, English is not the primary language, and this language barrier exacerbates the problems associated with limited health literacy. Such factors can affect Latina immigrant’s ability to seek and gain access to cancer treatment, mental health and social services systems. Language then becomes a barrier to accessing benefits, services, information, or understanding and coping with medical treatments, contributing to health inequities.

Findings from the structured questionnaire suggest that women with low English proficiency are more likely to have someone help them with paperwork than women with high English proficiency. Similarly, women with low English and moderate English proficiency are also more likely to have someone to interpret/translate for them than women with high English proficiency. While I hypothesized those with limited English proficiency would be less likely to have informational support, results from the structured questionnaire do not support this hypothesis. The Informational support measures assume that all the immigrant Latina women interviewed need help with paperwork, insurance issues, translation and resources. The significant negative relationship
between English proficiency and paperwork and translation support suggests that having informational support is due to need for informational assistance, not the availability of informational support. In other words, women with lower English proficiency levels have informational support because they need it, not necessarily because they have more access to it.

**Information and support needs**

“In the beginning when you do not have information, it frustrates you, you are lost”

[Isis, Venezuelan, Stage I]

Results from the key informant and in-depth interviews indicate Latina immigrants diagnosed with breast cancer need information about: 1) community resources (e.g., financial assistance, transportation), 2) treatment (e.g., side effects, medications) and psychosocial issues related to cancer treatment (e.g., sexuality and intimacy). This appears to be consistent with findings from a recent study that examined information and support needs of breast cancer survivors and found that Latina women desired more information on treatment-related and psychosocial-related subjects and reported more difficulty understanding written materials compared to women from other ethnic groups (Janz et al 2008). Similarly, Tichen, et al. also report that patients with limited English proficiency are less satisfied with information received and would like more information about their disease (Tichen 2003).

Further, women related the need to inform men and husbands about treatment side effects and the needs of cancer patients. Erwin et al (2005) report similar results. They found that Latina women expressed interest in including educational information about women’s health issues and treatment directed to men or inclusive of men in order to enlist men’s support in acquiring resources (e.g., transportation, bills) and increase their understanding (Erwin et al 2005; Erwin et al 2007).

**Stress and social support: Everyday realities and the burden of cancer**
“I live in the house month to month. I do not know if we are going to stay or move... I am always worried about money. Right now we need $2000. We can pay it little by little; these are things that cause me a lot of stress.” [Anita, Panama, Stage II]

The key informants interviewed had extensive experience working with Latin American women who had been diagnosed with breast cancer. They had an intimate grasp on the pulse of the Latina community and the needs of Latina cancer survivors. Key informants identified the problems and stressors Latinas encountered in the United States of which access to health care was the most prominent. In addition, they discussed other health-related issues such as lack of continuity of care, inadequate health insurance and socioeconomic status as important issues which also serve as potential sources of stress. Regarding Latina immigrants, they delineated the stressors they dealt with on a daily basis are magnified, in part, due to their status as immigrants in the United States and additional challenges of adjusting to a different culture, changing social roles and family dynamics.

Data from the in-depth interviews suggest the stresses and problems participants experienced can be grouped into two broad categories 1) structural/ socioeconomic and 2) disease-related. Women described the multitude of stressors associated with the financial toll of cancer treatment, that not only includes the cost of care but the loss of wages, and the burden it placed on the household and the family’s financial well-being. Interviews revealed the struggles immigrant women encountered accessing cancer care. Specifically the case examples of Gloria, Dafna and Agustina illustrate the influence of broader political economic forces on individual health outcomes. Women’s experiences are embedded within the larger context that includes immigration, health policy, access, and poverty. Furthermore, Latina immigrants also delineated the stress caused, in part, by treatment side effects and the impact these had on their femininity, sexuality and intimacy.
The data provide a rich and vivid picture of the everyday realities, stresses, and struggles Latina immigrants diagnosed with breast cancer encounter accessing care, navigating the health care system, as well as caring and providing for themselves and their family. These findings are consistent with the literature (Ashing-Giwa et al. 2006b) and have been reported, most notably in the Institute of Medicine report on the unequal burden of cancer (Institute of Medicine 1999). Although this report was written almost ten years ago, it appears little has changed. The case examples and stories shared by the women interviewed also poignantly illustrate what Paul Farmer calls structural violence, in which sickness is a result of the historical, social, and economic processes that constrict individual agency and affect the disease trajectory (Farmer 2003; Farmer et al. 2006).

As expected, findings from the structured questionnaire suggest that there was a moderate negative correlation between overall social support and stress. This indicates that participants who report having more stresses or problems also report less overall social support. In addition, having a household income of $10,000 or less and being unemployed were also associated with having less overall social support. Women who lived in poverty were also more likely to report being alone and isolated. Impoverished women, who in part, may be the ones in most need of support during a devastating illness like cancer, may feel powerless to ask for help. They may be embarrassed, do not want to burden others with their problems and/or may not have the resources to do so. The findings also illustrate the complexity of trying to understand the relationship between two multifaceted constructs like stress and social support.

Thus, research findings from Phase I and II support the case made by Cohen and Syme who argued for a contextual understanding of social support that includes the social environment in which it occur (Cohen & Syme 1985b). Findings illustrate how culture and structural factors that include chronic stressors related to socioeconomic
status, employment, immigration status, and social relations might intersect to influence social support and ultimately health and disease as suggested by the literature (Berkman & Glass 2000a; Cohen 2004a; Dressler 1991). However, further examination that includes a much larger sample and more statistically advanced techniques is needed to fully understand the interplay between these relationships.

**Staying connected, close ties, and length of time in the US**

“You need to look for support from other members of your family. You know, it did not cause me that much stress not having my family here… They called and were present through the phone and through their prayers.”

[Melania, Colombia, Stage I]

Key informant interview participants did not discuss length of time in the US per se. However, they discussed the close ties Latina immigrants had with their family, regardless of where they lived.

Results from both the in-depth and structured interviews suggest that regardless of length of time in the US there appears to be strong ties and communication with family in their native country. In addition, women also discussed how their family back in the native country depended on them for support in the form of remittances. Many went on to report that the cancer diagnosis affected their ability to continue to send money home. Participants report frequently talking with family and friends, especially during treatment. This brings to mind my conversation with Leslie (Stage III, diagnosed 1997, 2004, 2007). She talked to her mom and daughter who lived in Argentina several times a week. The day I interviewed her she has just gotten her cell phone bill, it was for over $700. This also illustrates some difficulties women encountered communicating and staying in touch with family in their native country.

Results also underscore the important role communication with family and friends plays in the lives of Latina immigrants who have been diagnosed with cancer, even if their family and friends are in their native country they are still sources of support. This
appears to be consistent with the immigration literature which states that family and extended family provide immigrants with significant emotional and economic support. (Kramer et al 1999; Vega & Amaro 1994; Zambrana et al 1997)

Findings from the structured questionnaire suggest that length of time in the US was not associated with social support. One might expect that women who have been in the US a longer period of time might have had more time to develop social relationships and support networks that might have been loss when they immigrated to the US and thus have report more social support than those who have been in the US a shorter period of time. A possible explanation for the lack of association might be related to the close ties that participants maintained with family and friends in their native country. Or another point to consider is that a larger proportion of study participants (65%) reported coming to the US with their spouse or family. Thus, those that came with family might not have experienced a disruption of social ties as suggested by the literature (Zuniga 2002). To explore this further I compared social support between women who came to the US alone and those that came with their spouse and/or family. Results show there was a significant difference in social support, with women who came to the US alone reporting less overall social support. It seems that it is the disruption of social ties that influences social support and not length of time in the US.

The literature suggest that acculturation and length of time in US influence social support among Hispanics (Finch et al 2003; Flaskerud & Uman 1996; Hovey et al 2000; Smart & Smart 1995). Length of time in the US has been used as a proxy for acculturation (Ashing-Giwa et al 2006b; Ashing-Giwa et al 2007). While acculturation has widely been used in public health research on Hispanics, anthropologists argue there are misconceptions underlying the use of this construct to explain cultural differences (Hunt et al 2004) and negates the fluidity of culture and the role of the social environment. A slightly higher proportion of participants who had been in the US ten
years or less reported having someone for emotional support from their native country compared to participants who had been in the US more than ten years, who report a slightly higher proportion of emotional support from someone in the US. As expected, findings from the structured interview show that communication with friends and family in native country declines with length of time in the US. However, it is notable that 62.5% of participants who had been in the US over ten years report communicating with family and friends in their native country at least once a week compared to 85% of those who had been in the US 10 years or less. Waldinger reports similar findings and notes that most Latino immigrants stay in regular contact with friends or family living in their country of origin (Waldinger 2007). He states that “the best way to characterize the immigrants’ “here-there” connection is to describe them as “in between.” p.28.

Regarding informational support, it appears that length of time in the US was not associated with informational support. Contrary to what expected there was no significant difference between women who had been in the US more than ten years and those that had been here 10 years or less.

**The shared experience of cancer survivorship**

Findings suggest that regardless of country of origin it is possible to collectively speak of Latina immigrants within the context of cancer survivorship. Regardless of nationality or immigration status the women interviewed faced similar challenges. As is illustrated by the case illustrations of Dafna, who was here legally form Cuba, and Agustina, who was undocumented from Colombia and the experiences the participants shared it appears that there were more similarities than differences within this context. I acknowledge the heterogeneity of the various ethnic groups that fall under the Hispanic label and suggest that there is a need to disaggregate these groups when looking at disease treads (Martinez-Tyson et al 2008). However, as the data suggest it is possible to talk about Hispanic/Latino culture within the context of this study.
Mexican, Cuban, Puerto Rican and other immigrants from various countries in Latin American and Spanish-speaking Caribbean come from distinct cultures, but those cultures have a shared heritage which stems from Spanish colonization, Spanish language (with regional variations), and religion (e.g., Catholicism) and the experience of having lived as minorities in a very race conscious United States (Flores-Ortiz 2000; Sánchez Ayéndez 1998). Chavez et al reports that the main differences between Latinas, European American and physicians his study were primarily driven by immigration (Chavez et al 1997b). Regardless of country of origin, Latina immigrants shared many more beliefs about breast cancer than their American-born Latina counterparts (Chavez et al 1993b; Hubbell et al 1996a; Hubbell et al 1997). Based on seven years of experience working with Latina breast cancer survivors, it is possible to state that even though Latina survivors may differ in nationality, they go through similar processes (immigration) and experiences (cancer diagnosis) that make it possible to focus on their shared experience as Latina immigrant cancer survivors.

**Strengths and limitations**

The following paragraph details the limitations and strengths of this study. Studies that use purposive and snowball sampling techniques are considered non-probability studies and thus have low external validity. In addition, participants were recruited through community networks and this may pose possible biases, thus limiting the generalizability of the findings outside this study population.

The index/scale used to assess social support was developed by the researcher and thus it is not possible to compare the social support findings to other studies that have not used this scale. Another limitation related to the measurement of social support in this study was the items that were not applicable to some of the women and thus were coded as missing. The psychometric properties of the social support scale could not be thoroughly evaluated (e.g., through test/retest) thus the results should be interpreted
with caution (See Chapter 6, Recommendations for Future Research). Some of the concepts that emerged from the in-depth interviews such as the concept of *resignar* were difficult to translate to English. However, this did not pose a problem in developing the Spanish structured questionnaire that was administered.

Due to the cross-sectional design of this study I was not able to explore or to follow women prospectively. The data does not provide information on how support needs and relationships might change throughout the disease continuum from diagnosis, to treatment, and finally through long term survivorship. Another study limitation is the sample was chosen based on participant availability and level of access. Furthermore, by limiting the sample to immigrant women in West Central Florida, the findings may not be generalizable to US born Latinas or to Latinas in other parts of the country, such as California. While over 10 Latin American nationalities were represented in the study sample, with the exception of Puerto Ricans, the number of participants from the other countries was small and thus intergroup variation could not be thoroughly explored. Another limitation is the sample size (n=60) used in Phase II. Due to the small sample size I was only able to run descriptive statistics and conduct univariate and bivariate analysis to assess associations between variables. Advanced statistical techniques, such as regression, should not be used on small sample sizes. Time and lack of funding were also limitations for this study. While time consuming some of the advantages of doing face to face interviews and orally administer questionnaires is that one is able to probe more deeply and that individuals who may not read well can be included (Bernard 2002). Further the use of mixed methods allowed for data triangulation which provides high internal validity.

In summary, despite the limitations described in the paragraphs above the researcher is able to address the study research objectives which are to contextualize the cancer experience of Latina immigrants diagnosed with breast cancer, to explore the
sociocultural domains of social support and identify the cultural and structural factors that influence this construct. Furthermore, the research process and lessons learned is invaluable and contributes to the doctoral training of a Latina doctoral student. Study findings provide a foundation for future research and a career that will be dedicated to addressing health disparities and Latino psychosocial and healthcare needs. The next chapter delineates suggestions for future research, recommendations for community-based organizations, clinical practice and psycho-oncology. The application of research findings at the local level is also presented. In addition, the anthropological significance of this study is provided.
Chapter 6: Recommendations and Conclusion

Introduction

In this research the qualitative data derived from the key informant and in-depth interviews was used to contextualize the cancer experience of Latin American immigrant women diagnosed with breast cancer. Data was also used to develop an emic perspective of social support and to identify the relevance of spirituality/faith, prececia, and family. This chapter begins with a brief overview and summary of research findings. This is followed by suggestions for future research. Thereafter, recommendations for community-based organizations, clinical practice, and psycho-oncology are provided. Information learned from the interviews also suggest that issues related to disclosure, communication, women’s role and protecting family also figure prominently in women’s lives and may be additional sources of stress. The quantitative data identified some of the cultural norms and structural factors that influence social support.

Contextualizing social support, stress and non-disclosure

Drawing from a number of theoretical assertions, personal observations and the literature, I proposed a conceptual model to explain how cultural and structural factors might influence social support. Specifically, the framework I proposed suggested that cultural norms and expectations about gender roles, language, particularly English proficiency, chronic stress and length of time in the US would influence social support. The trends and associations that emerged from the research are more complex than initially hypothesized. And while findings, in part, confirm the proposed conceptual model, they also suggest it might be worth rethinking. For example, the stress buffering model of social support may be diffused for Latina immigrants diagnosed with cancer as
disease-related stressors may seem minor compared with the larger social problems (SES, immigration status, poverty, distance from family) Latina immigrants may encounter on a daily basis. Furthermore, in the case of Latina immigrants, this model may not capture the complexity and intricacies of social relationships and cultural norms guiding social interactions; where sources of support, such as family can also be sources of stress. Findings from this study suggest a need to refine prevalent conceptualizations of social support to include the experience of Latin American immigrant women.

The findings that relate to disclosure deserve further discussion. Women delineated not sharing how they really felt physically/emotionally with their family during treatment and the stress telling their family about their diagnosis caused them. As previously mentioned, the topic of disclosure emerged, in part, from participant’s discussion about the things that caused them stress. Based on comments women made during the interviews and on personal observations about who women did and did not disclose information to, a possible model began to emerge. Women mentioned not wanting to take their young children’s innocence away, or burden their adult children who had their own lives, family and problems to deal with. Key informants observed that not communicating cancer-related issues with their children, regardless of their children’s age, was a much bigger issue for the Latina cancer patients than for cancer patients from other ethnic groups. Latin American immigrant women also revealed not wanting to tell or burden their parents, who were older and or were sick themselves and participants worried that negative news would cause them additional worry, stress and/or possibly make them ill. However, one of the limitations of this study is that I did not ask participants specifically who they did/did not tell and why. A few participants mentioned talking with their siblings, primarily sisters, or female cousins. It is also difficult to determine who women disclosed information to because I did not ask, for example, if
they had siblings or living parents. Had I asked those questions, I might have been able
to more fully understand if there was a pattern in who they told and if it made a
difference. Thus, if a participant did not mention a sister per se it could be because she
did not have one, not because she chose not to tell her. I was not able to explore this in
detail and suggest this is an area that warrants further study.

Beliefs and communication practices regarding non-disclosure are related to
broader cultural aspects of what is expected of women, by men and by family members.
Issues relating to nondisclosure also illustrate the saliency of cultural norms related to
women’s roles, such as *ama de casa* (homemaker), and Latina immigrant’s orientation
toward the home and family (Abraido-Lanza 2004b; Sanchez-Ayendez 1988; Sanchez-
Moreno 2004). Within this model, non-disclosure may serve to protect the family and
keep the *tranquilidad* (tranquility/harmony) in the household (i.e., reduce household
stress). Protecting the family from additional disease-related stressors takes precedence
over women’s personal/individual needs. Thinking back, when I asked participants what
caused cancer; stress was the second item on the list, behind poor nutrition. This may
be one of the reasons participants do not disclose; they may, in part, be protecting their
family from stress and thus preserving their health. Thus, findings suggest that we may
need to reconsider the stress buffering model of social support as it applied to Latina
immigrant women. While emotional support from family and assistance with
instrumental/tangible needs during treatment for cancer were associated with the
positive side of social support they are also be associated with the stress caused by
having to burden others with your problems; instead of buffering stress, seeking support
may also contribute to it.

Most of the literature on non-disclosure of cancer information centers on 1)
patient/ provider communication, i.e., how truthful the physician is with the patient about
his/her diagnosis and prognosis (Blazekovic-Milakovic et al 2006; Lapine et al 2001;
Mystakidou et al 2005) and 2) on family/ patient communication, i.e., where the family
does not disclose cancer information to protect the patient from knowing his/her
diagnosis and prognosis (Hallenbeck & Arnold 2007; Jiang et al 2007; Surbone 2006;
Tuckett 2004) and the cross-cultural implications of these. The latter has been reported
most frequently among Japanese, Chinese, Taiwanese and other Asian and non
Western groups (Andresen 2001; Fielding et al 1998; Harris et al 2003a; Mobeireek et al
groups both cancer patients and physicians relate complete cancer disclosure from the
physician to the patient is undesirable (Mitchell 1998). Further, the diagnosis of cancer
affects family structure and dynamics and families in an effort to protect patients from
despair exclude the patient from the information exchange (Mystakidou et al 2004).
However, I did not come across any literature that specifically discussed issues
surrounding patient’s non-disclosure of their disease to their family nor the implications
this might have on social support. Thus there is a need to explore non-disclosure within
the context of patient/family communication from the patient’s perspective, who and why
patients tell/do not tell and the possible effects non-disclosure might have on social
support, stress, and psychosocial well-being.

One aspect of the social support data from the structured interviews that struck
me was the percentage of women who stated they did not have specific types of
support. Normative role expectations about who should provide support may be one of
the reasons that explain the lack of support found. For example, out of the 26 women
who had children, 82% stated they did not have someone to help them with childcare.
Participants may have sought support from role appropriate providers and may not have
had it. Participants identified older daughters, mothers, sisters and other female relatives
as sources of support who would help care for children and maintain the household if the
woman was ill. However, Latina immigrant women may be less inclined to ask others for
help if she is here in the United States and her traditional sources of support are back home in her native country. Results point to the unique immigration-related circumstances surrounding the giving and receiving of support; such as the interdependence and connection between women diagnosed with breast cancer in the United States and their family and friends in their native country.

**Suggestions for future research**

We need to expand our understanding of the types of emotional and informational support needed and used by ethnically diverse groups who may have fewer opportunities to interact with or access mental healthcare professionals and rely more on informal support networks. Further, as findings from this study indicate we need a more in-depth examination of social support to understand the cultural and social contexts, as well as the cultural assumptions and expectations, that define how support is given and received among different ethnic groups (e.g., Haitians, East Indians) living in the United States. Many social support studies look at the frequency of contact or focus on very general measures of perceived support. Few have addressed the actual behaviors/actions that people engage in when giving/receiving support or the types of support that are important to individuals from diverse backgrounds (Kagawa-Singer & Wellisch 2003; Wellisch et al 1999).

Study findings lay the foundation for future research. We need to examine sociocultural factors and resources that enable Latinas diagnosed with cancer to maintain valued social roles in the family and community. As study findings illustrate, we need a better understanding of the impact of cancer upon the family of Latina cancer survivors. For example, do cultural beliefs about not burdening the family and cultural norms about communication apply to others in the family? Do the daughters, sons, mothers, husbands, and/or parents of Latinas diagnosed with cancer also keep a strong happy face and keep their worries and personal concerns to themselves to protect the
cancer patient? If so, how does this affect family support needs and social relationships within the family? How are familial relationships transformed by the cancer experience? We also need to examine the social support needs and cultural assumptions, beliefs, and values that constitute social support among spouses/male partners of Latina cancer patients. How does their wives’ cancer diagnosis affect their social roles and responsibilities? This information can be used to develop supportive services and educational interventions for spouses and caregivers. There is a dearth of information on social support among Latino men with cancer. What are the sociocultural factors that influence social support among Latino men diagnosed with cancer? What are their social support needs, and do they have similar beliefs regarding gender roles? What are the cultural norms and beliefs that guide from whom Latino men can give and receive social support?

It would be worthwhile to conduct a measurement study to refine and evaluate the psychometric validity and reliability of a culturally informed social support scale for Latinas that includes support items of the nonverbal type, like spirituality, prayer, and precencia which are not normally included in standardized social support scales. It might also be of interest to explore the social networks of immigrant Latina cancer survivors in relation to social support and psychosocial well-being. Further, a comparative study of social support between Latina cancer patients in US and their counterparts in their native countries would be beneficial. For example, comparing social support between Puerto Ricans living in the Mainland to Puerto Ricans living on the island would provide valuable and more in-depth insights on the influence of migration on social support and social relationships. A future study might also use pile sorts, rank order and cultural consensus analysis (Dressler 1991) to explore social support among a larger sample of Latino ethnic groups to explore intracultural variations and determine whether there is indeed a shared cultural model of social support.
Situating the study of breast cancer and social support within the anthropological context

As discussed in the Chapter 2 Literature Review anthropology has made several contributions to our understanding of the cancer experience through the use of intrinsic anthropological insights, orientations and methodology. In the following points I will discuss nine ways this research is intrinsically anthropological.

• First, through the use of ethnography the data provide a holistic view of the social support and the breast cancer experience and places this experience within the broader cultural and structural context.

• Second, the use of ethnographic methods also provides an emic view of breast cancer. In contrast, most of the public health and psychosocial literature on this topic is written from an etic perspective. Adler (1999) states that this is one of the strengths of anthropology; participants can describe their beliefs, practices and experiences using their own words (Adler 1999). Latina breast cancer survivor’s subjective views (emic views) are valued and they are regarded as experts on their own experiences.

• Third, exploring the social support within the context of immigration allows for a better understanding of local realities and the struggles Latina’s diagnosed with breast cancer encounter through their survivorship trajectory.

• Fourth, the combination of qualitative and quantitative methods is used in a complementary fashion and serves to triangulate research findings. Furthermore, the data from the qualitative in-depth interviews inform the wording, questions and items used in the structured questionnaire, adding to the questionnaire’s cultural relevancy. According to Hahn and Inhorn, while qualitative and quantitative methods are used in other fields the combination of the two is
anthropological (Hahn & Inhorn 2008). In addition, instead of using an existing scale (e.g., social support, chronic stress) I created culturally informed scales that included items in-depth interview participants identified as relevant. The way the social support scale was formatted also enabled me to probe deeper about who provided support (e.g., gender).

- Fifth, anthropology gives credence to the world view and lived experience. The qualitative data exemplify the lived experience of breast cancer and the stressors that influence social support among Latinas who have been diagnosed with this disease.
- Sixth, over several years of local fieldwork and participant observation in the community provide innate understanding and nuances of the issues and social support needs and informed the questions asked.
- Seventh, rapport is critical part of anthropological research (Hahn 1999). It was crucial that I build rapport with the women interviewed, especially given the sensitivity of the subject matter.
- Eight, the theoretical orientation that guides this research is grounded in critical biocultural anthropology, where in relation to breast cancer, the meaning of social support and the acts of giving and receiving assistance are explored within the larger contexts that include the cultural beliefs, social environment and chronic stressors.
- Finally, applied medical anthropology is concerned with putting research into practice and works to address health problems and improve the life and well being of individuals and communities. Thus, included in this chapter are recommendations for action which illustrate how findings from the dissertation
research can be used to inform community-based organizations, clinical practice and psycho-oncology.

**Recommendations for community-based organizations, clinical practice, and psycho-oncology**

This study has practical applications for health professionals and support providers that develop programs and provide services to Latina immigrants. The experience of migration and adjustment to the United States and the U.S. healthcare system is especially relevant to researchers and practitioners working with immigrant populations and women’s health issues. We need to critically consider each woman’s history, the influence of immigration on her family and the influence of the social environment on her psychosocial well being (Flores-Ortiz 2000; Trueba 1998). An understanding of the sociocultural factors that influence social support and the needs and experiences of Latinas immigrant breast cancer survivors is an important part of service provision, specifically ones related to education, information dissemination, and provision of culturally relevant psychosocial services. The information derived from this research can provide new perspectives for social workers, program leaders, mental health practitioners, and health educators concerned with assisting Latino cancer patients in stress management, addressing psychosocial needs, and navigating the healthcare system.

Recommendations include:

1. Consider the cultural dynamics and complexity of the Latino family, especially when tailoring or adapting cancer survivorship educational materials and/or psychosocial or mental health programs for Latinas. This suggests that we need to more critically look at the Latino family dynamic and the concept of *familismo* (Huerta & Macario 1999). We must consider the cultural dynamics and complexity of the Latino family, especially when tailoring cancer-related
resources to improve the quality of life for Latinas. Core Latino family values and relations must be considered during the production and/or organization of cancer survivorship educational materials and psychosocial or mental health programs for Latinas. Simply translating materials and putting a Hispanic family on the front cover, for example, may not address the underlying and overlooked needs and issues. There is a need to have a better understanding of how cancer affects the family unit; to must look beyond the individual that is affected by cancer.

2. Respect cultural norms and beliefs regarding Latina patient’s choice to disclose cancer diagnosis, personal worries, and concerns to their family but understand the added burden and stress this may cause immigrant Latina cancer patients and influence the availability of social support.

3. Develop culturally and linguistically appropriate venues where women can express themselves. Thus, providing Latina cancer patients with venues, like support groups, may give women the opportunity to express themselves, without fear or guilt that they are burdening their family, with others who have gone through a similar experience.

4. Take into account and acknowledge the importance of spirituality and prayer. When designing psychosocial interventions, out of respect for people’s religious beliefs, we separate personal beliefs and religion and are careful not to promote one belief system over another, but we need to acknowledge that spirituality and prayer are part of the Latino cultural fabric and consider their importance in developing such programs.

5. Consider gender roles and in which ways they influence the kinds of support provided by men and women when developing educational programs and support services for Latina cancer patients. Consider that Latina immigrant cancer patients consider other women (e.g., cancer survivors) to be trusted
sources of support and information. Thus, a peer-to-peer support program, which matches newly diagnosed Latina cancer patients with trained long-term survivors, may help Latina patients navigate the healthcare system and provide them with needed support and information.

6. Develop educational materials and programs that are inclusive of men/spouses that provide information about the physical and psychosocial impact of cancer and of the short and long term needs of women who have undergone cancer treatment.

7. Educate family and caregivers of Latina immigrants diagnosed with breast cancer about the short- and long-term physical and psychosocial effects of cancer and its treatment. This will inform families and caregivers, teaching them about cancer patients’ needs so they may better understand what their loved ones are experiencing. Further, family members may learn what they can do to be supportive without patients feeling like they are burdening their families or putting their own needs before their families.

8. Recognize that decisions about treatment and communication can be influenced by structural limitations and should be understood within this context.

9. Outreach and give special attention to Latina cancer patients who have immigrated to the US alone and are perhaps the most vulnerable to stressors and have the least support. Understanding how Latina immigrants cope with challenges and seek help has implications for enhancing, and perhaps informing, the forms of support delivery, as well as designs of social support programs.

10. Be aware of the importance of establishing relationships and building rapport when working with vulnerable or underserved populations. This may involve a lot of person time and outreach. When doing research or developing psychosocial
programs involving and concerning Latina immigrants, allocate time and funds to support relationship building through phone calls to the patient and follow-up.

11. Consider verbal and non-verbal forms of social support when developing support programs for immigrant Latinas. We ought to implement simple gestures such as calling, bringing soups/food(s) and/or small gifts, which are culturally appropriate ways of showing support in Hispanic culture, in order to demonstrate that we are aware of Hispanic culture and Latinas’ social support needs.

12. Recognize that regardless of time in the U.S., Latina immigrants maintain close ties and frequently communicate with family and friends in their native countries. Thus, enabling Latina immigrants (e.g., providing calling cards) to communicate with family and friends during cancer treatment(s) might be a way of providing support.

13. Provide patient education and information in the patients’ own language. This may entail having translators for patients who speak a little English, especially in an oncology setting, where medical jargon and complex terms are often used to explain and describe treatment plans. Spanish-speaking patients should be offered an interpreter, even if they speak a little English and feel they can get by with their level of proficiency. Providers are one of the main sources of informational support for cancer patients; thus it is crucial that patients are able to understand and communicate effectively with their doctors.

14. Provide Latina cancer patients with information about cancer treatment, as well as the short- and long-term psychosocial issues (e.g., sexuality and intimacy) that may arise due to cancer treatment. We need to make sure these kinds of information(s) are more readily accessible. We cannot assume that because information might be available online that it is accessible to immigrant Latina patients and their caregivers.
15. Make available information about community resources that may be able to provide financial assistance, low cost medications, free prosthesis, transportation, and existing support programs. We need to develop a Spanish language resource guide that outlines, in detail, where patients can find these kinds of assistance and resources.

16. Develop cross-cultural training programs that provide knowledge and skills needed to prepare mental health workers, psychologists, program organizers, and counselors to work with multicultural populations and address Latina patients’ psychosocial needs with respect, sensitivity, and in a culturally relevant manner.

17. Increase the pipeline of bilingual and bicultural mental health workers, psychologists, counselors, and patient navigators.

18. Inform policy makers of the need to include mental health and counseling services that address the psychosocial issues encountered by cancer patients as part of total cancer care.

**Application of preliminary findings at the local level**

This paragraph details how I have applied some of the knowledge and information I have learned from this study to my work in the community and with LUNA, Inc. First, the dissertation research process has definitely shaped my understanding of what it means to be a Latina diagnosed with cancer, and what it is like to navigate the healthcare system without knowing the language and/or with limited resources. The results of this study affirm the need for organizations, like LUNA, Inc., that work to provide education and support to Latinas diagnosed with cancer. Grassroots and community organizations that bring women together have potential become especially important to Latinas and may provide a safe haven for women to express themselves freely without the fear of burdening their families. In addition, they provide information
about cancer and its treatment that non-English speaking Latinas might not get from their providers. Since data collection occurred over a 12-month period, I had time to digest the information as well as apply the knowledge gained to the activities I planned and coordinated for LUNA, Inc. For example, data from the in-depth interviews reveal the dire need for information on sexuality and intimacy during and after cancer treatment. Thus, we included a session on sexuality and intimacy at Camp Alegria, a three-day retreat in April of 2008, lead by an oncology nurse for Latinas diagnosed with cancer. Forty-eight women attended this session. At the monthly support meeting in June, the group discussed sexuality and intimacy. The session was geared towards couples and women were encouraged to bring their spouses/partners. We added a caregiver workshop the last day of Camp Alegria, which was lead by a professor from the School of Social Work at University of South Florida.

Further, as a non-profit organization LUNA, Inc. is in its infancy; it is currently applying for 501-C3 tax-exempt status. LUNA, Inc. has a broader vision and hopes to provide assistance, disseminate information, and develop culturally-relevant interventions that will empower cancer survivors and their families. It is my hope that the knowledge and information obtained from my dissertation will be applied to further this vision and develop programs and services that will be anthropologically informed and thus better able to address the support needs of Hispanic cancer survivors in West Central Florida and beyond.

**Conclusion and contributions to anthropology**

As stated in the literature, Cohen argues for a contextual understanding of social support (Cohen 2004a). Further, the work by Dressler and Jacobsen illustrates how the social environment in which support occurs substantially influences the nature of support and its effects on health (Dressler 1985; 1991; Dressler et al 1986; Jacobson 1987). Findings shed light on the cultural and structural processes that mediate social support
among Latin American immigrants diagnosed with breast cancer. The mediating effects
of support are embedded within the larger, structured social and cultural contexts; these
in turn help to shape the nature and outcomes of support. As Pearlin states, “As in
virtually all instances where the well-being of people is at stake, personal problems
overlap with social problems and personal support systems are shaped by social
resources” (Pearlin 1985: 59).

Breast cancer not only affects individuals, it impacts their social relationships,
finances, work, and social roles. Study findings provide a rich and in-depth
understanding of social support, contextualize the breast cancer experience, and
illustrate the stresses and burdens of cancer among Latin American immigrant women
diagnosed with breast cancer. This research contributes to two areas of inquiry: medical
anthropology and cancer survivorship. Study findings contribute to anthropology by
adding to our understanding of the socio-cultural and structural factors that influence
social support within the context of immigration and demonstrating the relevance of
using a biocultural framework to understand the complexity of constructs such as social
support which are culturally embedded and occur within the larger social environment.
Thus, to truly understand the factors that mediate social support one must look at both
the cultural construction of stress and social support as well as political economic
structure in which support occurs. As Castro and Farmer (2007) delineate that “From the
onset, anthropological studies of health have been contextualizing, insisting on the
embeddedness in the social world of all that may be observed or elicited” (Castro &
Farmer 2007: 42). Anthropological insights elucidate the local realities and lived
experience of Latin American immigrant women diagnosed with breast cancer.
Anthropology has always been interested in social organization and human
relationships, and the findings from this study add to this literature (Brettell 2000). In
sum, this research enhances our understanding of how social support relationships may
be transformed through the process of migration to the United States in relation to the
cancer experience of immigrant Latina breast cancer survivors. Furthermore, findings
also inform us about the types of social-support resources Latina immigrant breast
cancer survivors' need and use to adjust and adapt to cancer and its long-term effects.
Conceptually, it contributes to our understanding of how social environment(s) and
processes of migration influence social support.
References


Baer RD, Nichols J. 1998. A quick guide to ethnic health beliefs and dietary patterns, Center for applied anthropology department of anthropology university of south florida, Tampa


Cope DG. 1995. Functions of a breast cancer support group as perceived by the participants: an ethnographic study. *Cancer Nurs* 18:472-8
DiGiacomo SM. 1999. Can there be a "cultural epidemiology"? Medical Anthropology Quarterly 13:436-57


Erwin DO. 2002. Cancer education takes on a spiritual focus for the African American faith community. *Journal of Cancer Education* 17:46-9


FCDS. 2006. Florida Cancer Data System.


Finch BK, Vega WAARCSMC, brian_finch@rand.org, Robert Wood Johnson Medical School NBNJ. 2003. Acculturation Stress, Social Support, and Self-Rated Health Among Latinos in California. *Journal of Immigrant Health* 5, no 3:109-17 (9 pages)


Arch Intern Med 151:366-70


*Field Methods* 13:3-19


Holland KD, Holahan CK. 2003. The relation of social support and coping to positive adaptation to breast cancer. *Psychology & Health* 18:15-29


Hovey JD, Magaña, Department of Psychology TUoTTO. 2000. Acculturative Stress, Anxiety, and Depression among Mexican Immigrant Farmworkers in the Midwest United States. *Journal of Immigrant Health* 2, no 3:119-31 (13 pages)


Institute of Medicine. 2006. *From Cancer Patient to Cancer Survivor. Lost in Transition.*

Isaksen AS, Thuen F, Hanestad B. 2003. Patients with cancer and their close relatives -
Experiences with treatment, care, and support. *Cancer Nursing* 26:68-74

between social support, stress, and health among women on Detroit’s East Side.
*Health Educ Behav* 29:342-60

*Medical Anthropology Quarterly* 1:42-67

Press

Janes CR, Pawson IG. 1986. Migration and biocultural adaptation: Samoans in

differences in adequacy of information and support for women with breast
cancer. *Cancer* 113:1058-67

Jehn KA, Doucet L. 1996. Developing Categories from Interview Data: Text Analysis and

patients and their families toward truth telling of different stages of cancer.
*Psychooncology* 16:928-36

Effective Recruitment Strategies for a Cancer-Prevention Trial in Older Hispanic
Women: A Clinical Trial Model. In *Preventing and Controlling Cancer in North
Publishers
Joslyn SA. 2002. Racial differences in treatment and survival from early-stage breast
carcinoma. *Cancer* 95:1759-66

Kagawa-Singer M. 1995a. Socioeconomic and cultural influences on cancer care of

Kagawa-Singer M. 1995b. Socioeconomic and cultural influences on cancer care of
women. *Seminars In Oncology Nursing* 11:109-19

- "You got to go where he lives". *Jama-Journal of the American Medical
Association* 286:2993-3001

Kagawa-Singer M, Pourat N. 2000. Asian American and Pacific Islander breast and
cervical carcinoma screening rates and healthy people 2000 objectives. *Cancer*
89:696-705

Kagawa-Singer M, Wellisch DK. 2003. Breast cancer patients' perceptions of their
husbands' support in a cross-cultural context. *Psycho-Oncology* 12:24-37

American and Anglo American women. *Culture Medicine and Psychiatry* 21:449-
80

social support on breast cancer screening in a multicultural community sample.
*Oncol Nurs Forum* 29:845-52

Kaufert JM. 1999. Cultural mediation in cancer diagnosis and end of life decision-
making: the experience of Aboriginal patients in Canada. *Anthropology and
Medicine* 6:405-21

women and body politics*, ed. M Lock, P Kaufert, pp. 287-309. Cambridge:
Cambridge University Press


Leatherman TL. 1996. A biocultural perspective on health and household economy in southern Peru. Medical Anthropology Quarterly 10:476-95


Lethborg CE, Kissane D, Burns WI. 2003. 'It's not the easy part': the experience of significant others of women with early stage breast cancer, at treatment completion. Soc Work Health Care 37:63-85


Li CI, Malone KE, Daling JR. 2002. Differences in breast cancer hormone receptor status and histology by race and ethnicity among women 50 years of age and older. Cancer Epidemiol Biomarkers Prev 11:601-7

Li CI, Malone KE, Daling JR. 2003a. Differences in breast cancer stage, treatment, and survival by race and ethnicity. Archives of Internal Medicine 163:49-56

Li CI, Malone KE, Daling JR. 2003b. Differences in breast cancer stage, treatment, and survival by race and ethnicity. Arch Intern Med 163:49-56


Markovic M, Manderson L, Kelaher MAKCfWsiSTUoMCVA, milicam@unimelb.edu.au, Key Centre for Women's Health in Society TUoMCVA, et al. 2002. The Health of
Immigrant Women: Queensland Women from the Former Yugoslavia. *Journal of Immigrant Health* 4, no 1:5-15 (1 pages)


Martinez M. 2004. RN, BSN. Tampa


Rodrigue JR. 1997. An Examination of Race Differences in Patients’ Psychological Adjustment to Cancer. *Journal of Clinical Psychology in Medical Settings* 4:271-80


Scarinci IC, Beech BM, Kovach KW, Bailey TL, Scarinci@uab.edu, et al. 2003. An Examination of Sociocultural Factors Associated with Cervical Cancer Screening Among Low-Income Latina Immigrants of Reproductive Age. *Journal of Immigrant Health* 5, no 3:119-28 (10 pages)


Materials specified: Table of contents
http://www.loc.gov/catdir/toc/fy0803/2007013895.html


Appendix A: Interview Guide for Key Informants

Date: __________  
Interviewed by: __________  
Location: ____________________ County: _____________

Describe the rational for the project and provide a brief overview of the project. The purpose of my study is to help us understand how social support relationships are transformed through the process of immigration and to learn about the support needs of Latinas during the diagnosis and treatment of breast cancer. I am also interested in understanding the challenges and strength of Latina cancer survivors and how cultural beliefs and expectations contribute to Latinas perceptions of social support.

The interview will take approximately 60 minutes. We can stop anytime. Your participation is voluntary and anything you say to me will be kept confidential. Because what you have to say is so important to me, I would like to tape record our interview. Is that OK with you?

(If Yes: Press Record): For our records then, please state if it is OK to tape record our interview?  
Thank you. I’m going to take some notes as we talk as well, so I don’t forget anything important.

Today is __________; organization ____________.

(If No): OK, and thanks. I will be taking notes as we talk, because I don’t want to forget anything that you tell me.

Key Informant Gender: □ Male □ Female

Do you consider yourself Hispanic/Latino?  Yes  No

What languages are you fluent in writing?
What languages are you fluent in speaking?
What is your educational background?
What do you do for a living?

How long have you been doing ________?

Thank you, now I will begin with questions that are a little broader and then ask questions that are a little more specific.

What do you think are the biggest problems that Hispanics in (__________) face?
What are the strengths of the local Hispanic/Latino community?
Appendix A: (Continued)

What health issues do you think are the most important for Hispanics/Latinos?

Besides doctors or nurses, who can Hispanic people go to when they have an illness here?

What are some of the changes Latinos/Hispanics experience when they immigrate to the US?
   How do these changes affect their social relationships? The family? Resources?

What are some of the beliefs in Hispanic culture about cancer?

How do you think cancer affects Hispanic immigrants?

How do you think cancer affects the Hispanic family?

Do you work with/provide services Hispanic cancer patients/survivors? Yes No

   Based on your experience, about what percent are: _____ women/ _____ men that you work with directly or indirectly.

   Are there any differences between the Hispanic men and women you see (gender differences)?

   If yes, can you describe some of these differences to me? Can you give me an example?

   From your experience are there different cultural expectations for men and women diagnosed with cancer (family roles, sick role, and caretaker role)?

What are the issues/challenges Hispanics diagnosed with cancer often face (health care, access, language)?

Do Hispanic men and women diagnosed with cancer face similar issues/challenges (e.g., with work, family, care etc…)? Please describe and can you give me some examples?

How do you think Hispanic women, in general, perceive cancer? Breast cancer? How do these perceptions change among Hispanic women who are diagnosed?

What are some of the terms Hispanics use to talk about cancer? Breast cancer?

Tell me about your experience working with Latina breast cancer survivors/patients.

   What is most rewarding about the work you do? What is the most challenging thing about the work you do?

Can you tell me about the different psychosocial and or mental health services and or support programs available for breast cancer patients?
Appendix A: (Continued)

You mentioned ________, are these programs services used by Latinas?

What might be some of the reasons why Latinas might not use support programs?

From your experience are there any cultural beliefs/taboo's that might affect Latinas use of these psychosocial/mental health services or support programs?

Are there any other barriers that might affect Latinas use of these psychosocial/mental health services or support programs?

What can we do to make these programs and services more available to Latinas and non-english speakers?

Hispanics are from various nationalities, do you see differences:
   Between the Hispanic subgroups (e.g., Cuban, Mexican, Puerto Rican).
      If yes, describe? Can you give me some examples?

   By immigration status (e.g., those that are here legally and those that are not).
      If yes, describe? Can you give me some examples?

   Between those that speak English and those that don’t?
      If yes, describe? Can you give me some examples?

   Between Latino/a men and women?
      If yes, describe? Can you give me some examples?

To recap, the purpose of my dissertation study is to help us understand how social support relationships are transformed through the process of immigration and to learn about the support needs of Latinas during the diagnosis and treatment of breast cancer. I am also interested in understanding the challenges and strength of Latina cancer survivors and how cultural beliefs and expectations contribute to Latinas perceptions of social support. What else do you think I should think about as this study moves forward?

Is there anyone else you think it might be good for us to talk to? (Organizations, social workers, support group facilitators etc…).
**Appendix B: English and Spanish In-depth Interview Guide**

Hello, my name is Dina Martinez. I am a student at the University of South Florida and I’m working on a study about the needs of Latina breast cancer survivors who were born in Latin America or in the Caribbean and live here now.

Would you be willing to answer some questions about this topic?

NO: I’m sorry you won’t be taking part in this study. Thank you for your time.

YES: Thanks. Before we begin, I’d like to make sure that you understand what we are going to do. Here’s an information sheet with details about the study [provide informed consent]. I’d like to talk with you for about an hour about these very important women’s health issues and your experience with breast cancer. Everything you say will be kept confidential and you don’t need to answer any questions you don’t want to. Because what you have to say is very important to me, I will take notes during our conversation. I will be tape recording the interview session because I don’t want to miss any of your comments. Please take a minute to look at the information sheet and I can answer any questions you might have. Do I have your permission to tape record the interview?

[...Pause…]

Do you have any questions? [Address any questions or concerns.]

Are you still interested in taking part?__________

NO: I’m sorry you won’t be taking part in this study. Thank you for your time.

YES: OK – let’s begin…

DEMOGRAPHICS: To begin, I would like to know a little bit about you.

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<thead>
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<th>Date:</th>
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<tr>
<td>ID number:</td>
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<tr>
<td>How old are you:</td>
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</table>
Appendix B: (Continued)

In these next few questions, I’d like to learn your opinions about important health topics, including women’s health issues. Your thoughts about these issues are important to me, and there is no right or wrong answer.
(Suggested prompt to use as needed to build lists: Is there anything else you can think of?)

What are the most important things in your life?

| 1. | 6. |
| 2. | 7. |
| 3. | 8. |
| 4. | 9. |
| 5. | 10. |

List all the things a woman should be: A woman should be_________?

| 1. | 6. |
| 2. | 7. |
| 3. | 8. |
| 4. | 9. |
| 5. | 10. |

What are the most important things a woman can do? The most important things a woman can do are:______

| 1. | 6. |
| 2. | 7. |
| 3. | 8. |
| 4. | 9. |
| 5. | 10. |

List all the different roles and responsibilities a woman has?

| 1. | 6. |
| 2. | 7. |
| 3. | 8. |
| 4. | 9. |
| 5. | 10. |

List all the ways a person can show someone who is sick or recovering from illness (e.g. breast cancer) that they love, understand and/or care about them?

| 1. | 6. |
| 2. | 7. |
| 3. | 8. |
| 4. | 9. |
| 5. | 10. |
Appendix B: (Continued)

List all the ways a person can help/aid someone who is sick or recovering from illness.

1.  
2.  
3.  
4.  
5.  
6.  
7.  
8.  
9.  
10.  

List all the people that can provide financial/material assistance to someone who is sick?

1.  
2.  
3.  
4.  
5.  
6.  
7.  
8.  
9.  
10.  

List all the people/things that can help someone make a decision about their health?

1.  
2.  
3.  
4.  
5.  
6.  
7.  
8.  
9.  
10.  

List all the things that make a doctor/physician a good doctor?

1.  
2.  
3.  
4.  
5.  
6.  
7.  
8.  
9.  
10.  

The following questions are about your childhood and about what people do when someone is sick.

1. Thinking back to your childhood, what were some of the things you learned about when people were sick or ill?

   a. Did men and women do different things to help out when someone was sick or ill?
Appendix B: (Continued)

i. What happened when your dad or a male person was sick?

1. What was expected of them?

2. Who took care of them?

ii. What happened when your mom or a female person was sick?

1. What was expected of them?

2. Who took care of them?

2. How did your family manage hard times or stressful events?

Now I am going to ask about your experience when you came to the US?

3. What was it like when you came to this country?

4. Why did you move/come to the United States?

5. Who came with you/ who stayed behind?

6. Do you still have family and friends back home?

   a. How often do you communicate with your family back home?

   b. Do they depend on you (e.g., for money, gifts, medicines)?
Appendix B: (Continued)

c. Did you tell them about your diagnosis?
   i. Why or why not?
   ii. How did they react?
   iii. Did this cause you stress?

7. Where do the majority of your friends and family live now?

8. Do you think that being an immigrant/Hispanic affects a person’s access to health care or the treatment they receive?
   a. Why or why not?

In the following questions I am going to ask you about your cancer experience, the support you received and about your immigration experience?

When you here the word cancer what comes to mind?

<table>
<thead>
<tr>
<th>1.</th>
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<tr>
<td>2</td>
<td>7.</td>
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<tr>
<td>3</td>
<td>8.</td>
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<tr>
<td>4.</td>
<td>9.</td>
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<tr>
<td>5.</td>
<td>10.</td>
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</table>

What are the important things a woman who is diagnosed with breast cancer should know about?

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<td>3</td>
<td>8.</td>
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<td>4.</td>
<td>9.</td>
</tr>
<tr>
<td>5.</td>
<td>10.</td>
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</tbody>
</table>
Appendix B: (Continued)

What are some of the things you can think of that can cause cancer?

1.  
2.  
3.  
4.  
5.  
6.  
7.  
8.  
9.  
10.  

List all the things that may affect the quality of treatment a person gets from the medical staff or doctor?

1.  
2.  
3.  
4.  
5.  
6.  
7.  
8.  
9.  
10.  

List all the things a person with breast cancer needs assistance with.

1.  
2.  
3.  
4.  
5.  
6.  
7.  
8.  
9.  
10.  

9. Tell me about your cancer experience?

9. What are the things that caused you the most stress during the diagnosis and treatment for breast cancer?

10. Do you consider yourself to be a breast cancer survivor?

   a. If yes, when did you consider yourself to be a breast cancer survivor?

   b. If no, why not?

11. As a woman how has cancer affected the way you see yourself?
Appendix B: (Continued)

12. In talking with women about their breast cancer experience the word “support”
comes up a lot, can you tell me in your own words what support means to you?

13. Who or what has been helpful since your diagnosis?
   a. Why was that important to you?

14. Who or what are the things that have made this process difficult?

15. When you were first diagnosed with breast cancer, to whom or where did you
    turn for help, support and or information?
   a. How satisfied were you with the help, support or information you
      received?
   b. Was there any one you wanted to involve but could not?
      i. Why?

16. In what way is life different now then when you were first diagnosed?
    (Probe: Has it changed your roles within your household? In what way? How
    has your relationship with your spouse, children etc changed since being ill?)

17. How would you describe the doctors/nurses who treated you?
   a. Describe for me a typical day at the doctor’s office.
   b. Who was/is involved with helping you to make decisions about the
      treatment you receive/d?

18. Who did you turn to for medical advice and/or information (doctor, friends,
    internet, support group, counselor, healer, and/or clergy)?

19. How important is religion/spirituality to you?
Appendix B: (Continued)

a. Did your feelings and beliefs about religion/spirituality change after you were diagnosed with breast cancer?

20. How did your relationship with your friends and family change during your diagnosis and treatment?

   a. Did people behave differently towards you?

   b. Can you give me an example?

21. In what ways did breast cancer affect your activities with church, community or social groups?

22. What did you want family, friends, neighbors, and/or church members to assist you during your diagnosis and treatment?

   a. Was there any kind of support you wanted but did not get?

23. If you were working at the time how did your supervisor or co-workers react to your diagnosis/treatment?
Appendix B: (Continued)

DEMOGRAPHICS: Before we end, I would like to learn a little more about you.

<table>
<thead>
<tr>
<th><strong>What language/s do you speak?</strong></th>
<th>___ English       Well / Not well</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>___ Spanish       Well / Not well</td>
</tr>
<tr>
<td></td>
<td>___ Bilingual</td>
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<table>
<thead>
<tr>
<th><strong>What language do you speak most at home?</strong></th>
<th>___ English</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>___ Spanish</td>
</tr>
<tr>
<td></td>
<td>___ Bilingual</td>
</tr>
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<table>
<thead>
<tr>
<th><strong>How old were you when you were first diagnosed?</strong></th>
</tr>
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<table>
<thead>
<tr>
<th><strong>When were you diagnosed with breast cancer (Month/Year)?</strong></th>
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<table>
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<tr>
<th><strong>Where did you live when you were first diagnosed?</strong></th>
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<table>
<thead>
<tr>
<th>___ Same house/Same city</th>
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<tbody>
<tr>
<td>___ Different house /Same city</td>
</tr>
<tr>
<td>___ Different city</td>
</tr>
<tr>
<td>___ Different state</td>
</tr>
<tr>
<td>___ Outside the US</td>
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<thead>
<tr>
<th><strong>What type of breast cancer were you diagnosed with?</strong></th>
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<table>
<thead>
<tr>
<th><strong>What kind of treatment did you receive?</strong></th>
</tr>
</thead>
</table>

| ___ Surgery:                                 |
| ___ Lumpectomy,                             |
| ___ Mastectomy,                             |
| ___ Other: ________________________________ |
| ___ Chemotherapy                            |
| ___ How many sessions? ________             |
| ___ Radiation                               |
| ___ How many sessions? ________             |
| ___ Do/did you take any pills or medications after treatment? |
| Yes                                        |
| No                                         |
| If Yes, what kind? ________________________ |

<table>
<thead>
<tr>
<th><strong>Did you have reconstructive surgery?</strong></th>
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| ___ Yes |
|___ No  |
## Appendix B: (Continued)

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>Do you currently have health insurance, Medicare or Medicaid?</td>
<td>___ Yes ___ No</td>
</tr>
<tr>
<td>Did you have insurance, Medicaid or Medicare when you were first diagnosed?</td>
<td>___ Yes ___ No</td>
</tr>
<tr>
<td>How many doctors did you see during your cancer treatment?</td>
<td>___ Yes ___ No</td>
</tr>
<tr>
<td>In what language did you receive most of the information about your cancer care/treatment?</td>
<td>___ English ___ Spanish ___ Bilingual</td>
</tr>
<tr>
<td>What languages do you prefer to receive your cancer care/treatment information in?</td>
<td>___ English ___ Spanish ___ Bilingual</td>
</tr>
<tr>
<td>What is the highest grade of school you completed?</td>
<td></td>
</tr>
<tr>
<td>What is current employment status?</td>
<td>___ Full time ___ Part time ___ Retired ___ Homemaker ___ Unemployed looking for work ___ Unemployed through disability or illness</td>
</tr>
<tr>
<td>What was your employment status when you were first diagnosed?</td>
<td>___ Full time ___ Part time ___ Retired ___ Homemaker ___ Unemployed looking for work ___ Unemployed through disability or illness</td>
</tr>
<tr>
<td>What kind of work do/did you do?</td>
<td></td>
</tr>
<tr>
<td>Did you work while you were receiving your cancer treatment?</td>
<td></td>
</tr>
<tr>
<td>What neighborhood do you live in? (name / zip code)</td>
<td></td>
</tr>
<tr>
<td>What is your current household income?</td>
<td>___ 10,000 or less ___ 10,001- 30,000 ___ 30,001-50,000 ___ Greater than 50,000 ___ Don’t know</td>
</tr>
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</table>
Appendix B: (Continued)

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
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</table>
| What was your household income when you were first diagnosed?           | ___ 10,000 or less  
___ 10,001- 30,000  
___ 30,001-50,000  
___ Greater than 50,000  
___ Don’t know                                                              |
| What is your current marital status?                                    | ___ Married / Living with partner  
___ Never married  
___ Divorced  
___ Widowed                                                              |
| What was your marital status when you were first diagnosed?             | ___ Married / Living with partner  
___ Never married  
___ Divorced  
___ Widowed                                                              |
| How many children do you have?                                          |                                                                        |
| If you have children how old are they?                                  |                                                                        |
| Since you were diagnosed and treated for breast cancer, have you been responsible for the care of another person? | ___ Yes  
___ No                                                                |
| How many people live in your household?                                 |                                                                        |
| What is your nationality/ where were you born?                          |                                                                        |
| When did you come to the United States for the first time?              |                                                                        |
| How long have you lived in the U.S.?                                   |                                                                        |
| How long have you lived in Tampa?                                       |                                                                        |
| How do you like it here?                                                |                                                                        |
| How often do you travel back to your home country?                      |                                                                        |
| Which of the following support programs have you used since you were first diagnosed with breast cancer? | ___ Look Good Feel Better  
___ Y-Me  
___ Reach to Recovery  
___ Support Group:  
___ Other:  
______________________________                                           |

Thank you. Do you have anything else you would like to add or anything I should ask other women like your self that I may have left out.
Hola, mi nombre es Dina Martinez, yo soy una estudiante en la Universidad del sur de la Florida y estoy haciendo una investigación sobre las necesidades de Latinas que han nacido afuera de los Estados Unidos, pero viven aquí ahora y que han sido diagnosticada con cáncer de seno.

Usted esta interesada en participar en esta encuesta y responder algunas preguntas sobre este tema?
NO: Lo siento, gracias por su tiempo.

Si: Gracias, Antes de empezar yo quisiera estar segura que usted entiende lo que vamos hacer hoy. Esta hoja tiene información sobre los detalles de este estudio. Me gustaría poder hablar con usted sobre temas importantes relacionados a la salud de la mujer y sobre su experiencia con cáncer de seno. Tamara como una hora. Todo lo que usted me diga será confidencia y no tiene que contestar una pregunta si no quiera. Por lo que usted tiene que decir es muy importante para mí yo voy a tomar algunas notas durante nuestra conversación. También voy a grabar la encuesta por que no quiero perder u omitir algo que me diga. Por favor tome un minuto para leer la hoja de información. Déjeme saber si tiene algunas preguntas. Tengo su permiso para grabar la encuesta?

[...Pause...]

Tiene alguna pregunta? [Address any questions or concerns.]

Todavía le interesa participar? __________

NO: Lo siento, gracias por su tiempo.

SI: Vamos a empezar...

Fecha: 
ID number: 
Que edad tiene usted?:

Me gustaría aprender su opinión sobre varios temas relacionado con la salud. Sus ideas y pensamientos sobre estos temas son importantes para mí. No hay respuestas incorrecta, solamente quiero saber su honesta opinión.
Appendix B: (Continued)

*(Suggested prompt to use as needed to build lists: Hay algo más?)*

**Cuales son las cosas más importantes en su vida?**

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Probe: If family is listed ask who constitutes family?

**Dígame todas las cosas que una mujer debe de ser? / Una mujer debe de ser______:**

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**Dígame las cosas más importantes que una mujer puede hacer? Las cosas más importantes que una mujer puede hacer es:______?**

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**Dígame todas las responsabilidades y roles que tiene una mujer?**

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**Dígame todas las formas que una persona puede enseñarle a alguien que esta enfermo o recuperándose de una enfermedad que son amados y queridos?**

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Dígame todas las formas que alguien puede ayudar/asistir a una persona que está enferma o recuperándose de una enfermedad?

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Dígame todas las personas que deben proveer ayuda financiera/material a una persona que está enferma.

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Dígame todas las personas/cosas que pueden ayudar a alguien tomar una decisión sobre su salud.

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Dígame todas las cosas que hacen a un médico bueno?

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Las siguientes preguntas son sobre su niñez y sobre lo que se debe hacer cuando alguien está enfermo.

24. Pensando a su niñez, que son algunas cosa que usted aprendió sobre lo que hacer cuando una persona cuando estaba enferme o no se sentía bien?
Appendix B: (Continued)

a. Los hombres y mujeres hacían diferentes cosas para ayudar a la persona que estaba enferma?

i. Que pasaba cuando su papa o un hombre en su familia estaba enfermo?

ii. Que se esperaba de ellos? Su posición cambiaba?

1. Quien los cuidaba?

iii. Que pasaba cuando su mama o una mujer en su familia estaba enferma?

iv. Que se esperaba de ellas? Su posición cambiaba?

1. Quien los cuidaba?

25. Como su familia manejaba los momentos difícil or estresante?

Ahora le voy a preguntar sobre su experiencia cuando vino a los EEUU?

26. Como fue su experiencia cuando llego a los EEUU?

27. Por que usted se mudo para los EEUU?

28. Quien vino con usted? Quien se quedo atrás?
Appendix B: (Continued)

29. Todavía tiene familia y amistades in su país?
   a. Que tan a menudo usted se comunica con ellos?

   b. Ellos depende de usted (por ejemplo, para dinero, medicinas, regalos)?

   c. Usted le hablo sobre su diagnosis?

      i. Por que?

         1. Si le hablo sobre su diagnosis, como reaccionaron?

         2. Si no le hablo, por que?

      ii. Esto le causo estrés a usted?

30. Adonde es que la mayoría de sus amigos y amistades viven ahora?

31. Usted cree que el ser inmigrante/nacido afuera de los EEUU afecta el la calidad
    y el tipo de tratamiento que una persona diagnosticada con cáncer recibe?

   a. Por que?

Las próximas preguntas serán sobre su experiencia con cáncer.

Cuando usted oye la palabra cáncer que es lo que le viene a la mente?

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Appendix B: (Continued)

Cuales son las cosas que una mujer diagnosticada con cáncer de seno debe de saber?

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Cuales son algunas de las cosas que pueden causar cáncer?

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Que cosas pueden afectar la cualidad de tratamiento para el cáncer que una persona recibe de su medico/clinica?

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Dígame todas las cosas con que una persona con cáncer del seno necesita ayuda.

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32. Cuénteme sobre su experiencia con el cáncer.

33. Cuales fueron las cosas que le causaron más estrés durante su diagnosis y tratamiento de cáncer?

34. Usted se considera como una sobreviviente de cáncer?
Appendix B: (Continued)

a. Si si, cuando fue que usted se vio como sobreviviente?

b. Si no, por que?

35. Como mujer, como le afectado el cáncer/ la forma que usted se ve?

36. Hablando con otras mujeres sobre su experiencia con cáncer del seno la palabra “apoyo” es usada frecuentemente, en sus propias palabras que significa apoyo para usted?

37. Que o quien asido útil desde su diagnosis con cáncer?

a. por que son importante para usted?

38. Que or quien han echo este proceso dificil?

39. Cuando primero le diagnosticaron con cáncer, a quien o a donde usted fue para ayuda, apoyo y/o información?

a. Que satisfecha estuvo con la ayuda, apoyo y/o información que recibió?

b. Habría alguna persona a quien usted quería involucrar en ese momento pero no pudo?

i. Por que?

40. En que forma su vida es diferente ahora, en comparación a cuando le diagnosticaron cáncer?
(Probe: Como ha afectado su hogar, su forma de ser, lo que usted hace, como su familia la trata? Como a cambiado su relación con sus esposo y hijos?)
Appendix B: (Continued)

41. Como usted describiría a los médicos y enfermeras que le atendieron?
   
   a. Me puede describir un día típico cuando tenía sita con su médico.
   
   b. Quien le ayudo a tomar las dediciones sobre su tratamiento?

42. Con quien hable o a quien fue usted para consejos o información medica? (doctor, friends, internet, support group, counselor, healer, and/or clergy)?

43. Que tan importante es religión/espiritualidad para usted?
   
   a. Sus sentimientos y creencia cambiaron después de la diagnosis? Como?

44. Como cambiaron las relaciones con su amistades y familia durante su tratamiento?
   
   a. Algunas personas se comportaron diferente con usted?
   
   b. Me puede dar un ejemplo?

45. Como le afecto el cáncer de seno en sus actividades sociales? (church, community or social groups)?

46. En que le ayudo su familia, amistades, vecinos y compañeros de la iglesia?
   
   a. Usted quiso algún tipo de apoyo pero que no recibió?

47. Si usted estaba trabajando durante su tratamiento como se comportaron su compañeros de trabajo/supervisor?
Appendix B: (Continued)

DEMOGRAPHICS: Para cerrar quiero aprender un poquito más acerca de usted.

| Que idioma usted habla? | ___ ingles bien / no muy bien |
| ___ español bien / no muy bien |
| ___ bilingüe |

| Que idioma habla usted en la casa? |
| ___ ingles |
| ___ español |
| ___ bilingüe |

| Que edad tenía usted cuando la diagnosticaron con cáncer? |

| En que año la diagnosticaron con cáncer? (mes/año)? |
| ___ En la misma casa/misma ciudad |
| ___ Diferente casa/diferente ciudad |
| ___ cuidad diferente: |
| ___ estado diferente: |
| ___ afuera de los EEUU: |

| Donde vivía usted cuando primero la diagnosticaron con cáncer? |

| Que tipo de cáncer del seno le diagnosticaron? |
### Que tipo de tratamiento recibió usted?

___Cirugía:  
___Lompectomía,  
___Masectomía,  
___otra: ________________  
___quemoterapia  
Cuantas sesiones? _______  
___Radiación  
Cuantas sesiones? _______  
___Tomo/toma algunas  
pastillas/medicamentos después de su tratamiento?  
    Yes  
    No  
    Sí, Sí, cuales? ________________

### Usted tuvo una cirugía de reconstrucción?

___ Si  
___ No

### Usted tiene seguro medico, Medicare or Medicaid actualmente?

___ Si  
___ No

### Usted tuvo seguro medico, Medicare or Medicaid cuando le diagnosticaron cáncer?

___ Si  
___ No

### Cuantos médicos/doctores vio/tuvo usted durante su tratamiento?

### En que idioma recibió usted la mayoría de información sobre su tratamiento para el cáncer?

___ inglés  
___ español  
___ bilingüe

### En que idioma preferiría usted recibir información sobre su tratamiento para el cáncer?

___ inglés  
___ español  
___ bilingüe

### Cual es el último grado escolar que usted completo?

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Appendix B: (Continued)

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| Que tipo de trabajo tiene usted actualmente?                           | ___ Tiempo completo  
|                                                                         | ___ Medio tiempo  
|                                                                         | ___ Retirada  
|                                                                         | ___ Ama de casa  
|                                                                         | ___ Desempleada buscando trabajo  
|                                                                         | ___ Desempleada por discapacidad o enfermedad  |
| Que tipo de trabajo tenía usted antes de ser diagnosticada con cáncer?  | ___ Tiempo completo  
|                                                                         | ___ Medio tiempo  
|                                                                         | ___ Retirada  
|                                                                         | ___ Ama de casa  
|                                                                         | ___ Desempleada buscando trabajo  
|                                                                         | ___ Desempleada por discapacidad o enfermedad  |
| Que tipo de trabajo tiene usted?                                       |                                                                         |
| Usted trabajó durante su tratamiento?                                   |                                                                         |
| En qué barrio/área de _____ vive usted? (name / zip code)               |                                                                         |
| Cuánto es el ingreso de su hogar en estos momentos?                     | ___ 10,000 o menos  
|                                                                         | ___ 10,001- 30,000  
|                                                                         | ___ 30,001-50,000  
|                                                                         | ___ Más de 50,000  
|                                                                         | ___ No se  |
| Cuánto era el ingreso de su hogar antes de ser diagnosticada?          | ___ 10,000 o menos  
|                                                                         | ___ 10,001- 30,000  
|                                                                         | ___ 30,001-50,000  
|                                                                         | ___ Más de 50,000  
|                                                                         | ___ No se  |
| Cual es su estado civil, actual?                                       | ___ Casada / Con pareja  
|                                                                         | ___ Soltera / nunca casada  
|                                                                         | ___ Divorciada  
|                                                                         | ___ Viuda  |
| Cual era su estado civil antes de ser diagnosticada cáncer?             | ___ Casada / Con pareja  
|                                                                         | ___ Soltera / nunca casada  
|                                                                         | ___ Divorciada  
<p>|                                                                         | ___ Viuda  |
| Cuántos hijos tiene?                                                   |                                                                         |</p>
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<th>Que edad tienen su hijos?</th>
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| Desde su diagnosis y tratamiento para el cáncer, ha tenido usted la responsable para el cuidado de otra persona? | ___ Si  
| ___ No                                                                                      |
| Cuantas personas viven en su hogar/casa?                                                     |
| Cual es su nacionalidad?                                                                  |
| Donde usted nacio?                                                                       |
| Cuando vino usted a los EEUU por primera vez?                                             |
| Que tanto tiempo (años/meses) usted ha vivido en los EEUU?                                 |
| Que tanto tiempo usted a vivido en (ciudad) ________?                                     |
| Como le ha gustado vivir aqui?                                                            |
| Que tan a menudo visita/ regresa a su pais?                                                |
| Usted a usado algunos de los siguientes programas después de su diagnostico con cancer? | ___ Look Good Feel Better  
| ___ Y-Me                                                                                   |
| ___ Reach to Recovery                                                                     |
| ___ Grupo de apoyo:                                                                        |
| ___ Otro:                                                                                |
|                                                                                          |

Gracias, Tiene algo mas que quiera compartir con migo or otras preguntas que puedo preguntarle a otras mujeres como usted?
Hello, my name is ____________. This study is about the support needs of Latina breast cancer survivors who were born in Latin America or in the Caribbean and live in the United States now.

Before we begin, I’d like to make sure that you understand what we are going to do. I’d like to ask you to answer questions about women’s health issues and your experience with breast cancer. What you have to say is very important to me. The first set of questions is about your breast cancer experience and social support. This will be followed by questions about your background, education, work, and your experience moving to the United States. The survey will take about 30-45 minutes to complete. If you need to stop and take a break please let me know.

Your participation in this survey is voluntary. There are no wrong or right answers to these questions. Everything you say will be kept confidential and you don’t need to answer any questions you don’t want to. Your responses and the responses of the other women being interviewed will be reported in a group format, as a whole and your responses will not be linked to your name. You should not feel that there is any pressure to take part in the study.

We don’t know if you will get any benefits by taking part in this study. But, by taking part in this study you may help us learn about the support needs of Latinas diagnosed with cancer and with information that we can use to develop a support programs in Spanish. We will not pay you for the time you volunteer while being in this study.

If you have any questions, concerns or complaints about this study, call Dina Martinez at 813-728-5895 or at 813-979-4291 or Dr. Linda Whiteford (dissertation advisor) at 813-974-0801

Would you like to take part in this study? ___ Yes ___ No If no, thank you for your time.

If yes, continue with the questionnaire and ask: Is this is a good time for you to talk uninterrupted?

If no, please let me know when is a good time for me to call you back.

Date and time: __________________________

Before we begin can you please tell me:

What is your age? ______

In what country were you born? __________________________

CANCER AND TREATMENT EXPERIENCE
Appendix C: (Continued)

The following questions are about breast cancer and your treatment experience. Answer the following questions as best you can.

In what year were you diagnosed with breast cancer? ______________
[If participant has been diagnosed with cancer previously, please list the year of the most recent diagnosis]

At what stage was your breast cancer diagnosed? ______________

What kind of surgery did you receive?
___ Lumpectomy
___ Mastectomy
___ Other: __________________
___ None/ Not applicable

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<td>Did you receive chemotherapy?</td>
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<td>Did you receive radiation therapy?</td>
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<td>Are you currently taking medications related to your breast cancer treatment (for example, such as arimidex or tamoxifen)?</td>
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<td>Did you have reconstruction surgery?</td>
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<td>Did you seek a second opinion when you were diagnosed?</td>
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<td>Did you have health insurance when you were diagnosed?</td>
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<tr>
<td>Do you currently have any kind of health/medical insurance?</td>
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At what clinics or hospitals did you get the majority of your cancer care?
__________________________________________

[Interviewer: Probe: Community clinic (for example, Judeo Christian, Clinica Guadalupana), Moffitt Cancer Center, St. Joseph’s Cancer Institute, Morton Plant Mease, Lakeland Regional, MD Anderson in Orlando, UCH, Tampa General, Private oncologists, Other]

When you received the cancer diagnosis did you live:
___ In the same house I live in now (Skip to question number #)
___ In a different house in the same city
___ In a different city
___ In a different state
___ Outside of the United States
If you moved after you were diagnosed with cancer, why did you move?

Have you participated in any of the following programs since you were diagnosed with cancer (Please check all that apply)?

___ Received counseling or talked to social worker
___ Reach to Recovery from the American Cancer Society
___ Look Good Feel Better/ Luzca Bien Sientase Mejor
___ Campamento Alegria
___ Grupo de apoyo: if yes, which one _________________________
___ Participated in a cancer walk or race
___ Otro: _____________________________

How long did you have to wait to see a surgeon or a medical specialist for care after you were diagnosed?

___ Less than a week
___ Two to three weeks
___ One to two months
___ More than two months

Did you work during your cancer treatment?

___ Yes
___ No

Now I would like to learn about your experience with your doctors. Please remember this information is not going to be shared with your doctors. I will read a statement to you. Please respond, no, sometimes and yes.

<table>
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<tr>
<th>Did you understand all the explanations and instructions you received from your doctor?</th>
<th>No</th>
<th>Sometimes</th>
<th>Yes</th>
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</thead>
<tbody>
<tr>
<td>Did you receive sufficient information about the treatment you received?</td>
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<tr>
<td>Where you able to communicate your worries and concerns to your doctors?</td>
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<tr>
<td>Did you feel your doctor listened to your concerns?</td>
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<tr>
<td>Did your doctors give you information about where you could go for support?</td>
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</tbody>
</table>

I am also interested in knowing how your experience of having cancer affects your life. Please answer the following questions based on your life at this time.
Appendix C: (Continued)

How would you rate your overall health?
___ Poor
___ Fair
___ Good
___ Excellent

Cancer affects women in many ways, in order to better understand how cancer has affected your life I am going to ask about how distressing were the following aspects of your illness and treatment? Please answer no, not at all, a little, or yes, a lot.

<table>
<thead>
<tr>
<th>Question</th>
<th>No, not at all</th>
<th>A little</th>
<th>Yes, a lot</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>How distressing has your illness been for your family?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Why?</td>
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<tr>
<td>Has your sexual/intimate relationship with your spouse/partner been negatively impacted by your illness?</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
</tr>
<tr>
<td>Has your illness and treatment interfered with your employment?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</tr>
<tr>
<td>Has your illness and treatment interfered with your activities at home?</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
</tr>
<tr>
<td>Do you ever feel isolated because of your illness or treatment?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Has the amount of support you received from others been sufficient to meet your needs during your illness and treatment?
___ No
___ Sometimes
___ Yes

I want you to think about all the different things us, as women, are to others, the responsibilities and obligations we have and the roles we play in peoples lives. I am going to ask you questions about these responsibilities and obligations. If the item is not applicable, please say it does not apply.
Appendix C: (Continued)

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Very much</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take care of children</td>
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<tr>
<td>Educate your children</td>
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<tr>
<td>Be sincere and honest</td>
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<tr>
<td>Provide for your family</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Be caring and affectionate</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Take care of your husband/partner</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Take care of your parents</td>
<td></td>
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<tr>
<td>Work (out side the home)</td>
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<tr>
<td>Actualisarse / Profesionalisarse</td>
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<tr>
<td>Maintain your home</td>
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</tr>
</tbody>
</table>

Now I would like to learn about how and when you communicated with your family and friends about the cancer diagnosis.

Did you tell your family about your diagnosis?
___ Yes, right away
___ Yes, but I waited to tell them
___ No, I have not told them about my diagnosis

If you waited to tell them about your diagnosis, why did you wait?
_____________________________________________________________
_____________________________________________________________

During your cancer treatment, how often did you keep in touch with your friends/relatives in your native country via phone or email?
___ Never
___ More than once a week
___ At least once a week
___ At least once a month
___ Once every few months
___ Not applicable

Were you able to communicate with your friends/relatives in your native country as much as you needed to during your illness and treatment?
___ No
___ Yes
Appendix C: (Continued)

If no, did this cause you additional stress or worry?
___ No
___ Yes

Have you ever felt you needed to keep a happy/strong face during your cancer treatment?
___ No
___ Sometimes
___ Yes

Have you ever felt you had to make a choice between working to support your family and following your treatment?
___ No
___ Sometimes
___ Yes

In the following section, I will read you a few sentences. Please remember there are no wrong or right answers. I just want your opinion, please tell me if you agree or disagree with the following statements.

It is best not to burden family and friends with personal concerns/worries.
___ Agree
___ Disagree

We have to accept suffering.
___ Agree
___ Disagree

We have to resign ourselves to what life brings, you can not change what is going to happen. (Resignar)
___ Agree
___ Disagree

Family needs should come before your own.
___ Agree
___ Disagree

Everything is going to be as God wants/as God wills.
___ Agree
___ Disagree
Appendix C: (Continued)

Now, I would like to learn about your experience with your health care.

<table>
<thead>
<tr>
<th>Have you experienced any problems or difficulty with the following things? Please tell me yes or no.</th>
<th>Yes</th>
<th>No</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting a mammogram (screening or diagnostic) appointments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finding a doctor or hospital that would provide cancer care to you</td>
<td></td>
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<tr>
<td>Getting or maintaining your health insurance</td>
<td></td>
<td></td>
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<tr>
<td>Making appointments for follow-up care</td>
<td></td>
<td></td>
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<tr>
<td>Paying medical bills</td>
<td></td>
<td></td>
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<tr>
<td>Paying for medications/ prescriptions</td>
<td></td>
<td></td>
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<tr>
<td>Finding cancer information in Spanish</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SOCIAL SUPPORT**

People sometimes look to others for companionship, assistance, or other types of support. Please remember there are no wrong or right answers I just want to learn about your experience and the kinds of support you have available. It is OK to answer that you do not have someone available. First, I am going to ask you, if you have the following kinds of support available to you if you need it? Then, if you do, I would like to learn who gives you this type of assistance and support. For example, is it your husband, mother, father, female friend, etc...). After you list each person, I will ask you a few brief questions about them. For example, how old are they, what language they speak etc.

[Interviewer: if they only list one person ask, “is there anyone else,” If the list more than 3 people ask them to select the top three.

<table>
<thead>
<tr>
<th>Do you have the following kinds of support available if you need it</th>
<th>No</th>
<th>Yes</th>
<th>If yes, who? You do not need to tell me their name just their relationship to you, for example, daughter, son, friend, neighbor, etc...) [if participant list more than 3 people, ask them to select the top 3]</th>
<th>What language do they speak?</th>
<th>Where do they live?</th>
<th>What is their ethnicity?</th>
<th>How old are they?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>M: my country</td>
<td>H: Hispanic</td>
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<td></td>
<td></td>
<td>U: USA</td>
<td>O: other ethnicity not Hispanic</td>
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</tr>
<tr>
<td>Task</td>
<td>Column 1</td>
<td>Column 2</td>
<td>Column 3</td>
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<tr>
<td>Someone who listens to you when you need to talk</td>
<td>1.</td>
<td>2.</td>
<td>3.</td>
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<tr>
<td>Someone to confide in or talk to about your problems</td>
<td>1.</td>
<td>2.</td>
<td>3.</td>
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<tr>
<td>Someone who is patient with you</td>
<td>1.</td>
<td>2.</td>
<td>3.</td>
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<tr>
<td>Someone who encourages you</td>
<td>1.</td>
<td>2.</td>
<td>3.</td>
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<tr>
<td>Someone to look over your pets if you were if you were hospitalized</td>
<td>1.</td>
<td>2.</td>
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<tr>
<td>Someone who understands your problems</td>
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<tr>
<td>Someone to help you if you were confined to bed</td>
<td>1.</td>
<td>2.</td>
<td>3.</td>
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<tr>
<td>Someone to drive you to the doctor</td>
<td>1.</td>
<td>2.</td>
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<tr>
<td>Someone to help you fill out medical-related paperwork</td>
<td>1.</td>
<td>2.</td>
<td>3.</td>
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<tr>
<td>Service Provided</td>
<td>Description</td>
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<td>2.</td>
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<tr>
<td>Someone to go to the pharmacy and get your medications/prescriptions</td>
<td>□ □ 1. 2. 3.</td>
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<tr>
<td>Someone to help you figure out insurance issues</td>
<td>□ □ 1. 2. 3.</td>
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<tr>
<td>Someone to help you with your household bills</td>
<td>□ □ 1. 2. 3.</td>
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<tr>
<td>Someone to help you cook if you were unable to cook</td>
<td>□ □ 1. 2. 3.</td>
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<tr>
<td>Someone to help with daily chores (washing dishes, clean, laundry) if you were not feeling well</td>
<td>□ □ 1. 2. 3.</td>
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<tr>
<td>Someone to help you with childcare if you were not feeling well</td>
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<tr>
<td>Someone to help you find resources</td>
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<tr>
<td>Someone to interpret / translate for you</td>
<td>□ □ 1. 2. 3.</td>
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<tr>
<td>Appendix C: (Continued)</td>
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<tr>
<td><strong>Someone who shows you love and affection</strong></td>
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<td><strong>Someone to do something enjoyable with</strong></td>
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<tr>
<td><strong>Someone to visit you at home or in the hospital if you were not feeling well</strong></td>
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<tr>
<td><strong>Someone to bring you soup/food if you were not feeling well</strong></td>
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</table>
Appendix C: (Continued)

Who helped you make decisions about your cancer care and treatment?
________________________________________________________________________

If you are upset or depressed do you have access to a therapist or mental health professional?
__ Si
__ No

Has your family accepted your illness?
__ Si
__ No

Thank you for answering the questions about the support you have available. I know that took a lot of time, courage and thoughtfulness. Do you need to take a break? [If yes, stop and take a break. If no, continue to the next set of questions.] We are almost done. The following questions will be about your background, education, and work experience. These will help me learn a little bit more about you.
DEMOGRAPHICS

Please tell me how well you speak and write in Spanish and English.

With regard to ENGLISH, how well do you:

<table>
<thead>
<tr>
<th></th>
<th>Very well</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand it when it is spoken to you</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speak it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Write it</td>
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</tbody>
</table>

With regard to SPANISH, how well do you:

<table>
<thead>
<tr>
<th></th>
<th>Very well</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand it when it is spoken to you</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Speak it</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Read it</td>
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<tr>
<td>Write it</td>
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</table>

The following questions are going to be about you and your household.

How many children do you have? ______

If you have children, how many children do you have under the age of 18?

________

How many people live in your home, besides you? ______

What kind of work do you currently have?

___ Full time
___ Half time
___ Retired
___ Homemaker
___ Unemployed
___ Unemployed due to disability or illness

What is your current employment/occupation?

_________________________________________
Appendix C: (Continued)

What is your current annual household income?
___ 10,000 or less
___ 10,001 - 30,000
___ 30,001-50,000
___ More than 50,000
___ Don't know

Where does your household income come from (Check all that apply)?
___ Your own salary or your partner’s salary
___ Social security
___ Pension or retirement fund
___ Economic assistance from son(s) or/and daughter(s)
___ Economic assistance from other relatives
___ Own business
___ Other sources__________________________

What is the highest grade of school you completed? ________________

What is your current marital status?
___ Married/ with partner
___ Single
___ Divorced/separated
___ Widowed

Do you drive?
___ Yes
___ No

What is your zip code? ________________

Do you belong to a church or other religious organization?
___ No
___ Yes

Please answer to what extent the following things are a problem or stressful for you. You can answer that they are not a problem at all, sometimes a problem or Yes, very much a problem for you.
Appendix C: (Continued)

<table>
<thead>
<tr>
<th>Are any of the following a problem or stressful for you?</th>
<th>No</th>
<th>Sometimes</th>
<th>Yes</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being far away from family/friends in your native country</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Relationship with my children</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Childcare</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Providing for my family</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Not being able to pay for medications</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Paying household bills (rent, electricity, water etc)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Living in an unsafe area</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Immigrations status</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Relationship with my spouse/partner</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>The type of work you do</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Work environment</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>People’s negativity/ la negatividad de otras personas</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
</tbody>
</table>

We are almost done, now the following questions are going to be about when you came to this county.

IMMIGRATION EXPERIENCE

What year did you move to the USA? _________

Who came with you to the United States (check all that apply)?

________________________________________

___ I came alone
___ My husband
___ Children
___ Whole family (e.g, parents or other relatives)

How long have you lived in this city (where you live now)?

___ Less than a year
___ One to five years
___ More than five years
Appendix C: (Continued)

How often do you keep in touch with your friends/relatives in your native country via phone or email?

___ Never
___ Once every few months
___ At least once a month
___ At least once a week
___ More than once a week
___ Not applicable

Did you send money back home before the cancer diagnosis?

___ Yes
___ No

If yes, did the cancer diagnosis affect your ability to send money to your family back in your native country?

___ Yes, very much. I was no longer able to send money
___ Yes, a little. I was not able to send as much money as I used to
___ No, it did not affect my ability to send money back home to my family

Do you belong to an ethnic/civic/social organization or club from your native county, like circulo cubano or el club ecuatoriano etc...?)?

___ Yes
___ No

Thank you for the time you have taken to complete this questionnaire. The information you provided is very helpful and will help me understand the experience of Latina women with breast cancer. Please don’t hesitate to call Dina at ____________ if you have any questions.
Hola, mi nombre es _________________. Este estudio es sobre el apoyo y las necesidades de mujeres Latinas que han sido diagnosticada con cáncer y que han nacido en otro país y ahora viven en los EEUU.

Antes que empecemos, quiero estar segura que usted entiende lo que vamos hacer. Le quisiera hacer varias preguntas sobre la salud y su experiencia con cáncer. Lo que usted va a compartir conmigo es muy importante para mí. La primera serie de preguntas serán sobre su experiencia con el cáncer de seno y apoyo. Después seguiremos con preguntas demográficas sobre su trabajo, educación etc. Y su experiencia cuando se mudo a los EEUU. Esta encuesta tomará unos 30-45 minutos. Si usted necesita parar o descansar por favor déjeme saber.

Su participación es voluntaria. Las preguntas no tienen respuestas ni buenas ni malas. Todo lo que usted comparte conmigo será confidencial y no tiene que responder a las preguntas que no quieras. Su respuestas igual que las respuestas de las otras señoras que están participando serán reportadas en forma de grupo, en fin sus respuestas no van a estar conectada a su nombre. No se sienta con presión de participar en este estudio.

No sabemos si se beneficiará de algún modo por participar en este estudio. Pero al participar en él, es posible que me ayude aprender sobre sus necesidades y el apoyo que necesitan mujeres diagnosticada con cáncer del seno. Podremos usar la información para desarrollar mejores programa de apoyo en español.

Si tiene alguna pregunta or preocupaciones sobre este estudio, puede llamar a Dina Martinez al 813-728-5895 o al 813-979-4291 o a la Dr. Linda Whiteford (profesora principal del la disertación) al 813-974-0801

Quiere participar en este proyecto?  __ Si  __ No      Si, no, gracias por su tiempo.

Si si, sigamos al la encuesta. Es este un buen tiempo para hablar con usted, sin interrupción?

    Si, no, por favor déjeme saber cuando será un buen tiempo para llamarla de nuevo.
    Fecha y hora: __________________________

Antes que empecemos, me puede decir:

Que edad usted tiene? _______

¿Dónde nació usted?____________________________
CANCER AND TREATMENT EXPERIENCE

Las siguientes preguntas serán sobre su experiencia con el cáncer de seno y el tratamiento que recibió.

¿En que año le diagnosticaron con cáncer? ______________
[Si el participante ha sido diagnosticada con cáncer anteriormente por favor escriba el año que fue diagnosticada recientemente]

¿En que etapa estaba su cáncer de seno cuando fue diagnosticada?

____________

¿Que tipo de cirugía recibió usted?

___ Lumpectomía
___ Mastectomia
___ Otra:__________________
___ Ninguna

<table>
<thead>
<tr>
<th>¿Usted recibió quimoterapia?</th>
<th>Sí</th>
<th>No</th>
<th>Comentario</th>
</tr>
</thead>
<tbody>
<tr>
<td>¿Usted recibió radioterapia?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>¿Actualmente usted está tomando medicinas relacionadas con su tratamiento de cáncer (por ejemplo como arimidex o tamoxifen)?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>¿Usted tuvo cirugía de reconstrucción?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>¿Usted buscó una segunda opinión cuando le diagnosticaron con cáncer?</td>
<td></td>
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<td></td>
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<tr>
<td>¿Usted tenía seguro médico cuando la diagnosticaron con cáncer?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>¿Actualmente, usted tiene algún tipo de seguro médico?</td>
<td></td>
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</tr>
</tbody>
</table>

¿En cual clínica o hospital usted recibió la mayoría del tratamiento de cáncer?
____________________________________________________________________

[Interviewer: Probe: Community clinic (for example, Judeo Christian, Clinica Guadalupana), Moffitt cáncer Center, St. Joseph’s cáncer Institute, Morton Plant Mease, Lakeland Regional, MD Anderson in Orlando, UCH, Tampa General, Private oncologists, Other]

¿Cuando usted recibió el diagnóstico de cáncer usted vivía:

___ En la misma casa en la cual vivo ahora (Skip to question number #)
___ En una casa diferente en la misma ciudad
___ En una ciudad diferente
___ En un estado diferente
___ afuera de los EEUU
¿Si se mudo después de ser diagnosticada con cáncer por que se mudo?

________________________________________________________________

¿Usted ha participado en algunos de estos programas después de ser diagnosticada con cáncer (Please check all that apply)?

___ Hablo con un trabajador social or terapista
___ "Reach to Recovery" de la asociación Americana de cáncer
___ Luzca Bien Siéntase Mejor
___ Campamento Alegria
___ Grupo de apoyo: si, si cual ____________________________
___ Participado en una caminata o carrera para el cáncer?
___ Otro: ____________________________

¿Que tanto tiempo usted tuvo que esperar par ver un cirujano or especialista de cáncer después de su diagnostico de cáncer de seno?

___ Menos de una semana
___ Dos a tres semanas
___ De uno a dos meses
___ Más de dos meses

¿Usted trabajo durante su tratamiento para el cáncer?

___ Si
___ No

Ahora, quiero aprender sobre su experiencia con sus médicos. Recuérdese que no voy a compartir esta información con sus médicos. Le voy a leer una oración. Por favor responda no, a veces or si.

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>A veces</th>
<th>Sí</th>
</tr>
</thead>
<tbody>
<tr>
<td>¿Usted entendió todas las explicaciones y instrucciones que le dio su medico?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>¿Usted recibió suficiente información sobre el tratamiento que recibió?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>¿Usted pudo comunicar sus preocupaciones y preguntas a sus médicos?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>¿Usted sintió que sus médicos oyeron sus preocupaciones y preguntas?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>¿Sus médicos le dieron información sobre donde puede ir para apoyo?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

También estoy interesada en aprender como el cáncer ha afectado su vida. Por favor base sus respuestas a las siguientes preguntas en su vida en este momento.
¿Cómo describe su salud en general?
___ Mal
___ Regular
___ Bien
___ Excellent

El cáncer afecta la vida de la mujer en varias formas, para entender mejor como el cáncer ha afectado su vida le voy a preguntar cuán estresante fueron los siguientes aspectos de su enfermedad y tratamiento. Favor de contestar no, un poco, sí o no aplica.

<table>
<thead>
<tr>
<th>¿Que tan angustiante ha sido su enfermedad para su familia?</th>
<th>No</th>
<th>Un poco</th>
<th>Si</th>
<th>No aplica</th>
</tr>
</thead>
<tbody>
<tr>
<td>Porque?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿Su enfermedad ha afectado negativamente a su relación intima/sexual con su esposo/pareja?</th>
<th>No</th>
<th>Un poco</th>
<th>Si</th>
<th>No aplica</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>¿Su enfermedad ha interfiriendo con su empleo?</th>
<th>No</th>
<th>Un poco</th>
<th>Si</th>
<th>No aplica</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>¿Su enfermedad y el tratamiento que ha recibido han interfiriendo con su actividades del hogar?</th>
<th>No</th>
<th>Un poco</th>
<th>Si</th>
<th>No aplica</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>¿Usted se ha sentido sola o aislada por su tratamiento o enfermedad?</th>
<th>No</th>
<th>Un poco</th>
<th>Si</th>
<th>No aplica</th>
</tr>
</thead>
</table>

¿El apoyo que usted ha recibido de otros ha sido suficiente para satisfacer sus necesidades durante su enfermedad y tratamiento?
___ No
___ A veces
___ Si

Yo le voy a pedir que piense en todas las cosas que nosotros como mujeres somos para otras personas, sobre las responsabilidades y obligaciones que tenemos y el papel que tomamos en la vida de los demás. Le voy a ser preguntas sobre estas responsabilidades y obligaciones. Si no aplican a usted por favor digame que no aplican para usted.
Algunas mujeres han compartido que el cáncer afecta su habilidad de hacer algunas cosas que, nosotras como mujeres, hacemos. Por favor dígame si el cáncer ha afectado su habilidad de hacer algunas de las siguientes cosas:

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Un poco</th>
<th>Sí</th>
<th>No aplica</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criar a sus hijos</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educar a sus hijos</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Ser sincera y honesta</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proveer para su familia</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Ser cariñosa y amorosa</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Cuidar a su esposo</td>
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<tr>
<td>Cuidar a sus padres</td>
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<tr>
<td>Trabajar (fuera de su casa)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Actualizarse / Profesionalizarse</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Mantener su casa</td>
<td></td>
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</tbody>
</table>

Ahora quisiera aprender sobre cómo usted se comunicó con su familia sobre el diagnóstico de cáncer.

¿Usted le habló a su familia sobre su diagnóstico?
___ Si inmediatamente
___ Si, pero espere un tiempo para decírselo
___ No, no le he hablado de mi diagnóstico

¿Si usted espera para decirle sobre su diagnóstico, por qué usted espera?
__________________________________________

¿Durante su tratamiento para el cáncer, que tan a menudo usted se comunicaba con su familia por teléfono o correo electrónico?
___ Nunca
___ Más de una vez a la semana
___ Por lo menos una vez a la semana
___ Por lo menos una vez a mes
___ Una vez cada dos meses o menos
___ No aplica

¿Usted se pudo comunicar con su familia y amistades en su país cuantas veces usted necesitaba durante su enfermedad y tratamiento?
___ No
___ Sí
Appendix C: (Continued)

¿Si no, esto le causó estrés o angustia?
___ No
___ Si

¿Sintió alguna vez que necesitaba mantener una apariencia fuerte y feliz durante su tratamiento de cáncer?
___ No
___ A veces
___ Si

¿Algunas veces usted ha sentido que tiene que escoger entre trabajar para proveer para su familia y seguir su tratamiento.
___ No
___ A veces
___ Si

En la siguiente sección, le voy a leer algunas oraciones. Por favor recuerde que no hay respuestas correctas o malas. Solamente quiero saber su opinión. Por favor dígame si esta de acuerdo con las siguientes oraciones.

Es mejor no cargar a su familia y amistades con preocupaciones personales.
___ De acuerdo
___ No de acuerdo

Hay que aceptar el sufrimiento.
___ De acuerdo
___ No de acuerdo

Hay que resignarse a lo que le trae la vida, uno no puede cambiar lo que va a pasar. (Resignar)
___ De acuerdo
___ No de acuerdo

Las necesidades de la familia deben de venir primero que las de uno
___ De acuerdo
___ No de acuerdo

Todo va a ser como Dios quiera (si Dios quiere)
___ De acuerdo
___ No de acuerdo
Ahora quisiera aprender sobre su experiencia con su cuidado médico.

<table>
<thead>
<tr>
<th>¿Usted ha tenido algún problema o dificultad con las siguientes cosas? Digame si o no?</th>
<th>Sí</th>
<th>No</th>
<th>Comentario</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtener citas para un mamograma (citas para un diagnostico)</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Encontrar un doctor u hospital que le proveerá tratamiento para el cáncer</td>
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<tr>
<td>Obtener o mantener un seguro medico</td>
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<tr>
<td>Hacer citas para seguimiento de cuidado medico</td>
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<tr>
<td>Pagando lo biles médicos</td>
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<td></td>
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<tr>
<td>Pagando los medicamentos y medicinas</td>
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<tr>
<td>Encontrar información en español</td>
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</table>

¿Usted tiene el siguiente tipo de apoyo si lo necesita?

<table>
<thead>
<tr>
<th>No</th>
<th>Sí</th>
<th>Si si, quien? No me tiene que dar el nombre, solamente la relación de esa persona a usted. Por ejemplo si es su hermana, amiga, esposo, tío, madre etc... [si el participante dice mas de 3 personas, pidale que seleccione las tres mas importante]</th>
<th>Que idioma hablan?</th>
<th>Adonde viven?</th>
<th>Etnicidad?</th>
<th>Que edad tiene?</th>
</tr>
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</table>

296
<table>
<thead>
<tr>
<th><strong>Appendix C: (Continued)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alguien que le escuche cuando usted necesita hablar</strong></td>
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<tr>
<td><strong>Alguien con quien usted pueda hablar con confianza y hablarle sobre sus problemas</strong></td>
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<tr>
<td><strong>Alguien que sea paciente con usted</strong></td>
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<tr>
<td><strong>Alguien que le de ánimo</strong></td>
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<td></td>
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<tr>
<td><strong>Alguien quien le ayude con los animales/mascotas si usted estuviera en el hospital</strong></td>
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<td></td>
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<tr>
<td><strong>Alguien quien entienda sus problemas</strong></td>
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<tr>
<td><strong>Alguien quien le ayude si estuviera confinado a una cama o postrado en cama</strong></td>
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<tr>
<td><strong>Alguien quien lleve/maneje al médico</strong></td>
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<tr>
<td><strong>Alguien quien le ayude a llenar los papeles/formularios médicos</strong></td>
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<td>-------------------------------</td>
</tr>
<tr>
<td>Alguien quien vaya a la farmacia a buscar sus medicinas</td>
</tr>
<tr>
<td>Alguien quien le ayude arreglar problemas relacionado con el seguro</td>
</tr>
<tr>
<td>Alguien quien le ayude con los billetes de la casa</td>
</tr>
<tr>
<td>Alguien quien le ayude a cocinar si usted no pudiera cocinar</td>
</tr>
<tr>
<td>Alguien quien le ayudara las cosas de la casa (fregar, limpiar, lavar) si usted no se sintiera bien</td>
</tr>
<tr>
<td>Alguien quien le ayude a cuidar sus niños si usted no se sintiera bien</td>
</tr>
<tr>
<td>Alguien quien le ayude a buscar recursos financieros o de la comunidad</td>
</tr>
<tr>
<td>Alguien quien le traduzca o le sirva de interprete</td>
</tr>
</tbody>
</table>
¿Quién la ayudó a tomar decisiones sobre su cuidado médico y tratamiento para el cáncer? ________________________________________________

¿Si usted se siente deprimida o con angustia; usted tiene acceso a un terapeuta o profesional de salud mental?

__ Sí
__ No

¿Su familia ha aceptado su enfermedad?

__ Sí
__ No

Gracias por contestar estas preguntas sobre el apoyo que usted tiene disponible. Yo sé que tomo bastante tiempo, fuerza y atención. Usted necesita tomar un descanso? [If yes, stop and take a break. If no, continue to the next set of questions.] Ya estamos casi acabando. Las siguientes preguntas son sobre su historia personal, educación, y trabajo. Me ayudarán aprender un poco más de usted.
Appendix C: (Continued)

DEMOGRAPHICS

Por favor dígame que tan bien usted habla y escribe en inglés y español.

Con relación al inglés, ¿qué tan bien usted:

<table>
<thead>
<tr>
<th></th>
<th>Muy bien</th>
<th>Un poco</th>
<th>Nada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lo entiende cuando le hablan?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lo habla?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lo lee?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lo escribe?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Con relación al español, ¿qué tan bien usted:

<table>
<thead>
<tr>
<th></th>
<th>Muy bien</th>
<th>Un poco</th>
<th>Nada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lo entiende cuando le hablan?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lo habla?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Lo lee?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lo escribe?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Las siguientes preguntas son sobre su hogar.

¿Cuántos hijos usted tiene? ______

¿Si tiene hijos, cuántos hijos tiene que son menor de 18 años? ______

¿Además de usted, cuántas personas viven en su hogar? ______

¿Actualmente, usted trabaja:

___ Tiempo completo
___ Medio tiempo
___ Retirada
___ Ama de casa
___ Desempleada buscando trabajo
___ Desempleada por discapacidad o enfermedad

¿Qué tipo de trabajo tiene usted? o ¿Qué trabajo hace actualmente?  

__________________________________________
¿Cuánto es el ingreso anual de su hogar en estos momentos?
- 10,000 o menos
- 10,000-30,000
- 30,001-50,000
- Más de 50,000
- No se

¿De donde provienen sus ingresos? Marque todas las que apliquen
- Su salario o el de su pareja
- Seguro Social
- Pensión o Retiro
- Ayuda económica de hijo(a)s
- Ayuda económica de familiares
- Rentas de propiedad o viviendas
- Negocio propio
- Otras fuentes_________________________

¿Cual es el último grado escolar que usted completo? ____________________

¿Cuál es su estado civil?
- Nunca casado/Soltera
- Casada/Unión consensual
- Separada/Divorciada
- Viuda

¿Usted maneja?
- Si
- No

¿En que barrio/área de ______ vive usted? _____________ (nombre / zip code)

¿Usted pertenece a una iglesia u otro grupo religioso?
- Si
- No
Appendix C: (Continued)

Por favor déjeme saber que tan estresante o problemático son las siguientes cosas para usted. Puede contestar que no son un problema para usted, a veces son un problema para usted o que sí son un problema para usted.

<table>
<thead>
<tr>
<th>¿Algunas de las siguientes cosas son un problema para usted o le causan estrés?</th>
<th>No veces</th>
<th>A veces</th>
<th>Si</th>
<th>No aplica</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estar lejos de mi familia y amistades que viven en mi país</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Relación con mis hijos</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>No poder pagar o comprar las medicinas</td>
<td>☐</td>
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<td>No poder pagar lo boles de la casa (renta, electricidad, agua)</td>
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<td>Relación con mi esposo/pareja</td>
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<td>La negatividad de otras personas</td>
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Ya casi estamos acabando, ahora las siguientes preguntas son sobre su experiencia cuando vino a este país.

EXPERIENCIA MIGRATORIA

¿En que año se mudo para los EEUU? _________

¿Quién vino con usted cuando se mudo a los EEUU? (marque todo lo que aplique)?
- ☐ Vine sola
- ☐ Mi esposo/pareja
- ☐ Hijos
- ☐ Mi familia (e.g, padres o otros familiares)

¿Cuántos años usted lleva viviendo en esta ciudad?
- ☐ Menos de un año
- ☐ De uno a cinco años
- ☐ Más de cinco años
¿Que tan a menudo usted se comunica por correo electrónico o por teléfono con sus familiares y amistades en su país?
___ Nunca
___ De ves en cuando
___ Una vez aL mes
___ Una vez a la semana
___ Más de una vez a la semana
___ No aplica

¿Usted ayudaba o mandaba dinero a su familia en su país antes de ser diagnosticada con cáncer?
___ Si
___ No

¿Si si, el diagnóstico de cáncer afectó su habilidad de mandar ayuda o dinero a su familia en su país?
___ Si, muchísimo, no pude seguir mandándole dinero
___ Si, un poco, No le podía mandar tanta ayuda o dinero como antes
___ No, no afecto mi habilidad de mandarle ayuda o dinero a mi familia en mi país

¿Usted pertenece a una organización o club social o cívico o de su nacionalidad, como el círculo cubano, ecuatoriano etc....)?
___ Si
___ No

Gracias por el tiempo que a compartido conmigo y contestar las preguntas de este cuestionario. La información que usted a compartido con migo nos ayudara mucho y a mejor entender la experiencia de mujeres Latinas diagnosticada con cáncer. Puede llamar a DINA al 813-728-5895 si tiene algunas preguntas.
Appendix D: List of Items Used in Each of the Scales

Chronic Stress Scale Items
Are any of the following a problem or stressful for you?
Relationship with my children
Providing for my family
Not being able to pay for medications
Paying household bills (rent, electricity, water etc)
Immigrations status
The type of work you do
Work environment

Overall Social Support Scale Items
Do you have the following kinds of support available if you need it
Someone who listens to you when you need to talk
Someone to confide in or talk to about your problems
Someone who is patient with you
Someone who encourages you
Someone to look over your pets if you were if you were hospitalized
Someone who understands your problems
Someone to help you if you were confined to bed
Someone to drive you to the doctor
Someone to help you fill out medical-related paperwork
Someone to go to the pharmacy and get your medications/prescriptions
Someone to help you figure out insurance issues
Someone to help you with your household bills
Someone to help you cook if you were unable to cook
Someone to help with daily chores (washing dishes, clean, laundry) if you were not feeling well
Someone to help you with childcare if you were not feeling well
Someone to help you find resources
Someone to interpret / translate for you
Someone who shows you love and affection
Someone to do something enjoyable with
Someone to visit you at home or in the hospital if you were not feeling well
Someone to bring you soup/food if you were not feeling well

Emotional Support Scale Items
Someone who listens to you when you need to talk
Someone to confide in or talk to about your problems
Someone who is patient with you
Someone who encourages you
Someone who understands your problems
Someone who shows you love and affection
Someone to do something enjoyable with
Someone to visit you at home or in the hospital if you were not feeling well
Appendix D: (Continued)

Provider Communication Scale Items
- Did you understand all the explanations and instructions you received from your doctor?
- Did you receive sufficient information about the treatment you received?
- Were you able to communicate your worries and concerns to your doctors?
- Did you feel your doctor listened to your concerns?
Appendix E: IRB Letter of Approval

March 29, 2007

Dinorah Martinez
19278 Wood Sage Dr.
Tampa, FL 33647

RE: Expedited Approval for Initial Review
IRB#: 105623E
Title: The Social Context of Stress and Social Support Among Immigrant Latinas Diagnosed with Breast Cancer
Study Approval Period: March 28, 2007 to March 26, 2008

Dear Ms. Martinez:

On March 28, 2007, Institutional Review Board (IRB) reviewed and APPROVED the above protocol for the period indicated above. It was the determination of the IRB that your study qualified for expedited review based on the federal expedited category number six (6) and seven (7).

Your English Informed Consent Forms were also approved.

Please note, if applicable, the enclosed informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on page one of the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form. Make copies from the enclosed original.

Please reference the above IRB protocol number in all correspondence regarding this protocol with the IRB or the Division of Research Integrity and Compliance. In addition, we have enclosed an Institutional Review Board (IRB) Quick Reference Guide providing guidelines and resources to assist you in meeting your responsibilities in the conduction of human participant research. Please read this guide carefully. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,

Paul G. Stiles, J.D., Ph.D., Chairperson
USF Institutional Review Board

OFFICE OF RESEARCH • DIVISION OF RESEARCH INTEGRITY & COMPLIANCE
INSTITUTIONAL REVIEW BOARDS, FWA NO. 0001669
University of South Florida • 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5618 • FAX (813) 974-5618
March 3, 2008

Dinorah Martinez
Anthropology Department
19278 Wood Sage, Dr.
Tampa, FL  33647

RE: Expedited Approval for Continuing Review
IRB#: 105623e
Title: The Social Context of Stress and Social Support Among Immigrant Latinas Diagnosed with Breast Cancer
Study Approval Period: February 29, 2008 to February 27, 2009

Dear Dinorah Martinez:

On February 29, 2008, Institutional Review Board (IRB) reviewed and APPROVED the above protocol for the period indicated above. It was the determination of the IRB that your study qualified for expedited review based on the federal expedited category number six (6) Collection of data from voice, video, digital, or image recordings made for research purposes. seven (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Also approved are the 3 informed consent forms: English -Key Informants, English -Adult 'Questionnaire', and the Spanish -Adult Questionnaire'.

***Please note your Co-PI may need to update their class in human subject's protection. Currently the expiration date on our database is 1-19-08.

Please note, if applicable, the enclosed informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on page one of the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form. Make copies from the enclosed original.

Please reference the above IRB protocol number in all correspondence regarding this protocol with the IRB or the Division of Research Integrity and Compliance. In addition, we have enclosed an Institutional Review Board (IRB) Quick Reference Guide providing guidelines and resources to assist you in meeting your responsibilities in the conduction of human participant research. Please read this guide carefully. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.
### Appendix F: Demographics of In-Depth Interview Participants n=28

#### In-depth Interview Demographics (n=28)

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<th>Item</th>
<th>Response</th>
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<td>Language spoken</td>
<td>Spanish only</td>
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</tr>
<tr>
<td></td>
<td>Spanish/English not well</td>
<td>32.1</td>
</tr>
<tr>
<td></td>
<td>Bilingual</td>
<td>39.3</td>
</tr>
<tr>
<td>Language spoken at home</td>
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</tr>
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<td></td>
<td>English</td>
<td>7.1</td>
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<tr>
<td></td>
<td>Bilingual</td>
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<tr>
<td>Educational attainment</td>
<td>Less than high school</td>
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<td></td>
<td>High school graduate</td>
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<tr>
<td></td>
<td>Some college or college graduate</td>
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<tr>
<td>Current employment</td>
<td>Home maker</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>Half time</td>
<td>25</td>
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<td>Full time</td>
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<td>Unemployed</td>
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<td>Disability</td>
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<td>Retired</td>
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<td></td>
<td>Half time</td>
<td>17.9</td>
</tr>
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<td></td>
<td>Full time</td>
<td>64.3</td>
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<td>Unemployed</td>
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<td>Worked during treatment</td>
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<td>50</td>
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<td>Percent of Hispanic density of zip code population</td>
<td>0.5-10%</td>
<td>21.4</td>
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<td>10.1-20%</td>
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<tr>
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<td>20.1-30%</td>
<td>17.9</td>
</tr>
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<td>30.1-40%</td>
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<td>40.1-50%</td>
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<td>Percent live in poverty area by census poverty category</td>
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<td>20.00-39.99%</td>
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<td>Current household income</td>
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<td></td>
<td>10,001-30,000</td>
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<td>50,000+</td>
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<td>Divorced</td>
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<td>Widowed</td>
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<td>Widowed</td>
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### Appendix F: (Continued)

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<td>Number of people in household</td>
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<td>Four people</td>
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<td>Five people</td>
<td>10.7</td>
<td>Six people</td>
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<td>Seven people</td>
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<td>Nationality/ County of origin</td>
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<td>Peru</td>
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<td>Venezuela</td>
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<td></td>
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<tr>
<td>Length of time in the USA</td>
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<td>21.5</td>
<td>6-10 years</td>
<td>14.3</td>
<td>11-20 years</td>
<td>17.9</td>
</tr>
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<td></td>
<td>21-30 years</td>
<td>35.7</td>
<td>3- plus years</td>
<td>10.8</td>
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<td>Length of time in city where they currently live</td>
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<td>6-10 years</td>
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<td>11-20 years</td>
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</tr>
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<td>21-30 years</td>
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<td>How often visit native country</td>
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<td>Once every two-three years</td>
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<td>Once every five years</td>
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<td></td>
<td>Once every ten years</td>
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<td>------</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>II</td>
<td>32.1</td>
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<tr>
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<td>III</td>
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<td>Radiation</td>
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<td>Do not have insurance</td>
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<td>Received cancer and treatment information in</td>
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<td>Sometimes</td>
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### Appendix G: Demographics of Structured Interview Participants

#### Demographics (n=60)

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<th>Ethnicity</th>
<th>Percent</th>
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<td>Columbia</td>
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<tr>
<td>Cuba</td>
<td>11.7</td>
</tr>
<tr>
<td>Dominican Republic</td>
<td>8.3</td>
</tr>
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<td>Ecuador</td>
<td>6.7</td>
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<tr>
<td>Guatemala</td>
<td>1.7</td>
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<tr>
<td>Honduras</td>
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<td>Mexico</td>
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<td>Peru</td>
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</tr>
<tr>
<td>Puerto Rico</td>
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<tr>
<td>Venezuela</td>
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<td>Under 18 years of age</td>
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<tr>
<td>Had no children</td>
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<td>Average number of children: 2.2</td>
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<th>Marital Status</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Never Married/Single</td>
<td>11.7</td>
</tr>
<tr>
<td>Married/Consensual Union</td>
<td>51.7</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>30</td>
</tr>
<tr>
<td>Widowed</td>
<td>6.7</td>
</tr>
<tr>
<td>Don't drive</td>
<td>23.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Household size</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Live alone</td>
<td>15%</td>
</tr>
<tr>
<td>Average household size: 2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current Employment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fulltime</td>
<td>36.7</td>
</tr>
<tr>
<td>Half time</td>
<td>6.7</td>
</tr>
<tr>
<td>Retired</td>
<td>13.3</td>
</tr>
<tr>
<td>Ama de casa (homemaker)</td>
<td>13.3</td>
</tr>
<tr>
<td>Unemployed looking for work</td>
<td>5</td>
</tr>
<tr>
<td>Unemployed due to disability/illness</td>
<td>25</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Household income</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>10,000 or less</td>
<td>28.3</td>
</tr>
<tr>
<td>10,001-30,000</td>
<td>33.3</td>
</tr>
<tr>
<td>30,001-50,000</td>
<td>15</td>
</tr>
<tr>
<td>More than 50,000</td>
<td>11.7</td>
</tr>
<tr>
<td>Don't know</td>
<td>11.7</td>
</tr>
</tbody>
</table>
### Source of Income

<table>
<thead>
<tr>
<th>Source of Income</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own/ Spouse Salary</td>
<td>63.3</td>
</tr>
<tr>
<td>Social Security</td>
<td>28.3</td>
</tr>
<tr>
<td>Economic Assistance from Children</td>
<td>18.3</td>
</tr>
<tr>
<td>Economic Assistance from Family</td>
<td>20</td>
</tr>
<tr>
<td>Rent from Other Properties</td>
<td>3.3</td>
</tr>
<tr>
<td>Own Business</td>
<td>3.3</td>
</tr>
<tr>
<td>Other</td>
<td>20</td>
</tr>
</tbody>
</table>

### Educational Attainment

<table>
<thead>
<tr>
<th>Educational Attainment</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>6th Grade or Less</td>
<td>16.7%</td>
</tr>
<tr>
<td>7th-11th Grade</td>
<td>6.7%</td>
</tr>
<tr>
<td>High School</td>
<td>41.7%</td>
</tr>
<tr>
<td>Some College</td>
<td>15%</td>
</tr>
<tr>
<td>College Graduate</td>
<td>13.3%</td>
</tr>
<tr>
<td>Graduate School</td>
<td>5%</td>
</tr>
</tbody>
</table>

### English

<table>
<thead>
<tr>
<th>Understand when spoken</th>
<th>Very Well</th>
<th>A little</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speak it</td>
<td>36.7</td>
<td>43.2</td>
<td>20</td>
</tr>
<tr>
<td>Read it</td>
<td>45</td>
<td>30</td>
<td>25</td>
</tr>
<tr>
<td>Write it</td>
<td>36.7</td>
<td>30</td>
<td>33.3</td>
</tr>
</tbody>
</table>

### Spanish

<table>
<thead>
<tr>
<th>Understand when spoken</th>
<th>Very Well</th>
<th>A little</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speak it</td>
<td>98.3</td>
<td>1.7</td>
<td></td>
</tr>
<tr>
<td>Read it</td>
<td>86.7</td>
<td>6.7</td>
<td>6.7</td>
</tr>
<tr>
<td>Write it</td>
<td>86.7</td>
<td>6.7</td>
<td>6.7</td>
</tr>
</tbody>
</table>

### Length of time in the US

<table>
<thead>
<tr>
<th>Length of Time in the US</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lived in the US 5 yrs or less</td>
<td>16.7</td>
</tr>
<tr>
<td>Lived in the US Between 6-10 yrs</td>
<td>20</td>
</tr>
<tr>
<td>Lived in the US Between 11-15 yrs</td>
<td>10</td>
</tr>
<tr>
<td>Lived in the US Between 16-20 yrs</td>
<td>6.7</td>
</tr>
<tr>
<td>Lived in the US more than 20 years</td>
<td>46.7</td>
</tr>
</tbody>
</table>

### Who came with you to the USA

<table>
<thead>
<tr>
<th>Who came with you to the USA</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>35</td>
</tr>
<tr>
<td>With Husband</td>
<td>25</td>
</tr>
<tr>
<td>With Children</td>
<td>28.3</td>
</tr>
<tr>
<td>With Whole Family</td>
<td>28.3</td>
</tr>
</tbody>
</table>
### How Often Communicate with Family in Native Country

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>3.3</td>
</tr>
<tr>
<td>Every Once in a While</td>
<td>15</td>
</tr>
<tr>
<td>Once a Month</td>
<td>10</td>
</tr>
<tr>
<td>Once a Week</td>
<td>45</td>
</tr>
<tr>
<td>More than Once a Week</td>
<td>25</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>1.7</td>
</tr>
</tbody>
</table>

### Sent Remittances Back Home Before Diagnosis

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>54.2</td>
<td></td>
</tr>
</tbody>
</table>

### Did Diagnosis Affect Ability to Send Remittances Home

<table>
<thead>
<tr>
<th>Effect</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Could No Longer Send Remittances</td>
<td>37.5</td>
</tr>
<tr>
<td>A Little, Could Not Send as Much as Before</td>
<td>43.8</td>
</tr>
<tr>
<td>Not at all</td>
<td>18.8</td>
</tr>
</tbody>
</table>

### Age range : 30-85 Yrs

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 50</td>
<td>45</td>
</tr>
<tr>
<td>50 and older</td>
<td>55</td>
</tr>
</tbody>
</table>

### Year Diagnosed

<table>
<thead>
<tr>
<th>Year</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>11.7</td>
</tr>
<tr>
<td>2004</td>
<td>15</td>
</tr>
<tr>
<td>2005</td>
<td>6.7</td>
</tr>
<tr>
<td>2006</td>
<td>28.3</td>
</tr>
<tr>
<td>2007</td>
<td>30</td>
</tr>
<tr>
<td>2008</td>
<td>8.3</td>
</tr>
</tbody>
</table>

### Stage at Diagnosis

<table>
<thead>
<tr>
<th>Stage</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>33.3</td>
</tr>
<tr>
<td>II</td>
<td>25</td>
</tr>
<tr>
<td>III</td>
<td>21.7</td>
</tr>
<tr>
<td>IV</td>
<td>1.7</td>
</tr>
<tr>
<td>Don’t know</td>
<td>18.3</td>
</tr>
</tbody>
</table>

### Treatment

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lumpectomy</td>
<td>28.3</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>70.1</td>
</tr>
<tr>
<td>Other</td>
<td>1.7</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>75</td>
</tr>
<tr>
<td>Radiation</td>
<td>61.7</td>
</tr>
<tr>
<td>Treatment Related Medications</td>
<td>55.9</td>
</tr>
<tr>
<td>Had Reconstruction</td>
<td>26.7</td>
</tr>
<tr>
<td>Got a Second Opinion</td>
<td>18.3</td>
</tr>
</tbody>
</table>

### Had Insurance at Time of Diagnosis

<table>
<thead>
<tr>
<th>Had Insurance</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>71.7</td>
<td></td>
</tr>
</tbody>
</table>

### Currently has Insurance

<table>
<thead>
<tr>
<th>Currently has Insurance</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>80</td>
<td></td>
</tr>
</tbody>
</table>
Appendix G: (Continued)

<table>
<thead>
<tr>
<th>Program Participation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Spoke to social worker</td>
<td>46.7</td>
</tr>
<tr>
<td>Reach to Recovery from ACS</td>
<td>16.7</td>
</tr>
<tr>
<td>Look Good Feel Better from ACS</td>
<td>43.3</td>
</tr>
<tr>
<td>Campamento Alegria</td>
<td>76.7</td>
</tr>
<tr>
<td>Support Group</td>
<td>50</td>
</tr>
<tr>
<td>Cancer Walk or Race</td>
<td>28.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Length of time had to wait to see cancer specialist after diagnosis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than a week</td>
<td>26.7</td>
</tr>
<tr>
<td>Two-Three Weeks</td>
<td>38.3</td>
</tr>
<tr>
<td>One to Two Months</td>
<td>23.3</td>
</tr>
<tr>
<td>More than Two Months</td>
<td>11.7</td>
</tr>
</tbody>
</table>

| Worked During Treatment                                           | 30    |


About the Author

Dinorah Martinez Tyson received a Master’s Degree in Public Health from the University of South Florida in 2003, a Master’s Degree in Applied Anthropology from Northern Arizona University in 1998 and Bachelor’s Degree Anthropology from Florida Atlantic University in 1996.

While in the Ph.D. program at the University of South Florida, Ms. Martinez Tyson has been employed as a research coordinator at Moffitt Cancer Center. During this time, she has intimately worked with the local Hispanic community. She has participated in several local Spanish language TV programs that explore Latina cancer issues. She has also been involved with LUNA, Inc. a local support group for Latinas diagnosed with cancer. The LUNA, Inc. mission is to provide support and offer culturally, linguistically relevant education to Hispanic breast cancer survivors and their family. She has experience conducting community-based participatory research and worked to develop community-based educational programs, such as Camp Alegria.