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The Experience of Living With Breast Cancer: Puerto Rican Women Tell Their Stories

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The Experience of Living With Breast Cancer:
Puerto Rican Women Tell Their Stories

A Dissertation Presented

by

MADÉLINE HERNÁNDEZ-RAMIREZ

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

September 2018

College of Nursing

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DEDICATION

I dedicate this dissertation to my son Israel J. Nieves-Hernández and my daughter Arelis M. Nieves-Hernández, my biggest gifts in life. God has honored me with the two biggest presents in the universe, your arrivals into my life. Both of you have inspired me to continue on my journey. I hope that my example in life guides you toward the very best. I also dedicate this to Mayra Pellot, my best friend since kindergarten. My friend, you have just begun the journey of breast cancer diagnosis and treatment. I hope this dissertation helps you understand, guides and gives you the strength to continue your life with a purpose.

With all my love,
Madeline

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To all my colleagues, coworkers, friends, and many others whom I haven’t even mentioned who have helped me directly or indirectly with this dissertation, “Thank you so very, very much.”

ABSTRACT

THE EXPERIENCE OF LIVING WITH BREAST CANCER: PUERTO RICAN WOMEN TELL THEIR STORIES

SEPTEMBER 2018

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Breast cancer is the most common form of cancer in women of all ethnic groups. Women living with breast cancer encounter not only physical problems but also psychological stress. The breast cancer diagnosis causes crisis for both patients and their families. Research of the lived experience of Puerto Rican women with breast cancer is scarce, and the little research found often classifies Puerto Rican women together with other groups such as Latin or Hispanic. While similarities of breast cancer experiences exist within Latin subgroups, aspects experienced by Puerto Rican women might be unique to them. Unique elements of a lived experience in a particular group can be influenced by sociocultural norms, behaviors, and beliefs.

The aim of this research was to gain a deep understanding of the lived experience of breast cancer diagnosis and treatment in Puerto Rican women and the cultural influence. This phenomenological study took place in the northern urban areas of Puerto Rico. Women between 35 and 45 years old diagnosed with breast cancer stage II or III were invited to participate through posters and flyers. The participants answered a demographic survey and engaged in in-depth interview sessions to describe their lived

experience before, during, and after their breast cancer diagnosis. A thematic analysis was done from the transcripts, generating several themes related to their unique and personal journey through the diagnosis and treatment of breast cancer. Data obtained from the survey and the interviews were transcribed verbatim. The data were then organized for proper analysis by themes.

Findings exhibit that Puerto Rican women encounter concerns similar to other women who have been diagnosed with BC. The major themes that emerged from their lived experience were the following: *Lack of knowledge about breast cancer* and its symptoms; *Fear* about what would happen with their lives; *Stress* through the treatment process; *Disturbed body image* from losing their hair, their breast, or showing their scar; *Faith* in God or a superior force; *Need for support* from relatives and friends; and *Need for self-disclosure*.

Keywords: breast cancer, Hispanic, Latina, Puerto Rican women, lived experience

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CHAPTER 1

STATE OF THE SCIENCE

Introduction

Breast cancer (BC) is the most common form of cancer in women of all ethnic groups, and its incidence in Latin women is increasing each year. Research has been conducted in the area of BC, including studying the physical, psychological, and social consequences, and the influence of ethnicity. Women with the diagnosis and undergoing treatment of BC are concerned with body image disturbance, sexual dysfunction, anxiety, and many other fears, including fear of death. These concerns might be affected by their cultural influences. The experience of living with the diagnosis of BC can affect the woman's life in its whole context. A diagnosis of BC can alter not only a woman's life, but also the lives of those closely related to her. Little published data exist regarding the epidemiology of BC in Puerto Rico, and most information explores only incidence and mortality (Morales et al., 2013); an ethnographic study was found describing the meaning of survivorship of BC in Puerto Rican women (Dyer, 2015). Most studies of Puerto Rican women are included as Latin or Hispanic groups since Puerto Rico accounts for either Latin or Hispanic. However, little research has been published in terms of the lived experiences of BC of Puerto Rican women, within their unique needs influenced by sociocultural norms, behaviors, and beliefs. BC experiences of ethno-cultural women were shaped by the social and personal context in which the women live (Howard, Balneaves, and Bottorff, 2007).

The needs of women with BC move beyond the physical or psychological. It is important to understand how the lived experience of BC diagnosis and treatment affects

their lives. Researchers have studied diversity in culture by putting together groups with similarities in characteristics to determine a group type, instead of separating them in research as subgroups. Each group carries on their unique ethnicity and sociocultural norms, thus individuality should be necessary. Since every culture is different, joining all Latinas into one group does not necessarily cover their needs. It is important to separate groups of people with the same ethnic background instead of grouping them with other similar cultures. The cultural background influences on every women's unique emotions after the impact of BC diagnosis.

Much has been written concerning ethno-cultural constructs and their application to the behavioral health treatment of Latinos (Andres-Hyman, Ortiz, Añez, Paris, & Davison, 2006). Every women's experience has been guided by the influence of their culture. Culture can also influence on the individual's preventive measures and medical follow up for screening. Studies that focused on Latinas have demonstrated that, compared to non-Latina Whites, Latinas desire more information about treatment but receive less (Yanez, Stanton, & Maly, 2012). The influence of the culture in Latinas demonstrate the need to identify that each subgroup to have their distinctiveness. Little consensus exists on how to identify, measure, and assess Latino cultural beliefs, values, and attitudes pertaining to health promotion and disease prevention behaviors (Abrahido-Lanza et al., 2007). Therefore, is important to develop assertive strategies in patient care. The heart of health behavior is attributions - the causal explanation process used to understand the world (Vaughn, Jacquez, & Baker, 2009). The attributions helps determine the way people to act and behave. Cultural differences in health attributions have major implications for medical professionals because attributions play an essential

role over time in the formation of beliefs concerning health and illness (Vaughn, Jacquez, & Baker, 2009).

In spite of significant advances in the diagnosis and treatment of most chronic diseases, evidence exists that racial and ethnic minorities tend to receive lower quality of care than nonminorities and that patients of minority ethnicity experience greater morbidity and mortality from various chronic diseases (Egede, 2006). As today, US continue to be the country of interest for all Latinos who searches for a better opportunity in life such as health. As the composition of the United States (US) changes, it is important that healthcare providers be aware of changing population trends and the values of major cultural and ethnic groups' belief systems that affect how people view health and healthcare (Maybin, 2012). It is also important to identify the needs of women's health care for those Puerto Rican that stays in the island. A phenomenological approach was selected to fully gain understanding of the lived-experience complexity of the BC diagnosis and treatment of Puerto Rican women within their culture.

Background of the Study

Previous studies identify Hispanics at socioeconomic risk for poorer cancer outcomes (Gany et al., 2011). Compared with the rest of the world population, Hispanics have the lowest survival rate of most cancers, even when adjusting for stages. In 2012, Hispanic women with BC accounted for the most common cause of death when compared to other ethnic groups (Centers for Disease Control and Prevention [CDC], 2015). Published research among Puerto Rican women diagnosed with BC is scarce. In fact, most studies found are focused on a group of Latin or Hispanics experience or are mainly from acculturated women who have been grown up in the US territories.

Generalizations about people from similar ethnic backgrounds may not always give the most accurate understanding for culturally diverse patients (Congress, 2004).

In a qualitative pilot study guided by the conceptual framework of pain and quality of life (QOL) of Hispanic patients with cancer, patients (n = 17) from Mexico, were interviewed (Juarez, Ferrell, & Borneman, 1998). It was determined by the researchers that QOL and the cancer illness experience are set in traditionally based values of family life, acceptance of God's will and religious beliefs that are interrelated, and culturally bound. Culture directly influences all QOL domains: physical, psychological, social, and spiritual (Juarez et al., 1998). The most difficult changes found in that study were the psychological well-being, which included anxiety, uncertainty, acceptance of the illness by family members, loss of independence, and coping with pain. Spiritual well-being and family were considered key elements to help survivors cope and deal with cancer, pain, and life crisis. Family's role and the faith were important indicators of QOL for BC survivors. For the Hispanic culture, the family's member role is an important issue for the women as well as their faith in God or superior force, in order for them to cope with the illness process. Although, this study was done with Mexican women, the results support the need to explore with the Puerto Rican women living on the island with their family values and religious beliefs rooted in their cultural background.

The first national study of BC knowledge, beliefs, and early detection was performed with 500 Puerto Rican women age 65 and older (Sánchez-Ayende, Suárez-Pérez, Oliver-Vázquez, Vélez-Almodóvar, & Nazario, 2001). The results revealed the following: Only 51.5% had received an explanation about mammograms from their

gynecologist; 88% believed that hitting or bruising the breast can cause cancer; 71% had never received an explanation on how to detect BC; and 39.4% had never had a mammogram. The main reasons given by the women for mammography noncompliance in that study were that they had no symptoms, did not know how to do breast self-examination (BSE), had no interest, had conflicting religious beliefs, or thought it was not important. No relationship between knowledge and early detection through breast screening was found. However, since beliefs of a culture impact preventive behavior of its individuals, these findings demonstrated poor knowledge and misinformation.

Although BC is the most common cancer in women regardless of race or ethnicity, it is the most common cause of cancer death in Hispanic women when compared with White, Black, Asian/Pacific Islander, and American Indian/Alaska Native women (CDC, 2015).

A descriptive study conducted in the US evaluated perceptions of BC screening barriers and facilitative conditions among immigrant women from five groups: Mexico, Puerto Rico, Cuba, El Salvador, and South America (Buki, Borrayo, Feigal, & Carrillo, 2004). A written survey provided data about sociodemographic characteristics, BC screening behavior, and acculturation to the dominant non-Hispanic White society of the US using the Acculturation Rating Scale for Mexican Americans (ARSMA), the wording of which had been changed to reflect the women's ancestry. The study revealed that women with Puerto Rican female ancestors had minimal knowledge about breast health because women's bodies were considered by them to be a secret and private subject. Also, they reported being frightened about the cancer illness process, making it a topic they rarely discussed. Regarding misinformation, these women believed that bumps to the breast could cause cancer, that risk factors were overestimated, and they thought that

anxiety and even talking about cancer itself can create cancer. Feelings of shame began when they thought about touching or showing their breast because it was considered the most sacred part of the body, making it a sin to touch oneself. Women under the study believed that they would be abandoned by their partners by having a deadly diagnosis such as BC. Strong barriers to early detection appeared when the women revealed that they had suffered bad experiences with screening procedures like Pap smears and mammogram. They had also stated that they distrusted healthcare providers. Although, in comparison with the other Latinas, the women from El Salvador and South America were more likely to comply with screening.

Latina BC survivors have a lower QOL than do Caucasian BC survivors. A qualitative study was performed in 2012 to determine the factors associated with QOL among 264 Latina BC survivors (Graves et al., 2012). Their QOL was measured in a cross-sectional sample using the Functional Assessment of Cancer Therapy-Breast (FACT-B) scale. Relationship between cultures was evaluated using regression models between cultural, social, and medical contexts, and overall QOL, and its subdomains. These Latina survivors were suffering culturally based feelings of BC-related stigma and shame consistently related to lower overall QOL, and lower well-being in each QOL domain. Variances of each final model were identified: physical well-being (adjusted $R^2 = 0.23$, $P < .001$), social well-being (adjusted $R^2 = 0.51$, $P < .001$), emotional well-being (adjusted $R^2 = 0.28$, $P < .001$), functional well-being (adjusted $R^2 = 0.41$, $P < .001$), and additional breast concerns (adjusted $R^2 = 0.40$, $P < .001$). The cultural values are directly related to the QOL of Latin women coping with BC. The findings suggested that factors affecting the QOL of all domains should be closely considered as an effort to improve the

survivorship experience. Culture shapes directly or indirectly a woman's unique survival experience.

Living with a chronic disease like cancer leads to a unique experience for those who are diagnosed. Every human being faces illness in a different way; Puerto Rican women are no exception. The literature demonstrates that Latinas' experience of BC has been described as that of a unique ethnic group, not individualized into subgroups. However, some differences and similarities have been reported in different studies when compared with Caucasian women. An example of this is explained in the Graves et al. study (2012) where Latinas' QOL was lower when compared to that of Caucasian women. It is thus important to identify women's particular needs during the process of living with BC and within the effect of their treatment. A Puerto Rican woman's experience of living with BC may be different from another woman living the same experience in another culture. Every woman faces diverse emotions through the experience of BC; again, Puerto Rican women are no exception. Puerto Rican women's experience of BC diagnosis and treatment has not been fully described as an individual subgroup of the Latin culture.

Significance

BC is a serious public health issue that affects the well-being of millions of women and their families throughout the world. Expanding knowledge in the field of BC and its significance among women within a culture has made the necessity of increasing their understanding of the patient's experience more urgent for nurses. Emotional factors and coping processes vary across cultures. Very few programs in Puerto Rico deal with the emotions of BC patients. The influence of culture upon QOL domains preceding the BC illness experience was researched for Mexican women. (Juarez et al., 1998).

It is important to consider that the emotions of Puerto Rican women may vary significantly between the women raised in the US and those living on the Puerto Rican island. Emotions that emerge from the lived experience of BC survivors can reflect the culture. Culture may influence the assertiveness in communication style of those women on the island when compared with the acculturated women in the US who might present in a more assertive manner regarding their BC diagnosis and treatment.

In a study to provide a view of the body image of three Puerto Rican BC survivors, Rodriguez-Loyola and Roselló-Gonzalez (2007) determined that consideration of the body as the main expression of femininity for women demonstrated that sensuality and sexuality were idealized by their culture. The results demonstrated that women under the study felt dissatisfaction with concern about their body image, fear of rejection, abandonment, need for social approval, low self-esteem, and sexual difficulties in a context on how they perceive their body. Mutilating surgical procedures, as occur from mastectomy as well as chemotherapy effects, were directly related to psychological problems in BC.

For Hispanic women, BC is the most commonly diagnosed cancer, generating distress for the individual, her partner, and family (Greer, Neville, Ford, & González, 2013). These researchers studied 12 immigrant Latina women in an effort to find their cultural voice and the meaning of femininity using Giorgi's phenomenological method. The study led to a well-described picture of the meaning of femininity for Latin women. The main topics that appeared were the power of feminine identity through motherhood; hardiness and sustainability to overcome adversity; connection of self and others; contemplative prevention to maintain breast integrity; and satisfaction meeting cultural

gender role expectations. In conclusion, the femininity meanings for the women under the study were mostly described as power, secure womanliness, and self-esteem. In Latin culture, femininity is seen as the major concern after a BC diagnosis.

A systematic review of the BC QOL literature was conducted among studies that provided a comparison of mental, physical, social, or sexual QOL between Latinas and other racial/ethnic groups. Results were that Latinas were more likely to report poor mental, physical, and social QOL, relative to non-Latinas (Yanez, Thompson, & Stanton, 2011). Latinas reported poorer QOL when compared to non-Latina Whites and Blacks. It is important that Puerto Rican women be separated as a group to identify their unique needs in treatment and support to manage a BC diagnosis and cope with the treatment. Based on a wide range of psychosocial elements that affect women with BC, it is important to investigate which responses are actually present in Puerto Rican women that affect their life and their family. Assessing and describing Puerto Rican cultural influences into women's experience on their emotional and coping process with BC diagnosis and treatment will be helpful in better understanding and providing a better care for patients in similar conditions.

Research background demonstrates the need for investigating the Hispanic population as their risk for poorer cancer outcomes continues rising within their unique characteristics. The need for researching Hispanics should be done in separated groups to explore their unique cultural influences at all levels: their emotions, feelings, treatment adherence, and treatment acceptance, etc. There is a gap to explore and gain a deep understanding of Puerto Rican women's BC lived experience as a unique group. Previous

studies demonstrate the influence of culture upon QOL domains in the Latin BC survivor, which preceded the illness process.

Statement of the Problem

The prevalence of BC in Puerto Rico had been increasing, becoming the second cause of death (Boletín del Registro Central de Cáncer, 2013), and considered the most common cause of death in women. The Central Cancer Registry Newsletter documented that in the year 2010 Puerto Rico reported an increase of 13,300 new cases of all types of cancer (2013). BC survivors face unique challenges to their social identities, their bodies, their social roles, their intimate relationships, and their families. This devastating illness process affects women's internal and external interactions. The BC diagnosis changes a woman's body image. Beauty with breasts has been emphasized in Puerto Rican culture; this body image change challenges a woman's perception of her femininity and sexuality. The problem historically is that little research attention has been paid toward the emotional needs of Puerto Rican women with cancer and their special needs within their culture. A gap exists in the research and due to the different cultures within the Latina or Hispanic community, it is important to study the experience of Puerto Rican women as a subgroup.

Purpose of the Study

The lived experience of BC diagnosis and treatment within the Puerto Rican culture has not yet been fully researched. The Puerto Rican women's needs may vary from those of other cultures. This phenomenological study attempted to gain an in-depth understanding of the meaning of the lived experience of BC diagnosis and treatment among a group of Puerto Rican women and how this diagnosis has impacted their lives.

Research Question

The research question for this study was the following:

What has been your life before the BC diagnosis?

What has been your lived experience since the moment of your BC diagnosis?

What has been your lived experience since your treatment?

How has your lived experience changed your relationship with family and loved ones?

Summary

Puerto Ricans living in the US and those living on the island are included in the statistics of many studies of what is referred to as a Hispanic or Latin group. Just as notable differences in risk factors among mainland Puerto Ricans versus island Puerto Ricans have been found (Morales et al., 2013), Puerto Rican differences from all Hispanic groups are always present. Acculturation may be considered as establishing differences of those Puerto Ricans from the mainland versus those from the island. The incidence of BC on the island has been increasing in recent years and, being the most prevalent of all cancers in Puerto Rico, it accounts for 30.3% of all female cancers with the highest mortality rates (Morales et al., 2013). BC is the first type of cancer in Puerto Rican women and the leading cause of morbidity and mortality in Puerto Rico (O'Neill et al., 2015). Studies reveal significant differences when comparing BC survivors from different ethnic groups. Most of the research found in the literature was of Puerto Rican women included into a Hispanic or Latin group. This aggregation allows statements to be made of a group whose discrete members do not necessarily have the same needs or are not influenced by the same factors. The literature describes Hispanic or Latin BC survivor women as diverse in several aspects of BC diagnosis and treatment coping when

compared with other cultures. In general, the literature makes evident the differences among ethnic and cultural groups regarding coping process among cultures. Puerto Rican BC survivors' needs may differ from other women within the Hispanic or Latin culture. Culturally based values of family, acceptance of God's will, and religious beliefs are just a few of the cultural bonds that may be present in different women within the Hispanic/Latin group. In order to discover the lived experience of the Puerto Rican women with BC diagnosis and treatment, a phenomenological qualitative study was conducted. This method investigates subjective phenomena in the belief that essential truths about reality are grounded in lived experience (Streubert & Carpenter, 2011).

CHAPTER 2

REVIEW OF THE LITERATURE

This chapter provides a review of the literature of concepts related to the study. It includes an overview of BC including uncertainty, screening, body perceptions, and quality of life through the experience of survivors and cultural influences among Latinas. Latina BC survivors adhere to certain cultural values and face unique issues as immigrants, potentially influencing overall QOL and doctor-patient communication (Lopez-Class et al., 2012). These factors may be the cause of identifying BC at a late stage. Gany et al. (2011) stated that Hispanics are at socioeconomic risk for poor cancer outcomes. Studies have demonstrated that Latinas' BC incidences are identified at a late stage and have poorer outcomes in treatment. Hispanic people have low survival rates for most cancers, even after adjusting for stages, when compared with the rest of the world population (CDC, 2015).

Overview of Uncertainty

BC is a devastating condition that leads a woman into many physical and psychosocial concerns. The impact of the diagnosis and treatment evokes multiple changes for every woman. The process of coping and dealing properly with the diagnosis varies from woman to woman based on their cultural background, accessibility of healthcare services, family support, and many other factors. Lack of knowledge or inability to make sense of an illness event caused by an unfamiliar or unexpected diagnosis can lead a patient to uncertainty. As a result, stress and coping behaviors strongly influence the illness adaptation process. Conceptualizing the uncertainty that impacts decision-making as a sense of doubt that blocks or delays action has three

essential features: (a) it is subjective (different individuals may experience different doubts from identical situations); (b) it is inclusive (no particular form of doubt, like ignorance of future outcomes, is specified); and (c) it conceptualizes uncertainty in terms of its effects on action (hesitancy, indecisiveness, and procrastination; Lipshitz & Strauss, 1997).

The concept of uncertainty in the cancer population was studied by Elphee (2008) and was defined as a risk to experiencing an inability to describe the meaning of the illness process and related events. In simple words, uncertainty describes a feeling of ambiguity about unpredictable events, usually regarding a chronic illness. Cancer patients are commonly exposed to these sets of feelings as a real concern or worries upon diagnosis. This feeling of uncertainty can affect their QOL in many different domains. Health well-being can be affected by the recurrence or even the progression of the cancer and with no control of the illness related to side effects, lack of knowledge, or new symptoms. Elphee emphasized the importance of integrating the concept of uncertainty into patient care, since it can evoke psychosocial adaptation or become a significant source of stress for patients.

A study of 280 BC survivors was done to compare the perceptions, uncertainties, and QOL of Latinas with Caucasian survivors (Sammarco & Konecny, 2010). In this descriptive comparative study, participants completed a survey at home and returned by mail the following: a personal data sheet, the Social Support Questionnaire, the Mishel Uncertainty in Illness Scale-Community Form, and the Ferrans and Powers QOL Index-Cancer Version III. The findings revealed a significant difference between the two ethnic groups. The Latinas reported greater levels of perceived social support and uncertainty,

while scoring lower than the Caucasian women on overall QOL. Ethnicity and cultural beliefs seemed likely to directly influence perceived social support, uncertainty, and QOL variables. This indicated that strong family support is culturally meaningful for Latinas in which *familismo* (family orientation) gives them their main source of emotional and psychosocial support. The Latinas were found to have higher levels of uncertainty and emotional distress than did the Caucasian survivors. The study also revealed the Latina value of *fatalism*, acceptance of fate and things that cannot be changed. This fatalism may be identified as a barrier to delivering preventive care measures and may determine BC screening.

Uncertainty or doubt is characteristic and might be present in every woman with a BC diagnosis. Women find themselves in the middle of in the process and might have their doubts based on their expectations, on their future. Latinas are not the exception for developing uncertainty nevertheless Puerto Rican women.

Breast Cancer Screening

In a phenomenological study cited earlier (Greer et al., 2013), 12 immigrant Latina women who had no diagnosis of BC described the cultural meaning of femininity. The concept of femininity can be challenged not only by a diagnosis of BC but also by other diseases and life occurrences. It is known that cultural values and beliefs shape individual behaviors. Greer et al. postulated that the cultural value of the Latina's gender role and expression of femininity is embedded in "gender-specific scripts" called *marianismo* and *hembrismo*. The concept of femininity was found to demonstrate the power of feminine identity as an interconnection between nurturing mother and reproductive power. Hardiness was considered sustainability in overcoming adversity and

transforming it to an inner strength. The results of the study demonstrated that femininity was described as having many different characteristics ranging from sacrificial, passive, fearful women to a socioecological view of empowered resilient women. Society, culture, and family shape the transformation of a girl to the feminine self. Positive perception of her body image, her physical body, and biological processes such as reproduction reinforce a woman's sense of self.

A national descriptive survey to identify BC knowledge, beliefs, and early detection practices among elderly Puerto Rican women (65 years and older) was performed by Sanchez-Ayendez, Suarez-Perez, Oliver-Vasquez, Velez-Almodovar, and Nazario in 2001. This survey was conducted in a sample stratified by socioeconomic status and area of residence of 500 women. Internal and external barriers affecting BC early detection practices and personal demographic characteristics that may influence noncompliance were evaluated. Internal barriers were defined as knowledge, beliefs, and self-perception of health. The external barriers were defined as related to health insurance, transportation, referrals to mammograms, and information provided about BC as well as BSE. Bivariate analysis was performed using contingency tables to identify the relationship between BC early detection practices and internal or external barriers. Logistic regression was used to determine the effect of barriers and other predicting variables for mammogram compliance. An affirmative answer to a belief statement implied misconception or ignorance about BC issues. The results of Sanchez-Ayendez et al. (2001) demonstrated that the women under study had some knowledge about BC, although 71% had never received an explanation about how to perform BSE, and 40% had never received a mammogram screening. They believed there was no need for

screening if they didn't have any present symptoms; no significance was found in the study between knowledge and early screening.

Research was added to the growing body of literature that focuses on differences between ethnic groups in use of cancer screening tests (Abrahido-Lanza, Chao, & Gammon, 2004). The authors evaluated data from the Health Promotion and Disease Prevention supplement of the National Health Interview Survey from 1991, with 43,732 respondents, and found that compared with non-Latina Whites, Latinas are less likely to ever have had a Pap test, clinical breast examination, or mammogram. These findings may demonstrate why Latina women are diagnosed at a later stage of breast or cervical cancer. The results for an analysis of multivariate logistic regression on mammograms and clinical breast examinations screening consisted of 535 (4.6%) Latinas and 11,209 (95.4%) non-Latinas. Latinas were less likely to undergo screening mammography, odds ratio (OR) = 0.71; 95% confidence interval (CI), CI = 0.57, 0.88. Screening in Latinas are left to the side as an important measure to prevent findings of BC at later stage.

Differences in culture, language, and socioeconomic status interact with and contribute to low ability to understand or act on medical/therapeutic instructions (Shaw, Huebner, Armin, Orzech, & Vivian, 2009). The researchers explored cultural influences in health literacy, cancer screening, and chronic disease management outcome. They found that the cultural beliefs around health and illness were an integral part of the patient's ability to understand and act on their medical treatment. In an attempt to understand the influential factors associated with decisions by diverse Latinas to obtain breast or cervical cancer screening, a qualitative study was conducted in 2012 by Torres, Erwin, Treviño, and Jandorf (2013). Interviews were conducted (n = 45) after participants

had attended a community-based educational program. The program was conducted in three geographic locations (Arkansas, New York City, and Buffalo, NY) with trained lay health advisors, breast or cervical cancer survivors, and program coordinators. The program had focused on topic-specific screening, guidelines, enrollment for screening services, diagnosis, treatment, and the recovery process, as well as dispelling myths and answering questions. In addition, semistructured telephone interviews were done with participants to understand factors that influenced their screening decisions. The researchers found that, compared with other racial ethnic populations, Latina women had limited knowledge on breast and cervical cancer screening. Cultural characteristics such as language barriers and importance to the family are target elements to participate or search for screening programs. Approximately, one third of the participants did not know where to go to receive screening services. After the educational screening program, it was learned that 23% of the women had intended to obtain a mammogram. The evidence demonstrates the importance of identifying behaviors that result in ignoring the importance of screening for BC as well as any other illness.

Although Latin BC screening has been investigated, little research has been published related to distinct Hispanic populations in different areas of the country. Ramirez et al. (2000), conducted telephone interviews with 4,732 women age 40 and older to identify screening methods between Mexican-Americans living in Texas, Central Americans living in San Francisco, Puerto Ricans living in New York, and Cubans living in Miami. The proportion of clinical breast exam (CBE) was lowest in Mexican-Americans. In adjustment correlates, significant group differences in lifetime and recent CBE and mammograms remained ($p < 0.001$). Ethno-regional differences persist among

Latin groups. These differences reinforce the importance for health researchers to individualize each group instead of grouping them as only one ethnicity category.

BC screening is the best tool to identify any malignancy at the very beginning stages. The earlier the screening begins, the earlier the diagnosis can be made instead of finding a BC mass at a later stage. Screening tools give women the opportunity to know themselves, recognize their bodies, and give themselves the chance to receive a better treatment at an earlier stage of cancer. Body Perception and Femininity

Women with BC face many different and unique challenges such as social identity, body, social role, intimate relationship, and even their family. It is evident that BC changes a woman's body image, femininity, and sexuality as well. In 2009, Martinez-Ramos conducted a study where 25 Latinas of Mexican origin with long-term BC were interviewed to explore their experience and report changes in their perceived notion of femininity after the BC diagnosis and surgery. The comparative analysis used data that were clustered and organized into broader themes and coded *in vivo* by similarities and differences. The women discussed openly that, as a result of surgery and the permanent effect of treatment, their bodies were no longer the same after BC. It was commonly reported by them that it was difficult to see themselves with their now deformed and mutilated bodies. The women expressed that having beautiful breasts symbolized femininity, beauty, and reproduction. They even expressed the sadness they felt when they looked at their changed bodies. They also stated that having BC had made them more aware of their femininity and of the influence that social and cultural forces had on their body image. Their sadness, loss, or anxiety about their body image had not been revealed or communicated to others, they said, to avoid the experience of fear stigma. It

was evident how social and cultural influences affect women with respect to their body image, intimacy, and sexuality after BC diagnosis. It was a big challenge for those Latina BC survivors to return “back to normal” life with their transformed body image.

A research study to determine frequency of body image and sexual problems after treatment for BC was conducted by Fobair et al. (2006). A total of 549 multi-ethnic (White, African-American, Latina, and Asian) women age 50 or younger who had undergone surgery and chemotherapy treatment were selected for the study. Half of the women sometimes experienced two or more body image problems. Among the sexually active women, greater body image problems were associated with mastectomy and possible reconstruction, hair loss from chemotherapy, concern with weight gain or loss, poorer mental health, lower self-esteem, and partner’s difficulty understanding her feelings. The study found overall that body image and difficulties related to sexuality and sexual functioning were common among cultures after surgical and adjuvant treatment.

A qualitative methodological study was performed by Martinez-Ramos, Garcia Biggs, and Lozano in 2013 with BC survivors (n = 25) to understand their perceptions about the significance of BC in their lives and how cultural values and beliefs impose unique meanings. These results showed that the impact of BC was a major life event for them and brought new meanings into their lives. Difficulty talking about the loss, fear of recurrence, stigma, and uncertainty were the concerns of most respondents. Awareness of their health, their roles within their families, body image, intimate and social relations, and their femininity were present in most of the responses. Need for support in coping and facing the new challenges of the illness process were identified, and family was recognized as strong support for them. The main worries of the survivors were being

stigmatized or being treated differently, overcoming their negative perception about themselves and the impact to their femininity, and the effects of the recovery and survivorship on social and family relations. Body image is one of the most important emotional concerns in BC women. The effect of the surgery scar, the hair loss, the weight loss or gained are factors that influence directly women's body image and are considered their major concern.

Emotional Concerns in BC

Any change that significantly impacts the life of a human being is a major factor that can cause emotional and psychological concerns or worries. Addressing emotional distress is becoming increasingly common in cancer care. BC diagnosis can cause emotional and psychological stress in every women. A cross-sectional telephone survey of 330 Latina BC survivors was done to examine the relationship between coping resources and self-rated health. The researchers (Nápoles, Ortiz, O'Brien, Sereno, & Kaplan, 2011) found that Latinas are at higher risk for psychosocial morbidity following BC than are Caucasian women and that the Latinas suffer disproportionately from issues related to distress, sexuality, pain symptoms, relationship with partners, employment, and financial hardship. Less acculturated and less educated Latinas reported poorer health. The results demonstrated that comorbidity (adjusted odds ratio [AOR] = 4.09; 95% CI [1.69, 9.89]) and having a mastectomy (AOR = 2.67; 95% CI [1.06, 6.77]) were indicators of higher risk of functional limitations for Latinas (n = 73), and 27% reported poor or fair self-rated health (n = 89). The study revealed that comorbidities place Latinas at increased risk for poor health.

Sleep quality becomes poor after a diagnosis of BC, and sleep disturbance remains as the first symptom of worries and concern. Functional well-being is usually

impacted by sleeping patterns, nutritional habits, and needs. In a descriptive study, done through telephone interviews, 32 women with BC and 35 with no metastatic BC were investigated in 2011 by Enderlin et al. to examine sleep quality as a predictor by cancer status. Measurements used were the Pittsburg Sleep Quality Index, Profile of Mood States, 3 days of home actigraphy, the Insomnia Severity Index, the Epworth Sleepiness Scale, and medical record reviews. Findings included that poor subjective sleep quality was predicted by a depressive mood ($p < 0.00005$), and the BC group was characterized by poor sleep quality, frequent nocturnal awakenings, and insomnia symptoms.

A prospective, longitudinal study examined BC patients ($n = 131$) in Alicante, Spain to describe changes and the long-term influence of general and specific control beliefs over psychosocial and emotional adjustment (Neipp, Lopez-Roig, Terol, & Pastor, 2009). The sample was randomized, and inclusion criteria were unilateral primary BC, free of other diseases, and participants were assigned to the standard follow-up protocol in an oncology unit with two time intervention points: a pre-check-up interview and later at 6 or 12 months. In the first intervention (Time 1), the interview was focused on sociodemographic, medical, psychological variables (using these scales: General Self-efficacy, Perceived Health Competence, Locus of Control, and Specific Control Beliefs), emotional status, and psychosocial adaptation variables. General Self-Efficacy and Perceived Health Competence scales were administered only in the second interview (Time2) held 12 months after the first interview. As a result of their psychosocial adaptation, there were no significant differences between Times 1 and 2. Perceived health competence was the best predictor of emotional status ($R^2 = .106$, $\beta = -.31$, $p < .001$ for anxiety; $R^2 = .070$, $\beta = -.26$, $p < .01$ for depression), and it was also the best predictor for

some psychosocial areas: for domestic environment, for extended family relationships, and for psychological distress.

Women from different ethnicities ($n = 92$) diagnosed with stage I or II BC were studied to describe their coping through their emotional approach (Stanton et al., 2000). Women treated were monitored by phone until treatment was completed within 20 weeks after their primary treatment such as surgery, chemotherapy, or radiation. Their coping process was assessed with the COPE 60-item inventory covering 15 coping strategies, and the Hope Scale assessment. Psychological adjustment was assessed through three indices at entry and 3 months later. The Profile of Mood States (POMS) described a negative or positive effect regarding their feelings in the past week, and health status indicators. Younger women reported more distress on the POMS than older women, $r = -.22$, $p = <.05$. The demographic and cancer-related variables did not interact significantly. The results demonstrated that women's use of coping through emotional expression following primary treatment tends to decrease their distress.

Body changes tend to generate stress and emotional concern for women facing BC. Frierson, Thiel, and Anderson (2006) conducted a study with 195 women with stage II or III BC, recruited at their postsurgery clinic visit prior to adjuvant therapy. Assessment was made using the Breast Impact of Treatment Scale (BITS), the 11-item version of the Body Satisfaction Scale (BSS), two types of data to measure sexual behavior and sexual affects, and to measure the cancer-related traumatic stress and distress, the 15-item Impact of Event Scale (IES), and the 65-item POMS. These instruments examined cognitions involving the re-experiencing, denial thoughts, and avoidant behaviors related to traumatic stress. The women's responses to their breast

changes were conceptualized as a stress reaction. This study produced significant results. The analysis of variance contrast was significant $F(1,192) = 49.06, p < .001$, with women who received modified radical mastectomy at significantly higher levels of body-change stress ($M = 29.18, SD = 13.14$) than women who had received breast-conserving surgery ($M = 16.09, SD = 12.65$). All regression models for psychological outcomes and sexual outcomes were significant. This comparison shows that women with modified radical mastectomy perceived a less traumatic stress reaction with their body changes, sexual behavior and sexual depression after surgery.

A prospective study was performed by David, Montgomery, and Bovbjerg in 2006 to examine the effects of optimism and pessimism on pre-surgical distress levels, and the effect of coping responses, and to investigate the mediational pathway contributors from optimism, pessimism, and coping and their effect on distress. Recruited were 60 women of different ethnicities who were scheduled for excisional breast biopsy or lumpectomy. The 12-item Life Orientation Test was used to assess optimism and pessimism, the Brief Cope (B-COPE) to assess cognitive and behavioral strategies/responses in managing stressful situations, and the Profiles of Mood States Short Version (POMS-SV) to assess affective dimensions and provide a total distress score. The researchers found that optimism and pessimism had a significant impact on the distress level in patients scheduled for BC-related surgery. It shows that optimism and pessimism were directly related to distress levels prior to surgery ($p < 0.05$): The greater the optimism, the lower the distress level; the greater the pessimism, the higher the distress level. Also, coping responses ($p < 0.05$) were related to distress mediated by optimism and pessimism. Women's response to BC diagnosis and treatment develops

stress and psychological concerns. These emotional concerns affect the quality of life of BC survivors.

Latin women who participated in their focus groups (n = 64) mentioned the following culture-specific barriers to BC detection: prohibitive female-gender roles, prioritization of health needs, and language concerns (Schlehofer & Brown-Reid, 2015). Prohibitive female-gender roles included women not wanting to touch their breasts or their partners not liking them to show their breasts to their healthcare provider. The second element, prioritization of health needs, included focus on the woman as the family caregiver taking precedence over her own healthcare needs. Third, for Latin women, language is a main concern when seeking medical care because not all Latinas speak English well enough to have a conversation with their care provider. BC impacts women's lives in all spheres, including emotional needs. It is important to research every woman diagnosed with BC to identify their unique needs in order to provide proper care. This supports the need to explore Puerto Rican women's experience of BC diagnosis and treatment within their culture considering the emotional need at all levels: at the diagnosis phase, the treatment phase, and even at the recovering phase.

Quality of Life in Breast Cancer Survivors

QOL is a broad concept that has been considered subjective and multidimensional, encompassing the physical, social, functional, and psychological/emotional well-being factors related to an individual's health status (Wildes, Miller, San Miguel de Majors, Otto, & Ramirez, 2010). The QOL of Latina and Caucasian BC survivors was examined in the comparative descriptive study of Sammarco and Konecny (2010) described earlier in this chapter. The 35-item Ferrans and Powers

QOL Index-Cancer Version III (QOL-CV) was used to assess the QOL of the 280 participants. The Caucasian women reported significantly higher levels of QOL than did the Latinas. The QOL results reflected that Latinas as an ethnic group were economically disadvantaged, medically underserved, lacked health insurance, and had even less social support. Culture and language are factors that affect QOL, especially the ability to communicate with healthcare providers.

The cross-sectional study performed by Wildes et al. (2010) with 117 Latina BC survivors was to evaluate the satisfaction of this population and their health-related QOL (HRQOL). Study measures were obtained through a sociodemographic questionnaire, illness characteristics, acculturation level, HRQOL to assess with Functional Assessment of Cancer Therapy-General (FACT-G), and a slightly revised version of the Satisfaction Index. Multivariate analysis was used to assess the influence of HRQOL. The Latina BC survivors had high satisfaction and generally good HRQOL, positively associated with FACT-G functional well-being ($r = 0.265, p = 0.004$). Acculturation of the participants to the US was moderate to high. Most of the questionnaires were answered in English, and a few in Spanish. These Latina BC survivors were reportedly quite satisfied with their cancer care doctors, and they reported HRQOL as quite good. Although the study shows a significant satisfaction with healthcare and QOL, it is important to recognize that this study focused on an acculturated population. Results may vary with a non-acculturated Latina population.

Many patients perceive changes in their QOL after BC diagnosis and surgery. A 6-month longitudinal study was conducted by Salonen, Kellokumpu-Lehtinen, Tarkka, Koivisto, and Kaunonen in 2010 to evaluate changes in QOL after surgery. A total of 64

women recently diagnosed with BC who had undergone surgery for the cancer were studied and evaluated 6 months after the surgery in a quasi-randomized intervention. Individual telephone support and education 1 week after the breast surgery were part of the first intervention. A second intervention, including face-to-face support and education, was done 6 months after the surgery, at which time a complete questionnaire was given to the participant with the request that it be completed and returned within 2 weeks. For the control group, the questionnaire was sent by mail 6 months after the surgery. The Ferrans and Powers QOL and overall QOL were used to measure and classify their QOL into domains of health and functioning, social and economics, psychological and spiritual and family. The researchers found that body image decreased significantly during the intervention ($p = 0.001$) and for the control group ($p = 0.007$); there were no statistical differences between the groups. Women who had not received chemotherapy or hormonal therapy had less risk for body image disturbance when compared with those who had received chemotherapy or hormonal therapy. Employed women were impacted with negative changes of body image less than those who were retired. Identifying factors that predict negative changes in QOL of patients with BC included the following: education, employment status, having underage children, undergoing chemotherapy, radiotherapy, and hormonal therapy. Logistic regression models for these variables were reported in OR with 95% CI in which the limit for significance was set at $p \leq 0.05$.

Social, cultural, and healthcare systems are factors considered to impact the QOL among Latina BC survivors. As seen in previous cited references, the difference between Latinas and Caucasian women is significant. Some cultural beliefs and values impact

significantly women's health prevention and screening choices. The decision-making process and the patient-physician communication process to access cancer care are guided by women's cultural behavior. The qualitative cross-sectional study conducted by Lopez-Class et al. (2012) examined, via individual interviews and focus groups, the factors that impact the QOL and survivorship experience of Latina immigrant BC survivors (n = 28). The individual interviews explored the participants' perceptions of their QOL and how certain cultural influences impact it, and the focus groups expanded the identified interview themes. Several identified themes were relevant to cultural values that impact this population's QOL. Many women noted the importance of their relationship with God as a source of strength in dealing with their cancer diagnosis. Other cultural values that were present and that affected their QOL were fatalistic beliefs about cancer, *personalismo*, or feelings of loneliness, secrecy/shame, or not feeling comfortable telling others about their BC, self-reliance, or trying to keep independent, and Latino *machismo* in the support and coping process with their partner. *Familismo*, or family support, was very significant to the QOL of the survivors. Besides the cultural values, the language barrier was another factor that affected this Latina population when navigating a new medical system.

The study performed by Graves et al. (2012) examined the QOL of Latina BC survivors (n = 10) through the lens of culture. Results were measured with a sociodemographic questionnaire and the following: cultural context factors were measured for shame/stigma with the Body Image After BC Questionnaire; cancer fatalism with a Spanish version of the Powe Fatalism Inventory; *familismo* with a modified Familism Scale; religious and spiritual coping with the Religious Coping Scale;

social context factors with the Duke-UNC Functional Social Support Questionnaire; medical context with the Satisfaction with Patient Satisfaction Questionnaire; and QOL outcome with the (FACT-B) scale. The researchers determined that cultural views have the potential to affect QOL both positively and negatively. Culturally based feelings related to BC stigma and shame were consistently related to lower overall QOL and lower well-being in each of the QOL domains. In social well-being, results showed that women with less body stigma had higher social well-being. Less BC stigma was also related to higher emotional well-being and greater satisfaction with the medical system. Stigma was strongly correlated with functional well-being. It was evident that varied patterns of the cultural and social behavior of the BC survivors across domains of QOL influenced directly the types of outcomes among the participants. QOL covers all domains for BC needs. It is important to identify all QOL domains needed in every BC women to identify, provide, and satisfy that need among the circumstances and their culture.

Summary

Understanding the experience of Latin women living with BC is complex. To understand the feelings or major worries of living with cancer, an exploration of Latin cultural behaviors must be undertaken. Women's individual experiences of health and illness can possibly transform them, bringing new meaning about themselves, their bodies, their health, and their future. The literature review makes it clear that Latina BC survivors experience different outcomes compared to non-Hispanic White women.

General concern after BC might be present in woman regardless of cultural ethnic issues. A Latino woman is usually the primary caregiver responsible for those at home who depend on her. After a diagnosis of BC and treatment, her role changes from

someone who gives care to someone who faces the need of care for herself. These women may consider the BC diagnosis as a catastrophic event in their lives. Latino men may have little to no knowledge of household responsibilities such as cooking or caring for the children and may resist helping with this “women’s work” (Kingsley & Bandolin, 2010). Having BC can lead to a major shift of responsibilities in the lives of these women. Thus, responsibilities change at the home of a woman with BC due to the changes the woman is experiencing. Engaging in the entire illness process is difficult and requires effort and time. Family roles may be disrupted, and stress can overcome family members. For a Latin woman, losing a breast or ovaries evokes deep sadness. These body parts represent the female part of her and her ability to fulfill an important role, that of mother (Kingsley & Bandolin, 2010). A Latin woman fears feeling incomplete for more than her tasks or role at her home. In addition, removal of her female body parts can lead her to many emotional concerns influenced by her culture.

Phenomenology

Phenomenology is a philosophical perspective that helps researchers explore and understand everyday experiences without presupposing knowledge of those experiences (Converse, 2012). Phenomenology is a method that seeks to explore, describe, and analyze the meaning of the individual lived experience (Marshall & Rossman, 2011). In phenomenology, the main purpose is to describe a phenomenon, or things as they occur. It puts findings of evidence into a philosophy of what it is. The phenomenology perspective tries to describe or understand the perspective or experience of a phenomenon. In addition, it tries to understand what it means for the people under study.

The phenomenological approach guided this researcher to learn more from the experience of the interviewed women with BC diagnosis and treatment. The researcher was the observer, interviewer, even the interpreter to explore deeply into the participants' lived experience. In-depth interviewing was used to understand the meaning of the experience of the phenomenon of BC diagnosis and treatment within a particular group and their cultural influences. The experience of a BC diagnosis and treatment as lived by a Puerto Rican woman guided by the phenomenological approach gave new knowledge. It was a significant way to demonstrate the lived experience of a group of participants from their own perspective and involvement in the inquiry phenomena. The focus of personal meaning to each woman allowed the researcher to draw a picture of the significance to them, their feelings, emotions, and the strength and encouragement needed to fight for life after a BC diagnosis.

Conclusion

It is evident that BC lived experience changes a woman's individual life with significant elements to be considered when healthcare is being delivered. This literature review has identified a gap in the literature and a need for more knowledge of the experience of the Puerto Rican woman.

Multiple events are faced by women with BC from the moment of diagnosis through the treatment and adaptation process. Emotional or psychological concerns influenced by their culture directly impact their healthcare outcomes. The literature review reveals that too little research has been done with Puerto Rican women diagnosed with BC. The in-depth interviews used in this study allowed access to the lived experience of each participating woman with BC. Results from the researched

experiences can add important and valid information to understanding and increasing the nurses' capacity for care and compassion, and developing proper individualistic care.

The findings of this study will provide a basis for nurses to gain access to and properly treat each woman whose culturally learned behavior may prevent her from engaging in screening and receiving new needed care. Integration of the knowledge gained from these BC survivors will make easier the nursing approach to patients based on the patient's special needs. Findings from this study will help nurses provide new strategies to pursue when working with Puerto Rican women in screening, diagnosing, and cancer research designed to provide an increased understanding of Puerto Rican women's lived experience of the diagnosis and treatment of BC within their culture.

CHAPTER 3

METHODOLOGY

The purpose of this phenomenological approach was to explore the lived experience of BC diagnosis and treatment within the Puerto Rican culture. This qualitative study was designed to provide an increased understanding of Puerto Rican women's lived experience of the diagnosis and treatment of BC within their culture. Identifying the factors involved in the lived experience through the influence of culture fills a knowledge gap within this vital health concern in Puerto Rican women, enabling nurses to treat them more effectively. It is relevant for the nurse to know, when considering patient's needs, how people react to potentially stressful events in their life such as dealing with the process of diagnosis and treatment of BC.

Characteristics of the Participants

The selected population for this study had particular characteristics. The target population was Puerto Rican women between 35 and 45 years of age who were at least 1 year past having been diagnosed with BC stage II or III. Participation required that they must be receiving or had finished receiving treatment such as, but not limited to, mastectomy or lumpectomy, chemotherapy, radiation, and/or any other conventional treatment. The number of participants to be recruited were a minimum of 12, or until data were saturated. All participants were invited to answer a demographic survey instrument and take part in at least two in-depth interviews. Selected participants were invited or recommended by a cancer center in the northern region of Puerto Rico. The sites taking part in the study are from the north side of the island, where most patients visited. The sample was obtained from the accessible population of women who were interested from

the flyer invitation (Appendix A) and matched the inclusion criteria established by the researcher.

Inclusion/Exclusion Criteria

The criteria for inclusion were northern urban Puerto Rican women from different socioeconomic and religious backgrounds, between ages 35 and 45, with BC stage II or III. Participation required having the ability to speak, read, and write in Spanish and being willing and able to sign consent to participate in the study. Exclusion criteria were as follows: not being northern urban Puerto Rican; not meeting the age frame (35–45); not meeting stage II or III of BC; not having at least 1 year since diagnosis; and having a psychiatric disorder, Alzheimer's disease, and/or senile dementia.

Procedure

The researcher requested approval from the University of Massachusetts Amherst Institutional Review Board (IRB) to do research with human beings. Once the request had been approved (Appendix B), the researcher contacted and requested permission from the oncologic office's administrator to post flyers that contained a brief description of the study, protocols, and proposal. The researcher also posted and distributed flyers with contact information for potential participants in numerous other institutions, stores, and medical offices. Women between 35 and 45 years old, who had been diagnosed and treated for BC stage II or III, following the inclusion criteria, responded and were asked to participate.

Women willing to participate contacted the researcher, who gave them, by phone or in person, a brief description of the study, its purpose, and the role of participants. Once a woman agreed to participate, informed consent (Appendix C) was signed, the

demographic survey (Appendix D) was completed, and a schedule of time and place for the first interview was determined and coordinated.

Individual in-depth interviews were conducted with each selected participant. A total of 12 participants had contacted the researcher interested in taking part in the study. Only nine had the opportunity to participate, as three of them had gone to the US mainland after Hurricane Maria. Data saturation was reached with the nine participants. The interviews were coordinated at the participant's convenience. Most of them selected their homes since they were a place to be alone and in peace. The women's choices of place, date, and time for the interview were given as they selected. The in-depth interviews lasted 45–90 minutes. The interviews took place from May–September 2017. The follow-up interview was scheduled within 1 to 2 weeks after the initial interview. Two individual interviews were performed with each participant.

Setting

The in-depth interviews were used for gathering data from all the participating women. The interview locations varied according to the participants' desires. The interviews took place in different cities of the northern urban region of Puerto Rico: Arecibo, Toa Alta, Vega Alta, Vega Baja, and Bayamón. All the interviews were conducted at the participant's home.

Data Collection

A qualitative in-depth approach had been chosen to explore the feelings, emotions, and cultural concerns of the participants from their individual and unique point of view of the BC lived experience within their culture. In-depth interviews allow participants to have more control in data collection, as they enhance disclosure and can

lead to better understanding of people within a culture. The goal of the individual in-depth interview was to gain access to and fully understand the complexity of the women's BC experience within Puerto Rican culture. Interviewing is a flexible technique that allows the researcher to explore meaning in greater depth that cannot be obtained with other techniques (Burns & Grove, 2009). The researcher gave the opportunity to the participants to express their feelings about the diagnosis and treatment of BC within their culture. In-depth interview is important in order to have the participant express their feelings and lived experience as it is.

The in-depth interview questions were used to clarify or prompt the women to talk more fully about their experiences. They were asked specifically about their lived experience after the diagnosis and treatment of BC. The interview was intended to look particularly at the women who are living the experience of BC diagnosis and treatment as well as the influences of their culture. The interview was considered open, with questions designed to prompt the woman to share her lived experience of surviving her BC diagnosis and treatment and how the culture had influenced the experience. A series of two in-depth interviews were held: The first interview focused on the woman's life history and details before the BC experience and also provided opportunity for her to tell her experience during and after the diagnosis. The second interview reflected upon the meaning of that experience within the culture. Seidman (2006) emphasizes three interview questions to allow the interviewer and participant to enter deeply into the experience and place it in context. Examples of designed questions are the following:

Would you please tell me, what has been your life before the BC diagnosis?

Would you please tell me, what has been your lived experience after the BC diagnosis?

Would you tell me, what has been your experience after sharing your experience?

In this case, participants were more available to participate in two separate in-depth interviews. The first one to focus on their lives before the BC experience and their lived experience after BC diagnosis. The second interview was more focused on their overall experience, including after sharing their story and experience with the researcher. The individual in-depth interview was tape-recorded and transcribed verbatim. Data were read and reviewed by the researcher for meaning units, analyzed, and interpreted over the entire period of data collection. Each interview was transcribed and coded by the researcher. The data were gathered until saturation was obtained and common threads were revealed, as thoughts and aggregated meaning units emerged as themes, developing a thematic structure and shaping the revealed experience into a context.

Summary of Findings and Interpretation

A process of reading, reflection, and writing was used to transform the data from the interviews into text that conveys the essence of the lived experience of the BC survivors. Giorgi's five basic steps (Giorgi & Giorgi, 2003) for analyzing data were used to guide this process:

1. Sense of the whole—data collection
2. Discrimination of meaning units—reading and listening to audiotapes
3. Transformation of expressions—coding
4. Synthesis of transformed meanings—organization and expression of data
5. Final synthesis—summarizing data

The analysis of the data from the interviews was interpreted according to the nature of the experiences presented by the women. Findings were translated from Spanish into English using Google Translate. A second English reviewer worked on the edits that reflect the correct findings. The researcher summarized the findings in order to organize the experiences reported by the women. The findings will become part of a published research presentation where confidentiality of the participants will be strictly maintained. The codes were grouped into categories that were considered along with the researcher's field notes and recorded as a reflection of the participants' responses during the interview for the final synthesis.

Validity

Gathering, interpreting, and reporting qualitative research findings require that researchers spend time planning how data were collected and then reading and rereading verbatim transcriptions of interviews and field notes (Streubert & Carpenter, 2011). It is important to spend time in this process in order to avoid threats to validity and increase credibility of the data obtained from each participant's lived experience when fully responding to every question. Open-ended questions were used and carefully delivered to avoid premature closure. Seidman (2006) states that with in-depth interviewing we recognize and affirm the role of the researcher who can respond to situations with skill, tact, and understanding.

The individual in-depth interview has particular benefits: It takes in a wide variety of information, combined with observation, and allows the researcher to learn about the participant's lived experience of BC diagnosis and treatment as lived by them. The

experience of recollecting information from their lived experience together with the observations enriched the findings and synthesis.

Munhall (2007) states that during data collection and analysis, prior knowledge can risk possible bias. Bracketing is the device used to guard against bias. The process of bracketing has been described as (a) separating the phenomenon from the world and inspecting it; (b) dissecting the phenomenon to unravel the structure, define it, and analyze it; and (c) suspending all preconceptions regarding the phenomenon, and confronting the subject matter on its own terms, to ensure that the researcher holds in abeyance any preconceived ideas while he or she is listening to, interacting with, and analyzing the stories of the participants (Wojnar & Swanson, 2007). To avoid judgment and prior knowledge about the experience and phenomena, the researcher continually tries to understand what the interviewee had expressed. To avoid allowing any personal knowledge to bias the experience being related, the researcher would put aside any emotions and feelings about the phenomena and focus on exploring the in-depth descriptions of the participant's lived experience. It is important for the researcher to express the responsibility for reliability and validity by implementing verification strategies. Presuppositions from nursing practice and experience in the field of cultural beliefs interaction were kept to the side by avoiding making comments, allowing the researcher to be open to the experiences of the BC survivor just as she had related them. BC had always been an interested research topic in a way to learn from the women's own lived experience about what the cancer has done to their lives. The researcher as a nurse, coming from the same cultural background was conscious about and careful to keep personal assumptions and ideas from influencing the data and analysis process. The researcher consciously avoided letting personal and cultural bias enter the study by

avoiding comments and nonverbal communication and by turning to accustomed exploration of the in-depth descriptions of the painful and sensitive human-lived experience as if never had known anything about BC.

Verification is the process of checking, of confirming, and making sure. The mechanisms used during the research process contribute to ensuring reliability and validity, and thus the rigor of the study (Munhall, 2007). To provide evidence of the validity of the research findings, the researcher conducted two in-depth interviews in order to reach credibility to establish accuracy of their statements. Once the data were organized into themes, they were interpreted and translated by the researcher. To ensure validity and reliability, the transcribed data was presented to the interviewed women to clarify perceptions and meanings and to get feedback on the themes and interpretations. Personal thoughts, self-reflections, responses, and gestures were described in the field notes of the researcher.

Scientific Ethics and Rigor

All interviews began with a scripted introduction of the study purpose and requirements for participation. Confidentiality was assured to the participants at all times. It was explained that participation in the study was completely voluntary and that participants were allowed to stop at any time they felt they could not continue. After all doubts and questions were clarified, an informed consent was read to all potential participants. Signing the informed consent was the participant's indication of understanding and her acceptance to participate in two interview sessions and a third one if needed. Collected data were not shared with anyone except the dissertation committee members. The investigator kept a diary or documentations of field notes and entries in

which she recorded after each interview the events and impressions she had received. Emotional state, speech patterns, body language, interruptions, general impressions, and thoughts during the interview were kept in these notes. After the first in-depth interview, each participant was asked to schedule the second interview for the purpose of respondent validation. One participant had asked to have all interview together in one session.

Limitations of the Study

Revealing emotions and feelings after BC diagnosis and treatment is a sensitive issue in Puerto Rican women, and it was expected that their lived experience with BC would be a difficult phenomenon to study. The Puerto Rican culture may differ from other cultures in the way of expressing emotions and feelings for an interview research study. The possible limitation of this research study was directly related to the sensitive nature of this area in nursing care. Influences such as religious and cultural beliefs may have not facilitated the women's participation. Women interested in taking part in the study had called the researcher to learn more about it. Exposing their feelings and emotions could be considered a cultural matter or could have been limited by concern about what others might think of their situation. A limitation was that only nine (9) participants took in part in the study out of twelve (12) who were interested.

The researcher made every effort to reduce these types of concerns in order to gain the participant's confidence and full answers in each interview. The main goal of the study, after all, was to gain full knowledge that could lead to development of a proper healthcare protocol for women undergoing treatment for BC.

Risk to Participants

It was expected that emotional risk and discomfort at times in the interview could be present. The researcher worked carefully to minimize any emotional risk or discomfort during the interviews. The participants were reminded that they could abandon the interview at any time if their emotional risk felt like too much and they would no longer feel comfortable during the interview. A list of referral resources was made available and given to each participant at the signing of informed consent in case the participant had need for it.

Participants were informed that each woman would be given a pseudonym to ensure their confidentiality. They were given the opportunity to select a name or have it be assigned by the researcher. The researcher kept all study questionnaires, including any data codes, in a locked file cabinet. Research records were labeled with a code. A master key that links names and codes was maintained in a separate, secure location. Electronic files containing identifiable information were password protected to assure privacy of the information. Any computer hosting such files also had password protection to prevent access by unauthorized users. The researcher and her faculty were the only persons who had access to the passwords.

Summary

Phenomenological descriptive study was chosen as the best qualitative research method to explore the lived experience of a target population with the diagnosis and treatment of BC within the influence of the Puerto Rican culture. Phenomenological research is used to explore the lived experience of individuals (Streubert & Carpenter, 2011). The goal of this research study was to gain knowledge of the lived experience and

feelings of these Puerto Rican women with BC as a particular phenomenon influenced by their culture.

The individual in-depth interview process in the selected sample of participants was important to discover what had been the lived experience of the diagnosis and treatment for BC within the selected population as influenced by their culture. The research process was directed toward the purpose of communicating the findings to nurses and improving care to BC survivors in Puerto Rico.

CHAPTER 4

RESULTS

The Puerto Rican Women Tell Their Stories

This phenomenological study presents the experiences of Puerto Rican women living with BC. Phenomenology provided an opportunity for these individuals to share their life story in order to illuminate previously misunderstood, unknown, or discounted experiences (Bogdan & Biklen, 1992). Data were gathered over a 6-month period. Posters and flyers were posted in May 2017. The response rate was slow. A total of 12 women made phone contact with the researcher and agreed to participate; only nine, however, were able to be interviewed, and they signed informed consent. The other three had moved to the mainland US due to Hurricane Maria and its impact to the island. Varieties of information are provided in this chapter to help the reader understand the research participants' experiences. Included quotations provide multiple perspectives, allowing the participants to speak for themselves.

This chapter presents the key findings obtained from nine in-depth interviews beginning with a brief description of each participant's lived experiences. The results of the study convey understanding of the lived experience they faced throughout their diagnosis and treatment for BC. Major findings will be discussed in this chapter, and an analysis will be presented in Chapter 5.

Participant Demographics

The participants lived in the northern urban region of Puerto Rico, and all of them had been diagnosed with breast cancer stage II or III. Their ages ranged between 35 and 45. Seven participants had been married for more than 10 years, and two others were

divorced. Eight of the women had decided to retire from work after their diagnosis, and only one had continued working. Education levels of the participants ranged from high school diploma to associate's degree. At the time of diagnosis, seven participants had children aged 5 to 16, one participant had children who were over 18, and one participant did not have any children. All participants considered that they had some source of religious faith: Four were Catholic, and five considered themselves Protestant. The following is a brief description of each participant:

Chelsy was 40 at the time of her BC diagnosis, divorced, with two adolescent children. She considered herself to have a very busy life with multiple roles. She had an associate's degree related to health. She had visited her physician once she found a palpable mass on her breast. She had retired from work after the BC diagnosis.

Astriam, was age 44 at diagnosis, married, a hard-working mother with one adolescent child and an adult child of 20. She holds an associate's degree. She sought medical care after feeling a mass on her breast. Retired from work once chemotherapy treatment began.

Becky, 45 at the time of BC diagnosis. Divorced with three adolescent children. Working mother with three shifts as a licensed practical nurse (LPN). She felt a mass on her breast that made her consider medical care. Retired from work after her medical treatment for BC.

Aleny, age 35 at the time of diagnosis. Married with two children of 6 and 7 years. Holds a cosmetology technical diploma. Describes herself as a very hard-working person. Worked 6 days a week in a restaurant. Had gone to seek medical care for regular checkup for Pap (Papanicolao) smear and breast examination.

Kurren, age 40 at time of diagnosis, divorced for more than 14 years. Working mother with two adolescent children. Sought a doctor for a palpable mass on her breast, has a strong family history for BC.

Aleiram, age 40 at time of diagnosis, married, no children. Holds a high school diploma. Active and very hard working woman. Has no children. Goes for regular medical checkups.

Rachy, 39 at the time of diagnosis, married, working mother with three children: one 6 years old, and two 16 and 17 years old. Felt a lump in one of her breasts, which made her seek medical care. Continued working after her chemotherapy treatment.

Ednaly, age 35 at the time of diagnosis. Holds a high school diploma. Another hard-working woman, works in the pharmaceutical industry. Married with two children: ages 6 and 11 when she was diagnosed. Sought medical care as a regular checkup after missing her regular checkup for 5 years.

Anatila, 44 at the age of diagnosis. High school diploma. Married with three children: two adolescents, 14 and 17 years old, and a young man. Working mother who sought routine medical care with no symptoms.

Themes Expressed by Participants

The major categories identified from the data were grouped under the following seven themes: *Lack of knowledge about BC, Fear, Stress, Disturbed body image, Faith, Need for support, and Need for self-disclosure* (see Figure 4.1). The analysis research question—*What is the lived experience and meaning of breast cancer diagnosis and its treatment?*—was addressed, and the participant's words are used here to illustrate the themes that emerged.

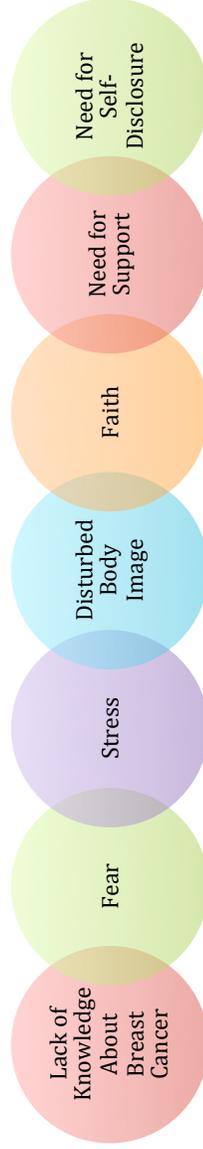


Figure 4.1: Themes that emerged from the interviews about the Puerto Rican women's life experiences with breast cancer.

Lack of Knowledge About Breast Cancer

Lack of knowledge about BC was considered an emerging theme since some participants did not go for medical advice regularly or only when they saw or felt any symptoms. Several respondents reported that they had not performed any regular breast self-examination. In fact, many of them sought medical care only after feeling a mass or lump on their breast, while others found out from their gynecologist when they went for the regular Pap smear and breast examination. Their stories are included in the following statements:

Chelsy: One morning, when I was brushing my teeth, I felt like a little ball in one breast. I thought I had hit myself there with something I couldn't remember, so I didn't pay any attention to it. Therefore, I waited one week for it to disappear, then a second week, and the third week the little lump was still there. Then I began to worry; I told myself this couldn't be just a little something. I didn't tell anyone, so no one could encourage me to seek immediate medical advice.

Other respondents reported that, since self-breast exam was not part of their daily routine, there was little opportunity to find a lump in its beginning stages.

Aleny: I felt pain in one of my breasts, so I told myself, it must be due to some blow or bump I hadn't noticed, maybe a muscle spasm at work. I had this pain for several weeks, even months taking anti-inflammatory over-the-counter medications. But I had no progress in getting better. After 4 months with this discomfort in my breast, I decided to visit my primary care physician.

Astriam: I touched a little bump on one of my breasts. Did not pay much attention to it, because I had a breast reduction 5 years ago and had a source of hematoma on my breast at that time. So I thought it was another hematoma on the other breast. After a few months, my breast began to look smaller, and the mass looked bigger. I began feeling more and more tired all the time."

Ednaly: I am a young person and never expected cancer to hit my life. I had a busy life, no time for breast self-examination or medical checkups. After the pregnancy with my last child, I hadn't visited a doctor. One day, I was watching the news, and there was a young woman talking who had cancer, and she had not

had any checkups after her pregnancy until her child was 5. She was giving advice to young women to seek medical guidance and checkups every year since she was dying of cancer. Weeks later after that news program, she had died. That encouraged me to visit my doctor because my last checkup had been before my pregnancy and my child was then 6 years old.

Aleiram: For the past 3 years prior to my diagnosis, my mammography results were inconclusive. Until this last mammogram, which came right away with a diagnosis.

The study participants had underestimated their risk for developing BC. They thought that, as they were considered young with no family history of cancer, they should not worry. Despite knowing about breast self-examination techniques, they had not considered them important at their age. The lack of awareness about cancer resulted in poor consideration being given to preventive screening measures. Participants visited their physician only when they felt ill or had any symptoms. Preventive medical checkups were not encouraged in their lives.

Fear

The second theme that emerged was *Fear* about what would happen after the diagnosis of cancer or after receiving treatment. As one participant stated, “The word *cancer* scares.” Most participants felt fear at some point in their life related to the cancer diagnosis or receiving the chemotherapy. All the participants except one were mothers, and their biggest fear was to die and leave behind their children or beloved ones.

Kurren: I remember a TV commercial where a girl opened the door and darkness came out through where the girl was, and a voice said “When cancers knock at your door.” I considered that this TV commercial had a strong impact. So I feared cancer from that moment, but never expected to hear that word again in my life...until a few years later...(tears emerge). After the biopsy results, the doctor told me, “Unfortunately it is cancer,” Oh wow! This word is so strong. I felt so much fear. Fear of death, fear of not seeing my kids growing up. Fear of not being there when they would need me most. Fear of going into the operating room and

not knowing what to expect. I was afraid to lose my hair because of the chemotherapy effects. I was so afraid to die, so much fear at that moment.

Aleiram: My biggest fear was not what I went through; my biggest fears are now that I am cancer free. Honestly, I am feeling good, but I am afraid every time I do a laboratory, a mammogram, all kind of scans, or even cancer markers. I am so much afraid to have a metastasis. Every time I feel something, I get so afraid of it. I don't really know what I would do if I am diagnosed again with cancer.

Ednaly: I was so afraid when the doctor said "It is cancer." I felt myself blurred. I felt stupid, as if I didn't understand what he was saying. I knew he was talking because I could hear his voice like so far away from where I was, while my mind was asking so many questions...I was in shock. It was like a horror movie in which I wanted to leave and clear up my mind. I did not react that quickly; it took me time to notice my sister and my husband were crying and asking so many things of the doctor. It was as if I was not there. I had so much fear of not seeing my children again, of losing my hair. Cancer is the worst nightmare you could ever have, and when you realize that is your own reality, that's even worse. I have to say now that I am cancer free, but still, there will always be fear and concern.

Fear about a diagnosis such as cancer is present in every human being. The fear may vary from person to person or even from culture to culture. People may experience fear as the result of an unknown experience or event. The process of a BC is not a new topic; it is, in fact, one of the most discussed subjects in the world. Breast cancer is a health-related issue that increases day by day and continues claiming lives everywhere despite age, sex, race, or religion. These participating women have described their specific fears through their journey of the BC process.

Stress

Stress was reported by some of the participants. Stress, in everyday terms, is considered when a person is experiencing feelings of overload and is struggling to deal with and overcome the demands they experience.

Anatila: I should say that I lived all the cancer process in stress until the day the doctor said I was cancer free. Every appointment, every chemotherapy was a

stressful situation to me. I felt stress to do my laboratories because I wanted to have good results. Oh, God, the day I received the news I was cancer free, it was the best time ever in my entire life. Thank God, it became good news... Nah, nah, nah!...It was the best news ever.

Rachy: Chemotherapy caused me so much stress. Every time I was sitting on that hateful reclined pink chair you could see my legs shaking. The day I saw the red chemo, I cried, just thinking of its effect and what it would do to me or how I was going to feel after it.

Becky: Stress feelings will always be present once you have been diagnosed with cancer. Now, that I am cancer free and have finished treatment, it still worries me every year when laboratories and studies need to be done. It is a stressful situation to wait for the results, hoping everything comes out with good news

All the study participants reported that they had experienced stress at some time during their diagnosis and treatment. Many reported that they continue to experience stress throughout their lives, hopeful that they will not hear the word *cancer* again. Some of the participants reported stress throughout the entire process since the day of the diagnosis. Others experienced stress just from the chemotherapy and its effects on them. In addition, one participant expressed that she felt stress just to sit down on the pink reclined chair for her chemotherapy. Several reported stress on what to expect from now on, from the moment they are cancer free until the end of their lives.

Disturbed Body Image

The subject of *Disturbed body image* is one that showed up for all the women once they had been diagnosed with BC. The scars, the hair loss, and weight gain/loss are several of the concerns of body image disturbance. Feeling unattractive was one of the symptoms reported by every woman.

Chelsy: The most difficult moment is when the hair begins to fall out. It looks dull, unhealthy, and thin. I avoided brushing my hair to delay the loss. However, nothing could delay the hair loss; every day I was losing my hair on my pillows,

on my clothes until I saw small patches of baldness on my head. Another thing that really bothers me is the scar on my breast. I believe I would never be ready to be with a man looking like this. (Tears emerge as she walks to the refrigerator and grabs a bottle of water to clear her throat.)

Aleny: Looking at the mirror, not seeing my hair, my eyebrows, it really bothered me. What really bothered me was when people told me that hair loss doesn't matter. Of course it matters, it does... (tears emerge). I looked in the mirror and tried to recognize myself. I did not look like me, not like the real me; the person in the mirror was not me (tears pool in her eyes). It took me time to learn how to draw my eyebrows. My body is not the same anymore. I was perfectly fine and in good toned shape; now I am fat and need to wear loose clothes or a double tank top under blouses to hide my mastectomy scars.

Anatila: The effects of the chemotherapy were felt in my body pretty quickly. The hair began falling out, and I looked ugly; yes, I felt horrible. I couldn't tolerate a wig. I felt so ugly during my treatment that I did not go out unless it was for my appointment or visiting church with a bandana around my head.

Body image plays a very important role in every woman, including Latinas. The study participants reported body image as an important component and concern in their lives. Breast cancer has a significant impact on women's body image in different ways. Women see their body image as their temple of femininity. The body image of these participants had been affected not only by the loss of hair and eyebrows but also by the increase or loss of weight and the mood changes.

Faith

The confidence of *Faith* generated by religious belief was reported by all participants. They all commented that they had faith in some religious belief as their main force to deal with or overcome their cancer process. The following extracts are examples of faith being the main success in treatment reported by some participants:

Chelsy: At the moment of the diagnosis of breast cancer, I was not visiting any church, but I have always had faith in God. This faith really helped me with all I

experienced through the cancer process. At the present time I visit church often to thank God for giving me health and life.

Aleny: I have always been a Christian, and my faith goes beyond everything in my life. I would not have been able to face cancer without God. I never question God by asking Why me? I thank God it was not any of my sisters because they would not have had the strength and faith I have. In fact, the day I was in the operating room for my mastectomy, I had a dream that two angels were just by my side, one at each side. That meant that God would always be at my side. Every day I open my eyes, I give thanks for another day of life to share with my beloved family.

Aleiram: At the time of diagnosis, I cried. I asked the doctor what happened with stage I or II? Why stage III? (Tears flowing.) I was very mad, even at God. Until I realized that this was an opportunity God was giving me. I started visiting the church, and faith began holding me. Thanks to God, I am now cancer free and I know it was He who carried me when I thought I could not go on any further with the symptoms of chemotherapy. Here I am, now with strength, back in life. I am glad you can use me as an example to let other women know about cancer.

Faith is considered the trust in something or in some major force. Faith in some major force or faith in God is the certainty that you will not be alone along the way. The study participants declared that their faith in God had helped them throughout their BC process. They said that their faith in God was the hope that they would be well and that there was promise for a new tomorrow.

Need for Support

Support is an important and necessary element for all cancer patients. Support from close relatives, partners or spouses, family, friends, and/or a professional therapist is very important for overcoming cancer. All the interviewed women declared their need for support in order to be successful with their treatment and new lifestyle. Participant expressions of this are the following:

Chelsy: I never visited a therapist or support center. This doesn't mean that I never needed it. In fact, I needed it so much. I think that there should be a

therapist or psychologist present at the time of being informed of the diagnosis. I met a woman from my son's college who saw me with a bandana on my head and asked if she could talk to me. I was surprised, but I gave her my phone number and she came over to my house. She had just lived through the experience of breast cancer herself and had noticed I was going through the same process. And she became my best and only friend. She accompanied me to all my medical treatments and spent long hours on the phone giving me so much support. I have to say that without her I would not have made it.

Rachy: My spouse became my main support. He was there for me every moment, every second, and he has never left me for a second since this hateful cancer diagnosis. My family has also been a great support; my mother, sisters, and the people from church have been there for me when I needed them the most. I have been so blessed to have them, that I have no need for a therapist or any support group.

Ednaly: Oh my God, my support... Wow!—definitively my sister. She is so strong, and I have gone through this with her and my husband. However, my sister, who is younger than me, has taken such good care of me as if I were her baby. I never felt alone; and there she was for anything at home, for my kids, and even giving support to my husband. I hope I can pay her back one day and take such good care of her as she has done with me. I feel so secure with her; she is my nurse, my friend, my everything.

Anatila: I not only needed someone to be there with me at the time of the diagnosis, but to accompany me through the whole process. My best friend became my support. I don't know how physicians can just give such a diagnosis and pretend we can handle that. They gave me so much information that I wasn't able to handle. If my friend hadn't been there, I would still be looking for the next step of treatment. I think they should have written down on paper the order of all the things I had to manage. Things like going to the health insurance, oncologist, surgeon, scans, etc.—oh my God! (hands to head). Thank God my friend was there; she asked questions, she wrote down notes because I was not able to.

One of the greatest needs for cancer patients is undoubtedly the need for support. Support is to hold up and help a person in need. Support must come from a special person in their life or from a professional person. Most of the participants found support in a loved family member or a friend. Only one participant said that her support came from someone she had not known, but someone who had gone through the same

process and used her own experience to help as a very best friend. Support is needed for a survivor to continue in life not only at their weak moments but through all the process as well.

Need for Self-Disclosure

The *Disclosure* of suffering the experience of BC is not an easy topic to share with anyone. Facing BC and the entire sequel it brings to her daily life, is the most difficult process any women could go through. Revealing how the survivor feels inside, her fears and her weaknesses, is not a topic easily shared with others. In fact, some survivors had identified the need for disclosure but had actually left that need aside.

Examples are presented as follows:

Astriam: One of the most difficult things was to share how bad I really felt inside. I could not talk about this with any of my kids, my mother, or sisters. I knew that, if I were to tell any of them how I really felt, they were going to suffer more and I didn't want to give them that pain.

Rachy: I have never talked to anyone about how I felt going through this (tears emerge). Excuse me for my tears...(pause), it's very hard remembering how I felt back at that moment, that still hurts. However, talking to someone helps (wiping her tears with a napkin). It feels a relief to take out something old that was hidden in a corner that I didn't want to leave out. It is something that cannot be talked about with anyone. I did not want my family to know what I was living.

Becky: There was definitely a need to talk about all the things I was going through, but not with my spouse or kids. I really needed to speak to someone who would not suffer from all I was going through. I had the need to tell someone all the times I wanted to give up and didn't want to fight. The need to say how afraid I was after surgery or after every chemotherapy, after seeing myself in the mirror... I was suffering in my big silence.

Strong experiences and emotions are not easy to share. Breast cancer survivors expressed the importance of the need for disclosure with someone professional.

Revealing their suffering from the process of BC diagnosis along with its treatment and

effects was one of the most difficult things for them to do. Survivors expressed all the emotions they had gone through that they had not shared before with family members or friends. They all agreed they had not wanted their family members or beloved ones to suffer for all the difficulties they had experienced themselves. In fact, they reported that they had found relief talking to the researcher about all of this.

Summary

The seven themes that emerged from the interviews were the most related and common topics among the participants' lived experience. Sharing their experience through their journey of BC allowed each one of them to reveal their unique emotions. The interviewed participants experienced a diversity of emotions from the moment of the BC diagnosis until the day they were considered cancer free, and even beyond that.

Participants expressed their wide-ranging emotions, especially their concerns, along their journey through the BC diagnosis and what they expected after their treatment is done. These lived experiences from a group of Puerto Rican BC survivors allows others to know a little bit more about this particular group of women. It is important for every woman diagnosed with BC to know that she is not alone, that she is not the only one with such a diagnosis and experiencing such diverse emotions. Knowing that other women have gone through the same experience allows us to give more useful information to new patients about the process they face from the very beginning of their treatment. This approach will help women newly diagnosed with BC to understand and manage in an acceptable way, knowing that all their emotions are normally expected.

CHAPTER 5

DISCUSSION

Breast cancer among Latina women is the most commonly diagnosed form of cancer and the leading cause of cancer death (American Cancer Society, 2018). In our current era of technology, of growth in medical services and innovations in therapies for BC, the effects of a BC diagnosis and treatment remain a major concern for women all over the world. Women must cope with all the effects that overcome the impact of the diagnosis of BC and its treatment. Besides, it is a challenge for every woman to keep up with all her multiple roles and tasks at work, school, and/or at home with family and children in today's society. Interviewing these nine women, taking them back to what had been their lives from the moment of their BC diagnosis, demonstrated their remarkable memory of the difficult turn their lives had taken. Talking about their experiences with me was not easy for them, but they agreed that sharing their deep, troubled memories about their BC had made them feel a profound release.

The interview process led to the opportunity to share their lived experience of the impact of BC and to reveal their experiences and emotions, as they had not been able to do until then. These were the major themes that emerged from their lived experience: lack of knowledge about considering their symptoms related to cancer; fear about what would happen with their lives; stress throughout the treatment process; disturbance of body image from losing their hair and their breast, or their scar; faith in God or a superior force; their need for support from close-related ones; and disclosure of their suffering.

Discussion of Major Themes

Lack of Knowledge About Breast Cancer

Most of the participants conveyed their lack of knowledge about routine checkups for early detection of BC. They revealed that they did not perform self-breast examination regularly. They said that since they did not have any close relatives with BC history, it had never worried them. The women reported that because they were not routinely scheduled for follow-up screening appointments, they ignored screening unless they felt something odd or unusual. Some said that since they were under 40 years old, a mammogram was not a part of their preventive routine checkup covered by their health insurance. A few of the women indicated that they considered they were not in the range for BC risk. This was because they did not have a family history of BC or were under 40 years old, which are the major considerations for preventive mammogram. One participant had done mammograms that were routinely covered by her insurance. Most of the women went to seek medical screening after they felt a palpable mass or a bump, which they never thought was cancer. One participant had associated the mass to previous cosmetic breast surgery, some of them related it to being hit, or a bump, or an inflammatory process, or even a muscle spasm. This is consistent with the literature. Buki et al. (2004) had cited in their study that Puerto Rican women exhibited misinformation about the etiology of the disease, such as believing that bumps to the breast can cause cancer.

Despite all the advances in healthcare, technologies and health promotions, lack of knowledge remains. In 2001, Sanchez-Ayendez et al. stated that the reason for non-compliance in early detection of BC related to mammograms in Puerto Rican women were due to lack of knowledge. Seventeen years later, with the new advances in

technology and access to information, the interviewed women of this study remain similar in their lack of knowledge about preventive screening. The existing literature has discussed issues related to cancer screening among Hispanic men and women in both rural and urban populations, and familiarity with some of these issues can facilitate our understanding of barriers to cancer diagnosis and treatments as well as survivorship challenges (Livaudais et al., 2010). Ashing-Giwa, Padilla, Tejero, & Kim, in 2004, concluded in their study that Asian and Latin women have less knowledge about their bodies and lack awareness about screening benefits and early detection of BC. It seems that the women of this current study underestimated their risk for BC, even though two of them had some health-related knowledge. Knowledge about screening for BC and early detection techniques were identified in the interviewed group. However, they had not taken screening seriously because they had not considered they would be at risk.

Fear

All participants reported fear at some point after the diagnosis of BC, or during their chemotherapy treatment. Participants may have expressed their concern as fear of what to expect from their treatment, or fear to die and to leave their children. Participants had identified the word *cancer* as a very terrifying thing that will lead them to death. One woman brought to mind a TV commercial she had seen years before where a girl opened the door and darkness came out through where the girl was, and a background voice said in Spanish “Cuando el cáncer toca tu puerta”—*When cancer knocks at your door*. She felt that this TV commercial had a strong impact in her, as it was the first time she had heard the word *cancer*. The participant never expected to hear that word applied to her

own body until years later when it did. Suddenly she understood the darkness of that commercial.

Puerto Rican participants in the study of Latinas done by Buki et al. (2004) believed that BC is a fatal and feared dire consequence of being diagnosed. The same study concluded that women anticipated fear and pain from mammography, but the most important fear was of being diagnosed with BC, which could lead to difficulties in doctor-patient relationship, as well as personal and family realms.

The participants in the current study considered cancer to be the worst thing in their lives. All of them expressed having fear at the time of the diagnosis, and even further, at every clinical study and medical appointment from then on. This reflects similarities with previous studies found in the literature. Fear was identified as the most common reaction to cancer diagnosis in the Livaudais et al. (2010) study on cancer survivorship experiences among Latinas. Lopez-Class et al. (2012) stated that many of the Latinas in their studies often viewed cancer as a fatal diagnosis, considering it equal to death. According to this literature, fear of cancer and/or its treatment equals a death sentence as a cultural matter. In a study about lived experiences of breast cancer survivors, Williams and Jeanetta (2015) stated that participants indicated they were “shocked” and “scared” when they were informed of their BC diagnosis. Ashing-Giwa et al. (2004) identified in their study of multi-ethnic survivors that participants expressed a similar fear regarding recurrence, death, pain, and suffering.

Stress

Women diagnosed with BC who have received chemotherapy treatment experience not only a number of adverse symptoms but also many concerns about the

treatment's adverse effects and how to keep up with their daily life issues. Participants in this current study related stress as their biggest concern mostly about the effect of the chemotherapy, hair loss, and body image. Others declared their biggest stress concerns were on the daily treatment and the adverse effects of it. Another expressed her stress concern when undergoing any kind of scan, MRI, laboratory test, and even worse the waiting time until her medical appointment to learn the results. One participant commented that her stress concern continues now that she is cancer free, that all studies from here on cause her a lot of stress, since she doesn't want to hear the word *cancer* again.

Our findings of stress concern are similar with other studies. Livaudais et al. (2010) revealed that participants with an accompanying cancer diagnosis presented their feelings of depression and isolation as a sense of disconnectedness. In another study with Latinas, Buki et al. in 2008 identified the psychological concern of the BC diagnosis as the greatest impact in the acute stage of diagnosis. Bidstrup et al. in 2015 stated that complete response for the distress thermometer, and the Hospital Anxiety and Depression Scale (HADS) were obtained from 76% of the women with breast cancer at a baseline during the first week before primary surgery and remaining for 4 and 8 months later.

Disturbed Body Image

Body image concern is present in every woman, and disturbance of body image in BC survivors is common. Body image concern is due not only to the mastectomy, the scar, and loss of hair, eyebrows, but even the body weight changes brought about by their treatment. The study participants reported disturbed body image due to the effects of the surgery and to the effects of the chemotherapy. Some participants complained of the hair

loss, considering it the biggest physical change that any other person could see. One participant cried just to remember how hard it was to see herself in the mirror without hair. Beyond that, losing her eyebrows made it even worse; she didn't know how to draw them properly, which affected her emotionally. Another participant said she hated her scar so much that she would not let anybody else see it. Every woman is different; thus the impact of BC affects a woman's body image one way or another. Our findings of body image disturbance are consistent with the literature.

Williams and Jeanetta (2015) stated in their study that participants informed them that hair loss was the aspect of the treatment that caused the most disturbance. In the same study, participants considered this as detrimental to their ability to cope and affected their self-esteem negatively. In another study, Buki, Reich, & Lehardy (2016) found that women in the acute stage reported struggling with body image issues due to the effects of their treatment. In the same study, the effects of the treatment caused the women to feel ashamed and embarrassed when undressing in front of their partners. Krigel, Myers, Befort, Krebill, and Klemp found in their 2014 study that participants had reported not only physical changes but also changes to their self as a whole. In the same study, the authors emphasized the obvious physical changes that the women worried about as first signs for others to classify them as "cancer patients."

Faith

All participants in the current study indicated that having faith in some religious or spiritual belief was a central and major power/strength that helped them continue in life with a purpose. Of all nine participants, only one had not been active in religious faith until the diagnosis of BC. The rest of the participants were very active in their spirituality

and religious faith. In fact, it was their faith that gave meaning to their life and enabled them to fight for themselves. As one participant stated, “I would not have been able to face cancer without God.” Some of them now see the cancer as a second chance in life given by God.

The findings of the current study about the importance of spirituality and religiosity are consistent with the literature. Wildes et al. (2009) concluded that Latinas reported higher levels of religiosity and spirituality in the recovering and coping process. Also, Buki et al. (2008) revealed that their participants had reported new attitudes in terms of spirituality/religion as feeling closer to God, which gave new significance to their lives. In another study, some of the women had fully embraced themselves as “warriors” and were “grateful to God to be alive” (Williams & Jeanetta, 2015). African-American and Latina women researched by Coreil, Corvin, Nupp, Dyer, and Noble (2012) identified the influence of faith and spirituality in the recovery process, both as a source of support for the survivor and as a way of emphasizing an optimistic attitude.

Need for Support

Support has always been one of the most important components in BC survivors to continue in life. Support has been identified as having that person who is capable of persuading you to keep standing and continue treatment when you have no hope or strength to continue. This is the person you can count on no matter what, the person who will still be there for you. The most important supportive person for the BC survivor has usually been identified as their spouse or partner, close family member, or closest friend. Most of the study participants reported having someone who had been there for them. In fact, one participant revealed that her support came from someone she hadn't even

known. The stranger had identified her as a cancer patient once she saw her with the turban wrapped around her head. This woman, who had recently completed her own journey with cancer, approached her and offered help. From there on, the woman became more than a supportive friend, but a sister. Some participants reported the need for a supportive person at the moment of being given their diagnosis. A few suggested that someone with a supportive specialty should be present at the moment of the diagnosis. Several reported that, at the time they were given their diagnosis, they had gone into a state of shock and were unable to understand the rest of the information given by their physician.

The literature has consistently and widely demonstrated the importance of support for all cancer survivors. In a study seeking to understand breast cancer survivors (Williams & Jeanetta, 2015), participants informed the researchers that having positive support from groups or individuals not only helped them to accept their condition but to fight against the cancer. In another study, family members emerged as a particularly valuable source of support for long-term survivors (Buki et al., 2008). Participants in the Livaudais et al. (2010) study expressed a desire that community support be established.

Need for Self-Disclosure

Some participants identified disclosure as an important issue in their lives once they had been diagnosed with BC. The need for self-disclosure has not been paid the attention it requires. One participant reported that she had not shared anything related to her cancer with anyone. The participants considered that it was so difficult to share their feelings and that it would bring worries that could hurt their beloved ones. One woman said that she would rather have had someone professional to talk with, not a family

member. Some of the women detailed that having a conversation with their family or beloved one was hard because they had not wanted their loved one to know how difficult the process had been for them, or how many times the survivor had given up, or how much she had cried. One participant had scheduled with a psychotherapist because she felt the need to disclose her angst about the process she was going through. Thus, all nine women agreed that talking in private, such as in these interviews, about the entire BC journey gave them an opportunity to relieve a big pressure that had been forming deep inside. Two of them expressed feeling released by talking to someone who wouldn't be hurt by their lived-experience stories. Some had felt comfortable enough to cry during these interviews without worrying about how their sorrow might have been received by a partner or family member.

Consistent with the literature review, Yoo, Aviv, Levine, Ewing, and Au (2010) had identified in their study that telling a family member about facing cancer was considered the most difficult task for a survivor, while, on the other hand, it can also be a way to strengthen emotional capital. The women of the current study agreed with the Yoo et al. participants. They too had not wanted to share their emotions as roughly lived by themselves for two reasons: They did not want to break the heart of a loved one, and they did not want to be felt sorry for.

Summary

Breast cancer evokes several changes in every women from any ethnicity background. Literature has shown that BC women from all over the world have described some similarities about their emotions and coping process. Puerto Rican women were not an exception. There were elements that are more common than uncommon when

compared with BC women from other ethnicities. The women in this study had shown some similarities in their response to diagnosis and treatment as any other women around the world: lack of knowledge, fear, stress, disturbed body image, faith, need for support, and need for disclosure.

The lack of knowledge in BC survivals for this research began with an underestimation of the early signs and symptoms of the participants. Research demonstrates the lack of knowledge for BC in many different ethnicities. For an example, a study conducted in England by Patel-Kerai, Harcourt, Rumsey, and Naqvi (2015) identified that Gujarati-speaking Indian women's signs and symptoms awareness for BC was limited. In a Latina study performed by Torres et al. (2013), it was found that, in comparison with other racial ethnic populations, Latina women had limited knowledge on breast and cervical cancer screening.

Participants felt fear or stress at some point during the BC diagnosis and treatment process. The feeling of fear was another theme related to the experience of living with BC among Iranian women (Joulaei, Joolaei, Kadivar, & Hajibabaei, 2012).

Disturbed body image is one of the most common concerns from BC diagnosis and treatment effects all over the world. Women from India considered themselves to have lost an important part of their body (Patel-Kerai et. al., 2015). In another study, substantial proportions of young women with BC experienced difficulties with body image and sexual functioning, albeit few women reported serious problems in these areas (Fobiar et al., 2006). Latinas described that the overall body image and difficulties related to sexuality and sexual function was a common theme among their culture after surgical and adjuvant treatment (Martinez-Ramos, Garcia, & Lozano, 2013). Faith was a common

theme with many women. Participants described faith as an important support and that engaging in religious activities helped them (Patel-Kerai, 2015). Latina participant women, in a focus group studied by Lopez-Class et al. (2012), noted the importance of God as a source of strength in dealing with their BC diagnosis.

Need for support and need for self-disclosure are common themes identified. Need for support is identified in many different studies. Lopez-Class (2012) has described that familismo or family support, was identified to be very significant in Latina BC survivors. Williams and Jeanetta (2015) identified that support from groups have helped participants to accept their condition but also to fight against the cancer. In this study, women have reported the need for self-disclosure; their experience about facing cancer could only be shared with someone not related to them. Yoo et al. (2010) had identified that the most difficult task for BC survivors was telling a family member about facing cancer.

Conclusion

Breast cancer continues to be one of the diseases that most affects the lives of women regardless of age, religion, race, or nationality. Participants of this study demonstrated that they have suffered the ravages of the BC disease. This study gave the opportunity to a group of Puerto Rican women to provide their lived experience from the initial impact of BC diagnosis in their lives up to the present recovery phase. Findings of this study suggest that Puerto Rican women, just as any other women, experience similarities through the impact of BC diagnosis. Puerto Rican women continue to underestimate their risk for developing cancer. Culturally, Puerto Rican women visit their physician only if they feel sick or notice a symptom. This population does not consider

preventive medical checkups as necessary. As a result, Puerto Rican women are being diagnosed at a later phase of cancer. Participants had considered themselves too young, healthy enough, and/or without any family history of BC, all of which led them to a BC diagnosis at a later phase of either stage II or III. Like most other women, they have confronted the impact of their diagnosis with fear, stress, and facing the implications of disturbed body image. Most of the participants expressed their concern about having to leave their children, fear of recurrence, and suffering. Disturbed body image was reported as to the effect of hair loss, gain/loss of weight, and/or absence of a breast. These women held onto their faith as their main weapon to fight for hope, remain positive, and overcome their breast cancer. The need for support was identified as special and imperative for all participants. Fortunately, most of the interviewed participants had found a support person who walked the journey of BC with them and did not let them give up. In Puerto Rican culture, support is mainly present through family and close friends. The interviewed women also reported the need for self-disclosure. The difficulties through their journey of BC were never fully shared until their interviews for this study. These women who have struggled with the impact of BC consider that it is important to have someone you trust enough to express to them the darkness of what you have been through.

Rigor and Trustworthiness

To ensure the trustworthiness of data analysis, researchers return to each participant's experiences (Streubert Speziale & Carpenter, 2011). In the current study, the researcher had the opportunity to interview twice each participant about their lived experience, thus ensuring trustworthiness. Triangulation is an approach to research that uses a combination of more than one research strategy in a single investigation (Streubert

Speziale & Carpenter, 2011). The data triangulation approach was used in this current research to describe Puerto Rican women's BC lived experience. This allows a more complete and holistic description of the phenomenon by exploring different points of their personal and unique experience, and verifying one against the others. In this way, the individual perspective and experiences from each participant can be confirmed against other participants. An image can be drawn from the findings to describe their lived experience. A range of 10 years of age for participants under study was used to explore different points of view. Data saturation was reached when no new topics emerged and experiences fitted into the emerged themes.

The results from this phenomenological research study of a nine-participant sample represents only a group of Puerto Rican women and is not transferable to other population representation. The dependability of quality data was reached by the application of phenomenological design within its implication.

Strengths and Limitations

This qualitative study involves representation of a group of northern Puerto Rican women describing their lived experiences. A strength of the study is that The participants had the opportunity to go back in time to the moment of their BC diagnosis. The opportunity to reflect back on what they had been through on their cancer journey brought them to tears. The experience of telling their stories as lived, gave them the opportunity to reflect and to give a rich understanding of their experience. Their expressed experiences contribute to the knowledge of nursing for a more comprehensive care for women with BC in the future. The participants were interested in taking part in the study, wanting to express their experience for the benefit of others in the future.

Having a confidential nurse-researcher interview them led to a more comfortable sharing of their personal experience than would be afforded by family members or loved ones. In fact, the researcher allowed them to relate all their emotions from their deep inside experience through the journey that began with their BC diagnosis.

A limitation considered was having only nine participants.

Implications for Future Research

It is a challenge in this technological era to identify lack of information on preventive measures and techniques for early detection of BC or for disregarding the symptoms. Future research should focus on identifying cultural factors that influence patient healthcare strategies for adherence to preventive measures. Despite all the technology or media information, BC continues to rise among women from all ethnicities. Findings from this current study provide an insight into understanding the need for Puerto Rican women to implement proper preventive care so that a BC diagnosis could be made at an earlier stage. Understanding their lived experience can help develop strategies that will focus on preventive techniques, support, and coping into a new BC lifestyle.

Relevance to Clinical Practice

Results from this study enlighten the need for continuing techniques on preventive measures to detect and manage BC with all its attendant concerns. Despite all the information accessible to our hands, Puerto Rican women remain in late detection for BC. It is important to consider culturally resonant strategies for a better preventive screening. Women, as described in the current study, identified the need to deal, manage, and cope with the devastating process of BC. Nursing and all healthcare professionals

need to encourage and promote the early detection of BC using measures beyond the risk factors. Strategies must be developed for letting Puerto Rican women with BC express their needs and concerns about having the disease in order to cope properly. Telling their story, as in this study, is a therapeutic intervention that should be considered as an aspect of healing in the nurse-patient relationship. Nursing practice, as well as nursing schools, should reinforce the need to identify and promote BC prevention and early detection, management, and supportive assessment considering the unique needs within the culture. It is crucial to promote early screening and checkups for BC as well as any other illness.

Relevance to Education

This research provides relevance to the world of nursing education. Considering the Puerto Rican culture, the focus on educating the target population should begin at an earlier age. Promoting breast self-examination with young girls during their adolescence is a way that they can begin to care. Preventive care is the clue for an earlier diagnosis with better results. Listening to illness stories is a key component of healing.

Summary

The lived experiences revealed in these nine in-depth interviews of Puerto Rican women brought up important issues and concerns emanating from their diagnosis of BC and continuing through their treatment. They brought up the themes of lack of cancer knowledge, fear, stress, disturbed body image, faith, the need for support, and the need for disclosure. This group of women demonstrated that they followed poor screening behavior for BC. This tendency might be particularly acquired from their culture.

Results demonstrated that participants in the present study visited their physicians only when they felt sick. In this particular case, they visited a physician only when they

felt a palpable mass in the breast. This led these women to a BC diagnosis at a later, more difficult stage such as stage II or III, instead of being diagnosed at the very beginning if they had used appropriate screening.

This study gave these women the opportunity to tell their stories about their health process. The experience of telling a nurse will give a therapeutic disclosure. In addition, learning from other similar stories around the world will give women the strength to overcome during the BC process. It is important to gain full knowledge about cultural behavior in order to encourage early BC screening at a younger age. The insight of the BC participants' stories was provided as a way to add the lived experiences of a group of women in how to develop, address, and give proper care to newly diagnosed patients regarding each one of their needs.

APPENDIX A
RECRUITMENT FLYER

“Cuéntame tu historia”

¿Eres mujer puertorriqueña entre 35 a 45 años de edad? ¿Ha sido diagnosticada con cáncer de seno en etapa II o III?

Este estudio es simplemente narrando su experiencia.



- No se identificará ni incluirá nombre de participantes.
- Este estudio toma entre 45 a 90 minutos contando su historia a una enfermera profesional en (3) tres sesiones de entrevistas separadas para su mejor conveniencia.
- Debes ser puertorriqueña para participar.

Este estudio es conducido por Madeline Hernández, Estudiante Doctoral en la Escuela Graduada de Enfermería de UMASS. Si le interesa participar o tiene preguntas acerca del mismo, por favor comuníquese al (787) 361-6476 ó mhern0@nursing.umass.edu

Este estudio ha sido aprobado por University of Massachusetts Institutional Review Board, Estudio # 2017-3774



APPENDIX B

IRB APPROVAL



University of Massachusetts Amherst
108 Research Administration Bldg.
70 Butterfield Terrace
Amherst, MA 01003-9242

**Research Compliance
Human Research Protection Office (HRPO)**
Telephone: (413) 545-3428
FAX: (413) 577-1728

Certification of Human Subjects Approval

Date: May 3, 2017
To: Madeline Hernandez, Nursing
Other Investigator: Genevieve Chandler, Nursing
From: Lynnette Leidy Sievert, Chair, UMASS IRB

Protocol Title: The experiences of living with breast cancer: Puerto Rican women tell their stories
Protocol ID: 2017-3774
Review Type: EXPEDITED - NEW
Paragraph ID: 6.7
Approval Date: 05/02/2017
Expiration Date: 05/01/2018
OGCA #:

This study has been reviewed and approved by the University of Massachusetts Amherst IRB, Federal Wide Assurance # 00003909. Approval is granted with the understanding that investigator(s) are responsible for:

Modifications - All changes to the study (e.g. protocol, recruitment materials, consent form, additional key personnel), must be submitted for approval in e-protocol before instituting the changes. New personnel must have completed CITI training.

Consent forms - A copy of the approved, validated, consent form (with the IRB stamp) must be used to consent each subject. Investigators must retain copies of signed consent documents for six (6) years after close of the grant, or three (3) years if unfunded.

Adverse Event Reporting - Adverse events occurring in the course of the protocol must be reported in e-protocol as soon as possible, but no later than five (5) working days.

Continuing Review - Studies that received Full Board or Expedited approval must be reviewed three weeks prior to expiration, or six weeks for Full Board. Renewal Reports are submitted through e-protocol.

Completion Reports - Notify the IRB when your study is complete by submitting a Final Report Form in e-protocol.

Consent form (when applicable) will be stamped and sent in a separate e-mail. Use only IRB approved copies of the consent forms, questionnaires, letters, advertisements etc. in your research.

Please contact the Human Research Protection Office if you have any further questions. Best wishes for a successful project.

APPENDIX C

INFORMED CONSENT

**Formulario de Consentimiento para Participación de Estudio de Investigación
University of Massachusetts Amherst
College of Nursing**

Investigador(es):	<i>Madeline Hernandez RN, MSN, PhD(c), Principal Investigator and Genevieve Chandler Ph.D., Associate Professor and Faculty Sponsor</i>
Título del Estudio:	<i>La experiencia de vivir con cáncer de seno: mujeres puertorriqueñas cuentan su historia</i>
Agencia Auspiciadora:	<i>Ninguna</i>

1. ¿QUE ES ESTE FORMULARIO DE CONSENTIMIENTO?

Este formulario es llamado Formulario de Consentimiento. Este le ofrece información sobre el estudio para que usted pueda tomar una decisión informada en la participación de esta investigación. Este consentimiento le ofrece información necesaria para conocer por qué se hace el estudio y como usted ha sido invitada a participar. También, describe lo que necesita conocer para participar así como riesgos, inconveniencias e incomodidades si alguna, durante la participación. Le recomendamos que tome su tiempo para pensar y leer y hacer preguntas en este momento o cualquier otro momento. Si decide participar, debe firmar este formulario y se le entregará copia del mismo para sus archivos.

2. ¿QUIEN ES ELEGIBLE PARA PARTICIPAR?

Los participantes elegibles deben ser mujeres puertorriqueñas entre 35 y 45 años de edad, tener diagnóstico de cáncer de seno etapa II o III, leer español y estar capacitada y dispuesta para firmar el consentimiento voluntario de participación del estudio.

3. ¿CUAL ES EL PROPOSITO DEL ESTUDIO?

El propósito de este estudio de investigación es describir la experiencia vivida en un grupo de mujeres puertorriqueñas con cáncer de seno.

4. ¿DONDE SE LLEVARA A CABO EL ESTUDIO Y CUANTO SERA SU DURACION?

El estudio será conducido en tres sesiones de entrevista profunda. Los datos se recolectaran en un período de seis (6) meses o en menos de un año. Cada participante

tomará parte en tres entrevistas separadas donde contará su historia o experiencia. El proceso de cada entrevista puede durar entre 30 a 90 minutos.

5. ¿QUE DEBO HACER?

Si usted está de acuerdo en participar en el estudio, se le hará una serie de preguntas como parte de la entrevista verbal, la misma será grabada si usted autoriza. Sus respuestas serán para describir la experiencia vivida y el significado de vivir con cáncer de seno como mujer puertorriqueña. Usted puede contestar u obviar alguna pregunta que la haga sentir incomoda. El investigador mantendrá la grabación de la entrevista en un sistema protegido por sistemas de contraseña donde solamente ella tendrá el acceso. Usted está al tanto de la audio-grabación por lo que tiene la oportunidad de autorizar o no la misma. Como investigador, puedo compartir parte de la entrevista y audio con mi profesor de disertación, Dr. Genevieve Chandler, pero con nadie más. Una vez completado el estudio de investigación, toda la información obtenida, archivos digitales y audios serán destruidos.

6. ¿CUALES SON MIS BENEFICIOES POR PARTICIPAR EN ESTE ESTUDIO?

Usted no se beneficiará directamente de este estudio de investigación; sin embargo, esperamos que su participación ayude a otras mujeres que atraviesan el proceso del cáncer de seno para que se beneficien a partir de su experiencia.

7. ¿CUALES SON LOS RIESGOS POR PARTICIPAR EN ESTE ESTUDO?

Los posibles riesgos o incomodidad por su participación puede incluir inconvenientes relacionados al tiempo que tome para completar el estudio. Riesgo mínimo puede ser no mayor de alguna incomodidad por compartir su experiencia. Sin embargo, usted recibirá una lista de información y centros de ayuda para pacientes con cáncer de seno.

8. ¿COMO MI INFORMACION SERA PROTEGIDA?

Los siguientes procedimientos se utilizaran para proteger la confidencialidad de sus respuestas. Para proteger su confidencialidad, el investigador no colocará su nombre en ninguna forma de entrevista. Se dará un número únicamente y este será identificado en las formas o si el participante prefiere se colocará un nombre falso. Si el estudio se pública o se utiliza para propósitos educativos, no llevará nombres. El investigador mantendrá todos los cuestionarios, incluyendo códigos que se relacionen al caso en un gabinete con cerradura. Las audio-grabaciones serán también identificada con códigos. La llave maestra que vincula información de los nombres y códigos estará en áreas seguras, separadas y con cerraduras. Solamente, los miembros del comité podrán tener acceso de los datos. Al concluir el estudio, el investigador publicará sus hallazgos. La información presentada será en formato de resumen y no se identificará ninguna información con el participante. Los datos estarán

disponibles para uso del investigador y análisis de datos. Todas las formas, documentos, notas, grabaciones serán destruidas tres años luego de cerrar el estudio. Todos los archivos electrónicos con información identificable estarán protegidos por código y al finalizar el mismo serán destruidos.

9. ¿QUE OCURRE SI TENGO PREGUNTAS?

Tome el tiempo que necesite para tomar su decisión. Estaremos contentos de contestar cualquier pregunta que tenga sobre el estudio. Si tiene preguntas futuras sobre el estudio o si tiene problemas relacionados a la investigación puede comunicarse con los investigadores, Dr. Genevieve Chandler al (413) 545-5094, gec@nursing.umass.edu o Madeline Hernández al 787-361-6476 or mhern0@nursing.umass.edu. Si tiene alguna pregunta relacionada a sus derechos como participante de estudio, puede comunicarse a la University of Massachusetts Amherst Human Research Protection Office (HRPO) al (413) 545-3428 o humansubjects@ora.umass.edu.

10. ¿PUEDO DETENERME DE PARTICIPAR EN EL ESTUDIO?

Usted no tiene que participar en el estudio si no desea. Si usted acepta voluntariamente participar en el estudio, pero luego cambia de parecer, puede detenerse de participar en cualquier momento que desee. Usted también decide si acepta que se grabe audio o no. No hay ninguna penalidad o consecuencia de ninguna índole si decide no participar.

11. ¿QUE OCURRE SI SALGO LESIONADA?

No existe daño o lesiones aparente por su participación en este estudio. La Universidad de Massachusetts no provee un programa de compensación de sujetos por daños o lesiones relacionadas a sujetos humanos de investigación, pero el personal del estudio le asistirá en el proceso de recursos para recibir tratamiento si fuese necesario.

12. DECLARACION DE CONSENTIMIENTO VOLUNTARIO

Al firmar este documento estoy de acuerdo en participar voluntariamente en este estudio. He tenido la oportunidad de leer cuidadosamente el consentimiento y me fue explicado en el lenguaje que uso y entiendo. He tenido la oportunidad para hacer preguntas y recibí respuestas satisfactorias.

Unidad del Oeste	Ponce, PR 00717		
Unidad del Sur	Hogar Niños Que Quieren Sonreír Calle Cabo Alverio #577, Hato Rey, PR 00918		(787) 725-0233
Puerto Rico Hope Lodge			
Ayala Sanchez, Angel	Manati	Psychologic Services	(787) 375-7608
Puerto Rico Hope Lodge	Hato Rey	Albergue	(787)764-2294
Auxilio Cancer Center	Hato Rey	Psychology and Oncology Services	(787) 758-2000
Susan G. Komen	Bayamon Vega Alta	Preventive Services, Counseling	(787) 774-3344
Casa Jose Foundation	Caguas	Counseling Support	(787) 370-8893
Cancer Comprehensive Center	Rio Piedras	All types of services	(787)763-4149

APPENDIX D

DEMOGRAPHIC SURVEY

CUESTIONARIO DE DATOS DEMOGRAFICOS

University of Massachusetts Amherst

School of Nursing

Investigador(es): *Madeline Hernandez RN, MSN, PhD(c), Investigador Principal y Genevieve Chandler Ph.D., Catedrática Asociada y Facultad Patrocinadora*

Título de Estudio: *La experiencia de vivir con cáncer de seno: la mujer puertorriqueña nos narra su historia*

Agencia Patrocinadora: *Ninguna*

Cuestionario Demográfico.

1. How old are you?

35-37

38-40

41-43

44-45

2. Estado Marital

Soltera

Casada

Divorciada

Viuda

3. Nivel de Educación

Diploma Escuela Superior

Curso Técnico

Grado Asociado

Grado Bachillerato

Grado Maestría

4. Pueblo de Residencia:

5. ¿Cuántos hijos tiene por grupo de edad?

Menos de 2 años

2 a 4 años

5 a 8 años

8 a 11 años

12 a 15 años

16 a 18 años

19 a 22 años

23 a 26 años

27 o más

6. Empleo

Empleo Propio

Institución Pública

Institución Privada

Otro _____

4. Ingresos en el Hogar
médica?

- Menos de \$20,000 anual
- \$20,000 to \$34,999
etc)
- \$35,000 to \$49,999
- \$50,000 to \$69,999
- \$70,000 to \$99,000
- \$100 o más

5. Tipo de Empleo:

- Tiempo Completo
- Tiempo Parcial
- No trabajo

6. Plan Médico

- Privado
- HMO Reforma Salud
- No Plan Médico

7. Religión: _____

8. ¿Cuándo fue el primer diagnóstico de cáncer de seno?

- Seis meses atrás
- 1 año atrás
- Más de un año

12. ¿Que la hizo buscar ayuda

- Chequeo Rutinario
- Síntomas (bulto, dolor,
etc)
- Otro: _____

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