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Maryellen D. Brisbois

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Chemotherapy-Induced Premature Menopause Among  
Latina Women With Breast Cancer:  
An Interpretive Description

A dissertation presented

by

Maryellen D. Brisbois

Submitted to the

University of Massachusetts Worcester

Graduate School of Nursing

in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Nursing

Worcester, Massachusetts

2013

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University of Massachusetts Worcester

Graduate School of Nursing

Chemotherapy-induced premature menopause among Latinas with breast cancer:  
An Interpretive Description

A Dissertation Presented

By

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August 14, 2013

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### **Dedication**

This dissertation study is dedicated to the courageous Latina women who shared their stories and allowed me to better understand their breast cancer experience. I am humbled by their contributions and will carry their voices and strength with me always.

## Acknowledgements

This dissertation would not have been completed without the support and encouragement of many remarkable people. I owe Dr. Jean Boucher, my dissertation committee chair, gratitude for her unwavering expertise, support, and guidance. Dr. Carol Bova, for challenging me to find the right path toward a meaningful dissertation topic; and Dr. M. Tish Knobf, for thoughtful feedback at every turn, and original work with chemotherapy-induced premature menopause in women with breast cancer.

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ABSTRACT

CHEMOTHERAPY-INDUCED PREMATURE MENOPAUSE AMONG  
LATINA WOMEN WITH BREAST CANCER: AN INTERPRETIVE DESCRIPTION

2013

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The description and interpretation of Latinas' experience with chemotherapy-induced premature menopause from breast cancer treatment were explored in this study, which utilized an interpretive descriptive method from a feminist lens, and Knobf's (1998, 2002) "*Carrying on*" theory. The specific aims of the study and the interview questions were guided by the state of the science literature. Overall, the impact of physiological effects, psychosocial effects, barriers, influencing factors that made their experience easier or harder, and how participants adjusted to a cancer diagnosis, treatment course, and menopause transition were described as bigger than the menopause experience alone. Participants also described a period of uncertainty or "ever-changing landscape" that began at the time of diagnosis and continued through survivorship. The impact of information, access to healthcare, acculturation levels, support, and a sense of control were elucidated as important factors in "working through" the experience. A

range of collateral data sources were employed. Study limitations and future implications for practice, research, and health policy were demarcated.

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## Chapter I

### State of the Science

#### Introduction

Breast cancer is the most commonly diagnosed cancer, and leading cause of cancer death among Latinas in the United States (U.S.). Approximately 17,100 Latina women were diagnosed with breast cancer in 2012; with 2400 deaths resulting (American Cancer Society [ACS], Surveillance Research, 2012). Approximately 33% of new cases of breast cancer occurred in women aged 35–54 (ACS, 2009–2010; National Cancer Institute [NCI], 2007), with approximately 25% in premenopausal women (ACS, 2009–2010; Jemal, et al., 2007; Jemal, Siegel, Xu, & Ward, 2010). There are nearly 2.8 million breast cancer survivors in the U.S. today (Howlader et al., 2013).

A diagnosis of breast cancer for a Latina woman can be particularly daunting as it is typically associated with a more aggressive disease pattern and less favorable prognosis when compared to women of other ethnic backgrounds (NCI, 2007).

Additionally, Latinas diagnosed with cancer have faced widespread barriers to accessing healthcare (American Cancer Society [ACS], 2013), receiving standardized treatment regimes, and treatment options (Hawley, Fagerlin, Janz, & Katz, 2008; Molina, Barton, & Loprinzi, 2005), inadequate information related to diagnosis, treatment, and survivorship (Fu et al., 2009; Im, Lee, Chee, Dormire, & Brown, 2010; Villarruel, Harlow, & Sowers, 2002), and lower satisfaction with care (Thind, Hoq, Diamant, & Maly, 2010).

Socioeconomic status (SES) is a critical factor affecting health and longevity (ACS, 2013). In the U.S., Latinas attain lower levels of education, are more likely to live in poverty, and less likely to have health insurance (ACS, 2013). Cancer disparities in Latinas are influenced by cultural factors, including language, beliefs, values, and

traditions, which affect underlying risk factors, health behaviors, beliefs about illness, and accessing medical care. Other factors, including environment, genetics, health status, and psychosocial factors, influence the cancer burden in Latino populations (ACS, 2013). Latinas with low acculturation and those with English as a second language reported the greatest unmet need for information and care support, representing a highly vulnerable subgroup (Hamilton et al., 2009; Janz et al., 2008).

For women with early stage breast cancer, neo-adjuvant or adjuvant chemotherapy is standard treatment, reducing the risk of both recurrence and mortality in women (Gradishar, 2003; Kelly & Hortobagyi, 2010). However, the emergence of chemotherapy is associated with short- and long-term physiological and psychosocial iatrogenic effects whose impact on recovery following treatment is beginning to emerge (Helgeson, Snyder, & Seltman, 2004). A common toxicity of chemotherapy, in pre- and perimenopausal women, is ovarian damage which may result in reversible or irreversible amenorrhea or chemotherapy-induced premature menopause (CIPM; Bines, Oleske, & Cobleigh, 1996). Despite the survival benefits of chemotherapy treatment, many premenopausal women live with long-term adverse effects of CIPM (Absalom et al., 2008; Molina et al., 2005).

In addition to chemotherapy, standard treatment typically involves breast-conserving surgery or mastectomy (with or without reconstruction), depending on tumor size, presence of metastatic disease, and patient preference (ACS, 2013). Treatment may also involve radiation therapy, hormone therapy (e.g., selective estrogen response modifiers, aromatase inhibitors, ovarian ablation), and/or targeted therapy (ACS, 2013).

Latinas are part of the youngest, largest, and fastest-growing minority population in the U.S. (U.S. Census, 2010a, 2010b), and they face significant challenges following a breast cancer diagnosis. Historically, it has been believed that all women going through the transition of menopause experience the same symptoms regardless of ethnicity (Im, Liu, Dormire, & Chee, 2008), with most research findings regarding menopause in non-Latina Whites (NLW; Bromberger et al., 2001). More recently, there has been a growing challenge to the current belief that menopausal symptoms are universal among women regardless of ethnicity and culture. The experience for Latinas has rarely been studied in the context of menopause (Bairan, Leval, & Smith, 2001; Villarruel et al., 2002): No studies were found regarding the Latina experience of breast cancer and CIPM, despite the potential negative influence on the quality of life (QOL) reported in white women.

### **Purpose and Aims**

Young women, who experience CIPM from breast cancer treatment, reported distress related to the early onset and abruptness of menopause with loss of fertility and menstrual function (Avis, Crawford, & Manuel, 2004). Psychosocial responses reported in an overview of the current literature are related, especially in women with young and adolescent children, to developmental stage in life, competing midlife demands, and coping difficulties in their partner (Knobf, 2007). There are no known studies that describe CIPM in Latina women with breast cancer.

Therefore, the purpose of this study was to describe the experience of chemotherapy-induced premature menopause among Latinas with breast cancer. The specific aims of the study were the following: (a) Describe the experience of Latinas with chemotherapy-induced premature menopause from breast cancer treatment, (b) Explore

how Latinas assimilate the experience of chemotherapy-induced premature menopause into their breast cancer experience, and (c) Compare and contrast findings to Knobf's (1998; 2002) "*Carrying on*" grounded theory (GT).

## **Background and Significance**

### **Neo-Adjuvant and Adjuvant Chemotherapy Treatment**

Neo-adjuvant chemotherapy (NC) is chemotherapy given before surgery and is characteristically the same chemotherapeutic agent used for adjuvant therapy (Gnant, Harbeck, & Thomssen, 2011; Greenberg, Stopeck, & Rugo, 2011). The major benefit of NC is that it can reduce the size of large tumors that can be removed by breast-conserving surgery instead of mastectomy (Kennedy, Gao, & Margenthaler, 2010). Adjuvant chemotherapy (AC) is given to patients following resection of a primary tumor (Greenberg et al., 2011). Adjuvant chemotherapy after breast-conserving surgery or mastectomy reduces the risk of breast cancer recurrence (Kennedy et al., 2010; Tanioka et al., 2010). In terms of survival, there is no difference between giving chemotherapy before or after surgery (Rastogi et al., 2008).

Chemotherapy is generally recommended for women with node-positive breast cancer (e.g., estrogen receptor [ER] and progesterone receptor [PR] positive status) and for women with node-negative disease with high-risk features, including (a) large tumor size, (b) premenopausal status, (c) ER and PR negative disease, and (d) HER2/neu positive disease (Gnant et al., 2011; Goldhirsch, Glick, Gelber, Coates, & Senn, 2001). Although chemotherapy is effective in both pre- and postmenopausal women (Green & Hortobagyi, 2002), the benefit is greatest in younger premenopausal women (Gradishar, 2003).

Anthracycline and taxane-based regimens are the most widely used chemotherapeutic standard across the globe (Gnant et al., 2011) and incorporated into the care of women with operable breast cancer (Green & Hortobagyi, 2002). These chemotherapy regimens improved the rate of disease-free survival and overall survival rates (Gnant et al., 2011; Gradishar, 2003).

There are several prognostic features evaluated prior to initiation of chemotherapy in this population that include (a) age at time of diagnosis, (b) histological grade of tumor, (c) nodal status, (d) number of positive lymph nodes, (e) tumor size, (f) ER and PR status, (g) presence of HER-2/neu positive disease, and (h) menstrual history (Abu-Hamar, Barakat, Elgantiry, & Nasef, 2010; Carlson et al., 2006). The decision to initiate chemotherapy is based on potential benefits and inherent risks associated with treatment (Green & Hortobagyi, 2002).

Endocrine therapies such as Tamoxifen® and aromatase inhibitors (AIs) are prescribed for women who are at higher risk for recurrence, or to prevent recurrence in the contralateral breast (Pinkerton, Stovall, & Kightlinger, 2009; Whalen & Pritchard, 2006). Over the past five decades, randomized trials of chemotherapy for early stage breast cancer have resulted in significant advances in treatment and improvements in morbidity and overall survival (Early Breast Cancer Trialists' Collaborative Group [EBCTCG], 2005; Green & Hortobagyi, 2002). This rapid advancement and varied combinations of chemotherapeutic agents over the last several years (Carlson et al., 2006) have resulted in difficulties in obtaining sufficient data about long-term side effects (Perez-Fidalgo et al., 2010) and difficulty in predicting the degree of ovarian damage from a specific chemotherapy regimen (Partridge, Burstein, & Winer, 2001).

Recent data have suggested that the major concerns of women receiving chemotherapy are premature menopause and infertility (Partridge et al., 2007). These data have become critical as the trend over the last 30 years has been for women to delay childbearing (Perez-Fidalgo et al, 2010). Chemotherapy and endocrine therapies could cause a decline in the QOL in all women for as long as 5–10 years after diagnosis (Avis, Crawford, & Manuel, 2005; Knobf, 2001).

### **Breast Cancer and Latinas**

Breast cancer is the leading cause of cancer death in Latina women and second in cancer deaths in all women in the U.S. (ACS, 2009–11). An estimated 17,100 Latina women were diagnosed with breast cancer in the U.S. in 2012, with 2400 deaths resulting (ACS, Surveillance Research, 2012). Incidence rates of breast cancer in Latinas in the U.S. from 2002–2006 were 90.2/100,000 versus 123.5/100,000 in NLW (Jemal et al., 2010). Mortality rates for Latinas versus NLW are 15.5/100,000 and 23.9/100,000, respectively (Jemal et al., 2010).

Latinas with breast cancer routinely have more negative prognostic factors at the time of diagnosis. These factors include (a) greater tumor size (19 mm versus 15 mm), (b) higher grade lesions, (c) higher proportion of BRCA gene mutations, which increase risk of breast and ovarian cancers (John et al., 2007), (d) greater number of positive lymph nodes, and (e) higher incidence of hormone-receptor negative and triple-negative breast cancers (Hill et al., 2010; Martinez et al., 2007; Patel, Colon-Otero, Bueno Hume, Copland, & Perez, 2010; Voelker, 2009). As a result of these factors, breast cancer in Latina women is complicated to treat (NCI, 2007).

From 2002–2006, 55% of breast cancers among Latinas were diagnosed at the local stage, compared to 63% of cases among NLW (ACS, 2009–11). The age-adjusted 5-year relative breast cancer survival rates from 1992–2000 in Latina women were 83% (95% CI; [1.22]) versus 87.5% (95% CI; [1.0]) in NLW, which suggested the risk of mortality was significantly greater for Latinas compared to NLW (Jemal et al., 2004). Although Latinas have lower incidence and mortality rates of breast cancer than NLW, they are more likely to be diagnosed at an earlier age and more advanced stage of the disease (NCI, 2007).

Access to timely treatment may also be a contributing factor in differences in survival among ethnic and racial minority breast cancer patients (Fedewa et al., 2011). Clinical trials demonstrate the greatest benefit of chemotherapy when administered within 7 to 8 weeks (e.g., 49–56 days) following definitive surgery (Fedewa, Ward, Stewart, & Edge, 2010). Fedewa et al. (2010) also found that the average time for all breast cancer patients to receive adjuvant chemotherapy was 41.46 days ( $\pm$  24.46 days). A study from the National Cancer Database ( $N = 107,587$ ) reported that Latinas had a higher risk of 60-day delay [RR, 1.31; 95% CI, 1.23 to 1.39] and 90-day delay [RR, 1.41; 95% CI, 1.26 to 1.59] in receiving adjuvant chemotherapy (Fedewa et al., 2010).

Ashing-Giwa & Lim (2010) examined emotional outcomes among a multiethnic cohort of breast cancer survivors ( $N = 703$ ) using the Functional Assessment of Cancer Therapy-General (FACT-G) and Short Form (36) Health Survey (SF-36). Results included less favorable emotional outcomes in Latin American participants ( $n = 183$ , 48%) when compared with European Americans ( $n = 179$ , 42%), AAW ( $n = 135$ , 34%), and Asian Americans ( $n = 206$ , 52%). Other indicators of less favorable outcomes

included lower income (e.g., < \$25,000 per year) 50%, lower level of education (e.g., high school or less) 40–48%, lack of English proficiency (50%), and younger survivors (Ashing-Giwa & Lim, 2010).

A systematic review of the breast cancer QOL literature was conducted among 22 studies that provided a comparison of mental, physical, social, or sexual QOL between Latinas and other racial/ethnic groups (Yanez, Thompson, & Stanton, 2011). Those reviewed included two qualitative studies, two longitudinal quantitative studies, and 18 cross-sectional quantitative studies. The range of sample sizes for Latinas in the quantitative studies was large ( $n = 16–492$ ). Results showed that Latinas reported lower income, being younger at time of diagnosis, and a likelihood of being diagnosed at a later stage than NLW (Yanez et al., 2011). In addition, Latinas were more likely to report poor mental, physical, and social QOL when compared to NLW (Yanez et al. 2011).

### **Natural Menopause—“*el cambio de vida*”**

The World Health Organization (WHO; 1996) has defined menopause as the permanent cessation of menstruation resulting from the loss of ovarian follicular activity. Menopause is clinically diagnosed when a previously menstruating woman with an intact uterus is amenorrheic for at least 12 months (Bordeleau, Pritchard, Goodwin, & Loprinzi, 2007; Lemcke, Pattison, Marshall, & Cowley, 2004), has vasomotor symptoms (VMS) and an elevated follicle-stimulating hormone (FSH) level (Lemcke et al., 2004). Menopause occurs as ovarian follicle activity stops and can occur naturally, or as the result of a surgical event or chemotherapy. The onset of menopause marks the end of fertility and generally occurs naturally between the ages of 45 and 55, with a mean age of 51 (North American Menopause Society [NAMS], 2004).

Latinas have viewed menopause or “*el cambio de vida*” (the change of life) as a natural phase, and describe a lack of basic knowledge about its course and ways to manage symptoms (Im et al., 2010; Villarruel et al., 2002). A woman’s experience during menopause is affected by culture, role changes, and societal attitudes toward menopause, health beliefs, physical and emotional health, and attitude toward menopause (Poniatowski, Grimm, & Cohen., 2001).

Im et al. (2009) identified four themes when exploring the menopausal experience of Latinas in the U.S. These themes included *el cambio de vida*, being silent, trying to be optimistic, and getting support (Im et al., 2009). Menopause is not openly discussed in Latina families because it is a private issue (Im et al., 2009). Latinas rarely share their menopausal symptom experience with their families, but they describe strong family support during the transition, and identify women going through menopause as needing more rest and reduced stress (Im et al., 2009).

Commonalities and differences of the menopausal symptom experience among ethnic minorities ( $N = 90$ ) from four major ethnic groups in the United States: NLW ( $n = 23$ ), Latinas ( $n = 27$ ), African-American women (AAW;  $n = 27$ ), and Asian women ( $n = 13$ ) were explored (Im et al., 2010). The themes common across ethnic groups were (a) just a part of life, (b) trying to be optimistic, (c) getting support, and (d) more information needed. Ethnic minorities may not openly discuss their menopausal symptom experience or report symptoms because of cultural beliefs and attitudes toward menopause (Im et al., 2010). This “minimizing theme among ethnic minority women might come from their unique cultural attitudes and values related to being women in their patriarchal culture and cultural stoicism” (Im et al., 2010, p. 32). Concern exists among healthcare providers

(HCPs) that women who disregard and remain silent about symptoms may be overlooking more serious disease processes (Im et al., 2009). Culture may influence beliefs related to the menopause experience, and symptoms may be perceived, evaluated, and acted upon within a system of culturally determined views (Im et al., 2008).

The relationship between psychosocial distress and natural menopause across ethnic groups was described by Bromberger et al. (2001). Results ( $N = 10,374$ ) showed that compared to NLW ( $n = 5109$ ) experiencing natural menopause, Latinas ( $n = 532$ ) reported the highest rates of distress and financial strain versus the total sample. Latinas also reported the poorest health (5.3%), least amount of support (16.6%), and less education (62.7%) when compared to the total sample (2.7%, 6.1%, and 35.8%, respectively; Bromberger et al., 2001).

Villarruel et al. (2002) conducted focus groups with Latinas ( $N = 18$ ), aged 35–60, who described the experience of natural menopause. Themes included primacy of health, importance of harmony, and balance. They also expressed that *el cambio de vida* was something one had to go through; that it represented a time of reorientation and restructure.

### **Chemotherapy-Induced Premature Menopause (CIPM)**

Natural menopause is characterized by estrogen deficiency that occurs over several years and causes symptoms or adverse health effects that vary according to the individual. CIPM causes estrogen deficiency more abruptly (Shapiro & Reicht, 2001); it causes physiological, sexual, and psychosocial symptoms, and long-term adverse health effects (e.g., increased cardiovascular risk and osteoporosis) in younger women. This

abrupt entry to menopause allows little time for adjustment and can be physically and psychologically challenging for women (Bachman, 1994).

CIPM is defined as the occurrence of amenorrhea after chemotherapy (Sukumvanich et al., 2010) with incidence rates from 21–100% (Bines et al., 1996; Minton & Munster, 2002). This variability in incidence reflects differences in the definition of amenorrhea, duration of follow-up, and woman's characteristics and treatment type (Perez-Fidalgo et al., 2010). CIPM is more prevalent in women >35 years of age (Amir, Freedman, Allen, Colgan, & Clemons, 2010).

In women younger than 40 years old, the onset of CIPM ranges from 6–16 months; for women  $\geq 40$ , the range is 2–4 months following initiation of adjuvant chemotherapy (Shapiro & Reicht, 2001). In clinical practice, HCPs use a variety of clinical signs to diagnose CIPM. These include age, menstrual history, presence of menopausal symptoms, and probability of ovarian damage from received chemotherapeutic agents (Amir et al., 2010). Examination of these alone may not be accurate, as women describe spontaneous conception following amenorrhea secondary to CIPM (Vital-Reyes, Tellez-Velasco, Chhieng, Grizzle, & Reyes-Fuentes, 2004). CIPM is associated with poorer QOL, decreased sexual function, menopausal symptom distress, psychological distress, infertility, and uncertainty about the late adverse health effects of CIPM (Knobf, 2006a). One study estimates that for each month of received chemotherapy treatment, 1.5 years of reproductive life is lost (Gerber, Dieterich, Muller, & Reimer, 2008).

Mar Fan et al. (2010) compared a sample of women ( $N = 41$ ) with breast cancer who experienced menopause resulting from chemotherapy with 57 healthy women who

experienced natural menopause. Both groups were evaluated at baseline and at one year to measure endocrine symptoms and QOL. There was a significant difference in scores of endocrine symptoms using the Functional Assessment of Cancer Therapy-Endocrine Symptoms (FACT-ES) scale at first ( $p = .05$ ) and second ( $p = .04$ ) time points. Women with CIPM reported more severe hot flashes (51% versus 19%;  $p = .003$ ) and fatigue ( $p = .04$ ) at the first time point than controls experiencing natural menopause; with no difference at the second time point (Houédé-Tchen et al., 2005; Mar Fan et al., 2010).

Molina et al. (2005) define CIPM as permanent amenorrhea lasting for several months (e.g., >12 months) following chemotherapy or endocrine therapy, a follicle-stimulating hormone (FSH) level of  $\geq 30$  MIU/ml, and negative pregnancy test. This definition can be misleading in women receiving endocrine therapy (Smith et al., 2006), since the return of menstruation tends to be unpredictable in this population (Amir et al., 2010). One study of women receiving AIs following chemotherapy reported that 27% of participants regained ovarian function at a median of 29 months (e.g., range 12–59 months; Lee, Gray, Sook Han, & Plosker, 2010).

Occurrence of CIPM is dependent on many factors including (a) age at breast cancer diagnosis (Meirow & Nugent, 2001; Poniatowski et al., 2001; Tham et al., 2007); (b) type of cytotoxic regimen (Meirow & Nugent, 2001; Minton & Munster, 2002; Perez-Fidalgo et al., 2010); and (c) cumulative dose of chemotherapy used (Goodwin, Ennis, Pritchard, Trudeau, & Hood, 1999; Perez-Fidalgo et al., 2010; Walshe, Denduluri, & Swain, 2006).

CIPM may be permanent or temporary; and, if permanent, women spend nearly half of their life in a menopausal state (Poniatowski et al., 2001); compared to one third

of women who go through natural menopause (Ganz et al., 2004). The length of amenorrheic episode in a breast cancer patient varies, from months to years between studies (Bines et al., 1996). Women who experience temporary menopause have an increased risk of premature menopause at an earlier age than those who received a reduced dose of chemotherapy or no chemotherapy (Partridge et al., 2007). Partridge et al. further found that temporary cessation of menses appears to be a marker for earlier onset of menopause.

Five-year survival rates for women with breast cancer now exceed 80% (ACS, 2009–2010) resulting in a substantial number of breast cancer survivors living with CIPM (Chen & Manson, 2006; Poniowski et al., 2001). Nevertheless, there is no accurate population estimate for the number of breast cancer survivors with menopausal-associated problems (Ganz et al., 2004), with the health consequences of CIPM poorly understood (Chen & Manson, 2006).

Young women who experience CIPM report distress related to the early onset and abruptness of menopause (Knobf, 2006b), and loss of fertility and menstrual function (Dunn and Steginga, 2000; Knobf, 2002). Psychosocial effects are related to developmental stage in life, competing midlife demands (Connell, Patterson, & Newman, 2006; Knobf, 2007), increased stress, and coping difficulties in their partner (Bloom & Kessler, 1994; Kingsley, 2010; Manne, Ostroff, Fox, Grana, & Winkel, 2009; Northouse, 1994); especially in women with young and adolescent children (Knobf, 2007). An arduous treatment regime, while negotiating work and family responsibilities, also creates a complex point in time for young women with breast cancer (Mujahid et al., 2011).

Despite the short- and long-term iatrogenic effects from chemotherapy and endocrine therapy, studies suggest CIPM may have a positive impact on disease-free survival. This finding may be associated with prolonged estrogen deficiency, although report findings are not consistent (Goodwin et al., 1999). In one study of women treated for breast cancer with CIPM, there was significant improvement in overall survival (hazard ratio [HR] for death, 0.72;  $p = .04$ ) and in disease-free survival (hazard ratio for recurrence, second malignancy, or death, 0.65;  $p < .001$ ; Swain, Jeong, & Wolmark, 2010). In this 12-month landmark study on ER status (Swain et al., 2010), amenorrheic women with ER-positive tumors had significantly better outcomes than those not amenorrheic (HR for death, 0.52;  $p = .002$ ); including recurrence, second malignancy, or death (HR 0.51;  $p = .002$ ). In contrast, women with ER-negative tumors had a similar outcome regardless of amenorrheic status (HR for death, 1.08;  $p = .76$ ; for disease recurrence, second malignancy, or death, 0.96;  $p = .85$ ; Swain et al., 2010).

Knobf (1998) described the process of how NLW assimilated CIPM during their breast cancer experience. The majority of women in this study ( $N = 26$ ) were white, married, well educated, and employed (Knobf, 1998, 2002). The study resulted in a mid-range theory that explained how white women responded to the basic problem of vulnerability that was related to CIPM and their breast cancer experience (Knobf, 2002).

**Physiological effects of CIPM.** Breast cancer survivors describe CIPM, sexual dysfunction, and infertility as the most distressing aspects of their experience (Avis et al., 2004; Schover, 2008). Vasomotor symptoms (VMS) are the most common acute symptoms of CIPM and include hot flashes, night sweats, chills, headache, sleep

disturbance, nervousness, irritability, and depression that often require clinical treatment and can affect QOL (Bordeleau et al., 2007; Lemcke et al., 2004).

VMS, especially hot flashes, have a negative impact on QOL, sleep quality, and cause increased fatigue, and worse physical health in women undergoing treatment for breast cancer (Bordeleau et al., 2007). In many studies, hot flashes are the most prominent symptom reported; these occur in 41–78% of women with CIPM (Ochayon, Zelker, Kaduri, & Kadmon, 2010).

Other physiological effects of CIPM include sudden onset of genitourinary symptoms, loss of fertility, low bone mineral density, cognitive impairment (e.g., memory, thinking clearly, and concentration), hypercholesterolemia (Falletti, Sanfilippo, Maruff, Weih, & Phillips, 2005; Phillips & Bernhard, 2003; Wefel, Lenzi, Theriault, Davis, & Myers, 2004), and weight gain (Clive & Dixon, 2002; Shapiro & Reicht, 2001; Tham et al., 2007). Symptom assessment in breast cancer survivors is important because physical and emotional symptoms can affect QOL (Fu et al., 2009), and the number of reported symptoms is significantly related to QOL (Chang, Hwang, Feuerman, & Kasimis, 2000).

One study (Green et al., 2010) assessed vasomotor symptoms, vaginal dryness, and trouble sleeping in Latinas ( $n = 142$ ) and NLW ( $n = 187$ ) aged 42–52. Latinas reported more VMS (34.1–72.4% versus 38.3%) than NLW ( $p = .029$ ), and vaginal dryness (17.9–58.6% versus 21.1%) among NLW ( $p = .028$ ).

Measurement of symptom burden of women who were  $\geq 3$  months post completion of adjuvant chemotherapy was conducted by Fu et al. (2009). The study ( $N = 139$ ) assessed the prevalence of 16 physical and emotional symptoms and identified

sociodemographic factors associated with symptoms. Factor analysis with factor loadings  $>0.5$  in this study reduced 16 symptoms to four symptom clusters for all populations that included (a) depression (e.g., sadness, anxiety, and grief/loss), (b) chemotherapy (poor appetite, nausea, lymphedema, and neuropathy), (c) hormone related (fatigue, poor sex drive, hot flashes, and poor memory), and (d) pain (insomnia, muscle aches, and bone pain). While most women ( $n = 97$ , 70%) complained of  $\geq 6$  symptoms, Latinas complained of  $\geq 10$  symptoms ( $n = 63$ , 45%,  $p < .05$ ; Fu et al., 2009). Latinas in the study ( $n = 63$ ) were also more likely to report chemotherapy-related symptoms ( $p < .05$ ) and pain-related symptoms ( $p < .05$ ) compared to NLW ( $n = 58$ ) and AAW ( $n = 180$ ) in the multiple linear regression models (Fu et al., 2009). Fu et al. further found that unemployed women in the study were more likely to report chemotherapy-related symptoms ( $p = .05$ ).

The severity of symptoms can influence adherence with therapy and satisfaction with treatment decisions (Molina et al., 2005). Nearly 20% of all women with breast cancer will stop or consider stopping endocrine therapy because of VMS, despite the importance of this treatment to prevent recurrence (Baber, Hickey, & Kwik, 2005).

**Psychosocial effects of CIPM.** Psychosocial factors also impact Latinas with breast cancer. Bromberger et al. (2001) suggested that while psychological distress during menopause may be more common in certain ethnic groups, a relationship between distress and psychosocial factors also exists. Psychosocial effects of chemotherapy include (a) distress (Dunn & Steginga, 2000), (b) anxiety and depression often lasting years after diagnosis and treatment (Burgess et al., 2005; Montazeri, 2008), (c) poorer QOL (Avis et al., 2005; Knobf, 2007), (d) health insurance and work-related concerns

(Institute of Medicine [IOM] & National Research Council (NRC), 2005; Tiedtke, de Rijk, De Casterle, Christiaens, & Donceel, 2010), (e) altered body image, poor sexual function, impaired self-esteem (Dunn & Steginga, 2000), and (f) uncertainty of disease relapse (Avis et al., 2004; Baber et al., 2005; Connell et al., 2006; Ganz et al., 2004).

Changes in sexual function and self-esteem may be most devastating in premenopausal women (Avis et al., 2005; Schover, 1994b). One study of sexual functioning in women who had received chemotherapy showed that sexual function was worse in those receiving this treatment versus no treatment, regardless of the type of surgery ( $p = .001$ ; Ganz et al., 2004). A woman's psychological reaction to diagnosis, treatment, or physiological symptoms may be an underlying source of sexual dysfunction (Schain, 1985).

Sexual functioning in women with breast cancer is influenced by their prescribed treatment regime including (a) type of surgery, (b) chemotherapy type, (c) endocrine therapy, (d) age, (e) hormone status, (f) overall physical and psychological well-being, (g) quality of relationship with partner, and (h) pre-existing sexual dysfunction (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998). Sexual dysfunction is prevalent among women treated with chemotherapy; this occurs in approximately 60–84% of breast cancer survivors (Barni, & Mondin, 1997; Hawkins et al., 2009; Shover, 1994a).

### **Latinos in the United States**

**Population trends.** Since 1980, the word Hispanic/Latino has been the U.S. federal designation used in national and state reporting systems (U.S. Census, 2010a), with cancer incidence rates for Latinos available since 1992 (ACS, 2009–2011).

Approximately 60% of Latinos are born in the U.S.; the other 40% are foreign-born and

not U.S. citizens at birth (ACS, 2009–2010). Although persons of Latino origin may be of any race, about 97% of U.S. Latinos are white (ACS, 2009–2010).

The Latino population increased by 15.2 million between 2000 and 2010 and accounted for more than half of the total U.S. population increase of 27.3 million; this accounts for 43%, or four times the nation's 9.7% growth rate (U.S. Census, 2010b). HCPs will need greater cultural competence to manage symptoms experienced during the menopause transition where cultural beliefs have been reported (Im et al., 2009). Needs based on social determinants and cultural beliefs for this population will be greater with the rising number of Latina women facing breast cancer. Most research regarding breast cancer has been conducted with white women, limiting understanding of the response of ethnic groups to breast cancer, based on their unique life experiences (Knobf, 2007).

**Cultural factors.** In the Latino culture, the woman is generally the primary caregiver and is responsible for the home and children (Kingsley, 2010), and she has strong feelings about her responsibility in this role (Buki et al., 2008). In addition to keeping healthcare appointments, side effects from treatment may threaten her established role in the family (Kingsley, 2010). *La familia* consists of a family network that often includes immediate and extended family, as well as close friends (Delgado, 2010). Latino culture emphasizes the importance of *la familia* (family), *respeto* (respect), *personalismo* (familiarity), *confianza* (trust), and *espíritu* (spirit; National Alliance for Hispanic Health [NAHH], 2001).

Familialism is proposed as one of the most important culture-specific values of Latinos that involves individuals' strong identification with, and attachment to, their nuclear and extended families (Marin & Marin, 1991). This value appears to provide a

natural support system, with a perceived obligation to supply material and emotional support, to extended family members, and to rely on family members for help and support (Marin & Marin, 1991). These values are found among all Latino groups and are independent of the number of years since migration or generational history (Marin & Marin, 1991). HCPs and researchers find that understanding and respecting *familialism* is helpful when providing care and studying this population (Delgado, 2010).

*Respeto* includes mutual and reciprocal respect and trust (Delgado, 2010). HCPs are given a high degree of respect, but Latinos may avoid disagreements, or be reluctant to ask questions about their medical treatment or instructions (ACS, 2009–2011; NAHH, 2001). Latinos may not seek second opinions or question a HCP's advice because of the cultural value of respect for the provider's status of authority (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004). Latino culture values *personalismo* over institutional relationships and prefers a provider who takes a personal interest in their life (ACS, 2009–2011). A relationship of *confianza* refers to a HCP respecting the patient's culture and showing interest (ACS, 2009–2011; NAHH, 2001).

*Espiritu* is the way Latinos view health: as a continuum of body, mind, and spirit (ACS, 2009–2011; NAHH, 2001). Spirituality is a broad term to describe an individual's subjective path of religious experience (Hill & Pargament, 2003; Masters, 2007). Spirituality may be defined as an individual's sense of peace, purpose, and connection to others, and beliefs about the meaning of life (National Cancer Institute [NCI], 2011). Spirituality may be found and expressed through an organized religion or in other ways (NCI, 2011). Spirituality is an important component of a woman's cancer experience and central to recovery and coping (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia,

2006). Spirituality has been identified as a predictor of health-related QOL among cancer survivors and seen as increasingly important in cancer coping research (O'Connell & Skevington, 2005). Latinas, in general, are part of a unique culture that uses a foundation of spirituality, and they report high levels of spirituality as key to recovery and coping—more so than NLW (Culver, Arena, Antoni, & Carver, 2002; Taylor, 2001).

Latinos are more likely than NLW to believe that cancer cannot be prevented and that death is inevitable after diagnosis (fatalism; Otero-Sabogal, Stewart, Sabogal, Brown, & Perez-Stable, 2003). Latinas seek healthcare less than women from other ethnic groups and have less positive attitudes about breast cancer than NLW (Acosta & Serrano, 2007). Fatalism has been identified in the literature as a dominant principle among Latinas and may be a barrier to cancer prevention strategies and early detection efforts (Espinosa de los Monteros & Gallo, 2010). Fatalism is defined as the general belief that all events are predetermined or caused by external forces, and that little or nothing can be done to change their course (Florez et al., 2009). When applied to one's health, fatalism is described as pessimistic attitudes regarding preventative health practices and disease outcomes (Espinosa de los Monteros & Gallo, 2010). However, evidence that supports the principle of fatalism as a prominent world view among Latinas is mixed (Florez et al., 2009), as is evidence that, because mortality rates are higher in this socially disadvantaged population, their fatalistic attitudes toward cancer are grounded in reality (Abraido-Lanza et al., 2007).

The importance of the connection between self and family was also described in the literature. Latinas reported feelings of anxiety, sadness, and crying spells during midlife, but often attributed their symptoms to life experiences, and not from natural

menopausal transition (Villarruel et al., 2002). These themes differ from menopause experience in NLW who consider menopause an indicator of physical aging, a moving away from the ideal of youth in society (Im et al., 2010). Additional cultural factors, including language, beliefs, values, and traditions, may also affect underlying risk factors, health behaviors, beliefs about illness, and medical care (Acosta & Serrano, 2007; ACS, 2009–2011). Cultural beliefs and lack of knowledge regarding cancer risk may influence screening and preventive behaviors that may result in disparities in Latinas' stage at diagnosis, treatment regimen, and survival (Ashing-Giwa et al., 2006; Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Hunter, 2000).

**Acculturation.** Latinas with low acculturation report the greatest unmet need for information (e.g., risk factors, symptoms, diagnosis, and treatment; Acosta & Serrano, 2007; Janz et al., 2008;), care support, and contact with other women who have breast cancer (Janz et al., 2008); these Latinas represent a highly vulnerable subgroup (Hamilton et al., 2009). Acculturation refers to the process wherein immigrants adopt attitudes, values, customs, beliefs, and behaviors of their new culture (ACS, 2009–2011; Marin & Marin, 1991). As individuals are exposed to a new culture, a process of culture learning and behavioral adaptation takes place (Marin & Marin, 1991). Green and Santoro (2009) found that, among Latinas, symptoms vary by country of origin and acculturation plays a complex role in menopausal symptoms. Acculturation is important to measure in a population to determine if differences exist within groups and to identify variables (Marin, Sabogal, & Perez-Stable, 1987).

A lack of proficiency in the English language is a major barrier to receiving adequate care for immigrants to the U.S., or those who are not acculturated (ACS, 2009-

2011). In 2007, 47 million people (18%) in the U.S. spoke a language other than English at home, with Latinos accounting for the majority of this population (U.S. Census, 2010a).

Latinas who migrate to the U.S. often acquire western habits reflecting those of industrialized nations and thus have a higher burden of breast cancer following relocation (Ortiz et al., 2010). Among Latina immigrants to the U.S., habits include an increase in smoking, alcohol intake, rate of obesity, poor diet quality, less physical activity (Lara, Gamboa, Kahramanian, Morales, & Bautista, 2005), decline in parity, and younger age at menarche (Ortiz et al., 2010). One study (John et al., 2007) considered the influence of migration history and acculturation on breast cancer risk in Latinas ( $n = 991$ ) versus controls ( $n = 1285$ ) aged 35–79 years. Results showed breast cancer was 50% lower in foreign-born Latinas than in those U.S. born, and risk increased with longer duration of residence in the U.S., younger age at migration, and increased acculturation (John et al., 2007).

**Disparities and social determinants of breast cancer among Latinas.** It is difficult, if not impossible, to discuss the impact of culture and ethnicity in nursing and not address their role in health disparities. Disparities in health (health disparities) are defined by the National Institutes of Health (NIH; 2001) as differences between populations and population subgroups in the overall level of health and the distributions of health and disease. These include differences in incidence, prevalence, mortality, burden of disease, and other adverse health conditions (NIH, 2001). Disparities in healthcare encompass both the health outcomes of care and other dimensions of care that include access, quality, and equity (Almgren, 2007). Nurse scientists are well poised to

tackle the research imperatives that result from health disparities (Heitkemper & Bond, 2003).

Latina breast cancer survivors, particularly those who are poor and speak limited English, often have inadequate insurance, receive unsatisfactory medical care, and there is some evidence that physicians provide less informational support to minority women with breast cancer (Ashing-Giwa et al., 2006; Janz et al., 2008). Many ethnic women report gaps in information given to them by HCPs about diagnosis, treatments, side effects, and guidelines for follow-up care (Sammarco & Konecky, 2008). One study (Siminoff, Graham, & Gordon, 2006) reported that patient demographic factors, such as race, lower income levels, advancing age, and lower education levels negatively influenced the amount of time physicians spent communicating with patients during healthcare visits. These differences may indicate an inadequate knowledge base for decision-making among members of racial or ethnic minorities, patients who are less affluent, older, and have less education (Siminoff et al., 2006); these patients represent a highly vulnerable subgroup (Hamilton et al., 2009; Janz et al., 2008).

The ACS (2009–2011) report states that of 164,000 reported deaths from cancer in the U.S. in 2007, approximately 60,000 (37%) could have been avoided if all segments of the population had the same cancer mortality rates as the most educated whites—showing the impact of income and education in prevalence of risk factors for cancer, access to health insurance, preventive care, early detection, and treatment. The causes of cancer disparities within different SES or ethnic groups are complex, and include interrelated social, economic, cultural, and health system factors (ACS, 2009–2011).

Despite these multiple barriers, ethnic minority women, especially those who do not speak English as their first language, are typically underrepresented in studies that examine QOL and psychosocial functioning of breast cancer survivors (Buki et al., 2008; Fu et al., 2009; Hamilton et al., 2009). While there is a growing body of literature on the breast cancer experience in African-American women (AAW; Bradley, 2006), there is a paucity of information about survivorship in other minority populations; specifically Latina and Asian women (Culver et al., 2002; IOM & NRC, 2005). This current underrepresentation reflected by the scarcity of reports focusing on the treatment experience of Latina women represents a major limitation in the current literature for addressing CIPM experiences in this population (Hawley et al., 2008).

Social determinants have been identified as the fundamental cause of health and disease (Link, Northridge, Phelan, & Ganz, 1998), and characterized as the social, environmental, economic, and cultural factors that shape or determine individual and group behavior (Kaplan, Pamuk, Lynch, Cohen, & Balfour, 1996). While there has been significant progress in reducing cancer mortality in the U.S., there are segments of the population who have not benefitted equally (Haynes & Smedley, 1999). Mortality rates in persons with lower SES (e.g., education, occupation, or residence) show little to no decrease, and in some cases, increased rates may have occurred (ACS, 2009-2011; Kinsey, Jemal, Liff, Ward, & Thun, 2008).

SES is the most critical factor affecting health and longevity (ACS, 2009–2011). In the U.S., Latinos attain lower levels of education than NLW and are more likely to live in poverty (ACS, 2009–11). In 2005–2007, 40% of Latinos had less than a high school education, compared to 11% of NLW (ACS, 2009–11). Bradley, Given, and Roberts

(2002) examined race and breast cancer survival and found that SES was associated with stage at diagnosis, type of treatment received, and likelihood of mortality even more strongly than race.

Common measures of socioeconomic resource distribution include occupation, wealth, poverty, debt, employment status, education, and health insurance coverage (Hiatt & Breen, 2008). Lower SES is also associated with financial, structural, and personal obstacles to healthcare (e.g., inadequate health insurance, reduced access to recommended preventive care and treatment, and lower literacy rates; ACS, 2009–2011). According to the U.S. Census Bureau, one in four Latinos live below the poverty level, with one in three uninsured; compared to one in 11 and one in eight, respectively, in NLW (U.S. Census, 2010a, 2010b). Low income women ( $N = 924$ ) who believed their diagnosis was delayed were also less likely to be satisfied with their care (Thind et al., 2010).

Latinas and AAW typically have lower paying jobs and unsupportive work settings (e.g., lack of paid sick leave, inflexible work schedules, temporary jobs, or multiple employers; Murphy & Graff, 2005; Reskin & Padavic, 2006). Individuals with lower paying jobs may receive no health insurance and are more likely to be diagnosed with advanced cancer and less likely to receive standard treatment and to survive their disease (Ward et al., 2008). Insurance type, stage of cancer at time of diagnosis, comorbidities, and type of facility are associated with chemotherapy delay (Fedewa et al., 2010).

Latinas may be at an increased risk for job loss because they may have difficulty navigating the health system, due to language and cultural barriers, leading to challenges

in balancing work and treatment (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Ashing-Giwa et al., 2006). It is unknown if women are more likely to be unemployed following a breast cancer diagnosis because symptoms interfere with their ability to fulfill their work obligations, or if potential consequences of unemployment (e.g., lower SES, financial instability, and loss of health insurance) exacerbate symptoms and prevent symptom management (Fu et al., 2009).

Mujahid et al. (2011) examined race and ethnic differences in treatment-related job loss and its financial impact in a population-based sample of women ( $N = 3,252$ ) diagnosed with breast cancer. Of these women, 10.4% (24.1% Latinas, 10.1% AAW, and 6.9% NLW;  $p < .001$ ) reported losing or quitting their job following diagnosis or treatment of breast cancer. Latinas were more likely to experience job loss compared to NLW (OR = 2.0;  $p = .013$ ) independent of sociodemographic factors (Mujahid et al., 2011). Latinas receiving chemotherapy were more likely to lose their job compared to NLW (OR 3.2;  $p < .001$ ); however, there were no significant differences between Latinas and NLW who did not receive chemotherapy. Mujahid et al. also found that women who lose their jobs are more likely to experience financial strain (27% versus 11%;  $p = .001$ ).

In addition to a more aggressive disease pattern and less favorable prognosis, decreases in cancer mortality rates in minorities have occurred later and more slowly compared to NLW (ACS, 2011). In 2007, 32.1% of Latinos lacked health insurance and regular sources of care when compared to other racial or ethnic groups (Ward et al., 2008), received unsatisfactory medical care, and experienced substandard HCP-patient communication (Ashing-Giwa et al., 2006).

As evident in the screening and treatment of breast cancer, cancer occurrence and survival are also influenced by multiple social factors occurring at once. Financial, ethnic, and SES (e.g., income and education) can impact rates of occurrence and survival. Much of this multifactorial disparity in cancer burden among minorities is reflective of obstacles to receiving healthcare related to cancer prevention, early detection, and high-quality treatment—and lower SES is the overriding factor (ACS, 2009–2011).

### **Summary**

Despite recent contributions of oncology nurse researchers to breast cancer, little is known about how minority women assimilate the breast cancer experience as they respond to the diagnosis, make treatment decisions, navigate the healthcare system, cope with treatment, and live as survivors following treatment. Racial and ethnic minorities face many barriers to receiving healthcare related to cancer prevention, early detection, and high quality treatment (Minority Cancer, 2008–2011). The inclusion of ethnic minority and underserved populations into studies necessitates a paradigm shift from health research to health disparities research (Ashing-Giwa, Padilla, Tejero, & Kim, 2004).

Most research findings regarding menopause are the result of studies in healthy white women. The experience of menopause in Latinas is not well understood and represents a complex transition that encompasses personal, cultural, familial, and traditional views. Few studies of breast cancer survivorship have included Latinas with low SES or those who do not speak English, and little information is available on the survivorship experience of Latinas with breast cancer. This paucity of information is coupled with the prediction that the Latina population in the U.S. is burgeoning.

To date, no studies regarding their experience with CIPM have been conducted. The influence of ethnic-specific cultural contexts on the menopausal symptom experience of Latina women is not well understood. Latinas have been insufficiently studied despite their growing proportion among breast cancer survivors, distinctive concerns, and unique issues as a special population. As more women survive breast cancer, interest is aimed at addressing QOL issues in survivorship (Janz et al., 2008). The changing demographics of the population in the U.S., the role of the societal mandate for nursing to understand the human response of all people, and the disparate breast cancer outcomes for Latina women provide a compelling argument to address the underrepresentation of ethnically diverse populations in cancer research (Knobf et al., 2007).

Findings of this current study make important contributions to survivorship in Latina women by understanding and interpreting their CIPM experience. Long-term QOL, self- and symptom-management, elimination of health disparities, and survivorship issues for breast cancer patients are high priority areas identified by the 2005 IOM & NRC report, *“From Cancer Patient to Cancer Survivor: Lost in Transition,”* the 2009–2013 Research Agenda for Oncology Nursing (Berger, Cochrane, & Mitchell, 2009), the National Institute of Nursing Research (NINR) Strategic Plan (2011), and the American Cancer Society (2009-2011).

This study contributes to nursing knowledge and informs nursing practice to promote physical and psychosocial adjustment of cancer and treatment effects. It provides data to inform the development of culturally sensitive interventions with the potential to improve young Latinas’ breast cancer treatment decision-making by preparing them for CIPM and its sequelae.

## **Chapter II**

### **Methodological Approach**

#### **Introduction**

A methodological framework is a set of principles and ideas that inform the design of a research study and, with its underpinning philosophy, influences how the researcher works (Burns & Grove, 2009). Methodological frameworks encompass a set of assumptions that undergird the entire research process (Keddy, Sims, & Stern, 1996) and enable the researcher to link study findings to a body of knowledge used in nursing (Burns & Grove, 2009).

Methodological frameworks have been more common in quantitative research; whereas, in qualitative research, the use of a framework was not as clear. Controversy exists as to whether frameworks should be used and how (Corbin & Strauss, 2008); some qualitative nurse researchers defend the absence of a theoretical foundation by claiming “nothing is known” about certain illness experiences (Thorne, Reimer Kirkam, & MacDonald-Emes, 1997). When used in qualitative research, a framework serves as a justification for the use of a particular methodology or guiding approach to research (Corbin & Strauss, 2008).

The purpose of this study was to describe the experience of chemotherapy-induced premature menopause (CIPM) among Latinas with breast cancer. The specific aims of the study were the following: (a) Describe the experience of Latinas with CIPM from breast cancer treatment; (b) Explore how Latinas assimilate the experience of CIPM into their breast cancer experience; and (c) Compare and contrast the study findings to Knobf’s (1998; 2002) “*Carrying on*” GT.

A qualitative interpretive description (ID) research methodology from a feminist lens was utilized as the methodological approach for this study. An overview of the origins, underpinnings, and usefulness of ID and feminist research (FR) is provided.

### **Origins of Interpretive Description**

ID began as a distinct nursing methodology (Sandelowski, 2000; Thorne et al., 1997) as nurse researchers endeavored to build methods that were bound in the “epistemological foundations, adhered to the systematic reasoning of our own discipline and yielded legitimate knowledge for our own practice” (Thorne et al., 1997, p. 172). The qualitative approaches derived from other disciplines did not always meet the demands of nurse researchers (Thorne et al., 1997). The use of traditional qualitative methodologies to challenge the dominant positivist quantitative inquiry failed to provide appropriate knowledge needed by the applied disciplines to address real practice problems (Thorne, 2008).

ID was made explicit as a retort to calls from qualitative methodologists for researchers to “come clean” (Corbin & Strauss, 2008; Thorne, 2008) about their rejection of “tyranny of method” (Sandelowski, 2000, p. 334) in favor of a less prescriptive approach (Oliver, 2012). Many nurse researchers had already detached themselves from these prescriptive methods, even in the face of leaving themselves vulnerable to accusations of “method slurring” and sloppy science and for not retaining methodological integrity in their work (Morse, 1989; Stern, 1994).

### **Interpretive Description**

ID is a qualitative research methodology that effectively informs nursing practice while maintaining sufficient rigor to ensure academic credibility (Thorne, 2008). ID is a

research approach in which the social, structural, cultural, and historic context of human experience is recognized as powerfully influential upon what we know, experience, and think (Garrick, 1999), and it seeks to understand how that context plays out in individual experience to the degree it can be known (Thorne, 2008). ID requires “integrity of purpose deriving from two sources:” (a) an actual practice goal and (b) an understanding of what we do and do not know from all existing empirical evidence (Thorne, 2008, p. 35).

ID description studies (a) “are conducted in as naturalistic a context as possible with respect to comfort and ethical rights of all participants; (b) explicitly attend to the value of subjective and experiential knowledge as fundamental sources of clinical insight; (c) capitalize on human commonalities and individual expressions of variance within a shared interest; (d) reflect issues that are not by time and context, but attend carefully to the time and context where the current expressions are enacted; (e) acknowledge a socially ‘constructed’ element to human experience that can’t be separated from its essential nature; (f) recognize that, in the world of human experience, ‘reality’ involves multiple constructed realities that may be contradictory; and (g) acknowledge an inseparable relationship between the knower and the ‘object’ of that inquiry interact to influence one another” (Thorne, 2008, p.74).

ID is known for having more flexible research procedures (Thorne et al., 1997) that address practice issues in a way that is logical to the discipline of nursing (Oliver, 2012). As an approach, ID can be applied to human health and illness experiences for the purpose of developing nursing knowledge and informing practice (Oliver, 2012; Thorne et al., 1997) such as the experience of CIPM among Latinas with breast cancer.

ID is appropriate for a study when little is known about a practice issue (Thorne et al., 1997), a less traditional method to describe elements of the human condition in health and illness is warranted, and legitimate knowledge for nursing practice is embedded in the research situation (e.g., the experience of Latinas with CIPM) that is likely to be explicated by an interpretive lens (Oliver, 2012).

### **Postmodernism**

Just as feminist perspectives have evolved over time, interpretive approaches have become explicitly associated with a postmodernist perspective (Thorne, 2008). A philosophical shift from logical positivism to postmodernism occurred (Whall & Hicks, 2002) as a result of the negative reaction to logical positivism.

Major tenets of logical positivism include the verification principle and posit that phenomena were scientifically meaningful only if they were empirically verifiable through sense experience, logical proofs, and mathematics (Phillips, 1987). From a postmodern perspective, the emerging mindset is that there is not one *Truth*, but multiple truths, and no universally known reality is defined by the physical-material world.

With postmodernism's attention to valuing multiple meanings, there is openness to ideas that include context, critiques, challenges, multiple interpretations, stories, narratives, text, and search for meaning and wholeness (Watson, Montgomery, & Dossey, 1999). Postmodernism is a blend of science, culture, behavior, politics, and literature (Rodgers, 2005) and proposes that members of different genders, ethnic groups, and socioeconomic classes see the world differently (Godfrey-Smith, 2003).

While the postmodern philosophy is often unrecognized (Whall & Hicks, 2002) and criticized (Stevenson & Beech, 2001) for lacking generalizability, its relativist

approach permits “anything” to be allowed as science and deconstruction that breaks down truth without replacing it (Stevenson & Beech, 2001). Given the shifting U.S. demographics toward diversity, efforts have been focused on developing frameworks, concepts, and perspectives that reflect specific cultural groups (Walker & Avant, 2005), as there is concern that dominant cultural perspectives were and are being applied to ethnic minority groups.

Postmodern positions enhance the capabilities of feminist researchers to meaningfully expose new questions or sharpen our focus on certain elements (Thorne, 2008). Many nurse researchers are influenced by the philosophy of postmodernism because of the shift to explore its usefulness in cultural diversity for education, research, and patient care (Whall & Hicks, 2002). Although this relationship is not unique, when combined, it loosens the androcentric ties (e.g., focused on men, often to the neglect or exclusion of women), thus enabling researchers to design inquiry with greater potential to reveal issues particular to the lives and experience of marginalized women (Plummer & Young, 2010).

### **Feminist Inquiry and Paradigm**

The origin of feminist inquiry was difficult to identify since work with feminist undertones continues to evolve (Whelehan, 1995). However, the idea of lessening the burden of social injustices incurred by women occurred in combination with women’s suffrage in the 1920s (Whelehan, 1995).

Feminism became visible in academic circles beginning in the early 1970s (Messer-Davidow, 2002). The goal of feminist research (FR) is to construct a critical dialogue that focuses on women’s experiences from a historical, cultural, and

socioeconomic perspective (Powers & Knapp, 2006). Thus FR aligned well with this study.

The goals of FR are to establish collaborative and non-exploitive relationships (e.g., by placing the researcher within the study to avoid objectification as in ID), and to seek to conduct transformative research (Creswell, 2007; Polit & Beck, 2012).

Fundamental issues in feminist research include the relationships of study participants to researchers, how participants' voices are heard, and how their stories are told. The feminist method requires a leveling of the usual power imbalance between researcher and participant; it promotes a balance between objectivity and subjectivity (Plummer & Young, 2010; Rafael, 1997).

FR takes diverse forms, but a shared set of epistemological features exists, which (a) value a women's lived experience as a legitimate source of knowledge; (b) appreciate the influence of context in the production of knowledge; (c) respect the role of reflexivity in the research process; (d) reject division of subjective and objective perspectives; (e) pay attention to gender, power, and transformative social action (Campbell & Bunting, 1991; Campbell & Wasco, 2000; Cook & Fonow, 1986; Harding, 1987; Lather, 1991; Ramazanoglu & Holland, 2002; Routledge, 2007; Webb, 1993); (f) carry messages of empowerment that challenge knowledge claims of those in positions of privilege; (g) ask new questions that place women's lives, and those of other marginalized groups, at the center of social inquiry; (h) share common points of view that connect the feminist struggle to oppression; and (i) question and critique androcentric bias (Hesse-Biber & Piatelli, 2007). These perspectives share a common ground that interacts where gender

has been viewed as a significant characteristic with other factors (e.g., race and class) to structure relationships between individuals (Campbell & Wasco, 2000).

The idea that knowledge is derived from experience is central to feminist inquiry, but the meaning of experience evolves over time (Plummer & Young, 2010). Women's experiences were the starting point for constructing dialogue regarding womanhood in early feminist inquiry, and ordinary experiences were considered to be similar among all women (Canning, 1997; Mulinari & Sandell, 1999) regardless of race or ethnicity. However, Hooks (1984) and Collins (1989) described a feminist backlash among African-American women (AAW) against the universality of affluent non-Latina whites (NLW) experience that shifted the meaning of the feminist experience. FR has moved from an original assumption that all women share experiences from a single standpoint (Collins, 1989), to one that considers how race, gender, sexual orientation, age, and SES impact and impede social justice (Oleson, 2005).

Contemporary feminist perspectives of experience emphasized subjective and personal narratives (Lather, 1991). The focus of FR has been on gender discrimination and discrimination in patriarchal societies, such as Latino families (Polit & Beck, 2012), and includes policy issues related to realizing social justice for women (Oleson, 2005). Nursing feminist researchers have challenged oppression and discrimination in healthcare systems and in underserved/understudied populations by disclosing the healthcare needs of vulnerable populations and subsequently empowering them (Im, 2010).

The utilization of FR has increased the level of ethical research because of its ideological perspective (Polit & Beck, 2012). With an emphasis on trust, empathy, and non-exploitive relationships, this mode of inquiry views any type of deception or

manipulation as abhorrent (Polit & Beck, 2012). Punch (1994) spoke about ethics in feminist research and noted, “You do not rip off your sisters” (p. 89). By confirming their concerns, women have recognized their issues as real and being heard (Andrist, 1997).

FR has explored women’s identities, sex roles, domestic violence, abortion activism, affirmative action (Creswell, 2007) and, more recently, issues regarding gender, race, poverty, health reform, menopause, sexuality, contraception, vulnerability, breast cancer screening, cancer pain, and HIV/AIDS (Meleis, 2007).

### **Interpretive Description With Feminist Inquiry**

While these perspectives did not organize the entire inquiry of the experience of CIPM among Latinas with breast cancer, a feminist lens was adopted pragmatically to help conceptualize the problem by experimenting in different ways to move beyond the self-evident (Oliver, 2012). FR involves an epistemological stance, or theoretical perspective, that gives direction to qualitative inquiry (Powers & Knapp, 2006).

Feminists encourage research “from the margins,” or research with marginalized people (Keddy et al., 1996, p. 450). The use of FR to augment ID when carrying out research with vulnerable groups (such as Latinas with CIPM) better served the interests of women by surfacing issues of gender and power that may influence the health experience (Plummer & Young, 2010) while explaining diverse realities in women’s studies (Wuest, 1995). Thus, the conceptual description that evolves can make a significant impact in advancing the cause of women (e.g., Latinas) by gaining knowledge regarding their perspective lives (Keddy et al., 1996). Combining the ID and FR paradigms created an ideal environment for allowing the voices of Latinas to be heard as they told their stories.

Knobf's (1998; 2002) study of the experience of premature menopause in women with early stage breast cancer followed qualitative inquiry methods with GT methodology. The study validated its feminist underpinnings and identifies vulnerability as the basic social problem for participants.

"*Carrying on*" is the process that explains how women responded to vulnerability as they attempt to assimilate chemotherapy-induced menopause into their breast cancer experience (Knobf, 2002). The study described the complexity of the experience and identified gaps in knowledge about menopausal symptom distress and factors influencing symptom management and outcomes (Knobf, 2002).

That study's sample was restricted to white women ( $N = 26$ ) because of the effect of culture on the meaning of menopause, interpretation of symptoms, attitude toward managing the menopausal experience, and the predominance of breast cancer in white women in the U.S. at that time (Knobf, 1998). Sampling underrepresented populations is recognized as important and deemed analytically relevant; thus, failing to include such variation might impede the full understanding of the phenomenon being studied (Sandelowski, 1995). Due to the changing demographics of the population in the U.S. toward diversity and the disproportionate burden carried by Latinas with breast cancer with CIPM, the underpinnings of this study included the overarching methodological framework of ID through a feminist lens.

## **Summary**

In addition to having an understanding of the sociodemographic characteristics of Latinas, researchers must become familiar with basic cultural values that may affect the process and outcome of a study (Marin & Marin, 1991). Due to a lack of studies

regarding the experience among Latinas with breast cancer and CIPM, ID with feminist underpinnings allowed for a better understanding of this complex point in time.

Nurses care for populations of increasingly diverse patients who come from a variety of ethnic backgrounds, speak different languages, and bring new and unexpected healthcare needs to the forefront (Walker & Avant, 2005). The lack of studies that focus on Latina breast cancer survivors indicated a need for ongoing research focusing on Latina cultural values and how these values influence QOL. Working with Latina samples who are more representative of the medically underserved and lower SES was necessary. Culturally competent, multicultural research has assisted the scientific community to better understand disparities that exist in health-related QOL, so benefits may be experienced by all patients (Ashing-Giwa & Kagawa-Singer, 2006).

“New knowledge pertaining to the subjective, experiential tacit and patterned experiences of the human health experience, not to advance theory, but to guide future decisions to apply evidence to the lives of real people through sufficient contextual understanding” is needed (Thorne, 2008, p. 36). Acknowledging the potential impact of race, ethnicity, culture, disparate health outcomes, patriarchal society, SES, barriers to healthcare and health insurance, delay in treatment, use of complementary alternative medicine, acculturation, and symptom burden in this population was important. Thus, ID with feminist inquiry was a relevant guiding methodological approach used in this study to explore the experience of Latina women’s breast cancer treatment, overall QOL, and survivorship.

## Chapter III

### Methods

#### Introduction

Interpretive description (ID; Thorne, 2008; Thorne et al., 1997) with feminist underpinnings was used in this study. The specific aims of the study were the following: (a) Describe the experience of Latinas with CIPM from breast cancer treatment; (b) Explore how Latinas assimilate the experience of CIPM into their breast cancer experience; and (c) Compare and contrast findings to Knobf's (1998; 2002) "*Carrying on*" GT. A review of the research design, sample, procedures for recruiting human subjects, obtaining consent, data collection, data management, and data analysis are described. Trustworthiness and reflexivity were established as described in this chapter.

#### Research Design

This study used ID (Thorne, 2008; Thorne et al., 1997) from a feminist inquiry lens because little was known about CIPM among Latinas with breast cancer.

#### Sample

**Inclusion criteria.** Participants were eligible for this study if they met the following criteria:

1. Latina by self-report;
2. English or Spanish-speaking;
3. Provided informed consent;
4. Diagnosed with breast cancer (stage 1–3);
5. Completed neo-adjuvant or adjuvant chemotherapy within the last 10 years;
6. Menses within 3 months prior to starting chemotherapy; and

7. CIPM identified as amenorrhea following chemotherapy treatment.

**Exclusion criteria.** Study exclusion criteria were the following:

1. Stage 0–1 breast cancer treated with surgery and/or radiation only;
2. Presence of endocrine disorders;
3. On non-chemotherapeutic agents that mimic menopausal symptoms; and
4. Advanced stage of disease (> stage 3).

## **Procedures**

**Study approval.** The Institutional Review Board (IRB) for protection of Human Subjects in Research at the University of Massachusetts Medical School (UMMS) approved this study. There was little physical risk to participating in interviews; however, participants could have experienced some emotional distress at being asked to describe their experiences and feelings regarding CIPM. No emotions were addressed by participants to the researcher during the interview process that uncovered any severe problems or distress that warranted a phone call to the participant’s physician for further consultation and evaluation. The researcher is an experienced nurse who planned to contact the dissertation chair anytime for such concerns. The consent form also provided contact information of the researcher and dissertation chair for the participant if any concerns arose.

**Recruitment.** Potential participants were actively recruited over a 17-month period. Initial recruitment efforts took place in an academic health center cancer-based clinic located in an urban setting where previous contacts had been made. Due to lack of Latina patients who fit the inclusion criteria at the cancer-based clinic, other sources were contacted via e-mail or telephone regarding the purpose of the study. Those contacted

were key informants, patient navigators, oncologists in community hospitals, nurse practitioners in oncology practices, community health workers, politicians in Latino neighborhoods, community health centers, breast cancer support groups, local “Y”, family health service groups, and national cancer organizations. Follow-up face-to-face meetings took place whenever possible to discuss the study and identify recruitment strategies.

Due to a continued lack of study participants and enrollment, an interview with an American Cancer Society spokesperson regarding the study was published via the *Worcester Telegram and Gazette*. Study information was also posted on social media networks (Facebook and Twitter) related to Latina health and breast cancer, and a breast cancer education session in which the researcher participated was aired on a Latino television station (Esperanza y Su Exito, WCCA TV 13, in Worcester, MA), and study fliers, in both Spanish and English, were posted with permission in local Latino neighborhoods (restaurants, beauty salons, churches, libraries, grocery stores). Other recruitment efforts included presenting the study overview and inclusion criteria to Latinas at a church group, at English as a Second Language (ESL) class, at Latino neighborhood meetings, and at a family health services staff meeting. Study fliers and information were also distributed and discussed at a local Latino festival. After 10 months of recruiting efforts, five participants were enrolled in the study.

Final recruitment included advertising through the Dr. Susan Love Research Foundation (DSLRF) Army of Women national database. Information regarding the purpose of the study, eligibility, and researcher’s contact details was distributed through their efforts. Interested participants were able to call the researcher directly, or provide

their name and phone number and/or e-mail address in order to be contacted. Once permission to provide contact information was obtained, potential participants were contacted by the researcher. Fifteen participants were recruited through the DSLRF.

Table 1 depicts the successful recruitment sources.

Table 1  
*Recruitment of Participants (N = 20)*

Source	Participants	Percentage
National Database	15	75
Snowball	2	10
Women’s Center	2	10
Interview (newspaper)	1	5
Total	20	100

**Sampling.** The plan was to use purposive sampling, followed by theoretical sampling, per ID (Thorne, 2008). However, since recruiting potential participants was challenging, theoretical sampling was not possible in this study. It was noted that potential participants who expressed interest in the study were more likely to follow through with the interview process when screened and interviewed on the same day, thereby decreasing attrition rates. Therefore, convenience sampling was utilized, with two interviews often completed on the same day, making it difficult to analyze data between interviews and develop an emergent sampling scheme. Thorne (2008) described a convenience sample as an “excellent source of insight for applied qualitative researchers about a phenomenon” with attention to the likelihood of commonalities of this group (p. 91).

In addition to convenience sampling, snowball (or chain) sampling as a type of non-probability sampling (Powers & Knapp, 2006) was used in this study, as early informants were asked to refer other study participants. The advantages of snowball sampling were that it allowed the researcher to spend less time screening people to determine if they were appropriate for the study and more time developing a trusting relationship with newly referred participants (Polit & Beck, 2012). Two study participants were accessed via snowball sampling.

**Consent.** Initial screening of potential participants via telephone was completed to determine if they met the inclusion criteria for the study. If a participant met the criteria, verbal consent was obtained and study risks and benefits were reviewed. Consent information was read to participants, in either English or Spanish per participant request; the option of having a professional Spanish interpreter during the screening, consent, and interview process was offered. Two participants (10%) requested that the Spanish interpreter be present via telephone for consent information and data collection procedures. A separate consent form was mailed to participants to sign and return to the researcher to obtain protected health information (PHI) from the participant's HCP. Once the participant returned the signed waiver, a request for PHI was mailed to the participant's HCP. Requested PHI included tumor markers (ER/PR status, HER 2 neu status, and P53 status) and genetic testing (BRCA1 and BRCA2).

**Data collection.** During data collection, participants were free to ask any questions about the study or about their rights as a research subject, and they were allowed as much time as needed. Strategies to decrease mistrust in potential participants that were utilized in this study included (a) explaining that names and personal identifiers

would not be shared with anyone outside the research team (researcher, interpreter, and dissertation chair); (b) providing an introduction before sensitive questions were asked; (c) asking open-ended questions and using probes to enhance responses; (d) using feedback from a professional Spanish interpreter as supplementary data (Merry et al., 2011); and (e) encouraging participants to choose which version (Spanish or English) of the consent form, demographic data sheet, and Brief Acculturation Scale for Hispanics (BASH) tool that they were most comfortable with (Marin & Marin, 1991).

Qualitative data were collected via telephone using a 2-way telephone recorder, with both digital and cassette recorders used as back-up devices. Participants were aware that the interviews would be recorded. Telephone interviews occurred with the participant, researcher, and professional Spanish interpreter (when requested by participant). After the researcher and/or Spanish interpreter reviewed the research study informational material and consent form with the participant, verbal consent was obtained. A copy of the IRB-approved consent form (Appendices A1 and A2) was mailed to participants who enrolled in the study for their records. Participants were mailed a \$20.00 honorarium per interview for their participation.

Participants were then asked several questions from the interview guide regarding their experience with menopause (*el cambio de vida*) from chemotherapy as part of their treatment for breast cancer (Appendices B1 and B2). Participants were encouraged to answer all questions freely. Verbal intonations heard during the interview were recorded for notation on transcripts. Recruitment and data collection continued to the point at which the practical question driving the study had been reasonably answered (Oliver, 2012). This pragmatic approach allowed for the belief that there is always another

perspective of a situation (such as the complex world of the CIPM experience among Latinas), that the perspectives of those interviewed can shift over time, conclusions are tentative and temporary, and inquiry is never done (Oliver, 2012).

In approximately six months' time after the first interview, two participants were contacted for member checks to answer questions regarding their menopause (*el cambio de vida*) experience over time, to clarify previous interview discussions, and to review data and explore emerging patterns and themes after transcription. Following final revision of themes, and at the completion of the study write-up, three participants were e-mailed a written summary of results for feedback.

***Instruments.*** Demographic data and acculturation scale items were read via telephone to each participant, in English or Spanish, with responses noted by the researcher. In addition to interviews, a wide range of data from numerous collaborative data sources was collected, and described later in Chapter 3 as triangulation data. The demographic data sheets (Appendices C1 and C2) were used to collect descriptive information regarding age, marital status, cancer stage, treatment regimen, socioeconomic status (SES), and country of origin. Demographic data collection took approximately 15 minutes to complete.

The Brief Acculturation Scale for Hispanics (BASH; Marin & Gamba, 1996) instrument was administered verbally to participants via telephone (Appendices D1 and D2) to measure acculturation level. This 4-item scale was shortened by the authors from 12 items without sacrificing predictive value, validity, or reliability (Marin et al., 1987). The BASH scoring uses a 5-point Likert-type scale with responses ranging from “only Spanish” to “only English” with the total score range from 1–5 for each item with a

cutoff score of 2.9. The 12-item BASH scale includes an internal consistency of 0.90 (Marin et al., 1987).

The 4-item acculturation scale correlated highly with generation, length of time in the U.S., subjective evaluation of acculturation, country of birth, and language chosen for the interview (Norris, Ford, & Bova, 1996). Results supported the use of this 4-item measure of acculturation as a simple, inexpensive measure that involved minimal respondent burden (Norris et al., 1996). There were two versions of the scale (Spanish and English) that respondents choose from to complete. The BASH instrument data collection took approximately five minutes of the participant's time to complete.

**Data management.** Audio-recordings of telephone interviews and field notes were transcribed verbatim by professional transcriptionists within a 2–3 week time frame following each interview. The researcher listened to all recordings and reviewed them with the professional Spanish interpreter (when required for interviews), and dissertation chair prior to importing data into NVIVO v.9 ® software for data management. All recordings in Spanish were transcribed by the professional Spanish interpreter who was present during those interviews. Demographic and acculturation data collected prior to interviews were entered into IBM® SPSS® v.21 Statistics, with verification through double entry of data. Tumor marker and genetic data were also entered into IBM® SPSS® v.21 Statistics.

All data inputted into IBM ® SPSS ® v.21 Statistics, NVIVO v.9 ® software, and all interview transcriptions were de-identified with confidentiality of data maintained by assigning code numbers known only by the researcher and dissertation chair to each participant's data. Only those code numbers appeared on data collection forms. All

research data were secured in a locked file cabinet at all times, with electronic files stored on an encrypted and password-protected computer on a research drive that was backed up every 24 hours. Audiotapes and research documents will be destroyed 1 year after publication of results, or a maximum of 5 years after transcription.

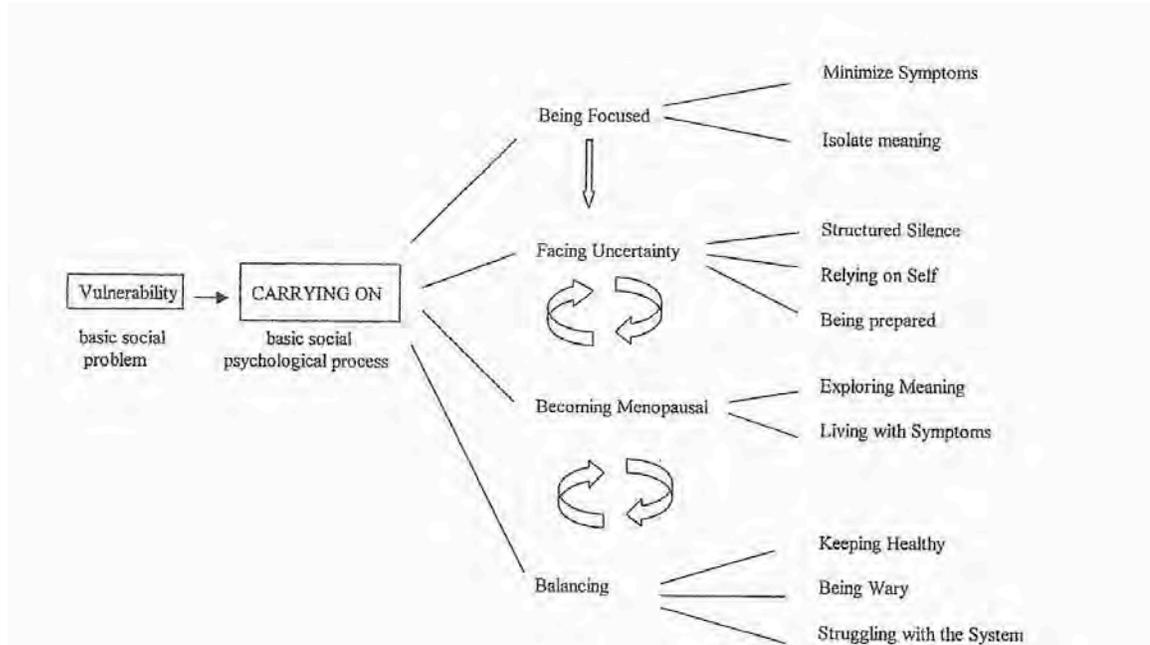
All electronic devices used for data collection and analysis were password protected and encrypted by the Information Technology Department at the University of Massachusetts Medical School. The researcher met regularly with the dissertation chair to review issues related to entering data, coding, or missing data. The researcher listened to all English recordings to verify them with the transcription; the dissertation chair listened to approximately 40% of the interview tapes.

**Data analysis.** ID methodology with feminist underpinnings and Knobf's "Carrying on" GT were used to analyze data regarding Latinas' experiences with CIPM from breast cancer treatment. The basic guidelines for ID inquiry (Thorne, 2008) were followed, including a critical analysis of existing theoretical and clinical knowledge about CIPM in Latinas within the discipline to inform the initial conceptual framework, and through an iterative process of collection and analysis. In order to create conceptual categories, the researcher broke down the data by hand into segments, closely examined them, and compared them to other segments for similarities and dissimilarities to identify commonalities in the CIPM experience. The researcher was able to generate new insights useful to practice application by asking, "What are the main messages here?" and "What is it that I know now, having done this study, which I did not know before, or that I did not know in the same way?" (Thorne, 2008, p. 195). Prior to beginning coding,

classifying, or creating linkages, the analytic techniques of repeated immersion were utilized (Stern, 1994).

Following the first five interviews, emerging results were reviewed initially by the researcher with the dissertation chair and professional Spanish interpreter (when necessary); then every two to three weeks as more interview data were collected. Further immersion in the field, through continued interviews, use of collateral data sources, alternating with strategic periods of immersion in the data occurred to refine the inquiry (Stern, 1994). The dialectic between individual cases and common patterns was addressed (Thorne et al., 1997) until interviews were completed and the practice question had been reasonably answered (Thorne, 2008), as no new stories were told by participants. At the final level, the researcher examined the emergent themes against Knobf's (2002) "Carrying on" theory (Figure 1) comparing and contrasting to evaluate similarities and differences. Knobf (1998, 2002) studied CIPM in 27 white women using GT methodology. Knobf's "Carrying on" theory describes the basic process that explains how women in her study responded to vulnerability as they attempted to assimilate CIPM into their breast cancer experience.

Figure 1. Knobf's (2002) Carrying On: A Substantive Theory



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**Trustworthiness.** The goal of establishing trustworthiness in a research study was to provide the researcher with the tools that allowed credible findings to be produced. Lincoln and Guba's techniques (1985) of prolonged engagement (e.g., including persistent observation, and triangulation), peer debriefing, clarifying researcher bias, and member checking were used to maintain credibility in this study.

The researcher allowed sufficient time (approximately three years) to achieve adequate learning of the Latina culture, test misinformation, and build trust. By reaching out to the Latina community at large and by participating in community and support groups and meetings, and through ongoing dialogue with key informants, the researcher was able to gain a more in-depth understanding of Latina culture.

The opportunity to build trust was through reiteration to Latina participants that all information was kept confidential, identity and responses remained anonymous, there

were no hidden agendas, and input would influence the inquiry process. Many participants asked what prompted the study; the researcher responded that the CIPM experience had previously been studied in white women and was not understood in Latinas. Six participants (30%) included personal thank-you notes with their returned signed consent form, and expressed their support and reiterated enthusiasm for the study.

Prolonged engagement also allowed for the building of relationships and developing rapport with participants via member checks and follow-up interviews, and throughout the community to obtain a wide scope of accurate data. Feedback from the national breast cancer database was also elicited regarding the interview process, and participants described a positive research experience.

Triangulation was used as another mode of improving the probability that findings and interpretations would be credible. Triangulation was accomplished by using a range of collateral data sources in addition to interview, demographic data, BASH, and PHI data to support interview data when writing results.

The process of exposing oneself to a peer who has no vested interest in the research study is called peer debriefing. This process also allowed the testing of the working hypothesis to occur. Peer debriefing included formal and informal discussion that served as an opportunity for the inquirer to “clear the mind of emotions or feelings that may be clouding good judgment or preventing emergence of sensible next steps” (Lincoln & Guba, 1985, p. 308). The researcher reflected on past experiences, biases, prejudices, and orientations that likely shaped the interpretation and approach to the study (Creswell, 2007) with the dissertation chair, professional Spanish interpreter, and a colleague—especially following an emotional interview.

The final method of achieving the goal of trustworthiness was to include member checks in order to receive critical feedback about factual errors or interpretive deficiencies (Polit & Beck, 2012). This was achieved by continuous (formal and informal) checking of interview data, review of written work, and summarizing the final report with stakeholders (dissertation chair, professional Spanish interpreter, five study participants, and collateral data sources) since member checking is seen as “the most critical technique for establishing credibility” (Lincoln & Guba, 1985, p. 314).

Applicability of the study is seen as the transferability of the results. To ensure findings were transferrable between the researcher and those being studied, thick description was necessary (Creswell, 2007). Thick description resulted as the study of Latinas emerged to enable another scientist to transfer empirical matter.

**Reflexivity.** Reflexivity was employed by the researcher, who had chosen this area of research because of a passion for the topic, and personal interest that stems from experience, and with some degree of knowledge about the intended area of study (Birks & Mills, 2011). From a feminist perspective, reflexivity enabled the researcher to subjectively acknowledge her own perspective and develop an understanding of the participant’s position in this particular context (Cook & Fonow, 1986).

The researcher acknowledged the need for the continuous process of reflexivity (self-reflection of one’s personal biases, preconceived notions, assumptions, theoretical predispositions, and ideological commitments inherent in qualitative research). Field notes that recorded personal experiences, reactions, and insight into feelings were utilized and shared with the dissertation chair and a colleague. This reflexive practice promoted transparency by the researcher in a presupposed power relation embedded in researcher-

participant relationships (Anderson, 1991; Harding, 1987), which is important in the study of Latinas.

**Collateral data sources.** As with other research methods, the use of inductive analytic techniques on data sets generated through sources different from interview or observation are utilized in ID. Through informal discussions with key informants, participation at breast cancer support groups, attendance at a Barbershop Outreach Program, Livestrong© Cancer Survivorship Training for Promotores and Community Health Workers (CHW), review of 54 social media pages via Twitter © and Facebook ©, magazines, local and national political news (television, online, and newspaper format) related to Latinas, a wealth of information was captured in field notes.

Key informants described widespread disparities and lack of information among Latinas with breast cancer, despite ongoing work with patient navigators to close the gaps. Language barriers, income levels, and limited or no access to healthcare were described as the “perfect storm” in contributing to Latinas’ vulnerability.

The researcher attended a breast cancer support group at a local woman’s center with eight women from a variety of ethnicities and ages. The atmosphere was welcoming, and group members shared a variety of concerns and strategies regarding recent post-operative complications from reconstruction surgery, how to manage ongoing lymphedema, when to report new onset of hip pain, the pros, cons, and side effects of starting aromatase inhibitors (AIs), and provided updates on the health of regular group members not present. All women were English-speaking and thought by the researcher to be within the age range of 50 to 80 years old. All members were noted to be postmenopausal per their discussion about AI use. Finding a bilingual or Spanish breast

cancer support group within 50 miles of the researcher's home or workplace proved to be a monumental challenge despite dozens of phone calls and e-mail inquiries to surrounding hospitals, women's centers, and national cancer organizations with offices within that radius. Bilingual support groups listed on Websites were never organized or held, or were earmarked for all types of cancer regardless of gender. Finally, two groups for Spanish-speaking Latinas with breast cancer were found 50 miles east and west of the researcher's home.

The Black Barbershop Health Outreach Program, as part of a larger national initiative, represents barbershops as cultural institutions that regularly attract Black and Latino men. This program provided an environment of trust and an avenue to disseminate health education and information (Gomes, & McGuire, 2001). Attendance at this program was recommended by a key informant as a potential model for future information dissemination and intervention work with Latinas with breast cancer through neighborhood beauty shops.

By taking part in a Livestrong© Cancer Survivorship Training for Promotores and Community Health Workers (CHW), the focus on understanding current strategies to improve the quality of life of Hispanic/Latino cancer survivors was evident. Promotores and CHW were trained to work together with cancer survivors, to keep track of the day-to-day physical and emotional concerns of cancer survivorship.

Twitter© and Facebook© pages were all cancer or health related, and most were specific to breast cancer. They included personal blogs, physician and nurse pages, local organizations and foundations, and national or government organizations and institutes that "tweeted" or "posted" information from a variety of perspectives. Many of these

pages were specific to Latino/Latina health; some had a breast cancer focus. Much of the focus was on having a voice or active role in asking questions regarding cancer, continuing cancer disparities, the impact of culture and community on cancer screening and care, health behaviors to avoid (alcohol, smoking, and obesity), socioeconomic factors, access to care and health insurance, and the importance of culturally proficient care.

Latina magazines informed readers how to do breast exams, the importance of making time for screening mammography (even if feeling healthy), demystifying the mammogram procedure, how to overcome being “scared” in order to improve early detection relative to survival, reducing risk factors through exercise, eating well and keeping body mass index below 25. Magazines also included information about increased risk to readers if a family member had breast cancer, if they started their periods early, or if they had children later in life. Biological differences among Latinas are also described as a potential cause for poorer survival rates when compared to other ethnicities. Taking control was a major theme. One breast cancer Website for Hispanic American/Latina women quoted Maria Yanez: As an old saying goes, “No hay peor lucha que la que no se hace,” which translates in English as “There isn’t a worse fight than the one that isn’t made.”

In September 2012, cancer was reported on television via CNN Health to have surpassed heart disease to become the leading cause of death among Hispanics in the U.S. (ACS, 2012). From a political perspective, education, jobs, healthcare, and immigration reform were the top issues for Hispanic registered voters in late 2012; 50% of

respondents cited healthcare as extremely important with more reporting concern about healthcare than immigration (Pew Research Hispanic Center, 2013).

The U.S. presidential election in November 2012 highlighted Latino population trends and voting practices. The Hispanic population is the fastest growing population and the largest minority group in the U.S.; Hispanics make up approximately 16.3% of the population, with an increase to 19–24% expected by 2050 (U.S. Census, 2010a). Latino registered voters preferred President Barack Obama over Republican challenger Mitt Romney by 71% to 27%; Latinas voted for Obama over Romney by 76% to 23% despite having the longest polling place wait times when compared to non-Latino white, and African-American voters (Pew Research Hispanic Center, 2013).

Common patterns from all collaborative data sources included (a) reducing cancer risk through certain health behaviors, (b) awareness of risk factors specific to Latinas, (c) establishing trust, (d) conquering fear, (e) the importance of screening, early detection and treatment, (f) how to communicate and through which avenues, (g) the importance of having a voice in the political arena, (h) need for information dissemination, (i) impact of disparities, (j) getting support, and (k) improving QOL. These patterns align with interview data and may represent a shift in focus to improve Latinas' health.

## **Summary**

The purpose of this qualitative exploratory study was to describe the experience of chemotherapy-induced premature menopause among Latina women with breast cancer. The interpretive description approach by Thorne (2008) and Thorne et. al (1997) with feminist underpinnings was used to identify the problem area in this study as it aligns more closely with a postmodern approach.

An overview of the sample, inclusion and exclusion criteria of potential participants, and setting have been discussed. Data collection, management, and analysis techniques using the ID method have been outlined. The protection of human subjects, with potential implications and strategies for inclusion of Latina participants, trustworthiness techniques, and reflexivity have been discussed. The findings of this study provide an interpretive description of the participants' experience with CIPM to inform practice and for targeted intervention studies.

## Chapter IV

### Findings

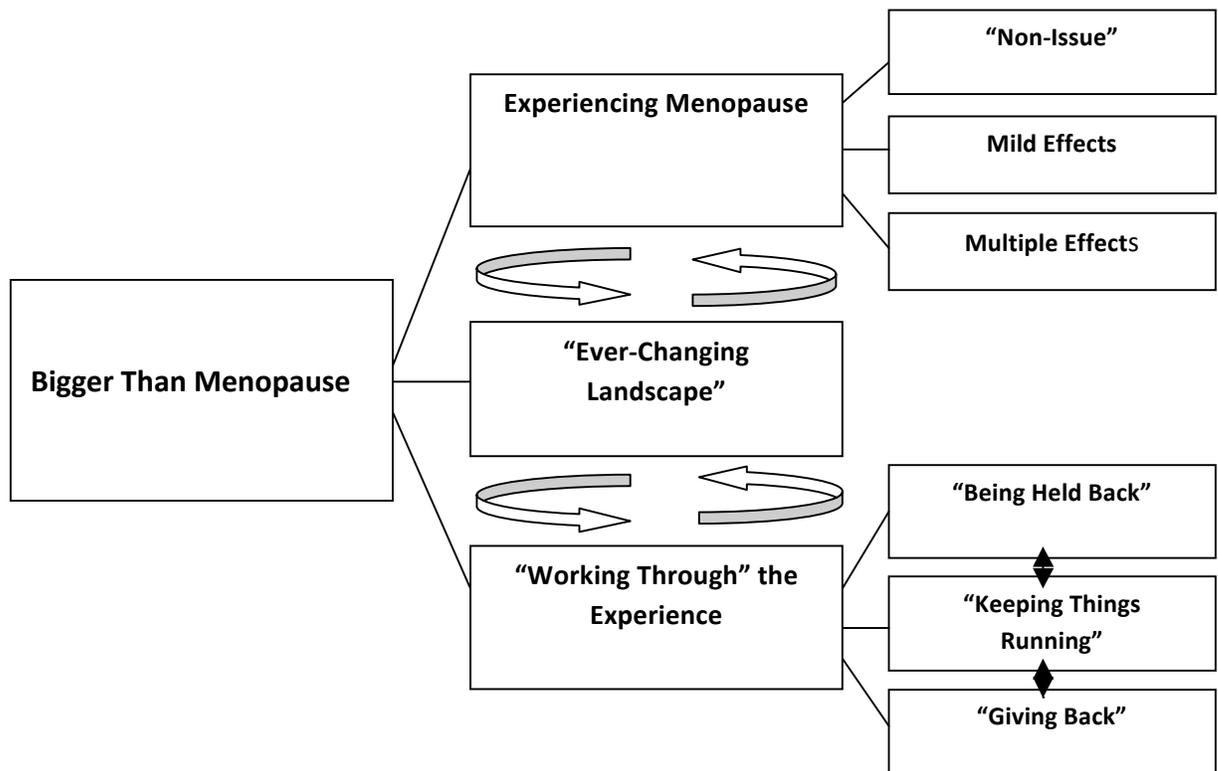
#### Introduction

Interpretive description (ID) methodology with feminist underpinnings, and Knobf's "Carrying on" theory were used to analyze data regarding Latinas' experiences with chemotherapy-induced premature menopause (CIPM) from breast cancer treatment. Sample characteristics and illustrative participant quotes have been provided for the overarching theme and subthemes. The use of quotation marks for the themes and subthemes signifies the participant's own words from the interviews. While it is impossible to elucidate physiological effects from psychosocial effects, overlapping characteristics were noted in the review of the literature, as well as in the participants' recollection of their experience.

One overarching theme, *Bigger than menopause*, and three subthemes, *Experiencing menopause*, "Ever-changing landscape," and "Working through" the experience were discovered from the data. *Bigger than menopause* describes the experience that participants had with a concurrent cancer diagnosis, treatment course, and menopausal experience, and how these were assimilated into their lives. *Bigger than menopause* is comprised of three subthemes: *Experiencing menopause*, "Ever-changing landscape," and "Working through" the experience. The first subtheme, *Experiencing menopause*, describes the experience of physiological effects of menopause from chemotherapy treatment by participants and is comprised of three categories: "Non-issue," *Mild effects*, and *Multiple effects*.

The second subtheme, *“Ever-changing landscape,”* describes the experience of physiological and psychosocial effects from diagnosis and treatment by participants as a complex point in time with shifting perspectives throughout the cancer trajectory. The final subtheme, *“Working through” the experience* describes how participants assimilated a cancer diagnosis, treatment course, and menopause experience into their lives and was expressed through three categories: *“Being held back”* (facing barriers), *“Keeping things running”* (establishing a sense of normalcy), and *“Giving back”* (advocating for others). The overarching theme, subthemes, and categories are depicted in Figure 2.

Figure 2. Overarching Theme, Subthemes, and Categories



## Sample

A total of 22 women who met the inclusion criteria were recruited for telephone interview. Interview data from two women were excluded from final analysis as they were later found not to meet the inclusion criteria. One woman experienced CIPM > 15 years ago, and the other had received treatment for breast cancer outside of the U.S. Therefore, all results that follow were based on interviews with 20 study participants. Five percent ( $n = 1$ ) of the final sample were recruited through a newspaper interview of the researcher, ten percent ( $n = 2$ ) from a women's health center; and 75% ( $n = 15$ ) from a national breast cancer database. Two participants (10%) were accessed via snowball sampling. Eight additional women expressed interest in the study but were not eligible based on the following: no treatment with chemotherapy ( $n = 1$ ), already postmenopausal prior to chemotherapy ( $n = 1$ ), non-Latina by report ( $n = 2$ ), or did not answer initial or follow-up phone calls or e-mail messages ( $n = 4$ ) to determine eligibility. It was noted that potential participants who expressed interest in the study were more likely to follow through with the interview process when contacted the same day by phone or e-mail. Data collection occurred between May 2012 and December 2012.

Demographic data questionnaires (Appendices C1 and C2) included use of a professional Spanish interpreter, age at time of interview, marital status, state of residence, work status, years of education, annual household income, adequacy of income to meet household needs, country of birth, years living in U.S., breast cancer stage, breast cancer treatment, number of years since diagnosis, and insurance status. Protected health information (PHI) including tumor marker pathology, and genetic mutation testing were

collected and reported in detail, including a glossary of tumor marker and genetic mutation definitions (Appendix E).

Table 2 illustrates in detail the demographics of the study participants. The final sample included 20 Latinas from 12 states in the U.S., with a mean age of 48.2 years (SD 6.8, range 38–60). Ten percent of participants ( $n = 2$ ) requested the interview in Spanish. Fifty-five percent ( $n = 11$ ) were married, and 75% ( $n = 15$ ) worked either full-time or part-time, with a mean education level of 15.2 years (SD 2.9, range 10–19). The mean annual income of the sample was \$80,287 (SD 50,503, range 0–\$200,000). Seventy-five percent ( $n = 15$ ) reported their income as adequate or more than adequate to meet their household needs. Ninety percent of the women reported having health insurance. Sixty percent ( $n = 12$ ) were born in the U.S., followed by 10% born in Puerto Rico ( $n = 2$ ) and Mexico ( $n = 2$ ), and 5% ( $n = 1$ ), in the countries of Brazil, Cuba, Guatemala, and Spain. Of those not born in the U.S., the mean age of years living in the U.S. was 32.0 years (SD 11.4, range 13–46).

The majority of participants (70%) had stage 2 or stage 3 breast cancer. The average number of years since initial diagnosis was 4.6 years (SD 2.6, range 0.17–11). Two participants (10%) reported a recurrence of breast cancer, although their data were comparable to other women in the study. The majority of study participants (65%) had a combination of chemotherapy, surgery, and radiation treatment. Nine participants (45%) were prescribed AIs, 40% ( $n = 8$ ) Tamoxifen®, and 15% ( $n = 3$ ) trastuzemab.

Tumor markers of three participants (15%) were reported as ER/PR (+), Her2 neu (-) and P53 (-), followed by those of two participants (10%) as ER/PR/Her2 neu (-), one participant as ER/PR (+) Her2 neu (-), and one participant as ER (+)/PR (-) Her2 neu (+).

Three participants (15%) had information and results for BRCA1 and BRCA2 testing, which reported no mutations; 17 (85%) participants did not have BRCA1 and BRCA2 results in the returned reports. It is not known whether participants were tested for these mutations.

Table 2

*Participant Demographic Results*

Category	Participant Response (N)	Percentage
State		
• California	7	35
• Arizona	2	10
• Massachusetts	2	10
• Alaska	1	5
• Florida	1	5
• Illinois	1	5
• Michigan	1	5
• Missouri	1	5
• Montana	1	5
• New York	1	5
• South Carolina	1	5
• Washington	1	5
Age		
• 30–40	3	15
• 41–50	10	50
• 51–60	7	35
Marital status		
• Married	11	55
• Separated/divorced	5	25
• Single	3	15
• Widowed	1	5
Work status		
• Full time	12	60
• Part time	3	15
• Disabled	2	10
• Other	2	10
• Retired	1	5
Highest education level		
• GED	2	10
• High school diploma	4	20

• Associate's degree	5	25
• Bachelor's degree	3	15
• Master's degree	5	25
• Doctoral degree	1	5
Annual income		
• <10,000	2	10
• 10,001–30,000	0	0
• 31,000–50,000	3	15
• 51,000–70,000	2	10
• 71,000–90,000	5	25
• 91,000–110,000	1	5
• >111,000	4	20
• Missing	3	15
Adequacy of income for needs		
• Less than adequate	5	25
• Adequate	12	60
• More than adequate	3	15
Insurance		
• Private	14	70
• Public	4	20
• Uninsured	2	10
County of birth		
• United States	12	60
• Mexico	2	10
• Puerto Rico	2	10
• Brazil	1	5
• Cuba	1	5
• Guatemala	1	5
• Spain	1	5
Years of residence in U.S.		
• 10–20	2	10
• 21–30	1	25
• 31–40	4	40
• 41–50	1	30
Stage of disease at diagnosis		
• Unknown	1	5
• 1	5	25
• 2	8	40
• 3	6	30
Type of treatment		
• Chemotherapy only	1	5
• Chemotherapy and surgery	6	30
• Chemotherapy, surgery, and radiation	13	65

Other treatment		
• Aromatase inhibitor	9	45
• Tamoxifen	8	40
• Trastuzumab	3	15
Tumor markers		
• ER/PR/Her2 neu (-)	2	10
• ER/PR (+)	1	5
• Her2 neu (-)		
• ER(+) PR (-)	1	5
• Her2neu (+)		
• ER/PR (+) Her2neu (-)	3	15
• P53 (-)		
• Missing	13	65
Genetic mutations		
• BRCA 1 and 2	3	15
• No mutation		
• Missing	17	85

The mean participant acculturation BASH score was 4.2 (SD 1.1, range 1–5). Eighty five percent ( $n = 17$ ) of women scored  $> 2.9$ , indicating that they were highly acculturated, and 15 % ( $n = 3$ ) of the participants were less acculturated (scored  $< 2.9$ ), resulting in a highly acculturated sample. Cronbach’s Alpha coefficient for the BASH in this study was 0.92.

### **Chemotherapy-Induced Premature Menopause Among Latinas With Breast Cancer**

Participants were first asked the broad question (Appendices B1 and B2), “Can you tell me what it was like to experience menopause from your chemotherapy treatment?” All vividly recalled their experience, with nearly 75% answering the question by describing the physiological effects from treatment, and the point in the chemotherapy cycle when their periods stopped. As participants described their physiological effects, they often had difficulty in differentiating their symptoms as being an aftermath of menopause or from chemotherapy treatment. As probes were used, participants described

psychosocial effects that occurred simultaneously during their treatment course. Many women incorporated their own strategies to help manage physiological effects; others reached out for support with psychosocial effects. What one participant found helpful in a particular situation or as a positive resolution to an effect, another participant did not.

Participants shared thoughtful individual and personal reflections about the impact of the experience on themselves, their families, and community. Stretches of silence occurred at times during interviews where probes were then used, per the interview guide, and based on previous interview data to illicit responses. In addition, some participants seemed distracted during the telephone interview due to interruptions at home or work, or from driving in their car. Several women spoke very quietly or quickly and seemed upset through their verbal intonations during the interview. One participant described being “emotional.” Those women were offered support and given the option of stopping the interview, but all opted to complete it.

Participants described themselves as “shy,” “modest,” and “proud.” They maintained that their cancer diagnosis and menopause experience had “put things in perspective” for them. One woman said, “It’s the best thing to be alive at this point, is the way I look at it. And it’s the best thing that I live my moments to the max because you never know.” This sentiment was reiterated many times. A strong character and personality were described as being essential by several participants. They described an attitude of “fighting” for themselves and their families following their breast cancer diagnosis. They also shared their passion for telling their story as a way to help other Latinas with breast cancer.

**Bigger than menopause.** *Bigger than menopause* was the overarching theme as described by study participants. This theme was generated by participants as a result of reflecting that their menopause experience was part of a larger context. Women described the physiological effects of menopause and their ability to manage these effects (subtheme: *Experiencing menopause*). They also described the impact of physiological and psychosocial effects as being a “complex experience” with “so many things going on at the same time.” This included maintaining relationships with HCPs, changing family roles, upholding work obligations, garnering information and support, respecting cultural norms, and addressing spirituality (subtheme: “*Ever-changing landscape*”). “*Working through*” the experience describes how participants assimilated a cancer diagnosis, treatment course, and menopause experience into their lives. One participant stated, “The cancer was worse than the menopause. I mean I could have menopause and be just fine.” Another participant described this time:

For a woman who is not going through cancer treatment and chemo, but is going through menopause and all of that, is like stop; and your emotions are as mean as it is. And then to be going through that [treatment] and having it [menopause] makes the night sweats and all that stuff even worse.

**Experiencing menopause.** The first subtheme that developed from the *Bigger than menopause* theme was *Experiencing menopause*, comprised of three categories: “*Non-issue*” (effects were minimized in relation to cancer diagnosis), *Mild effects* (effects were few in number and self-managed) and *Multiple effects* (effects were several in numbers and not self-managed).

Sixty percent of participants ( $n = 12$ ) received verbal or written information from their HCP that they may experience menopause from chemotherapy. One woman described her preparation when she said this: “I expected it and was told it was going to happen. I wasn’t surprised when it started to happen.” One woman stated she was informed about CIPM when “they give you a book, you know, so it has all of the symptoms of what you’ll be experiencing.”

***Physiological effects.*** Participants described a wide variety of physiological effects from their CIPM experience (Table 3). Strategies utilized to minimize physiological effects were also described. Amenorrhea was common among all women, with hot flashes and changes in mood being the most pronounced effects. Hot flashes varied in time of onset, intensity, frequency, and duration. Some characteristics of hot flashes, as part of the CIPM experience, were described as being like “an oven,” “something burning from the inside out,” and “a feverish kind of thing.” For some women, hot flashes were prominent “immediately upon starting chemotherapy,” and for others, they began after a “month or two.” The strength of hot flashes was reported as not being “that bad” to being “intense,” “really hot,” and “uncomfortable.” Some women described having “2–3 episodes of hot flashes per day,” while others described them as being “very, very frequent.” One participant described her CIPM experience this way:

It turned out to be surprisingly upsetting, just because it was another thing outside of the norm and not a choice, not that menopause is a choice for anyone. But I just felt it was difficult to deal with, and then I had hot flashes and that sort of thing; it was quite challenging.

A decrease in appetite was also described. For some women, the change in appetite was related to chemotherapy treatment and medications that were taken simultaneously to minimize treatment side effects. They described food as tasting “bad” or an overall decrease in food intake during this time. Fatigue was described ranging from being a short-term effect: “I don’t have my get up and go like I used to” to a prolonged effect: “there’s still some fatigue. It was really bad when you’re going through it, but they did say it takes years.”

Sexual dysfunction was described by the women as decreased libido with “no sex drive whatsoever” or “issues with sex because of the menopause.” One woman stated, “I couldn’t have an intimate relationship with my husband.” Fertility was not reported as a concern by participants, but may be related to the mean sample being > 40 years of age and none had planned to have children at the time of diagnosis.

Table 3  
*Reported Physiological Effects*

Effect	Participants	Percentage
Amenorrhea	20	100
Hot Flashes	18	90
Appetite Change	9	45
Fatigue	9	45
Sexual Dysfunction	9	45
Night Sweats	8	40
Sleep Disturbance	7	35
Cognitive Impairment	6	30
Pain	6	30
Headache	5	25
Nausea	4	20
Weight Gain	4	20
Genitourinary	2	10

Other experiences, including night sweats, sleep disturbance, cognitive changes, pain, weight gain, and incontinence, were also depicted. Some women described having night sweats but did not recall their impact as being negative. Others described their experience with night sweats as “interrupting their sleep” and being “uncomfortable.” One woman described the experience like this: “I remember waking up in the middle of the night and sweating completely and it was not so very nice.”

Sleep disturbance was described by some participants as intermittent. For other women, the impact of sleep disturbance was recalled; one woman stated she had “a lot of trouble sleeping during treatment. I didn’t sleep at all. Like, I would sleep a couple of hours here and there.” Another described her difficulty with sleep this way: “You know how you feel so tired but you cannot sleep and you feel like screaming? That’s how I felt.”

Several women described cognitive impairment (i.e., memory, thinking, or concentration) from CIPM. Several participants described “chemo brain” as a short-term effect. One woman stated, “My memory overall is not the same as it once was and I don’t know if I can attribute it to menopause or the chemo but they kind of went hand in hand” and “I had quite a bit of difficulty thinking or remembering things.” Women ( $n = 4$ ) with home responsibilities or careers that required them to remember a lot of information or to think critically described the negative impact of being cognitively impaired. One woman had a vivid recollection of her experience with cognitive impairment in how it related to her career:

I definitely felt a precipitous decline in my memory, and just my ability to absorb information and write about it in the way I had been used to,

dramatically decreased in the immediate aftermath of chemotherapy, and the next year or so. It has improved somewhat or considerably it's improved...I'm just not as sharp as I used to be. It definitely feels now like I've lost my edge. I don't remember things, details of things that used to please me to be able to remember. So the change was so stark, before and after treatment, that I can't think it's just normal aging. I'm just—my ability to focus and concentrate for long periods of time has declined and continues to not be what it was before.

Several women described muscle, bone, and joint pain as effects from treatment. They mostly attributed their pain to Neulasta® injections they received following each chemotherapy treatment. Despite its origin, they described how the pain interfered with and had a negative impact on their ability to exercise during treatment, as well as being able to work at home and in their job. Women also described headache and nausea, but felt most likely these effects were a result of chemotherapy or other medications they were taking at the time. Several women described their experience with weight gain following treatment. One participant said, “I guess the other thing I would notice is I have, I have gained probably about 20 pounds. And I'm gaining it in my stomach, where I never, you know, I really have always gained it everywhere.”

The impact of physiological effects from menopause is described by participants through a wide range of experiences. Three categories emerged from the *Experiencing menopause* subtheme: “*Non-issue*” (effects were minimized in relation to cancer diagnosis), *Mild effects* (few in number and self-managed) and *Multiple effects* (several in numbers and not self-managed). Thirty five percent ( $n = 7$ ) found the menopause

experience was easier due to perimenopausal status at time of treatment and described the transition as “positive,” feeling a “sense of relief,” or “waiting for it to come.” One woman described this time as “I did not expect to have periods for much longer anyway, and so the fact that they finally stopped was almost a good thing.” Another woman expressed “the fact that I didn’t have a period was really not a big dot on the radar. It was truly a non-issue for me” (category: “*Non-issue*”).

Twenty percent ( $n = 4$ ) described mild effects from menopause (category: *Mild effects*). They described the onset of amenorrhea, and experiencing “just hot flashes.” One participant described her experience this way: “Even my hot flashes weren’t that severe. It was very minor. If they would last like maybe twenty seconds. And it was really, really minor. I would say 4 or 5 a day.” Several participants ( $n = 7$ ) described complications they attributed to chemotherapy and radiation treatment (e.g., neutropenia, uncontrolled blood sugar levels, cardiomyopathy, hyperthyroidism, hypotension, stroke, sepsis, perforated bowel, and severe radiation burns). They viewed menopause as a secondary concern overshadowed by a shift of their focus to the complication as it unfolded. One woman explained, “I didn’t know if all this other stuff [perforated bowel] was more important for me, but I forgot that I was in menopause.”

Forty five percent ( $n = 9$ ) described the impact of multiple effects (category: *Multiple effects*). They described the transition as “emotional,” “uncomfortable,” “harsh,” and “difficult.”

**“Ever-changing landscape.”** A subtheme that emerged from the *Bigger than menopause* theme was “*Ever-changing landscape*.” Participants described the experience as “complex” and themselves as “uncertain” and “vulnerable.” Participants described a

sense of being “in way over my head,” and “brand new to this world of cancer,” starting at the time of diagnosis and continuing throughout treatment and into the survivorship phase. One participant stated, “You know everything happened real fast.” Another participant stated, “It ain’t over until it’s over and then it’s still not over,” to explain the durability of the experience. One participant articulated her thoughts in this context:

And I keep worrying about what the outcome was going to be. I found that at the beginning of the diagnosis, it’s an ever-changing landscape. And so just the anxiety of being on sort of a roller coaster was very anxiety provoking.

In addition to the *Experiencing menopause* subtheme, participants included the impact of psychosocial effects, as well as barriers they encountered, as part of their diagnosis and treatment experience that comprised the “*Ever-changing landscape*” subtheme.

***Psychosocial effects.*** Participants described a wide variety of psychosocial effects they experienced in conjunction with menopause experience (Table 4). Strategies utilized to minimize psychosocial effects were described.

Table 4  
*Reported Psychosocial Effects*

Effect	Participants	Percentage
Depression	15	75
Fear/Anxiety	14	70
•Disease Relapse	7	35
•Death	6	30
•Addiction	2	10
Frustration/Anger	12	60
Mood Change	10	50
Isolation	8	40
Insurance/Work Concerns	8	40
Loss	8	40
Body Image	7	35

Psychosocial effects included reports of “depression” among 75% of participants, although it was not known if they had been screened for depression, or if depression had been diagnosed by a HCP. Women’s descriptions of depression ranged from “I was never depressed” to feelings of “sadness” in reference to a particular point in time, to “I did experience depression because there were so many things going on at the same time.” Others stated that they had experienced symptoms of depression they did not report to their HCP. One woman described the impact of her depression: “I have a real depression, sometimes I don’t even want to live. I do not want to be like this.” Another woman described the impact of depression:

My experience with depression was that initially I was kind of just energized to fight it and get through chemo so I wouldn’t describe myself as depressed initially. I got severely depressed towards the end of treatment, towards radiation time, and I certainly recall my radiologist saying that was a very common experience to have surgery and chemo and sort of feel like you’re told the chemo is the worst of it, that radiation really isn’t so bad. Then the experience of radiation is extremely difficult after being through all the chemo and so forth, and so that was the point at which I really just felt true despair and I didn’t care one way or another what happened.

Several women described depression as related to specific “moments” during treatment, or other events going on simultaneously in their lives at that time. One woman described her experience with a “port”:

They couldn't find veins so we ended up putting a port in. And when they put it in, I got an infection. We were supposed to go to a play, my daughter and I. I got up in the morning and took a shower and all of this pus was coming out. I went "damn." So then I went running to the emergency room. That was the only time I was depressed. I was there all day and then I was feeling sorry for myself. I got my crying out.

Fear is also described, related to the following: a diagnosis of cancer, disease recurrence, death, and addiction to prescribed medications. Several participants described Hispanics as being "scared" regarding a cancer diagnosis for themselves or for someone in their circle of family and friends as it has a connotation of death. One woman had an overall sense of fear and stated, "Sometimes I just feel scared" or have "intruding thoughts." Another woman said this:

I was scared. This was new to me, being scared to that extent. This was a new; feeling a feeling of "I have no answer." What am I going to do? I don't know what to do. I can't turn that way; I can't turn this way. There's no one I can call. There's nothing I can do to fix this.

Several women described their fear of a recurrence of disease, and were not aware that they could have a recurrence many years after initial treatment had ended. One participant shared this: "The worry of recurrence was overwhelming." Fear of death was articulated by several women and described by participants: "It is hard to allow yourself to think 'Am I going to be here in ten years?'" and "The most difficult part was I was really concerned about leaving them [young daughters] and the effect this would have on them. So yeah, that was the most difficult part, just because they were little."

Two women who were prescribed medications for sleep difficulty and symptoms of depression explained, “But no, it’s addicting and I don’t want to become an addict and then you tell me that you’re not going to give me medicine because I’m an addict.” And the other said, “She [HCP] did suggest a narcotic that you can become addicted to, and I decided to see how far I could take it without it,” which may have impacted their ability to manage those effects.

Anxiety was described in several ways by the study participants. As with reports of depression, anxiety was the term most commonly used to describe certain points of the women’s experience. It was not known if women were screened for, or diagnosed with, anxiety by their HCP. Some women described a sense of being “very jumpy,” “antsy,” or “fidgety.” Others described “true despair” and “shock” as a reaction to their breast cancer diagnosis. One participant shared how she would “cry for everything”:

I was supposed to be okay but I was crying. I couldn’t be alone like on my days off. I was like panicked to be alone. I guess I didn’t want to deal with what’s going on and finally, you know, I thought I was crawling out of my skin. Anxiety attacks. I would just start eating my nails and the skin on my nails to where I would make me bleed and I didn’t realize it. I think I was, that I was so stressed and I would never do that before.

Frustration and/or anger were also common reactions described by the women but were detailed from many perspectives. Participants stated being “mad and short and pissed” and “irrationally angry.” Others expressed frustration with Latinos’ lack of information and education regarding breast cancer, denial about cancer among Latinos, dealing with a myriad of symptoms simultaneously, lack of financial assistance (i.e.,

housing, food, reconstruction surgery), lack of appropriate breast cancer support programs (i.e., language and age appropriateness), and anger at God. One woman described being “mad at God” because of her diagnosis and having young children: “At that time, there was an anger in me. My youngest was only four months old when I was diagnosed, so I didn’t see why God would let something like that happen.” These psychosocial effects are later described as barriers.

Half of the participants ( $n = 10$ ) described changes in mood as a subsequent effect of menopause. They described being “moody,” “emotional,” and “going up and down.” Some described this as being a new experience for them. Some women expressed that they did not always perceive these changes in themselves, but that their family members made them aware. Changes in mood are described by one participant: “But moody, that moodiness, a lot of moodiness...very similar to, you know, like PMS, where you know, kind of irrationally angry, easily emotional.”

Forty percent ( $n = 8$ ) of the women vividly described their experience with isolation that coincided with their CIPM experience. Isolation was not identified during the review of the literature for this study. As with other effects, there were varying degrees of isolation reported. One woman described isolation as occurring “with chemotherapy, but not with menopause.” Another participant described her experience: “To be honest, I have no desire for anything or to do anything. I don’t want to be around anybody; very sad.” One participant described her feelings of isolation and anxiety as the result of her compromised immune system:

I went to my first appointment with the chemotherapist and then my hair fell out and I was anxious about that. And then my eyebrows and

eyelashes fell out; it was the whole immune system going down. Just constantly having to use hand sanitizers and not go to public places. I was really isolated. And that made me very anxious. I think it was more of an internal anxiety more than anything. I'm an avid moviegoer, and I stopped going to movies. I love to go out and eat, and I stayed away from restaurants. I would go to bookstores, then I started ordering my books online or downloading them to my iPad. It was just the fear of being around people and getting sick.

Another participant recalled her awareness when asked if she experienced isolation:

I definitely felt isolated. I felt isolated from everyone even though I continued to come to work, and you know participate in activities at my kid's school, and so forth. I just felt like, just separate and apart from everyone else in the world. A couple members of my family were ready for me to stop complaining and-and so it felt like you know, rather than getting support at the end when I most needed it, they were as weary of the process as well, and wanted to pretend that it wasn't there, and have me, you know, just take it on the chin a little better. But that was the point when I was really feeling so alone and nobody else in the world understood.

She went on to describe the difficulty with the experience of feeling isolated in spite of being with people:

I have two sisters that I'm very close with and I even found it difficult to relate to them. They tried like crazy to stay, you know, there and helpful to

me and—but I was so angry and felt it was so unfair that I was not a likeable person to be around, even for people who wanted to be there for me. So the experience of isolation was extreme.

Two additional women stated that being isolated was by choice: “Um—maybe, I mean, I kind of wanted to be,” and “I was never isolated unless it was by personal choice by trying to get away for a moment” and not as a negative effect.

Even as 90% of participants had insurance (private or public) and had not incurred any treatment costs or difficulty with referrals, several women expressed concerns about their health insurance coverage. They described the inability to select their HCP of choice, have coverage for reconstructive surgery, and be reimbursed for services paid “out of pocket” as being negative. One participant stated that not having the ability to choose her own HCP “compromised my treatment” and that she went along with the recommended HCP because she “was the only one handling all that stuff and just couldn’t deal [advocating for herself] mentally.”

Two participants without health insurance described their experience when first diagnosed with breast cancer: “I was referred to one of the best doctors in [city], and because I didn’t have insurance, the doctor was not able to see me. I was turned away from supposedly one of the best doctors at the hospital because of no insurance.” This same participant also described the inability to have reconstructive surgery. She stated that when she finished chemotherapy she “wanted to do reconstruction, I was not able to do it because of lack of insurance. I’ve heard from other women that have tried to do, like, a double mastectomy. I’ve heard that the insurance will not cover both.” Another participant described the impact of being uninsured this way: “I could not receive

healthcare since I did not have a medical/health plan and no money to pay. I lost everything in [state]. I had my house, my work [home business], and I had to leave everything.”

This period was also identified as a time of significant losses: self, self-esteem, identity, control, and their hair. Loss of self is described by several women as being “not me anymore” and “I’ve never been the same.” Another participant said, “I went through a lot of like, after the chemotherapy, like my body just hasn’t been the same anymore.” Loss of self-esteem is described by one participant: “It made me feel older, less attractive. It definitely, you know, hit my self-esteem.” Another participant described her experience with losing her hair as the first of many losses when stating the following:

That was the hardest. That was hard—I have long—not long, it goes below my shoulder and I knew it was going to fall out so I had chemo, and two weeks—one or two weeks after chemo—I cut my hair like a pixie cut. And I cried a lot that day. I’m getting my hair cut not because I want to, but because I have to. And after I had the second round of chemo, she just buzzed it. I didn’t want to find hair all over the place. First I cut it off short so I could get used to that, and then two weeks after that was when I buzzed it. Bite the bullet; it’s going to go. It was upsetting, real upsetting. I think that’s harder than anything else. It was wrong when I had to shave my—my hair went away before the reaction to the chemo hit really bad. So the first thing that was hard for me was losing my hair.

One participant described this point in time as “becoming cancer girl.” She described this loss of identity “as whatever you were before the diagnosis, whether you were funny or

smart or whatever it was that you just become cancer girl and that's what everybody thinks when they see you, and I certainly came to dislike that."

Loss of control is described as "everything changed" and "I had not depended on anyone before" and I "always took my own decisions." One participant explained it: "I feel dependent with no choices." Another described regaining control over time: "I do still get a little bit emotional but nothing compared to when, even if you looked at me. I have control of me now." Another participant looked back and described it: "There was a time where that [loss of control] was difficult to accept, and that my life would be at this point it is from now on."

The women also expressed alterations in body image related to many changes going on with them simultaneously. Weight gain following treatment was difficult for several women. One participant recalled her body image at that time as "Not a big issue, but sure, I hated being bald. I hated losing my eyebrows and eyelashes. And I hate that my breasts are two different sizes and I have scars, yeah." Another participant explained it this way: "It was uncomfortable in the sense that I would get sweaty and self-conscious of whether I smelled—things like that." Regarding her body image following surgery, one participant offered this:

After the surgery for a long time, I kept bandaged because I didn't want to look at myself. I had to learn to look at myself in the mirror; to accept that I did not have a part of my body, and how it looks now. I have to learn to accept my body first so I can be in front of others.

Another participant described the impact of body image in more detail:

I worked very hard to try and stay looking sort of what I call normal or not sick. You know I did the wigs and false eyelashes and makeup and spent a lot of time doing that because I wanted to continue to operate in the world and not feel like a sick person.

**Barriers.** There were a number of barriers encountered by the women, which were described as beginning prior to diagnosis for some, and which continued throughout the treatment experience for others. These are listed in order (Table 5) with most reported barriers described first, although many women described a combination of these occurring simultaneously. Most of these barriers were thought to make the women’s experience more difficult or complex.

Table 5  
*Reported Barriers*

Barrier	Participants	Percentage
Lack of Information	15	75
Access to Healthcare	12	60
Support (financial/program)	9	45
Culture	7	35
Pink Ribbon Symbol	5	25
Language	2	10

Seventy five percent (  $n = 15$ ) of the women described information being provided to them in relation to their diagnosis as either non-existent, inaccurate, or incomplete from HCP in relation to breast cancer, cost and course of treatment, potential physiological and psychosocial effects from treatment, available support, complementary and alternative medicine (CAM), and insurance approval. Some women were able to

access information from the Internet that they deemed helpful, while others were overwhelmed by the information found there. One participant recalled this:

I'm one of those as soon as I found out my diagnosis, I was in the Internet. I was reading books, talking to people that had gone through what I was going through. For me, information is power. And so I wanted to be armed as much as possible.

Another participant described her experience on the Internet: "I kind of poked around on some online communities, but again thought they were kind of more negative. There was a lot of, like, there so many more bad stories than good."

A lack of information about breast cancer and treatment among their family members, friends, and community was also described, causing them to feel "powerless because they don't know what to do." One participant said this:

I think that they [Latinos] misunderstood it. There was some ignorance and I don't mean that in a bad way. There was some sort of unknown about what it was. When I was first diagnosed, what I knew about cancer was that people died from it. That's what I knew cancer was. But obviously I went through it and I started to research, and be more resourceful. My siblings were not willing to ever do that, or didn't know enough to get educated on it, because culturally, that's what cancer means. Once you get cancer, you'll die from it and there's no hope. They were not going beyond that.

Access to healthcare and appropriate support and programs were also identified as barriers by 60% ( $n = 12$ ) of the women. Barriers to access, per women's report included

the inability to choose their own HCP and/or specialists, lack of choices regarding treatment course and CAM options, little attention to individualized spiritual support, and convenience to nearby oncology clinics. These barriers were further hindered by lack of insurance, inadequate finances, and lack of transportation.

Lack of insurance and time constraints were also described as a limitation to screening mammography, receiving reconstruction surgery post mastectomy, and the ability to choose elective bilateral mastectomy when unilateral mastectomy was performed due to diagnosis of breast cancer in one breast.

Nearly half of all women (40%,  $n = 8$ ) expressed being “disappointed” in local agencies, and national breast cancer organizations where they were referred because needed financial support (e.g., housing, food, and reconstruction surgery) was unavailable. These agencies and organizations were found to offer little assistance for day-to-day financial concerns and needs. One participant made this observation:

It’s strange to have something [breast cancer] in common, and have services be out there, but not really feel welcomed to use them. And I forgot about that because they purport to be out there for all, and they say that, and they’re pretty proud of that, but they just don’t get it.

Twelve women (60%) felt support programs available for breast cancer patients were helpful and they described a “camaraderie” and sense of “being around people that felt the same way.” Through the support groups, they described learning about breast cancer and what questions to ask their HCP. Others did not feel comfortable being part of the available support programs because they could not relate to other women there (e.g., age, treatment, or disease course). Several women ( $n = 5$ , 25%) described a negative

experience when attending a support group, and one participant described her experience as “detrimental.” Women who attended programs that offered strategies to combat appearance-related side effects of treatment described them in a positive light.

The impact of culture was seen as a barrier in 35% ( $n = 7$ ), due to Latino beliefs, traditions, and religious practices regarding breast cancer that differed from U.S. culture. This was further described by women who felt as though they were treated differently by their HCP, family members, friends, and co-workers following their breast cancer diagnosis. One participant stated it this way:

Because we're all Latinas we would understand the culture of the area and understand why our husbands are acting this way, why our husbands don't understand, why our husbands left us because we're no longer good anymore in our culture. That's how we are made to feel, that once we have this we're not good anymore and that plays a number on your body image. Because we only have one breast, or we have no breasts, or one is smaller than the other, or one is lopsided, or one has scars. We women can have [inaudible], but on top of that, we're no longer desirable.

One other participant said this: “There was always a conflict between that understanding of the way it is done here [U.S.] and the way it's done in our culture and country.”

Regarding culture in Latinas, one participant gave this description:

They're very shy and they don't want people to know they are hurting, and I consider because I was like that too. Like, “I'm proud.” You want them to see that you can handle this. Maybe that's true for a lot of people, but I noticed it in a lot of Hispanic women. They're like the head of the house,

but you have to keep the house together, so they're not allowed to be tired or be sad you know. I don't know if that would be considered a barrier.

They can't express their emotions.

Another participant recalled her experience with the men in her family and community following a mastectomy this way: "They will not talk about it to this day. They don't want to look at it. I saw the difference in the way the [country] men treated me after surgery."

One participant described her mother's reaction to her treatment options: I struggled a lot with my mother because she, from day one, was in denial and she was like, "oh, you shouldn't, you know, get chemo. It's going to make you get, you're going to get, it's going to make it worse." Or "you're crazy for doing a bilateral mastectomy. You're ruining your body. You're ruining." You know, it was really hard for the culture to understand or realize, understand my decision, a bilateral mastectomy. It was really hard for the culture to understand why I had made such a, what do you call it, a heart or such a harsh decision to remove my breast, you know; I think that was probably the only culture shock that I had.

The impact of the pink ribbon as the symbol for breast cancer was initially conveyed by a participant during a later interview. The remaining 25% ( $n = 5$ ) of women described their thoughts when asked what meaning the pink ribbon symbol surfaced for them. One participant said this: "The pink ribbon obviously brings to mind breast cancer. And I wear the pink ribbon when I go to events and such. So it's definitely not something that I shy away from." Another described her stance regarding early awareness and detection:

I don't mind it [pink ribbon]. I don't love it. I don't embrace it. I don't like early awareness and early detection because, not that I don't like it, but I just don't think that's where the focus should be. I think we need to focus on a cure. And, and how do you, how do you avoid it in the first place. But, preventive, that's the word I'm looking for; prevention and a cure. Like, for somebody like me at age 36, when I'm not even on the radar yet for having mammograms. So I think we're all very aware. The efforts need to go into—cure, vaccines, environment; that kind of thing.

Another participant stated her thoughts:

Women are being used for money, to get money for a lot of things. I know research and everything costs money, but I watched a program on TV about women who don't agree with all this hype, and pink, and “oh wow, isn't this great?” and all that. It's not great. It's not great to have breast cancer, or to lose your breasts, or to take poison, or to be radiated. When you do all that, it's not great. I think women are being used. All this airbrushing, and “frou frou,” and all this stuff is all very condescending and very dehumanizing. Hispanic women don't like that.

Two women requested a Spanish interpreter during the interview process, with two additional women describing their observations and discussions with other Latinas regarding language as a barrier to receiving quality information and appropriate care. One participant shared this observation: “I started to realize because I spoke English, I do speak the language, and I would get more out of the services at the center than they were able to.” Another explained, “I don't know how a woman would cope [with a language

barrier]. I would see women really compensating [sic] under the circumstances. Yeah. It's pretty crazy." Even when information was available to English-speaking women, one participant noted that "Even for those of us who speak English—I have a lot of education, but there isn't a language to speak. There isn't that comfort. And then there's just not having the words." This lack of "language" was also seen by one participant as a potential barrier to participating in research studies.

One participant described her observations of the additional burden that undocumented and/or illiterate Latinas with breast cancer face: difficulty in access to language-appropriate information, and free care, which often leads to these women opting to forego prescribed treatment, even when available. She stated the following:

The majority would say "there was nothing for us." The majority of the women in our [support] group were undocumented women. They're not here in the U.S. legally. The federal made them not look for any help with health insurance. That was a major reason why they said there was nothing for us. They were afraid there was nothing for them because they're undocumented. That would scare them to death. "Oh, my goodness, they're going to send me back, and I can't go back."

Another participant described the difference in culture among Latinas, saying that they "need to appeal":

Mainstream America deals with things differently than Latinas. Maybe younger Latinas are different, but women my age and older, maybe forty and older, there's a different way of doing things. So that has to be considered. We have to know how to reach people and how to make it safe for people to talk.

Women ( $n = 3$ ) whose responses to the BASH scale found them to be “less acculturated” may face further barriers. These women expressed the greatest unmet need for support and information regarding risk factors, symptoms of breast cancer, meaning of diagnosis, financial concerns (insurance, housing, and food), transportation issues, language barrier, lack of treatment options, lack of information about treatment effects and symptom management, and cultural conflict.

**Easier or harder.** During the interview process, women were asked what made their overall experience easier or harder. Responses were extensive, but they shared common patterns. Many women described their age at time of diagnosis, relationships with HCP, family, friends, god, and community of support as either instrumental or detrimental, to whether their experience was positive or negative. Others took prescribed medications, implemented dietary changes, CAM, cultural practices, and exercise regimes into their lives, often to decrease treatment effects, establish an overall feeling of well-being, or to reestablish a sense of control.

All women were pre- or perimenopausal at the time of their diagnosis. While some women found it difficult to assimilate their breast cancer diagnosis into their lives because they were busy working or caring for children, others felt they were stronger and able to endure prescribed treatment than they would if they were older. One participant stated that she believed “I am very young to be going through this,” and one participant’s mother was described as being in denial: “Like this can’t be happening. You’re too young.” One participant explained the impact of age from her perspective:

I was 37 when I was diagnosed with cancer for the first time. I was very young. I did not know how to take in what was happening to me; that I

had cancer and may lose a breast. I did not understand, at that age. I thought that if I lost a part of my body nobody would care about me or love me anymore. Many people at that age think the same way. I told myself that I wanted to live, I was only 37 years old, and I wanted to move forward.

Age was also a factor when receiving financial support or during support groups. One participant described her inability to get housing assistance because she was “too young”; others described feeling uncomfortable at support groups with older women because their experience was different.

Nearly 75% of the women described a positive experience with their HCP.

Participant and HCP relationships that were positive included these factors: having an interpreter present, trust, kindness, positive discussions about treatment outcomes, options for treatment, holistic care, and information provided to facilitate understanding, appropriate referrals for services, and patience. Relationships described in a negative light included a language barrier with no interpreter present, lack of acknowledgement, feeling rejected and rushed, poor communication, lack of information, not being treated because of cost, and lack of integration of culture and spirituality into their plan of care. Women who described negative relationships, and were able to advocate changing HCP during treatment, were found to have a more positive experience moving forward. One participant stated that her HCP was “the number one influence” that made her experience easier. Counselors, psychologists, and psychiatrists were described as being very supportive “during all the phases you go through.” One participant stated her

psychologist was “kind of my champion when I didn’t have one.” They also stated that while their HCPs were important, they also shared responsibility for their overall health.

For most women, support of family was a positive attribute during their experience. Immediate family and close friends were noted to be helpful with meals, rides to and from treatment, and with their children. Some women described their husbands as a source of support, and children as being “supportive but not helpful”; for others, the opposite was true. Friends who have gone through breast cancer with a similar course of treatment were described as their “go-to” people.

Three women described the burden of their diagnosis as affecting their young daughters. One said, “They [daughters] grew up very fast; they changed from girls to young women to deal with me.” Other women felt as though they were treated differently by family and friends following their diagnosis. One participant described it: “the lack of knowledge in Hispanics didn’t help...they didn’t reach out as much.” One participant described her thoughts: “You know who your family and friends are after you are diagnosed with breast cancer. It’s almost like leprosy in some people’s eyes, unfortunately. But you know who your real friends are once you are in a thing like that.” Many women described support from family members not residing in the U.S. via phone conversations as being positive. Support from co-workers was also described as helpful during this time.

Women were vocal about the role of religion or spirituality during their experience. About 50% ( $n = 10$ ) reported being a part of, or actively participating in formal religion, while others had spiritual beliefs and practices that they found beneficial in helping them through this period. Along with prayer, the use of holy water, being part

of nature, meditation, reading the Bible and other spiritual books, and viewing religious DVDs were also seen as having a positive impact. Some women incorporated practices from several religions simultaneously into their lives, creating their “own spiritual path.” One woman stated, “I left it [my life] in God’s hands,” with the belief that God’s involvement would suffice.

Eighty percent ( $n = 16$ ) of the women described the role of prayer during their treatment as being positive. One participant said, “Hispanics, we pray every day no matter what. So it’s like, it’s just that normal. We pray a little bit more when we’re aching.” While they all described their individual prayer practices, many were also in the prayers of their family, friends, and communities (religious and geographical). Even if a participant did not pray herself, a sense of comfort when being prayed for, or “a peaceful feeling” when she knew others prayed for her. Another participant describes her ambivalence about being prayed for: “I noticed a lot of people had a hard time with the news, and they didn’t know what to say. And so then they said things [prayers] that made them feel better, and so I let them.” One participant described a negative reaction to others praying for her:

I had the opposite experience that some people were deeply religious would respond to me and offer prayers and in fact sort of proselytize to me a little bit. And I really didn’t like people doing that. I felt like they were managing their own sadness and anxiety about my condition by offering their religion as something that could help me. And I felt they were being pretty selfish in doing that because I didn’t relate to it.

During an early interview, one participant described her sense that the diagnosis was a challenge from God when she stated this: “God was challenging me to leave the kind of life I had at that time. It was like he was testing me to change to a better life,” and another participant felt it was “Kind of like my cross to bear.” Another participant recalled her mother thinking that her diagnosis was a result of witchcraft, which she described this way: “Well, maybe somebody did ‘witch’ my mother you know was like, believed that maybe it was witchcraft, and I was like, ‘no, it isn’t witchcraft.’”

Thirty five percent ( $n = 7$ ) of the women felt strongly that their diagnosis was not related to God; 30% ( $n = 6$ ) felt as though God had some control over their diagnosis; 15% ( $n = 3$ ) were unsure or “went back and forth,” and four women (20%) were not asked the question as they shared that they were agnostic or did not believe in a higher power. One participant explained her perspective:

I did not, nor do I feel that this was a punishment. I think that it was something I was not able to control. I know enough, and I’m realistic with the fact that there are diseases that can happen to anyone. So I don’t believe I was targeted. There are family members in my family that do believe that; they have said it happened for a reason. I don’t believe that, I don’t understand that, and I don’t see it that way, but I also don’t say that it’s wrong.

Another participant described it this way:

It has crossed my mind and God uses certain people for the sake of other’s suffering in what he wants versus what others want. Not for oneself but for the sake of others. So I kind of have to think it was God’s will.

One woman spoke of her ambivalence regarding this topic:

I don't think at the time I did. Now I do, but at the time, no. I was very fortunate; I was never given that, "you're going to die." I was looked at in the face and they said, "This is really bad. You need to get in and get this taken care of now"; that sense of urgency. I think now it's definitely God's will, I guess in that I'm helping other women...I figure it's part of God's plan and God's will that I use my experiences to help.

As described earlier, the role of support groups was fragmented among respondents. For some, finding a support group that was a good fit materialized for some women following an initial referral. These groups were characterized as being tailored to their specific needs as well as of their husbands and children, offering guidance regarding which questions to ask their HCP, feeling a sense of community, Latina-based, within their age group, and incorporating exercise programs. Other women never felt comfortable being part of a support group because of their husband's negative response to attending, their age, negative stories, lack of strategies to solve ongoing concerns, and not Latina-based. Several women who could not find a support group nearby, or were not comfortable with a group they attended, started their own support groups. Others described transportation to groups as an ongoing concern.

The use of CAM to combat treatment effects was described as being beneficial by some women. Reiki, visual and guided meditation, breathing exercises, massage therapy, yoga, music therapy, and acupuncture had varying degrees of usefulness in minimizing fatigue, hot flashes, and sleep disturbances. Some women drank herbal teas, used marijuana, and supplemented their treatment with vitamins and herbal medicines that

were not always sanctioned by their HCP. Women also described being offered homeopathic remedies by people in the Latina community, often without using them as they were unaware of the ingredients. Many women tried other strategies to reduce symptoms of hot flashes and night sweats, including use of fans, layering of clothing, and exercise to improve depression, anxiety, and sleep patterns.

Medications for reports of hot flashes, depression, anxiety, and sleep disturbance were usually helpful when prescribed short term. Those medications most commonly reported during interviews were Ambien® and Effexor®. Women had some concerns about adding additional medications to their treatment regime, and fear of addiction was also expressed.

Many lifestyle changes were implemented by the women during this phase in an attempt to improve their health. These included quitting smoking, decreasing alcohol intake, losing weight, eating organic foods, eliminating or decreasing intake of red meat, fast foods, sugary and fatty foods, and practicing various forms of exercise. The implementation of regular exercise by participants was touted as decreasing joint pain, improving cognition, minimizing hot flashes, improving sleep patterns, and decreasing symptoms of anxiety and depression. The most common exercise reported was walking.

Culture played an important role in the women's experience. Latina women describe themselves as not wanting to "do anything about" breast cancer because of fear that if they lose their breast, their husband will leave them. Latinos are described by participants as having a "dominant" role in their household. Denial, lack of information re: myths and misconceptions about diagnosis, treatment and CIPM were also reiterated.

**“Working through” the experience.** The third subtheme “*Working through*” the *experience* describes how participants assimilated a cancer diagnosis, treatment course, and menopause experience into their lives and was expressed through three categories: “*Being held back*” (facing barriers), “*Keeping things running*” (establishing a sense of normalcy) and “*Giving back*” (advocating for others).

The characteristics of categories were often subtle and overlapped at times, with women shifting back and forth between subthemes depending on their ability to adjust to vulnerability and uncertainty during each stage of treatment course, find support or information to overcome barriers and conflict, and assimilate the menopause transition into their breast cancer experience. The more information, accessibility to care, appropriate support, higher acculturation level, and sense of control participants had, the more likely they would progress from “*Being held back*,” to “*Keeping things running*,” to “*Giving back*.” One participant described this time:

They’re very shy and they don’t want people to know they are hurting, and I consider [sic] because I was like that too. You want them to see that you can handle this. Maybe it’s true for a lot of people, but I noticed it in a lot of Hispanic women. They’re like the head of the house, but you have to keep the house together, so they are not allowed to be tired or sad, you know.

**“Being held back.”** The category “*Being held back*” describes three participants (15%) who experienced barriers that included difficulty receiving information related to their diagnosis, treatment course, and potential effects from menopause, access to healthcare (health insurance, choices, and transportation) lacked comprehensive support,

were less acculturated, and described a loss of control. These women described themselves as “struggling” and experienced unpredictable and unresolved effects (physiological and psychosocial), and treatment courses, which was described by one participant as “*Being held back.*” One participant described the experience:

I started to realize that because I spoke English, I would get more out of the services than they were able to. I don’t know how a woman would cope [with a language barrier]. I would certainly see women really compensating under the circumstances.

**“Keeping things running.”** The category “*Keeping things running*” describes the experience of ten participants (50%) who were able to access healthcare with few challenges, were more acculturated, faced fewer barriers by accommodating to language and information, had adequate income to meet household needs, were aware of most probable effects (physiological and/or psychosocial), exercised spiritual behaviors and received some emotional support, and had a sense of control regarding their future. They were able to “*Keep things running*” (uphold work and family roles), advocate for themselves, and maintain a sense of “normalcy” in their daily lives. One participant shared the following:

I was trying to make plans all the time as to how to deal with everything. I had two fairly young children at the time, so my thoughts were constantly preoccupied with keeping things running for them and keeping my job and so forth, and I was just in a state of perpetual anxiety.

**“Giving back.”** The category “*Giving back*” describes the experience of seven participants (35%) who experienced no difficulty in accessing healthcare, received

appropriate support, were highly acculturated, described no barriers, had minimal effects from treatment, or were able to resolve or seek help for effects (physiological and psychosocial). They recognized that in spite of their diagnosis and subsequent experience, it was important to tell their story and help other Latinas by participating in research studies to “make the best of the situation.” Some articulated that participating in support groups and walks that supported breast cancer research was important; there was value in walking in memory of a friend or having “More of us, Latinas, be the face of breast cancer in our culture, because we identify with each other.” Several women started their own support groups and provided emotional and educational support within their own communities.

One participant formed a group that included women who spoke only Spanish: Some of them were unable to read or write, had no transportation, and were undocumented. She felt that she needed to “Reach the woman that hides, who doesn’t want to be found” and “That it’s taboo to come out to these things [support groups].” These women shared a sense of camaraderie by working together and reaching out to empower other Latinas with breast cancer.

## **Summary**

Twenty Latina women with early stage breast cancer who experienced CIPM from breast cancer treatment were interviewed in order to learn their experience. In addition, demographic data, acculturation data, PHI, and collateral data were collected for triangulation purposes. One overarching theme or main message, *Bigger than menopause*, emerged from the data as participants initially described the physiological effects related to menopause and treatment (subtheme: *Experiencing menopause*) when

asked, “Can you tell me what it was like to experience menopause from your chemotherapy treatment?” It became evident that their experience was *Bigger than menopause* and effects from treatment as participants also described their diagnosis, treatment regime, psychosocial effects, and menopause experience as an “*Ever-changing landscape*” that encompassed uncertainty and vulnerability. Study participants associated the ease of their menopause transition to the following: (a) relationships with HCPs; (b) access to healthcare; (c) appropriate support; (d) culture; (e) language barriers and acculturation levels, especially in undocumented women or those with difficulty reading/writing; (f) changing family roles; and (g) upholding work obligations.

“*Ever-changing landscape*” was described by participants as a complex point in time with shifting perspectives throughout the cancer trajectory. Absence of a positive relationship with their HCP, access to care, information, and support, cultural differences, and language barriers were described as making their transition and ability to assimilate the breast cancer and menopause experience into their daily lives more difficult.

The subtheme “*Working through*” *the experience* described another perspective regarding how women adjusted to their cancer diagnosis, treatment course, and menopause experience simultaneously. Three types of experiences emerged. The more accurate and timely information, access to care and options, higher language skills and acculturation score, support, and control women had related to how they moved through the following categories: “*Being held back*” (facing barriers, struggling), “*Keeping things running*” (establishing a sense of normalcy), and “*Giving back*” (advocating for others).

Participants also described the impact of isolation as part of their CIPM experience. Nearly half the women described feelings of isolation during and following

treatment. Similarly, the pink ribbon was not seen in a positive light by several women who could not relate to it, or understand the “cheerleading” about a disease with a difficult treatment course and unpredictable future. These findings align with Thorne’s (2008) question, “What is it that I know now, having done this study that I did not know before or in the same way?” (p. 195) as these were not noted in the review of the literature prior to study initiation and may require further attention.

## Chapter V

### Discussion

The purpose of this qualitative study was to describe the experience of chemotherapy-induced premature menopause (CIPM) among Latinas with breast cancer. Interpretive description with feminist underpinnings was used as the methodological approaches to guide the study. Knobf's "Carrying on" theory was utilized to compare and contrast findings of the current study. Thorne (2008) described the purpose of interpretation as simply helping to understand the rules and reasons surrounding human behavior, and the way culture and experience interact. Interpretive description (ID), as a flexible and practice-focused methodology, allowed the experiences of Latinas with CIPM from breast cancer treatment to be described and interpreted, in order to make real-world applications.

The main findings from study participants revealed one overarching theme that described their experience as *Bigger than menopause*, and their ability to assimilate their menopause experience into their breast cancer trajectory and lives impacted by the magnitude of physiological and psychosocial effects, access to healthcare, information and support, a sense of control, and level of acculturation.

#### **Bigger Than Menopause**

*Bigger than menopause* was the overarching theme as described above. As reported by Avis et al. (2004) and Shover (2008), breast cancer survivors categorize CIPM, sexual dysfunction, and infertility as the most distressing aspects of their experience. Similar findings by Avis and Shover depicted an overall description of the experience of CIPM as related to physiological symptoms. However, participants in the

current study described their menopause experience as part of a larger context, and not the most distressing aspect; sexual dysfunction was reported by less than half of the participants, with concerns regarding fertility not expressed. The subthemes of *Experiencing menopause*, “*Ever-changing landscape*,” and “*Working through*” the *experience* that emerged in this study were similar to other women’s experiences (Knobf, 1998, 2002). While these similarities are noted and described later in the chapter, responses by some participants suggested that areas of further exploration may be warranted regarding isolation and symbolism identification by Latinas as breast cancer survivors.

In addition to the psychosocial effects reported in the literature, participants in the current study described feelings of isolation; these were regardless of available support. While isolation was not an anticipated response regarding their experience, it was vividly described by 40 % ( $n = 8$ ) of the women who felt “separate and apart from everyone else in the world.” Browall, Gaston-Johansson, & Danielson (2006) identified feelings of isolation in 20 post-menopausal women who had received chemotherapy for breast cancer. In that study, isolation was related to a lack of stamina to associate with friends, causing a decrease in all normal social interactions, including time spent with family. Nurses are in a unique position to identify and address social isolates, as social isolation is a nursing diagnosis (Carpenito-Moyet, 2006) that is characterized by a person’s subjective feelings of aloneness.

The impact of the pink ribbon as the predominant symbol of breast cancer was described in the current study as being difficult to relate to from a personal and cultural perspective for participants who did not see themselves as part of that larger aggregate

population. Park, Zlateva, and Blank (2009) describe the way participants' "self-identify" (e.g., survivor, victim, patient, person with cancer) after a cancer diagnosis is complex and in relation to their individual psychological functioning, and how they appraised and coped with cancer. Cancer survivors, as described by Kaiser (2008), are often associated with breast cancer, and are represented as triumphant, happy, healthy, and feminine (Batt, 1994; King, 2006). These dominant breast cancer images have been directly criticized as they may encourage women to conceal the physical effects of cancer (Kaiser, 2008). This concealment may be alienating (Potts, 2000), especially to those who experience ongoing effects of treatment, have a poor prognosis, or ultimately die from the disease. While some participants described "wearing" a pink ribbon to breast cancer-related events, others did not "like early awareness and detection" as its branding message, but rather felt the focus should be shifted toward prevention and cure. Some participants were more vocal about the image of breast cancer reported by the media as "hype." This current study may be among the first to note Latinas' perception of the pink ribbon as the symbol for breast cancer. These emerging concepts or issues of isolation and difficulty to relate to current mainstream breast cancer ethos may require further inquiry.

From the Latinas' perspective and with attention to postmodernism's value of multiple meanings from a variety of data sources, the impact of barriers (information, access to healthcare, comprehensive support, and low acculturation) suggested that some Latina women with breast cancer saw their world through a slightly different lens when compared to Knobf's (1998) sample that included white women. Ashing-Giwa et al. (2006) and Janz et al. (2008) found that Latina breast cancer survivors, particularly those who reported low incomes and those who spoke limited English, often had inadequate

insurance, received unsatisfactory medical care, and less informational support.

Sammarco and Konecky (2009) reported that ethnic women described gaps in the information given to them by their HCPs regarding diagnosis, treatment, side effects, and guidelines for follow-up care. This aligns with the descriptions of participants in the current study who described these as barriers that made their experience more complex, and their transition difficult.

### **Comparison and Contrast to Knobf's Study**

When comparing the current study findings with Knobf's (2002) study, demographic data collected by Knobf's included date of birth, marital status, ethnic group, education level, employment status, and occupation. The mean age of women in Knobf's study was 40.2 years ( $\pm 3.7$ ), compared to 48.2 years (SD 6.84, range 38–60) in the current study. Age at time of interview may be difficult to compare as years since diagnosis varied greatly between the two studies. Knobf reported an average time since diagnosis as 4.5 years ( $\pm .43$ ), with the current study reporting a mean of 4.6 years since diagnosis (SD 2.6, range 0.17–11).

The majority of women in both studies were well-educated, married, and employed. It was difficult to make comparisons related to occupation, as the current study does not have parallel data. Data were collected using different methodologies (GT and ID) and may reflect differences in reporting results, including demographic data, and order that stages and themes are reported. Terminology used reflects the language and statistical data from each study.

Vulnerability and uncertainty during the women's experience with menopause and breast cancer were reported in both studies. Rogers (1997) defines the experience of

vulnerability as one that creates stress and anxiety and that affects physiological, psychological, and social functioning, and ultimately one's health. The Knobf study (1998) describes vulnerability as the basic social problem for the women who experienced premature menopause as a consequence of chemotherapy treatment. Descriptions of vulnerability related to diagnosis, responses to menopause and treatment effects, alterations in self-concept/self-esteem, loss of control over body and health, uncertainty, unpredictability of symptoms, and unknown risks of future health problems are similar in both studies. Mishel (1998) defines uncertainty in illness as "the inability to determine the meaning of illness-related events [that] occur in situations where the decision-maker is unable to assign definite values to objects and events, and/or is unable to accurately predict outcomes because sufficient cues are lacking" (p. 256). The abruptness of menopause and associated symptoms/effects are similar in course and intensity. Fertility is not reported as a concern in either study, but may be related to the mean samples being > 40 years of age and none planned to have children at time of diagnosis. The impact of uncertainty, political, economic, and structural vulnerabilities were described across interviews as barriers to menopause adjustment and transition among women and described in the current study as an *"Ever-changing landscape."*

Common characteristics that identified stages or themes did overlap. Both studies described age of participants in relation to perceived cancer recurrence, a focus on long-term effects, establishing collaborative relationships with HCPs, and a strong emphasis on healthy lifestyle behaviors to establish an overall feeling of well-being—all to re-establish a sense of control, or balance. The current study participants' discussion

regarding treatment complications, barriers, acculturation, integration of CAM, and spirituality to augment support are not defined in Knobf's results.

While the majority of women in the current study described a positive experience with their HCP, they described the information provided to them in relation to their breast cancer diagnosis, treatment plan, and survivorship trajectory as either non-existent, inaccurate, or incomplete. Participants also often sought information related to breast cancer from the Internet to fill information gaps, but they experienced both positive and negative outcomes from that source. A number of studies (Arora, Finney Ritten, Gustafson, Moser, & Jawkins, 2007; Raupach & Hiller, 2002) have concluded that breast cancer patients are often dissatisfied with the extent of information needs being addressed (e.g., content and delivery). This aligns with the literature that suggests patients benefit from communications that strive toward a professional demeanor, receptivity, sensitivity to language, attention to time and space, and emotional compassion (Thorne et al., 2008). One participant expressed her desire to have her HCP "Break it [information] down for me" and described a sense of being "rushed through the appointment and when I left, I left there with no answers." In addition to articulating a lack of information regarding breast cancer themselves, participants also described a lack of information evident among their family, friends, and the Latino community as a whole.

### **Assimilating the Menopause Experience**

Previous studies found that patients whose primary language was not English have more difficulty communicating with their HCP (Ashing-Giwa et al., 2006) and need the most help understanding information related to their breast cancer (Janz et al., 2008). Information available in Spanish was described as almost non-existent in the current

study, which may present a barrier to Latinas with low acculturation (Janz et al., 2008). Those women noted to be less acculturated (scored < 2.9 on the Brief Acculturation Scale for Hispanics) in the current study experienced barriers related to difficulty receiving information and described themselves as “struggling” and “*Being held back.*” This aligns with the literature that describes Latinas with low acculturation having the greatest unmet need for informational support, which may result from lack of access to information, or not being mindful that information is available to them (Janz et al., 2008). For some women, even as information was provided, difficulty in processing or understanding the information may have occurred, with less acculturated Latinas not receiving information sensitive to cultural issues, which may lead to further dissatisfaction (Janz et al., 2008). This supports one participant’s view on information:

Depending on yourself, depending on your family, depending on how long you’ve been in the States; [information] can be a positive or a negative thing. Culture still plays a huge part in my generation and having knowledge is not necessarily a good thing.

A growing body of literature has described the information needs for women following a breast cancer diagnosis (Griggs et al., 2002; Raupach & Hiller, 2002), with most studies focusing on information needs during the diagnosis and treatment phase, and less information regarding women’s needs during survivorship (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Time of diagnosis is important as communication with the HCP will set the stage for the way a cancer illness will be experienced (Thorne et al., 2008). Participants in the current study, however, described an ongoing need for information dissemination throughout their cancer trajectory.

While support of family and friends was an affirmative component of participants' experience, nearly half of all the women in the current study expressed being "disappointed" in local agencies and national breast cancer organizations. Referral for assistance with financial support regarding food, housing, and reconstructive surgery was unavailable while agencies and organizations offered little assistance for their day-to-day financial concerns and needs.

Some participants felt breast cancer support programs available were helpful and described a "camaraderie" of "being around people who felt the same way," while other participants could not "relate" to the women due to differences in age, treatment, or disease course. Despite the benefits of peer support for some women, studies report that between 18% and 32% of HCP-referred women to a support group never utilized this potential resource (Ashing-Giwa et al., 2006; Napoles-Springer, Ortiz, O'Brien, Diaz-Mendez, & Perez-Stable, 2007). Several reasons that support groups were thought to be underutilized, which are consistent with the current study, as well as the literature include lack of family support to attend, age of group members, negative stories, not needing one, not aware of groups in their local area, transportation concerns, and non-Latina based (Janz et al., 2008; Napoles-Springer et al., 2007). Support groups tailored to Latina women's specific needs, the husband and children's needs, and including cultural, spiritual, and linguistically appropriate services were seen as beneficial by participants and supported in the literature (Napoles-Springer et al., 2007; Wildes, Miller, San Miguel de Majors, & Ramirez, 2009).

### **Implications for Practice**

Data from this study identified areas of practice in need of further development. The *Bigger than menopause* theme identified participants' experiences as more complex

than the physiological effects of menopause and treatment alone. HCPs must develop a trusting relationship and view patients from the physical, psychosocial, emotional, spiritual, and cultural domains to ensure patients' needs and concerns are being identified. This includes providing strategies for physiological and psychosocial effects that are unresolved. Referral to the North American Menopause Society Website (<http://www.menopause.org/>) for information regarding healthy lifestyle behaviors, maintaining heart and bone health, and natural remedies for a myriad of physiological effects from breast cancer including hot flashes, mood swings, urinary incontinence, night sweats, difficulty falling asleep, sexual discomfort, depression, and headaches may be beneficial for English-speaking women (although information in Spanish is limited on this site).

Additionally, women may be screened for distress, social isolation, depression, and anxiety throughout the cancer trajectory. Depression and anxiety can affect social relationships and cause distress during and following cancer treatment (Jacobsen, Holland, & Steensma, 2012). Nurses are in a unique position to identify and address social isolates, as social isolation is a nursing diagnosis (Carpenito-Moyet, 2006) that is characterized by a person's subjective feelings of aloneness. This may require screening of Latinas with breast cancer throughout their breast cancer trajectory, as well as tailored interventions that may include support group referrals, building family networks, enhancing spirituality, and use of Internet-based supports. This aligns with the 2005 IOM and NRC Report that emotional distress should be an essential focus during survivorship and addressed through psychosocial care.

HCP efforts should be increased to disseminate correct information in both English and/or Spanish at each phase of the breast cancer trajectory via a professional interpreter, trained peer support, community health worker, or patient navigator. Providing breast cancer patients with needed information and support is an essential component of quality care; the time of diagnosis is the time when communication with HCPs is particularly important in setting the stage for the way the cancer illness will be experienced (Janz et al., 2008). Information that includes age (e.g., sexuality, impact of menopause, competing demands of family and work), that is culturally, spiritually, and linguistically appropriate, includes family members, treatment choices (including CAM options) were identified by participants as essential components. Information may be augmented through written materials in both English and Spanish, and recommendations to appropriate Web-based and support group resources. The ability to access and understand information is a central element to manage one's health and illness (Sorenson, Gavier, & Helleso, 2012).

Referral to support groups tailored to specific needs (e.g., age, Latina based) as well as to the needs of their husbands and children that are culturally, spiritually, and linguistically appropriate may be beneficial. Small groups with a positive message and incorporation of self-care strategies may be valuable, with attention to the availability of local support groups as well as transportation concerns.

As this is the first study that explores the experience of breast cancer and CIPM in Latinas, it expands a narrow evidence base. Importantly, it supports long-term QOL, self- and symptom-management, elimination of health disparities, and survivorship issues for breast cancer patients, which are high priority areas identified by the 2005 IOM and NRC

report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” the 2009–2013 Research Agenda for Oncology Nursing (Berger et al., 2009), and the National Institute of Nursing Research (NINR) Areas of Research Emphasis (2006).

### **Implications for Research**

Since there is a paucity of empiric data related to CIPM among Latinas with breast cancer, their experience is as yet unknown. Recruiting unrepresented Spanish-speaking Latinas with CIPM from breast cancer to better identify their needs is crucial, as Latinas, especially those who do not speak English as their first language are typically underrepresented in studies that examine QOL and psychosocial functioning of breast cancer survivors (Buki et al., 2008; Fu et al., 2009; Hamilton et al., 2009). Latinas with breast cancer who are Spanish-speaking, with low acculturation scores, and who face barriers with access, language, undocumented status, and support may represent a highly vulnerable subgroup with further research needed in this aggregate. The use of patient navigators and/or community health workers for study recruitment (Steinberg et al., 2006), increasing access to care and knowledge, promoting behavior change (Andrews, Felton, Wewers & Heath, 2004), and reducing cancer disparities (Bone et al., 2013) in ethnic minority women may be beneficial. Incorporation of the Barbershop Outreach Program as a model for use in Latina beauty shops to provide an environment of trust, and an avenue to disseminate breast health education and information is another beneficial route to take. Grassroots efforts to create neighborhood support groups where access is limited should be further explored.

Research in Latinas with CIPM needs more attention regarding the *Bigger than menopause* theme, and interventions for the *Experiencing menopause*, “*Ever-changing*

*landscape,*” and “*Working through*” the *experience* subthemes. Research must now focus on HCP concerns regarding information and support with special attention to cultural, linguistic, and spiritual elements. Consideration of using community-based participatory research to aid in recruitment is also recommended (Alvarez, Vasquez, Mayora, Feaster, & Mitrani, 2006).

### **Implications for Health Policy**

Latinas in the current study faced barriers to accessing healthcare, health insurance, treatment options, information related to diagnosis, treatment effects, and survivorship. Psychosocial problems created or exacerbated by cancer (e.g., depression or lack of information to manage illness) can be addressed through appropriate psychosocial health services, as all Latina patients and families should expect and receive comprehensive cancer care.

As the Latino population in the U.S. grows, attitudes about policy issues, beliefs, values, and experiences will have a growing impact on the nation and influence health policy. Disparities in health (health disparities) are defined by the National Institutes of Health (NIH, 2001) as differences in populations and population subgroups in the overall level of health and distributions of health and disease. Disparities in healthcare encompass both the health outcomes and other dimensions of care that include access, quality, and equity (Almgren, 2007). In 1999, Congress requested that the IOM assess the extent of racial and ethnic disparities in healthcare; research findings in over 100 studies indicated that minorities are less likely than whites to receive needed services (Institute of Medicine, 2004). Additionally, a growing body of scientific evidence demonstrates that many people living with cancer report dissatisfaction with the amount and type of

information regarding their diagnosis, available treatments, and ways to manage their illness and health that is understandable to patients (Institute of Medicine, 2005).

### **Limitations**

The study limitations predominantly reflected the challenge in recruiting participants for this study. Most participants, recruited through a national breast cancer database, were highly educated, economically stable, and with access to the Internet. Significantly, the current sample was highly acculturated, well-educated, and with high annual household income, which may not be indicative of all Latinas.

Additionally, all interviews were completed via telephone, making participant observation difficult. This method of interviewing may have impacted the researcher's ability to discern nonverbal cues from participants.

Lastly, 10% of the study participants were Spanish-speaking and requested the interviews in Spanish. It is unknown whether their experience can be translated to other Latinas, or if the presence of a professional Spanish interpreter during telephone interviews had an effect on participant responses.

### **Conclusions**

Interpretive description (ID) methodology with feminist underpinnings and Knobf's "Carrying on" GT were used to analyze data regarding 20 Latinas' experiences with CIPM from breast cancer treatment. One overarching theme, *Bigger than menopause*, and three subthemes, *Experiencing menopause*, *"Ever-changing landscape,"* and *"Working through" the experience* emerged from the data. Collateral data from a variety of sources were described with common patterns that aligned with interview data results.

Findings were then compared and contrasted with Knobf's study results. While women in both studies were able to assimilate the CIPM experience into their breast cancer experience, they experienced unresolved physiological and psychosocial effects from menopause and treatment. Three participants in the current study expressed the impact of barriers (e.g., information, language, and support) that they described as "*Being held back.*" This subtheme was not expressed by participants in Knobf's study, and the impact of these barriers on assimilating the CIPM experience into their breast cancer experience needs further exploration.

In addition, isolation was not identified during the review of the literature for this study, but was described by almost half of the participants. Future work should also examine Latinas' relationship to the pink ribbon symbol to determine if they view survivorship differently, or may benefit from other identifiers.

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## Appendix A1

### IRB-Approved Consent Form (English version)

**UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL  
COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN  
RESEARCH**

#### **CONSENT TO PARTICIPATE IN A RESEARCH PROJECT**

Title: Chemotherapy-induced premature menopause among Latina women with breast cancer.

Principal Investigator: Jean Boucher PhD, RN

Co-Investigator(s): Maryellen D. Brisbois MS, RN

Sponsor: American Cancer Society

Research Subject's Name: \_\_\_\_\_ Date: \_\_\_\_\_

#### **Invitation to Take Part and Introduction**

You are invited to volunteer for a research study regarding your experience with menopause (el cambio de vida) as a result of your chemotherapy treatment for breast cancer. A total of 12 women will take part in a series of interviews from the University of Massachusetts Medical Center, as well as area hospitals and breast cancer support groups in Massachusetts.

#### **Purpose of Research**

The purpose of this research is to better understand Latinas unique experience and needs related to menopause (el cambio de vida) as a result of chemotherapy treatment for breast cancer. There are currently no studies regarding this experience in Latinas and it is hoped that your responses will be beneficial to other Latinas who experience menopause from their chemotherapy treatment.

#### **Your Rights**

It is important for you to know that:

#### **Your participation is entirely voluntary.**

You may decide not to take part or decide to quit the study at any time, without any changes in the quality of the health care you receive.

**You will be told about any new information or changes in the study that might affect your willingness to participate.**

### **Screening Visit**

You will be asked several brief questions to see if you meet the requirements for being in the research study. You will have the option of having a professional Spanish translator provided for you if needed during the screening visit and interviews. Interviews will take place at a location that is convenient for you or at the University of Massachusetts Medical School.

### **Visit 1 (Interview)**

During the first visit, you will be asked to fill in some information about yourself in two separate questionnaires. These questionnaires will be available in both English and Spanish and should take approximately 10 minutes each to complete.

You will then be asked several questions regarding your experience with menopause (el cambio de vida) from chemotherapy you have received as part of your treatment for breast cancer. These interviews will be recorded but kept confidential which will take an hour of your time.

### **Visit 2 (Interview)**

In approximately three months' time after your first interview, you may be asked questions regarding your menopause (el cambio de vida) status over time which will take an hour of your time.

### **Visit 3 (Interview)**

You *may* be asked to participate in a third interview to clarify previous interview discussions or further discuss your menopause (el cambio de vida) experience at that time which will take an hour of your time. .

## **CONFLICT OF INTEREST DISCLOSURE**

None

## **RISKS**

There is little known risk to participating in interviews. You may experience some emotional distress at being asked to describe your experience. If you do experience distress or feel uncomfortable answering any of the questions you are asked, you may decide to not answer a question, take a break from answering questions, or stop the interview process.

## **BENEFITS**

There is no direct benefit to you from being in this study. However, your participation may help others with this condition in the future as a result of knowledge gained from the research.

## **REASONS YOU MIGHT BE WITHDRAWN FROM THE STUDY WITHOUT YOUR CONSENT**

You may be taken out of the research study if the investigator decides that continuing in the study would be harmful to you.

## **COSTS**

There will be no additional cost to you from being in this research study.

## **COMPENSATION**

Compensation will be provided in appreciation of your time to offset any expenses (time, travel, child care, or parking) for participating in this research study.

## **CONFIDENTIALITY**

Your privacy is important to us. Your research records will be confidential to the extent possible. In all records, you will be identified by a code number and your name will be known only to the researchers. Your name will not be used in any reports or publications of this study. However, the study sponsor (*American Cancer Society*), and the UMMS Institutional Review Board and/or their representatives may inspect your medical records that pertain to this research study. We will not allow them to copy down any parts of your identifiable information (e.g. your name) or take any of your identifiable information from our offices.

**YOUR PARTICIPATION IN THIS PROJECT IS ENTIRELY VOLUNTARY.  
YOU MAY WITHDRAW FROM THE STUDY AT ANY TIME.**

**THE QUALITY OF CARE YOU RECEIVE AT THIS HOSPITAL WILL NOT BE  
AFFECTED IN ANY WAY IF YOU DECIDE NOT TO PARTICIPATE OR IF  
YOU WITHDRAW FROM THE STUDY.**

## **RESEARCH INJURY COMPENSATION**

If you are injured or have any harmful effects as a direct result of your being in this research, treatment will be made available to you at UMass Memorial Medical Center

(UMMMC). You will not have to pay any charges resulting from the harmful effect or injury of a study procedure that would not have otherwise been done as part of your regular care.

## **QUESTIONS**

Before you sign this consent form, please feel free to ask any questions you may have about the study or about your rights as a research subject. If other questions occur to you later, you may ask Dr. Jean Boucher, PhD RN, at 508-856-5755, the Principal Investigator. You may take as much time as needed to think this over. If at any time during or after the study, you would like to discuss the study or your research rights with someone who is not associated with the research study, you may contact the Administrative Coordinator for the Committee for the Protection of Human Subjects in Research at UMMS. The telephone number is (508) 856-4261.

## **CONSENT TO PARTICIPATE IN THE RESEARCH PROJECT**

**Title: Chemotherapy-induced premature menopause among Latina women with breast cancer**

P.I. Name: Jean Boucher, PhD, RN

Subject's Name:

I understand the purpose and procedures of this research project and the predictable discomfort, risks, and benefits that might result. I have been told that unforeseen events may occur. I have had an opportunity to discuss the risks and benefits of this research with the investigator and all of my questions have been answered. I agree to participate as a volunteer in this research project. I understand that I may end my participation at any time. I have been given a copy of this consent form.

\_\_\_\_\_ Date: \_\_\_\_\_  
Subject's signature

**Title: Chemotherapy-induced premature menopause among Latina women with breast cancer**

P.I. Name: Jean Boucher PhD RN

**STATEMENT OF PERSON OBTAINING CONSENT**

I, the undersigned, have fully explained the details of this clinical study as described in the consent form to the subject named above.

\_\_\_\_\_ Date: \_\_\_\_\_  
Signature of person obtaining consent

**INVESTIGATOR'S DECLARATION**

**As the principal investigator or co-investigator on this study, I attest to the following:**

- the nature and purpose of the study and study procedures, as well as the foreseeable risks, discomforts and benefits have been explained to the above-named subject
- this subject has been given the opportunity to ask questions and to have those questions answered by knowledgeable research staff
- this subject meets the inclusion/exclusion criteria for this study

I have considered and rejected alternative procedures for answering this research question.

\_\_\_\_\_                      \_\_\_\_\_  
PI Signature                      Date

## Appendix A2

### IRB-Approved Consent Form (Spanish version)

**UNIVERSIDAD DE MASSACHUSETTS ESCUELA DE MEDICINA**  
**COMITÉ PARA LA PROTECCIÓN DE HUMANOS COMO SUJETOS EN**  
**INVESTIGACIÓN.**

**CONSENTIMIENTO PARA PARTICIPAR EN UN PROYECTO DE**  
**INVESTIGACIÓN.**

Título: Quimioterapia – induce menopausia prematura en mujeres Latinas con cáncer de seno.

Investigador Principal: Jean Boucher PhD, RN

Co-Investigador(es): Maryellen D. Brisbois MS, RN

Patrocinador: Asociación Americana del Cáncer

Nombre de la Persona Objeto del Estudio: \_\_\_\_\_

Fecha: \_\_\_\_\_

#### **Introducción e Invitación a Formar Parte de la Investigación**

Lo estamos invitando a formar parte voluntariamente de un estudio de investigación con respecto a su experiencia con la menopausia (el cambio de vida) como resultado de su tratamiento de quimioterapia para cáncer en el seno. Un total de 12 mujeres formarán parte en una serie de entrevistas, ellas serán del Centro Médico de la Universidad de Massachusetts, o de hospitales del área y grupos de apoyo para el cáncer de seno en Massachusetts.

#### **Propósito del Estudio**

El propósito de este estudio es entender mejor la experiencia única y las necesidades relacionadas a la menopausia (el cambio de vida) de mujeres Latinas como resultado del tratamiento de quimioterapia para cáncer de seno. Actualmente no hay estudios al respecto a esta experiencia en mujeres Latinas y esperamos que su respuesta pueda beneficiar a otras mujeres Latinas quienes tendrán la experiencia de menopausia con su tratamiento de quimioterapia.

#### **Sus Derechos**

Es importante para usted saber que:

### **Su participación es completamente voluntaria.**

Usted puede decidir no formar parte o abandonar el estudio en cualquier momento, sin cambios en la calidad del cuidado médico que usted recibe.

### **Usted será informado acerca de cualquier nueva información o cambios en el estudio que puedan afectar su deseo de participar.**

### **Visita para Evaluar su Participación.**

A usted se le harán una serie de preguntas breves para ver si usted cumple con los requisitos para ser partícipe del estudio de investigación. Usted tendrá la opción de tener un intérprete profesional (Español) en caso de que lo necesite durante la visita de evaluación y las entrevistas. Las entrevistas se realizaran en un lugar que sea conveniente para usted o en la Escuela de Medicina de la Universidad de Massachusetts.

#### **1ra. Visita (Entrevista)**

Durante la primera visita, se le pedirá que llene algunos datos acerca de usted en dos cuestionarios. Estos cuestionarios estarán disponibles en Inglés y Español y le tomará aproximadamente 10 minutos en completar cada uno de ellos.

Se le harán luego varias preguntas sobre su experiencia con la menopausia (el cambio de vida) por la quimioterapia que usted ha recibido como parte de su tratamiento para cáncer de mama. Estas entrevistas serán grabadas pero se mantendrá la confidencialidad; estas tendrán una duración de una hora de su tiempo.

#### **2da. Visita (Entrevista)**

En aproximadamente tres meses después de la primera entrevista, se le preguntará respecto a la menopausia (el cambio de vida) y su estado con el tiempo esta tomará como una hora de su tiempo.

#### **3ra. Visita (Entrevista)**

Quizás le pidamos hacer una tercera entrevista para clarificar las entrevistas anteriores o discutir sobre su menopausia (el cambio de vida) experiencia que algunas veces puede tomar una hora de su tiempo.

### **CONFLICTO DE INTERESES**

Ninguno

### **RIESGOS**

Hay un pequeño riesgo conocido por participar en las entrevistas. Usted puede experimentar algo de agotamiento emocional o angustias cuando le pregunten al respecto de su experiencia. Si usted experimenta agotamiento emocional o se siente incómoda al

contestar alguna de estas preguntas, usted tendrá la decisión de no contestar, tomar un descanso al responder las preguntas o parar el proceso de la entrevista.

### **BENEFICIOS**

No habrá un beneficio directo para usted al formar parte de este estudio. Sin embargo, su participación puede ayudar a otras personas con la misma condición en el futuro como resultado de los conocimientos adquiridos en la investigación.

### **RAZONES POR LAS QUE USTED PUEDE SER RETIRADO DEL ESTUDIO SIN SU CONSENTIMIENTO.**

Usted puede ser retirado del estudio de investigación si el investigador decide que continuar con el estudio pudiera ser perjudicial para usted.

### **COSTOS**

No habrá ningún costo adicional para usted por participar en el estudio de investigación.

### **COMPENSACION**

Se le dará una compensación en apreciopor su tiempo (tiempo, viaje, cuidado de niños y estacionamiento) por participar en el estudio de investigación.

### **CONFIDENCIALIDAD**

Su privacidad es importante para nosotros. Las grabaciones de la investigación serán confidenciales a la medida de lo posible. En todas las grabaciones usted será identificada a través de un número código y su nombre solo lo sabrán los investigadores. Su nombre no será utilizado en ningún reporte o publicación de este estudio. Sin embargo, el patrocinador del estudio (Sociedad Americana del Cáncer) “UMMS Institutional Review Board” y/o sus representantes pueden revisar sus registros médicos que sean pertinentes a este estudio de investigación. Nosotros no permitiremos que copien ninguna parte de su información que lo identifiquen (por ejemplo su nombre) o tomen alguna información de identidad de nuestras oficinas.

### **SU PARTICIPACION EN ESTE PROYECTO ES ENTERAMENTE VOLUNTARIA. USTED PUEDE RETIRARSE DEL ESTUDIO EN CUALQUIER MOMENTO.**

### **LA CALIDAD DE SU CUIDADO RECIVIDO EN EL HOSPITAL NO SE VERA AFECTADO DE NINGUNA MANERA SI USTED DECIDE NO PARTICIPA O SI USTED SE RETIRA DEL ESTUDIO.**

### **COMPENSACION POR LESIONES DE LA INVESTIGACIÓN**

Si usted sufre algún daño o ha tenido efectos que le hacen daño como resultado de estar en esta investigación, tratamiento será disponible para usted de parte de “UMass Memorial Medical Center” (UMMMC). Usted no tiene que pagar ningún cargo como resultado de algún efecto o daño como resultado a procedimientos de este estudio que no ha de otra manera hecho como parte de su atención medica regular.

## **PREGUNTAS**

Antes de que usted firme esta hoja consentimiento, por favor no dude en hacer cualquier pregunta que usted tenga acerca de este estudio o sobre sus derechos como parte de esta investigación. Si otras preguntas se le ocurren luego usted le puede preguntar al Dr. Jean Boucher, PhD RN, en el (508)856 5755, la Investigador(a) Principal. Usted puede tomar el tiempo que necesite para pensar sobre esto.

Si en algún momento durante o después del estudio, usted le gustaría discutir sobre el estudio o sus derechos dentro de la investigación con alguien que no esté asociado con el estudio de investigación, usted puede contactar al Comité para la Protección de Humanos como Sujetos en Investigación en el UMMS. El número de teléfono es (508) 856 4261.

## **HOJA DE CONSENTIMIENTO PARA EL PARTICIPANTE EN EL PROYECTO DE INVESTIGACIÓN**

**Título: Quimioterapia–induce a la menopausia prematura en mujeres Latinas con cáncer de seno.**

Nombre del Investigador Principal: Jean Boucher, PhD, RN

Nombre de la Persona Objeto del Estudio (Participante):

\_\_\_\_\_

Yo entiendo el propósito y el procedimiento del proyecto de investigación y las molestias previsibles, riesgos y beneficios que este puede ocasionar. Me han notificado acerca de los acontecimientos imprevistos que pueden ocurrir. Tuve la oportunidad de discutir los riesgos y beneficios del estudio con el investigador y todas mis preguntas fueron contestadas. Yo estoy de acuerdo en participar como voluntaria en este proyecto de investigación. Yo entiendo que puedo terminar mi participación en cualquier momento. Me han dado una copia de esta Hoja de Consentimiento.

\_\_\_\_\_

Firma del Participante

Fecha: \_\_\_\_\_

**Título: Quimioterapia – induce a la menopausia prematura en mujeres Latinas con cáncer de seno.**

Nombre de P.I. Jean Boucher PhD RN

**DECLARACION DE LA PERSONA QUE OBTIENE EL CONSENTIMIENTO**

Yo, el que firma, he explicado completamente el detalle de este estudio clínico como lo describe en la hoja de consentimiento al tema mencionado arriba.

Firma de la persona que obtiene el consentimiento: \_\_\_\_\_

Fecha: \_\_\_\_\_

**DECLARACION DEL INVESTIGADOR**

**Como el investigador principal o el co-investigador de este estudio, Yo atestigo y doy fe de lo siguiente:**

- **La naturaleza del tema arriba mencionado, el propósito del estudio y los procedimientos del estudio, así como los riesgos previsibles, molestias y beneficios han sido explicados.**
- **Este tema ha dado la oportunidad de preguntar y tener respuestas a esas preguntas a través de un personal de investigación con mucho conocimiento.**
- **Este tema cumple con los criterios de inclusión /exclusión para el estudio.**

Yo he considerado y rechazado procedimientos alternativos para contestar las preguntas de esta investigación.

\_\_\_\_\_  
PI Firma

\_\_\_\_\_  
Fecha

**Appendix B1**  
**Interview Guide (English Version)**

I'm interested in talking with Latina women with breast cancer about their experience with the change of life (el cambio de vida) from chemotherapy treatment.

Aim	Questions	Probes
Describe Latinas' experience with chemotherapy-induced premature menopause from breast cancer treatment	<p>Tell me what it was like to experience menopause from your chemotherapy treatment.</p> <p>What went on?</p> <p>What did you do about it?</p> <p>Symptoms: physical, psychological, other?</p> <p>Did you experience barriers to receiving care?</p>	<p>Can you tell me more about that?</p> <p>What do you mean by that?</p> <p>Can you describe that for me?</p> <p>Tell me how you feel about this.</p>
Interpret the experience of chemotherapy-induced premature menopause from breast cancer treatment among Latinas	<p>Tell me about what made going through this change of life harder? Easier?</p>	<p>Age, etc?</p> <p>Family?</p> <p>Emotionally?</p> <p>Spiritually?</p> <p>Support?</p> <p>Cultural aspects?</p> <p>Complimentary alternative medicine (CAM)?</p> <p>Other?</p>

## Appendix B2

### Interview Guide (Spanish Version)

#### Guía para la entrevista (Versión en Español)

Yo estoy interesada en hablar con mujeres Latinas con cáncer de seno acerca de su experiencia con el cambio de vida por el tratamiento de quimioterapia.

Meta/ Objeto	Preguntas	Indagar
Describir la experiencia de las mujeres Latinas con menopausia prematura inducida por la quimioterapia del tratamiento del cáncer de seno.	Dígame cómo fue la experiencia de menopausia a partir de su tratamiento de quimioterapia ¿Qué paso? ¿Qué hizo usted al respecto? ¿Síntomas: físicos psicológicos, otros? ¿Usted experimento barreras para recibir cuidados?	¿Podría usted decirme un poco más acerca de eso? ¿Podría describirme eso un poco más? Dígame como se siente usted respecto a eso.
Interpretar la experiencia de la menopausia prematura inducida por la quimioterapia del tratamiento del cáncer de mama entre las mujeres Latinas	¿Hábleme acerca de lo que le hizo pasar este cambio en su vida... ¿Más difícil? ¿Fácil?	¿Edad, etc.? ¿Familia? ¿Emocionalmente? ¿Espiritualmente? ¿Apoyo? ¿Aspectos Culturales? ¿Complemento con Medicina Alternativa (CAM)? ¿Otros?

## Appendix C1

### Demographic Data Questionnaire (English Version)

Demographic Data Sheet

Subject # \_\_\_\_\_

Date \_\_\_\_\_

Translator (0) Y\_\_\_\_ (1) N \_\_\_\_\_

The following information will be collected at time of participant interview:

1. Age: (at last birthday in years) \_\_\_\_\_
2. Marital Status:
  - (0) (  ) Married
  - (1) (  ) Widowed
  - (2) (  ) Single
  - (3) (  ) Separated/Divorced
  - (4) (  ) Living with partner
  - (5) (  ) Other
3. Current work status:
  - (0) (  ) Working full time
  - (1) (  ) Working part time \_\_\_\_\_
  - (2) (  ) On leave from work
  - (3) (  ) Disabled
  - (4) (  ) Retired
  - (5) (  ) Student
  - (6) (  ) Other
4. Education:

How many years of education did you complete? \_\_\_\_\_

Did you receive a:

GED	Yes (1) ( <input type="checkbox"/> ) No (0) ( <input type="checkbox"/> )
High school diploma	Yes (1) ( <input type="checkbox"/> ) No (0) ( <input type="checkbox"/> )
Associate degree	Yes (1) ( <input type="checkbox"/> ) No (0) ( <input type="checkbox"/> )
Bachelor's degree	Yes (1) ( <input type="checkbox"/> ) No (0) ( <input type="checkbox"/> )
Master's degree	Yes (1) ( <input type="checkbox"/> ) No (0) ( <input type="checkbox"/> )
Doctoral Degree	Yes (1) ( <input type="checkbox"/> ) No (0) ( <input type="checkbox"/> )
5. What is an estimate of your total annual household income? \_\_\_\_\_
6. How would you rate your current household income?
  - (0) (  ) Less than adequate for meeting my household needs
  - (1) (  ) Adequate for meeting my household needs
  - (2) (  ) More than adequate for meeting my household needs
7. In what country were you born?
  - (0) (  ) United States
  - (1) (  ) Puerto Rico (US territory)
  - (2) (  ) Mexico
  - (3) (  ) Dominican Republic
  - (4) (  ) Other: please specify: \_\_\_\_\_

8. If you were born someplace other than mainland United States (U.S.), please write how many years you have lived in the U.S. \_\_\_\_\_ years
9. What was your stage of breast cancer at time of diagnosis?
- (0)  Unknown
  - (1)  Stage 1
  - (2)  Stage 2
  - (3)  Stage 3
  - (4)  Stage 4
10. What did your breast cancer treatment include?
- (0)  Chemotherapy only
  - (1)  Radiation only
  - (2)  Surgery only
  - (3)  Chemotherapy and radiation
  - (4)  Chemotherapy and surgery
  - (5)  Surgery and radiation
  - (6)  Chemotherapy, surgery, and radiation
  - (6)  Tamoxifen
  - (7)  Other (please list) \_\_\_\_\_
11. How many months or years has it been since you first learned you had breast cancer?
- \_\_\_\_\_
12. What was your insurance status at time of treatment?
- (0)  Private
  - (1)  Public
  - (2)  Uninsured

*Thank you for completing this data sheet!*

## Appendix C2

### Demographic Data Questionnaire (Spanish Version)

Hoja de Datos Demográficos (Versión in Español)

Participante # \_\_\_\_\_

Fecha \_\_\_\_\_

Interprete (0) Si \_\_\_\_\_ (1) No \_\_\_\_\_

La siguiente información será recolectada en el momento de la entrevista:

1. Edad: (de acuerdo a su último cumpleaños en años) \_\_\_\_\_
2. Estado Civil:
  - (0) ( ) Casada
  - (1) ( ) Viuda
  - (2) ( ) Soltera
  - (3) ( ) Separada/Divorciada
  - (4) ( ) Viviendo con pareja
  - (5) ( ) Otro
3. Trabajo Actual:
  - (0) ( ) Trabaja tiempo completo
  - (1) ( ) Trabaja a medio tiempo \_\_\_\_\_
  - (2) ( ) Con permiso de trabajo
  - (3) ( ) Incapacitado
  - (4) ( ) Retirado
  - (5) ( ) Estudiante
  - (6) ( ) Otros
4. Educación:

¿Cuántos años de educación terminó usted? \_\_\_\_\_

Usted recibió un:

Diploma de Educación General "GED"	Si (1) ( ) No (0) ( )	Si (1) ( ) No (0) ( )
Diploma de Bachillerato	Si (1) ( ) No (0) ( )	
Título Técnico	Si (1) ( ) No (0) ( )	
Título de Maestría	Si (1) ( ) No (0) ( )	
Título de Doctorado	Si (1) ( ) No (0) ( )	
5. ¿Cuál es el ingreso anual estimado de su hogar? \_\_\_\_\_
6. ¿Cómo calificaría usted su actual ingreso de su hogar?
  - (0) ( ) Menos que el adecuado para cubrir las necesidades de su hogar.
  - (1) ( ) Adecuado que cubre las necesidades de su hogar.
  - (2) ( ) Más que el adecuado para cubrir las necesidades del hogar.
7. ¿En qué país nació usted?
  - (0) ( ) Estados Unidos
  - (1) ( ) Puerto Rico (territorio Estado Unidos)
  - (2) ( ) México
  - (3) ( ) República Dominicana
  - (4) ( ) Otro por favor identifique: \_\_\_\_\_

8. Si usted nació en algún otro lugar fuera del territorio de Estados Unidos (U.S.A); por favor escriba ¿cuántos años ha usted vivido en los Estados Unidos?  
\_\_\_\_\_ años.

9. ¿Cuál era su etapa/grado del cáncer en el seno en el momento del diagnóstico?

- (0) ( ) No Sabe
- (1) ( ) Estado 1
- (2) ( ) Estado 2
- (3) ( ) Estado 3
- (4) ( ) Estado 4

10. ¿Que incluyo el tratamiento para el cáncer de seno?

- (0) ( ) Quimioterapia solamente.
- (1) ( ) Radiación solamente.
- (2) ( ) Cirugía solamente.
- (3) ( ) Quimioterapia y radiación.
- (4) ( ) Quimioterapia y cirugía.
- (5) ( ) Cirugía y radiación.
- (6) ( ) Quimioterapia, cirugía y radiación.
- (6) ( ) Tamoxifen
- (7) ( ) Otro (por favor liste) \_\_\_\_\_

11. ¿Cuántos meses han pasado desde que usted supo que tenía cáncer de seno? \_\_\_\_  
anos

12. ¿Cuál era su estatus o condición con el seguro médico en el momento del tratamiento?

- (0) ( ) Privado
- (1) ( ) Público
- (2) ( ) Sin seguro

*¡Gracias por llenar la hoja de datos!*

## Appendix D1

### Brief Acculturation Scale (English Version)

In general, what language (s) do you read and speak?

1	2	3	4	5
:_____:	:_____:	:_____:	:_____:	:_____:
Only Spanish	Spanish better than English	Both equally	English better than Spanish	Only English

What language (s) do you usually speak at home?

1	2	3	4	5
:_____:	:_____:	:_____:	:_____:	:_____:
Only Spanish	Spanish better than English	Both equally	English better than Spanish	Only English

In which language do you usually think?

1	2	3	4	5
:_____:	:_____:	:_____:	:_____:	:_____:
Only Spanish	Spanish better than English	Both equally	English better than Spanish	Only English

What language (s) do you usually speak with your friends?

1	2	3	4	5
:_____:	:_____:	:_____:	:_____:	:_____:
Only Spanish	Spanish better than English	Both equally	English better than Spanish	Only English

## Appendix D2

### Brief Acculturation Scale (Spanish Version)

Por lo general, qué idioma(s) lee y habla usted?

1	2	3	4	5
Solo Español	Español mejor que Inglés	Ambos por igual	Inglés mejor que Español	Solo Inglés

Por lo general, en qué idioma(s) habla en su casa?

1	2	3	4	5
Solo Español	Mas Español que Inglés	Ambos por igual	Mas Inglés que Español	Solo Inglés

Por lo general, en qué idioma(s) piensa?

1	2	3	4	5
Solo Español	Mas Español que Inglés	Ambos por igual	Mas Inglés que Español	Solo Inglés

Por lo general, en qué idioma(s) habla con sus amigos(as)?

1	2	3	4	5
Solo Español	Mas Español que Inglés	Ambos por igual	Mas Inglés que Español	Solo Inglés

## Appendix E

### Glossary

**ER (Estrogen receptor)** A protein found inside the cells of the female reproductive tissue, some other types of tissue, and some cancer cells. The hormone estrogen will bind to the receptors inside the cells and may cause the cells to grow.

**ER- (Estrogen receptor negative)** Describes cells that do not have a protein to which the hormone estrogen will bind. Cancer cells that are estrogen receptor negative do not need estrogen to grow, and usually do not stop growing when treated with hormones that block estrogen from binding.

**ER+ (Estrogen receptor positive)** Describes cells that have a receptor protein that binds the hormone estrogen. Cancer cells that are estrogen receptor positive may need estrogen to grow, and may stop growing or die when treated with substances that block the binding and actions of estrogen.

**PR (Progesterone receptor)** A protein found inside the cells of the female reproductive tissue, some other types of tissue, and some cancer cells. The hormone progesterone will bind to the receptors inside the cells and may cause the cells to grow.

**PR+ (Progesterone receptor positive)** Describes cells that have a protein to which the hormone progesterone will bind. Cancer cells that are PR+ need progesterone to grow and will usually stop growing when treated with hormones that block progesterone from binding.

**PR- (Progesterone receptor negative)** Describes cells that do not have a protein to which the hormone progesterone will bind. Cancer cells that are PR- do not need progesterone to grow, and usually do not stop growing when treated with hormones that block progesterone from binding.

**HER2/neu** A protein involved in normal cell growth. It is found on some types of cancer cells, including breast and ovarian. Cancer cells removed from the body may be tested for the presence of HER2/neu to help decide the best type of treatment. HER2/neu is a type of receptor tyrosine kinase.

**HER2 positive** Describes cancer cells that have too much of a protein called HER2 on their surface. In normal cells, HER2 helps to control cell growth. When it is made in larger than normal amounts by cancer cells, the cells may grow more quickly and be more likely to spread to other parts of the body.

p53 gene A tumor suppressor gene that normally inhibits the growth of tumors. This gene is altered in many types of cancer.

BRCA1 and BRCA2 Human genes that belong to a class of genes known as tumor suppressors. Mutation of these genes has been linked to hereditary breast and ovarian cancer and increases a woman's risk of developing breast and/or ovarian cancer.