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The Lived Experience Of African American Women With Breast Cancer-Related Lymphedema

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**THE LIVED EXPERIENCE OF BREAST CANCER-RELATED LYMPHEDEMA IN
AFRICAN AMERICAN WOMEN**

by

DEBORAH A. COLLINS-BOHLER

DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

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MAJOR: NURSING

Approved by:

Advisor

Date

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Dedication

This dissertation is dedicated to God Almighty for without his favor and grace I would not have succeeded. I also dedicate this dissertation to the loving memory of my beloved and precious Aunt Betty Jean Smith who was a survivor of bilateral breast cancer for more than 30 years. My aunt also had bilateral breast cancer-related lymphedema and was the impetus for this research investigation. I give special thanks and gratitude to my mother who has always encouraged me to endeavor to persevere. I also thank my son, Dorian for his relentless faith, encouragement and expertise in assisting me through to the completion of my research project and final defense process. To the amazing women of color who without them there would be no research study or stories told to describe their experiences. To each one of them I humbly and sincerely thank for their unselfish willingness to be a part of this investigation.

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CHAPTER ONE

In Chapter One the definition of breast cancer-related lymphedema, the problem of breast cancer-related lymphedema, the purpose and research questions, and the identification of the significance of the research study are presented.

Background

Breast cancer is the most common type of cancer among African American women (Eversley et al., 2005; Henderson, Gore, Davis & Condon, 2003). In the United States (U.S.), an estimated 20 to 40% of the more than 2.4 million breast cancer survivors (BCS) are at risk for or are living with post-treatment breast cancer-related lymphedema (BCRLE) (Eversley et al., 2005; Ridner & Dietrich, 2008) an accumulation of lymphatic fluid in the interstitial tissue that causes swelling, most often in the arm (s), and occasionally in the chest (Amer, 2005; Petrek & Heelan, 1998). In the U.S. this translates into hundreds of thousands of women living with complications resulting from BCRLE as a result of cancer treatment. Studies have shown that the patient population at greatest risk for BCRLE as well as the unfavorable outcomes of BCRLE, such as, premature morbidity and negative quality of life (QOL) outcomes (Aziz, 2002) is African American women (Bradley, Given, & Roberts, 2003; Kiel & Rademacker, 1996; Kwan et al., 2010; Pezner, 1986; Shinagawa, 2000). However few of these investigators have included sizable numbers of African Americans in their studies and to date, there have been no published studies that explore the experience of BCRLE solely from the perspectives of African American women despite the increased risk for BCRLE.

Breast cancer-related lymphedema can result in pain, debility, mental, physical and social problems; can compromise health related quality of life; and can have an impact on choices about work, social and sexual interactions, and self-esteem (Armer & Fu et al., 2004; Morrell, et al., 2005; Petrek & Heelan, 1998; Petrek, Senie, Peters, & Rosen, 2001). BCRLE can develop immediately following surgery or months or even years later. The possibility of developing BCRLE continues throughout a women's lifetime (McWayne & Heiney, 2005).

Early detection and mass mammography screening and therapeutic improvement have led to substantial increases in the number of long-term breast cancer survivors (Radina, Armer, Culbertson, & Dusold, 2004). A long-term survivor is defined as a person who is still alive five years after diagnosis. Longer life expectancies, earlier detection of breast cancer by screening,

and more successful treatment of breast cancer contribute to the increase in the population of long-term breast survivors (American Cancer Society, 2006).

Risk factors associated with the development of BCRLE have been related to stage of disease, age, body mass index (BMI)/obesity, and post operative infections (Bernstein, Teal, Joslyn, & Wilson, 2003; Cohen, Payne, & Tunkel, 2001; Kiel & Rademacker, 1996; Marcks, 1997; Pezner et al., 1986; Sakorafas, Peros, Cataliotti, & Vlastos, 2006; Starritt et al., 2004). While no explanation fully explains why some patients develop BCRLE and others do not; it is known that African American women develop BCRLE at a higher rate than Caucasian women (Bradley, Given, & Roberts, 2003; Kwan et al., 2010).

African American women have been reported as having greater numbers of aggressive cancer treatments compared to Caucasians and African Americans are more likely to report BCRLE than Caucasians (McWayne & Heiney, 2005; Meeske et al., 2009). Having lower incomes and receiving chemotherapy have also been associated with increased risks for BCRLE (Meeske et al., 2009). Additionally, the type of treatment including axillary lymph node dissection and/or radiation has been described as a major cause of BCRLE. Similar to other chronic conditions, BCRLE cannot be cured and the treatment requires patients to make considerable lifestyle changes and maintain daily and lifelong care to decrease the swelling and prevent exacerbations (Radina et al., 2004).

Stage of disease at diagnosis and treatment may differ between African American women and Caucasian women for several reasons. First, more African American women are participating in mammography screening, although they may not have access to appropriate treatment (Smith-Bindman, et al., 2006; Coward, 1999). In addition free and lower cost mammograms are available to African American women with low incomes, but they may not be able to afford higher cost and less invasive breast cancer treatments. Finally, more African American women are diagnosed with more advanced stages of breast cancer (Radina, Armer, Culbertson, & Dusold, 2004; Smith-Bindman, et al., 2006).

African American patients have been reported as having a greater number of aggressive cancer treatments compared to Caucasians (McWayne & Heiney, 2005; Meeske et al., 2009; Ridner & Dietrich, 2008), and have higher incidence of BCRLE due axillary lymph node dissection (ALND) and radiation intervention (Thomas-MacLean, Miedema, Tateemichi, 2005). Advanced disease, more radical treatments including more extensive surgeries, higher

levels of obesity (Eversley, et al., 2005) as well as having lower incomes and receiving chemotherapy (Meeske et al., 2009) have all been linked to an increased risk for BCRLE (Eversley et al., 2005). Perception of body image and body shape has also been reported to increase psychological morbidity in patients with BCRLE (McWayne & Heiney, 2005).

Obesity or a body mass index (BMI) greater than 30 has been reported to be an important factor that increases the risk of BCRLE. Being overweight may lead to the need for increased radiation dose that may be associated with the development of BCRLE (Park et al, 2008). Obesity also is a risk factor for infection and poor wound healing (Marcks, 1997). In the U.S., obesity occurs at higher rates in African Americans, compared with Caucasians. Cultural factors, including dietary and exercise behaviors, are reported to play major roles. Many obesity-related diseases (e.g., diabetes, hypertension, and breast cancer) are more prevalent in African Americans.

Statement of the Problem

Research has used BCRLE samples comprised almost exclusively of married and well-educated Caucasian women. Few studies (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003; Eversley et al., 2005; Joslyn, 2002; McWayne & Heiney, 2005) have included sizeable numbers of African American breast cancer survivors. No studies have been found that explicitly investigate the phenomenon of the lived experience of African American women who have acquired BCRLE and those that do include African American women in the sample; have not focused on any potential differences by race. Culturally-sensitive interventions for African American women with BCRLE that focus on psychosocial, psychological, and physiological dynamics would enhance understanding of how this patient population copes with the distress of this condition. This descriptive, qualitative, phenomenological inquiry enhanced understanding on African American women's experiences in living with BCRLE. The findings from this study may be used to help healthcare providers examine the long-term effects of BCRLE on the survivorship of African American women.

A review of the research literature concerning African American women and BCRLE revealed a paucity of findings. Very little published data was found on the effectiveness of follow-up care in preventing, managing, or improving long-term effects of BCRLE and its treatment. Previous research has identified instances where African American women may experience inferior quality of breast cancer treatment and poorer outcomes compared to

Caucasian women (Elmore, Nakano, Linden, et al., 2005; Ghafoor, Jemal, Ward, et al., 2003; Kwan et al., 2010; Shavers, Harlan, Stevens, 2003, Yoon et al, 2008). What has been determined is that breast cancer survivors with BCRLE have higher levels of anxiety and depression, more substantial financial burden (Shih, et al., 2009), as well as greater difficulty in maintaining relationships than those without this condition (Ridner, 2005).

Coping is a frequently studied concept in cancer research and studies have shown that similarities and differences exist between African American and Caucasian women coping with BCRLE (Bourjolly & Hirschman, 2001; Culver, Arena, Antoni & Carver, 2002; Reynolds, et al, 2000). Reynolds et al. (2000) evaluated and compared coping styles and survival rates in 847 women. The results of the study illustrated that African American women [n=442] suppressed their emotions, used spirituality, and practiced positive reappraisal strategies to cope with breast cancer and its treatment. In contrast, Caucasian women [n=405] were found to express their emotions, practiced problem solving, and used escapism to cope. The investigators reported that both African American and Caucasian women who did not express their emotions or did not receive emotional support had lower survival from breast cancer than women who expressed their emotions and received emotional support (Reynolds, et al, 2000).

Breast cancer-related lymphedema can develop immediately following surgery or months or even years later (McWayne & Heiney, 2005). The possibility of developing lymphedema continues throughout a woman's lifetime. In addition to having to cope with the emotional stress associated with cancer and its treatment, many women with breast cancer also find themselves dealing with changes in their appearance as a result of BCRLE. These physical changes can lead to body image dissatisfaction, depression, and impaired quality of life (McKenzie & Kalada, 2003). The powerful effects of BCRLE can result in changes in confidence, self-esteem, perceptions of appearance (i.e., body image; McWayne & Heiney, 2005), family and other interpersonal relationships, daily activities, employment, and financial and social life (Armer & Fu, 2004; Hull, 2000; Tobin, Lacey, Meyer, & Mortimer, 1993; Velanovich & Symanski, 1999).

In a qualitative study, Yoon and colleagues (2008) examined the burden of symptoms by treatment-related and patient-related characteristics in 1,219 breast cancer survivors. The investigators completed telephone surveys in English and Spanish among participants. The outcomes of that study suggested that various patient characteristics (e.g., low educational

level, marital status, age) including comorbid conditions, may alter patient's experiences with symptoms following breast cancer treatment (Yoon et al., 2008). African American women were diagnosed more often and at an advanced stage of disease due to underutilization of mammography, frequently present with more aggressive breast tumors, and are more likely to have a diagnosis of one or more comorbidities (Banerjee, George, Yee, Hryniuk, & Schwartz, 2007). African American women have the highest rates of hypertension (HTN), diabetes (DM), and metabolic syndrome (MS; Meeske et al., 2009) which places them at greatest risk for unfavorable outcomes associated with BCRLE.

African American women are the largest segment of breast cancer survivors affected by BCRLE and the lack of research dedicated to investigate the health needs of this population exposed a gap in the literature. Few published research articles have been found regarding the personal, functional, and psychosocial adjustments that are needed to cope effectively with lifestyle changes and alterations resulting from BCRLE. Hare (2000) found that depression and maladaptive coping were exacerbated by difficulty in adjusting to chronic disease. Breast cancer survivors with BCRLE have higher levels of anxiety and depression, more substantial financial burden (Shih, et al., 2009), as well as greater difficulty in maintaining relationships than those without this condition (Ridner, 2005).

Purpose of the Study

The lack of research findings regarding experiences with BCRLE among African American women is the gap in the literature. Little is known about how BCRLE influences the daily lives of African American women (Rosedale, 2009). The purpose of this study was to explore the experiences of African American women living with BCRLE. The primary goal of the study was to understand the possible effects of living everyday with symptoms of BCRLE on African American women.

Specific Aim and Research Question

This research was consistent with the American Nurses Association (2003) social policy statement that support nursing practice that is characterized by attention to the full range of human experience and the integration of knowledge gained from understanding of patients' subjective experiences. The aim of this study was to describe African American women's' experience of living with BCRLE. Phenomenology was used to describe the meaning of the lived experience from the perspective of the participants. Through this research design, an

attempt to gain a deeper understanding of the lived experiences of African American women with BCRLE was studied by describing the essences of the lived experiences. Essences are elements that convey the true meaning of the phenomenon under study for the participants involved. Descriptive language was used to convey the essence or true meaning of the participants' experiences.

The research question developed for this study was: What are the lived experiences of African American women who have breast cancer-related lymphedema?

Definition of Breast Cancer-Related Lymphedema

Lymphedema, also known as lymphatic obstruction, is a condition of localized fluid retention and tissue swelling caused by a compromised lymphatic system. Breast cancer-related lymphedema is an accumulation of lymphatic fluid in the interstitial tissue that causes swelling, most often in the arm (s), and occasionally in the chest (Armer, 2005; Petrek & Heelan, 1998). Studies have reported that approximately twenty percent of patients who have undergone axillary treatment for breast cancer will develop BCRLE at some point during their lives (Armer, Fu, Wainstock, Zagar, & Jacobs, 2004; Petrek, Presman, & Smith, 2000; Wilke, et al., 2006). In addition to the fear of cancer recurrence, BCRLE is one of the most devastating post-treatment sequelae. The unpredictable nature of breast cancer-related lymphedema puts every breast cancer survivor who has undergone axillary treatment for breast cancer, at a life-time risk for its development.

Reports of BCRLE incidence vary widely owing to the lack of standard diagnostic methods, type of cancer treatment and follow-up after treatment (Armer, 2005). Incidence ranges from 10% to 56% following axillary lymph node dissection (ALND), 0% to 23% after sentinel lymph node biopsy (SLNB), and 2% to 51% after a combination of axillary radiation and lymph node surgery (Cox & Oakes, 1994). The prevalence increases with time since treatment (Erickson, Pearson, Ganz, Adams, & Kahn, 2001; Petrek & Heelan, 1998). Breast cancer-related lymphedema can cause impaired mobility of the affected arm, psychosocial and psychological morbidity, all of which can lead to decreased quality of life (McWayne & Heiney, 2005).

In general, global quality of life (QOL) and more specifically, health related quality of life (HRQOL), have progressively gained attention in work with breast cancer patients. Quality of life and HRQOL often are measured by changes in physical and mental functioning,

psychosocial problems, objective and subjective measures, including the presence of a variety of symptoms (Smith, Avis, & Assmann, 1999). The terms QOL and HRQOL are frequently used interchangeably. However within the context of this paper, the preferred idiom is HRQOL. The effect of cancer treatment on HRQOL is well documented and BCRLE is recognized as an added problem that is known to influence multiple aspects of patients' lives and the lives of their loved ones.

Significance to Nursing

Nursing's social policy statement (American Nurses Association, 2003) indicated that nursing practice is characterized by attention to the full range of human experience and integration of knowledge gained from understanding of patients' subjective experiences. "Nurses' ability to care for patients is predicated on shared understanding about the meaning of illness and treatment and the effect of experience on identity and ongoing life" (Rosedale, 2009, p. 181). The ways women perceive and respond to their symptom experiences are vitally important in understanding the long-term effects of breast cancer and its treatment on survivors (Armstrong, 2003; Budin, Cartwright-Alcares, & Hoskins, 2008). These statements emphasized the need for nurses to understand the subjective experiences of all women including African American women with BCRLE and be prepared to address common adaptation problems in their practice.

It has been recognized that patients with BCRLE have underlying psychosocial issues (Ridner, 2009). Few investigators have published research regarding African American patients with BCRLE. The findings from this research question augments understanding of BCRLE, its influence on African American women that can lead to an understanding of the healthcare needs and management of BCRLE in this patient population. Structuring research studies that focus on African American women diagnosed with BCRLE; the effects of the physical and psychosocial aspects of breast cancer patients can assist healthcare providers in developing meaningful, responsible, and culturally-congruent intervention plans. Research outcomes can enhance clinicians' understanding of the diverse influence that BCRLE has on African American women. The findings may be useful to assist investigators from diverse theoretical perspectives to identify future research questions that can use a grounded theory approach to develop a theory of living with BCRLE.

CHAPTER TWO

Literature Review

The relevant literature supports an understanding of the issues involved in coping with body image changes in African American women living with breast cancer-related lymphedema. This chapter presents an overview of the incidence and prevalence of BCRLE, diagnosis and treatment issues, perceptions of body image and coping strategies among African American women, previous research on BCRLE, along with information on patient-related risk factors such as body mass index (BMI), race, and age, and comorbidities. Additionally, this chapter includes associations between the main areas of interest and links concepts together to establish a framework that facilitates an understanding of experiences in coping with BCRLE.

Overview: Breast Cancer-Related Lymphedema

Breast cancer is the most common form of cancer among women in the western world. At least 20% of all patients who undergo axillary breast cancer treatment will develop breast cancer-related lymphedema (BCRLE). The exact causes of BCRLE are not well understood. BCRLE is an accumulation of lymphatic fluid in the interstitial tissue that occurs as a result of a blockage or interruption that alters the flow of lymph through the lymphatic system. This condition is commonly associated with surgical excision of lymph nodes (Armer, Stewart, & Shook, 2009; Edwards, 2000; Mortimer, et al., 1996; Roses, et al., 1999) and/or treatment with radiation or chemotherapy (Rockson & Rivera, 2008) and can also develop as a result of infection, skin damage, overuse or trauma (Romero, 1999). BCRLE often results in devastating physical limitations and psychological and psychosocial obstacles (Armer et al., 2009).

Ninety six percent of patients who develop BCRLE will do so within the first three years after treatment (Paskett, Naughton, McCoy, Case, & Abbott, 2007; Norman, Localio, Potashnik, et al., 2009). Everyone who undergoes axillary treatment for cancer is at a life-time risk for development of BCRLE. African American women have higher morbidity rates of BCRLE due to being diagnosed at an advanced stage of disease, requiring more extensive intervention including both radiation and dissection (Eversley et al., 2005; Ridner & Dietrich, 2008; Thomas-MacLean, Miedema, Tatemichi, 2005). Yet, few investigators have included African American women in their studies (Aziz & Rowland, 2002; Armer & Fu, 2004). In studies that have discussed racial differences, the samples have been too small to support any

exploration on how BCRLE risk factors or symptom management differs among African American women (Meeske et al., 2009).

Breast cancer-related lymphedema is the most debilitating complication following surgical and/or radiation therapy to the axilla in breast cancer treatment (Shih, et al., 2009). Onset may be gradual or sudden, and may occur early (within three years of breast cancer diagnosis) or later (up to as many as 30 years after diagnosis) (Petrek, Senie, Peters, & Rosen, 2001). Typically women experience swelling in the arm or fingers which may progress to pitting edema or a firm thickening of the skin (Paskett & Stark, 2000). Other symptoms include numbness, stiffness, or pain in the affected arm (Passik, Newman, Brennan, & Holland, 1993). Previously the extant breast cancer literature has not recognized intra/interethnic diversity of women with BCRLE. African American women were not included in most studies which limit what is known regarding possible differential BCRLE symptomology in this patient population (McWayne & Heiney, 2005).

There are two major types of lymphedema (LE): primary and secondary. Primary lymphedema has a congenital origin and is rare (Rockson & Rivera, 2008). Usually this type of LE has a genetic etiology (Lacovara & Yoder, 2006). Secondary lymphedema (SLE) (also referred to as acquired lymphedema) is the most common type of LE in the United States (Rockson & Rivera, 2008). Secondary lymphedema which includes BCRLE is a type, occurs as a result of a blockage or interruption that alters the flow of lymph through the lymphatic system and can develop from an infection, malignancy, surgery, scar tissue formation, trauma, deep vein thrombosis, radiation, or other cancer treatment. BCRLE is most commonly associated with surgical excision of lymph nodes (Edwards, 2000; Mortimer, et al., 1996; Roses, et al., 1999) or their irradiation (Rockson & Rivera, 2008) and can also develop as a result of infection or trauma.

Acute breast cancer-related lymphedema lasts 1 month to 6 months and has a pitting quality. In acute BCRLE the excess fluid collects in the subcutaneous tissue space that can easily expand. Noticeable fluctuations in size are typical with increased size being more evident at night (Hull, 2000). The focus of the proposed study is chronic BCRLE which is present longer than 6 months and the affected skin becomes harder, thicker, and brawny in appearance (shiny induration with skin discoloration). A brawny skin texture is due to deposits of

destroyed red blood cells. This change occurs over time as the fluid becomes embedded in the subcutaneous connective tissue and joint movement becomes restricted (Hull, 2000).

Once breast cancer-related lymphedema is established it cannot be cured. Patients experience prolonged susceptibility to BCRLE throughout their survivorship (Nielsen, Gordon, & Selby, 2008) exposing them to the constant threat of unpredictable and recurrent periods of exacerbations. Treatment is aimed at reducing symptoms and restoring function. Management is directed toward controlling symptoms and avoiding exacerbations. Methods of treatment for BCRLE include excisional or reconstructive surgery; pharmacotherapy including the use of blood thinners such as Warfarin, antifungal agents, and diuretics; and physiotherapy including the use of compression garments, bandaging and manual lymph drainage (Fu, Ridner, & Armer, 2009).

Prevalence/ Incidence of BCRLE in African American Women

The true prevalence of BCRLE is unclear, owing to variable levels of awareness and reporting, and the lack of a universally accepted definition. BCRLE is most commonly defined as an arm volume excess greater than 200 ml or 10 percent in the ipsilateral arm as compared with the contralateral arm (Armer, 2005; Hayes, Janda, Cornish, et al., 2008). These definitions have limited value because BCRLE may be expressed as localized swelling in the wrist, fingers or elbow that can be noted by the patient and not be observed in overall measurements of arm volumes (Pain, Vowler & Purushotham, 2005).

The true incidence of BCRLE is unknown. The rates of BCRLE reported in research literature vary from 4% to 56% (Petrek, Pressman, & Smith, 2000; Beaulac, McNair, Scott, et al., 2002; Paskett, Nauhgton, McCoy, et al., 2007; Shih, Xu, Cormier, Giordano, Ridner, Buchholz, et al., 2009). Obscurity in determining incidence is due to the varying criteria used to define BCRLE (Armer, 2005; Hayes, Janda, Cornish, et al., 2008). Reported incidence rates and predictive factors vary because time since treatments, study population, and criteria used to define BCRLE widely differ in published studies. Another strong factor is diverse study sample sizes have been small and have not reported associations between risk factors and BCRLE (Paskett, Nauhgton, McCoy, et al., 2007; Shih, Xu, Cormier, Giordano, Ridner, Buchholz, et al., 2009). Rates of BCRLE also vary according to the population of women studied, methods of treatment, duration of follow-up, and degrees of swelling used to define the presence of BCRLE (Geller, Vacek, O'Brien, & Secker-Walker, 2003).

Although the prevalence of breast cancer is higher for Caucasian women than for African American women, morbidity and mortality rates are higher for African American women with late stage disease (Eversley et al., 2005; Ridner & Dietrich, 2008). However, little is known about racial and ethnic differences in post-treatment symptoms among breast cancer survivors and what has been determined is based on studies with small sample sizes of African American women (Eversley et al., 2005).

In a quantitative research study, Joslyn (2002) analyzed racial differences in breast cancer treatment of women with early-stage breast cancer and the effects on survival rates. Comparisons were made by race, age hormone receptor status, and stage at the time of diagnosis. Subjects included African American women (n=10,073) and white women (n=123,127) diagnosed with Stage I, IIA or IIB breast cancer in the National Cancer Institute's Surveillance, Epidemiology, and End Results program between 1988 and 1998. Roughly eight percent of this sample was African American women. These women were that were reported as having higher incidences of advanced stages of breast cancer (> Stage II) and thus receive greater numbers of mastectomies and adjuvant therapies such as chemotherapy or radiotherapy and worse survival rates (Joslyn, 2002).

In a quantitative retrospective study, Eversley et al., (2005) interviewed 116 women in an urban area in northern California. The purpose of this study was to determine racial differences in the number of post-treatment symptoms among women who had undergone surgical treatment for breast cancer. The sample population included Caucasian (n=35), African American (n=35), Latina women (n=29), and women of other races (n=17). Findings revealed that Caucasians were more likely to have health insurance and diagnosed with stage I breast cancer compared to African Americans ($p \leq 0.01$). African Americans were more likely to report symptoms of pain and BCRLE ($p \leq 0.001$). Overall the study findings suggested that increased rates of post-treatment symptoms are experienced by low income and ethnic minority women. Yet post-treatment symptoms have not been explored extensively among African American patients with breast cancer (Eversley et al., 2005).

Advanced disease, more radical treatments including more extensive surgeries and higher levels of obesity have all been linked to an increased risk for BCRLE (Ridner & Dietrich, 2008). Ridner and Dietrich (2008) compared the self-reported comorbid conditions and medication usage between breast cancer survivors with and without BCRLE. A

convenience sample of 64 breast cancer survivors with BCRLE and 64 breast cancer survivors without BCRLE were age matched within three years. Twenty-one additional non-age-matched breast cancer survivors with or without BCRLE were also included. The only information provided to describe the study participants was that the groups was primarily Caucasian, married, well-educated and well insured. No additional information describing the racial composition of the study was provided. Statistically significant group differences were found in BMI, orthopedic issues, cardiac medications, hormone blockers and osteoporosis medication and calcium supplement intake. Study results suggested that comorbid conditions of obesity, hypertension, arthritis, and orthopedic problems may influence the development of BCRLE. Overall women with BCRLE were found to be older and had lower incomes. No study outcomes were associated to race.

Risks for Breast-Cancer-Related Lymphedema in African American Women

Risks for BCRLE have been categorized as: 1). Disease-related factors, for example, tumor staging and number of positive lymph nodes (LN); 2). Treatment-related factors, such as, number of LNs removed via axillary dissection or sentinel lymph node biopsy, radiation and infection; and 3). Patient-related factors, such as body-mass index (BMI)/weight, race/ethnicity, and age (Paskett, Naughton, McCoy et al., 2007; Szuba, Struss, Sirsikar, & Rockson, 2002). A combination of patient-related factors such as age and body mass index/weight (Ridner & Dietrich, 2008); disease-related factors for example, stage of disease at diagnosis and treatment-related factors like extent of surgery and radiation to the axilla have been associated with predisposition for BCRLE (Carter, 1997; Purushotham et al., 2005). Data collected in this current study on patient characteristics included: type of axillary treatment, symptoms, body mass index, age income, education, comorbidities, and insurance status.

Traditionally, if breast cancer is invasive, axillary lymph node dissection (ALND) was recommended. An ALND procedure involves the removal of a bulk of the lymph node tissue (containing $\geq 10 - 15$ lymph nodes) to be examined for cancer (Nielsen, Gordon, & Selby, 2008)). In this procedure there is no way of telling which lymph node has the cancer and each node has to be cut in order to detect cancer. Approximately 5 – 10% of all patients who specifically undergo ALND experience BCRLE including some form of pain (McMasters, Wong, et al, 2001). Pain may occur from stretching of soft tissues and obesity but it may also

be related to conditions such as infection, thrombosis, nerve injury, entrapment syndromes, or tumor recurrence (Newman, Brennan, & Passik, 1996).

There are over 2.4 million women who were treated before the advent of sentinel lymph node biopsy (SLNB) and are now at higher risk for developing BCRLE (Paskett, Naughton, McCoy, Case, & Abbott, 2007; Rosemary, & Rosedale, 2009). These 2.4 million women need to understand that BCRLE is a chronic threat that can impact their lives (Nielsen, Gordon, & Selby, 2008). Sentinel lymph node biopsy is a newer technique (as compared to ALND) to determine if breast cancer has spread to the lymph ducts or lymph nodes and requires the removal of only one or a few lymph nodes. Sentinel lymph node biopsy can allow patients to avoid the complications associated with a BCRLE (Rosemary, & Rosedale, 2009). However recent research studies have indicated that symptoms of BCRLE remain a significant complication in 6% to 50% of women who undergo breast cancer treatment (Paim, Lima, Fu, Lima, & Cassali, 2008). Sentinel lymph node biopsy has been found to be most appropriate for women with early-stage breast cancer (Serner et al., 2001; Takei et al., 2010). Women with more advanced breast cancer requiring more radical treatment are generally not candidates for SLNB.

Patient characteristics that influence the experience of symptoms following breast cancer treatment include: low income, low education, marital status, older age, comorbidities. Race has not been well studied (Bromberger, Meyer, Kravits, et al, 2001; Ganz et al., 2004; Kenefick, 2006; Stanton, Bernaards, & Ganz, 2005). Yoon and colleagues (2008) interviewed 1,219 breast cancer patients (all 50 years or older) to examine the burden of symptoms by treatment-related and patient-related characteristics. The racial diversity of the study sample [N=1,219] was Black women 12% [n=112], Hispanic English speaking 8% [n=103], Hispanic Spanish speaking 9% [n=104], Other 6% [n=66], and White 65% [n=834]. The authors reported that the study population was a multi-ethnic, multi-lingual, cohort of breast cancer survivors. Forty-six percent of the sample had one or more comorbidities, more advanced staged breast cancer and were on Medicare. The findings suggested that comorbidity was a significant predictor of symptoms, especially following chemotherapy.

Conversely, Yoon and colleagues (2008) reported that primary symptoms associated with BCRLE did not vary by patient characteristics such as income, education, and insurance status, which contradicts other research findings (Janz, Mujahid, Lantz, et al, 2005; Yoon et al.,

2008). The study examined the burden of symptoms by treatment type and patient characteristics in a population-based sample of newly diagnosed breast cancer patients. Using the Los Angeles County SEER Registry Rapid Case Ascertainment 1,219 telephone interviewed surveys was completed. The study sample consisted of 112 (12%) Black, 103 (8%) Hispanic, English speaking, 104 (9%) Hispanic Spanish speaking, 66 (6%) Other and 834 (65%) were White. The study's findings indicated that comorbidity is a significant predictor of symptoms. The only finding attributed to race was the observation that fewer Black women reported experiencing symptoms (Yoon et al., 2008). This outcome may have been attributed to the few numbers of Black women included in the study.

Depression as Related To Coping Associated with Breast Cancer-Related Lymphedema

Depression in patients with breast cancer and its treatment are common occurrences. The American Cancer Society (2006) estimated that, based on clinical data, more than 25% of breast cancer survivors (BCS) undergoing treatment become clinically depressed. In the context of cancer, depression has been defined as an unpleasant emotion of a psychological, social, and/or spiritual, nature that interferes with the ability to efficiently cope with cancer, its physical symptoms, and its treatment (Wilke, 2003). Feelings of depression range along a continuum, from sadness and vulnerability to functionally disabling (Vachon, 2006).

Depression can be complicated by several factors. Patients at later stages of cancer or with more physical symptoms are at increased risk for depression. This is especially significant for African American women who have more advanced stages of breast cancer (Eversly et. al., 2005). Other complicating factors that increase the risk for depression include poor prognosis, a history of psychiatric problems, excessive anxiety, and low self esteem. What's more, patients who have had difficulty coping with stressors in the past and those with a history of substance abuse may be more apt to become depressed (Goodwin, Zhang, & Ostir, 2004).

Rosedale & Fu (2010) performed a phenomenological study to describe women's unexpected and distressing symptom experience after breast cancer treatment. The study sample consisted of thirteen women 1 to 18 years after breast cancer treatment. Reported symptoms were pain, loss of energy, impaired limb movement, cognitive disturbance, changed sexual experiences, and breast cancer-related lymphedema. The four themes derived from the participant's experiences included living with lingering symptoms, confronting unexpected situations, losing precancer being, and feeling like a has-been (Rosedale and Fu, 2010). An

interesting and recurring notation in the study was that “the women were surprised that the symptoms they experienced during treatment never disappeared but remain part of their lives” (Rosedale & Fu, 2010 pg. E29). A primary finding was that “the lack of preparation for unexpected situations intensified the distress from the symptoms, which created the unexpected situations” (Rosedale & Fu, 2010, pg. E32). Unfortunately no correlations were made with race. To date despite these investigators’ findings little remains to be known about how African American women live with BCRLE or compare and contrast on how race might be an issue.

Diagnosing Breast Cancer-Related Lymphedema

High numbers of lymph nodes removed and type of lymph node dissection procedures have been correlated with the development of BCRLE (Francis, et al. 2006; Chagpar et al., 2007; Schrenk et al., 2003). Number of lymph nodes removed has been considered to be the greatest predictor of the development of BCRLE (Kosir, et al., 2001). Stage of breast cancer can indirectly allude to number of lymph nodes removed, but the number of lymph nodes removed (whether ultimately positive or negative for metastasis) is the most predictive indication for development of BCRLE (Kosir et al., 2001). Morbidity, including pain and numbness has also been associated with the number of lymph nodes removed (McCarter et al., 2001; Schrenk et al., 2003). The removal of fewer than four lymph nodes can accurately stage breast cancer and the removal of more than that adds to morbidity (Chagpar et al., 2007).

Breast Cancer-Related Lymphedema in African American Women

As previously discussed what has been identified in the literature is that more advanced disease, more radical treatment (largely associated with greater number of lymph nodes removed), older age, and low income, may influence BCRLE development among African American women (Eversley et al., 2005; Joslyn, 2002; Ridner & Dietrich, 2008). Additionally, conditions which are prevalent in African Americans such as overweight/obesity/BMI, hypertension and diabetes have also been linked to the increased risk for BCRLE. Yet few investigators have included African American women in research exploring BCRLE and little remains to be known about how African American women live with BCRLE.

Obesity in African American Women

The occurrence of obesity is highest among African Americans and people of lower socioeconomic status and is linked to variety of chronic diseases such as, hypertension, diabetes, cardiovascular disease and hyperlipidemia (Schuler et al, 2008). There are various

theories attempting to explain the differences between African American and Caucasian women including genetic, diet and exercise, socioeconomic status, and socialization and leisure activities (Sobal & Stunkard, 1989). Rucker & Cash, (1992) suggested that differences in obesity may be related to differences in body-shape perceptions. According to these authors, differences between African American and Caucasian women in how they see their body (perceptual body image) and how they feel about their body (attitudinal body image) may influence their responses to changes in body weight and weight control. Further Chandler et al., (1994) hypothesized that a greater acceptance of overweight figures and higher levels of body shape satisfaction at heavier weights in African American women contributed to higher obesity rates and may influence how African American women perceive their body image after developing BCRLE.

Comorbid Conditions in African American Women

A prominent symptom of BCRLE is pain. Painful BCRLE is more common in women who are overweight than in women of healthy weight (Armer, 2005). In the absence of other complications, pain associated with BCRLE is due to the stretching of tissue to accommodate excess lymph fluid. As fluid increases, the arm becomes more swollen, weak, and achy. More swelling causes more pain (Hull, 2000). Chronic pain and neural irritation after axillary dissection and radiation are relevant sequelae of BCRLE (Jud, Fasching et al. 2009). Pain associated with BCRLE causes a great deal of distress and dysfunction for breast cancer survivors and in many instances, causes fear of cancer recurrence (Passik & McDonald, 1998). In particular pain due to BCRLE in African American women may be more related to neural irritation caused by more radical treatment and being overweight.

Many patients also complain of heaviness, fullness, achiness, or fatigue of the limb (Cohen, Payne, & Tunkel, 2001). Additionally breast cancer-related lymphedema is often accompanied by related problems that include range of motion (ROM) deficits and sensation changes. These problems, whether present alone or in combination, have negative effects on psychosocial well-being and functional status (Hull, 2000).

Older age and low income may be associated with BCRLE and may be factors that increase the likelihood of comorbid conditions that increase the risk of BCRLE. Age is discussed as a risk factor because fibrosis of the lymphatic system occurs from the fourth decade of life on (Hayes, Janda, Cornish, Battistutta, & Newman, 2008). Comorbidities such as

obesity, hypertension, arthritis, and orthopedic problems have been suggested as influencing the development of BCRLE (Ridner & Dietrich, 2008).

Coping with Breast Cancer-Related Lymphedema in African American Women

In the 1990's studies began to explore experiences of patients with BCRLE and its effect on their activities of daily living (Tobin, 1993). Anxieties, depression, anger, frustration, social isolation, problems with intimate relationships, body image changes, and loss of self-esteem have been associated with BCRLE (Passik et al, 1995). Passik et al. (1995), found that use of "avoidance coping" to be a predictor of poor psychosocial functioning. Avoidant coping is characterized by evading problems rather than dealing with them directly (Passik, Newman, Brennan, et al., 1995). The authors concluded that by sharing the psychosocial problems that patients with BCRLE experience, patients can provide a better understanding of the impact of BCRLE and how to help them to cope more effectively. Given the increasing number of breast cancer survivors and the need to reduce the psychosocial morbidity associated with treatment, continued research on coping strategies to manage BCRLE is imperative. Adjustment to the diagnosis and treatment of breast cancer primarily depends on how well an individual copes with the sequelae of the disease.

Coping has been used synonymously with words such as adaptation, acceptance, resilience, problem-solving, and adjustment (Passik & McDonald, 1998; Pieterse et al, 2007; Radina & Amer, 2004; Wade, Nehmy, & Koczwara, 2005). Coping has been described as the cognitive and behavioral attempts to tolerate or to eliminate both internal and external stressors (Folkman & Lazarus, 1980). Researchers have pointed out that coping for patients with breast cancer and its treatment occurs through a process of using strategies for physical or emotional relief, serenity, and equilibrium (Radina & Amer, 2001). Although previous research has indicated that coping strategies are associated with adjustment to breast cancer-related lymphedema in Caucasian women, this level of research has not been done with African American women with BCRLE (Bourjolly & Hirschmann, 2001; Reynolds, et al, 2000).

A number of studies have reported on the psychological and psychosocial impact that BCRLE has on breast cancer patients (Maunsell, Brisson, & Deschenes, 1993; Hull, 2000; McWayne & Heiney, 2005; Radina, Armer, Culbertson, & Dusold, 2004; Ridner, 2009). Unfortunately, most of these studies have not included descriptive data regarding African Americans. From a psychosocial viewpoint, women with BCRLE experience greater pain,

depression, anxiety, impaired function, less social support and lower self-esteem (Maunsell, Brisson, & Deschenes, 1993; Hull, 2000; McWayne & Heiney, 2005; Ridner, 2009). Concerns regarding the disfigured appearance of their arms have contributed to increased social isolation and depression in many of these patients (Carter, 1997; Fu, 2005; Ridner, 2009). The physical, functional, and psychosocial morbidity associated with BCRLE, pain, range of motion restrictions, and sensation changes all contribute to depression in patients living with this condition (Hull, 2000; Fu, 2005).

Tobin et al. (1993) was the first investigator to explore the psychological morbidity associated with BCRLE. Tobin et al. (1993) used a mixed method, which consisted of both semi structured interviews and a questionnaire titled "The Social Stress and Support Inventory" to assess six areas of the patient's life. The purpose of the study was to evaluate the how stress may intensify psychological morbidity. Fifty women with BCRLE were matched with 50 controls without BCRLE for age, duration since treatment, and type of treatment received. The participants were all younger than 70 years old and had been treated for breast cancer at least one year prior to onset of disease. The control group had no disease and was matched for age, duration since treatment, and type of surgery performed. The mean age for both groups of patients was 56.7 years. Findings of the study showed that women with BCRLE experienced more functional impairment, psychosocial maladjustment and increased psychological morbidity. Although this was reported as the first study to explore the psychological morbidity associated with BCRLE no information was provided that described the racial components of the sample population.

In a qualitative study Carter (1997) interviewed 10 women with BCRLE. The purpose of the study was to explore women's experiences of lymphedema. The women ranged in age from 36-75 years. Some women experienced depression, anxiety, and impairments related to their intimate, work, and social relationships. Overall the experiences of the study participants were categorized into three themes: 1.) Abandonment by medicine, 2.) Concealing the imperfect image, and 3.) Living the Interrupted Life. Carter (1997) commented that physicians' limited knowledge about lymphedema, conflicting treatment information, and the limited number of available treatment centers caused distress for the participants. The author concluded by recommending future research to explore the effect of BCRLE on quality of life and functional ability as well as the psychosocial impact of BCRLE on body image, self esteem,

and social support (Carter, 1997). No race related demographics nor associations between race and the study's outcomes were provided.

Passik and colleagues (1995) identified several predictors of adjustment difficulties including: psychological distress, physical impairment, and social dysfunction. Their quantitative study included 69 women between the ages of 20 and 75 years, undergoing rehabilitation for BCRLE. The demographics showed 82.45 was Caucasian, 11.8 % of the study population was identified as Black and 5.9 % was Hispanic. The participants were assessed by physical examination and validated self-report assessment instruments that measured demographics, psychological distress, sexual functioning, social support, coping style, pain, and physical functional status (Passik, Newman, Brennan, & Tunkel, 1995). Identified predictors included pain (any level of intensity), decreased social support, and use of avoidance coping. An avoidant coping style was most significant predictor of adjustment difficulties. Women who relied on avoidant coping had more psychological morbidity, physical limitations and body image concerns (Passik, Newman, Brennan, & Tunkel, 1995). These findings were also supported in research studies by Passik & McDonald (1998) and Tobin Lacey, Meyer, & Mortimer (1993). No significant associations were found between race and the study outcomes.

In addition to the presence of pain other predictors of dysfunction include: the absence of social support, and an avoidant coping style. Avoidant coping is characterized by avoiding problems rather than dealing with them directly (Passik, Newman, Brennan, et al., 1995). In a historic quantitative study Passik and colleagues (1995) assessed sixty-nine women presenting for rehabilitation treatment for BCRLE by physical examination and validated self-report assessment instruments measuring demographics, psychological distress, sexual functioning, social support, coping style, pain, and functional status. The composition of the study sample was Caucasian (n= 52), Black (n= 8), and Hispanic (n= 4). The study's analyses revealed that women with BCRLE had higher levels of psychological distress, and high levels of sexual, functional and social dysfunction. However, none of these findings were associated with race.

Only a few studies have reported on the coping aspect of living with BCRLE. In a comprehensive literature review on psychological aspects of BCRLE, Passik and McDonald (1998) concluded that feelings of isolation may heighten the avoidance and social withdrawal. Lack of meaningful socialization increases a sense of isolation and withdrawal and prevents

women from obtaining assistance with daily activities, developing a sense of worth, or developing practical coping strategies (Passik & McDonald, 1998). An avoidant coping style was identified as a significant predictor of adjustment difficulties for women with BCRLE (Passik & McDonald, 1998). Passive or avoidant coping styles have been associated with increased morbidity in patients with BCRLE (Passik et al., 1995). Women who use these coping strategies have been found to have more psychological distress and physical dysfunction (Cohen, Payne, & Tunkel, 2001). None of the findings in this literature review were associated with race.

In a qualitative study performed by Johansson and associates (2003), 10 Caucasian women ages 36 through 75 years of ages were interviewed in order to explore their experience of arm lymphedema. The findings indicated that there are many different practical and psychosocial problems related to arm lymphedema. Three main themes describing difficulty in dealing with the management of BCRLE were categorized as: 1.) attitudes from people in their surroundings, including reactions to the problem from other people and reactions from the women on the attitudes of other people, 2.) discovery and understanding of BCRLE as a chronic disease and its treatment, 3.) coping, including both problem-focused and emotional-focused strategies. The findings of the study suggested that the problems that these women faced daily were particularly important and healthcare providers should understand the significance of these issues. In conclusion, the authors encouraged healthcare providers to listen to patients and devise multidisciplinary interventions to strengthen patient's coping skills (Johansson et al., 2003).

Radina et al. (2004) performed a qualitative, secondary analysis on 18 Caucasian women ranging in age from 37 to 87 years. The parent study, Patient Perceptions of Chronic Illness explored health perceptions and coping with specific chronic conditions within diverse racial and ethno-religious groups (Armer, Conn, Rogers, Clawson, & Tripp-Reimer, 1998). The secondary study investigated the perceptions and experiences of a subgroup of participants with BCRLE. The Self-regulation Theory was used as a template to understand the participants' use of health information to cope with BCRLE and evaluate the accuracy of participants' health information that may have influenced their abilities to make appropriate prevention or treatment choices (Radina et al., 2004). The two predominant themes that emerged were 1.) Perceived causes of lymphedema which included treatment for breast cancer, exercise, skin

damage, and allergic reactions, and 2.) Management of lymphedema which included ways of coping with BCRLE in terms of their BCRLE management experiences, including the use of compression treatments, physical activities, pumps, medications, and therapists and therapy centers as well as maintaining a positive attitude (Radina et al., 2004). The results of the study revealed that these participants had a relatively clear understanding of BCRLE.

Psychosocial problems include depression, anxiety, and functional impairment, maladjustment to illness, ineffective coping strategies and suboptimal quality of life (Maunsell, Brisson, Deschenes, 1993; Tobin et al., 1993). Investigators have focused more on limb volume reduction rather than management of symptoms of BCRLE (Radina, Armer, Daunt, Dusold, & Culbertson, 2007). Researchers have not determined the best strategies for symptoms of BCRLE and much of the search for viable options are left up to patients (Radina et al., 2007). Radina (2007) used a quantitative study to examine the symptom management practices of breast cancer survivors with BCRLE by identifying and quantifying self-care practices. The parent study for this report focused on anthropometric measurements of limb volume changes and the occurrence of self-reported symptoms among breast cancer survivors with and without BCRLE (Armer, 2000). The convenience sample consisted of 40 women with BCRLE ages 44 to 81 years. Thirty-eight of the study participants were Caucasian and two were African American. Study findings revealed three main themes: 1). Recommended management techniques including non-pharmaceutical strategies recommended by healthcare providers such as manual lymph node drainage, compression garments, and elevation, 2). Pharmaceutical treatments including medications and chemotherapy, and 3). Lay symptom management techniques such as common sense, folk, complementary or alternative methods (e.g. rest, drinking water, exposure to heat, applying ice) (Radina et al., 2007). Findings from this study advocate that effective management practices for patients with BCRLE reduce symptoms. However, there was no data reported to suggest that racial differences in management practices may exist.

The concept of loneliness has been viewed as a social deficit (Rosedale, 2007). Rosedale (2007) advocated that loneliness may be among the psychosocial variables embedded in women's experiences following breast cancer treatment. In the first study to describe loneliness from the patient's perspective, Rosedale (2009) examined the phenomenon of survivor loneliness in breast cancer survivors. The study sample was 13 female, breast cancer

survivors, 33 – 74 years, who had completed breast cancer treatment at least one year or more prior to the study. Three of out of thirteen (n=13) participants were African American (n=3). The purpose of that study was to describe the experience of loneliness. The authors noted that nursing literature showed the concept of loneliness as being considered a social deficit or pathological phenomenon. That belief didn't capture the in-depth meaning or essence of the experience provided by the study participants (Rosedale, 2009). Six essences of the experience of loneliness were identified as: emerging consciousness, transcending time, misunderstanding, inauthentic mirroring, and fragile vital connections and withholding truth. Study findings supported the assertion that breast cancer survivors experience survivor loneliness. In the study, all participants reported that they concealed the feelings they experienced to shield others from the truth and in doing so contributed to their experience of loneliness (Rosedale, 2009). None of the study outcomes were associated with race.

Coping strategies have been associated with adaptation to breast cancer but little is known about how African American women cope with or manage breast cancer (or its treatment) as compared to Caucasian women (Bourjolly & Hirschman, 2001). Support groups have been found to contribute to the healing process and survival of individuals coping with any chronic illness (Fobair, 1997) however, African American breast cancer survivors tend not to use support groups because these groups have often been perceived as not culturally sensitive (Brag and Gullatte, 2001). Rather, spirituality and prayer have been found as some of the most frequently used coping strategies by African American women (Ashing-Giwa, 2004). Faith-based cancer support groups have been recognized as more culturally appropriate and practical resources for African American women who tend to rely on family members, friends, ministers, and church members to assist with coping (Brag & Gulatte, 2001). African American women have reported having a determination to live for self as well as for their family members. A coping strategy and source of motivation reported by African American women, has been the fact that their families were dependent upon them (Henderson, Gore, Davis & Condon, 2003). Few studies have included African American women living with BCRLE and how they cope with this condition. What has been suggested is that spirituality may be an important variable to assess among breast cancer survivors with BCRLE (McWayne & Heiney, 2005).

Older Age a Risk Factor for Breast Cancer-Related Lymphedema

Older age has been assumed to be at a higher risk for BCRLE, yet few studies to date have documented the age-related incidence and prevalence of BCRLE, signs and symptoms, or efficacy of treatment (Armer & Fu, 2005). Armer & Fu (2005) conducted a descriptive-exploratory, cross-sectional method to explore the age differences in BCRLE occurrence and self-reported symptoms in post-breast cancer patients. This secondary analysis was performed using data from a parent study that examined the occurrence of BCRLE and related signs and symptoms among breast cancer survivors. Although the exact racial composition of the study was not provided the sample was described as 95% Caucasian, with 49 women aged 60 or older and 51 women younger than 60. Findings revealed that the occurrences of BCRLE were 30.6% for women older than 60 and 41.2% for women younger than 60. One assumption for the higher among younger women is that older women commonly experience chronic illness comorbid conditions and may expect/accept symptoms as a normal part of aging or may be taking medications for pain and as a result less frequently report symptoms (Armer & Fu, 2005). Very little is known about the impact of BCRLE on women as they age. The lack of inclusion of African American participants in this study precludes understanding of BCRLE and its differential impact of aging in this patient population.

Impaired Functionality Resulting from Breast Cancer-Related Lymphedema

Many breast cancer survivors with BCRLE experience varying degrees of functional impairment (Fu, Axelrod, & Haber, 2008). Functionally, BCRLE makes accomplishing household chores and occupational roles difficult (Armer & Fu, 2005) and due to the heaviness and bulkiness of the affected arm may prevent women from wearing their usual clothing, gripping lifting, and holding objects (Fu & Rosedale, 2009).

Starritt et al (2004), examined breast cancer patients who underwent breast surgery (including ALND) and completed a questionnaire which assessed problems after surgery, including whether or not they have noticed an increase in arm size. Lymphedema was assessed in 107 patients (82 male, 25 female) who had previously undergone complete level I-III axillary dissection. Of the 107 patients, 17 had also received postoperative axillary radiotherapy. The median age was 56.9 years and no data was reported on race. Thirty one percent reported that their ability to perform activities of daily living had been impaired after an ALND. However the perception of functional deficit did not correlate with actual BCRLE

(Starritt et al 2004). These results indicated that post-operative factors other than just a swollen and heavy limb (numbness, paresthesia, etc.) may contribute to the perception of functional deficit. No associations between race and the study's outcomes were reported.

Carter (1997) pointed out that BCRLE interfered with some breast cancer survivors' work involving lifting, gripping, holding, and fine motor dexterity. Women were worried about their job performance and security as well as worsening lymphedema and cancer recurrence.

Fu (2008) performed a study to describe the experiences of work of breast cancer survivors with BCRLE. Twenty-two women ranging in age from 42 to 64 years and employed participated in this descriptive phenomenological study. The racial composition of the sample included eight Caucasian women, seven African American women, and seven Chinese women. Findings revealed three main themes illuminating the experience of work for breast cancer survivors with BCRLE, namely: 1.) Having a visible sign: disability versus a need for help, 2.) Having physical limitations: being handicapped versus the inconvenience, and 3.) Worrying constantly versus feeling fortunate (Fu, 2008). "Women used words like 'handicapped', 'debilitating', and 'inconvenient' to describe their experience of work with BCRLE" (Fu, 2008, p. 23). Findings revealed that more African American women as compared to Caucasian women were reported as having jobs involving heavy lifting and constant use of the affected limb and hand. These women suffered more profoundly from the physical and functional consequences of BCRLE in their workplace and as a result endured increased levels of distress (Fu, 2008).

Pain Resulting from Breast Cancer-Related Lymphedema

Self-report of symptoms of the arm has been considered an easier tool than clinical measures for health care providers to use in diagnosing BCRLE and making appropriate referrals for treatment (Geller et al 2003). Self-reported symptoms have been measured using a variety of questions (Norman et al., 2009). However, self-report and objective measures do not always agree. In fact, objective measures such as measuring arm volume, may not be sensitive enough to pick up subtle changes that cause symptoms. Subjective report of sensation changes is helpful in early diagnosis of BCRLE and may be the earliest indicator of increasing interstitial pressure changes or measurable volume change (Kosir et al, 2001).

Pain of any intensity is a significant predictor of functional, psychosocial, and psychological problems (McWayne & Heiney, 2005). Eversley et al (2005) examined racial

differences in reported post-treatment symptoms among breast cancer survivors. One hundred sixteen women ranging in age from 18 to 60 years participated in this descriptive survey. Thirty percent were Caucasian, 30% were African American, and 15% were of other racial background. Findings revealed that generally African Americans were more likely to report pain and limb swelling due to BCRLE as compared to Caucasians ($p \leq 0.001$). Reasons for increased rates of pain among African Americans likely include more radical treatments as a consequence of being diagnosed with more advanced disease (Eversley et al., 2005).

The Influence of Breast Cancer-Related Lymphedema on Health-Related Quality of Life

Breast cancer survivors with BCRLE experience a wide range of potentially debilitating outcomes. The influence of BCRLE on the health related quality of life (HRQOL) of patients is extensive, encompassing psychosocial aspects, physiological status, and functional status (Armer et al., 2008). McWayne and Heiney (2005) conducted a comprehensive literature review investigating the psychological and social sequelae of BCRLE. Eighteen studies were reviewed including 14 quantitative and 4 qualitative trials. The literature correlated BCRLE with psychological sequelae such as frustration, distress, depression, and anxiety. Social sequelae were comprised of changes in role function, lack of social support and pain. Passik et al. (1995) and Beulac (2002) were the only authors in that review to report nonwhite participants in their demographics. Although the Passik (1995) study included Black participants, they did not correlate race with any of the study's outcomes.

Conversely, Beulac and colleagues (2002) performed a prospective, quantitative, cohort study in which 151 women with BCRLE completed The Functional Assessment of Cancer Therapy-Breast (FACT-B) questionnaire to assess quality of life. Significant differences in total FACT-B scores were seen for race, range of motion, menopausal status, body mass index, arm volumes, and BCRLE. Race was categorized as white and nonwhite. Racial correlations were disappointingly limited to the following few excerpts. The total FACT-B score for white women was 120.3 ± 1.4 compared with 108.9 ± 4.9 for nonwhite women ($P=0.006$). The study analysis suggested that BCRLE, nonwhite race and postmenopausal status were independently associated with decreased quality of life scores.

Changes in Perceptions of Body Image Resulting from Breast Cancer-Related Lymphedema

Research findings about African American women's body image satisfaction are limited and contradictory. Some studies convey that African American women are satisfied with their bodies (Altabe, 1996; Gore, 1999; Malloy & Herzberger, 1998; Nichter, 2000) and refer to protective factors such as family support, strong racial identity, and an acceptance of large body size. Other studies found that African American women are just as likely as Caucasian women to have body image concerns (Demarest & Allen, 2000; Patel & Gray, 2001; Pumariega et al., 1994; Thompson, 1994).

The visible appearance of BCRLE or of the compression or bandage garments commonly used in its treatment can make privacy issues more difficult, causing social anxieties and constant social reminders of the cancer disease. The garments are considered unattractive by many women and can lead to decreased social activity and decreased self-esteem (Fu & Rosedale, 2009; Johansson et al., 2003). Study participants described compression garments as ugly, terrible, uncomfortable, and not feminine. Some women preferred to conceal their arms by wearing custom clothing (Fu & Rosedale, 2009; Johansson et al., 2003). Many women consider these items bulky and not flattering and for many others these items are not affordable. Such concerns can result in social anxiety leading to social isolation (Fu & Rosedale, 2009; Johansson et al., 2003). The disfigurement of the hand and/or arm can be painful, difficult to conceal and interfere with activities of daily living.

In a qualitative, phenomenological study Johansson and colleagues (2003), interviewed twelve women with BCRLE. Racial composition of the study sample was not provided. The purpose of the study was to integrate everyday experiences using a classic critical method as described by Flanagan (1954). The findings indicated that there are many different practical and psychosocial problems related to BCRLE. Three themes were identified as: 1.) Attitudes from people in their surroundings, including reactions to the problem from other people and reactions for the women on the attitudes of other people, 2.) Discovery and understanding of BCRLE as a chronic disease and its treatment and 3.) Coping, including both problem-focused and emotional-focused strategies. Findings of the study indicated that problems integrated in the daily lives of these participants were of low frequency but were considered important to the women. The authors advocated that health care professionals should be knowledgeable

regarding these types of problems (Johansson et al., 2003). Racial composition of the study sample was not provided.

Fu and Rosedale (2009) used a descriptive, phenomenological method to explore and describe the lived experiences of 34 women with BCRLE. The racial composition of the study population was 29% White (n=10), 33% African American (n=11), and 38% Chinese (n=13). Each participant was interviewed three times for a total of 102 interviews. Each participant was given at least three opportunities to give her perceptions and relate events to her experiences. Four themes were revealed including: 1). Living with perpetual discomfort, 2). Confronting the unexpected, 3). Losing pre-lymphedema being, and 4). Feeling handicapped. Many of the women were amazed by the number of symptoms experienced with BCRLE and astonished by the realization that the symptoms never disappear, but instead, go through waves of exacerbation and remission (Fu & Rosedale, 2009). The investigators concluded that distress caused by BCRLE may have temporal, situational, and attributive parameters and measures of quality of life may not fully capture symptoms of distress (Fu & Rosedale, 2009). Women in this study believed that they were visibly marked by BCRLE as evidenced by the visibility of their swollen arms, puffy hands, and compression wraps, sleeves and gloves. The women expressed feelings of being unattractive, ugly and embarrassed. Women also expressed concerns about being deprived of wearing attractive, light weight, frilly, fashionable clothing and accessories (Fu & Rosedale, 2009). Unfortunately associations of outcomes with race were not examined.

Lack of Preparation for Breast Cancer-Related Lymphedema

The American Cancer Society (ACS, 2006), the National Cancer Institute (NCI, 2006) and the National Lymphedema Network (NLN, 2006) have emphasized the importance of patient education that provides information about lymphedema and risk reduction behaviors (Fu et al., 2009). Nevertheless patient education has not been standardized in terms of who, what, and how to deliver information to patients. Researchers (Bosompra, Ashikaga, O'Brein, Nelson, Skelly, & Beatty, 2002, Ridner, 2006) have operationalized lymphedema education as survivors' status of receiving information from a variety of delivery approaches, such as distribution of pamphlets, brief verbal instructions, or discussions with healthcare provides (Fu & Axelrod, 2008). Many patients treated for breast cancer have not received any information about BCRLE (Bosompra et al., 2002; Ridner, 2006).

The qualitative studies in the literature review by Carter (1997), used a combination of semi-structured interviews with a second follow-up interview (Carter, 1997), tape-recorded focus groups (Hare, 2000) and ethnographic approaches using a variety of sources such as, interviews, follow-up interviews with participants and healthcare professionals and observation of a support group (Radina & Amer, 2001). Some common findings among these studies were themes related to lack of information about BCRLE before diagnosis; problems with body image; difficulty making the adjustments to living with an incurable chronic condition; permanent role change; and loss of independence, purpose and self-worth (McWayne & Heiney, 2005).

Axelrod and Haber (2008) asserted that patients who received information on BCRLE report fewer symptoms and practice more risk reduction behaviors. The investigators examined the effect of providing BCLRE information on patient's symptoms and the practice of risk reduction behaviors. A cross-sectional design was used to obtain data from 136 female breast cancer survivors. Seventy-four percent of the participants were White (n=101), nine percent were African American (n=12), thirteen percent were Asian (n=17), and four percent were Hispanic or multiracial (n=6). Two demographic and medical information tools were used to answer two following questions regarding status of receiving BCRLE information: 1). Have you received any information or education that explains how to reduce your risk of BCRLE from your healthcare providers? 2). If yes, please explain in detail. This study used a convenience sample with the majority of the participants being White and well educated. None of the outcomes were associated with race therefore it was not possible to examine disparities in patient education among the different racial groups.

Summary

Historically the extant breast cancer literature has not recognized intra/interethnic diversity, poverty, and comorbidities of women with BCRLE. African American women have not been included in studies which limit what is known regarding coping with BCRLE in this patient population (McWayne & Heiney, 2005). Unfortunately, during the past decade not much has changed. Gaps in knowledge related to race and how African American women experiences BCRLE remain disturbingly broad.

There is a paucity of research literature reporting on clinical studies that focus on African American women with BCRLE. Even when African Americans have been included,

sample sizes have been small and the data regarding them have been muted or absent. Understanding the lived experience of African American women with BCRLE and its effect on the patient's daily lives can enhance knowledge to understand their challenges. The time for qualitative inquiry attributing a voice to convey the multidimensional ramifications of BCRLE on African American breast cancer survivors is now. Using a qualitative, descriptive, phenomenological methodology will expand knowledge beyond the concepts of symptoms, prevalence, severity and distress and augment understanding of how African American women describe how they live with BCRLE.

CHAPTER THREE

Methods

The methodology and research design/methods that were used to collect and analyze the data needed to address the research question developed for this study are presented in this chapter. The topics included in the chapter are restatement of the research problem, research design, and data analysis. Methodological problems are also discussed as well as the strategies for addressing these problems.

Restatement of the Research Problem

African American women are at the greatest risk of all patient populations for development of breast cancer-related lymphedema (BCRLE) primarily because of having more advanced disease at diagnosis requiring more radical treatments. However, African American women have been largely underrepresented in BCRLE research. This study explored how African American women described what it is like to live with BCRLE including perceptions of the physical and emotional effects of changes in body image, challenges presented in coping with the chronic and recurrent exacerbation of symptoms, adaptation and lifestyle changes, as well as the accessibility of resources.

Research Design

Qualitative research design was used in this study to provide an in-depth exploration of African American women's' perception of the living with BCRLE. The choice of design was based on the assumption that individuals form their own opinions of life and reality. Therefore, this perceived life knowledge and knowledge itself are related and mutually interdependent (Guba, 1990). An assumption underlying this study was that reality can be interpreted and understood and is dependent upon subjective interpretation (Lundman, 2004). The aim of qualitative phenomenology is to describe life experiences and how phenomena appear to people with similar experiences in their lives (Husserl, 1913). The interest is not focused on the facts presented, but rather in the meanings that are derived by the individual (Karlsson, 1993). A descriptive, phenomenological method based on Husserl's philosophy was used to examine African American women's lived experience with BCRLE. From the perspective of knowledge development, a descriptive phenomenological study of African American breast cancer survivors with BCRLE is essential. Qualitative studies with primarily Caucasian

participants have revealed that breast cancer survivors with BCRLE may feel hopeless and distressed (Carter, 1997; Fu & Rosedale, 2009; Greensdale, & House, 2006; Rosedale & Fu, 2010). Yet, none of those studies explored African American women's experiences of BCRLE in their daily lives. Little is known about how African American women with BCRLE perceive their experience of symptoms in their daily lives. The intent of this investigation was to provide greater understanding of the challenges African American women face and provide evidenced based information to utilize in structuring culturally targeted treatment plans for women with BCRLE.

A researcher applying phenomenology is concerned with the lived experiences of the people being studied (Greene, 1997; Holloway, 1997; Kruger, 1988, Maypole & Davies, 2001). According to van Manen (2002) the primary aim of phenomenology is gaining meaning of our everyday experiences. The underlying aim of this study was to understand the meaning of BCRLE from the lived experience of African American women as they describe how they cope with this condition. This qualitative inquiry was not supported by a specific theory and may not lead to a conclusive argument or set of concepts. Unlike other methodologies that aim to construct theories or present answers, the goal of this phenomenological study was to describe the experiences of living with BCRLE. Van Manen (2002) encouraged researchers to approach phenomenological method not as a controlled set of procedures, but rather as means to augment understanding.

Phenomenology is an inductive, descriptive research approach. With its focus on human phenomena, this type of research design was appropriate to guide this study.

Two reasons why phenomenology was suited to the study are:

1. this type of research was particularly useful for describing the lived experiences of study participants through "sense perceptions such as hearing, touching, tasting and smelling, and other phenomena such as remembering, believing, and judging" (Ray, 1985, p. 127), and
2. breast cancer patients in this study reported personal perceptions while describing their lived experiences with BCRLE.

A qualitative, descriptive, phenomenological design was used in this study to gain new perspectives on this topic of which little was known and to gain more in-depth information that may have been difficult to convey quantitatively (Brink & Wood, 1998). Qualitative methods

are appropriate in situations where variables that might later be tested quantitatively, need to be identified, or where the researcher has determined that quantitative measures cannot adequately describe or interpret a situation. In this instance, variables identified in this study might be used later to count and construct statistical models in an attempt to explain observations. The research concerns in this study were framed as open-ended questions to support discovery of new information (van Manen, 2002).

As a qualitative research methodology, phenomenology offered an alternative to the positivist view of science, and presented an innovative manner to interpret consciousness and individuals' involvement in the world (Beck, 1994). Although the origins of phenomenology can be traced back to Kant and Hegel; Vandenberg (1997) regarded the German philosopher, Edmund Husserl (1859-1938) as the originator of phenomenology. Husserl rejected the belief that objects in the external world exist independently and that the information about objects is reliable. He argued that people can be certain about how things appear, or present themselves to their consciousness (Eagleton, 1983; Fouche, 1993). "Realities are treated as pure 'phenomena' and the only absolute data from where to begin. Thus, Husserl named his philosophical method 'phenomenology', the science of pure 'phenomena' " (Eagleton, 1983, p.55).

The underlying support for this study was based on assumptions grounded in Husserlian descriptive phenomenology (Husserl, 1962; Porter, 1998; Porter, 1999). The assumptions include: 1). "Natural knowledge begins with experience (Erfahrung- the German term for empirical observation) and remains within experience" (Porter, 1998, p. 45) namely that "breast cancer survivors' experiences of BCRLE emerge from the experiences in which women interact with the condition of having BCRLE" (Fu & Rosedale, 2009, p. 850); 2). "Every experience...has intentionality" (Husserl, 1962, p.222) explicitly, "breast cancer survivors can purposefully reflect on their experiences of having BCRLE" (Fu & Rosedale, 2009, p. 850).

Spielberg (1982) cited four constants through Husserl's philosophy:

1. Ideals of rigorous science: Objective scientists can critique and clarify their concepts and assumptions in order to obtain deeper concerns of people and science.
2. Philosophical radicalism: Husserl believed that the human experience contains a meaningful structure. Philosophy consists of ontology (the nature of relations of being) and epistemology (the nature of knowledge, especially validity). His descriptive (eidetic) phenomenology sought universal essences, their structure and relations, based on

descriptive reduction. The phenomenology of essences seeks insight into what is experienced.

3. Ethos of radical autonomy: A central focus of this constant was that people are responsible for themselves and their culture.
4. Respect for wonders: The central focus of this constant was the being that is aware of its own being and of other beings.

Husserl's phenomenological studies "uncovered and described the fundamental structure of our life world" (Cohen & Omery, 1994, p. 139). His phenomenology emphasized description of a person's lived experience.

A qualitative, descriptive phenomenological study based on Husserl's (1913/1962) and Streubert's (1991) nurse-developed methodology was used to guide this study of the lived experience of African American women with BCRLE. The ideas support Streubert's descriptive method (Rosedale, 2009). The study findings may be used to help nurses examine the phenomenon of African American women living daily with BCRLE from a variety of theoretical perspectives.

Establishing Rigor

Phenomenology involves probing through data to identify common themes and patterns of relationships in a phenomenon. The methodology used in this study involved four strategies: 1.) Intuiting which was the process of thinking through the data so that a true comprehensive or accurate interpretation of what was meant in a particular description. Intuiting resulted in a common understanding about the phenomenon under investigation (Streubert, Speziale, & Carpenter, 2003, p. 60). During the interviews open-ended questions were used in order to facilitate responses (Streubert, Speziale, & Carpenter, 2003), 2.) Bracketing was addressed by withholding assumptions and presuppositions in order to improve the rigor of the research. This crucial process was maintained throughout the research process especially during data analysis to remain unbiased and help to establish trustworthiness of the results (Streubert, Speziale, & Carpenter, 2003, p. 55), 3.) Analysis of the phenomenon was based on the data obtained and on how the data were presented. The PI listened to, compared and contrasted the participants' responses to the questions to identify recurring themes and interrelationships (Brink & Wood, 1998), and 4.) Describing was the communication and description of the distinct, critical

elements of the participants described their experiences. This was final step of discovery (Brink & Wood, 1998).

Nurse researchers adopt the phenomenological approach because of the nursing profession's holistic philosophy that cares for mind, body and spirit (Streubert, Speziale, & Carpenter, 2003). As a guide to nursing practice, Streubert and Carpenter's methodology provided the following advantages: 1.) It was an appropriate approach to researching human experience and 2.) As a research method it was a rigorous, critical, systematic investigation of phenomena (Streubert, Speziale, & Carpenter, 2003).

Trustworthiness established the validity and reliability of qualitative research and establishes rigor (Streubert, Speziale, & Cartpenter, 2003). The goal of trustworthiness was to accurately represent the experiences of the participants. Rigor or trustworthiness of this research process and findings was established using the following criteria: credibility, transferability, dependability, and conformability.

Credibility refers to an accurate portrayal of what is being studied (Lincoln & Guba, 1985). To assure credibility four techniques were employed:

1. A journal containing field notes including the researcher's impression of the interviews, behaviors, and emotional responses was maintained. This journal revealed how the researcher developed perceptions.
2. "Member checks" were completed. Each participant was asked to corroborate findings. Member checks took the form of a second interview to confirm representation of the participant's thoughts pertaining to the lived experience of BCRLE and to correct any misinterpretations that may have occurred during the first interview.
3. Audio taping was used to test, collect and store data, findings and interpretations.
4. Peer debriefings with the dissertation committee members were completed four times during the study period. This provided the principal investigator (PI) with opportunities to share the progress of the study, test growth and obtain expert guidance for redirection. During these meetings, methodology, journal entries and field notes were critiqued. The committee members posed questions and provided feedback that directed ongoing study strategies.

Using these descriptive, qualitative, phenomenological guidelines lends credibility to this study. Findings of this study are being reported that accurately portray the perceptions of the research participants (Sandelowski & Barroso, 2002).

Transferability is also called fittingness and in qualitative research refers to the ability to fully describe characteristics of the sample in a way that permitted adequate comparisons to other samples (Streubert, Speziale, & Carpenter, 2003). The maximum variation sampling strategy used in this study resulted in participants who had varied personal and BCRLE demographics (e.g., age, marital status, length of time with BCRLE, type of breast cancer treatment, etc.). This sampling technique facilitated generalizability of the study's findings to other African American women with BCRLE (Sandelowski, 1995). Furthermore, the PI utilized a semi-structured interview guide to assist in eliciting rich responses to questions based on the specific research aim. The presentation of broad descriptions of participants as an explanatory factor in the analysis of data further lends to the transferability of this study (Gibbs et al., 2007).

Dependability refers to the consistency of findings (Holloway, 2005). Audiotapes and verbatim transcriptions were completed in a timely manner to ensure that the data was dependable. Multiple reviews were completed to assist in the accurate portrayal of participant's accounts (Ayers, 2007). Each tape was translated into written dialogue and reviewed by the PI and compared with the tapes for accuracy. The written text was then condensed into codes used to develop themes. To check for accuracy these themes were verified with the participants during the second interview. The audit trail included documentation from field notes, transcribed interviews, and journal entries. After completing the study, a qualified external auditor can complete an audit.

Confirmability refers to the objectivity of interpretations by the researcher and ensures that the findings are unbiased (Lincoln & Guba, 1985). The purpose of confirmability was to illustrate that the evidence and thought processes when applied to another study, can result in the same conclusions (Streubert, Speziale, & Carpenter, 2003). Review of the data included discussions and code checks of the data during the debriefing process. This study used the following auditing criteria: data was collected from tape recordings, verbatim interviews were transcribed, the PI read and compared the transcriptions to taped interviews for accuracy, and

maintain a reflexive journal including how the data was coded and categorized assisted in establishing rigor.

Sampling Selection/Recruitment

The population for this study was adult, African American women with BCRLE. To be included in the sample these participants had to be at least 18 of age, an African American female, and self-reported or diagnosed with BCRLE prior to enrolling in the study.

A purposive sample of 11 participants a sample that had reached a level of data saturation (i.e., informational redundancy) was identified for recruitment (Sandelowski, 1995). Criteria for inclusion in the study required that participants be (a) be self-identified as African American women, (b) able to speak, read, and write English, (c) between the ages of 18 and 89 years old, (d) self-reported or diagnosed with BCRLE prior to enrolling in the study, (e) cognitively intact, and (f) completed axillary dissection and/or sentinel lymph node dissection at least six month prior to being enrolled in the study (the focus of the current study is chronic BCRLE which is present longer than 6 months). Participants were recruited from Karmanos Cancer Institute (KCI). Referrals of participants were be made by a nurse practitioner (certified as a lymphedema specialist), a physical therapist (certified/specialized in lymphedema), and other healthcare professionals. All participants were determined as an eligible research candidate by the Principal Investigator.

Maximum variation sampling was used in this qualitative descriptive study. This sampling strategy allowed exploration of common and unique expressions related to BCRLE across a broad range of demographically varied cases (Sandelowski, 1995). Some of the variations included experiences associated with the development of BCRLE such as symptoms, comorbidities, and obesity/body mass index. Open-ended interviews allowed particular issues of interest to be discussed, and permitted each participant to take the discussion in directions that reflected her own experience.

Protection of human subjects

The recruitment and selection process primarily consisted of referrals from Karmanos Cancer Institute, in Detroit, Michigan and other healthcare providers. Prior to beginning the research process, the Protocol Review and Monitoring Committee at Karmanos Cancer Institute approved the research proposal for scientific merit [see Appendix A]. Additionally approval was obtained from the Human Investigation Committee (HIC) at Wayne State University [see

Appendix B]. This HIC approval covered the approval of the flyer approved for distribution [see Appendix C]. Letters of support and recruitment support were also obtained from healthcare professionals committed to referring potential research participants [see Appendix D]. Utilizing healthcare professionals in the referral process proved successful in the recruitment of participants for this study.

Recruitment procedures

Identification of potential participants who met the inclusion criteria followed an approved protocol by the Protocol Review and Monitoring Committee at Karmanos Cancer Institute and the HIC. A flyer stating the purpose of the study, eligibility requirements for participation, inclusion/exclusion criteria, length of time of participation, role as a participant, and identification and contact information of the PI [see Appendix E].

Compensation

Monetary compensation for participating in research recognized that the individual's time and contribution was valuable (Dickert & Grady, 1999). Compensation for the participant's travel and time to complete two interviews was offered. Wayne State University outlines additional policies regarding compensation to research participants. Each participant was given ten dollars for the initial interview and twenty dollars for the second interview. Every participant signed a dated receipt/ voucher confirming the date and monetary amount received [see Appendix F].

Data collection instruments

Two face-to-face, audio-taped interviews using open-ended questions were completed with each participant. A mutually agreeable time and place was established for the interviews. It was important that these interviews be conducted in a place where the participants felt comfortable and secure. The initial interviews lasted from approximately 45 to 60 minutes and the second interview lasted from about 20 to 30 minutes. Data collection instruments used in this study included: Demographic, Medical History and BCRLE Symptoms List Self Report Form, and Breast Cancer-Related Lymphedema Interview Guide. [see Appendix G and H]. The PI conducted each interview.

Demographic, Medical History and BRLE Symptoms Self-Report Form. The demographic, medical history and BCRLE symptom list data for this study was obtained by using an original pen and paper self-report form developed by the PI [see Appendix H]. Items

on this instrument included information pertaining to age, date of birth, marital status, educational level, health insurance, and employment status. Additional survey items included year at diagnosis of BCRLE, stage of breast cancer at time of diagnosis, length of time living with BCRLE, type of breast cancer treatment, current medical problems/comorbidities, self-reported weight/height, and past or current symptoms associated with BCRLE.

Breast Cancer-Related Lymphedema Interview Guide. Interview questions from the interview guide provided examples of open-ended questions and probes for each question. The questions were asked in such a way as to address issues that have been reported as problem areas for patients with BCRLE.

Data collection procedures

The PI asked each participant to sign an informed consent that outlined the purpose, risks, benefits, voluntary nature of participation, confidentiality of responses, duration of the study, and key contact persons. The informed consent included an explanation that the findings from the study may be disseminated findings in the form of a research report without using the names of the participants [see Appendix I].

Participants were informed that their participation was totally voluntary and they may withdraw from the study at anytime without any penalties or change in the health care, privacy, confidentiality and anonymity would be maintained, and that results of the study would be disseminated as a research report without the mention of participants' names. After the consent form was signed by the participant, a copy was given to the participant and a copy was kept in a locked cabinet with the research file. Documentation that the informed consent process occurred was noted in a narrative note placed in the research file. Upon enrollment to the study the participants were not referred to by name rather by using a de-identified code number.

All information collected about participants during the course of this study was kept confidential to the extent permitted by law. Participants were identified in the research records by a code number. None of the participants withdrew after consenting to participate in the study.

The initial screening process allowed the PI to determine each participant's eligibility for the study. This process included observation of each participant's physical and cognitive state, and the answers to the qualifying questions regarding diagnosis of BCRLE, length of time with BCRLE, and type of breast cancer surgery. No indication of cognitive impairment was

noted for any of the participants screened for inclusion in the study. Following consent and initial screening, each participant was asked to answer questions from the Demographic, Medial History and BRLE Symptoms Self Report Form. To ensure clarity, and avoid issues of literacy these questions were read aloud by the PI.

The PI conducted all interviews. Each interview was audio-taped. A numerical code was used to identify participants and their data. Investigator notes, tapes, transcripts, and the codebook linking the tapes and transcripts to participants were kept in separate locked files in the PI's home office.

A micro tape recorder was used to collect information, tapes were transcribed verbatim, and the PI made occasional paper and pencil notes during and after interviews. This process assisted with highlighting specific areas of the PI's perceptions.

Breast Cancer-Related Lymphedema Interview process. For each question, a set of sub questions were used to obtain more directed questions that focus on problem areas women have described in coping with lymphedema. The sub questions relate to: 1.) body image, 2.) family-social roles, 3.) experiences in living with BCRLE, 4.) symptomology, 5.) physical changes and functioning, and 6.) educational preparedness.

The PI recognized that the first question needed to be focused on the holistic perspectives of living with BCRLE. Following the introduction, the initial question was: Describe what it is like for you to have BCRLE? This question aided in structuring a picture of each individual's views of having BCRLE. The question also helped identify holistic aspects of the participants' experience.

Specific questions were then asked about effects of living with BCRLE on each individual's body image, family-social roles, symptoms of BCRLE and effects on functions in everyday living and educational preparedness: "How would you describe your discovery of your BCRLE"? Later questions extended the focus on perceptions of living with BCRLE: a) "BCRLE can affect how a woman sees herself. Describe how BCLE has affected the way you see yourself as a woman", b) "Describe how you cope with BCLE"? If a participant's response required further clarification, the PI paraphrased what the woman said, and whenever needed solicited more information by using phrases such as "Can you give me an example?", "Say more about that", or "What do you mean by that?"

An additional question was asked to determine the effect of non-obvious racial perspectives: “Do you think that any of the concerns that you have mentioned would be different if you were not an African American woman”? The last open-ended question allowed participants to elaborate on any other concerns related to being an African American woman living with BCRLE.

Recruitment and interview timeline. The recruitment and interview period lasted 6 months- from January, 2012 to May, 2012. Eleven participants were interviewed following the initial contact.

Although saturation had been reached, an additional 1.5 months of active recruitment was conducted after the 6th interview to obtain a minimum goal of 11 participants. This effort was successful.

Management/Analysis of Data

Data was analyzed using thematic analysis. Data analysis occurred concurrently with data collection. Audio files from the taped recordings were reviewed to ensure clarity and completeness of each interview. Each interview was transcribed into a computer file and printed to provide a paper record. The paper copy was compared with the audiotape for accuracy. Analytic memos from notes taken during and after interviews were reviewed in combination with the transcripts. Verbal and non-verbal notes from the analytic memos were placed in chronological order and inserted, as notes into the transcripts.

Identification of themes emerging from the interview responses collected from the participants, with the process referred to as "open coding" (Strauss & Corbin, 1990). Categories were identified and grouped. The goal was to create descriptive categories that linked underlying meanings together to form a preliminary framework for analysis. Words, phrases, or events that appeared to be similar were grouped into the same category. These categories were gradually modified or replaced during the subsequent stages of analysis that followed. The unit of analysis was the reviewed line by line text of each of the individual interviews. The next stage of analysis involved re-examination of the categories identified to determine how they linked (a complex process called "axial coding") (Strauss & Corbin, 1990). Data were coded and listed according to the topical areas suggested by the research question. Additional categories were added to identify themes that did not fit under the topical areas or board categories. Based on the identified criteria some categories were merged. The Rashomon effect

(Sandelowski, 1998; Wolcott, 1994) was selected as a format to arrange data whereby the same event was described from the perspective of each participant in the study. Similarities and contrasts in summaries were identified from participant's responses. These summaries may yield concepts, hypothesis for future grounded theory or further phenomenological study. Data saturation was identified by the replication of data within categories (Gibbs et al., 2007). In the final stage of analysis any data that did not fit into one of these categories were categorized under alternative concepts. All tape recordings will be destroyed by shredding following data analysis and final approval of the dissertation project by Wayne State University.

CHAPTER FOUR

FINDINGS

The goal of this descriptive, qualitative phenomenological research is to describe (as opposed to interpret) a “lived experience” of a phenomenon. The goal of this descriptive, qualitative phenomenological study was to describe and facilitate understanding of the lived experience of African American women with BCRLE. Characteristics of the lived experience for the purpose of this study included experiences in living with BCRLE symptoms including physical changes, functioning, body image, coping mechanisms, family and social roles, and patient- healthcare provider relations. This chapter describes the sample and presents primary findings/themes identified from the interview data.

Description of Sample

Eleven participants met the inclusion criteria and consented to participate in the study. All interviews were conducted by the principal investigator (PI). Two interviews were performed with each participant. A total of twenty interviews were conducted in the participant’s homes, one interview took place at the participant’s place of business and one interview was held in the physical therapy department at the Rehabilitation Institute of Michigan. The duration of the first interviews averaged from about 45 to 60 minutes and the second interviews averaged from about 30 to 45 minutes. The final sample consisted of eleven women whose ages ranged from 50 to 73 years ($M= 62$, $SD= 6.65$) (see Table 1). Three participants were between 50 and 60 years old, seven participants were between the ages of 61 and 70 years old, and one participant was between 70 and 80 years old. The educational background of the participants included four high school graduates; two participants had some college preparation; and five participants reported having a college degree. Over half of the participants were employed. One participant owned her own business. One participant worked part-time; four participants worked full-time; two participants were retired; and three participants were unemployed ($n= 11$; see Table 1).

Table 1 Participant's Socioeconomic Demographics

Participant	Age	Education	Employment	Health Insurance	Marital Status	Household Size
1	73	College Degree	Retired/No	Yes	D	1
2	69	College Degree	Part time	Yes - Veterans	W	3
3	61	College Degree	Full time	Yes - Private	D (x2)	4
4	63	HS/GED	Retired	Yes - Medicare/Private	D	3
5	64	College Degree	Full time	Yes - Private	W	1
6	63	HS/GED	NO	Yes - ???	D	2
7	56	Some College	NO	Yes - Medicare	S	4
8	56	Some College	Full time	Yes - Medicare	D	2
9	69	HS/GED	Retired/No	Yes - Medicare/Private	W	1
10	50	HS/GED	Full time	Yes = Medicaid /BCC	S	3
11	61	College Degree	Full time	Yes - BC/BS	D	1

None of the participants were married. Two participants were single and one of those participants had a live-in-partner. Six participants were divorced and one participant had been divorced twice. The remaining three participants were widowed. Four participants lived alone, two participants lived with their mothers, and the remaining five participants had 3 to 4 people living with them (mothers, children and/or grandchildren).

The stage of breast cancer when diagnosed with BCRLE ranged from stage 0 to stage 4. Nine participants had BCRLE beyond Stage 0. Six participants reported stage 3 or stage 4. All participants had undergone an axillary lymph node dissection (ALND); three participants had a sentinel lymph node biopsy (SLNB); another three participants reported having had a combination of both an ALND and a SLNB. Three participants had radiation therapy and six participants had a combination of radiation and chemotherapy and one participant did not have radiation or chemotherapy (see Table 2).

Table 2 Participant's Association with Stages of Breast Cancer and Type of Treatment

Participant	Stage of Breast Cancer	ANLD	SNLB	Radiation	Chemotherapy	Lymph Nodes Removed
1	3	YES	YES	YES	YES	12
2	4	YES	NO	YES	YES	>20
3	?	YES	No	YES	YES	NA
4	2	YES	NO	YES	NO	32
5	1	YES	YES	YES	NO	7
6	4	YES	YES	YES	YES	40
7	3	YES	NO	YES	YES	12
8	3	YES	NO	NO	NO	27
9	?	YES	NO	YES	NO	10
10	3	YES	NO	YES	YES	30
11	0	YES	NO	NO	NO	14

ALND = axillary lymph node dissection

SLNB = sentinel lymph node biopsy

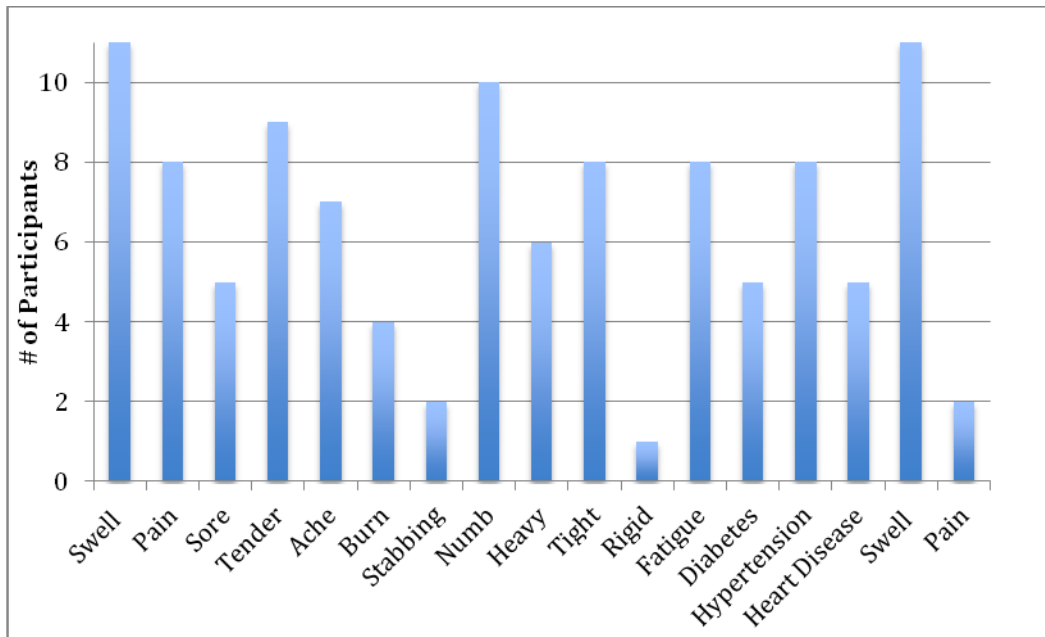
Four participants reported living with BCRLE from one to three years. Three participants had lived with BCRLE from 4 to 7 years. Four participants had BCRLE from 8 to 12 years and one participant had BCRLE for 26 years. The average height was 5'3" (64.95 inches). The average weight was 192.3 lbs. A BMI over 25 indicates being overweight and 90.9% of the participants were considered overweight (BMI > 25). An adult who has a BMI between 25 and 29.9 is considered overweight. An adult who has a BMI of 30 or higher is considered obese (Centers for Disease Control and Prevention, 2012). In this study all of the participants had a BMI over 25 with one exception. Eight participants were obese (30.2, 30.3, 30.8, 32.6, 32.8, 36.5, 39.3, and 50.4) (see Table 3). Being overweight or obese and having BCRLE for a longer period of time were not associated with more symptoms. It has been suggested that preexisting co-morbid conditions of obesity, hypertension, diabetes, and heart disease may influence the development of BCRLE. In this study hypertension was the most reported co-morbidity. Eight participants reported having pre-existing hypertension; five participants reported having heart disease; and five participants had diabetes (see Figure 1). Three participants had a combination of pre-existing diabetes, hypertension and heart disease; two participants had both diabetes and hypertension and two participants had hypertension and

heart disease. Participants who reported greater numbers of preexisting co-morbid diagnoses did not consistently report more symptoms.

Table 3 Participant's Body Mass Index and years with BCRLE

Participant	Time Since Diagnosis (yrs)	Height	Weight	BMI
1	10	5' 3"	185	32.8
2	2	5' 2"	165	30.2
3	26	5' 6"	202	32.6
4	1	5' 6"	188	30.3
5	5	5' 4"	162	27.8
6	10	5' 6"	258	50.4
7	1	5' 6"	226	36.5
8	7	5' 10"	180	25.8
9	4	5' 2"	135	24.7
10	8	5' 4.5"	229	39.3
11	1.5	5' 5"	185	30.8

Figure 1 Participant's Association with Symptoms and Co-morbidities



The majority of participants in this study had been diagnosed with breast cancer at Stage 2 or greater and had undergone an axillary lymph node dissection (ALND). Three participants had a sentinel lymph node biopsy (SLNB) and another three participants reported having had a combination of both an ALND and a sentinel lymph node biopsy. Nine participants had radiation therapy and six participants had chemotherapy and six of the participants had a combination of radiation and chemotherapy. Ninety percent of the participants had a BMI over 25. However being overweight and having BCRLE for a longer period of time were not related to more symptoms. These findings suggested that advanced disease, more radical treatments including ALND, radiation and chemotherapy, and higher levels of obesity are associated to an increased risk for BCRLE in African American women. This study supported the findings of previous studies that determined African American women reported a greater number of aggressive cancer treatments such as ALND compared to Caucasians (Eversley et al., 2005; McWayne & Heiney, 2005; Meeske et al., 2009; Ridner & Dietrich, 2008), and have higher incidence of BCRLE due axillary lymph node dissection (ALND) (Thomas-MacLean, Miedema, Tateemichi, 2005). The findings of this study were consistent with previous findings that substantiate SLNB to be most appropriate for women with early-stage breast cancer (Sermer et al., 2001; Takei et al., 2010). Women with more advanced breast cancer, such as African American women are not generally candidates for SLNB (Sermer et al., 2001).

The prevalence of these comorbid illnesses were prominent in African American women and suggest a predisposition for BCRLE. However the severity of symptoms is likely related to a combination of variables in addition to comorbidities. African American women have the highest rates of hypertension (HTN) and diabetes (DM) which places them at greatest risk for unfavorable outcomes associated with BCRLE. Comorbid conditions of obesity, hypertension, and cardiac problems may influence the development of BCRLE (Banerjee, George, Yee, Hryniuk, & Schwartz, 2007; Meeske et al., 2009; Ridner & Dietrich, 2008; Yoon et al., 2008).

Findings from Interview Data

Five themes were derived from the women's experiences in living with BCRLE. The first theme was identified from the participants' descriptions of what it was like to live with breast cancer-related lymphedema and whether or not the participants hid or shared their

feelings with others. The participants' responses seemed to say that since breast cancer was a personal concern, the visible, physical symptoms of BCRLE caused a private health condition to become public and caused embarrassment. The visibility of BCRLE made having an illness harder to conceal. Thus BCRLE made a private condition more apparent: *Living with Breast Cancer-related Lymphedema*: "Sometimes your personal health is your personal business and nobody else's". Eighty percent of the women in this study reported that the physical changes caused by BCRLE negatively affected how they perceived their bodies. The overarching theme relevant to the physical changes had remarkable influence on body/self-image which represented more than physical appearance and/or sex appeal. The second theme emerged from participants' beliefs about the symptoms they had and how these tenacious and unpredictable symptoms affected their level of functioning in everyday life: *Enduring the Unexpected*: "I'm having this thing the rest of my life!" The third theme emerged from the participants' perceptions and beliefs regarding changes in how each participant saw herself as a woman after acquiring BCRLE: *Diminished Perceptions of Self Image*: "it kinda of uh attacked my self-image". The majority of participants reported that they had not been involved in community service or support groups. However, the participants that had been involved in community service and/or support groups reported that the groups were not culturally sensitive and often did not discuss topics of interest. Therefore those types of support resources were described as least helpful in coping with BCRLE. God, church, family, friends and significant others were acknowledged as key support systems. These factors were prevalent influences in overcoming feelings of helplessness and hopelessness. Hence, the fourth theme emerged from the participants' responses to the question of how they coped with BCRLE: *Feeling Triumphant*: "My support comes from God ...and my family". To varying degrees participants reported healthcare providers were unconcerned and/or unformed about BCRLE. Those perceived behaviors caused distrust and was suggested to amplify perceptions of feelings of rejection, unconcern, uncompassionate and unsupportive attitudes on the part of some healthcare providers. The fifth theme, *Distrust of physicians and other healthcare providers*: "There is no one black woman ". "Just listen to us..." was identified by participants' perceptions of how they were treated by healthcare professionals and what they had to say in response to that treatment. The emotional and vibrant responses of participants follow each theme.

Theme 1: Living with Breast Cancer-related Lymphedema: “Sometimes your personal health is your personal business and nobody else’s”. To capture participants’ holistic experience in living with BCRLE, each participant was asked the broad question to describe what it was like to have BCRLE. This theme emerged from participants’ responses which suggested perceptions of the women’s experiences in living with BCRLE, including feelings of isolation and despair, and the tendency not to their share feelings and concerns with others. The prevalent theme was that BCRLE caused a private condition to become public. The effects of BCRLE made having an illness harder to conceal from family, friends, and the general public and was reflected in the participant’s descriptions of: 1). what it was like to have breast cancer-related lymphedema, 2). the reactions of family members, friend, and/or others to their breast cancer-related lymphedema, and 3). whether or not they hid feelings about breast cancer-related lymphedema issues.

Views regarding concerns/feelings about living with BCRLE were varied. Most of the participants in this study reported concealing their feelings about breast cancer and BCRLE for a number of reasons such as depression, fear of rejection, lack of knowledge, avoidance of confrontation with others, and resentment. Unfortunately, participants’ level of comfort in being able to choose whether or not to discuss concerns about their breast cancer was altered with the onset of BCRLE. Participants’ descriptions suggested a belief that their prerogative to decide with whom to disclose feelings represented a source of empowerment. This perception of power over a situation in which they perceived to have little to no control was seriously threatened with the onset of BCRLE. Women used terms such as “privacy” and “personal” to describe how they felt about having BCRLE. Participants shared a variety of reasons why the subject of BCRLE was considered to be private and/or personal. It appeared that because breasts are related to sexuality which is a very personal aspect of one’s; life women considered BCRLE a private matter. However once they developed swollen arms and hands having some sort of illness (whether suspected breast cancer or not) became more apparent. This viewpoint suggested that the perceived loss of power caused women to become more resolute in avoiding self-disclosure of their concerns. By withholding their feelings about BCRLE and maintaining privacy these women perpetuated a sense of social isolation. Expressed views of BCRLE being a private/personal experience and why these concerns were not discussed with other people were indicated by the following examples:

...once you get lymphedema it becomes public. That was one of the reasons I was so afraid of getting it (BCRLE) because its noticeable...when you look at someone with that (BCRLE) you know they have had cancer I was really worried about that... it's a personal thing... I don't discuss it with my family... Not even all of my friends... it's just something that you don't tell everyone...you have to get comfortable with it... I know it was something that I was going to have to live with... I don't know it's just a personal thing... (Participant 004).

Yeah it (BRCLE) draws a lot of attention in this senior citizen's apt building... They say 'ooh you better go do something about that arm'... one lady even told me if my arm got any bigger that they would have to cut it off... I don't really talk about it. Not even to my kids... (Participant 006).

Sometimes your personal health is your personal business and nobody else's...Yeah because number one, people has stopped and said, "Why are you wearing one of those? "What's wrong with you? Sometimes it's really none of your business that's personal to me... You don't know me and don't ask me... I know one particular person um who...it tears her up when she sees me. And she just breaks down and cry... Most of them (family members and close friends) don't know my feelings...because this is me, this is my body, my pain. "Ya'll don't have it... first the breast cancer and radiation and chemotherapy... I still have some more chemotherapy to go through... then the lymphedema in both arms and then my leg... I don't know I got angry and angrier and couldn't stop crying and on day at the doctors I exploded and loss my temper and they put me in the hospital for a few weeks...I still go to therapy... I never told my son or brother (live-ins) the whole story... I don't want them to know... (Participant 007).

I feel like it's my privacy... They (people in general) asked... "Why do you keep a top on? Then I say I don't want to talk about it.... I've got to be comfortable with that person, then I let them know...Okay if my children come over and they see my arm swelling, they act like it's their arm. They flip out, MOM, your arm is swelling! So sometimes I pull the sleeve down so they don't bother me about my arm... leave my arm alone...Friends, some don't know, some do...Them that don't know say, Oh Ms. XXX your arm is swollen, what's wrong? Then I say I don't want to talk about it... And them that really don't know... just look... I don't let nobody know about that arm, I keep it mostly to myself... (Participant 009).

In contrast two participants (010 and 011) expressed more positive outlooks. One woman was the youngest participant (010) who welcomed opportunities to talk about her lymphedema and found it therapeutic. She reported a willingness to speak about BCRLE and answer questions about her arm and share her feelings with family members and people on her job. This woman unlike the majority of participants that maintained their privacy had established social networks with others. She freely engaged in self-disclosure and found that experience to be therapeutic. She utilized the obviousness of her condition to develop a caring

and sharing relationship with her sister in-law. On a small scale, she had established informal social support connections and was able to reciprocate with her work partner and others on the job, her sister in-law and other family members. The following responses emphasized her positive influence and supportive nature in promoting a healthful coping with BCRLE:

Talking about it helps me... most people don't know about lymphedema... to anybody that will listen... And then I have a sister-in-law, she's going through it... she has lymphedema. She had both breast removed and has it in both arms. So we sit down and chit chat about a lot of things. She's a good support. We kinda lean on each other... at work letting my partner know about it... I mean we're a good team so I'm glad. I'm thankful for that that she knows what's going on because that takes a lot of slack at our job so that's pretty good... I explained my situation and things about lymphedema and my arm to my supervisor and manager from the very beginning... when some of the other girls at work ask me about my arm or sleeve I tell them about it... (Participant 010).

Participant 011 was the only self-employed woman and provided a profound and unique perspective. She considered speaking about lymphedema a serendipitous focus in her life and had become a proactive advocate in promoting the quality of life for African American women with BCRLE as reflected in the following responses:

... I have had the opportunity and the blessing to be involved with so many breast cancer survivors even before I was diagnosed with breast cancer and had lymphedema... for several years before I started my business in mastectomy and prosthetic fitting I volunteered with a breast care outreach specialist going around Michigan and speaking to African American women about the importance of getting timely mammograms... we spoke at many breast cancer support groups... when I retired 15 years ago I decided to start this business... I thought WOW this is what I want to do with the rest of my life... I have had the opportunity to discuss with countless breast cancer survivors about all sorts of issues including lymphedema... I became aware of many problems with African American women in receiving approval for cancer related appliances and the lack or limitations of appliances for African American Women like sleeves in colors closer to the skin tones of African American women... (Participant 011).

The majority of participant's perceived that unless a person had acquired BCRLE they did not understand what it was like to live with this condition. Most of the participants said that people (in general) made inappropriate comments regarding the appearance and/or size of their arms which caused them to feel uncomfortable or embarrassed. For example, two of the participants (003 and 005) in this study expressed concerns for a need for privacy because they felt that only other women who had developed BCRLE could understand what it was like to

live with the condition. Neither of these women had taken part in activities that put them in direct contact with other women with BCRLE, such as support groups. All the same, they made comments that until you experienced having BCRLE you could not understand the dilemma. One participant (005) stated that she refused to discuss any aspects of having BCRLE with anyone other than other women with BCRLE. Other participant's responses suggested that thoughtless, negative and/or hurtful comments made by friends, family members, and/or others heighten the reluctance of women to discuss sensitive issues (such as swollen arms and hands, compression garments and changes in social interaction) related to BCRLE:

... don't tell me oh that's ok you look fine in that dress... I know how I feel... I think it's being selfish on my part but they don't have it, I do and you have not experienced it. If someone that didn't experience it talks to me no, because I'm going to be short with them... you're not experiencing what I'm experiencing... because you're not experiencing it, these are my personal feelings and they are real to me. (Participant 003).

I don't want nobody else feeling sorry for me... they (girlfriends) say ah ah stop using that (BCRLE) as a crutch, just say you don't want to go.... until you walk a mile in my shoes, you don't know what I'm talking about... You don't know how it feels to be in these shoes... (Participant 005).

The majority of participant's descriptions of the experience of living with breast cancer-related lymphedema revealed the tendency not to disclose their feelings about their concerns regarding this condition. Participant's beliefs the people in general did not understand the physical and emotional effects caused by BCRLE contributed to a hesitance to self-disclosure. Most of the participants reported a number of reasons for concealing their feelings including fear of rejection, lack of knowledge, avoidance of confrontation with others and resentment.

Theme 2: Enduring the Varied and Daily Unexpected Impact of breast cancer-related lymphedema: "I'm having this thing the rest of my life!" Often, the most visible manifestations of BCRLE are pain and swelling in the arm and/or hand and occasionally the neck or chest on the surgical side. BCRLE causes other troubling symptoms such as fatigue; decreased range of motion; skin changes; and sensations of tightness, heaviness, burning, or numbness in the affected areas. In many instances individuals are the first to notice the symptoms of BCRLE. In this study, all of the participants were the first to discover the onset of BCRLE. The prevalent theme suggested by participants' responses was that from the beginning of their experiences with BCRLE these women faced struggles with repeated bouts of

unexpected symptoms. The acknowledgement of self-discovery of BCRLE was made irrespective of the participant's surgeon, stage of disease, type of surgery, or type of health insurance. Participants shared that they were not informed about the risk factors for the development of BCRLE. When symptoms started to occur they had no knowledge of what was happening or how to appropriately respond. Some women thought the cancer had recurred. One participant explained *"I thought it was my fault and kept looking to see what I had done to cause this"*. The initial self-discovery experience was described using words such as surprise, devastation and fear. The ongoing unexpected and unpredictable symptoms, while also surprising, devastating and fearful led to an unrelenting impact on everyday life experiences. As a result of not knowing how to respond, some participants encountered avoidable accidents that resulted in injuries due to the symptoms of swelling, pain, decreased sensation and weakness in their arms and/or hands. The challenges posed by the lack of knowledge as to why they were experiencing these symptoms caused distress. This distress was amplified as women tried to find ways to accommodate for BCRLE in their lives and in some cases work. All of these factors were daily emotional reminders of the underlying breast cancer as well as the difficulties related to BCRLE. The participants' responses proposed the lack of information in preparing these women for BCRLE intensified their distress when unexpected symptoms started to manifest.

"I'm having this thing the rest of my life!" The majority of participants in this study supported the assertion that symptoms caused by breast cancer-related lymphedema (BCRLE) included surprise and devastation in the realization that the life-altering symptoms resulting for a "cured" cancer were never-ending (a shocking reality to many) and resulted in frequent exacerbations. Most of the women reported that they had not received any information regarding the risk for developing BCRLE, the development of and persistence of symptoms, or its effects on function. This reality shock led to feelings of anxiety, depression, hopelessness and helplessness. Explicit and varied emotions were associated with living with the persistent and often excruciating symptoms. The majority of participants (n= 8) described how from the beginning they had stressful reactions to the unexpected realization of the chronic nature of the BCRLE. A primary area of concern was whether or not developing this condition indicated the recurrence of breast cancer. Most women had recently completed treatment for breast cancer which remained the focus of their attention. This was the main reason one participant (002)

reported that she was unable to remember how much she had been informed about the risks for BCRLE prior to her surgery. Most women were unaware of the risk for BCRLE. As it became apparent that an additional cancer-related condition had developed they became more distressed. Symptoms caused by BCRLE were reported as unpredictable and difficult to control. The following responses suggested that the lack of educational preparation for symptoms of BCRLE intensified distress and were projected in feelings such as anger, frustration, depression, fear, and worry:

I was really devastated when I realized I had lymphedema because I thought I had gotten past that... Angry, I was angry. I felt like why me? I thought it was my fault and kept looking to see what I had done to cause this. And I also paid attention to my symptoms more and I became more frustrated as I thought its (BCRLE) getting worst instead of better...I worry about it (breast cancer) getting worst... that is my biggest fear so far... I think the most distressing thing about the lymphedema is that you never know when it's going to come back... (Participant 001).

But even if they had told me, you're still surprised by a recurrence of this kind... I think the most distressing thing about the lymphedema is that you never know when it's (BCRLE) going to come back... You can be symptom free for weeks at a time... but despite your best efforts, it will come back... I just look forward to the times when I don't have it... you never know... It's never going to be healed. Because I thought I was through and everything was done, everything had been removed and I was just fine... I was concerned that this (swelling) may come back... (Participant 002).

I'm having this thing the rest of my life! It's been 26 years with lymphedema... My arm swoll up about a year and a half after my surgery. My arm just started to swelling. I started having problems lifting and couldn't get a tight grip on things... I didn't know what was going on... it kept swellin'... and started aching all the time... (Participant 003).

Two participants (004 and 011) had prior knowledge regarding BCRLE. Participant 004 reported that while at some of her doctor's visits prior to her having radiation treatments she noticed swelling in some of the other patients' arms. She asked them about it. This participant developed BCRLE following her radiation treatment. She never inquired about BCRLE any further until after she developed symptoms. However those brief encounters with patients who had the condition lessened the shock at the time her BCRLE symptoms started. Her responses suggested that regardless of the level of formality; receiving accurate information minimizes distress caused by the lack of educational preparation. Participant 004 responses summarized the importance of having preparatory information prior to developing BCRLE:

I know it (BCRLE) existed because I had seen women with their arms and hands swollen at the doctor's office and had asked what was wrong. So I knew that lymphedema existed... I knew it had something to do with having breast cancer removed. It (BCRLE) was one of the biggest things I worried about after acquiring breast cancer... it wasn't something I was expecting to get but I knew it was a possibility... I was hoping it wouldn't be as severe as some of the ladies I had seen with it and it's not so far... I worry about it getting to the point that I can't use the arm... (Participant 004).

Participant 011 was the most atypical woman in this study in terms of her familiarity and prior exposure to the topic of BCRLE. She previously had numerous interactions with other African American women with BCRLE and presented a different perspective at the time she discovered that she had BCRLE. This participant attributed prior knowledge of BCRLE and having exposure to women who had acquired the condition as primary reasons for her more unique perspective:

I became aware of what lymphedema was and was therefore on guard and knew what to look for... I had this business for thirteen years before I had lymphedema... so you see I was at an advantage so to speak... You have to be your own best advocate, you have to read, you have to talk to who you need to talk to... and I did research in terms of what garments I should wear...and that those things must fit properly so that the circulation in certain areas is not cut off... I understand need for the elevation, I know what areas and how to drain my lymph nodes and all that information and they all work together... Knowing how to manage it (BCRLE) is the most important and things go a lot smoother... You have to be your own best advocate, you have to read, you have to talk to who you need to talk to... and I did research in terms of what garments I should wear... (Participant 011).

Accommodating to the function changes caused by breast cancer-related lymphedema. Lack of information regarding BCRLE also intensified emotions caused by the endless struggles in the constant battle with recurrent and unpredictable exacerbations of symptoms. Because participants in this study were uninformed, the unexpected effects of BCRLE on everyday functioning were especially frightening. Everyone who undergoes axillary treatment for cancer is at a life-time risk for development of BCRLE. There is no cure for BCRLE. Individuals are subject to lifelong bouts of recurrent exacerbations and cumbersome daily management regimes. The women in this study reported that what was most shocking was the fact that the symptoms never completely resolved and exacerbations are unpredictable. They realized that the symptoms associated with BCRLE had become a permanent part of their lives. Since acquiring BCRLE, participants admitted to varied levels of impaired function in

performing activities of daily living such as driving, bathing, dressing and cooking, social roles (i.e., babysitting and community service), fulfill tasks at work, and enjoying hobbies. Participants described numerous unanticipated interruptions in their daily lives due to the annoying physical discomforts caused by this condition. Participants described having difficulty performing many household tasks such as vacuuming or grocery shopping, because of swelling and pain, aggravated by repetitive motion and lifting. Responses from the participants suggested that the two primary areas impacted by BCRLE in performing activities of daily living (ADLs) were discomfort from symptoms and impairments in function. The following responses are examples of how symptoms such as pain, swelling and numbness interfered with the performance of ADLs:

...some pain, some discomfort and swelling is always there... If I move too quickly, or attempt to carry something that sometimes is a problem... I noticed I have a deficit of strength... in that arm...I would say I have more pain than swelling... But there are times I have to take an aspirin or Motrin to reduce the pain and stiffness in the joint of that arm... (Participant 002).

... I get a lot of infections in that arm... it feels like worms or something is crawling around in my arm... O yeah pain is always right here (pointing to mid left arm)... occasional tingling and numbness... itching gets worse with infections... I get antibiotics for the infections... I'm on so many medications I don't know what is causing this nausea and diarrhea... My arm has infection right now... I have swelling and itching all the time... (Participant 006).

...I have lymphedema in both arms... it is worse on the side where the remove lymph nodes... I also have swelling in my right leg... it has gotten so big and painful just like my arms. This leg has been getting bigger and bigger just this year... I didn't know I could get it in the other arm or in my legs... (Participant 007).

... this arm always hurts... like an aching... I am always rubbing my arm... I notice a lot of weakness... I wear a sleeve most of the time when I'm traveling I got to wear a sleeve... I don't always wear it like I should... one reason is I noticed the sleeve I have had silicone on it and like it was pressing a lot on my arm... that's another reason why I wasn't wearing it because it was making my arm hurt worse than it was... I notice my left hand get numb for no reason... It's the pain first, the numbness second and the swelling third... (Participant 008).

Women complained of not being able to perform daily activities due impaired dexterity and immobility in arms and hands. The following responses suggested that the unanticipated magnitude of the effects of BCRLE caused varied levels of distress while attempting to perform

daily routine activities such as personal care, household chores, dressing and bathing, and driving. In most instances the women were unaware of the implications for restrictions in functioning. Many participants had accidents and learned by trial and error as to the limits of their functional capabilities. The participant's responses suggested that the lack of educational preparation increased the risk for perpetuating symptoms and fortuitously sustaining injuries. The passionate responses in the following examples illustrate the underlying sentiments conveyed in each scenario:

I don't know if it will ever go away. It may go away within a year's time and you may get 75% of your feeling back you may only get 50%... I have to watch what I pick up something is hot, I don't realize it's hot right away you know if you grab a handle or something because you can't feel it... I have to realize that I can't carry the grocery bag in my left hand and need to switch... if I drop a coin on the floor it's hard for me to pick it up because of the numbness... Opening a jar or... a cellophane bag where you pull it apart... I have to get my grandson or someone to open this up for me. If I'm buttoning up shirt and the buttons are small someone has to button it up for me... (Participant 004).

If I lift something too much... or sweep its going to blow up... I can't squeeze a rag out like I want tight enough... There's no energy there (arm)... it just goes dead... I wear a sleeve when it (symptoms) gets out of control... I have to put it on because then it hurts me so bad and burn so bad it have me crying... I have the sleeve on now... the sleeve is uncomfortable... it's hot and holds heat. You're already burning... but it helps the swelling go down... it fits tight like a casket... I don't do no housework...this arm won't let me...I don't have the strength. If I do something I'll drop it...I lose grip... I can't hold no skillet in my left hand... I've dropped the skillet on my foot before... (Participant 009).

a lot of times you don't know when your hands are going to give out or I do like picking up my grandbaby even though she is kind of a ton.. I just don't have to ability to pick her up... doing little activities like sometimes reaching for certain things... my hands are really numb... How far can I put my arm behind me and it's like an everyday process... Sometimes my hands close up... you have to wait until you can get that functioning back into your fingers in order to do something... it's like 5 to 10 minutes sometimes... That can be annoying. You could be writing and the pen you know just clings in your hand... It's really annoying because I'm a compulsive cleaner so, you can be doing one thing, the reaching and stuff like that and you feel it coming on so you have to take out time to sit back and let this pass... (Participant 010).

"I want to be able to conquer it" Some of the women in this study had to give up activities such as hobbies or volunteering. However, other women created techniques to compensate for the functional limitations caused by BCRLE. Four participants found ways to remain active despite the hindrances caused by BCRLE symptoms. Participant 004 merely

changed the type of tasks she took on as a church volunteer in the kitchen. She had made friends in that church group, enjoyed the interaction and pleasure in providing service to others and didn't want to totally give up that activity. The following responses suggested that making even minimal changes in lifestyle and/or daily activities can allow women to make accommodations to remain socially engaged and maximize independence as revealed in the following response:

I still usher in church and I still help in the kitchen (church)... it's just some things in the kitchen I can't do like lift heavy pots and wash lots of dishes... (Participant 004).

Another participant (005) limited the type of chores she did around the house. Although she was less than pleased with her altered life style, she made a personal choice to limit her social activities and incorporate the management of BCRLE on a daily basis:

I can't do what I use to do. I use to keep an immaculate house but with this lymphedema, as long as my bedroom is straight and my kitchen... I stay at home a lot more these days. I feel more comfortable at home... Besides work and church, I'm done... I wear a gauntlet so the swelling doesn't go down into my hand while wearing the sleeve... I wear my sleeve every day and I go to physical therapy... I put it (arm) on the pump once a day...in the evening between 5 and 7... (Participant 005).

Two other participants (010 and 011) described how they either retrained themselves in a skill and/or reprioritized their activities of daily living in order to make accommodations to BCRLE. These two participants were the most optimistic and socially astute. Their responses suggested that an alternative coping technique such as positive reappraisal coping (the reframing a situation to see it in a positive light) can influence women's motivation in seeking out ways to make accommodations to BCRLE:

I don't I want it to be a hindrance to me. I want to be able to conquer it... at first it did interfere (with ADLs), but I got (learned) to be even handed with a lot of stuff... So I have to be able to use both hands... So when this hand goes dead I can still use the other one... I still drive. At first it (BCRLE) interfered with driving but I learned how to use my left hand... I learned how to be even handed too with writing... Saturdays that's my safe haven day, I'm at home I'm not doing anything so I don't wear the sleeve... but on Mondays through Friday and part of Sunday I'll put it on. My glove and everything... I keep up with my exercise... I'll usually take a ball (hand exercise ball) with me...the hands don't do as bad anymore since I've been using the little squeeze ball... Every now and then I do finger stretches on my dash board... if you're just sitting there you can feel a tingling feeling. It just feels like a bunch of needles sticking you constantly... If I didn't wear both of them (sleeve and glove) every day you can see all the fluid popping up in one spot (the uncovered area)... (Participant 010).

I love to garden and so I'll take my pain medication early in the morning you know cause I know I'm going out to garden and I'll do what I can and the rest I'm not going to worry about... So I just adjust... Controlling pain is very very, very important. Because if you don't control it the pain is going to knock you on your back... I understand that, you know there are certain things that I can and can not do with this arm and it is my dominant arm... Just deal with it... You have to, you have to... We have to get a grip, uh just look at that person over there it could be worse... (Participant 011).

There was something distinctly analogous about these four participants who were able to make accommodations to BCRLE. Each of these women tended to have a more optimistic outlook regarding the ill effects of BCRLE as compared to the other participants. They had supportive relationships with their family members and had community involvement (social or employment). Each of these women aggressively sought out information about BCRLE via the internet, word of mouth and/or from healthcare providers. They seemed to have a more commanding attitude regarding their health care needs. All of these variables are consistent aspects of positive reappraisal coping techniques (looking at the glass half full versus half empty).

The remaining seven women were more socially isolated. Two women (one who admitted that she coped by denial and the other through escapism) had issues of unmet psychological needs and were receiving individual psychotherapy. Other women described feeling depressed, sad, and/or overwhelmed as revealed in the following examples:

I feel sad about it because it's sooo big... (Participant 006).

...when it bothers me, I get uptight... sometimes I get depressed... (Participant 009).

I cope by denying it... I go to therapy (counseling)... (Participant 003)

Sometimes if I'm really upset, I stay upstairs in my room... I need somebody to talk too especially when these arms and legs go to swelling and hurting and getting me down... (Participant 007).

The “double whammy of Breast Cancer-Related Lymphedema. Participants in this study had fervent responses when describing the chronicity of BCRLE. Participants reported negative feelings such as anger, frustration and embarrassment while dealing with the emotional and physical impact of the condition. Responses from the majority of participants

suggested that in addition to concerns about having breast cancer the additional worries regarding BCRLE led to them feeling overwhelmed, depressed, and uptight. Avoidance coping is characterized by evading problems rather than dealing with them directly (Passik, Newman, Brennan, et al., 1995). Regardless of age, time since diagnosis of BCRLE, or severity of symptoms participant's responses suggested that the additional worries brought on by BCRLE put women at greater risk for psychological morbidity and mental instability. It appeared that a feeling of "double whammy" is what had most women unable to accommodate the life changes caused by BCRLE. Participant 001 provided a response where she referred to a feeling of having a "double whammy". This was the oldest participant. She believed that by having acquired BCRLE in addition to being diagnosed with breast cancer she had two cancer-related diseases attacking her simultaneously. She reported that this circumstance created a feeling being overwhelmed beyond what words could describe. Her responses summarized the sense of feeling overwhelmed as expressed by women in this study:

I have been double whammied... once I got treatment for the cancer then my swollen arm became another problem... I think it is a lot to accept and even harder to explain... (Participant 001).

Three participants (006, 009, and 010) expressed additional concerns regarding feelings such as sadness, depression, and/or a general sense distress. The responses in the following examples were among the most commonly expressed and suggested a need to further emphasize the risk of heightened emotional distress caused by BCRLE:

I feel sad about it because it's sooo big... people tell you things about the arm... I don't say nothing to them... It just makes me feel funny... a lady at bingo said "your arm is going to bust wide open and they will have to cut it off...my daughter said when are you gonna do something about that arm? Things like that makes me feel sad... (Participant 006).

...when it bothers me, I get uptight... sometimes I get depressed because a lot of things I want to do I can't do... it's there and there's nothing I can do... I deal with it... I don't like nobody to pet me... I've been like that for about a week, going on two weeks. I don't know why I get depressed sometimes... (Participant 009).

Avoidance Coping and distraction. Avoidance coping is characterized by evading problems rather than dealing with them directly (Passik, Newman, Brennan, et al., 1995). An avoidant coping style has been identified as a significant predictor of adjustment difficulties for

women with BCRLE (Passik & McDonald, 1998). Participant 003 admitted to copying by denial. She explained how she coped was by not directly dealing with BCRLE unless the physical symptoms flared up. As well, participant 007 reported that she frequently escaped to her room or stayed in bed. Both of these participants were receiving psychotherapy on regular basis. The following responses emphasized the importance of additional referrals such as psychiatric or social services when needed as reflected in her responses:

I cope by denying it... I go to therapy (counseling)... about 10 or 12 years ago. I can just talk. One to one... It really helps me... I started several years ago may be I don't allow it to be on my plate every day. It's only on my plate when I can't get my arm in a blouse or the pain is so bad that the swelling gets up into my chest, or I can't wear what I want to wear that makes me irritable and I have to think about it... (Participant 003).

Sometimes if I'm really upset, I stay upstairs in my room... I read a book or do a word search anything for diversion or I stay in bed... it depends on what kind of mood I'm in... I need somebody to talk too especially when these arms and legs go to swelling and hurting and getting me down... (Participant 007).

Distraction was another form of coping noted in participants in this study.

Participants 008 and 009 used distraction to remain positive. Women engaged in activities such as reading, shopping, traveling, or just hanging out with friends. Their responses suggested that engaging in enjoyable individual and group activities can promote positive coping and adaptive responses to BCRLE stressors and can minimize distress and depression:

I try to stay as positive as possible and keep myself busy doing the things I love to do so I don't dwell on it so much... I know it's there but if I enjoy life and have fun I don't get depressed... I never get depressed... I try to keep busy doing the things I like to do... Like I have had the opportunity to travel more since my job provides discounts, I've recently been to Amsterdam and Prague. I like to go to the casino with my mother and hang out with my friends doing a lot of things like movies, and concerts... (Participant 008).

I try to make myself busy. Sometimes I go to the casino to keep from being depressed. I love to go shopping. I love to hear music... (Participant 009).

Breast cancer-related lymphedema can result in the accumulation of fluid in various sites in the body including the arms, legs, chest and the trunk. There is no scientific rationale that fully explains why some individuals develop BCRLE or why it may develop in multiple areas. Swelling occurs because the remaining lymph nodes are unable to consistently prevent blockage and maintain appropriate flow of lymph through the lymphatic system. Once the

lymphatic system has been injured such as with the removal of lymph nodes swelling due to interruption in the flow of lymph can occur in one or more sites in the body. Two participants (003 and 007) had acquired BCRLE in both arms. Participant 003 also developed shortness of breath and lymphedema in her neck and chest. Additionally participant 007 developed lymphedema in one of her legs. These two participants voiced similar views regarding the emotional struggles they encountered in living with the recurrent and unpredictable exacerbations of symptoms of BCRLE. Interestingly these were two participants who were receiving psychotherapy which began after their diagnosis of BCRLE. Their responses suggested that having multiple sites of BCRLE symptoms amplify emotional distress, therefore increases the risks for becoming clinically depressed:

I have lymphedema on both sides... it's very very painful... it's embarrassing, I can't move it, it gets swollen so bad... numb and sore to the touch... when it swells it swells to the extent that it's numb... I have it in both arms but this arm (surgical side) is worse... I do everything to make sure nothing touches that arm when it's swollen... I get so depressed and frustrated because by it being in both arms there are time I fell like a invalid... I can't hardly do nothin... And to lift something with it like my grandbabies... I am feelin hurt that I can't raise them up with it (swollen arm) ... One (symptom) that I didn't notice that you had was shortness of breath... it inhibits me; it seems like it goes into my chest wall or something and therefore I get the feeling like I'm having a heart attack or something... The pressure from the swelling goes into my neck... exercise and I need to watch my caffeine intake... those things contribute to the swelling in my swollen arm... (Participant 003).

I am so angry about this... first cancer... now this (BCRLE)... It (BCRLE) affects me a lot. Sometimes I can't even put my own sleeves on and pull them to where they are supposed to be... talking about putting them on a certain way so it won't tear, it's hard to do... especially when you have it in both arms... now I notice my right leg having the same pain and swelling as my arms... I got more angry, upset and depressed about that... and still am... I can't even wash my own hair... I don't even want the doctor to touch it... if I bump it against something it is very painful... Oh they (family) can tell when I'm not in a good mood. I be mean, I be evil, and I will tell you off in a minute... I wasn't always like this... but since the cancer and lymphedema... I guess it is just soooo depressing... I'm working on it... I don't have nobody but my one friend, the research nurses, and my lymphedema nurse to talk to. I need somebody to talk too especially when these arms and leg go to swelling and hurting and getting me down... (Participant 007).

Participant 005 was very adamant about not wanting anyone to feel sorry for her. She believed that that type of interaction lead to self-pity and made her feel even more depressed. Her responses suggested that unmet psychological needs can lead to social isolation and despair:

... I don't want sympathy, I don't want pity... just let me deal with it in my own way. One thing is that I'm grateful to be alive... sometimes we get our moods; we get our self-pity. So I say, "Oh girl get over that! Be thankful that you are alive"... sometimes it gets depressing. You start feeling sorry for yourself. I try not to talk about it unless you know like it's somebody I can confide in... it makes me feel sad and I don't want nobody else to feel sorry for me... Because when you start feeling sorry for yourself you just get in a rut... Leave me alone! (Participant 005).

"I don't know if I can keep this job". Over 50% of the participants in this study worked at least part-time. One participant worked part-time as a nurse administrator for a group of privately owned home care agencies and reported no work-related problems due to BCRLE. Four participants had full-time jobs that required repetitive movements, frequently lifting up to various weights. Lifting requirements varied and included lifting people and/or equipment/furniture. For the participants in this study some of the physical job activities that required heavy lifting and frequent use of their affected arms often resulted in increased pain, swelling and discomfort. Depending on the type of occupation work experiences varied. The situations ranged from no effects caused by work related activities, to minor complaints of increased painful swelling, to a most extreme case leading to the termination of employment. These responses suggested that women with jobs that require repetitive motions involving the arms and hands, lifting, and reaching were at greater risk for physical and functional complications and work-related distress:

I am a nurse (in administration/part-time) and it doesn't affect my ability to do my job... (Participant 002).

Sometimes it inhibits me on my job... I work with juveniles... Sometimes I do restraints with this arm... it is not as strong as my right arm... so that inhibits me with some of my performance (job)... I always have to remind myself when I perform a restraint... get someone to help me... my co-workers have always been willing to help... actually since lymphedema I don't and can't do restraints one to one... I can only restraint someone with assistance... (Participant 003).

... my job is as a caregiver... they (employer) got equipment to help with the lifting... without that equipment I won't be able to lift my patients... that's why I'm still with the agency... full-time... midnights... (Participant 005).

I work at the airport... at work I have to push and pull up on the buggy bin for the luggage and I notice when I do that it (arm) hurts... I have to use both arms to pull up the bridge so that passengers can get their luggage... (Participant 008).

Participant 010 had a remarkable story to tell regarding how BCRLE affected her at work. She was extremely worried about losing her job because of the decreased strength in the affected arm and the need to have a partner in order to complete job assignments, as well as the need to attend periodic physician and therapy appointments. This woman was a single mother and the head of household of two teenage daughters. She was making minimum wage and needed to work. The following emotional excerpts taken from her first and second interviews provided a good example of her account of how attempting to manage BCRLE led to the termination of her job. Her responses emphasized why employers as well as healthcare providers need to be informed about the implications of BCRLE:

First interview: Oh My God I don't know if I can keep this job... I work for Molly Maid...It affects my work a lot... I mean you're wiping off stuff, with rag in hand and you only have so much time to be in a home and if you're taking out 10 to 15 minutes to stop to get your arm situated then that's longer you're being in this home trying to clean it up. Symptoms come without warning. So it's a good thing I have a good partner (at work). She takes on a lot of slack for me. We work as partners all the time...Yeah she knows about it (BCRLE)...I am blessed to have her as my partner... I need my job... (Participant 010).

Second interview- I just got fired from my job 3 days ago. My manager was upset that I had to take so much time off the go for therapy... I had to change my time around before for doctor's appointments and therapy... I've been working for that company for over a year and they know I have breast cancer and lymphedema... I tried to explain THIS IS MY LIFE...I HAVE TO GO FOR TREATMENT... I keep telling them I'm willing to work just work with me please! This time I had twelve weeks of therapy and I only had two more weeks to go... my supervisor usually moves my schedule around so that I can work and go to medical appointments... for some reason , I don't know why, she had a problem with me this time and said I was taking too much time from work going to therapy ... I had given her my therapy schedule when I first got it... But she said it was too much and they gave me five days off for not having a doctor's excuse... I came back and worked that Wednesday and when I got home the manager called me and told me that I was terminated for taking too much time for medical appointments... I explained that he should know that the time was not entirely taken off but my schedule was adjusted and times were moved around, but he still fired me... I just went down and filed for unemployment... (Participant 010).

The participants in this study were at least 50 years old, unmarried, overweight, hypertensive, had stage 3 or stage 4 breast cancer, had undergone axillary dissection surgery, and had some form of third party health insurance. Most participants were reluctant to self disclose their perceptions of BCRLE which contributed to feelings of privacy about those issues. Participants seemed to express a sense that because breasts are related to sexuality and

the subject of BCRLE became a very personal aspect of one's life. The participant's responses suggested that thoughtless, negative and/or hurtful comments made by friends, family members, and/or others heighten the reluctance of women discuss sensitive issues (such as swollen arms and hands, compression garments and changes in social interaction) related to BCRLE. The hesitance to self-disclose was attributed to participant's beliefs that people in general did not understand the physical and emotional effects caused by BCRLE also contributed to. Most of the participants reported a number of reasons for concealing their feelings including fear of rejection, lack of knowledge, avoidance of confrontation with others and resentment.

Responses from the participants also suggested that two primary areas impacted by BCRLE in performing activities of daily living (ADLs) were discomfort from symptoms and impairments in function. The participant's responses reported that the lack of educational preparation increased the risk for perpetuating symptoms and sustaining injuries. The women in this study described that what was most shocking was the fact that the symptoms never completely resolved and exacerbations are unpredictable. They realized that the symptoms associated with BCRLE had become a permanent part of their lives. Regardless of age, time since diagnosis of BCRLE, or severity of symptoms participants expressed feelings that the additional worries brought on by BCRLE put women at greater risk for psychological morbidity and mental instability. Finally, some of the participants had job duties that required heavy lifting and frequent use of their affected arms and hands which often resulted in increased pain, swelling and discomfort. Their responses indicated that women with jobs that require repetitive motions involving the arms and hands, lifting, and reaching were at greater risk for physical and functional complications and work-related distress.

Theme 3: "it kinda of uh attacked my self-image" Responses from the participants in this study supported the assertion that they found themselves not only dealing with changes in their appearance, but changes in the overall sense of self-image. The overarching theme relevant to self-image by study participants was more than an altered perception of body image. Participants reported that the powerful effects of BCRLE resulted in changes in self-confidence, self-esteem, perceptions of body/self- image and changes in family and other interpersonal relationships, daily activities, and social life. Descriptions of thoughts and behaviors related to these altered states suggested varying levels of perceptions of changes in

body image in that they would never be physically the same after acquiring BCRLE. These changes represented more than body image, physical attractiveness and/or sex appeal. These women described loss of a sense of who they thought they were before the advent of lymphedema, loss of independence, and the loss of intimacy in relationships. This may infer a larger concern encompassing an alteration in their self-image. Participants expressed how they didn't feel the same and how BCRLE imposed changes in attire and perceptions of physical attractiveness. Expressed views regarding body image suggested that the effects of BCRLE had monumental psychological effects on how women perceived the physical changes in their bodies. Their concerns exceeded outer appearance or sex appeal and went deeper altering psychosocial functioning. The following responses suggested that women living with BCRLE had to make a number of permanent adjustments in their lives which caused varied degrees of decreased self-esteem and social isolation. The symptoms of BCRLE had become an eternal part of their lives and things would never be the same for them as revealed in the following excerpts:

...it kinda of uh attacked my self-image... my clothes began to not fit me... As a woman; I think that the lymphedema has affected how I see myself. I'm not too much of a sexual person... But I don't feel that I'm the same... I think the change in my body and how I see myself was distressful... I still like who I am... I have the same relationships with my family members and friends... But in some ways this thing makes me feel weak... (Participant 001).

That lymphedema... it takes something from me... I can't wear short sleeves... most of the time I wear the long sleeves... I try to cover it up with a shawl or something to cover... It changed my appearance to where I don't wear short sleeves. I wear basically long sleeves... I have this big mass hanging over my arm... I have to buy a larger blouse because of the arm swelling when it sweeps I can't get my jacket on which means I got to get a larger jacket... most of my tops are ill fitting... I have to buy larger tops in order for my arms to fit... it bother me sometimes, but it is what I deal with... It makes me feel less sexy because of this big swelling in my arms... I don't feel adequate or attractive because of the arm swelling... you want to have the arm look slim... I'm not a small woman but my arms are supposed to be smaller... that annoys me that I have to buy that larger top/extra-extra-large sometimes... when I want to wear a nice crisp, sleeveless blouse; No not with all this meat hanging. That adjustment in my attire bothers me... (Participant 003).

I don't go anywhere, I don't want to be bothered with nobody. I rather stay in my room in the bed... Depends on what kind of mood I'm in and the pain I had the night before... sometimes I don't wanna go nowhere with these (bilateral sleeves) on...out shopping and this and that... They (people in general) look at you strange... like you got some kind of

skin disease just because you're wearing this... You know they have said, "You look like you got burned or something"... I don't like it. And when I have to go out to different social places and events I got to wear these and they don't come in colors. You feel like you don't belong... These don't come in colors... This embarrasses me... they (sleeves) are ugly and they are uncomfortable; ok in the winter but not in the summer... you walk around attending different events, the show, dinner... and you got to wear these... it makes you feel like an odd ball... Most of time I rather stay at home... I can't wear nothing tight underneath my arm pit because of the pain... I have to cut my blouses and wear an extra t-shirt underneath ... I also can't wear a bra and have a few camisoles... I try to wear something I can pull over and cut away to fit... I don't have much money... it makes me angry because you got to go out and buy a lot of new clothes... and you could have put that money and did something else with it... (Participant 007).

... it will never be like the way it was... I notice now since I've had it (BCRLE), you know, I'm kind of have a self-complex against my arm... I use to drive and dress and put on short sleeves, trying to be cute and stuff and you know that this arm, when you look in the mirror like, who is that? And you like UGH. I always wear long sleeves because when I wear a short sleeve and I look in the mirror I say woe my arm looks soooo fat, and the other one looks ok... you can tell the difference and you know it is something you can't control and you want to shrink it back to normal... (Participant 008).

Participant 011 remained unique in her responses. She was the most enthusiastic participant in every subject discussed. In person, she portrayed her verbal image. She was consistently smiling and soft-spoken, yet direct and straightforward in her responses. On both visits she was well-dressed and manicured. She wore her compression sleeve and matching gauntlet during each interview. She readily admitted to an awareness of her changed body image. However, in contrast to most of the other participants she considered the changes in her body as another spiritual challenge. Her responses suggested that on a consistent basis her positive reappraisal coping techniques minimized distress and depression as illustrated in the following excerpts:

Yes it does change your body image because your body has changed ... I see this as another challenge... But it's OK cause when I have to wear my sleeve it's my sleeve and it's on my arm and if anybody else doesn't like it then that's too bad... that's your problem...to me it (arm) looks just like a blessing because I'm still here... It is important to take time out for yourself... Take care of yourself... for instance I get a body message whenever I feel the need .That uh not only help to drain fluid but provides psychological comfort as well... Even something as simple as getting a manicure or pedicure... stay feminine, stay fixed up... You have to.... (Participant 011).

“ It makes you feel like an invalid at times”. Participants in this study reported a loss of independence in activities of daily living caused by BCRLE. The general response from participants was that they were annoyed and frustrated in not being able to perform many of the customary tasks associated with female head of households, mothers and grandmothers. These losses contributed to and accentuated feelings of despair in causing women to feel helpless as illustrated in the following responses:

I lost some of my independence... I had been an independent woman and handled all of my business and able to take care of myself. Then my ability went down some... I had to become depend on others ... I became one of those semi-independent women... dressing myself and such... you know you just make uh adjustments... I ended up having to have some come in and help me... Yeah it was family... if I had to go a long way... help me clean house... prepare meals... help me do my activities of daily living... it was frightening... (Participant 001).

... that inhibits me from doing things that I would normally do... still for me to have it this long, this year it will be 27 years ... like my house is old and I started renovating... if ... I was used to doing what I wanted to do... That makes me angry because I have to get someone in there to help me... I have to wait for my daughter to get home. She gets angry if I lift while she's gone... I have to lift something too much for my arms... I have to get my grandkids or my kids in there...(Participant 003).

... it makes you feel like an invalid at times... my kids noticed that... you're supposed to always be the person that's strong to do for you kids, not for your kids to turn around and do for you... I'm a person that likes a challenge so I'll keep working at it to build up whatever I need to build up (arm strength)... Sometimes it's annoying. I don't let people see it bothers me. A certain part I want to work on is putting my arm in the midst of my back. You know how you get that scratch and itch... how far I can put my arm behind me and it's like an everyday process... I want to conquer it. That's annoying... an example... so I couldn't button my shirt and it's kind of bad because of your child and asking them can you button my shirt up because my hands are numb or my hands just won't act right. I kind of put you in a state where I don't want them to ever have to do for me... I'm getting ready to tear up so... Or ask them to tie your shoe... its nerve racking to me... (Participant 010).

Impact on personal intimacy. Women in this study expressed concerns regarding the impact of the loss of intimacy in relationships with others since acquiring BCRLE. Participant 002 spoke about how the issues surrounding BCRLE (at least partially) disrupted her marriage which subsequently led to divorce. She reported that her concerns regarding BCRLE were never pointedly discussed with her husband. The following examples of her responses point to multiple stressors such as concerns regarding changes in body/self- image, concealing feelings

from others, and lack of information in preparation for BCRLE all of which (especially in combination) have the potential to cause disruption in relationships:

Let me put it briefly, we separated and eventually divorced... No I'm sure it (BCRLE) wasn't the whole reason... I may have reduced certain sexual contacts because I think that my husband was worried about it and weary that if he touched me in the wrong place or squeezed me in the wrong place that he might be hurting me... so gradually I guess in trying to spare him any embarrassment, I uh stopped having as much sex and moved out of the regular bed and started sleeping by myself... he slept in the room by himself... I became less and less interested in sexual relations... the arm swelling did affect our relationship. Sometimes African American women are not too free in the discussion of body image. We may say; or I'll say I kept that body image concern to myself. In fact, I even kept my sexual intimacy with my husband to myself. I didn't discuss that... (Participant 002).

Two participants (003 and 006) expressed a loss of intimacy in not being able to hold or hug their grandchildren. Their responses suggested that something as simple as the inability to embrace loved ones can intensify feelings of distress:

I can't raise up my grandkids... It has something to do with love; it's just an expression, being able to hold them... (Participant 003).

... sometimes I babysit my grandkids... but I don't lift them, I can't... I would really like to be able to do that... or just give 'em a big hug... (Participant 006).

Two participants (009 and 010) provided responses that expressed loss of relationships with their significant other either due to death or separation and further underscores the impact of loss of intimacy in relationships associated with BCRLE:

before my husband died, wasn't no problem with him. He was the one to help me go through everything. Then after he left me with prostate cancer... I don't need nobody no more... I met one person a long time ago, 7 maybe 8 years ago, but that got on my nerves... that was my last boyfriend... he was alright with the lymphedema... He said it didn't bother him. Since he felt that way, I felt a little bit better about myself... We broke up and grew apart... I don't have no outside friend, like a man. I don't want to be bothered... lots of times I'm by myself... Even if I go to the casino or shopping I go by myself. I fell better going by myself I don't have nobody rushing me... I can stay until I'm ready to come back. I be so tired... I get in my big chair and look at TV... (Participant 009).

I had a boyfriend... we are no longer together. But when he was there, we were good friends...at first it was unbearable depressing to feel alone... after him I felt nobody else will want me...The lymphedema wasn't the whole reason for feeling this way but it did

add to it... first was the breast cancer and then the lymphedema on top of it... (Participant 010).

In contrast another participant (005) expressed a more positive portrayal of intimacy in her long-term relationship with her boyfriend. Her responses described that good communication and an understanding to accept the decision to discuss or not discuss BCRLE can help facilitate in a more positive relationship:

I do have a male friend... the same one through all these years. He's been here since day one... he said you know whatever you decide to do we'll do. You want to talk about it we'll talk about it. If you don't want we won't. And he is still doing what he does... he is a big help to me... I appreciate that... (Participant 005).

Participants described loss of a sense of who they thought they were before the advent of lymphedema, loss of independence, and the loss of intimacy in relationships. Their responses inferred that there was a larger concern other than body image and/or sexuality that comprised an alteration in their self image. Participants in this study expressed concerns that BCRLE had negatively influenced interpersonal aspects of their lives such as marital and family relationships. One participant spoke about how the issues surrounding BCRLE (at least partially) disrupted her marriage which subsequently led to divorce. Other participants were annoyed and frustrated in not being able to perform many of the customary tasks associated with female head of households, mothers and grandmothers. These losses contributed to and give emphasis to the feelings of despair in the realization that things would never be the same as before BCRLE.

Theme 4: Feeling Triumphant: “My support comes from God ...and my family”.

The women in this study identified God, church, family, and friends as key support systems in their lives. The prevalent theme indicated by participants' responses was that although a strong sense of anger, hopelessness/helplessness and fear of the unknown was evident; faith/spirituality as well as the support from family and friends was persistently acknowledged as an eminent force that helped to overcome those feelings. God and church were expressed as elements of spirituality. Spirituality was revealed as the primary source of inspiration as summarized by the following response:

My thing is I couldn't have fear and faith at the same time. I had to have one or the other and I choose faith ... It's just something I have to live with... I wouldn't say I'm ok with it. I'd prefer not to have it. If I could get rid of it I would... I know it's something I have

to live with and deal with... That the Lord is going to see me through this... I know that in order for me to continue to live and to be here I had to have my lymph nodes removed because my cancer had spread to the lymph nodes... I guess prayer is what I use most to cope. When I was diagnosed with this, I just ask the Lord I said, "Lord I know your will is going to be done. Help me to accept your will and help me to accept it with grace so I can be grateful". You know I didn't want to do a whole lot of whopping and hollering and crying woe is me and why is this happening to me. Because my thing is cancer doesn't know anyone by name... Babies are diagnosed with cancer... it's just something I had to accept.... (Participant 004).

“My family is one of those ‘ole southern Baptists”. Family and friends were also acknowledged as most important support systems in the lives of participants in this study. Most of the participants reported having positive relationships with their immediate and extended family and friends. These relationships were not disturbed by BCRLE. The following responses reveal that family and friends were primary informal support systems in meeting the needs of women with BCRLE. Family and friends provided assistant with personal care, household chores, transportation, and provided emotional support. Participants expressed feelings of gratitude for having loving and caring family members and friends. The following responses highlight the important roles of family and friends in the lives of women living with BCRLE:

My family is one of those ‘ole southern Baptists. If one person is ill and can't function, somebody steps in and takes over for them. So whatever was going on with me they were going to accept it...They just said, "Ok"... So it wasn't any difference in my relationship with my family. They filled in the gap and became more supportive...I thought the best thing to do was come out matter of factually and tell them. When you try to hide something it makes it worse...You have to be honest and direct. Tell them and don't hide... 'cause they already knew I was feeling bad... (Participant 001).

my support is my family and my friends... the company I work for they're African American. This particular gentleman lost his mother to breast cancer and he is very sympathetic, he's very supportive... (Participant 005).

A good friend of mine comes in and helps me and she takes me shopping to church and doctor's appointments... My brother does the heavy house work and the yard work... I don't have any female relatives and my family is small... I can call a lady who is my mentor (a person with mental health services) and I can call on the ladies of Delta (African American sorority outreach program)... (Participant 007).

My family is great. I really have to give kudos to them. They were really great through the whole progress... My daughters are great, my siblings, my mother God bless her soul. They are all fantastic. They do a lot for me even though I sometimes felt like an invalid...They were right there through everything... my daughters help me (25years and

18 years)... Yes my daughters. Just watching them and looking at me saying well if you can go through this we can do whatever we need to do... Oh my God, I have a sister-in-law that is so amazing. I love her to death. When I get into those moods where I'm not feeling well, she cooks... she'll bring me my favorite cream of broccoli soup. She'll call to make sure everything is okay. She is just fantastic... (Participant 010).

“What they were concerned with would not concern me”. Responses varied when participants were asked whether or not they had sought out and/or participated in community services such as self-help and support groups. The majority of participants reported that they had had no involvement with community support groups (n = 8). Participants expressed mixed sentiments when describing why they had not support group involvement. Participant 001 who had been involved in church groups and breast cancer and BCRLE support/self-help groups had varied experiences. She reported that the BCRLE support groups that she attended were not as supportive as she had anticipated. She was disappointed that the topics of discussion were usually not culturally sensitive and often not important to her. The explanations for lack of involvement in support groups contained varied responses including for the most part disinterest or lack of knowledge. The following responses suggested that lack of culturally sensitive issues influence the low attendance of African American women in support groups as reflected in the following responses:

Women's groups [at church] were just talking in general about problems women have when you pass menopause and some of your life challenges... I find that helpful but decided to try a couple of support groups for women with breast cancer. Going to women's support groups was the least helpful. Sometimes they were helpful but most times they weren't. One thing about it they didn't talk about lymphedema... if I had a women's group that was mainly African American women that probably would have been more helpful to me. Or even if they talk abit about lymphedema. But as it was I had groups with Caucasian women and what they were concerned with would not concern me. So I was sitting up in the room and sometimes they were telling me something about having sex with their husbands, that didn't concern me. I was concerned about whether my cancer had spread and whether my treatment was ok and what was going to happen to my children (adult). That's what I was more concerned about... When I went to a support groups that was mainly Caucasian women they had other things that bothered them. It worried them to think that they were no longer sexual. It worried them that they could not wear sexy clothes. I was more concerned about my family... with another group (BCRLE) they were interested in their appeal to their husbands or significant other... I went because I thought they had things that could help me... But... (Participant 001).

Participant 011 voiced similar feelings regarding why she had not sought out a support group:

... No I have never attended a support group for myself... My support comes from God. I don't know of a support group that um, I should be a part of. Cause I don't want to go and listen to um, things that are not important to me. I don't want to know about how because how your sex life has been affected. I'm not sexually active but I think if if I had a sex partner and he thought less of me because of lymphedema then he doesn't deserve me... Maybe that's a little cocky but that's how I feel... Being able to interact with so many women here in my business cause I talk with them if feel like this a support group one on one... Yes it might come back but what is worrying going to do, I have put all my trust in God... You know he has kept me this far and if it comes back so be it I'm going to be fine. So I think when, you worry all that anxiety and fear is detrimental... uh just take it one step at a time... Even more than that just be grateful for this moment... Whatever life you've lived or whatever life you are going to live, just be grateful (Participant 011).

Participant 003 had not sought out support groups but had received one to one psychological therapy counseling. The focus of these therapy sessions was to help support her in coping with breast cancer and BCRLE and other struggles in her life. Her responses further suggested that additional referrals such as psychiatric or social services are inimitably helpful when needed as reflected in her responses:

... I haven't gone to a support group... I go to therapy (counseling)... I think I may always go... this has helped to save my life... sometimes I think I can only talk too, you know open up with my therapist... we talk about whatever is bothering me and I have talked about my anger and frustrations with lymphedema... (Participant 003).

Participant 008 didn't think she had have enough information about what a support group was to make an informed decision as to whether or not to attend a meeting. Her responses further stressed the need for information regarding the accessibility and availability of support groups:

I was gonna you know I thought about going to one... But I never did... I wasn't sure if they could help me... I didn't know what it was like... maybe I am a little afraid... (Participant 008).

Participant 010 (the youngest participant) reported that she never felt the need to go outside of her family for assistance in coping with BCRLE. She reported good family relationships with her parents, children, siblings and their partners. In fact she admits to being very supportive to a sister-in-law who had recently been diagnosed with breast cancer and was planning to have surgery. She said that they were very close and supportive to one another. As previously discussed this participant had informal support connections. Her responses

suggested that positive interpersonal relationships and opportunities to communicate feelings and concerns promote healing and well-being in women with BCRLE as further evidence in the following example:

No... I never have attended a support group of any kind... I think that one reason I didn't seek groups; my family was too big for that... I'm close to my daughters, my father, brothers and sisters... I have plenty of people to help me and listen and care about me. Having lymphedema has never really changed that (family closeness)... (Participant 010).

Faith-based cancer support groups have been recognized as more culturally appropriate and practical resources for African American women who tend to rely on family members, friends, ministers, and church members to assist with coping (Brag & Gulatte, 2001). Although not focus specifically on BCRLE, two participants (002 and 005) reported involvement in faith based support groups provided a venue to assist with coping. The potential of faith based groups as an alternate forum to assist African American women with coping is illustrated in the following examples:

... I'm in a church group that gives me support... I never gone to another group for support with this (BCRLE)...we pray for one another and talk about various issues in life... I have not talked specifically about lymphedema but I have talked about being my marital problems of which having lymphedema I believe played a part... in general this has helped me cope with everything... (Participant 002).

We have this little bonding circle at church. I would attend that ... I wasn't offered anything dealing directly with lymphedema... In the church they were older...The group it was like what you'd call a mother's nurturing and beyond... they still have it... I don't get a chance to go as often...they talk about different things in life general... sometimes I do talk about breast cancer and the feelings I have about lymphedema at times... (Participant 005).

The majority of participants reported that they had no involvement with community support groups. Participants expressed diverse sentiments when describing why they had not support group involvement including disinterest, lack of knowledge, and/or motivation. God, family and friends were persistently acknowledged as the prominent factors that helped women cope with BCRLE. Participants reported having positive and unconditional relationships with their family members and friends for which they expressed feelings of gratitude. Faith-based cancer support groups have been recognized as more culturally appropriate and practical resources for African American women who tend to rely on family members, friends, ministers,

and church members to assist with coping (Brag & Gulatte, 2001). Women who had been involved in church based groups agreed with this viewpoint. Two participants admitted to avoiding dealing with BCRLE through denial or escapism. Both of these participants were receiving psychotherapy on regular basis. Both women considered this intervention to be irreplaceable and vital component in their experience with BCRLE, which promotes the importance of the need for additional referrals such as psychiatric or social services.

Theme 5: Distrust of physicians and other healthcare providers: “There is no one black woman “. “Just listen to us...” Responses from participants supported the assertion that a lack of information about breast cancer-related lymphedema before diagnosis commonly led to a perception that healthcare providers and especially physicians did not care about them as individuals. Most participants’ responses indicated that between the time of their surgery and the initial discovery of symptoms of BCRLE they received no information regarding this condition.

Responses from Healthcare Providers. The emotions of the participants in this study varied and in most instances nurses and physical therapist were perceived to have shown more care and concern as compared to physicians who were generally considered less concerned. Descriptions of feelings of rejection, unconcern, uncompassionate, disrespectful, and non-supportive attitudes by some healthcare providers were identified as contributing factors to participants’ feelings of distrust:

... nurse C (lymphedema nurse) referred me to CNy (physical therapist)... the physical therapist, she showed me how to wrap the arm and everything... and helped me get a sleeve... CNy made me more knowledgeable... while she was doing therapy... she told me what to look for and what to be aware of and what to do... So she really really helped me quite a bit... I didn’t know anything about lymph nodes actually being removed and causing this condition. That I didn’t know until after I developed it... she was the most helpful person (healthcare provider)... she showed that she cared... she was very honest... I was comfortable with CNy. She gave me printed materials to read... she answered all of my questions... C was very helpful too... (Participant 004).

I got no information about lymphedema before my surgery... seems like the medical people should be able to give me some better answers than what they been telling me when I told my doctor he showed me how to exercise it and rub it and he recommended that I wear sleeves and to the Rehabilitation Institute of Michigan and a lymphedema specialist C (lymphedema nurse)... C referred me to CNy (physical therapist)... I developed lymphedema in both arms and still don’t know why... I had physical therapy for a couple of weeks back in October of 2011 and it was very helpful... as time went on

the lymphedema nurse was very helpful and she had one to one with me. If I didn't understand it she'd explain it to me... (Participant 007).

I never got any information about lymphedema before I got it... The first lymphedema person I started seeing was C (lymphedema nurse) she you know kind of explained to me what it (lymphedema) was 'cause I never knew anything about lymphedema before I got it... I didn't even know anything about lymph nodes being in our bodies... she told me about the symptoms and what to do... Then she gave me a prescription for me to go to therapy... She helped me the most... The therapist gave me a lot of brochures and a lot of different exercises to do; she said it won't take it way but it king of you know will help a little bit... (Participant 008).

No I was told anything about lymphedema before the surgery... when I started having swelling I went to my doctor and he was helpful... it was a lot of the stuff the doctor and the nurse told me... I talked to a lot of older people that were in the hospital at the time and had their sleeves before I even got mine and they told me a lot... after the fact the lymphedema nurse and the physical therapist were the most informative and helpful to me... (Participant 010).

Distrust of healthcare providers. Among African Americans distrust of physicians has been attributed to the lack of interpersonal and technical competence, perceived quest for profit and expectations of racism during routine provision of health care (Jacobs, Rolle, Ferrans, Whitaker, & Warnecke, 2006). Participants in this study reported the negative aspects of physicians' attitudes to be a source of emotional distress. Most participants (n = 10) provided negative descriptions of relationships with physicians. For the most part healthcare providers were perceived as reserved and uninterested in listening to them. The following thought-provoking responses illustrated a distrust of healthcare providers. The participants also offered suggestions to improve those relationships. These responses illustrate that issues of trust and distrust should be considered in clinical practice to facilitate confidence and improve healthcare relationships among African Americans (Jacobs, Rolle, Ferrans, Whitaker, & Warnecke, 2006) as evidenced in the following examples:

I'd like my doctor to be more understanding and kind of hone in on my specific problems wishes or needs instead of just focusing on the disease. I'd like my nurse to have more time so that she could be a bit more supportive, giving me education and maybe being able to refer me to community resources... how lymphedema might be one of the side effects, he (doctor) could speak on that before I had the surgery, but after I have it, I'd like for him to come in there and tell me I needed some things and what might happen... the assistance from the doctor and nurse and showing their concern can help your self

control and fear and that's giving me more power over my disease and that's what I would appreciate... (Participant 001).

... when I first told my doctor about the swelling he said don't worry about that (arm swelling). The swelling will go down and I would be ok. But it just seem to come back on its own about a year later... I thought whether the cancer would come back... They just wanted me to know go home take whatever therapy they had to offer, check for swelling myself...they seem to give me the impression that they expected me as an African American woman to handle and cope with it myself... I think there might be a perception in the greater healthcare industry that an African American woman will look after herself... let the patient know that there will be times that this lymphedema will come back on its own... that would have been helpful. I would have known what to expect... (Participant 002).

Just listen to us... But they don't listen. They take everything causal. It's not their body so they really don't care... they really don't listen to what you're saying... They need to listen... Just listen! What I'd like for them (healthcare providers) to do is look at each of us differently. The controls of our bodies are different... My body is not like anybody else's... (Participant 003).

... I was assigned to a oncologist... he wasn't any help, I didn't go back to him... I changed doctors... the next guy was a little better but then I had to set him straight... he wanted to only give me 5 minutes. I said you come in and you're only going to give me 5 minutes. There are questions that I need to know that you need to answer, you know you're talking about me, my life... he gave me some brochures and said what time is my next appointment... like they ask me how was my pain. I said 10 and they keep right along... and the second doctor he got upset because I wouldn't go into some type of study that they were going to do. I said I don't understand it (the study) and I'm not going to be nobody's guinea pig.... my primary (doctor) was no better I called her and went to see her after dealing with those other two doctors and she said, ah ah ah, I don't have time to be bothered with all these folks... I just wanted to take the pain away... she was an internal medicine doctor... I'd like to see... I believe that since I'm African American from a different culture they (doctors) can't relate to me. I still feel that way... I was angry to be very honest with you... they (previous doctors) just washed over it with you so that you can shut up... I now have the greatest primary doctor. She is African American, she understands, she understands it all... (Participant 005).

... I told my doctor when I saw the swelling and he said, "Don't tell me about it, it's not my problem... No I never got no reading books and nothing... one of the nurses said you got lymphedema... I have a lot of infections in this arm... I get a lot of medicines and antibiotics when it gets infections... I don't have the same doctor but he don't say nothing to me about it... I forgot who gave me a prescription for a sleeve. But it didn't fit. It was too tight and hurt my arm... I never had therapy... I 'd like to say to the doctor... YOU COULD HELP ME...it is his job and he is getting paid for that... One thing he didn't think about me and my arm is still getting bigger... (Participant 006).

Some of the available information on lymphedema needs to be publicized more in these hospitals... doctors should know more off the top of their heads. Don't just blah, blah, blah, blah and then download this from the internet. You being my doctor you should be able to tell me more about it... (Participant 007).

By us not being knowledgeable in a lot of things, I think they should be more patient and more sympathetic and you know and not try to label us as something different because we're African Americans... when you go to a healthcare provider and they are not patient enough and don't show compassion enough that kind of makes us feel kind of insignificant... (Participant 008).

I think they (healthcare providers) should listen a little bit more to the things a person is telling them and not speculate what's going. And look into it a little bit more to help... instead of you know just brushing it off. Okay, we're going to pass you off the next person. I think that would be the biggest thing for me... (Participant 010).

... my doctors are excellent and God know they saved my life... but in regards to lymphedema to them it is just a small thing... it is something that you know it is sometimes not well understood... it can get to the point where you can get panicky and desperate in not understanding what is going on with that arm... I have heard women complain about this... (Participant 011).

“ even if you give me something to read, somebody has to break it down in laymen terms”. The participants in this study reported receiving little to no information from their healthcare providers regarding the risk for developing this BCRLE prior to surgery. The lack of information caused women to independently seek out information in a number ways. Some women had difficulty comprehending information they received. Participants reported feeling frustrated and at times discouraged, as they continued to search for the crucial knowledge required to understand and make informed decisions to manage this condition. The following responses accentuated the importance to provide adequate information for the preparation of women who are at risk for BCRLE. This educational information is imperative in minimizing the ill-effects of BCRLE and maximize overall healthcare-related quality of life. Several participants (002, 003, and 008) resorted to various methods of seeking information such as library and internet searches and are revealed in the following responses:

I think when you find out something like that (BCRLE) you begin to read a lot. I went to the library and read up about lymphedema... I went on the internet to see if I could find other people who might have experienced the same thing... (Participant 002).

I went to Wayne State Medical Library and read up on everything I needed to know... So my knowledge basically came from Wayne State Medical Library... I researched everything ... (Participant 003).

I went back to Karmanos that's when they (doctor/staff) sent me to C (lymphedema specialist (RN)... she recommended me to the therapist for that (BCLE)... (Participant 008).

Participants (004, 005, 006, 007, 008, and 010) reported that level of literacy and/or format of presenting information regarding BCRLE written in brochures and taken from the internet were confusing and difficult to understand. Participant 004 reported accessing the internet was the least helpful in acquiring knowledge. She was often frustrated when she did not fully understand information and there was no opportunity to ask questions. Responses from the participants suggested that educational information intended for patients should be presented in layman's terms and should include referral information and contact numbers that of resources that provide answers to questions. Healthcare providers should consider the level of education, reading ability, and individual level of understanding of what is being read and verbally communicated when providing healthcare education to patients:

I guess that the web was the least helpful... It gives you information but to talk to someone that knows is better... It doesn't have that personal touch... (Participant 004).

... my daughter went on the internet and she found me some material... basically I did a lot of reading from information my daughter found... sometimes I found the information too broad with percentages of this and that... (Participant 005).

I never got any information... I don't read to good but I would try to read it... (Participant 006).

In the beginning I got most of my information from Karmanos and the library... I sent out for some information from the American Cancer Society. Some of the information was confusing and hard to understand if you're not a medical person. I didn't understand all of the words... (Participant 007).

... even if you give me something to read, somebody has to break it down in laymen terms... I read it over and over and still wasn't understanding it. Okay you read it now if you're in the master's field and you read it you could understand, but knowing nothing and you read it and it's like somebody trying to tell you something in French... I didn't really understand a lot of what I read, but I got the idea. It takes longer for me to grasp what you are saying, especially something dealing with medical... (Participant 008).

I read brochures I got from Karmanos... I understood most of it... I read things from the internet and asked my physical therapist questions and she helped me understand better... questions I asked a lot of questions... (Participant 010).

In contrast participant 011 had received educational preparation and was better informed about BCRLE. She was aware of what signs indicated the development of BCRLE and clearly understood the risk reduction practices. Her responses further put the accent on the value of educational preparation to minimize symptoms and associated distress:

I became aware of what lymphedema and was therefore on guard and knew what to look for... I had this business for thirteen years before I had lymphedema...so you see I was at an advantage so to speak... my breast cancer was insitu... and I was actually at stage zero... the tumor however was very large but it was all contained... I discovered my lymphedema myself... uh I started noticing numbness in my dominate arm...So when you go to the doctor and say my arm hurts...to be told just give it a little more time and it will go down... however I knew in my mind from what I had the opportunity to learn that this was lympedema... I contacted a lymphedema therapist she showed me how to the lymph drains and uh I understood that I needed to get a pump and milk the arm to get it down and then to get a properly fitted sleeve.... But you see that was because of my advantage in having my past experience and my business that's how I knew of the lymphedema specialist... (Participant 011).

Participants were asked the final question: Do you think that any of the concerns that you have mentioned would be different if you were not an African American Woman? In most instances racism was perceived to be associated with alleged differences in treatment by healthcare providers to African Americans. Most of the participants (n = 7) in this study perceived a lack of cultural consciousness, mutual respect, and sincerity in their physician. They included examples of how they were treated during their experiences with BCRLE. Participants (003, 005, 007, 010, and 011) expressed concerns regarding the lack of positive support. Their responses suggested that African American women expected health professionals to provide expert, caring, compassionate, and respectful treatment.

... if I was a male I wouldn't have to worry about this arm swelling because there is more research on white women and men... Black women seem to have more advanced breast cancer...mine was advanced... I delayed and I knew I had uh problems... (Participant 003).

I think that if I was white or from a different culture, things would have been different. You know I would have been prepared more... I finally got one (primary doctor) that was real nice. I told him about the first two and how I don't like being referred to as "you people"... he (first doctor) said you people! Now that really gets me riled up...my

doctors were not African American. And so my feelings were the non-blacks don't understand what African Americans go through... (Participant 005).

If I was not African American I definitely think the process would have been different... Seems like the other races be treated more better than my race... I've seen it at Karmanos since my diagnosis with breast cancer and this lymphedema... for example to way some people talk to you and they will talk to a white lady right next to you better and take more time with them... I've talked with other black woman about at Karmanos at some of them feel the same way... Sometimes some of them talk sharp to you... I don't care what your race is I'm your patient and I'm not gonna let you talk to me any kind of way. You're a human being, I'm a human being and before you got this job, you should have learned how to talk English and treat people... (Participant 007).

I think everything would have been different... I think the doctors would have come to me and let me know what was going on before I came to them and told them what my symptoms were. I think they would have let me know a lot more and my sleeves and glove would have been right there. I think that at least coming out of surgery having lymph nodes taken, they would have explained right along that little path but instead it was more so like okay you'll find out on your own. Whatever happens happens. I think there would have been a big difference... (Participant 010).

Hum I probably would have been treated different if I was of a different color... Um you know we have it harder anyway as African American women. We are looked at differently kinda like work horses... we suppose to be able to endure the pain, work longer, and harder, not smarter and all those things unlike some other women are allowed to do... In talking with my clients it is apparent that white women are treated differently in terms of extending a compassionate caring attitude... (Participant 011).

Five participants (004, 005, 007, 008, and 011) presented realistic and reasonable options in supporting and promoting positive and informative health care interventions to address the concerns of African American woman living with BCRLE as expressed in the following examples:

They need to prepare you for it (BCRLE) before you go through your surgery and you come out and your arm is still the same size, but three years down the line, here comes this lymphedema... they need to let you know that this could happen I had been through surgery, physical therapy and my arm had not swollen. Not thinking that once I started radiation it happened... and you haven't escaped it... they need to prepare you that eventually this can happen... I can imagine women 5, 6 or more years later to have it happen... They (healthcare providers) need to let you know up front... they should let you know if your insurance carrier doesn't cover it and that there are other options, agencies... maybe foundations that would help pay for the sleeve or a portions of the payment. Something is better than nothing... (Participant 004).

The only thing I would strongly suggest it that you (healthcare providers) give us (African American women with BCRLE) a support group I think that there should be a place to go that you can let a person who has had it and know what you are going through do the teaching or let them have something to do with setting the program up... let them be the spokesperson for breast cancer lymphedema to African Americans... Start from the very beginning... go step by step... (005).

Number one they should have workshops...maybe on Saturdays. They should send us information through the mail. They should sit down with us one to one... Bring other people in who have had this and let them explain what they went through and how they made it through. They should take time to listen to me. Just like they have breast cancer support groups at all the different churches, they need to do it for lymphedema... (Participant 007).

... once you have lymphedema it would be nice to have a class or something someone that could be there that could break it down simple so that we can understand what's going on and that like in those charts. That would help more so than giving us a bunch of brochures and stuff. Because if you read it and still don't understand it, you get nothing... a class to break it down I think would make us feel more comfortable... even for some if you got to go from the first grade red, green, blue, something like that ... (Participant 008).

I know that you have to be your own best advocate... You have to um pick doctors that are good... what doctors and other healthcare providers need is compassion, knowledge, respect, and caring and concerned about what you do... In terms of support groups I would like to see them focused on us trying to help each other and not just a social group... only here recently have I become aware that support groups for breast cancer don't really focus on lymphedema and there is a need for support groups for women with lymphedema particularly African American women... I'm willing to do my part... they can meet here. I can provide all sorts of information like insurance coverage. They can try on and become aware of all the different appliances that are available. I don't mind I like talking about lymphedema. I like the idea of starting a support group for BCRLE for women like me. They can meet here on some Saturday afternoons. A no nonsense straight to the point program of information and support... I like that idea. Could you help get it started? I'm excited... (Participant 011).

Socioeconomic more than race. Two participants (001 and 002) expressed concerns that perceived difference in treatment by some women was more closely related to socioeconomic issues rather than race. Their responses indicated that regardless of race or ethnicity, women of lower socioeconomic status generally face problems such as financial constraints and limitations in health care services as reflected in the following excerpts:

... It's not so much your race it's your payment... If you can pay for it, you get it. If you don't pay for it, you don't get it... like I said, race may not have anything to do with it...

I think every minority has some of the same problems...I think you can't go cultural or racially specific...I think there are other things that would relate more such as socioeconomics. If I'm a low socioeconomic status person that would make a difference... There is no one black woman...There is a poor black woman who has no education and has certain aspirations and goals to their life. Then there's a black woman who has a professional job and able to support her children, maybe she's gone through high school, and maybe she has a year or two of community college, that's a different black woman. Then there's another black woman who has the education she has some type of professional job she has a college degree and she's working in other areas...so there's no one black woman... (Participant 001).

I don't know that almost sounds like a social economic problem rather than a racial problem...we're like every other American woman. We have families, we have love lives, we're active, we go to church, we raise children, grandchildren and great grandchildren and lymphedema... I have the same problems that, you know a Caucasian woman has... (Participant 002).

Summary

Five themes emerged from participants' descriptions of perceptions and behaviors pertaining to the lived experience in living with breast cancer-related lymphedema. The first theme was identified from the participants' descriptions of what it was like to live with breast cancer-related lymphedema and whether or not the participants hid or shared their feelings with others: Living with Breast Cancer-related Lymphedema: "Sometimes your personal health is your personal business and nobody else's". The second theme emerged from participants' beliefs about the BCRLE symptoms they had and how these tenacious and unpredictable symptoms affected their level of functioning in everyday life: Enduring the Unexpected: "I'm having this thing the rest of my life!" The third theme emerged from the participants' perceptions and beliefs regarding changes in how they saw themselves as a woman after acquiring BCRLE. The physical changes caused by breast cancer-related lymphedema represented perceptions of dissatisfaction with body image. Participants acknowledged their bodies had changed and would never be like it was before. The overarching theme relevant to the physical changes had remarkable influence on body-image which represented more than physical appearance and/or sex appeal. The fourth theme emerged from the participants' responses to the question of how they coped with breast cancer-related lymphedema. Participants expressed feelings of triumphant over BCRLE: Feeling Triumphant: "My support comes from God ...and my family". The fifth theme, Distrust of physicians and other healthcare providers: "There is no one black woman ". "Just

listen to us...” was identified by participants’ perceptions of how they were treated by healthcare professionals and what they had to say in response to that treatment.

The majority of participant’s descriptions of the experience of living with breast cancer-related lymphedema revealed that most women did not disclose their feelings about their concerns regarding this condition. Participant’s beliefs the people in general did not understand the physical and emotional effects caused by BCRLE contributed to a hesitance to self-disclosure. Most of the participants reported a number of reasons for concealing their feelings including fear of rejection, lack of knowledge, avoidance of confrontation with others and resentment. One participant reported having a feeling of having a double whammy because she had acquired breast cancer and BCRLE as well as breast cancer. She reported that the experience caused her to feel overwhelmed to a point which she couldn’t find words to describe how she felt. In contrast, two participants welcomed the opportunity to share their feelings about living with BCRLE. One participant reported she found talking about her experiences with BCRLE as therapeutic and helped her to cope with her feelings.

Most women had not been involved with community service or support groups. However four participants had been involved with various types of community service or support groups. One woman that had attended a support group for women with lymphedema reported that the groups were not culturally sensitive and often discussed topics that she was not interested in. Two women reported having attended church groups and reported that those experiences although not focused on lymphedema did provide some support in coping with BCRLE. Two women who had not attended a support groups but had been receiving one to one psychotherapy sessions that they believed was generally supportive in helping them cope with BCRLE. Finally one woman reported that although she had considered seeking out a support group she had no idea of what to expect and therefore shied away from the notion.

Every participant described self-discovery in being the first to notice symptoms of breast cancer-related lymphedema. Strong assertions were made regarding the lack of receiving information from healthcare providers regarding the risk factors and symptoms of BCRLE prior to developing the condition. Women acquired education regarding BCRLE in a variety of ways including: internet searches, library searches, written material such as brochures and handouts, word of mouth, and previous exposure to and conversations with women who had BCRLE. The least helpful method of acquiring information was reported as reading some of the written

material and accessing the internet. One participant reported that although she received written material she was too embarrassed to reveal that she couldn't understand what she read. Another participant indicated that the internet was helpful. However she conveyed that method of inquiry lacked a personal touch. Her lack of understanding was related to not being able to obtain timely answers to pressing questions. In most instances physicians were identified as the least helpful whereas the lymphedema nurse and physical therapist were reported as the most helpful.

Participants reported difficulties performing household chores and work-related tasks due to the swelling and pain caused by repetitive movements and lifting of the arm (s). Two participants had developed BCRLE in both arms. One woman had BCRLE symptoms in her neck, chest and arms. The other woman had developed BCRLE in both arms and one leg. These two participants expressed similar views regarding the struggles they encountered in living with the recurrent and unpredictable exacerbations of symptoms of BCLRE as well as intensified frustration and impairments in mobility and dexterity. Furthermore, one participant reported an experience regarding the ultimate loss of her job related to her attempts to manage BCRLE.

Participant reported that the powerful effects of BCRLE led to changes in self-confidence, self-esteem, perceptions of body image, interpersonal relationships, daily activities and social life. However two participants perceived this dilemma as a challenge and a positive opportunity to share their experience rather than an obstacle in the perception their image of womanhood.

God, church, family, friends and significant others were acknowledged as key support systems. These factors were prevalent influences in overcoming feelings of helplessness and hopelessness. In this study women primarily used spirituality and positive reappraisal to cope with BCRLE. One participant that had been the recipient of psychotherapy, admitted to using denial as a form of avoidance coping in dealing with the unpleasant consequences of BCRLE.

To varying degrees participants reported healthcare providers were unconcerned and/or ununiformed about BCRLE. Those perceived behaviors caused distrust and was suggested to amplify perceptions of feelings of rejection, unconcern, uncompassionate and unsupportive attitudes on the part of some healthcare providers. In this study the majority of participants attributed racism as a primary reason for a perceived difference in the treatment of African

American women. Two participants related their perceived difference in treatment in socioeconomic issues rather than race. These women opined that regardless of ethnicity women from lower socioeconomic backgrounds and those with inadequate insurance coverage are treated inferiorly. Five participants suggested realistic and reasonable options in supporting and promoting positive and informative health care interventions to address the concerns of African American women living with BCRLE. One participant offered her time, experience, expertise and place of business to provide a forum for a support group for African American women with BCRLE. She volunteered her place of business as a location where African American women with BCRLE could meet, obtain up to date information regarding available appliances and health insurance options and coverage, and provide a forum for encouragement and mutual support.

CHAPTER FIVE

Discussion

The purpose of this qualitative study was to explore African American women's experiences in living with breast cancer-related lymphedema (BCRLE) including physical changes, functionality and perception of body image, family and social roles, coping techniques, and patient-healthcare provider relations. Data from this study contributes to the gap in nursing knowledge by assisting the profession to achieve a culturally-specific understanding of the influence of BCRLE on the lives of African American women. The findings suggest that BCRLE is a tenacious, unpredictable and recurrent condition which impacts the daily emotional and physical functioning, and perception of self-image in African American women with BCRLE. God and faith, and family are key support systems used by African American women to cope with BCRLE. All these factors support the necessity for culturally sensitive and compassionate care to African American women with BCRLE by healthcare professionals which is especially critical, yet missing.

A discussion of the five themes: (1.) Living with Breast Cancer-related Lymphedema: "Sometimes your personal health is your personal business and nobody else's" (2.) Enduring the Unexpected: I'm having this thing the rest of my life!, (3.) Diminished Perceptions of Self Image: "it kinda of uh attacked my self-image, (4.) Diminished Perceptions of Self Image: "it kinda of uh attacked my self-image", and (5.) Distrust of physicians and other healthcare providers: "There is no one black woman ". "Just listen to us..." that emerged from this study is presented in this chapter. This chapter also includes a discussion of the comparison of the findings regarding African American women with BCRLE from this study to findings in similar studies in the literature; strengths and limitations of the current study; implications for clinical practice and future research, and conclusions.

Living with Breast Cancer-related Lymphedema: "Sometimes your personal health is your personal business and nobody else's"

An important finding from this study that contributes to nursing knowledge is the understanding of the feelings of being forced to take private concerns to a public arena after African American women develop BCRLE. The prevalent theme suggested that the participants had concerns regarding the privacy of their disease becoming public and that only other women

who had acquired BCRLE understood. The theme was reflected in the participant's descriptions of: 1). what it was like to have breast cancer-related lymphedema, 2). the reactions of family members, friend, and/or others to their breast cancer-related lymphedema, and 3). whether or not they hid feelings about breast cancer-related lymphedema issues.

The majority of participants in this study reported concealing their feelings about BCRLE and expressed feelings of depression, fear of rejection, lack of knowledge, avoidance of confrontation and resentment. Summarized sentiments such as: "I try not to talk about it much...it gets depressing."; "I don't let nobody know about that arm I keep it mostly to myself..."; "It's just something you don't tell everyone..." suggested that for a variety of reasons women felt the need to withhold their concerns about their experiences with BCRLE. Participants in this study also reported that people failed to realize or understand what it was like to have undergone treatment for breast cancer; live with the lifelong symptoms; and failed to understand the implications of their ongoing symptoms. Rather than disclose their feelings, the majority of women kept their concerns to themselves. Internalizing their concerns were reflected in comments such as: "Sometimes your personal health is your personal business and nobody else's..."; "I feel like it's my privacy..." As a result of concealing their feelings participants became less willing to disclose their feelings to people. Thus they became more socially isolated

No previous studies were found that discussed issues in the chronic illness literature regarding issues of privacy relative to signs of disease or that explicitly investigated the experiences of African American women living with BCRLE. However this study supported findings from previous studies that revealed loneliness and depression in women following treatment for cancer (Auchincloss, 1995; Rosedale, 2010; Wilke, 2003). During their course of illness women with gynecological cancer have been noted to struggle with feelings of loneliness and isolation (Auchincloss, 1995). A term used in a study performed by Rosedale (2010) was "survivor loneliness". Survivor loneliness was referred to as a feeling of being alone which led to "a changed sense of identity and connection, and a lowered threshold for distress" (Rosedale, 2009, pg. 175). In Rosedale's qualitative study, also based on Husserl's phenomenology, women described experiences after treatment for breast cancer. All of the participants in that study experienced some degree of survivor loneliness including situations where women sometimes withheld the truth about their feelings of loneliness and isolation.

According to the author of that study, survivor loneliness ultimately led to heightened psychological distress. By concealing their feelings to shield others from the truth the women ultimately contributed to their feelings of loneliness (Rosedale, 2010).

The tendency of the women in the present study to conceal their feelings led to a sense of separateness in emotions that women described as “private” or “personal” concerns about their illness. Women seemed to attain a sense of control in keeping their concerns hidden from others. The sense of control was manifested in avoiding self-disclosure. Concealing feelings regarding the presence of an illness was less burdensome when the sole diagnosis was breast cancer. Unlike BCLRE, the signs of breast cancer were virtually undetectable. The onset of BCRLE threatened that control due to the obvious presence of symptoms. People started asking questions when symptoms became more apparent and women started behaving and dressing differently. The stares and questions from the general public caused most women to reduce their social contacts and to become more determined not to share their concerns with others. Another explanation could also be because, “breasts” are a very private body part for women and they would prefer to keep the information to themselves. It is not common in every day conversation to talk about one’s breasts unless a person feels very safe confident. Similarly, Sacerdoti et al., 2010 discussed a major obstacle in their qualitative gynecological, study of women following treatment for uterine cancer. Women were reported as not feeling comfortable talking about sexual issues. According to the authors the patient’s reluctance to bring up delicate sexual issues with medical professionals was often corresponded by the avoidance of the professionals to address sexuality. As a result this aspect of treatment was often unaddressed (Sacerdoti et al., 2010).

Self-disclosure or the sharing of personal information with others through verbal communication is an integral part of social interaction (Quinn & Chaudoir, 2009). However in the present study, most participants perceived that self-disclosure would result in unfavorable outcomes such as social ridicule. Several participants reported negative feelings caused by comments made by people regarding their swollen arms/hands, attire, and/or compression garments. Disclosure can provide an opportunity to express thoughts and feelings, develop a sense of self, and build intimacy within personal relationships (Derlega, Metts, Petronio, & Margulis, 1993; Jourard, 1971). However, when people who bear a concealable stigmatized identity, personal information that is socially not well understood or not readily apparent to

others such as BCRLE, in self-disclosing this information to others, they risk experiencing negative outcomes or even becoming the targets of derision (Quinn & Chaudoir, 2009). Only one participant expressed concerns she thought that people in general attributed her swollen arm to drug abuse.

Breast cancer is the underlying disease from which BCRLE emerges. The discussion of BCRLE implicates breast cancer. Participants in this study did not elucidate to what degree they had freely discussed their breast cancer. Consequently the majority of women seemed to conceal concerns about both the breast cancer and BCRLE. The additional burden of worry attributed to both conditions amalgamated with other physical and emotional challenges participants faced, heightened distress. For example the following response by one participant illustrates this sentiment: “once I got treatment for the cancer then my swollen arm became another problem... I think it is a lot to accept and even harder to explain...” The intense levels of distress caused women to become overwhelmed which contributed to their reluctance to self-disclose.

Two participants who engaged in self-disclosure generally had more optimistic outlooks and positive experiences in living with BCRLE. They reported similar emotional challenges and concerns as described by the majority of participants regarding the adverse effects of BCRLE. However, what these women shared in common was that they expressed less depression, were more socially active and had established supportive social networks with family, friends and others in the community. They were willing to share their experiences in living with BCRLE with others. The self-disclosure process served to enlighten people who had no knowledge of the condition. They answered questions to clarify BCRLE and the reasons for compression garments. One participant extended her compassion for educating people with and without BCRLE by establishing a business focused on the needs of women with BCRLE.

Enduring the Unexpected: “I’m having this thing the rest of my life!”

Rosedale & Fu (2010) performed a phenomenological study to describe women’s unexpected and distressing symptom experience after breast cancer treatment. The study sample consisted of thirteen women 1 to 18 years after breast cancer treatment. Reported symptoms associated with BCRLE were pain, loss of energy, impaired limb movement, cognitive disturbance, and changed sexual experiences. Compared to other women with BCRLE (Rosedale & Fu, 2010) the women in this study were “surprised that the symptoms

they experienced during treatment never disappeared but remain part of their lives” (Rosedale & Fu, 2010 pg. E29). A most important finding was that “the lack of preparation for unexpected situations intensified the distress from the symptoms, which created the unexpected situations” (Rosedale & Fu, 2010, pg. E32). The majority of participants in this study also described feelings of shock, devastation and fear with the realization that they had acquired breast cancer-related lymphedema. Most of these participants’ responses indicated a fear about the return of cancer as well as concerns about the symptoms of BCLRE caused varied degrees of anxiety, depression, hopelessness and helplessness among participants. Symptoms were reported as unpredictable and difficult to control which led to heightened feelings of distress.

Participants in the present study were equivalent to other women with BCRLE in qualitative breast cancer research (Carter, 1997; Fu and Rosedale, 2009; Rosedale & Fu, 2010) who reported receiving insufficient information from their healthcare providers regarding the risk for developing BCRLE prior to surgery. In the current study, none of the participants received information from their healthcare providers regarding the risk for BCRLE or its symptoms prior to acquiring this condition. The lack of pre-education regarding risk factors and symptoms contributed to the feelings of distrust and of being ignored by healthcare providers. The lack of information created emotional concerns that were apparent in participant’s responses. Participants described feelings such as devastation, surprise and fear when recalling how they discovered BCRLE. Several women in the present study like other women with BCRLE (Rosedale & Fu, 2010), reported not knowing what was happening to their bodies. Others reported having accidents such as dropping heavy objects or burning themselves, and engaging in activities which perpetuated the intensity of symptoms due to lack of knowledge regarding management skills. The majority of participants expressed anger and resentment from not being informed about BCRLE. Participants opined that it was the professional responsibility of the physician to ensure that they were provided appropriate BCRLE education. The health provider’s (i.e., physician’s) indifference was suggested to have contributed to evitable pain and suffering among these women.

Often, the most visible manifestations of BCRLE are pain and swelling in the arm and/or hand and less often in the neck or chest (Amer, 2005; Petrek & Heelan, 1998). Functionally, BCRLE makes accomplishing household chores and occupational roles difficult (Armer & Fu, 2005) and due to the heaviness and bulkiness of the affected arm may prevent

women from wearing their usual clothing, gripping lifting, and holding objects (Fu & Rosedale, 2009). BCRLE causes symptoms such as pain, swelling, fatigue, decreased range of motion, and sensations of tightness, heaviness, burning, or numbness. In many instances patients are the first to notice the symptoms of BCRLE (Fu, Axelrod, & Haber, 2008), and that was true in the sample of women in this study. Subjective report of sensation changes is helpful in early diagnosis of BCRLE and may be the earliest indicator of increasing interstitial pressure changes or measurable volume change (Kosir et al, 2001).

Onset of BCRLE may be gradual or sudden, and may occur soon after surgery or as many as 30 years after diagnosis (Petrek, Senie, Peters, & Rosen, 2001). In the present study the average years living with BCRLE was 6.8 years. The average length of time between surgery and noticing BCRLE was reported as between one to three years. Educational management of symptoms information should include and a potential plan of action to take when symptoms start to occur and a list of available community resources. It is imperative that women with breast cancer receive information regarding the risk factors and the signs and symptoms of BCRLE prior to as well as after undergoing surgery.

The women in present study, like other women with BCRLE (McWayne and Heiney, 2005; Rosedale & Fu, 2010) complained of swelling and pain as the primary symptoms that caused distress and dysfunction. Ninety percent of the women in this study were overweight. Hypertension was reported as the most prevalent comorbid condition and heart disease and diabetes were equally reported as the second most reported illnesses associated with BCRLE. Eight participants reported having hypertension, five participants reported having heart disease, and five participants had diabetes. Three participants had a combination of diabetes, hypertension and heart disease, two participants had both diabetes and hypertension and two participants had hypertension and heart disease. Participants who reported greater numbers of comorbid diagnoses did not consistently report more symptoms. Findings from the present study further indicated an association of comorbid conditions such as obesity, diabetes, hypertension and heart disease with BCRLE.

This research confirmed McWayne and Heineys' (2005) study of the psychologic and social sequelae caused by BCRLE. McWayne and Heiney (2005) found that typically women with BCRLE experience pain, swelling in the arm or fingers, and numbness in the affected arm. Many patients also complain of heaviness, fullness, achiness, or fatigue of the limb, range of

motion deficits and sensation changes. These problems, whether present alone or in combination, have negative effects on psychosocial well-being and functional status. The findings from this study endorsed the argument for healthcare providers to use psychological and social measures and physiologic parameters related to intra/interethnic diversity and comorbidities when evaluating the impact of BCRLE (McWayne & Heiney, 2005).

This study sustained the findings of Axelrod and Haber (2008) which proclaimed that Caucasian women who received information on BCRLE reported fewer symptoms and practice more risk reduction behaviors. That study used a convenience sample of 136 female breast cancer survivors with the majority of the participants being White and well educated. None of the study's outcomes were associated with race.

Primary concerns of the women in this study included varied levels of diminished independence and impaired function in performing activities of daily living such as driving, bathing and dressing, cooking and social roles (i.e., babysitting and community service) since acquiring BCLRE. Every participant described interruptions in their daily lives due to the annoying, painful and persistent symptoms. BCRLE can impede one's ability to perform chores, fulfill tasks at work, and enjoy hobbies. Participants similar to other women with BCRLE (Armer & Fu, 2005 ; Fu, Axelrod, & Haber, 2008; Fu & Rosedale, 2009) had difficulty performing many household tasks such as vacuuming or grocery shopping, because of swelling and pain aggravated by repetitive motion and lifting with the affected arm.

Several women in this study realized that they had to give up certain leisure activities such as gardening, sewing, and sports that involve strenuous upper body effort because these activities aggravate their symptoms. One participant was saddened that she had to give up tennis because of BCRLE symptoms. However another participant asserted that she found a way to accommodate to her circumstance and was able to continue to enjoy her favorite hobby of gardening despite the symptoms of BCRLE. Findings from the present study emphasized the importance of an awareness of women's needs for providing effective educational interventions that enhance knowledge in the daily management skills. This information should include risk reduction of symptoms and suggest ways to make accommodations (Radina et al., 2004) in their daily lives to promote psychosocial stability and improve quality of life.

Participants in this study suggested that employers were perceived to play a pivotal role in the lives of working women with BCRLE. The majority of the participants in this study

worked at least part-time. Depending on the type of job their work experiences varied. The situations ranged from no effects caused by work related activities, to minor complaints of increased painful swelling, to the most extreme case of the repercussion of being terminated from their employment. Several women in this study had jobs that required repetitive movements of their arms, gripping and lifting. Participants described varied degrees of the assistance and support from employers in the workplace. Conversely, one women suffered notable emotional and financially due to the lack of support and/or understanding from employers.

One participant reported that without her employer purchasing additional equipment to help with lifting and transferring patients she would not have been able to fulfill the job requirements of her occupation as a Caregiver. Another participant was especially worried about her job performance and job security, due to having to go to numerous medical appointments. Her story was particularly thought-provoking. Despite her willingness to disclose personal information about her diagnosis and functional limitations with her employer; she ultimately lost her job. That single mother reported that she needed the income from that job. She expressed a combination of feelings such as sadness, devastation, and anger when recalling her efforts to avoid losing her job as a Maid. She was required to perform a variety of tasks which included repetitive lifting, gripping, reaching, etc. Although she wore her compression garments and exercised she was plagued with frequent exacerbations. The effects of BCRLE relegated her to work with an assistant and schedule frequent medical appointments. The findings of this study upheld the argument that intensity of the physical and emotional stressors associated with the unrelenting underlying symptoms of BCRLE and work involving lifting, gripping and repetitive arm movements can escalate distress and anxiety in the workplace.

Breast cancer-related lymphedema has been reported as having interfered with some breast cancer survivors' work involving heavy lifting, gripping, holding and fine motor dexterity. Some of the women in this study similar to women in other studies (Carter, 1997; Fu, 2008) confirmed that the impaired physical function from BCRLE not only handicapped them in performing their work but also caused emotional distress. African American women have been reported to have suffered profound physical and emotional impairments and emotional distress caused by management in the workplace (Fu, 2008). The findings from the present

study were consistent with Fu's (2008) observations that employment requiring significant lifting and repetitive motions of the arms augment distress and worry for African American women with BCRLE.

The difficulties some African American women with BCRLE face in the workplace have created a perceived double jeopardy. This double jeopardy results from being an African American woman with a chronic disease (s) and lower employment options. Previous findings of Carter (1997) and Fu (2008) reported that BCRLE impaired physical functioning including job performance. Carter (1997) and Fu (2008) found that women whose job involved heavy lifting and/or repetitive movements of the affected arm were either African American or Chinese. The advent of BCRLE adds to the distress African American women encounter due to the challenges of lower paying, more physically demanding jobs and disproportionate rates of unemployment. Unfortunately, as a result African American women with BCRLE are at risk for a potential double jeopardy because of BCRLE.

In January 2012 for the nation as a whole, unemployment was 8.3. Among whites, unemployment was 7.4%; among Latinos it was 10.5%, and the unemployment rate for Black women was 13.6%. The employment-population ratio represents the percentage of the population that is employed and it can be interpreted as the probability that a member of the population is employed. It captures employment prospects better than the unemployment rate, since jobless individuals who are not in the labor force are not calculated in the unemployment rate. In January 2012, the employment population ratio stood at 51.0% for Black women (UC Berkeley Labor Center, 2012). Once unemployed, African Americans are less likely to find jobs and tend to stay unemployed for longer periods of time (National Women's Law Center, 2011).

The prevalence of multiple comorbid illnesses (hypertension, diabetes, obesity) were prominent in these African American women and suggest a predisposition for BCRLE. However the severity of symptoms was likely related to a combination of variables in addition to comorbidities. This research sustained the findings of Carter, 1997. Carter (1997) who identified themes related to lack of information about BCRLE before diagnosis and difficulty making the adjustments to living with an incurable chronic condition, (Carter, 1997). In a qualitative study Carter (1997) interviewed 10 women with BCRLE. The purpose of the study was to explore women's experiences of lymphedema. The women ranged in age from 36-75

years. Some women experienced depression, anxiety, and impairments related to their intimate, work, and social relationships. Overall the experiences of the study participants were categorized into three themes: 1.) Abandonment by medicine, 2.) Concealing the imperfect image, and 3.) Living the Interrupted Life. No race related demographics nor associations between race and the study's outcomes were provided.

Similarities findings of Carter, 1997 and the present study were: concerns regarding changes in body/self-image, the influence of symptoms on physical function in activities of daily living, effect on interpersonal relationships and impact on employment. Concerns regarding the disfigured appearance of their arms contributed to increased social isolation and depression in many of the women from both studies. Carter (1997) mentioned in her qualitative study that lymphedema interfered with some breast cancer survivors' work involving heavy lifting, gripping, holding and fine motor dexterity. Women were worried about their job performance and security as well as worsening lymphedema and cancer recurrence. Similar findings were made in the present study including a situation where a participant was fired from her job as a result of her attempts to manage her healthcare. In the Carter (1997) study women shared concerns regarding physicians' limited knowledge about lymphedema and conflicting treatment information. Likewise participants in the present study expressed concern that in some situations physician were not well informed about BCRLE as revealed in these remarks: "I told my doctor when I saw the swelling and he said, "Don't tell me about it, it's not my problem"; "Certain things he (physician) didn't know about lymphedema..."

Differences between the women in the two studies were: stage (s) of breast cancer, age range of participants, and reasons contributing to attitudes towards physicians. The privacy versus public issue of the women in the present study was not established in the Carter (1997) study. Women from both studies shared less than favorable remarks about their physicians. However, the women in Carter's (1997) group described feelings associated with a perception that their physicians were more interested in the disease process of breast cancer instead of their BCRLE. They reported that once surgery was completed physicians generally didn't pay much attention to their concerns especially questions regarding management of BCRLE.

Contrastively, women in the present study seemed to say that physicians tended to ignore them and treated them differently (negatively) because of their race. This perception of disparity in treatment contributed to feelings of distrust toward physicians. In comparing the

findings of these two studies it appeared that regardless of race, women with BCRLE experienced a wide range of similar physical, psychosocial and psychological sequelae. Participants in both studies spoke of the lack of education in preparing them to manage and cope with symptoms, feelings of lack of support from healthcare providers, and challenges in embracing a new and changed self/body image.

Previous studies have found that educational preparation has a significant influence in women's adjustment to breast cancer (Driksen, 2000; Helgeson, Cohen, Schulz & Yasko., 2000; Lavery & Clarke, 1996). For instance, studies of Caucasian women who had not received adequate information tended to experience more difficulty adjustment to breast cancer (Helgeson, Cohen, Schulz & Yasko., 2000; Lavery & Clarke, 1996). African American women have reported receiving insufficient information and lack of emotional support from their health care providers (Henderson et al., 2003). The reported experiences of African American women with traditional health care services have placed them at risk for inadequate adjustment to their breast cancer (Jacobs et al., 2006; Wilmoth & Sanders, 2001).

Participants in this study implied that information regarding BCRLE should be written in less technical terms. One participant admitted that she had difficulty reading and comprehending information. Reading wasn't the best method of learning for her. Several women were concerned that the information written in reference books, brochures and presented on the internet was difficult to read and understand. Some reports described the main concern of participants was that there were no options for alternate methods to obtain information. The following comments summarized participants' feelings: "...once you have lymphedema it would be nice to have a class or something where someone could be there that could break it down simple so that we can understand what's going on... That would help more so than giving us a bunch of brochures and stuff..."

In contrast to the majority, two participants acknowledged that they had prior knowledge of the risk for BCRLE related to breast cancer treatment. However this information had not come directly from healthcare providers. Rather this information came from exposure to other African American, breast cancer survivors with BCRLE. One participant acquired her pre-surgical BCRLE education during physician office visits. She asked women with BCRLE questions about their swollen arms and compression garments. She admitted to not thinking much about the topic until she started to develop symptoms. However, that exposure appeared

to lessen her quandary in discovering BCRLE. Another woman had been involved in a speaker's bureau teaching African American woman about the importance of early detection and advocating mammography screening. Prior to her breast cancer diagnosis she had knowledge of BCRLE. She was aware of the subtle symptoms and felt comfortable doing additional research regarding compression garments and management techniques. These examples suggested that regardless of the level of formality, educational preparation of women with BCRLE is phenomenal in minimizing distress such as devastation and fear of the unknown. For these reasons, health care providers need to be cognizant of necessity to provide timely educational information and resources to patients prior to and following surgery.

Diminished Perceptions of Self Image: "it kinda of uh attacked my self-image"

The women in this study described adverse feelings regarding diminished perceptions of self-image that went beyond mere body image changes. Similar to other women with BCRLE (Fu & Rosedale, 2009; Rosedale & Fu, 2010; Johansson et al., 2003), women in this study described compression garments as ugly, terrible, uncomfortable, and unfeminine. They were embarrassed by the visible signs of BCRLE including swollen arms, puffy hands, and compression wraps, sleeves and gloves. Participants also expressed concerns of being deprived of wearing attractive, light weight, frilly, fashionable clothing and accessories. For these women a perception of body image was greatly influenced by dress, appearance, and other symbols of femininity.

The participants in this study described feelings of deeper losses including a sense loss of who they thought they were before the advent of lymphedema, which included loss of independence and the loss of intimacy in relationships. Participants expressed how they didn't feel the same and how BCRLE imposed changes in attire and negative perceptions of physical attractiveness. Comments such as "... it will never be like the way it was... I notice now since I've had it (BCRLE), you know, I'm kind of have a self-complex against my arm"; "It makes me feel less sexy because of this big swelling in my arms... I don't feel adequate or attractive because of the arm swelling" revealed how women expressed changes in their lives. Their concerns exceeded outer appearance or sex appeal and went deeper altering psychosocial functioning. Women expressed the realization that their lives were forever changed due to the permanent effects of BCRLE and were saddened by the physical changes. They described

various alterations in life style that affected their physical appearance, as well as their everyday interactions with family and friends.

The findings of this study were analogous to other women following breast cancer treatment (Rosedale and Fu, 2010). Rosedale & Fu (2010) performed a phenomenological study to describe women's unexpected and distressing symptom experience after breast cancer treatment. The study sample consisted of thirteen women 1 to 18 years after breast cancer treatment. The four themes derived from the participant's experiences included living with lingering symptoms, confronting unexpected situations, losing "precancer" being, and feeling like a has-been (Rosedale and Fu, 2010). Unfortunately no correlations were made with race. However, women in that study too reported that following breast cancer treatment, they did not feel the same about their bodies. Women reported that they felt slowed down and physically compromised because "things with lymphedema cannot be done in a speedy way" (Rosedale and Fu, 2010). Moreover, in that study women said they felt visibly marked by the lymphedema experience. Symptoms such as swollen arms and hands and the appearance of compression garments made them feel ugly and embarrassed. Women shared feelings regarding a "fashion deficit" where they described having "to dress for lymphedema" rather than for themselves and were forced to wear long sleeves (Rosedale and Fu, 2010). Women also described a sense that their bodies had betrayed them and could no longer be trusted as a result of unpredictable exacerbations of symptoms (Rosedale and Fu, 2010).

In the present study, loss of independence was associated with impaired functionality. Participants reported varied degrees of dependence upon others family members and friends for assistance with activities of daily living and instrumental activities of daily living. Participants shared feelings of sadness when recalling how others assisted them with simple tasks such as tying shoes or buttoning a blouse. For these women, perceptions of altered self-image and the interruption in carrying out activities of daily living indicated a strong influence on their perceptions of self and could potentially contributed to depression. This study sustained the findings of previous studies that reported that women with BCRLE experienced loss of independence secondary to impaired function (Hull, 2000; McWayne & Heiney, 2005; Ridner, 2009). This study also upheld the argument that the physical and functional changes caused by BCRLE contribute to depression in patients (Hull, 2000; Fu, 2005).

Findings from the present study that were parallel to other studies included the notion that a cancer diagnosis and treatment often diminished body image, hold the potential to minimize feelings of positive self-image and the residual effects of cancer treatment such as disfigurement can caused substantial emotional trauma including intimate relationships (Juraskova et. al., 2003; Sacerdoti, Lagana, & Koopman, 2010'; Wilmoth, 2001; White, 2000). Wilmoth (2001) found that surgery is often perceived by women as an assault on their sexual identity. Similarly, medical treatment of gynecological cancer typically affects body parts associated with womanhood and femininity causing considerable body changes that are likely to alter body image (Sacerdoti et. al., 2010). Juraskova et al. (2003) discovered that satisfactory sexual experiences among gynecological cancer survivors are associated with expressions of intimacy. Among findings identified in a gynecological qualitative study was a theme of intimate relationships (Sacerdoti et. al., 2010). The study sample consisted of sixteen (N=16) gynecological cancer survivors between the ages of 28 to 58 years old (Sacerdoti et. al., 2010). Eight women were European-American, one was Asian-American and one was Mexican-American. Unfortunately no other identifiers of the racial composition of the sample were provided. According to Sacerdoti et al. (2010) the purpose of the study was to explore women's intimate experiences surrounding their sexuality and body image once they completed gynecological cancer treatment. Outcomes of that study indicated that all the women were dissatisfied with their bodies and felt "maimed" due to the sequela of cancer treatment which served as constant reminders of their cancer. Women reported their experiences of sexuality and body image after diagnosis and treatment had negatively impacted their intimate relationships (Auchincloss, 1995). Following gynecological cancer treatment women struggled to discuss their feelings with family and friends because these individuals often were unable to understand their experiences and was uncomfortable with such discussions (Auchincloss, 1995).

Participants in this study expressed a sense of the loss of intimacy beyond issues of sexuality. Several participants described interruptions in their relationships with previous spouses or boyfriends, and/or family members in general (e.g. hugging grandchildren). One participant asserted marital problems and ultimately her divorce was at least partially due to BCRLE. She attributed the avoidance of self-disclosure and lack of comprehensive understanding of implications of BCRLE as the impetus for the loss of intimacy with her

husband. Other reports described loss of intimacy arising from loss of expressions of closeness secondary to the loss of the ability to physically embrace loved ones such as holding or hugging grandchildren. These findings suggested that the loss of intimacy associated with the sense of touch had a devastating impact on women's self-image; it related to a loss of a sense of "who I am" and contributed to a perception of isolation. This loss of intimacy perpetuated social isolation and feelings of separateness. The findings of this study indicated that efforts must be made to incorporate intimacy education into the training of health care professionals, for women with BCRLE to minimize social isolation and enhance their quality of life.

Feeling Triumphant: "My support comes from God ...and my family"

Participants in this study described intense emotions associated with a determination to overcoming negative feelings of fear, hopelessness and helplessness posed by BCRLE. Women admitted to feelings that the uncontrollable effects of BCRLE were permanent. Most women perceived that they had to "deal with it" or "accept" or "adjust" to their situations. While participants expressed feelings of a sense of hopelessness, helplessness and fear of the unknown; they reported using spirituality and positive reappraisal to cope with those feelings. Previous studies supported the idea that African American women tend to suppress their emotions, used spirituality, and practiced positive reappraisal strategies to cope with breast cancer and its treatment (Bourjolly & Hirschman, 2001; Culver, Arena, Antoni & Carver, 2002; Reynolds, et al, 2000). Those findings were validated in this study. Participants in the present study suppressed their emotions by hiding what they termed as private and personal concerns about BCRLE from others. Several women achieved positive appraisal through activities such as meditation, shopping, hanging out with friends, and travel. Finally in the present study, spirituality was the most prevalent coping technique practiced by the majority of participants.

Spirituality and prayer have been found as the most frequently used coping strategies among African American women to cope with chronic illnesses (Ashing-Giwa, 2004). This comportment was evident in the present study. Every participant acknowledged the support from God, church, family and friends were crucial and eminent force to help overcome feelings of hopelessness, helplessness and fear. The majority of participants (n= 10) reported spirituality (God/church) as their primary support system. Reports described behaviors such as going to church, pray, reading the bible, meditation, and speaking with spiritual leaders. The following summarized the nostalgia expressed by these women: "...I couldn't have fear and faith at the

same time...”; “I am too blessed to be stressed...”

The findings from this study supported the findings of Northouse et al. (1999) who found that optimism was related to a high quality of life among African American women with breast cancer. This perspective may account for the more optimistic responses from participants especially when describing the feelings of overcoming or triumph due to the support from God, church, family and friends. Participants in this study reported to perceiving family members and friends as key support systems in coping with BCRLE. Participants reported that family and/or friends stepped in and assisted or provided numerous forms of support such as with household chores, personal care, transportation and emotional support. An interesting finding was that several participants referred to their “church family” with as much passion as used in reference to their blood relatives. This finding was consistent with Henderson and others’ (2003) observations that African American women tend to rely on family members for support when coping with breast cancer (Brag & Gulatte, 2001). Furthermore, Henderson et al., (2003) argued that further research is needed to explore coping strategies of positive appraisal and seeking social support as these may be important factors in how African American women with survive breast cancer.

This study supported the findings of a qualitative study of African American women coping with breast cancer, having a positive attitude and receiving social support from family members and friends helped them cope with their illness (Henderson et al., 2003). Bourjolly and Hirschman, (2001) found differences in the type of social support used between African American and Caucasian with breast cancer. Those authors concluded that Caucasian women relied more on their spouses whereas African American women relied more on God and social support such as family and friends to cope with breast cancer (Bourjolly & Hirschman, 2001). Support groups have been found to contribute to the healing process and survival of individuals coping with chronic illnesses (Fobair, 1997). However African American women tend not to use support groups because these groups have often been perceived as not culturally sensitive and do not provide them with the information and emotional support they need to cope with breast cancer (Brag & Gullatte, 2001; Wilmoth et al., 2001). This perception was supported in this study. Most of the women in this study had not been involved with support groups. Participants expressed varied sentiments when describing why they had not sought after support group involvement including disinterest and lack of knowledge. Evidence of this

influence was supported by two participants reported similar negative perceptions of support group involvement. One woman shared her experience of her involvement in two different support groups; one for women with breast cancer and another for breast cancer survivors with BCRLE were not helpful. She expressed disappointment that the topics of discussion were usually not culturally sensitive and often were not important to her. Additionally, another participant voiced similar feelings based on her previous exposure to support groups. She voiced similar feelings in that she didn't want to attend a support groups that discussed issues that were not important to her. Finally a third participant expressed not having sought out a support group to her general lack of knowledge on that subject.

Church settings can provide an acceptable alternative forum for establishing support groups for African American women with BCRLE. Faith-based cancer support groups have been recognized as more culturally appropriate and practical resources for African American women who tend to rely on family members, friends, ministers, and church members to assist with coping (Brag & Gulatte, 2001). African American women have reported having a determination to live for self as well as for their family members. The findings of this study supported the argument that spirituality may be an important variable to assess among breast cancer survivors with BCRLE (McWayne & Heiney, 2005).

The notion that faith-based support groups were more appropriate for African American women was supported by the two participants who reported belonging to a church group which provided a good source of support. Those participants reported that the church was a setting where they felt comfortable and could deal with some of their feelings about BCRLE. This study supported previous research findings that faith based support groups are culturally appropriate and practical for African American women (Brag & Gulatte, 2001; Henderson, Gore, Davis & Condon, 2003; McWayne & Heiney, 2005).

Participants in this study suggested that the women who had adapted successful coping strategies (i.e. positive reappraisal) had more positive outlooks and were less likely to become depressed or distressed. Two participants admitted to receiving psychotherapy to support psychosocial coping and adjustments to the life changes as a result of BCRLE. Both women avoided self- disclosure and minimized social interaction. One of those women admitted to using denial/avoidance to as a coping strategy. The other participant retreated to her bedroom away from others and engaged in escapism as a copy technique. Avoidant coping is

characterized by evading problems rather than dealing with them directly (Passik, Newman, Brennan, et al., 1995). The findings of this study supported previous studies (by Passik & McDonald, 1998; Tobin Lacey, Meyer, & Mortimer, 1993) that identified predictors of experiencing more distress in coping included pain (any level of intensity), decreased social support, and use of avoidance coping (Passik, Newman, Brennan, & Tunkel, 1995) as revealed in these responses: “It (pain) wakes you up it hurt so bad”; “...some pain, some discomfort and swelling is always there...”; “I need somebody to talk too especially when these arms and leg go to swelling and hurting and getting me down...”; “I don’t go anywhere, I don’t want to be bothered with nobody. I rather stay in my room in the bed... Depends on what kind of mood I’m in and the pain.” An avoidant coping style was most significant predictor of adjustment difficulties. Similar to other women with BCRLE the women in this study who relied on avoidant coping had more psychological morbidity, physical limitations and body/self- image concerns (Passik, Newman, Brennan, & Tunkel, 1995; Passik & McDonald, 1998, Tobin, Lacey, Meyer, & Mortimer, 1993).

This research substantiates Henderson et al., (2003) study of coping strategies among African American women with breast cancer. Henderson and colleagues (2003) found that positive reappraisal and social support were the most commonly used coping strategies among African American women with breast cancer. Their sample consisted of 86 African American women with breast cancer from the ages of 35 years old to 76 years old. Many of those women were married, well-educated, and had relatively high incomes. These authors hypothesized that the coping strategies of positive reappraisal, social support, and planful problem solving would be related to sociodemographic variables such as age, marital status, education, income and length of time since diagnosis. However what they found was that socioeconomic status did not play a significant role in the coping strategies used by African American women with breast cancer (Henderson et al., 2003). Conversely, socioeconomic status was not associated with coping strategies used by the women in the present study. Hence, this study concur with the arguments that positive reappraisal, social support from family and friends, planful problem solving (utilizing an analytic approach to solve a problem or stressful situation) and avoidance were used more among that sample of African American women and were not associated with socioeconomic status (Folkman and Lazarus, 1988).

The results from this study coincide with previous studies that found positive reappraisal, social support; planful problem solving and avoidance were used more among African American women as compared to Caucasian women (Ashing-Giwa, 2004; Aziz & Rowland, 2002; Bourjolly & Hirschman, 2001; Farmer & Smith, 2002). One of the reasons why positive reappraisal may be used more among African American women is because this coping strategy has a religious dimension as indicated in previous research (Culver et. al., 2002).

**Distrust of physicians and other healthcare providers: “There is no one black woman “
“Just listen to us...”**

Many of the women described feeling as if they were invisible and had not taken seriously by healthcare providers. This study also further validates the findings of Johansson et al. (2003) in the recognition that the problems women with BCRLE faced daily were extremely important and that healthcare providers should have knowledge about these issues. Healthcare providers should listen to these patients and devise multidisciplinary interventions to strengthen patient’s coping skills (Johansson et al., 2003). The findings of this study concur with the argument that these factors contribute to distrust of physicians and other health care providers and should be considered in clinical practice to facilitate trust and improve the provision of health care to African American patients (Jacobs et al., 2006).

Participants in this study proposed that healthcare providers were unconcerned and/or uninformed about BCRLE. Those perceived behaviors contributed to feelings of distrust and was suggested to amplify perceptions of feelings of rejection, unconcern, uncompassionate and unsupportive attitudes on the part of some healthcare providers. Some women described their perceptions of health care providers as follows: “... I was assigned to a oncologist... he wasn’t any help, I didn’t go back to him”; “they don’t listen. They take everything causal”; “YOU COULD HELP ME... One thing he (physician) didn’t think about me and my arm is still getting bigger...”; “when you go to a healthcare provider and they are not patient enough and don’t show compassion enough that kind of makes us feel kind of insignificant...”

Participants attributed racism as an underlying cause for these insensitive attitudes and behaviors. That sentiment was summarized in these remarks from participants: “I think that if I was white or from a different culture, things would have been different.”; “If I was not African

American I definitely think the process would have been different... Seems like the other races be treated more better than my race...”; “Hum I probably would have been treated different if I was of a different color...Um you know we have it harder anyway as African American women. We are looked at differently kinda like work horses...” The findings of this study were similar to previous research by Jacobs, Rolle, Ferrans, Whitaker & Warnecke, (2006). In the study by Jacobs and colleagues, were seeking to understand what trust and distrust in physicians meant to African Americans. The authors found of the African American women (n= 32) and African American men (n= 34); patients indicated that trust was determined by the lack of interpersonal and technical competencies, perceived quest for profit and expectations of racism and experimentation during routine physician visits (Jacobs et al., 2006).

Every participant in the present study indicated some degree of perceived indifference and insensitivity exhibited by healthcare providers. In most instances the healthcare provider most referred to was the physician. Several participants in this study reported that the physician’s failure to listen was a primary problem. Reports further described physicians as being rushed, not taking time to answer questions, and unknowing. The physician’s indifference was suggested as the most offensive. The following comments summarized the strong feelings of participants: “I think that if I was white or from a different culture, things would have been different.”; “I don’t like being referred to as “you people”...”; “Sometimes some of them (physicians) talk sharp to you... I don’t care what your race is I’m your patient and I’m not gonna let you talk to me any kind of way.” The majority of participants indicated that race was the primary reason for the perceptions of negative attitudes of healthcare providers.

Two participants related their perceived difference in treatment by health care providers to result from socioeconomic issues rather than racial. These women opined that regardless of ethnicity, women of lower socioeconomic status and those without adequate health insurance coverage are treated inferiorly. Their generally beliefs were based on a perception which is summarized in the following comment: “... It’s not so much your race it’s your payment... If you can pay for it, you get it.” These two participants were unique in their opinions that inadequate or no health insurance coverage is the foremost underlying basis for disparity in healthcare among African American women.

Participants in this study offered realistic and practical ideas in suggesting meaningful health care interventions that addressed their concerns of living with BCRLE. They proposed the following recommendations: 1.) BCRLE education before and after breast cancer surgery, 2.) classroom type education with flexible times including evenings and weekend hours, 3.) education series led by an African American women with BCRLE, 4.) alternative methods of teaching including audio and visual modalities in laymen terms, and 5.) support groups established and facilitated to meet the concerns of African American women with BCRLE as opposed to solely focusing on breast cancer. Women shared the following examples of suggestions to healthcare providers: “Number one they should have workshops...maybe on Saturdays. They should send us information through the mail”; “They need to prepare you for it (BCRLE) before you go through your surgery”; “... once you have lymphedema it would be nice to have a class or something and someone that could be there that could break it down simple so that we can understand what’s going...”; “... only here recently have I become aware that support groups for breast cancer don’t really focus on lymphedema and there is a need for support groups for women with lymphedema particularly African American women...”

This study endorsed the findings of Radina (2007) to examine the symptom management practices of patients with BCRLE by quantifying self-care practices. Radina (2007) asserted that effective management practices for patients with BCRLE reduce symptoms. Additionally the findings of this study upheld the argument for understanding the importance of the role of healthcare providers in providing well-timed and reliable education to women at risk for BCRLE and to involve themselves in supportive dialogue concerning lymphedema risk reduction and symptom management behaviors (Axelrod and Haber, 2008; Greenslade & House, 2006; McWayne & Heiney, 2005).

Strengths and Limitations of the Study

Strengths of the present study include, that at the present time, it seems to be the only study of its kind to examine the lived experience of how African American women describe what it is like to live with BCRLE. Descriptions from African American women included perceptions of the physical and emotional effects of changes in body/self-image, emotional and functional challenges presented in coping with the chronic and recurrent exacerbation of symptoms, adaptation and lifestyle changes, as well as, interpersonal relationships with healthcare providers. The opportunity to study African American women with BCRLE

provides a unique perspective of this patient population. The findings from this study will help advance culturally-sensitive interventions for African American women with BCRLE that focus on psychosocial, psychological, psychosexual, and physiological dynamics. The discoveries of this study will enhance understanding of how this patient population copes with the distress of this condition and the long-term effects of BCRLE on the survivorship of African American women. Findings also support and advance the current body of literature which adds to the applicability of the findings to other settings. The study's outcomes will be useful to assist investigators from diverse theoretical perspectives to identify future research questions that can use a grounded theory approach to develop a theory of living with BCRLE.

Other strengths included the application of rigorous qualitative phenomenological research methodology that guided data collection (i.e., use of a semi-structured interview guide derived findings from the extant literature), member checks including the corroboration of information with each participant during a second interview, and analysis of data (i.e., review of transcript coding by other health professionals [e.g., the investigator's nursing faculty advisor and a lymphedema nurse practitioner certified as a lymphedema specialist and experienced in lymphedema research]).

A limitation of this study as with most qualitative studies is the generalizability of the findings. The sample was limited primarily to middle-aged to older African American women from an urban cancer medical center in the metropolitan Detroit area. Findings therefore are not generalizable to all African American women with BCRLE in other settings. In addition, variations and differences in perceptions of the lived experience of breast cancer-related lymphedema may not have been entirely reflected during the two brief interviews sessions. Similar to other women who received cancer treatment (Sacerdoti et al., 2010) the researcher believes that some women may not have felt comfortable talking about sexuality and body image issues dealing with their BCRLE which may have limited what they openly discussed. As with most qualitative studies, the inability to validate information from personal interviews was an additional limitation of this study.

Finally, descriptions of the lived experience of these women reveal that they had a fairly poor understanding of BCRLE. One possible reason for this was that the sample was generated in an area where local access to information was not well promoted. Thus, these participants'

level of knowledge may not represent all African American women with BCRLE in the United States accurately, in areas where BCRLE education is more widely advertised.

Implications for Clinical Practice

Patient education is the most essential intervention for patients who have or are at risk for BCRLE (Casley-Smith, 1996; Paskett & Stark, 2000; Runowics et al., 1989; Sakorafas, 2001). Breast cancer patients need to be educated both preoperatively and postoperatively about the risks for BCRLE. Nurses and other health care providers must recognize the importance of providing effective educational mechanisms that enhance knowledge explaining the management skills to reduce the adverse effects of BCRLE. Patient education is imperative when considering that the breast cancer survivors are typically the first to detect the onset of symptoms (Radina et al., 2004; Kosir 2001). Starting with the first postoperative visit, patient education should identify and explain the risk factors and how to recognize symptoms and avoid behaviors that perpetuate symptoms, teach appropriate management skills required to minimize symptoms and alleviate discomforts, and discuss methods regarding how to make accommodations in their daily lives that enhance functionality, psychosocial stability and improve quality of life.

Healthcare providers ought to understand that the lack of educational preparedness has tremendous negative influences on the experience of living with BCRLE. The present study indicated that nurses and physical therapist were considered the most accessible sources of BCRLE information/education. As patient educators these clinicians assume vital roles in facilitating patient's understanding of health-related issues and the provision detailed and accurate information (Fu et al., 2008). In their practices oncology healthcare providers should consider equipping themselves with information state of the art BCRLE literature, technology, and diverse methods of communicating the information to patients. Every woman who has undergone axillary breast cancer treatment is at a lifetime risk for acquiring BCRLE (Nielsen, Gordon, & Selby, 2008). With that in mind healthcare providers must place emphasis on providing timely, accurate, understandable, and accessible information about BCRLE to their patients. The lifetime commitment to reduce the risk of BCRLE requires time and effort from healthcare providers and patients in order to ensure preserving a good quality of life for patients (Fu et al., 2008).

The findings of this study sustained the arguments initiated by Serovich et al. (2009) and Chesney et al. (2003) that practitioners should screen and identify individuals who possess strong avoidance in disclosure and assist them in finding alternative methods of disclosure such as written disclosure. Serovich et al. (2009) proposed that practitioners ought to focus intervention strategy efforts on teaching individuals effective communication skills to improve their chances of electing positive, supportive responses. Whereas Chesney et al., 2003 advocate interventions focused on identifying controllable vs. uncontrollable aspects of the disclosure process to help individual's cope in the face of negative responses. Furthermore, the findings from the present study strengthened the argument for understanding disclosure from the perspective of each individual which can be accomplished through utilization of frameworks such as Disclosure Processes Model (Chaudoir & Fisher, 2010).

The Disclosure Processes Model (DPM) framework encourages researchers and practitioners to ask two important questions: when and why is interpersonal, verbal disclosure beneficial for individuals who live with concealable stigmatized identities? The DPM proposes that antecedent disclosure goals may alter the effect of disclosure on various individual (i.e., psychological, behavioral, and health) and dyadic (i.e., trust, liking, intimacy) outcomes, but play a lesser role in affecting social contextual outcomes (i.e., cultural stigma, norms for disclosure) (Chaudoir & Fisher, 2010). The findings from this study also promote the importance of assessing and assisting women who live with BCRLE to embrace the power of disclosure to enhance their quality of life.

BCRLE remains a common problem following breast cancer treatment. Since there is no definitive cure, prevention by limiting and/or eliminating risk factors is of the utmost importance (Coward, 1999). Early diagnosis of BCRLE is significant because often it does not rescind and can get worse with time. Prompt intervention with appropriate therapeutic measures may prevent progression and minimize swelling in the limb (s). Traditionally, nurses, physical therapist, and physicians and have fulfilled prime roles in the responsibility for educating women about BCRLE. While it may be difficult to integrate during the preoperative phase, healthcare providers should still provide basic information regarding the reason for the breast cancer treatment, risk factors, and signs and symptoms of developing BCRLE.

Review of BCRLE risk factors in the postoperative period and continued assessment and education are essential to a comprehensive approach to postoperative BCRLE care.

Starting with the first postoperative follow-up visit the initial BCRLE information should be reiterated and patients should be allowed to ask questions and be provided appropriate resources including (but not limited to) the availability of educational programs, support group options, mental health counseling, and community services. This is an ideal point in time for oncology nurse case managers and lymphedema nurse specialists to work collaboratively in providing accurate educational information and facilitating appropriate community referrals. A crucial referral should be to the physical therapist. These experts shall provide a baseline assessment of patients and start patients on a program of upper limb exercises (elevation, gently isometric exercises) in the immediate postoperative period to promote gravity or passive drainage of lymph, in an attempt to prevent the formation of BCRLE (Sakorafas, 2001). It is essential that the presence or absence of BCRLE is monitored during follow-up after breast cancer therapy, preferentially by using objective measurement's (i.e., volumetric or circumferential) (Sakorafas, et al., 2006).

The assessment of the signs and symptoms of BCRLE formation can be taught to patients and should remain a principal area of focus in the follow-up assessments by all healthcare providers. Physical therapists should be committed to provide ongoing BCRLE education, specialized techniques to management BCRLE and control of symptoms, assess for signs and symptoms of BCRLE progression, and identify signs of maladaptive coping such as depression and social withdrawal. Physical therapist must remain well informed of community resources such as basic insurance coverage regarding compressive garments and other adaptive devices, and community resources including support group options. Well-timed, patient education activities concerning appropriate and effective management techniques for BCRLE will undoubtedly improve treatment experiences of all women.

For the women in the current study, the residual effect of 'not knowing' had detrimental consequences from the beginning of the BCRLE experience. Ignorance intensified pain and suffering, perpetuated distress and impaired functionality, and created feelings of despair and contributed to social isolation. As revealed from the review of the literature, educational preparedness has an immense effect upon virtually every aspect of the lives of African American women living with BCRLE. Participants in this study conveyed that much of the information received from healthcare providers, contained in brochures and reference books, and displayed on the internet was difficult to understand. Healthcare providers and educators

should assess the patient's level of accurately understanding BCRLE. This information should be used to determine alternative methods of effective and appropriate educational techniques, including the development of low literacy formatted reading material. Information is relatively useless if the patients can't understand the information. Knowledge is vital and facilitates positive adaptation of African American women throughout the life-time span of this chronic condition.

Findings of this study augmented understanding regarding the work-related experiences of African American women with BCRLE. The present study implied that returning to work, and maintaining employment are important variables in the experience of living with BCRLE. Jobs that require lifting, gripping and repetitive arm movements put women at a greater risk for work-related emotional distress (Carter, 1997; Fu, 2008). The women's experiences from the present study encourages clinicians to explore the meaning of work in the lives of African American women with BCRLE and development interventions aimed at empowering employers to understand the impact of BCRLE on patients (Fu, 2008). During the follow-up care, health providers need to identify ways to address stressful situations that arise in the workplace and help establish resolutions to support women with BCRLE. Actions such as these will promote better understanding on the part of employers and improve employer/employee relationships.

Health care providers must be well informed and understand that the emotional, physical and functional changes caused by BCRLE are contributing risk factors for intensifying depression and distress. These problems, whether present, alone or in combination, have negative effects on psychosocial well-being and functional status. Healthcare providers ought to use psychosocial measures to assess variables such as support systems, isolation, work history, and signs of depression and/or distress when comprehensively evaluating for the impact of BCRLE.

To capture real-life experiences coping practices healthcare providers should include the development of wide-ranging assessments of psychological and psychosocial statuses obtained thorough medical histories. Historical evaluations should include aspects of preexisting problems with substance abuse, mental health, coping strategies of positive appraisal and seeking social support as these may be important factors in how African American women cope with BCRLE. Through attentive and empathetic assessment oncology

nurses and other healthcare providers can promote positive adaptive coping techniques among African American women with breast cancer-related lymphedema. It is important for all health care providers to be vigilant regarding feelings of misunderstanding, separation, fear and resentment that patients may be express. Women have described sentiments such as these when speaking of issues contributing to the perceptions of distrust and trust of healthcare providers (Carter, 1997; Fu, 2008).

Implications for Future Research

Some of the areas participants in this study indicated cause for concern and improvement in treatment. First, participants were initially unlearned as to the cause and management of BCRLE symptoms. This was rather surprising to the researcher especially because all of the women were receiving treatment from a large urban, academic and research oriented medical center. Similar findings were discussed in previous studies of women with BCRLE (Carter, 1997; Fu, 2008). However what was distinctly different in present study was that all the participants were African American women who had been treated in a renowned cancer treatment facility with proclaimed comprehensive approaches to treating breast cancer in women. What would be interesting is a research investigation to compare a matched group of Caucasian women treated at the same institution and compare their responses regarding the issue of educational preparation and related concerns. Would there be significant differences between their responses? Whether the responses were similar or dissimilar or somewhere in-between; the outcomes would provide valuable implications for clinical practice.

Secondly, the significance of culturally sensitive support groups has not yet been supported empirically (Brag and Gullatte, 2001). This is an underdeveloped venue in need of refining. A place to begin would be facilitating focus groups with African American women with BCRLE to further explore the discussion of support groups including topics for discussion and preferable settings and locations. Petitioning African American women with BCRLE to take leadership roles in these support groups could make a tremendous difference in facilitating women's active roles of gaining empowerment and ownership in developing ways to ameliorate African American women's experiences in living with this dreaded condition. Third, most of the women described feeling of being offended and/or ignored by health care providers and physicians in particular. These ill perceptions attributed to sentiments of distrust of healthcare providers.

Future research should investigate real time situations whereby healthcare providers allow time to listen to patients in order to complete assessments for psychosocial and functional problems and referrals, provide medical information in a comprehensible mode, and offer mutual reciprocity and respect to patients with BCRLE. Adapting these modalities will assuredly enhance interpersonal relations between African American patients and health care providers.

Subsequent research should target patient education. Seemingly the most important preventive and management endeavor is providing patients with BCRLE information through pre and post treatment education (Casley-Smith, 1996; Paskett & Stark, 2000; Runowics et al., 1989). During the stressful and often chaotic, post diagnostic and preoperative phases of treatment some women may be provided ephemeral BCRLE material. However, when facing a critical and potentially life threatening decision regarding cancer treatment; less immediate, less urgent, and less life threatening information such as BCRLE may not be well appreciated or even recalled. Review of BCRLE risk factors in the pre and post-operative periods and continued assessments and education are vital to a comprehensive approach in providing BCRLE healthcare (Radina et al., 2004). Prospective, interventional research studies are needed to evaluate the effectiveness of education and teaching practices regarding the prevention and management of BCRLE.

Forthcoming research should focus on ethnically diverse and intra-ethnic subgroups of breast cancer survivors to help elucidate differences and similarities between races and among members of the same race. These findings will assist in the development of an emerging picture of disparities in breast cancer survivorship that compasses a broader range of socioeconomic variables. Moreover subsequent research is needed to examine the physical and psychosocial experiences of African American breast cancers survivors to elucidate the mechanisms leading to their poorer outcomes (Paskett et al., 2008). Future phenomenological research should be conducted with different groups of breast cancer survivors with BCRLE to explore the similarities and differences regarding the essential structures if the experience to assist healthcare providers educators and researchers in defining the construct, identifying, and studying its attributes (Fu, 2005). A mixed research methodology incorporating both quantitative and qualitative aspects would yield greater understanding and interpretation of findings into specific clinical interventions to better educate and support women with BCRLE.

To develop evidence-based guidelines for patients coping with BCRLE, it is imperative to better understand women's experiences in the context of their everyday lives, incorporate that data into conceptual frameworks, and develop interventions that can be adapted to meet the needs of women with various demographic. Prospective, longitudinal studies are also needed to further examine these dimensions and explore the relationship between physical symptomology, emotional distress, and psychosocial distress after breast cancer treatment (Fu & Rosedale, 2009).

Women with BCRLE may be reluctant to bring up sensitive sexual issues (including body image) with healthcare providers. Subsequently the physical and psychosexual complications of BCRLE are often unmet. Future efforts should be made to improve this situation by improving the critical role of oncology nurses to assist women with BCRLE in obtaining needed support and assistance with their body image and sexual related problems. Zhao and colleagues (2003) have suggested that nurses should undergo training to learn how to conduct proper sexual health assessments. Nurses should assertively though compassionately initiate discussions about body image and sexuality issues. This form of intervention would offer women with BCRLE an opportunity to express their concerns and obtain appropriate referrals for additional services such as individual, patient-partner counseling and/or family counseling.

In the present study all of the participants were unmarried and/or the head of household and work offered the primary source of financial income. The majority of working women in the present study had jobs that required performing tasks that provoked symptoms such as lifting, and repetitive movements of the arms and hands. Unfortunately this scenario was a primary source of heightened distress and worry. Future studies should focus on the implications that BCRLE has on the lives of all working women with BCRLE. Comparisons and contrasts in work-related experiences should be made between African American women and other ethnic groups. These findings will ultimately lead to the interventions that improve the conditions in the workplace. Employers should be included as target populations in such studies as their perspectives would be particularly valuable as they are key elements in the circumstance.

Tomorrow's researchers should focus on demographic subgroups of women to help elucidate differences in survivor's health-related quality of life (HRQOL) and to allow research

and healthcare providers' resources to be focused where they are needed the most. These findings will assist in the development of an emerging picture of disparities in breast cancer survivorship. Not only do African American women face diagnosis of breast cancer with more advanced disease and higher breast cancer mortality, but the findings of the current study revealed that these women also have small, but clinically meaningful decrements in physical HRQOL. More research is needed to examine the physical and psychosocial experiences of African American breast cancer survivors to elucidate the mechanisms leading to their poorer outcomes (Paskett et al., 2008).

An interesting finding in this study was that some participants believed that the underlying reason for the difference in treatment of African American women resulted from socioeconomic issues as opposed to race. Further research is warranted that concentrates on the question of whether risk factors for BCRLE differ among African American women with varying social and economic factors. The research findings will help to better recognize and understand what variables other than race that facilitate disparities among these patients. A large multi-centered, quantitative, prospective, longitudinal study would be of great value. A sample of hundreds to thousands of African American women with BCRLE would provide unparalleled findings regarding concerns of this patient population about the effects from the lack of information, the significance of culturally sensitive support groups, and issues of distrust of health care providers.

Conclusions

BCRLE is clearly a chronic condition which negatively affects the quality of life of African American women. This underscores the importance of awareness, prevention, early diagnosis, and treatment of BCRLE. Understanding those factors that increase the odds of BCRLE will allow healthcare providers, researchers, and educators to more accurately identify those at greatest risk and to develop programs and practices that best meet the needs of women with breast cancer. For example, a weight management program that promotes weight loss or prevention of weight gain postoperatively may reduce the incidence of BCRLE among those at greater risk. Similarly, providing BCRLE prevention education to women who undergo more extensive axillary node dissection and/or chemotherapy may reduce the prevalence of swelling or the severity if swelling does develop. Finally, since every woman who undergoes axillary treatment for breast cancer is a potential victim of BCRLE pre and postoperative educational

preparedness intervention should be a mandated. In so doing, women with BCRLE of all races and ages will ultimately enjoy better quality of life (Paskett et al., 2007).

With the lack of literature on the explicit experiences and perceptions of African American women living with breast cancer-related lymphedema, this study provides an unprecedented foundation for better understanding factors that influence perceptions in this patient population. Findings from this study support the assertion that a holistic and culturally relevant approach is needed to adequately assess the perceptions of African American women in the following areas: (a) how the lack of knowledge regarding the consequences of BCRLE influence African American women's perceptions in living BCRLE, (b) how the effects of the tenacious, unpredictable and recurrent symptoms of BCRLE impact daily functioning in African American women with BCRLE, (c) the influence of BCRLE on African American women's perception of their self-image, (d) the importance of faith and family as key support systems used in the coping technique by African American women with BCRLE, and (e) the implications of trust issues in the provision of culturally sensitive and compassionate care to African American women with BCRLE by healthcare professionals. All of these findings can be used to guide related research and clinical interventions. Research outcomes can enhance clinicians' understanding of the diverse (and in some cases similar) influence that BCRLE has on African American women. The findings may also be useful to assist investigators from diverse theoretical perspectives to identify future research questions that can use a grounded theory approach to develop a theory of living with BCRLE.

Consistent with the guidelines of the Nursing's social policy statement (American Nurses Association, 2003) and the American Cancer Society (2006, 2007b, and 2008) indicated that nursing practice is characterized by attention to the full range of human experience and integration of knowledge gained from understanding of patients' subjective experiences. "Nurses' ability to care for patients is predicated on shared understanding about the meaning of illness and treatment and the effect of experience on identity and ongoing life" (Rosedale, 2009, p. 181). This statement emphasized the need for nurses to understand the subjective experiences of all women including African American women with BCRLE and be prepared to address common adaptation problems in their practice. This study also illuminated the importance of identifying effective strategies for assessing patients' psychosocial dispositions, coping strategies including avoidance. Additionally, an informed awareness of patients

experience in living with BCRLE is necessary to develop adequate assessment and supportive interventions for these women. Furthermore, the perception of improved care is the patient's expression of satisfaction with their care, which also fosters positive adaptation including trustful relationships with healthcare providers.

The stories as told by the African American women in this study captured the essence or true meaning of their experiences. Knowledge was gained to better understand how African American women perceived the effects of BCRLE from the viewpoint of the participants. The findings of this study provide substance for discuss of implications for future research studies that focus on African American women diagnosed with BCRLE; the effects of the physical, psychosocial, and psychosexual aspects of BCRLE and issues of trust and distrust of health care providers among African American women with BCRLE.

APPENDIX A

Protocol Review and Monitoring Committee Approval-Karmanos Cancer Institute



Protocol # 2011-150

TO: Deborah Collins-Bohler, R.N.

FROM: Protocol Review and Monitoring Committee (PRMC)

DATE: November 16, 2011 (Revised)

Your clinical trial proposal entitled: **2011-150: The Lived Experience of African American Women With Breast Cancer-Related Lymphedema** was reviewed after your response (dated November 15, 2011) to the provisional approval requests and was found satisfactory. Your clinical trial has been **APPROVED** for activation for the period of **November 16, 2011 through October 18, 2012** at the Karmanos Cancer Institute by the Protocol Review and Monitoring Committee.

- The research design is sound enough to yield the expected knowledge.
- The aims/objectives are likely to be achievable within a given time period.
- The rationale for the proposed number of participants is reasonable.
- The scientific design is described and adequately justified.
- There is a clear differentiation between research procedures and standard care and evaluation.

Please submit this letter with your protocol submission to the Wayne State University Human Investigation Committee (HIC). **The HIC will not review the study without prior PRC approval.**

If your protocol will continue beyond the above date, please note that you must submit a completed continuation form to the Protocol Review and Monitoring Committee at least 8 weeks before the expiration date. If your study will not continue beyond the approval date, please submit a completed closure form when the study terminates.

All approvals and amendments to your protocol or consent form should be submitted to the Clinical Trials Office.

I wish you success in your study.

Mark Edelstein, M.D., Ph.D., Chair
Protocol Review and Monitoring Committee

4100 John R
Detroit, Michigan 48201
(800) KARMANOS (1-800-527-6266)
info@karmanos.org | www.karmanos.org



APPENDIX B

Human Investigation Committee Approval

WAYNE STATE
UNIVERSITY

IRB Administration Office
87 East Canfield, Second Floor
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
<http://irb.wayne.edu>

NOTICE OF EXPEDITED APPROVAL

To: Deborah Collins-Bohler
College of Nursing

From: Dr. Scott Millis *S. Millis, PhD*
Chairperson, Behavioral Institutional Review Board (B3)

Date: January 10, 2012

RE: IRB #: 124811B3E
Protocol Title: 2011-150: The Lived Experience of African American Women with Breast Cancer-Related Lymphedema
Funding Source: Unit: College of Nursing
Protocol #: 1112010425

Expiration Date: January 09, 2013

Risk Level / Category: Research not involving greater than minimal risk

The above-referenced protocol and items listed below (if applicable) were **APPROVED** following *Expedited Review* Category (#6 #7)* by the Chairperson/designee for the Wayne State University Institutional Review Board (B3) for the period of 01/10/2012 through 01/09/2013. This approval does not replace any departmental or other approvals that may be required.

- Revised Protocol Summary Form (received in the IRB Office 01/09/2012)
- Protocol (received in the IRB office 12/08/2011)
- Receipt of PRMC Approval (approval period 11/16/2011 to 10/18/2012)
- Research Informed Consent (dated 01/09/2012)
- Flyer
- Data collection tools: Demographic, Medical History and BCRLE Symptoms Self Report Form and Breast-Cancer-Related Lymphedema Interview Guide

- * Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval **before** the expiration date. Data collected during a period of lapsed approval is unapproved research and can never be reported or published as research data.
- * All changes or amendments to the above-referenced protocol require review and approval by the IRB **BEFORE** implementation.
- * Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (<http://www.irb.wayne.edu/policies-human-research.php>).

NOTE:

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the IRB Administration Office must be contacted immediately.
2. Forms should be downloaded from the IRB website at **each** use.

*Based on the Expedited Review List, revised November 1998

APPENDIX C

Human Investigation Committee Approved Flyer

Wayne State University College of Nursing

RESEARCH STUDY

Seeking African American Women for breast cancer
lymphedema research study

If You are:

- African American
- female
- 18 years of age or older
- English speaking
- diagnosed with lymphedema in one or both arms or hands

You may be eligible to take part in a clinical trial being conducted by Wayne State University's College of Nursing.

You will be asked to participate in two short interviews. The time required for the first interview will be about one hour and the second interview will be about 30 minutes.

You may not be eligible to participate if:

- You have lymphedema from any other cause except axillary surgery for breast cancer

Additional inclusion and exclusion criteria will be assessed at the time of your screening.

For more information contact:

Deborah Collins-Bohler RN, MSN

313-4053757 APPROVAL PERIOD

JAN 10 '12

JAN 09 '13

WAYNE STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

APPENDIX D

Oncology Letters of Support

September 6, 2011

Deborah Collins-Bohler RN, MSN
Wayne State University
College of Nursing
5557 Cass Ave.
Detroit, MI. 48202

Letter of Support

Dear Deborah,

I am writing this letter to support your application for your research project to address the critical need for better understanding of the impact that lymphedema has on the lives of African American women with breast cancer. Your study: "The Lived Experience of African American Women with Breast Cancer-Related Lymphedema" will provide better understanding of the perception of living with this dreadful condition as described from the patient's point of view. I provide services to this patient population and will refer women that may qualify as participants to your attention.

In conclusion, I support your efforts. This research regarding how high risk breast cancer survivors make decisions in living with lymphedema and its consequences will provide much needed data to enhance healthcare to all breast cancer survivors in the community at large.

Sincerely,

Cynthia Dinsmore, PT, CLT
Cynthia Dinsmore, PT, CLT



Wayne State University
School of Medicine

Department of Surgery
6-C, University Health Center
4201 St. Antoine
Detroit, Michigan 48201

September 6, 2011

Deborah Collins-Bohler RN, MSN
Wayne State University
College of Nursing
5557 Cass Ave.
Detroit, MI. 48202

RE: Letter of Support

Dear Deborah,

I am writing this letter to indicate my support of your research study titled "The Lived Experience of African American Women with Breast Cancer-Related Lymphedema." I am deeply committed to understanding the impact of this debilitating condition and its impact on the quality of life in breast cancer survivors. I strongly support research to elucidate and reduce disparity in the treatment of the life-long disability of breast cancer-related lymphedema.

I will generously work with you to provide support through identification of potential candidates for recruitment to your research project and will ask my colleagues at the Walt Breast Center to do likewise.

I look forward to the success of your application.

Sincerely,

May Ann Kosir, MD, FACS
Associate Professor of Surgery and Oncology
Department of Surgery and Karmanos Cancer Institute
Wayne State University School of Medicine

APPENDIX E

Compensation Voucher

The Lived Experience of African American Women with Breast Cancer-Related Lymphedema

(Participant receipt of gratuity)

I _____ acknowledge that I have received \$10.00/gift certificate for my participation in the research study "The Lived Experience of African American Women with Breast Cancer-Related Lymphedema".

_____ Date: _____

_____ Date: _____

I _____ acknowledge that I have received \$20.00/gift certificate for my participation in the research study "The Lived Experience of African American Women with Breast Cancer-Related Lymphedema".

_____ Date: _____

_____ Date: _____

APPENDIX F

Demographic, Medical History and BCRLE Symptoms Self Report Form

Age ____ years Date of Birth _____ (mm/dd/yyyy)

Marital Status: (please check all that apply)

Single ____ Living with Partner ____

Widowed ____ Divorced ____

Married ____

Number of children _____

Number of persons living in the household _____

Level of Education Completed:

Less than high school ____ Some college ____

High school diploma/GED ____ College degree ____

Employed: Yes __ No __ **Type of work you do/did:** _____**Health insurance:** Yes __ No __**Year of breast cancer was diagnosed:** _____**Type of breast cancer treatment:** Axillary lymph node dissection ____ sentinel lymph node biopsy ____ Both ____ Other _____**Length of time with breast cancer-related lymphedema:** months ____ years _____**Height** _____ **Weight** _____**Medical History (Please check if you currently have or have been treated for any of the following):**

Diabetes ____ Hypertension ____ Heart Disease ____

Demographic/Medical History/BCRLE Symptom Questionnaire (continued)**Symptoms related with Breast Cancer-Related Lymphedema (Please check if you currently or in the past have experienced any of the following):**

Swelling ____ Pain ____ Soreness ____ Tenderness ____ Aching ____

Burning ____ Stabbing ____ Numbness ____ Heaviness ____ Tightness ____

Rigidity ____ Fatigue ____

APPENDIX G

Breast-Cancer-Related Lymphedema Interview Guide

Concerns with physical, psychosocial, and functional problems in daily living have been reported by women with breast cancer-related lymphedema. I am going to ask you to describe your thoughts and feelings about the effects of breast cancer-related lymphedema on physical changes, your personal roles and relationships, ability to perform your activities of daily living such as bathing, dressing, household chores, and employment. Information related to concerns of African American women living with breast cancer-related lymphedema is important to recognize and understand the healthcare needs and management of breast cancer-related lymphedema in your daily lives.

1. Describe what is it like for you to have breast cancer-related lymphedema?

a. Probes

- i. Body image/appearance/self-image
- ii. Other physical changes (e.g. ADLs, bathing/dressing, housework child care, driving)
- iii. Emotional changes (attitude, mental status)

2. How would you describe your discovery of your breast-cancer-related lymphedema?

a. Probes

- i. What type of breast cancer treatment did you receive?
- ii. How long after you breast cancer treatment where you diagnosed with breast cancer-related lymphedema?
- iii. Who first discovered that you had breast cancer-related lymphedema (e.g. healthcare provider or self-reported)?
- iv. At what stage of breast cancer where you at the time of diagnosis?

3. Describe symptoms you have had since your diagnosis of breast cancer-related lymphedema and how these symptoms have affected you?

a. Probes

- i. What were the first symptoms you experienced?
- ii. What symptoms bother? Explain how.

- iii. How has management of symptoms affected your daily routine, including your job performance?
- iv. Please describe how your life has changed with because of these symptoms?
- v. How did those changes make you feel?
- vi. Have symptoms of breast cancer-related lymphedema ever caused problems when you travel?

4. Can you explain how you gained knowledge about breast cancer-related lymphedema?

- a. Probes
 - i. What type of education preparation did you receive before or after your breast cancer treatment?
 - ii. Were healthcare providers helpful or not? Explain how.
 - iii. If you did receive some education, can you tell me how whether or not that information was accurate or helpful? Explain why or why not.
 - iv. Did you know where to go for additional information? Do you feel that this is an ongoing problem? Anything in particular made a difference?

5. Breast cancer-related lymphedema can affect how a woman sees herself. Describe how breast cancer-related lymphedema has affected the way you see yourself as a woman?

- a. Probes
 - i. Body image/appearance (personal, physical, sexual)
 - ii. Family - social roles
 - iii. Other relationships

6. Family and friends can react to the visible and not so visible aspects of a chronic condition. Please describe how your family, friends, or other people have reacted to your breast cancer-related lymphedema?

- a. Probes
 - i. Has breast cancer-related lymphedema affected your relationships with your spouse, other family members, friends, or others? Please describe/give examples

- ii. Do you currently (or in the past) hide any of your feelings about breast cancer-related issues from your family, friends or others?

7. Describe how you cope with breast cancer-related lymphedema?

- a. Probes
 - i. What causes the most distress in living with breast cancer-related lymphedema?
 - ii. What types of support do you have to help you to cope with breast cancer-related lymphedema?
 - iii. What do you think is the most helpful in assisting you to cope with breast cancer-related lymphedema?
 - iv. What do you think is the least helpful in assisting you to cope with breast cancer-related lymphedema?
 - v. Have you sought out community services (e.g. self-help/support groups, church, social services, and counseling)?

8. Do you think that any of the concerns that you have mentioned would be different if you were not an African American woman?

- a. Probes
 - i. Body image/appearance
 - ii. Educational preparation (BCRLE)
 - iii. Coping strategies
 - iv. Diagnosis and treatment
 - v. Symptom management
 - vi. Support from healthcare providers
 - vii. Health insurance

9. What else would you like healthcare providers to understand about how breast cancer-related lymphedema affects your daily living and role as an African American woman?

The second interview will be used to ask additional specific and unscripted questions to provide clarification to previous statements made by the participants.

APPENDIX H

The Lived Experience of African American Women With Breast Cancer-Related Lymphedema

Research Informed Consent

Title of Study: The Lived Experience of African American Women with Breast Cancer-Related Lymphedema

Principal Investigator (PI): Deborah Collins-Bohler
Wayne State University College of Nursing
(248) 250-9894

Funding Source: Wayne state University/Wayne State University College of Nursing

Purpose

You are being asked to be in this research study of the perceptions of the how African American women describe what it is like to live with breast cancer-related lymphedema (BCRLE) because you have reported having breast cancer-related lymphedema. The purpose of this study is to explore the experiences of African American women living with BCRLE and their everyday experiences. This study is being done at Wayne State University and Barbara Ann Karmanos Cancer Institute. The estimated number of study participants to be enrolled at Wayne State University and Karmanos Cancer Institute is 6 to 12 women. **Please read this form and ask any questions you may have before agreeing to be in the study.**

African American women are at the greatest risk of all people for breast cancer-related lymphedema (BCRLE) because of having more advanced disease at diagnosis that requires more advanced treatments. However, there have not been many studies about African American women with breast cancer-related lymphedema. To understand how African American women describe what it is like to live with BCRLE requires research on how BCRLE affects their lives.

Study Procedures

The Principal Investigator will ask each participant to sign an informed consent that outlines the purpose, risks, benefits, voluntary nature of participation, confidentiality of responses, duration of the study, and key contact persons. Each participant will complete a Demographic, **Medical** History and BCRLE Symptoms Self-Report Form. Items on this instrument will include information pertaining to age, date of birth, marital status, educational level, health insurance, and employment status. Additional survey items include age at diagnosis of BCRLE, stage of breast cancer at time of diagnosis, length of time living with BCRLE, type of breast cancer treatment, current medical problems, medications, height/weight, and past and present symptoms associated with BCRLE.

Two interviews using open-ended questions will be completed with each participant, which will include two face-to-face interviews that will be tape recorded. The interviews will take place at an agreed upon time and location, including but not limited to home visits, therapy visits or physician visits at Karmanos Cancer Institute.

Submission/Revision Date: January 9, 2012
Protocol Version #: 1

Page 1 of 4

Participant's Initials

HIC Date: 08-11

The Lived Experience of African American Women With Breast Cancer-Related Lymphedema

will have access to tape recordings. All tape recordings will be destroyed following data analysis and final approval of the dissertation project by Wayne State University.

Voluntary Participation/Withdrawal

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study you can later change your mind and withdraw from the study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study

Questions

If you have any questions about this study now or in the future, you may contact Deborah Collins-Bohler, RN, MSN at the following phone number [248-250-9498]. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

The Lived Experience of African American Women With Breast Cancer-Related Lymphedema

Consent to Participate in a Research Study

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

Signature of participant / Legally authorized representative *

Date

Printed name of participant / Legally authorized representative *

Time

Signature of witness**

Date

Printed of witness**

Time

Signature of person obtaining consent

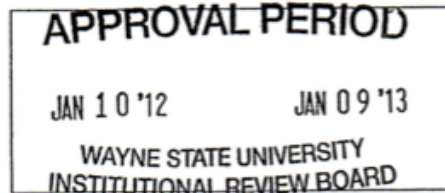
Date

Printed name of person obtaining consent

Time

*Remove LAR reference if you don't intend to consent participants that have or may have a LAR.

**Use when participant has had this consent form read to them (i.e., illiterate, legally blind, translated into foreign language).



Signature of translator

Date

Printed name of translator

Time

Submission/Revision Date: January 9, 2012
Protocol Version #: 1

Page 4 of 4

Participant's Initials

HIC Date: 08-11



APPENDIX I

Post Interview Summary Form

1. Respondent Behavior

2. Interview time, interruptions or distraction

3. Primary themes and/or issues/concerns

4. Interviewer's emotional responses/concerns

5. Other

6. Theme revisions/ new themes, sub-themes

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ABSTRACT**THE LIVED EXPERIENCE OF BREAST CANCER-RELATED LYMPHEDEMA IN
AFRICAN AMERICAN WOMEN**

by

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African American patients have been reported as having a greater number of aggressive cancer treatments compared to Caucasians (McWayne & Heiney, 2005; Meeske et al., 2009; Ridner & Dietrich, 2008), and have higher incidence of BCRLE due axillary lymph node dissection (ALND) and radiation intervention (Thomas-MacLean, Miedema, Tateemichi, 2005). Research regarding BCRLE has used BCRLE samples comprised almost exclusively of married and well-educated Caucasian women. Few studies (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003; Eversley et al., 2005; Joslyn, 2002; McWayne & Heiney, 2005) have included sizeable numbers of African American breast cancer survivors. No studies have been found that explicitly investigate the phenomenon of the lived experience of African American women who have acquired BCRLE and those that do include African American women in the sample; have not focused on any potential differences by race. The purpose of this descriptive, phenomenological qualitative study was to explore African American women's experiences in living with breast cancer-related lymphedema (BCRLE) including physical changes, functionality and perception of body image, family and social roles, coping techniques, and patient-healthcare provider relations. The final sample consisted of eleven women whose ages ranged from 50 to 73 years ($M= 62$, $SD= 6.65$) (see Table 1). Three participants were between 50 and 60 years old, seven participants were between the ages of 61 and 70 years old, and one participant was between 70 and 80 years old. All interviews were conducted by the principal investigator (PI). Two semi-structured interviews were performed with each participant. A total of twenty interviews were conducted. Five themes emerged from the analysis of the data and included: (1.) Living with Breast Cancer-related Lymphedema: "Sometimes your personal health is your personal business and nobody else's" (2.) Enduring the Unexpected: I'm having

this thing the rest of my life!, (3.) Diminished Perceptions of Self Image: “it kinda of uh attacked my self-image, (4.) Diminished Perceptions of Self Image: “it kinda of uh attacked my self-image”, and (5.) Distrust of physicians and other healthcare providers: “Just listen to us...” For the women in the current study, the residual effect of ‘not knowing’ had detrimental consequences from the beginning of the BCRLE experience. Ignorance intensified pain and suffering, perpetuated distress and impaired functionality, and created feelings of despair and contributed to social isolation. As revealed from the review of the literature, educational preparedness has an immense effect upon virtually every aspect of the lives of African American women living with BCRLE. Participants in this study conveyed that much of the information received from healthcare providers, contained in brochures and reference books, and displayed on the internet was difficult to understand. Healthcare providers and educators should assess the patient’s level of accurately understanding BCRLE. This information should be used to determine alternative methods of effective and appropriate educational techniques, including the development of low literacy formatted reading material. Information is relatively useless if the patients can’t understand the information. Knowledge is vital and facilitates positive adaptation of African American women throughout the life-time span of this chronic condition.

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EDUCATION/TRAINING

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