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PHENOMENOLOGICAL STUDY

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BREAST CANCER-RELATED LYMPHEDEMA IN HISPANIC WOMEN: A
PHENOMENOLOGICAL STUDY

by

JUANITA C. ACEBEDO

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Ph.D.
School of Nursing

Barbara K. Haas, Ph.D., R.N. Committee Chair

College of Nursing & Health Sciences

The University of Texas at Tyler
December 2016

The University of Texas at Tyler
Tyler, Texas


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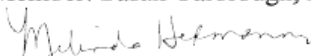
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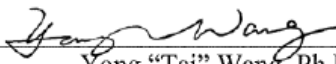

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Abstract

BREAST CANCER-RELATED LYMPHEDEMA IN HISPANIC WOMEN: A PHENOMENOLOGICAL STUDY

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As the numbers of breast cancer survivors continue to increase, it is essential to study BCRL as those affected carry a lifetime risk of developing this complication. Equally important, the study of BCRL is critical for health care professionals who undoubtedly will be confronted with caring for those affected.

The aim of this study was two-fold: 1). to explore the magnitude of BCRL and the ways it is currently addressed by healthcare professionals and 2). to explore the lived experience of Hispanic breast cancer survivors living with BCRL.

A review of the literature revealed the incidence of BCRL among breast cancer survivors varies widely from as low as 8% to as high as 56%. The varying range is primarily due to different diagnostic methods and a lack of purposeful follow-up to assess for BCRL. As one of the more debilitating sequela of breast cancer treatments, BCRL has implications for health care professionals.

Since scant research exists involving Hispanic women with BCRL and little is known about their experience, a qualitative study using interpretive phenomenology was conducted to ascertain the lived experience of Hispanic women with BCRL. Thirteen

Hispanic women were interviewed in the language of their choice (English or Spanish). Data analysis was done using Ricœur's methodology. Findings from the study revealed three major themes. The first two deal with the women's sense of loss and acceptance. The third, which directly speaks to health care professionals, is the perception of the women that they were ill-prepared to live with breast cancer treatment complications, including BCRL.

Chapter One

Overview of the Program of Research

Over a 29-year career as a Registered Nurse, certified mastectomy fitter for the last seven years, and co-owner of a durable medical equipment company located in a predominantly Hispanic community, the principal investigator has been profoundly interested in breast cancer-related lymphedema (BCRL). Throughout the years of attending to breast cancer survivors seeking mastectomy prosthetics, numerous stories of living after surviving breast cancer were heard. A great number of those survivors discussed learning to live with the complications of breast cancer treatments, including BCRL and the sequela of symptoms associated with it. Aside from the physical symptoms, women affected with BCRL relayed dealing with emotional and psychosocial issues. How these women dealt with their condition was the motivation to study BCRL, particularly within the Hispanic community as it is an understudied population.

Breast cancer-related lymphedema, characterized as an accumulation of lymphatic fluid to the arm closest to the affected breast, is a consequence of breast cancer treatments and is one of the most common complications reported by breast cancer survivors (American Cancer Society [ACS], 2015a; National Cancer Institute, 2007). Breast cancer survivors often report BCRL symptoms not only manifest in physical symptoms but also in emotional and psychosocial aspects (Clough-Gorr, Ganz, & Silliman, 2010; Fu & Rosedale, 2009; Thomas-MacLean, Miedema, & Tatemichi, 2005). As life expectancy rates among breast cancer survivors are projected to rise so will the number of women affected with BCRL (ACS, 2015a).

Though Hispanic women have a lower breast cancer incidence than their Caucasian counterparts, they tend to have advanced cancer disease at diagnosis (ACS, 2015b). Additional ethnic disparities exist with Hispanic breast cancer survivors experiencing disproportionate post breast cancer treatment for symptoms (Eversley et al., 2005). Since few studies exist on BCRL in Hispanic women, the researcher sought to explore the lived experiences within the cultural context of two particular concepts – familism (familismo) and personalism (personalismo).

Introduction to Articles

This program of research began with an exploration of the existing literature related to BCRL, reported in Chapter Two. This first manuscript titled “*Minimizing Breast Cancer-Related Lymphedema*” focuses on understanding and exploring the extent that BCRL occurs and to examine current trends used to assess and treat BCRL. This initial work was published in *Practice Nursing*; permission from the editor to include the manuscript in the dissertation portfolio is found in Appendix A.

General findings from the review of selected articles highlighted the magnitude of the problem. Although the exact incidence rate is unknown, there is general consensus that it is high and it is underreported. The lack of consensus among health care professionals in diagnosing and treating BRCL contributes to the problem of addressing BCRL in its early stages. A major gap identified in the review of BCRL was the absence of the perspective of Hispanic women.

Since Hispanic women with BCRL are an underrepresented group, the next step in this program of research was a qualitative study examining the experiences of Hispanic

women. Prior to beginning the study, Institutional Review Board (IRB) approval was obtained (Appendix B). Flyers in English (Appendix C) and Spanish (Appendix D) were approved to recruit participants. All participants signed an informed consent, either in English (Appendix E) or Spanish (Appendix F), according to their preference. After consent was obtained, the participants completed a Demographic Questionnaire (Appendix G). The interviews were conducted in either English or Spanish using a study interview guide (Appendix H). Findings of this study are reported in Chapter Three in the manuscript titled, “*Breast Cancer-Related Lymphedema in Hispanic Women: A Phenomenological Study.*”

Chapter Four is a summary of the work to date in this program of research focused on BCRL in Hispanic women. Recommendations for practice are included. Suggestions for next steps in this research trajectory are also provided.

Chapter Two

Minimizing Breast Cancer-Related Lymphoedema

Abstract

The advent of new medical breakthroughs has made an impact on the treatment of breast cancer, the second most common type of cancer affecting women. However, breast cancer-related lymphoedema is a major complication affecting women at a high rate. This article reviews previous studies on the care of breast cancer-related lymphoedema and searches for gaps that nurses can fill. CINAHL, Medicine, and nursing and health sciences databases were used to search for studies published between 2008 and 2014. Editorial pieces and studies in which the full text was not available were excluded. Thirty-five articles were reviewed and five were excluded. The level of evidence of these articles ranged from 1-VI. The key results of the studies included indicate the prevalence of BCRL varies greatly owing to the different types of assessment and diagnosing techniques that are used. Nurses usually have initial contact with these patients, and they can make significant contributions to the care of patients with breast cancer-related lymphoedema, in assessment, education and intervention.

Keywords: breast cancer-related lymphedema, complications, prevalence

Breast cancer-related lymphoedema is characterized as an abnormal accumulation of lymphatic fluid in the arm nearest the breast treated for breast cancer (Fu et al., 2008; McClure et al., 2010; Gautam et al., 2011; De Valois et al., 2012). This increase in lymphatic fluid is caused by a blockage in the normal flow in the lymphatic system (Fleysher, 2010; McClure et al., 2010). The fluid blockage could have resulted from injury, removal of lymph nodes or breast cancer treatments trauma. As protein-rich fluid accumulates, it starts to seep into the interstitial tissues, owing to the dense osmotic pressure created by the lymph fluid (Armer et al., 2011; Chang & Cormier, 2013). The resulting effect is an abnormal swelling of the affected limb, causing a sense of painful heaviness which affects the woman's being – physical, mental, emotional, and social. This article reviews previous studies on the care of breast cancer-related lymphoedema and searches for ways in which nurses can help women with this condition.

Literature Review

The Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline and nursing and health sciences databases were used for the literature search. The search terms used were: cancer-related lymphoedema, breast cancer, breast neoplasm, and upper lymphoedema. Studies published between 2008 and 2014 were included in the search. Editorial pieces, literature in which the full text was not available, and literature which was not published in the English language, were excluded. In total, 35 articles were reviewed and 5 were excluded. The level of evidence of the included articles ranged from I-VI.

Magnitude of the Problem

The American Cancer Society (ACS, 2014) notes that although the incidence of breast cancer has declined in the past decade, one in eight women will be affected with this disease during her lifetime. In total, 49,936 women and 349 men in the United Kingdom (U.K.) were diagnosed with invasive breast cancer in 2011, and 78% of adult female invasive breast cancer patients diagnosed in 2010-2011 in England and Wales are predicted to survive ten or more years (Cancer Research UK, 2014).

Medical advances in treatment have resulted in a high breast cancer survival rate. However, the triumph of the increase in breast cancer survivorship has been overshadowed by one of its main treatment side effects, breast cancer-related lymphoedema (DiSipio et al., 2013; Pativa et al., 2013). Armer et al. (2011) call breast cancer-related lymphoedema the most ‘dreaded sequelae of breast cancer treatments.’

The swelling or oedema of the arm causes distressing symptoms, such as pain, numbness, heaviness, stiffness, fatigue and compromised arm mobility (Fu et al., 2008; Chung et al., 2011; Chang & Cormier, 2013; O’Toole et al., 2013). These symptoms further impair the patient’s functional and self-care abilities, causing significant psychological distress (Fu et al., 2008; McClure et al., 2010; Kim, 2012). The accumulation of these symptoms have an effect on the woman’s quality of life (Armer et al., 2011). McClure et al. (2010) noted that studies have shown that these heightened emotional symptoms were more common in lymphoedema sufferers than in women with only a breast cancer diagnosis. Fleysler (2010) adds that if lymphoedema is not addressed early, the condition will progress and worsen into an incurable problem.

Gautam et al. (2011) add: ‘Survivors may find lymphoedema more distressing than mastectomy, because hiding the physiological manifestations and loss of function... harder.’

Causes and Incidence

Lymphoedema can be attributed to breast cancer treatments such as surgical removal of the breast (mastectomy), lymph node removal, radiation, and/or chemotherapy (Smoot et al., 2010; Chung et al., 2011; Bar Ad et al., 2012; Shah et al., 2012). Huang et al. (2013) reported a 12-26% possibility of breast cancer-related lymphoedema occurring 12 months after surgery. Armer et al. (2011), however, report a 40% incidence, while McClure et al. (2010) estimate an incidence of 20%.

A study by Dominick et al. (2013) found that women who underwent mastectomy and radiation therapy doubled their risk of developing breast cancer-related lymphoedema. Bar Ad et al. (2012) reported that a progression of breast cancer-related lymphoedema was commonly seen within 5 years of onset. According to O’Toole et al. (2013), breast cancer-related lymphoedema incidence in patients who are followed up for longer periods can be as high as 34-94%. Shah et al. (2012) added that chemotherapy treatments have been shown to increase the incidence of breast cancer-related lymphoedema, and this increase may be due to the aggressiveness of the breast cancer treatment modality. DiSipio et al. (2013) have suggested the incidence of breast cancer-related lymphoedema may be as high as 96%, as reported in individual studies, but a lack of consensus in defining and assessing breast cancer-related lymphoedema makes it difficult to obtain a reliable percentage. The varying incidence rates may be due to the

fact that most clinicians base their diagnosis on patient symptomatology alone, instead of the basis of objective measurements from the start of breast cancer treatments (Hack et al., 2010)

Contributing Factors

The literature indicates that breast cancer treatments play a significant role in breast cancer-related lymphoedema development, but other factors appear to aggravate the problem. A study by Bar Ad et al. (2012) reported that women older than 65 years of age had a higher risk of developing breast cancer-related lymphoedema, compared with those less than 65 years of age.

Several studies showed a body mass index (BMI) of greater than 25.0 kg/m² was also a strong predictor of breast cancer-related lymphoedema development (Fu et al., 2008); Swenson et al., 2009; Smoot et al., 2010; Ridner et al., 2011). Lack of exercise and self-care (which may result from unmanaged pain, treatment side effects or limited limb range mobility) are also contributing factors to breast cancer-related lymphoedema (Chung et al., 2011). Upper extremity limitations and impairment can still occur after breast cancer treatment, even if lymphoedema is not present (Smoot et al, 2011), which is something nurses need to be aware of.

Existing Models of Care

Traditional assessment tools

Lymphoedema is currently diagnosed primarily through patient symptoms; however, treatment may come too late for patients who have already developed symptoms, such as pain, heaviness, numbness or swelling (Hack et al., 2010).

Since patient's self-report can be unreliable, one objective measuring tool for assessing breast cancer-related lymphoedema is the use of circumferential measurement (Czerniec et al., 2010). This method requires the affected limb to be measure at specific points; these measurements are then compared to the contralateral or unaffected arm Shah et al. (2012); however, suggest that this method has its limitations, since there is no congruency in the measurement points. O'Toole et al. (2013) add that women who undergo bilateral mastectomies are even more difficult to diagnose early, since there is no arm to use as a control.

Another lymphoedema assessment method is bioimpedance spectroscopy, which measures the electrical impedance flow through the arm (Czerniec et al., 2010). This method is usually impractical for the practitioner, since it requires trained individuals, equipment cost and dedicated office space (O'Toole et al., 2013). Thus, the discrepancies above make it difficult to assess breast cancer-related lymphoedema uniformly.

Mainstream intervention methods

Lymphoedema cannot be cured, but can be managed and symptoms controlled (Breast Cancer Care, 2014). Complete decongestive therapy is considered the gold standard in treating breast cancer-related lymphedema and is performed by trained therapists in lymphoedema therapy (Chang & Cormier, 2013). Complete decongestive therapy typically involves daily manual lymph drainage or gentle massage of the ipsilateral arm to stimulate lymphatic fluid, followed by multilayered compression bandaging to maintain reduced arm volume (Lasinski, 2013). In addition, complete

decongestive therapy involves long-term self-care, so educating patients on self-care practices such as proper skin care and risk-reducing behaviors, daily exercises, and use of compression garments are critical for successful long-term management of breast cancer-related lymphedema (Chang & Cormier, 2013; Lasinski, 2013).

Once the arm is reduced to its smallest size, compression garments are added as a long-term management method. These have a limited use because some women may have difficulty applying the compression garments by themselves, while others find compression garments very uncomfortable to wear, so non-compliance can be an issue. The addition of skin and nail care is an important component in the treatment of breast cancer-related lymphoedema.

Another non-invasive method to treat breast cancer-related lymphoedema is the use of intermittent pneumatic compression devices (Chang & Cormier, 2013). These medical devices utilize sequential compression to stimulate the movement of the lymph fluid to the trunk area, where it can then be reabsorbed by the major lymphatic system. Surgical intervention may be used as a last resort when breast cancer-related lymphoedema is causing serious complications, such as cellulitis and lymphangitis, or when uncontrolled pain becomes an issue (Chang & Cormier, 2013).

Complementary and Alternative Medicine (CAM)

The National Center for Complementary and Alternative Medicine (<http://nccam.nih.gov>) has defined CAM as methods used outside of mainstream medical approaches that either complement mainstream medicine or are altogether an alternative option to mainstream medical approaches. These can be herbal or natural products, mind

and body medicine (*e.g.*, yoga, tai chi, acupuncture) or other types of body manipulation techniques, such as massage or traditional healing techniques (Wanchai et al., 2013). Several studies have reported a sense of wellbeing and a reduction in breast cancer-related lymphoedema with the use of CAM (Finnane et al., 2011; Van Puymbroeck et al. 2013).

Gaps in Nursing

Breast cancer-related lymphedema is not a common talking point with women undergoing mastectomy or breast cancer treatments, even though this complication has a high occurrence rate. The condition will impact physical activities of daily living, thus placing additional psychological demands on the patient and affecting quality of life (Chachaj et al., 2010). Although lymphoedema is often managed by lymphoedema trained specialists, nurses are well positioned to provide effective and supportive patient education (Ridner et al., 2012).

One of the main challenges nurses face is the lack of uniform definition of breast cancer lymphoedema. O'Toole et al. (2013) conclude that inconsistencies in the definition impede the early identification required for proper treatment. Ridner et al. (2012) urge nurses to become acquainted with the symptomatology of lymphedema and the psychological and social impact it has on the lives of the women affected. This could serve as an impetus for all health professionals, particularly nurses, to be proactive in early identification and assessment.

Just as it is standard practice for nurses to take basic biometrics, such as vital signs and weights, additional assessments, such as arm measurements and lymphoedema

assessment, can be easily incorporated when caring for breast cancer survivors (Ridner & Dietrich, 2008). Chung et al. (2011) agree, stating ‘nurses should take better precautions against lymphoedema by providing customized patient education based on each woman’s awareness level and potential and vulnerability.’

Empirical patient education makes a difference in patient outcomes as evidenced in a study by Fu et al. (2010). A study by Ridner et al. (2011) suggests women with breast cancer-related lymphoedema do receive information on lymphoedema, but specific education on self-care practices are limited partly because of healthcare providers’, including nurses’, limited knowledge of breast cancer-related lymphoedema. These self-care practices include risk-reducing behaviors such as exercise, weight management, avoiding arm constriction, and preventing arm infections (Fleysher, 2010).

Review Limitations

The limitations of this literature review include the limited number of articles examined. Other databases were not used in the search and articles not published in the English language were excluded; therefore, it is possible that not all relevant or related articles were identified.

Conclusions

As the lifespan of breast cancer survivors increase, breast cancer-related lymphoedema occurrence will become more evident. Most often, patients will be seen in the primary care setting; thus, nurses should be aware of this common complication of breast cancer treatment. Patient education should include arm exercises, weight management, early signs and symptoms of breast cancer-related lymphedema and proper

skin care. Nurses should keep up to date with current assessment techniques and treatment modalities and empower breast cancer survivors to take control of their health.

References

- American Cancer Society. (2013). What are the key statistics about breast cancer?
Retrieved from <http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-key-statistics>
- Anderson, R. T., Kimmick, G. G., McCoy, T. P., Hopkins, J., Levine, E., Miller, G., . . . Mihalko, S. L. (2012). A randomized trial of exercises on well-being and function following breast cancer surgery: The RESTORE trial. *Journal of Cancer Survivors, 6*(2), 172-81. doi: 10.1007/s11764-011-0208-4
- Aringa, Y. (2012). Holistic management of lymphoedema in Japan: Two contrasting cases. *Journal of Lymphoedema, 7*(2), 40-43. Retrieved from http://www.woundsinternational.com/pdf/content_11237.pdf
- Armer, J. M., Brooks, C. W., & Stewart, B. R. (2011). Limitations of self-care in reducing the risk of lymphedema: Supportive-educative systems. *Nursing Science Quarterly, 24*(1), 57-63. Retrieved from <http://dx.doi.org/10.1177/0894318410389058>
- Bar Ad, V., Dutta, P. R., Solin, L. J., Hwang, W., Tan, K. S., Both, S., ... Harris, E. E. (2012). Time-course of arm lymphedema and potential risk factors for progression of lymphedema after breast conservation treatment for early stage breast cancer. *The Breast Journal, 18*(3), 219-225. Retrieved from <http://dx.doi.org/10.1111/j.1524-4741.2012.01229.x>

- Breast Cancer Care. (2014). Treating lymphoedema. Retrieved from <http://www.breastcancercare.org.uk/breast-cancer-information/treating-breast-cancer/lymphoedema>
- Cancer Research UK. (2014). Breast cancer statistics. Retrieved from <http://cancerresearchuk.org/cancer-info/cancerstats/types/breast>
- Chachaj, A., Malyzszak, K., Pyszel, K., Lukas, J., Tarkowski, R., Pudelko, M., ... Szuba, A. (2010). Physical and psychological impairments of women with upper limb lymphedema following breast cancer treatment. *Psycho-Oncology*, *19*, 299-305. Retrieved from <http://dx.doi.org/10.1002/pon.1573>
- Chang, C. J., & Cormier, J. N. (2013). Lymphedema interventions: Exercise, surgery, and compression devices. *Seminars in Oncology Nursing*, *29*(1), 28-40. Retrieved from <http://dx.doi.org/10.1016/j.soncn.2012.11.005>
- Chung, C. W., Hwang, E., & Hwang, S. W. (2011). Details of lymphedema, upper limb morbidity, and self-management in women after breast cancer treatment. *Korean Journal of Women Health Nursing*, *17*(5), 474-483. Retrieved from <http://dx.doi.org/10.4069/kjwhn.2011.17.5.474>
- Cooper, G. (2012). Lymphoedema treatment in palliative care: A case study. *British Journal of Nursing*, *12*(15), 897-903. doi: 10.12968/bjon.2012.21.15.897

- Czerniec, S. A., Ward, L. C., Refshauge, K. M., Beith, J., Lee, M. J., York, S., & Kilbreath, S. L. (2010). Assessment of breast cancer-related arm lymphedema - comparison of physical measurement methods and self-report. *Cancer Investigation, 28*, 54-62. Retrieved from <http://dx.doi.org/10.3109/07357900902918494>
- De Valois, B. A., Young, T. E., & Melsome, E. (2012). Assessing the feasibility of using acupuncture and moxibustion to improve quality of life for cancer survivors with upper body lymphoedema. *European Journal of Oncology Nursing, 16*, 301-309. Retrieved from <http://dx.doi.org/10.1016/j.ejon.2011.07.005>
- DiSipio, T., Rye, S., Newman, B., & Hayes, S. (2013). Incidence of unilateral arm lymphoedema after breast cancer: A systematic review and meta-analysis. *Oncology, 14*, 500-514. Retrieved from [http://dx.doi.org/10.1016/S1470-2045\(13\)70076-7](http://dx.doi.org/10.1016/S1470-2045(13)70076-7)
- Dominick, S. A., Madlensky, L., Natarajan, L., & Pierce, J. P. (2013). Risk factors associated with breast cancer-related lymphedema in the WHEL Study. *Journal of Cancer Survivorship, 7*, 115-123. Retrieved from <http://dx.doi.org/10.1007/s11764-012-0251-9>
- Finnane, A., Liu, Y., Battistutta, D., Janda, M., & Hayes, S. C. (2011). Lymphedema after breast or gynecological cancer: Use and effectiveness of mainstream and complementary therapies. *The Journal of Alternative and Complementary Medicine, 17*(9), 867-869. Retrieved from <http://dx.doi.org/10.1089/acm.2010.0456>

- Fleysher, L. A. (2010). Keeping breast cancer survivors lymphoedema-free. *British Journal of Nursing*, *19*(13), 826-830. doi: 10.12968/bjon.2010.19.13.48858
- Fu, M. R., Axelrod, D., & Haber, J. (2008). Breast cancer-related lymphedema: Information, symptoms, and risk-reduction behaviors. *Journal of Nursing Scholarship*, *40*(4), 341-348. doi: 10.1111/j.1547-5069.2008.00248.x
- Fu, M. R., Chen, C. M., Haber, J., Guth, A. A., & Axelrod, D. (2010). The effect of providing information about lymphedema on the cognitive and symptom outcomes of breast cancer survivors. *Annals of Surgical Oncology*, *17*, 1847-1853. Retrieved from <http://dx.doi.org/10.1245/s10434-010-0941-3>
- Gautam, A. P., Maiya, A. G., & Vidyasagar, M. S. (2011). Effect of home-based exercise program on lymphedema and quality of life in female post mastectomy patients: Pre-post intervention study. *Journal of Rehabilitation Research & Development*, *48*(10), 1261-1268. Retrieved from <http://dx.doi.org/10.1682/JRRD.2010.05.0089>
- Hack, T. F., Kwan, W. B., Thomas-MacLean, R. L., Towers, A., Miedema, B., Tilley, A., & Chateau, D. (2010). Predictors of arm morbidity following breast cancer surgery. *Psycho-Oncology*, *19*, 1205-1212. Retrieved from <http://dx.doi.org/10.1002/pon.1685>
- Huang, T.-W., Tseng, S.-H., Lin, C.-C., Bai, C.-H., Chen, C.-S., Hung, C. S., . . . Tam, K.-W. (2013). Effects of manual lymphatic drainage on breast cancer-related lymphedema: A systematic review and meta-analysis of randomized controlled trials. *World Journal of Surgical Oncology*, *11*(15), 5-8. Retrieved from <http://www.wjso.com/content/11/1/15>

- Kim, S. J. (2012). Impact of the type of compression materials on manual dexterity of patients with breast cancer-related lymphedema (BCRL). *Journal of Physical Therapy Science, 24*(10), 969-973.
- Lasinski, B. B. (2013). Complete decongestive therapy for treatment of lymphedema. *Seminars in Oncology Nursing, 29*(1), 20-27. doi: 10.1016/j.soncn.2012.11.004
- McClure, M. K., McClure, R. J., Day, R., & Brufsky, A. M. (2010). Randomized controlled trial of the breast cancer recovery program for women with breast cancer-related lymphedema. *The American Journal of Occupational Therapy, 64*(1), 59-72.
- National Center for Complementary and Alternative Medicine. (2013). What is CAM? Retrieved from <http://nccam.nih.gov/health/whatiscam>
- O'Toole, J., Jammallo, L. S., Skolny, M. N., Miller, C. L., Elliott, K., Specht, M. C., & Taghian, A. G. (2013). Lymphedema following treatment for breast cancer: A new approach to an old problem. *Critical Review in Oncology/Hematology, 88*, 437-446. Retrieved from <http://dx.doi.org/10.1016/j.critrevonc.2013.05.001>
- Paiva, D. M., Rodrigues, V. O., Cesca, M. G., Palma, P. V., & Leite, I. C. (2013). Prevalence of lymphedema in women undergoing treatment for breast cancer in a referral center in southeastern Brazil. *BMC Women's Health, 13*(06), 1472-6874. Retrieved from <http://dx.doi.org/10.1186/1472-6874-13-6>

- Ridner, S. H., & Dietrich, M. S. (2008). Self-reported comorbid conditions and medication usage in breast cancer survivors with and without lymphedema. *Oncology Nursing Forum*, *35*(1), 57-63. Retrieved from <http://dx.doi.org/10.1188/08.ONF.57-63>
- Ridner, S. H., Dietrich, M. S., & Kidd, N. (2011). Breast cancer treatment-related lymphoedema self-care: Education, practices, symptoms, and quality of life. *Support Care Cancer*, *19*(5), 631-637. doi: 1007/s00520-010-0870-5
- Ridner, S. H., Dietrich, M. S., Stewart, B. R., & Armer, J. M. (2011). Body mass index and breast cancer treatment-related lymphedema. *Support Care Cancer*, *19*(6), 853-857. Retrieved from <http://dx.doi.org/10.1007/s00520-011-1089-9>
- Ridner, S. H., Sinclair, V., Deng, J., Bonner, C. M., Kidd, N., & Dietrich, M. S. (2012). Breast cancer survivors with lymphedema: Glimpses of their daily lives. *Clinical Journal of Oncology Nursing*, *16*(6), 609-614. doi: 10.1188/12.CJON.609-614
- Shah, C., Arthur, D., Riutta, J., Whitworth, P., & Vicini, F. A. (2012). Breast-cancer related lymphedema: A review of procedure-specific incidence rates, clinical assessment aids, treatment paradigms, and risk reduction. *The Breast Journal*, *18*(4), 357-361. Retrieved from <http://dx.doi.org/10.1111/j1524-4741.2012.01252.x>
- Smoot, B., Wong, J., Cooper, B., Wanek, L., Topp, K., Byl, N., & Dodd, M. (2010). Upper extremity impairments in women with or without lymphedema following breast cancer treatment. *Journal of Cancer Survivorship*, *4*, 167-178. Retrieved from <http://dx.doi.org/10.1007/s11764-010-0118-x>

- Swenson, K. K., Nissen, M. J., Leach, J. W., & Post-White, J. (2009). Case-control study to evaluate predictors of lymphedema after breast cancer surgery. *Oncology Nursing Forum*, 36(2), 185-193. Retrieved from <http://dx.doi.org/10.1188/09.ONF.185-193>
- Van Puymbroeck, M., Burk, B. N., Shinew, K. J., Kuhlenschmidt, M. C., & Schmid, A. A. (2013). Perceived health benefits from yoga among breast cancer survivors. *American Journal of Health Promotion*, 27(5), 308-314. Retrieved from <http://dx.doi.org/10.4273/ajhp.110316-QUAL-119>
- Wanchai, A., Armer, J. M., & Stewart, B. R. (2013). Complementary and alternative medicine and lymphedema. *Seminars in Oncology Nursing*, 29(1), 41-49. Retrieved from <http://dx.doi.org/10.1016/j.soncn.2012.11.006>

Chapter Three. Breast Cancer-Related Lymphedema in Hispanic Women: A

Phenomenological Study

Abstract

Objective: This study explored the lived experience of Hispanic/Latino women dealing with BCRL.

Participants: A convenience and purposive sampling of 13 Hispanic women, 42-80 years old with diagnosed breast cancer-related lymphedema for over one year, were recruited December 2015 – April 2016.

Methods: Using interpretive phenomenology, Hispanic women with BCRL were individually interviewed using open-ended questions to explore common themes experienced by this particular ethnic group. Sampling continued until data saturation was met. Recruiting took place through four health care practices in south Texas. Data consisted of field notes, researcher journaling, recorded audio interviews, and the respective transcriptions. Data analysis occurred through three main steps: naïve reading, interpretive reading, and interpretation of the whole.

Results: All 13 participants self-identified as Mexican-American. Three major themes were identified: (1) *Sense of loss*, (2) *Resignation to the new self*, and (3) *I didn't know*. The first theme involved a negative transformative experience, grieving the loss of the old "better" self. The second theme refers to the acceptance of the new self with all the physical and psychosocial limitations. The final theme, *I didn't know*, highlights the uncertainty women experienced after their breast cancer treatments and the development of their breast cancer-related lymphedema.

Conclusion: While similar in some respects to the experience of non-Hispanic women with BCRL, findings in this study of Hispanic women with BCRL identified “familism” and a lack of understanding that may impede treatment. Health care providers need to be aware of the needs of their Hispanic patients experiencing BCRL.

Key words: breast cancer-related lymphedema, phenomenology, lived experience,
Hispanic women

According to the American Cancer Society (2015), breast cancer has been on the decline since 2000. This decline is attributed to cancer research, increased public awareness, and decreased use of hormonal replacement therapy. Additionally, the American Cancer Society (ACS) notes breast cancer survivorship has increased due to early detection, early screening and detection, and improved treatment modalities. The approximately 10 million breast cancer survivors worldwide, including the 2.8 million breast cancer survivors living in the United States, are a testament to all the concerted efforts addressing the number one cause of death for women from cancer (American Cancer Society, 2015).

Breast cancer survivors, however, continue to face treatment-related challenges even after cancer is successfully treated. One of the most common complications survivors of breast cancer face is breast cancer-related lymphedema (BCRL) characterized by an abnormal accumulation of lymph fluid to the ipsilateral arm (Clough-Gorr, Ganz, & Silliman, 2010; Johansson et al., 2003). This increase in lymphatic fluid is caused by a blockage in the normal flow of the lymphatic system (Fleysher, 2010; McClure, McClure, Day, & Brufsky, 2010). As protein-rich lymph fluid accumulates, it seeps into the interstitial tissues due to the dense osmotic pressure present in the lymph fluid resulting in arm edema (Chang & Cormier, 2013; Fleysher, 2010).

The primary cause of BCRL is injury or removal of the lymph nodes and the surrounding lymph vessels. Injury may be due to commonly used breast cancer treatments such as surgery, radiation, or chemotherapy (ACS, 2015). If the remaining lymph vessels cannot drain the lymph fluid, the surrounding tissue starts to swell.

Ensuing debilitating symptoms such as arm swelling, heaviness, numbness and pain lead to deep psychological and emotional effects which affect a woman's ability to self-care (Armer, Brooks, & Stewart, 2011; Bosompra, Ashikaga, O'Brien, Nelson, & Skelly, 2003; Chachaj et al., 2010; Radina, Armer, & Stewart, 2014).

Literature Review

Even though the American Cancer Society (2015) highlights the 2.8 million breast cancer survivors in the United States (U.S.), the number of women who have to live with the life-long debilitating condition of BRCL are largely overlooked. The prevalence of BCRL varies greatly due to the lack of uniform methods of classifying, diagnosing, and monitoring it (National Cancer Institute, 2007; Panobianco et al., 2014; Thomas-MacLean, Miedema, & Tatemichi, 2005). If the conservative figure of 26% (Clough-Gorr et al., 2010) is used, there are well over 700,000 breast cancer survivors in the U.S. alone dealing with this chronic condition. Importantly, breast cancer survivors continue to have a lifetime risk of developing BCRL due to the compromised lymphatic drainage system (Fu, Axelrod, & Haber, 2008; McWayne & Heiney, 2005; Shigaki, Madsen, Wanchai, Stewart, & Armer, 2013). In spite of the large number of women affected by BRCL, Shigaki et al. (2013) underscore the scant research focused on understanding the long-term effects BCRL has on breast cancer survivors.

One primary concern facing women with BCRL is the physical changes, including arm swelling, heaviness, stiffness, and numbness (Bosompra et al., 2003; Fu et al., 2008; Williams, 2012). These symptoms result in functional limitations, which are a

constant reminder of their whole cancer ordeal. In a qualitative study by Johansson et al. (2003) of a group of twelve Swedish women, one breast cancer survivor stated:

I've always been the kind to never ask for help. I really hate having to ask...It feels like a big defeat. Yes, that I felt like a strong woman before and I feel like a weak person now. (p. 38)

These distressful physical symptoms start a chain reaction that may also cause major psychological issues such as depression, problems with self-image, loss of self-confidence, social withdrawal, and distress due to pain and over loss of intimacy (Fu & Rosedale, 2009; McWayne & Heiney, 2005; Panobianco et al., 2014; Ridner et al., 2012).

Ultimately, quality of life is negatively affected as the breast cancer survivor deals with the chronic comorbid conditions that follow and may occur even years after breast cancer treatments are completed (Clough-Gorr et al., 2010; Fleysher, 2010; McWayne & Heiney, 2005; Shigaki et al., 2013). Most troublesome is the fact that most women with BCRL report little to no education regarding the disease or instruction on self-care by healthcare professionals (Armer et al., 2011; Bosompra et al., 2003; Heppner et al., 2009; Thomas-MacLean et al., 2005).

Most quantitative and qualitative studies in breast cancer-related lymphedema involve predominantly non-Hispanic White and non-Hispanic Black women. In their review of 244 studies, Lopez-Class, Gomez-Duarte, Graves, and Ashing-Giwa (2012) note the lack of existing research available regarding the Hispanic population.

Furthermore, low literacy levels and cultural factors, such as the concepts of “familism” (where family needs and commitment are valued over self) and “personalism” (where

relationship to the healthcare provider is integral), may influence health outcomes (Gonzalez & Keller, 2004; Pagan et al., 2012).

Breast cancer studies specifically involving breast cancer survivorship show existing differences between Latina/Hispanic women and their non-Hispanic White and non-Hispanic Black (Eversley et al., 2005; Lopez-Class et al., 2012; Sammarco & Konecny, 2010). In this review, no literature specifically addressing BCRL in Hispanic women was found. In south Texas, particularly in the Rio Grande Valley which borders Mexico, Hispanics are the predominant ethnic group. The Pew Research Center reported that in 2013, Hispanics constituted 88-91% of the population (www.pewhispanic.org), further supporting the need to conduct research in this population.

Research Question

Understanding the lived experience of Hispanic women dealing with breast cancer-related lymphedema can shed new insights for health care providers and expand the existing knowledge base to be culturally relevant as healthcare providers treat this group of minority women. Therefore, the research question addressed in this study was: What is the lived experience of Hispanic women dealing with breast cancer-related lymphedema?

Research Design and Philosophical Underpinnings

A qualitative research design using interpretive phenomenology guided this research. Interpretative phenomenology, also known as hermeneutics, is concerned with exploring human experiences as they are lived (Tuohy, Cooney, Dowling, Murphy, & Sixmith, 2013). Although Edmund Husserl, the German philosopher and mathematician,

developed phenomenology as a method of scientific inquiry, it was Martin Heidegger, one of his many successors, who furthered the interpretative phenomenological approach (Wojnar & Swanson, 2007).

One of the underlying assumptions of interpretive phenomenology is the recognition that an individual's reality is influenced by everything that is connected to the person, such as social and cultural links (Tuohy et al., 2013). In regards to the individual's lived experience, Wojnar and Swanson (2007) note, "their very experience of health is in the context of family traditions, community values, and the broader sociopolitical context" (p.174). Heidegger coined this concept as "dasein," meaning individuals could not completely separate themselves from the effects daily living and choices had on their lived experience (Wojnar & Swanson, 2007).

Another key assumption of interpretive phenomenology is that the researcher cannot be completely abstracted from the process of exploring an individual's lived experience. In fact, it is the researcher's conjectures and knowledge which give a clear meaning to the lived experience that may not even be fully apparent to the participant (Lopez & Willis, 2004). Wojnar and Swanson (2007) specify that it is the "understanding and co-creation by the researcher and the participants what makes interpretations meaningful" (p.176).

Interpretive phenomenology allows for rich and deep understanding of the lived experience of Hispanic women with breast cancer-lymphedema. In order to capture the whole essence of the lived experience, every contextual link, such as linguistic, cultural, and societal influences must be explored and acknowledged. Furthermore, as Tuohy et

al. (2013) state, interpretative phenomenology lends itself to the “hermeneutic circle” where there is continued dialogue and interaction between the participant and researcher as they collaboratively examine and re-examine the lived experience to identify the essence of that particular experience.

Methods

Procedures

Sample population. This study took place in the Rio Grande Valley located in south Texas. The inclusion criteria for this research study included Hispanic women who had developed breast cancer-related lymphedema (BCRL) after breast cancer treatments. The sample population reported living with BCRL for at least one year.

The participants were required to be able to read or write in English and/or Spanish and be over 20 years old. Convenience and snowball sampling techniques were used. Sampling took place until saturation of data was met. A total of 13 participants were interviewed.

Recruitment. Four healthcare facilities, a Durable Medical Equipment (DME) company and three oncology offices, served as recruiting sites. The DME provides mastectomy prosthetics, compression sleeves, and compression pumps to women who are dealing with BCRL. Through their medical record database, individuals who met the inclusion criteria were identified. The three mastectomy fitters from the DME contacted each of the identified individuals by phone and informed them of the study. A recruitment flyer in English or Spanish, as preferred by the participant, was mailed to

each one. Additionally, the study recruitment flyers in both English and Spanish were posted in the DME's mastectomy fitting room.

The oncology practice consisted of three separate offices located in two counties of the Rio Grande Valley. The researcher was employed as a research nurse at these three offices and was granted permission to identify and contact participants who met the inclusion criteria. As participants were identified, the researcher contacted each by phone and informed them of the study purpose. If interested, an appointment to meet was made.

Ethical principles. After Institutional Review Board approval was received, careful consideration was taken to follow ethical principles for human research. Since not all participants were bilingual, both English and Spanish Informed Consents were approved by the IRB. Participants were assured the right and opportunity to accept, decline, or withdraw from the study at any point during the study process.

Sample Description

All 13 participants had experienced BCRL for over one year. All reported having a breast biopsy to confirm malignancy prior to breast surgery. Twelve participants had total mastectomies and one participant reported having a lumpectomy. Nine women were also treated with chemotherapy and three women reported receiving chemotherapy and radiation in addition to their breast cancer surgery. Only one participant reported having breast surgery without additional treatment. Four participants reported experiencing BCRL symptoms (pain, swelling, heaviness, numbness, etc.) immediately after surgery. Four participants reported having BCRL symptoms between one to three months. Three reported BCRL symptoms were noticed nine months after breast cancer surgery. The

remaining two participants reported BCRL symptoms began less than nine months after surgery.

All participants identified themselves as Hispanics of Mexican origin. Nine participants were born in the U.S. and the remaining four were born in Mexico. Those born in Mexico had been living in the U.S. border area between 10 – 71 years (M = 33). The majority of participants were married, bilingual, unemployed outside the home, and had an educational level of high school or less. Refer to table 1 for detailed demographic information.

Table 1. Sample Demographics

Variable	N (%)
Age:	
Range: 42 – 80 years	
Mean = 63.07	
Education:	
Less than high school	5 (39%)
High school	2 (15%)
Vocational education	4 (31%)
Some college/ College graduate	2 (15%)
Marital Status:	
Married	6 (46%)
Single/ Divorced	5 (39%)
Widowed	2 (15%)

Employment	
Full-time	0
Part-time	5 (38%)
Not employed outside the home	8 (62%)
Language	
Bilingual	10 (77%)
Spanish only	3 (23%)
English only	0
Language spoken at home	
Spanish	12 (92%)
English	1 (8%)
BMI	
Range: 27.3 – 47.6	
Mean = 34.6	

Data Collection. Prior to scheduling the individually recorded interviews, the researcher began journaling in a separate binder to facilitate reflexivity. This process was ongoing throughout the study. In addition, multiple sources of data including audio-taped face-to-face semi-structured interviews, filed notes, and the demographic data from were used to increase the rigor and the trustworthiness of the study. Data collected in paper form were kept in the researcher’s private locked office in a locked file. Only the researcher had access to the locked file.

Establishing a trusting relationship was crucial in having an effective interview. The researcher, who is bicultural and bilingual and self-identified as Mexican-American, made every effort to create a climate of trust with each of the participants. Therefore, prior to beginning each of the interviews, time was taken to interact in a social manner in keeping with cultural norms. Full disclosure of the aim of the study was explained and each participant was allowed to ask questions.

All of the recorded interviews were conducted in quiet, private areas. Audio recording of the interviews were done with two digital voice recorders and back-up batteries for both audio recorders were on hand to prevent the possibility of data loss. The researcher was acutely aware of her own body language, eye contact, and tone of voice to help the participants feel comfortable when sharing their experiences. Thus, minimal note-taking was done during the interview process; thorough note-taking was done immediately after each interview. Verbatim transcription was done within 24 hours of each interview.

The taped interviews were conducted in a semi-structured manner to allow for more interactive communication between the participant and the researcher. Questions were open-ended and follow-up probing questions were used as necessary to elicit in-depth responses. Because the main goal of the study was to understand Hispanic women's experience with BCRL, the grand tour question asked was: "How has breast cancer-related lymphedema impacted your life?" Depending on the participants' responses, probing questions followed. Examples of probing or follow-up questions were: 'tell me more about that...'; 'what I hear you saying is ...' Moreover, the use of

researcher silence between questions was employed to give the participant time to reflect on the interview questions.

Each participant was asked to speak about her life experience with BCRL. The aim of this approach was to elicit responses that would give a deeper understanding of the phenomenon of living with BCRL with particular interest in the cultural beliefs or behaviors that impacted the lived experience. Ten interviews were conducted in the participants' homes as the preferred interview location. The remaining three interviews took place at the researcher's private office. The interview time varied between participants but generally ranged between 45 to 90 minutes.

Following each interview, the researcher wrote detailed field notes with observations of the home, participant's body language, behaviors, attitudes, and any other noteworthy impressions of the interview. After the twelfth interview, data redundancy was observed. An additional interview was conducted to confirm data saturation. As no new themes emerged, the interviews concluded with the thirteenth participant.

Data Analysis. Data analysis took place within 24 hours following each participant's audiotaped interview. Each interview was transcribed verbatim by the researcher using the password-protected computer. The interviews transcribed in Spanish and translated to English were reviewed by another bilingual nurse to confirm the essence of the themes. Paul Ricoeur's approach to data analysis was followed and included the following steps once transcription of the taped interviews was concluded (Streubert & Carpenter, 2011). During the first step, naïve reading, the researcher read and re-read the transcriptions individually and as a whole to gather the impressions of lived experience.

Incorporating Creswell’s (2014) steps for data analysis and using an iterative process, the researcher read the transcripts in whole and in part to experience immersion in the data and to understand the data within the context of the research question and the phenomenological design. Additionally, the researcher’s field notes and journaling notes were integrated in the data analysis and constant comparison between the data was performed.

Next, structural analysis or interpretive reading was conducted. The researcher looked at the themes and sub-themes arising from the data and then labeled them for organizational purposes. The hand-written notes taken during the interview were also reviewed to add to the data analysis. To organize the data, an excel spreadsheet was used and each question was assigned to a row. Next, participant’s responses to each of the questions was placed in its corresponding row. For instance, all the participants’ responses to question one were placed under that particular question. The same process was followed for the remaining questions in the Interview Guide. An example of the coding process is shown in Table 2.

Table 2. Coding Example

Question/Transcription Data	Key Words/Phrases	Theme
1. Tell me about your arm lymphedema. How has it affected your life?		
008: I used to cut my grass, clean my garden and a lot of other things. I wasn't paying anyone. I can't do anything now because my arm feels so heavy. This arm doesn't help me. I used to dig in my garden all the time but not anymore.	I can't do anything now because my arm feels so heavy.	Sense of loss of old self.

<p>2nd Interview:</p> <p>It's not the same anymore. I get tired very easily. [Long pause] I never was the type to be just inside my house. No, not me. I used to cut my own grass. I was always outside. I have a tractor, you know, to cut my grass. Now, it's just there in the garage. I pay my neighbor to come and cut my grass. I pay him \$25 dollars. I was always with my roses, too... but my arm is so heavy. My body is not balanced anymore. My arm is so big now that I can't walk for a long time anymore... I used to even change my own car oil. I would buy the oil and the filter and do it myself. I used to do everything on my own. But after the surgery, everything changed. Now I can't even be outside in the sun for a long time because it affects my arm, you know. It gets worse when I'm outside in the sun.</p> <p>I just have to accept it... I can't do anything about it. Even how I look, I have to accept it. I don't even like to use a bra anymore (laughs). I have the prosthesis but I don't like to wear it because it's so heavy and the foam is too hot. I just wear loose shirts and no bra (laughs). I don't care. It's not like I have to please anyone (laughs). Well, I can't do anything about it anyways. I don't like to think about it. The only thing is... I feel bad because now I can't do what I used to like to do before and that makes me feel bad.</p> <p>Yes, yes, I miss my freedom. Used to go everywhere by myself. I used to go visit my sisters. They all passed away already. I can't go out like that anymore. If someone comes to take me, I'll go but not by myself. If someone comes to invite me for ice cream, I go.</p> <p>I don't get depressed. I can't do anything about it. I just have to accept things... the way they are.</p> <p>It was my destiny and what can I say? I can't blame God. That's what was meant for me, and I'm happy here in my house. I've lived here for a long time. I know my neighbors and they watch out for me. It's quiet here and I'm used to living here. I've live here for a long time. That lot next to me was mine but I sold it a long time ago. I didn't want to pay taxes anymore (laughs).</p>	<p>It's not the same anymore. I get tired very easily.</p> <p>I used to do everything on my own. But after the surgery, everything changed.</p> <p>I just have to accept it. Even how I look, I have to accept it.</p> <p>I can't do anything about it anyways. I don't like to think about it.</p> <p>I miss my freedom.</p> <p>I don't get depressed.</p> <p>It was my destiny. I can't blame God. That's what was meant for me.</p>	<p>Sense of resignation.</p>
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The final step, interpretation, involved reviewing the interpretations several times and describing the themes and sub-themes. Emerging information was then manually coded. The researcher went back and forth from the field notes and journal entries to the transcripts and emerging themes to search for substantive themes as suggested by Thomas-MacLean et al. (2005) and Creswell (2014). Data analysis occurred concurrently with data collection and continued until all interviews were complete. Throughout the analysis process, the research team was involved in reviewing and confirming emerging themes. Those themes were further coded into broader emerging themes. Four participants were re-interviewed to elicit deeper understanding. After the broader codes were reviewed, the researcher concurred with the emerging themes.

Ensuring an audit trail was critical in establishing credibility of the study. Several approaches were taken to ensure the audit trail. First, each participant was given an opportunity to verify her own thematic findings once the transcription and coding were done. Second, another Hispanic nurse familiar with the culture reviewed the de-identified transcriptions and coded themes. Finally, two expert qualitative researchers had full access to field notes, transcription, and coding. Themes were verified through independent analysis.

Findings

Three major emerging themes were identified. The first two, *Sense of loss of the old self* and *Resignation to the new self*, contained sub-themes dealing with the physiological, psychological, emotional, and spiritual aspects of living with breast

cancer-related lymphedema. The final theme, *I didn't know*, deals with the vacuum that exists due to the perceived lack of education and self-efficacy Hispanic breast cancer survivors continue to face today.

Sense of loss of the old self

Functional limitations. Without exception, when the question was asked, “Tell me about your arm lymphedema?” and “How has it affected your life?” the participants spoke of the symptoms in the affected arm which caused the most problems. Pain, spasms, swelling, numbness, and lack of strength were the most commonly reported adverse symptoms. These physical symptoms affected all aspects of their daily activities. When asked what type of activities, participants primarily reported household activities such as cooking, cleaning, and mopping, doing dishes, and the ability to self-care, such as bathing and dressing. The participants spoke of their deep sense of loss of their old selves, comparing what they could no longer do because of their physical limitations. Those who were not employed mostly spoke of the limitations on the activities they enjoyed prior to developing lymphedema. Fictitious names are used.

It [lymphedema] has affected me because I can no longer do what I used to do before [long pause] ... like being in my garden, in my plants. Before, I could be outside with my plants, digging. I would grab the hoe, the machete, cut the yard, trim the trees. But no more. I can't do that anymore because if I do, my arm starts to swell right away. - Linda

I used to cut my grass, clean my garden and a lot of things. I wasn't paying anyone. I can't do anything now because my arm feels so heavy. ... I was never the type to be just inside my house. No, not me. I used to cut my own grass. I was always outside. I was always with my roses, too... but my arm is so heavy now. My body is not balanced anymore. My arm is so big now that I can't walk for a long time. I can't even use the clothes I like. - Rosa

I can't sleep very well (crying)... I can't do any housework like cleaning, mopping, doing my dishes. I just can't. - Sofia

Fear of hurting self. Most of the participants expressed having fear of hurting themselves or having a heightened sense of awareness in order to avoid injury to self, something they had not experienced before. One common fear was having additional complications, such as arm infections. Five reported having experienced repeated hospitalizations due to arm infections caused by the lymphedema. Melita, a 73 year-old, said, "... I'm always scared that any little thing is an infection, so, I'm very conscious of everything I do and I don't let mosquitos bite me in my arm." Sofia, a 70 year-old who has dealt with lymphedema for over eight years, related:

I've had to go to the hospital a lot of times because my whole arm gets so swollen; it gets red like a tomato and very hot, hot. Every time I end up in the hospital, I have to have antibiotics and then therapy for my arm. I've been in the hospital so many times; I can't keep count.

Even those participants who have not had an infection related to BCRL expressed fear.

Nena, who is only 42 years old stated, "I'm afraid my arm will get worse. I've seen other women with their arms big and that scares me; I don't want to get like that."

Feelings of Helplessness. Although all the participants acknowledged that having physical limitations due to the arm lymphedema was expected, they were faced with dealing with feelings of helplessness. Nellie, another 42 year-old, described feeling frustrated because she felt so helpless. She said, "I feel frustrated because I feel slow. The lymphedema makes me feel slow (long pause), feel old... that being 42 years old and I need so much help. I'm always looking for help." As she thought of her teenage daughters, she added, "I find it kinda unfair. I don't want them to think, 'Oh, mom is

handicapped.’ After a long pause she said, “... not that it makes me feel less of a mom, but the lymphedema makes me feel limited, like disabled. I can’t act as fast as before.”

Other participants spoke of their sense of helplessness stemming from their loss of freedom. Luz, an 80 year-old never-married participant, who always did things by herself, said, ‘I’m not free. I need help for everything and I get tired so easy. I need help to dress, to cook, to clean. I can’t go out by myself. I miss my freedom.’ Alicia, a 69 year-old, echoed those same sentiments saying:

My family knows they have to help me to do things. I want to do things like I did in the past but I know I need help. I don’t feel the same anymore. It makes me feel bad that I can’t do simple things for myself anymore (crying).

Other participants voiced feelings of despair caused by the sense of helplessness.

I just feel bad (crying). I’m not the same anymore. I have a hard time doing anything for myself, and I wasn’t like that before. I used to be a very outgoing person. I used to like to be with other people. I was a happy person, and now my life is completely different ...(long pause). I’m always in pain, always hurting. - Sofia

Anxiety and fear are always with me. When I get a little pain, I don’t know what it is. Is it serious? I see my sisters and they are able to do whatever they want. Not me. I stop and think to myself, ‘I can’t do everything I want. I have to take care of myself, be careful.’ Like I see other women and I think, ‘they don’t have any cares in the world.’ I’m not the same anymore, physically, emotionally. Any little thing, any little pain and I’m like, what’s wrong, what’s this? I don’t want to think the cancer is coming back. My wish is to see my children grow up.’ - Nena

Resignation to the new self and moving forward

Moving Forward. While all participants discussed issues related to loss of the “old” self, they also expressed resignation to the changes and noted the need to move beyond their limitations caused by the breast cancer-related lymphedema. This internal locus of control was the driving force to move forward. As Linda put it, “I can live with

the lymphedema; I'm just grateful to be alive." Nena agreed stating, "I have to resign myself to live like this... the worst thing is to have cancer. As long as the cancer doesn't come back, I can deal with whatever." Others expressed it as "un dia a la vez" or one day at a time.

There's nothing good about having lymphedema. I can't just get up and go but I'm just happy to be alive now. I just take it one day at a time. I need to move forward and be positive. - Lourdes

I can't just sit down and think about it. I have to keep myself busy. I just have to bear with it. I just have to live with what I have and take it one day at a time. - Lucia

If I'm busy, I don't think about it [lymphedema]. But if I'm sitting down or trying on clothes and I look at my arm, I'm like, 'Oh, god, my arm's so big.' I try not to think about it and keep myself busy. If you don't help yourself, no one is going to help you. You need to be at peace with yourself and take it one day at a time. Things happen for a reason. - Carmela

I could have been dead but I'm still here because of my faith, the love of my family and my friends. - Eloisa

Finding Strength in Support. Married participants, although feeling self-conscious of their altered body image due to their mastectomies and arm lymphedema, reported finding strength in having understanding and supportive husbands.

I ask my husband, 'I'm mutilated. Do you feel bad for me?' and he tells me, 'It's your life and I didn't marry you because of your breasts.' To him what matters is who I am, not how I look. When he knows I can't do something, he's right there to help me. Thank God I have a good husband. - Nena

My husband is there 100% for me. The breast cancer surgery and now the lymphedema have made me feel very self-conscious. It's been years I haven't changed clothes in front of my husband, but to him it doesn't matter how I look. To me it does; to him it doesn't. He's very good to me. - Maria

Nellie, whose husband had a stroke almost at the same time she was undergoing breast cancer treatments added, “From the very beginning he has told me that he doesn’t care how I look. We’re closer and this lymphedema hasn’t affected our relationship or intimacy. All this experience has only brought us closer together.”

Even those who didn’t have a spouse sought support from their families, friends, or their home providers. Eloisa said, “If it wasn’t for my family and friends, I would be very depressed and very down all the time.” Linda, a divorced 70 year-old, living in a housing complex for retired people said, “I have friends here in the apartments. They’re just like me, by themselves, like 15 ladies. We get together for crafts or we go out to eat... so they help me out a lot.” She, like other participants, had Primary Home Care (PHC), which is a service under the Texas Department of Aging and Disability Services (DADS). These services are a benefit for low-income people who have functional limitations and need assistance with activities of daily living (see www.dads.state.tx.us). Through their Family Care Services, participants were able to have a family member, friend, or layperson assigned as their home provider to help them with personal care and other activities of daily living. Four of the participants interviewed had these services. Alicia put it this way, “Can you imagine how I would be if I didn’t have her [provider]? She’s here every day and helps me with whatever I need. I know I would have a hard time without her.”

My destiny. Yet, other participants found moving forward in their lives was mitigated by an external locus of control such as the belief in destiny or a Higher Power, believing the breast cancer and the arm lymphedema experience were part of a larger

scheme in life, something out of their control. Ana, a 65 year-old, said, “I’ve never had any negative thoughts. I prayed to God and told him, ‘I’m at your mercy. Do whatever you want with me.’” Luz and Eloisa described it this way:

It was my destiny. I can’t be mad at anybody and I can’t get depressed. Everybody has their destiny and I don’t blame anyone. God knows why I had breast cancer and now lymphedema. I just have to accept this. I can’t blame God. - Luz

I don’t feel sorry for myself. The Lord sent me this and He knows why. I’ve never said, ‘Why me?’ I say, ‘What are we going to do about it?’ And from then on I’ve never felt sorry for myself or sit there and get scared. - Eloisa

Even Rosa, whose husband had died in recent months, expressed it this way:

I think it’s worse [living with lymphedema] since my husband died, but I know that I’m strong and I just have to keep on going. I just have to get myself to keep on going. I don’t have any other choice. This is what was given to me. God decides. If this is what I have to live with, then I just have to live with it.

“I didn’t know what I had.” Finally, one of the prominent themes emerging from the data was the perceived lack of BCRL education and preparedness that participants felt they received. All agreed more could have been done to educate them about the risk of developing BCRL. Maria said, “If they had told me about lymphedema, I would have paid more attention to it. As a matter of fact, I didn’t even know lymphedema existed.” Another participant added, “I was never told to look out for it [arm lymphedema]. No one told me I was going to have swelling. I was the one who started to worry about it, because you know, my arm was getting bigger and bigger. I mean it got so big!” And Rosa shared the same thoughts saying, “I didn’t understand what I had; I really didn’t. Nobody told me anything. My arm just got bigger and bigger.”

Some participants blamed themselves for not knowing about lymphedema. For instance, Nena said, “Like I told you, I wasn’t prepared for this; I didn’t expect this. Maybe they told me and I didn’t pay attention.” Other participants thought physicians were not familiar with breast cancer-related lymphedema. The following are direct quotes:

I don’t think doctors know too much about lymphedema. Don’t you think? To me, I don’t think they know about lymphedema. I went to see the doctor and he sent me for a scan of my throat, my heart, everywhere, because he didn’t know what this [lymphedema] was... - Linda

I wasn’t told anything. I don’t think the doctors here know about lymphedema. I was the one who kept looking for information. I had no help. - Lourdes

I told my doctor [oncologist] the first time I noticed my arm getting swollen and she ignored me. I told her the second time and she sent me to therapy. Then my primary doctor told me to stop therapy. - Luz

Sofia was more critical, saying:

I thought everything was going to be better after the breast surgery... and I think the doctors are really not there for you...I think badly sometimes, but I think they did their job and that’s it. Nobody gave me instructions. They just want to finish their job. Why didn’t they tell me before? - Sofia

Yet others felt more information on BCRL would have made a difference:

I really could have used someone who could have just opened my eyes or something and told me, ‘Look, if you insist on doing what you were doing in the past, this can be a consequence,’ and no one told me. Maybe in the hospital there can be something where the patient can be told [given information]. I wasn’t told. - Anita

I wasn’t expecting this. I thought I had to just eat right after my breast surgery. Nobody told me anything. Maybe if someone had told me this [lymphedema] could happen, I would have been prepared, but nobody said anything. - Alicia

I think anything [information] would have helped. Maybe things would be different if I had more information. - Eloisa

Nellie specifically singled out the health care professionals saying, “They [doctors/nurses] really didn’t talk to me about lymphedema. I think if someone, like a nurse, would have given me information, it would have helped.”

Discussion

This study focused on the lived experience of Hispanic women with breast cancer-related lymphedema and the impact of two key concepts, familism and personalism, on their lives. Familism deals with the concept expressed as family needs above self (Gonzalez & Keller, 2004; Pagan et al., 2012). Existing studies corroborate the findings that women living with BCRL experience challenges with self-care and functional limitations (Armer et al., 2011; Ridner et al., 2012). Furthermore, these functional limitations lead to psychosocial issues (Fu & Rosedale, 2009; McWayne & Heiney, 2005; Ridner et al., 2012). Only two participants had young children in the home and both felt their role as a mother was hindered by the arm lymphedema. One participant felt she needed to “humble herself” to accept she needed help. The other participant with young children agreed she did not take time for herself, especially when it came to doing exercises to her affected arm because she did not give herself the time; therefore, by the end of the day she was too exhausted. “At the end of the day, I’m just tired and all I want to do is go to sleep,” she said. These findings of “self-sacrifice or others-sacrifice” are corroborated by the recent study of Radina et al. (2014)

In relation to social and spousal support, this study revealed participants found strength in their web of support. Those who were married reported a close relationship with their spouses in spite of having physical disfigurement caused by their breast

surgery and lymphedema. These findings are contrary to the findings in Ridner et al. (2012) who found a difference in social and spousal relationships in women who were non-Hispanic. As one participant put it, “Thank God for my husband. My mastectomy, my lymphedema doesn’t affect him. It still affects me but because of all the support my husband gives me, I haven’t felt low.” On the contrary, Sofia, whose husband had recently died said:

He did everything for me. He was a kind man that... I think there are a few men like him. He really took care of me. You know, I have lymphedema but it never bothered me like it bothers me now. When he was alive, we just lived with it. I was in and out of the hospital but it was just part of our lives. We still were active. We’d go here. We’d go there. He was a hunter; we liked to go hunting. So my mind was not focused on just the lymphedema. But now [that he’s gone], that’s all I think about. I know that I’m hurting because I miss him. I miss him so much...

The other participants who were not married actively sought support from friends, family, and even their hired home provider. Luz, who lives alone, said of her home provider, “I’m glad I have Mary Lou. She’s like my family. Every Friday she gets me ready. She helps me with a bath and dresses me and takes me to our favorite restaurant. I don’t know what I would do without her.”

The common theme throughout all participants, *I didn’t know what I had*, speaks to the lack of personalism, the concept which describes the essential connection with healthcare professionals (Gonzalez & Keller, 2004; Pagan et al., 2012). This perceived disconnect was described by participants as a lack of concern for their well-being. Others questioned the depth of knowledge physicians have regarding BCRL. Nonetheless, it was clear that all participants perceived a disconnect from their health care providers.

Strengths and limitations

A major strength of this study is the inclusion of Hispanic women, a previously understudied population. Conducting the study in the language of the participant's choice further contributed to the strength of the study. The study design is also a strength since subsequent contact with each of the participants yielded richer data.

The study also has limitations. While all participants were Hispanic, most participants were referrals from the medical equipment company where they were receiving either compression garments or pumps for their arm lymphedema. Those participants referred from the oncology office either received or were receiving physical therapy for their arm lymphedema. Thus, the participants may not represent those whose lymphedema is not being addressed.

Another limitation of the study was that, although most participants were low-income and had a low educational level, all participants had health insurance. Each had access to healthcare providers and the referral sources. Some participants had additional health insurance support which also provided them home support. It would have been interesting to see if there were any differences in themes if, for example, participants who did not have any health insurance had been included in the study and if participants had spouses who were less supportive had also been included.

Finally, since this was a qualitative study and depended on self-report, the reporting cannot be validated. Perhaps if the study was a mixed-methods design, integrating quantitative data, the findings could provide greater insight. For instance, the degree and length of time of the breast cancer-related lymphedema was not part of the

study. Moreover, eight of the thirteen participants (62%) were over the age of 65, which is typical retirement age in the United States. Including an equal number of participants less than 65 years old or the inclusion of family member interviews may have impacted the findings of the lived experience and may have provided more meaning to the concept of familism.

Conclusion and Implications

Based on the findings of this study, it is noted that Hispanic breast cancer survivors continue to experience health challenges even after completing breast cancer treatments. A common theme of this study suggests breast cancer survivors who have developed lymphedema find themselves in a negative transformative state, grieving the loss of the person they once were to one learning to adapt to their “new” inferior self, one with constant physical and psychosocial limitations. Similar findings were reported in Fu and Rosedale (2009) and Heppner et al. (2009) with non-Hispanic breast cancer survivors.

However, for this study’s participants, there was an apparent use of an external locus of control described as the belief in a ‘destino’ or destiny which mitigated their coping and ability to move forward. Even though the participants believed they could not control what they had (lymphedema), they actively sought medical help or reported self-care practices, such as arm exercises, arm massage, and the use of compression sleeves and compression pumps to alleviate the BCRL symptoms. Additionally, taking it “un dia a la vez” or one day at a time approach kept them from feeling overwhelmed with their new negatively transformed self.

Another clear implication is the need to address the perception that health care professionals do not provide adequate information on arm lymphedema. All 13 participants voiced their concern, and expressed the need for a more formal approach to educating women undergoing breast cancer treatments on the risk and care of BCRL. It is a clarion call to nursing professionals to become educated on BCRL and seek ways to incorporate teaching breast cancer survivors about the resources available to them.

Finally, additional research using a mixed-methods approach, integrating quantitative data, could add breadth and depth to the findings. Including more participants under the age of 65 and inclusion of family member interviews may contribute additional insight into the lived experiences of Hispanic women with BCRL and give more meaning to the concept of familism.

References

- American Cancer Society. (2015). Breast cancer facts and figures 2013-2014. Retrieved from <http://www.cancer.org/acs/groups/@research/documents/document/acspc-042725.pdf>
- Armer, J. M., Brooks, C. W., & Stewart, B. R. (2011). Limitations of self-care in reducing the risk of lymphedema: Supportive-educative systems. *Nursing Science Quarterly*, 24(1), 57-63. Retrieved from <http://dx.doi.org/10.1177/0894318410389058>
- Bosompra, K., Ashikaga, T., O'Brien, P. J., Nelson, L., & Skelly, J. (2003). Swelling, numbness, pain, and their relationship to arm function among breast cancer survivors: A disablement process model perspective. *The Breast Journal*, 8(6), 338-348. Retrieved from <http://www.ebscohost.com>
- Chachaj, A., Malyzszak, K., Pyszel, K., Lukas, J., Tarkowski, R., Pudelko, M., ... Szuba, A. (2010). Physical and psychological impairments of women with upper limb lymphedema following breast cancer treatment. *Psycho-Oncology*, 19, 299-305. Retrieved from <http://dx.doi.org/10.1002/pon.1573>
- Chang, C. J., & Cormier, J. N. (2013). Lymphedema interventions: Exercise, surgery, and compression devices. *Seminars in Oncology Nursing*, 29(1), 28-40. Retrieved from <http://dx.doi.org/10.1016/j.soncn.2012.11.005>
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage Publications.

- Clough-Gorr, K. M., Ganz, P. A., & Silliman, R. A. (2010). Older breast cancer survivors: Factors associated with self-reported symptoms of persistent lymphedema over 7 years of follow-up. *The Breast Journal, 16*(2), 147-155. Retrieved from <http://dx.doi.org/10.1111/j.1524-4741.2009.00878>
- Eversley, R., Estrin, D., Dibble, S., Wardlaw, L., Pedrosa, M., & Favila-Penney, W. (2005). Post-treatment symptoms among ethnic minority breast cancer survivors. *Oncology Nursing Forum, 32*(2), 250-256. Retrieved from <http://dx.doi.org/10.1188/05.ONF.250-256>
- Fleysher, L. A. (2010). Keeping breast cancer survivors lymphoedema-free. *British Journal of Nursing, 19*(13), 826-830.
- Fu, M. R., Axelrod, D., & Haber, J. (2008). Breast cancer-related lymphedema: Information, symptoms, and risk-reduction behaviors. *Journal of Nursing Scholarship, 40*(4), 341-348.
- Fu, M. R., & Rosedale, M. (2009). Breast cancer survivors' experiences of lymphedema-related symptoms. *Journal of Pain and Symptom Management, 38*(6), 849-859. doi: 10.1016/j.jpainsymman.2009.04.030
- Gonzalez, A., & Keller, C. (2004). Mi familia viene primero (my family comes first): Physical activity issues in older Mexican American Women. *Southern Online Journal of Nursing Research, 4*(5), 2-20. Retrieved from <http://www.snrs.org>

- Heppner, P. P., Tierney, C. G., Wang, Y.-W., Armer, J. M., Whitlow, N. M., & Reynolds, A. (2009). Breast cancer survivors coping with lymphedema: What all counselors need to know. *Journal of Counseling & Development, 87*, 327-338. Retrieved from <http://www.wiley.com>
- Johansson, K., Holmstrom, H., Nilsson, I., Ingvar, C., Albertsson, M., & Ekdahl, C. (2003). Breast cancer patients' experiences of lymphoedema. *Scandinavian Journal of Caring Science, 17*, 35-42. Retrieved from www.ebscohost.com
- Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research, 14*(5), 726-735. Retrieved from <http://dx.doi.org/10.1177/1049732304263638>
- Lopez-Class, M., Gomez-Duarte, J., Graves, K., & Ashing-Giwa, K. (2012). A contextual approach to understanding breast cancer survivorship among Latinas. *Psycho-Oncology, 21*, 115-124. Retrieved from <http://dx.doi.org/10.1002/pon.1998>
- McClure, M. K., McClure, R. J., Day, R., & Brufsky, A. M. (2010). Randomized controlled trial of the breast cancer recovery program for women with breast cancer-related lymphedema. *The American Journal of Occupational Therapy, 64*(1), 59-72.
- McWayne, J., & Heiney, S. P. (2005). Psychologic and social sequelae of secondary lymphedema. *Cancer, 104*(3), 457-466. doi: 10.1002/cncr.21195
- National Cancer Institute. (2007). Lymphedema after cancer: How serious is it? Retrieved from <http://www.cancer.gov/about-cancer/treatment/research/lymphedema-after-cancer>

- Pagan, J. A., Brown, C. J., Asch, D. A., Armstrong, K., Bastida, E., & Guerra, C. (2012). Health literacy and breast cancer screening among Mexican American women in South Texas. *Journal of Cancer Education*, 27, 132-137. Retrieved from <http://dx.doi.org/10.1007/s13187-011-0239-6>
- Panobianco, M. S., Campacci, N., Fangel, L. M., Prado, M. A., De Almedia, A. M., & Gozzo, T. D. (2014). Quality of life of women with lymphedema after surgery for breast cancer. *Revista de Rede de Enfermagem do Nordeste*, 15(2), 206-213. Retrieved from <http://dx.doi.org/10.15253/2175-6783.2014000200004>
- Pew Research Report. (2013, August 29). Mapping the Latino population, by state, county, and city. Retrieved from http://www.pewhispanic.org/files/2013/08/latino_populations_in_the_states_counties_and_cities_FINAL.pdf
- Primary Home Care (PHC). (n.d). Retrieved from <http://www.dads.state.tx.us/providers/PHC>
- Radina, M. E., Armer, J. M., & Stewart, B.R. (2014). Making self-care a priority for women at risk of breast cancer-related lymphedema. *Journal of Family Medicine*, 20(2), 226-249. doi: 101177/1074840714520716
- Ridner, S. H., Sinclair, V., Deng, J., Bonner, C. M., Kidd, N., & Dietrich, M. S. (2012). Breast cancer survivors with lymphedema: Glimpses of their daily lives. *Clinical Journal of Oncology Nursing*, 16(6), 609-614. Retrieved from <http://dx.doi.org/10.1188/12.CJON.609-614>

- Sammarco, A., & Konecny, L. M. (2010). Quality of life, social support, and uncertainty among Latina and Caucasian breast cancer survivors: A comparative study. *Oncology Nursing Forum*, 37(1), 93-99. Retrieved from <http://dx.doi.org/http://dx.doi.org/10.1188/10.ONF.93-99>
- Shigaki, C. L., Madsen, R., Wanchai, A., Stewart, B. R., & Armer, J. M. (2013). Upper extremity lymphedema: Presence and effect on functioning five years after breast cancer treatment. *Rehabilitation Psychology*, 58(4), 342-349. Retrieved from <http://dx.doi.org/10.1037/a0034657>
- Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed.). Philadelphia, PA: Wolters Kluwer/ Lippincott Williams & Wilkins.
- Thomas-MacLean, R., Miedema, B., & Tatemichi, S. R. (2005). Breast cancer-related lymphedema: Women's experiences with an underestimated condition. *Canadian Family Physician*, 51, 246-247. Retrieved from <http://www.cfpc.ca/cfp>
- Tuohy, D., Cooney, A., Dowling, M., Murphy, K., & Sixmith, J. (2013). An overview of interpretive phenomenology as a research methodology. *Nurse Researcher*, 20(6), 17-20. Retrieved from <http://www.ebsco.com>
- Williams, A. F. (2012). Living with and beyond breast cancer. *Journal of Community Nursing*, 26(1), 6-11. Retrieved from <http://www.ebscohost.com>
- Wojnar, D. M., & Swanson, K. M. (2007). Phenomenology: An exploration. *Journal of Holistic Nursing*, 25(3), 172-180. Retrieved from <http://dx.doi.org/10.1177/0898010106295172>

Chapter Four

Summary and Conclusion

The future for breast cancer survivors is promising, partly due to early diagnosis, early treatment, and new treatment modalities (ACS, 2015a; NCI, 2007). Nonetheless, while these figures are optimistic, the juxtaposition of breast cancer-related lymphedema as a leading complication of breast cancer treatments should present a moment to reflect on the need for continued treatment of women surviving breast cancer. It is not enough to survive breast cancer; the quality of life for survivors must also be addressed.

This program of research began after personally seeing breast cancer survivors deal with a condition which to some had no name and which to most had no prior existence. The first article reported in Chapter Two, “*Minimizing Breast Cancer-Related Lymphedema*,” was the result of that piqued interest in the subject. Peer-reviewed articles were selected to identify the magnitude of the problem, identify current treatment modalities, and identify any gaps and implications for health professionals, particularly nursing. Findings suggested breast cancer survivors with BCRL find themselves dealing with a constant reminder of their breast cancer ordeal. Moreover, this visual reminder of a swollen arm was intertwined with debilitating symptoms and functional limitations. Gaps in the literature were identified. One gap was the lack of preparedness on the part of health professionals and the lack of education breast cancer survivors perceived they received from their health care providers, primarily the physicians and the nurses who cared for them. Another significant gap identified was the lack of ethnic representation by Hispanic women.

The findings from the first manuscript served as a foundation for the second manuscript, *Breast Cancer-Related Lymphedema in Hispanic Women: A Phenomenological Study*, reported in Chapter Three. Using a qualitative study design, 13 Hispanic women with BCRL were interviewed with the intent to explore their lived experiences within the context of their culture and two distinct concepts within their culture, familismo (familism) and personalismo (personalism). A third concept frequently mentioned by the participants was that of destino (destiny), which needs further investigation. This study contributes to the current science by including Hispanic women who are underrepresented. Furthermore, this study corroborates the findings reported in other studies which identify the perception women voice as lack of education on and self-care in breast cancer-related lymphedema.

The findings from this research study underscore implications for the medical and nursing professions. Breast cancer survivors, while getting over one major hurdle in their cancer ordeal, continue to face physical, emotional, and psychosocial issues with the development of breast cancer-related lymphedema. This study revealed cultural concepts within the Hispanic population which need to be taken into consideration by all health care professionals. The study findings have direct implications for nurses, as the Hispanic participants indicates the need for more education and knowledge related to BCRL. Furthermore, the emerging findings will serve as the basis to extend the program of research in Hispanic women with BCRL, adding to the body of research and to the ethnic representation of Hispanic women.

In conclusion, this research study highlights one of breast cancer's relatively little understood complications. More importantly, it gave voice and presence to an ethnic minority group of women, which is slowly becoming the largest ethnic minority in the United States as reported by the U.S population projections (Colby & Ortman, 2014). As healthcare professionals, nurses are in a prime position to make a difference in the health outcomes women with breast cancer-related lymphedema face and change the existing perceptions of the women affected.

References

- American Cancer Society. (2015a). Breast cancer facts & figures 2015-2016. Retrieved from <http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-046381.pdf>
- American Cancer Society. (2015b). Cancer facts & figures for Hispanics/Latinos 2015-2017. Retrieved from <http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-046405.pdf>
- Clough-Gorr, K. M., Ganz, P. A., & Silliman, R. A. (2010). Older breast cancer survivors: Factors associated with self-reported symptoms of persistent lymphedema over 7 years of follow-up. *The Breast Journal, 16*(2), 147-155. <http://dx.doi.org/10.1111/j.1524-4741.2009.00878>
- Colby, S. L., & Ortman, J. M. (2014). Projection of the size and composition of the U.S. population: 2014-2060, Current Population Reports, 25-1143. Retrieved from <http://www.census.gov/content/dam/census/library/publications/2015/demo/25-1143.pdf>
- Eversley, R., Estrin, D., Dibble, S., Wardlaw, L., Pedrosa, M., & Favila-Penney, W. (2005). Post-treatment symptoms among ethnic minority breast cancer survivors. *Oncology Nursing Forum, 32* (2), 250-256. doi: 10.1188/05.ONF.250-256
- Fu, M. R., & Rosedale, M. (2009). Breast cancer survivors' experiences of lymphedema-related symptoms. *Journal of Pain and Symptom Management, 38*(6), 849-859. doi: 10.1016/j.jpainsymman.2009.04.030

National Cancer Institute. (2007). Lymphedema after cancer: How serious is it?

Retrieved from <https://www.cancer.gov/about-cancer/treatment/research/lymphedema-after-cancer>

Thomas-MacLean, R., Miedema, B., & Tatemichi, S. R. (2005). Breast cancer-related lymphedema: Women's experiences with an underestimated condition. *Canadian Family Physician, 51*, 246-247. Retrieved from <http://www.cfpc.ca/cfp>

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Appendix A. (Continued)

9/18/2016

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Appendix B. IRB Approval



THE UNIVERSITY OF TEXAS AT TYLER
3900 University Blvd. • Tyler, TX 75799 • 903.565.5774 • FAX: 903.565.5858

Office of Research and
Technology Transfer

Institutional Review Board

December 8, 2015

Dear Juanita Acebedo,

Your request to conduct the study: *Breast Cancer-Related Lymphedema in Hispanic Women: A Phenomenological Study*, IRB #F2015-30 has been approved by The University of Texas at Tyler Institutional Review Board under expedited review. This approval includes the written informed consents that are attached to this letter, and your assurance of participant knowledge of the following prior to study participation: this is a research study; participation is completely voluntary with no obligations to continue participating, and with no adverse consequences for non-participation; and assurance of confidentiality of their data.

In addition, please ensure that any research assistants are knowledgeable about research ethics and confidentiality, and any co-investigators have completed human protection training within the past three years, and have forwarded their certificates to the IRB office (G. Duke).

Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:

- This approval is for one year, as of the date of the approval letter
- **The Progress Report form must be completed for projects extending past one year.** Your protocol will automatically expire on the one year anniversary of this letter if a Progress Report is not submitted, per HHS Regulations **prior** to that date (45 CFR 46.108(b) and 109(e): <http://www.hhs.gov/ohrp/policy/contrev0107.html>)
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity

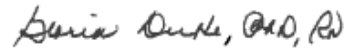
EQUAL OPPORTUNITY EMPLOYER

Appendix B. (Continued)

- **Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others**
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.

Best of luck in your research, and do not hesitate to contact me if you need any further assistance.

Sincerely,



Gloria Duke, PhD, RN
Chair, UT Tyler IRB

EQUAL OPPORTUNITY EMPLOYER

Recruitment Flyer

Attention

Research Study

Seeking: Hispanic women with breast cancer-related lymphedema (swelling in the arm) caused by breast cancer treatment. The study will consist of a one to two-hour interview over the effects of breast cancer-related lymphedema on everyday life activities. If interested in participating in this study, please call the Principal Investigator Juanita Acebedo at 778-0325 or email at jacebedo@patriots.uttyler.edu.

Thank you

Appendix D. Spanish Recruitment Flyer

Letrero Para Recruit

Atención

Un Estudio De Investigación

Se busca: A mujeres Hispánicas con la condición de linfedema (hinchazón) de los brazos causada por los tratamientos de cáncer del seno. Este estudio se llevará por medio de una entrevista de una a dos horas y será sobre los efectos de la linfedema en las actividades diarias. Si está interesada en participar en este estudio, por favor de llamar a la investigadora Juanita Acebedo al número celular 956-778-0325 o al correo electrónico: jacebedo@patriots.uttyler.edu.

Gracias

Appendix E. English Informed Consent

THE UNIVERSITY OF TEXAS AT TYLER

Informed Consent to Participate in Research

Institutional Review Board #F2015-30

Approval Date: December 08, 2015

Project Title: Breast Cancer-Related Lymphedema in Hispanic Women: A
Phenomenology Study

1. Principal Investigator: Juanita C. Acebedo

2. Participant Name:

3. Simple Description of Project Purpose:

You are being asked to be part of this study because you are a Hispanic woman with breast cancer-related lymphedema (arm swelling), a common complication of breast cancer treatments. This study attempts to understand how living with breast cancer-related lymphedema affects Hispanic women.

The research consists of participants completing a questionnaire and have a recorded interview conducted by the researcher. Each session consisting of the questionnaire and interview is between one to two hours. These sessions will be conducted in a private location (participant's home, researcher's office, or a mutually agreed location).

4. Research Procedures: If you agree to be in this study, we will ask you to do the following things:

- a. Meet with the researcher at a time and place that is convenient to you.
- b. Answer a demographic questionnaire
- c. Talk about what it is like to live with breast cancer-related lymphedema.

Appendix E. (Continued)

- d. This interview may last about 90-120 minutes.
- e. Allow your conversations with the researcher to be recorded.
- f. Maybe meet again if more information is needed.

5. Potential Risks:

You may become slightly distressed when discussing your health. Should you become distressed, the researcher will stop the interview. You can choose to take a break and continue, or to stop for the day and re-schedule, or completely withdraw from the study with no problems.

6. Potential Benefits:

There may be no potential benefits to you personally for providing this interview. Some women may feel better after sharing their feelings. Findings from the research may help healthcare providers better understand and care for women with breast cancer-related lymphedema.

Understanding of Participants:

7. I have been given a chance to ask any questions about this research study. The researcher has answered my questions. I understand any and all possible risks.
8. If I sign this consent form I know it means that:
 - I am taking part in this study because I want to. I chose to take part in this study after having been told about the study and how it will affect me.
 - I know that I am free to not be in this study. If I choose to not take part in the study, then nothing will happen to me as a result of my choice.
 - I know that I have been told that if I choose to be in the study, then I can stop at any time. I know that if I do stop being a part of the study, then nothing will happen to me.
9. I have been promised that that my name or other identifying information will not be in any reports (presentations, publications) about this study unless I give my permission. The UT Tyler Institutional Review Board (the group that makes sure

Appendix E. (Continued)

- 10. that research is done correctly and that procedures are in place to protect the safety of research participants) may look at the research documents. This is a part of their monitoring procedure and will be kept confidential.
- 11. If I have any questions concerning my participation in this project, I will contact the principal researcher:
- 12. If I have any questions concerning my rights as a research subject, I will contact Dr. Gloria Duke, Chair of the IRB, at (903) 566-7023, gduke@uttyler.edu.

CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY

I have read and understood what has been explained to me. I give my permission to take part in this study as it is explained to me. I give the study researcher permission to register me in this study. I have received a signed copy of this consent form.

Signature of Participant Date

Witness to Signature

- 13. I have discussed this project with the participant, using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks. I believe the participant understood this explanation.

Researcher/Principal Investigator Date

Appendix F. Spanish Informed Consent

THE UNIVERSITY OF TEXAS AT TYLER

**Consentimiento Informado Para Participar en Investigaciones
Junta de Revisión Institucional #F2015-30**

Fecha de Aprobación: 8 de diciembre 2015

1. **Titulo del Proyecto:** Límfedema relacionada al cancer del seno en mujeres Hispanas: Un Estudio de Fenomenologia
2. **Investigador Principal:** Juanita C. Acebedo
3. **Nombre de la Participante:**
4. **Sencilla Descripción del Propósito del Proyecto:**

Se le está pidiendo que tome parte de éste estudio porque usted es una mujer Hispana con límfedema relacionada al cancer del seno (hinchazon del brazo), una complicación común causada por los tratamientos del cancer del seno. Éste estudio intenta entender como viviendo con la límfedema afecta a la mujer Hispana.

El estudio de investigación consiste de que la participante complete un cuestionario y tenga una entrevista grabada conducida por la investigadora. Cada session consistiendo de el cuestionaria y la entrevista grabada es de una a dos horas. Éstas sesiones se conduciran en una localidad privada (hogar de la participante, oficina de la investigadora, or otro lugar de acuerdo mutuamente).

5. **Procedimientos de la Investigación: Si usted está de acuerdo con éste estudio, se le preguntará lo siguiente:**
 - a. Encontrarse con la investigadora a la hora y lugar que es conveniente con usted.
 - b. Contestar el cuestionario demográfico.
 - c. Hablar tocante cómo es vivir con la condición de la límfedema relacionada al cancer del seno. Esta entrevista puede ser de 90 a 120 minutos.
 - d. Permitir que las conversaciones con la investigadora sean grabadas.

Appendix F. (Continued)

6. Riesgos Potenciales:

Puede ser que se ponga ligeramente angustiada cuando se habla de su salud. Si el caso es que se ponga angustiada, la investigadora terminará la entrevista grabada. Usted puede elegir tomar un periodo de descanso, o puede terminar la entrevista por el día y volver a la entrevista a otro tiempo, o puede completamente retirarse del estudio sin problemas.

7. Beneficios Potenciales:

Puede que no haya ningún beneficio para usted por proveer esta entrevista. Algunas mujeres podrán sentirse mejor después de compartir sus sentimientos. Los resultados de este estudio podrán ayudar a los proveedores de salud entender y cuidar mejor a las mujeres hispanas con linfedema del brazo a causa del cáncer del seno.

Entendimiento de las Participantes:

8. Se me ha dado oportunidad de preguntar cualquier pregunta acerca de este estudio de investigación. La investigadora ha contestado mis preguntas. Yo entiendo todos los posibles riesgos.
9. Si yo firmo este consentimiento, ¿qué quiere decir que:
10. Se me ha prometido que mi nombre o otra información que me indentifica no se usará en ningún reporte (presentaciones, publicaciones) de este estudio a menos que yo de mi permiso. La Junta de Revisión Institucional (el grupo que se encarga de que esta investigación se lleve a cabo correctamente y que los procedimientos estén en lugar para proteger la seguridad de los participantes de investigación) podrán mirar los documentos de investigación. Esto es parte del procedimiento de monitoreo y será confidencial.
11. Si yo tengo alguna pregunta sobre mi participación en este proyecto, yo me pondré en contacto con la investigadora principal.
12. Si yo tengo alguna pregunta sobre mis derechos como participante de investigaciones, yo me comunicaré con la Dr. Gloria Duke, presidente de la Junta de Revisión Institucional, al (903) 566-7023 o al correo electrónico: gduke@uttyler.edu

Appendix F. (Continued)

Consentimiento/Permiso Para Participación en éste estudio de Investigación

He leído y entiendo lo que se me ha explicado. Yo doy mi permiso para participar en éste estudio como se me ha explicado. Le doy mi permiso a la investigadora para registrarme en este estudio. He recibido una copia firmada de esta forma de consentimiento.

Firma de la Participante

Fecha

Testigo de Firma

13. Yo he discutido éste proyecto con la participante, usando lenguaje común y apropiado. Yo creo que ha sido completamente informada en el propósito de éste estudio y sus posibles beneficios y riesgos. Yo creo que la participante entendió ésta explicación.

Investigadora Principal

Fecha

Appendix G. Demographic Questionnaire – English & Spanish

Demographic Questionnaire

(Cuestionario Demográfico)

Study Code Number:

Alias Name (*Nombre*): _____

Contact # (*Numero de contacto*): _____

1. Age (*edad*): _____ Height (*altura*) : _____ Weight (*peso*):

2. Place of birth (*lugar de nacimiento*):

1 U.S born (*Estados Unidos*) 2 Foreign born (*Nacida en el extranjero*)

3. Years in the U.S. (*Años en los Estados Unidos*): _____

4. Hispanic/ Latino Origin (*Origen Hipano/Latino*):

1 Mexico (*México*) 2 Central America (*Centro América*) 3 South

America (*Sur América*) 4 Cuba (*Cuba*)

5 Puerto Rica (*Puerto Rico*) 6 Other (*Otro*): _____

5. English-Speaking ability (*Su habilidad de hablar en inglés*):

1 Well (*bien*) 2 Not well (*no bien*) 3 Not at all (*de ningún modo*)

6. Highest level of education (*El nivel mas alto de educación*):

1 < High school (*menos de preparatoria*) 2 High school graduate or GED

(*Preparatoria o equivalente*) 3 Vocational/some college (*Educación vocacional o*

algun colegio) 4 College or professional degree (*Colegio o título profesional*)

Appendix G. (Continued)

7. Marital status (*estado matrimonial*):

- 1 Not married (*no casada*) 2 Married/Partner (*casada/con pareja*)

8. Employment status:

- 1 Employed (*Empleada*) 2 Not employed (*Sin empleo*)

9. Income (*Ingreso*):

- 1 less than \$10,000 (*menos de \$10,000*)
2 \$10,000 – \$20,000 3 \$21,000 – \$30,000
4 \$31,000 - \$40,000 5 \$41,000 - \$50,000
6 more than \$51,000 (*más de \$51,000*)

10. What type of breast cancer treatment did you have? (select all that apply): *¿Que tipo de tratamiento de cancer del seno tuvo? (seleccione todo que aplica)*

- 1 biopsy (*biopsia*) 2 lumpectomy (*tumorectomía*) 3 partial mastectomy (*mastectomía parcial*)
4 mastectomy (*mastectomía*) 5 radiation (*radación*)
6 chemotherapy (*quimioterapia*) 7 hormone therapy (*terapia hormonal*)
8 other (*otra*): _____

11. Breast that was affected by cancer (*Ceno que fue afectado*):

- 1 Right (*Derecho*) 2 Left (*Izquierdo*) 3 Both (*Los dos*)

12. Dominant arm (*Brazo dominante*) :

- 1 Right (*Derecho*) 2 Left (*Izquierdo*)

Appendix G. (Continued)

13. How soon did you notice any heaviness, swelling, pain, numbness to your arm?

(¿Que tan pronto sintio pesadez, hinchazón, dolor, entumecimiento en el brazo?)

- 1 immediately after surgery (*imediatamente después de la cirugía*)
- 2 1-3 months after surgery (*1 – 3 meses después de la cirugía*)
- 3 4-6 months after surgery (*4 – 6 meses después de la cirugía*)
- 4 7-9 months after surgery (*7 – 9 meses después de la cirugía*)
- 5 more than 9 months after surgery (*más de 9 meses después de la cirugía*)

14. What other chronic health conditions do you have? (*¿De que otra condición crónica padece usted?*)

- 1 Diabetes (diabetes) 2 High blood pressure (alta presión) 3 other (otra): _

Appendix H. Interview Guide – English and Spanish

Interview Guide

Guia de Entrevista

1. Tell me about your arm lymphedema (breast cancer-related); how has it affected your life?

¿Dígame de su linfedema del brazo relacionado al tratamiento del seno de cáncer?

2. How has your arm lymphedema affected your daily activities?

¿Como ha su linfedema del brazo afectado sus actividades diarias?

3. What arm lymphedema self-care practices were given to you by your health care practitioner? And which practices do you perform on a daily basis?

¿Que auto-cuidado personal para la linfedema le dieron sus proveedores de salud? Y cuales practicas hace usted diarias?

4. What information would have helped you better care for yourself?

¿Que información le ha deber ayudado más para cuidarse?

5. Is there anything positive that has occurred because of your arm lymphedema?

Explain.

¿Hay algo positivo que ha ocurrido por su linfedema del brazo? Explicar

6. Is there anything negative that has occurred because of your arm lymphedema?

Explain.

¿Hay algo negativo que ha ocurrido por su linfedema? Explicar.

Appendix H. (Continued)

7. If you're married or have a significant other, how has your condition affected your relationship?
¿Si usted está casada o tiene un significativo, como ha su condición afectado su relación?
8. Follow up question to #7: How has BCRL affected your sexual relationship?
¿Cómo ha la línfedema afectado su relación sexual?
9. How has your arm lymphedema affected your family?
¿Cómo ha su condición de línfedema afectado a su familia?
10. What kind of support system do you have to help you deal with your condition?
Do you feel it is adequate?
¿Que tipo de apoyo tiene usted para que se ayude con su condición? ¿Piensa usted que es adecuado?
11. Is there any information you would like to share that will shed more insight into your life with BCRL?
¿Hay alguna otra información que usted quisiera compartir que daría más perspicacia o revelación hacia su vida con la condición de la línfedema del brazo?

Appendix I. Biographical Sketch

NAME Juanita C. Acebedo	POSITION TITLE Doctoral Candidate, The University of Texas at Tyler Tyler, TX
eRA COMMONS USER NAME (credential, e.g., agency login)	

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	MM/YY	FIELD OF STUDY
Pan American University	ADN	05/87	Nursing
The University of Texas at Brownsville	BSN	05/99	Nursing
The University of Texas at Brownsville	MSN	05/02	Nursing
University of Texas at Tyler	PhD	12/16	Nursing

A. Personal Statement

B. Positions and Employment

2016- Current	BSN Program Lecturer, The University of Texas Rio Grande Valley, Edinburg, TX
2015-2016	Clinical Research Coordinator, Texas Oncology, P.A., Weslaco, TX
2014-2015	BSN Program Lecturer, The University of Texas Pan American, Edinburg, TX
2013-2014	ADN Nursing Instructor, Texas State Technical College, Harlingen, TX
2009-2013	Administrator, MediForce, LLC, Harlingen, TX
2003-2008	Medical Sales Representative, Cardinal Health, Inc., Waukegan, IL

Appendix I. (Continued)

1999-2003	Quality Improvement Coordinator, Valley Baptist Medical Center, Harlingen, TX
1992-1998	Hospice Clinical Manager, Valley Baptist Medical Center, Harlingen, TX
1989-1992	Charge Nurse, Coronary Care Unit, Valley Baptist Medical Center, Harlingen, TX
1988-1989	SICU Staff Nurse, Kuakini Medical Center, Honolulu, HI
1987-1988	ICU Staff Nurse, Knapp Medical Center, Weslaco, TX

C. Professional Memberships

American Nurses Association

Texas Nurses Association

National League for Nurses

Phi Kappa Phi Honor Society

Sigma Theta Tau Honor Society of Nursing

D. Research Support

N/A