

**ENHANCING SELF-EFFICACY:
WILL IT IMPROVE QUALITY OF LIFE AND LYMPHEDEMA
MANAGEMENT
FOR PATIENTS WITH BREAST CANCER RELATED LYMPHEDEMA?**

by

GWEN EVELYN MCGHAN

A Thesis submitted to the
Faculty of Graduate Studies
in Partial Fulfilment of the Requirements for the Degree of

MASTER OF NURSING

Faculty of Nursing
University of Manitoba
Winnipeg, MB Canada

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FACULTY OF GRADUATE STUDIES

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Abstract

Current breast cancer treatments increase life expectancy, but they also affect quality of life. One after-effect of breast cancer treatment is lymphedema. As a chronic, incurable, and sometimes disfiguring condition, the effects of lymphedema take both a physical and psychological toll. The purpose of this pilot study was to examine the impact of enhancing self-efficacy on breast cancer survivors' lymphedema self-management and quality of life. The quantitative data showed the scores for self-efficacy and quality of life trended up from baseline while the reduced level of lymphedema achieved during treatment was maintained. The follow-up focus group revealed three themes, that of the survivor experience, the lymphedema experience, the shared group experience. The results of this study highlight the importance of psychosocial interventions and how they can provide a basis for nurse researchers and clinicians in promoting improved self-management and quality of life for patients with breast cancer related lymphedema.

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Chapter I

Statement of the Problem

For Canadian women, breast cancer is the most common cancer with an estimated 22,300 newly diagnosed cases in 2006 (Canadian Cancer Statistics, 2006). Although breast cancer is the second leading cause of cancer related death in women, with an estimated 5,300 deaths in 2006, mortality rates for breast cancer are declining (Canadian Cancer Statistics, 2006). Current treatments increase life expectancy, but they also affect quality of life, resulting in an increased interest in the sequelae of breast cancer treatments (Bosompra, Ashikaga, O'Brien, Nelson, Skelly & Beatty, 2002; Hack, Cohen, Katz, Robson & Gross, 1999; Muscari, 2004).

One chronic after-effect of breast cancer treatment is lymphedema. The reported incidence rates for lymphedema vary widely with reported rates ranging from 5% to 60% (Hinrichs, Watroba, Rezaishiraz, Giese, Hurd, Fassl et al., 2004; Rampaul, Mullinger, Macmillian, Cid, Holmes, Morgan et al., 2003). This broad range of incidence rates is due in part to how lymphedema is defined, the type of breast cancer therapy provided, and the time since treatment (Erickson, Pearson, Ganz, Adams, & Kahn, 2001). In a review article examining the incidence of lymphedema after breast cancer treatment, Erickson and colleagues (2001) found the overall reported incidence of lymphedema was 26%. In a recent study on sentinel node biopsy versus standard axillary treatment for breast cancer, the researchers found that 12 months after surgery 5% of patients who had sentinel node biopsy and 13% of patients who had standard axillary treatment developed lymphedema (Mansel, Fallowfield, Kissin, Goyal, Newcombe, Dixon, et al., 2006).

Lymphedema is an accumulation of excess water, interstitial fluid, plasma proteins, bacteria, and cellular waste products in the interstitial tissues resulting from impaired clearance of the lymphatic system or an excessive production of lymph (Coward, 1999; Muscari, 2004). As a chronic, multifactorial condition, the effects of lymphedema include more than edema in the affected limb. Other effects known to occur include: pain, altered sensation, impaired function, repeated and persistent infections, fatigue, and limitations in arm range of motion (Armer, Radina, Porock, & Culbertson, 2003). Additional symptoms associated with lymphedema include: discomfort, cramping, heaviness, tightness, aching, paresthesia, and skin dryness of the affected limb (Kligman, Wong, Johnston, & Laetsch, 2004). As an incurable and sometimes disfiguring condition, lymphedema takes both a physical and psychological toll and ultimately affects breast cancers survivors' quality of life (Hack et al., 1999; Muscari, 2004).

The physical changes and psychosocial consequences of lymphedema can result in changes to the person's role within the family, work, and society. This change in status can lead to negative feelings and alterations in body image, sexuality, emotional well-being, and self-perception (Hare, 2000; Muscari, 2004). Despite these consequences, lymphedema has traditionally been viewed as a relatively unimportant and untreatable side effect of life-saving treatment for breast cancer and has been largely ignored by researchers (Bosompra et al., 2002; Morgan, Franks, & Moffatt, 2005; Sitzia & Harlow, 2002). Additionally, lymphedema has historically been viewed as a nonlethal condition and therefore has received less funding and attention compared to other areas

of cancer research (Bosompra et al., 2002) despite its significant impact on a woman's life.

Notwithstanding this historical lack of research, there is now growing evidence that lymphedema is a significant and complex problem that can present considerable challenges to breast cancer survivors (Morgan et al., 2005). Previous studies have shown patient education is of paramount importance for lymphedema prevention and management. Armer and colleagues (2003) found early intervention with acute lymphedema is associated with decreased symptom distress and can reduce the risk of chronic lymphedema. Early intervention and education enables patients to manage lymphedema and take precautions to reduce the risk of exacerbating their condition and to seek care promptly should symptoms develop (Ridner, 2002). Although education is essential to this group of patients, lymphedema research has tended to focus on incidence, prevalence, risk factors, and treatment options with little focus on patients' knowledge level and the practice or intent to practice preventative behaviours (Bosompra et al., 2002). A review of the literature revealed a dearth in the research investigating the direct relationship between educational interventions and lymphedema management. Research on patient education programs targeting the interrelationship between knowledge, current health practices, and intention to practice health-promoting behaviour is limited (Bosompra et al., 2002). There is a need to research factors motivating breast cancer survivors with lymphedema to participate in lymphedema management behaviours, given intention to practice such behaviours is generally low (Bosompra et al., 2002).

Purpose of the Study

To add to the existing body of knowledge about educational interventions for lymphedema, the purpose of this quasi-experimental, prospective study is to explore if an educational intervention to increase knowledge and self-efficacy will influence lymphedema management practices and quality of life in breast cancer survivors with breast cancer related lymphedema.

Research Questions

One month after completing the self-efficacy educational intervention:

- 1) Will women with breast cancer related lymphedema have improved self-efficacy scores?
- 2) Will women with breast cancer related lymphedema have improved quality of life scores?
- 3) Will women with breast cancer related lymphedema maintain the level of lymphedema achieved during the acute lymphedema treatment phase?

Operational Definitions of the Research Variables

The following definitions are for the major concepts examined in this study. The literature review in the following chapter provides further detail and clarification for these concepts.

1. Breast Cancer: A malignant tumor in the glandular tissues of the breast. Breast cancer is not one disease, but rather multiple diseases that vary depending on the location of the cancer, the type of cancer, and the degree of cancerous invasion (Dell, 2005).

2. Breast Cancer Surgery: The two main types of surgery used to treat breast cancer are breast saving surgery (lumpectomy) and breast removing surgery (mastectomy). With both types of surgery, lymph node surgery of either sentinel node biopsy or axillary node dissection may be performed (Dell, 2005).
3. Lymphedema: An imbalance between capillary filtration and lymph drainage and results from the failure of lymph drainage when capillary filtration is not increased (Mortimer, 1998). The Comparative Circumferential Measurement Method (Brown, 2004) will be used to assess the degree of lymphedema.
4. Self-efficacy: People's belief in their ability to accomplish set tasks (Bandura, 1997). Self-efficacy will be measured by Strategies Used by People to Promote Health, a self-report instrument (Lev & Owen, 1996).
5. Quality of Life: A complex, multidimensional concept that includes the general overall well-being in a person's physical and psychological life, a satisfaction with current life situations and is dynamic in nature (Haas, 1999; Mast, 1995; Meeberg, 1993). To measure quality of life, the Functional Analysis of Cancer Treatment-Breast+4, a self-report measurement tool will be used (Coster, Poole, & Fallowfield, 2001).

Significance of the Study

The results of this pilot study will contribute to the oncology nursing literature by testing a nursing intervention using Bandura's (1997) self-efficacy theory as a framework. Oncology nurses and clinical nurse specialists are in an ideal situation to influence the self-efficacy of breast cancer survivors. By encouraging patients to adopt and perform self-care strategies, nurses can help patients set realistic and attainable goals

for self-care and provide appropriate guidance where necessary. The significance of this study is to highlight the importance of psychosocial educational interventions and how they can provide a basis for nurse researchers and clinicians in promoting health and quality of life for breast cancer survivors with lymphedema.

Chapter II

Review of the Literature

Introduction

To examine the current state of knowledge relevant to breast cancer related lymphedema and its relationship with self-efficacy and quality of life, a review of the literature was conducted. The literature review included different search engines such as CINAHL and MEDLINE. In using MEDLINE, the MeSH term “lymphedema” was combined with other MeSH terms of “breast cancer”, “breast cancer treatment”, “incidence”, and “quality of life”. Upon finding relevant studies, the reference lists were then searched to further expand the quest for information. The result of this review is organized into the following sections: Breast Cancer; Breast Cancer Surgery; Lymphedema; Self-efficacy; and Quality of Life. The discussion will now turn to a more detailed examination of each of the above topics.

Breast Cancer

For Canadian women, breast cancer is the most common cancer with an estimated 22,300 newly diagnosed cases in 2006 (Canadian Cancer Statistics, 2006). One in nine Canadian women are expected to develop breast cancer during their lifetime (Canadian Cancer Statistics, 2006). Although breast cancer is the second leading cause of cancer related death in women, with an estimated 5,300 deaths in 2006, mortality rates for breast cancer are declining (Canadian Cancer Statistics, 2006).

Breast cancer is not one disease, but rather multiple diseases that differ in histological, biological, and immunologic characteristics (Chapman & Goodman, 2000). Breast cancer can vary depending on the location, type, and degree of cancerous invasion

(Dell, 2005). Most types of breast cancer affect the milk ducts or the lobules where milk is produced. In situ breast cancers are confined to the duct or lobule. Invasive cancers extend into the breast tissue and have the ability to metastasize (Dell, 2005).

Breast cancer is identified according to which structures are affected and staged according to size and invasiveness. The following is one type of breast cancer staging broken down into tumor size, lymph node involvement, and metastasis.

Table 2.1 Breast Cancer Staging

Stage	Tumor Size	Lymph node involvement	Metastasis
I	≤ 2cm	None	No
II	A: < 2 cm B: 2-5 cm C: > 5 cm	A: Same side as breast and movable B: None, or same side as breast and movable C: None	No
III	A: < 5 cm OR > 5cm B: Any size with extension to chest wall or skin, or inflammatory type C: Any size	A: Same side as breast and fixed, or same side internal mammary nodes Same side as breast and movable or fixed, or internal mammary nodes B: Any nodes or none C: Same-side infraclavicular or internal mammary and axillary nodes	No
IV	Any size	Any nodes	Yes

Identifying and Staging Breast Cancer (Adapted from Dell, 2005)

Another form of pathological staging of breast cancer is that recommended by the American Joint Committee on Cancer (AJCC). The most critical components for staging breast cancer in this system are whether any lymph nodes are involved and whether distant metastases are known to be present. The following is a simplified version of the AJCC pathological staging (Chapman & Goodman, 2000):

- | | |
|-----------|---|
| Stage I | Tumor 0-2 cm in size; negative lymph nodes and no evidence of metastasis |
| Stage II | Small tumor with positive lymph nodes or a larger tumor with negative lymph nodes |
| Stage III | More advanced locoregional disease with suspected but undetectable metastases |
| Stage IV | Distant metastases are present |

Once a breast cancer diagnosis has been made, the staging of the disease is conducted to establish the most appropriate approach to treatment (Chapman & Goodman, 2000). Treatment for breast cancer varies depending on the stage and can include surgery, radiation, chemotherapy, and hormonal therapy (Love, 2000). As breast cancer treatment has been shown to be associated with lymphedema, particularly axillary node dissection, the discussion will now turn to breast cancer surgery.

Breast Cancer Surgery

The goal of surgery in the breast is to remove or treat the cancer so it does not return to the breast (Love, 2000). There are two main types of surgery used to treat breast cancer; breast saving surgery (or lumpectomy) and breast removing surgery (or

mastectomy). In a lumpectomy only the tumor and surrounding margin of normal tissue is removed (Dell, 2005). In a mastectomy the entire breast including the nipple and area around the nipple are removed. There are three different types of mastectomy: 1) the simple or total mastectomy in which the entire breast is removed without any lymph node dissection; 2) the modified radical mastectomy in which the breast and axillary lymph nodes are removed; and 3) the radical mastectomy in which the breast, axillary lymph nodes and chest muscle under the breast are removed (Dell, 2005). The radical mastectomy was performed more frequently in the past, but is rarely performed today. With both lumpectomy and mastectomy, sentinel lymph node biopsy and axillary node dissection may be performed.

Axillary node dissection remains the standard approach for the surgical management of women with invasive breast cancer (Armer, Fu, Wainstock, Zagar, & Jacobs, 2004) and refers to the complete removal of 10-30 axillary lymph nodes with the goals of obtaining information key for diagnosis, staging of the cancer, recommending therapy for control of local disease, and determining prognosis (Armer et al., 2004; Pressman, 1998; Ronka, von Smitten, Tasmuth & Leidenius, 2005; Schrenk, Rieger, Shamiyeh & Wayand, 2000). The most important purpose of axillary node dissection is its near perfect ability to determine the histologic node status of the axilla in women with newly diagnosed, minimal breast cancer and is the reason it remains the gold standard of treatment (Zack, 2001). However, routine performance of axillary node dissection has been considered to expose a large number of breast cancer survivors, particularly those with node-negative disease, to potentially unnecessary complications and increased risk for breast cancer related lymphedema and its related signs and symptoms (Armer et al.,

2004; Haid, Koberle-Wuhrer, Knauer, Burtscher, Fritzsche, Peschina et al., 2002; Leidenius, Leivonen, Vironen, & von Smitten, 2005). In addition to symptoms such as discomfort, numbness, and pain, lymphedema remains the major morbidity resulting from axillary node dissection with incidence rates reported as high as 60% when combined with axillary radiation (Hinrichs et al., 2004; Powell, Taghian, Kachnic, Coen, & Assaad, 2003) and the most feared outcome of breast cancer treatment after cancer recurrence (Armer et al., 2004).

For these reasons, over the last decade, sentinel lymph node biopsy has increasingly been performed as an alternative to axillary node dissection as part of diagnosis, staging, and treatment for breast cancer (Armer et al., 2004; Baron, Fey, Borgen, & van Zee, 2004; Burak, Hollenback, Zervos, Hock, Kemp & Young; Veronesi, Paganelli, Viale, Luini, Zurrada, Galimberti et al., 2003). Sentinel lymph node biopsy is a less invasive approach to diagnosing lymph node metastases in breast cancer by mapping the lymphatic route of tumour cells to the first draining lymph node(s). A sentinel lymph node is defined as the first lymph node(s) most likely to drain the primary tumour in a regional lymphatic basin, and thus the first site of metastasis (Armer et al., 2004; Ronka et al., 2005; Veronesi et al., 2003). In a seminal study, sentinel lymph node biopsy was introduced by Giuliano, Jones, and Guenther (1994) as a technique, using blue dye, for mapping the axilla lymphatic system in breast cancer patients with the purpose of identifying the sentinel node. Since that time, various techniques have been used in sentinel lymph node biopsy to identify the sentinel node, including gamma probe-guided and/or dye guided methods with or without lymphoscintigraphy (Ronka et al., 2005; Schijven, Vingerhoets, Rutten, Nieuwenhuijzen, Roumen, van Bussel et al., 2003;

Schrenk et al., 2000). Due to its technique, sentinel lymph node biopsy generally requires less invasive surgery and, if successful, allows accurate staging and avoids unnecessary axillary node dissection (Haid et al., 2002; Ronka et al., 2005; Veronesi et al., 2003). Sentinel lymph node biopsy is thought to minimize morbidity associated with axillary node dissection, such as pain, numbness, and acute and chronic lymphedema. Previously, concern has been expressed about sentinel lymph node biopsy not being as accurate as axillary node dissection for diagnosing and staging breast cancer (Krag & Ashikaga, 2003). However, a study on sentinel lymph node biopsy as an alternative to axillary node dissection found sentinel lymph node biopsy is associated with a 1% - 5% false negative rate (Nwariaku, Euhus, Beitsch, Clifford, Erdman & Mathews, 1998). Another study comparing the diagnostic findings of sentinel lymph node biopsy with axillary node dissection in the same group of patients found that sentinel lymph node biopsy successfully revealed axillary lymph node status with 97% accuracy (Krag, 1999). In a literature review of sentinel lymph node biopsy accuracy, the axillary lymph node status of nearly 2000 patients was accurately defined in 95% - 100% of the cases (Hsueh, Turner, Glass, Brenner, Brennan & Guiliano, 1999).

In addition to the accuracy of sentinel lymph node biopsy, the incidence of breast cancer related lymphedema has also been investigated. Breast cancer related lymphedema varies greatly among different studies. In a comprehensive review of the literature, it was found the incidence of breast cancer related lymphedema ranged from 6% to 30% (Petrek & Heelan, 1998). The review noted the study with the shortest follow-up (12 months) reported the lowest incidence (6%); while the study with the longest follow-up (11 years) reported the highest incidence (30%). Comparisons of

breast cancer related lymphedema across studies have been complicated by the differences in the definition of lymphedema, differences in measurement techniques, type of breast cancer treatment, study patient criteria, length of study follow-up, and interval between breast cancer treatment and measurement (Loudon & Petrek, 2000; Petrek, Senie, Peters & Rosen, 2001). Other methodological problems with breast cancer related lymphedema incidence studies are the studies are usually retrospective, have relatively small sample sizes, and often come from a single institution, which can undermine the internal and external validity of the studies.

Accounting for these methodological limitations, studies comparing sentinel lymph node biopsy and axillary node dissection were analyzed. In a study examining morbidity after sentinel lymph node biopsy, it was found that patients undergoing this surgical intervention experienced significantly less breast cancer related lymphedema than patients receiving axillary node dissection (Purushotham, Upponi, Klevesath, Bobrow, Millar, Myles, et al., 2005). The study performed pre-operative measurements on both arms to control for this confounding variable and conducted a randomized controlled trial to determine the treatment effect of sentinel lymph node biopsy. Limitations to the study were the large number of study versus control comparisons and the inability to double-blind due to the surgical nature of the intervention. The strengths of the study were it addressed a specific clinical question (physical and psychological morbidity after sentinel lymph node biopsy) and used an appropriate design to examine this question. Temple and colleagues (2002) compared breast cancer related lymphedema experienced by patients after sentinel lymph node biopsy versus axillary node dissection in a prospective study over a 12-month period using a validated

measurement tool. The study concluded women undergoing sentinel lymph node biopsy had significantly less sensory morbidity and lymphedema than women undergoing axillary node dissection. One of the strengths of the study was the measurement design; arm measurements were performed before and at consistent intervals after surgery. The limitations of this study are the short length of follow-up and the sample was not reflective of the target population; women with breast cancer at risk for developing lymphedema. In yet another study comparing morbidity between axillary node dissection and sentinel lymph node biopsy, the researchers found women undergoing sentinel lymph node biopsy had a 5-fold lower risk of developing lymphedema than women undergoing axillary node dissection (Schijven et al., 2003). However, bias was introduced into this study because it was retrospective, used different historical cohorts for the sentinel lymph node biopsy and axillary node dissection groups, and did not consistently measure lymphedema. The strength of the study was the similarity between the two groups in patient characteristics such as stage of breast cancer, time since surgery, and radiation therapy. Other studies also support the contention that sentinel lymph node biopsy decreases the incidence of breast cancer related lymphedema. Schrenk and colleagues (2000) evaluated patients 4-28 months after surgery and found a significantly higher rate of subjective lymphedema, pain, and numbness in patients after axillary node dissection compared with sentinel lymph node biopsy. In a retrospective study, Haid and colleagues (2002) found patients who had undergone axillary node dissection had significantly more pain, numbness, and lymphedema than patients who had undergone sentinel lymph node biopsy. Ronka and colleagues (2005) evaluated the one-year morbidity after sentinel

lymph node biopsy and axillary node dissection and concluded risk of severe lymphedema after sentinel lymph node biopsy is only minimal.

Recently, the results of the first large prospective randomized controlled trial comparing sentinel lymph node biopsy to axillary node dissection, including repeated quality of life assessments, were published. The trial called the Axillary Lymphatic Mapping Against Nodal Axillary Clearance (ALMANAC), randomly assigned 1031 patients to undergo either sentinel lymph node biopsy or axillary node dissection (Mansel, Fallowfield, Kissin, Goyal, Newcombe, Dixon et al., 2006). Due to large differences between the sentinel lymph node biopsy and axillary node dissection groups, the Steering Committee for the ALMANAC trial decided the trial should be terminated early (Mansel et al., 2006). The resulting conclusion from the trial was that sentinel lymph node biopsy is associated with decreased arm morbidity, including lymphedema, and for patients with early-stage breast cancer with negative nodes, should become the treatment of choice (Mansel et al., 2006).

The trend of linking sentinel lymph node biopsy to evidence of lower arm morbidity, as supported by the ALMANAC trial, appears well established in the literature. Studies comparing sentinel lymph node biopsy to axillary node dissection support the conclusion that axillary node dissection does consistently and significantly increase the incidence of lymphedema and arm morbidity compared to sentinel lymph node biopsy. The promise of sentinel lymph node biopsy decreasing the incidence of breast cancer related lymphedema is an important finding given lymphedema's tremendous physical and psychological toll on breast cancer survivors with the condition.

Lymphedema

Lymphedema is due to the imbalance between capillary filtration and lymph drainage and results from the failure of lymph drainage when capillary filtration is not increased (Mortimer, 1998). During breast cancer treatment, damage to the lymphatic system may occur due to surgery, radiation, or infection (Pain & Purushotham, 2000). Surgical removal of lymph nodes and breast tissue obstructs the lymphatic circulation while radiation damages the lymph nodes resulting in fibrosis of the nodes, which over time prevents the passage and filtration of lymph. Finally, infection in the affected area may cause fibrosis, which may occlude lymph vessels. As a result of the damage caused by these sources, the lymphatic system is unable to transport the normal amount of fluid and proteins from the affected area and is posited to be the primary reason why lymphedema occurs after breast cancer treatment (Ridner, 2002).

However, the etiology of breast cancer related lymphedema is not fully known, and contributing factors have not been thoroughly studied (Loudon & Petrek, 2000). Breast cancer related lymphedema is thought to be associated with a range of factors, primarily those causing trauma to the lymphatic system. Studies have shown that lymphedema rates for combined axillary radiation and axillary node dissection are higher than rates for axillary surgery without radiation (Goffman, Laronga, Wilson, & Elkins, 2004; Hinrichs et al., 2004; Powell et al., 2004). Rampaul and colleagues (2003) reported that approximately 25% of patients who had undergone axillary node dissection developed lymphedema, with this number increasing to 38% for those who had undergone axillary node dissection plus radiation therapy. In addition to axillary radiation, research has also shown that number of axillary nodes removed increases the

risk for developing lymphedema (Herd-Smith, Russo, Grazia Muraca, Rossell Del Turco & Cardona, 2001; Mansel et al., 2006). The type of surgical procedure performed has also been found to increase breast cancer related lymphedema incidence (Haid et al., 2002; Leidenius et al., 2005; Ronka, von Smitten et al., 2005; Schijven et al., 2003; Schrenk et al., 2000; Veronesi et al., 2003).

Regardless of the cause, stasis of the lymph combined with the impaired clearance of the area devoid of lymph nodes permits persistent swelling in the affected limb (Sitzia & Harlow, 2002). The build-up of interstitial macromolecules leads to fibrosis and provides an excellent medium for repeated episodes of lymphangitis and cellulitis (Petrek, Pressman, & Smith, 2000). These chronic inflammations lead to further fibrosis and impairment of the affected limb. Lymphedema results from the functional overload of the lymphatic system in which lymph volume exceeds transport capabilities (Petrek et al., 2000) and is diagnosed according to various factors. Three physical measures of lymphedema are available, including circumferential measures at various points along the affected limb, volumetric measures using limb submersion in fluid, and skin/soft tissues tonometry in which soft tissue compression is quantified (Petrek et al., 2000). The first measurement technique is circumferential measurements, which is the most frequently used method in quantifying lymphedema (Gerber, 1998). In this technique, a tape measure is used to determine hand and arm circumference at designated and corresponding landmarks along the affected and unaffected limbs. Bony landmarks such as the ulnar styloid, olecranon, and metacarpal phalangeal joints are used and the difference at each point is calculated, and then the sums of the differences are added together to determine the degree of lymphedema (Brown, 2004; Gerber, 1998). Increases

in arm circumference in the affected limb of greater than 2 centimetres over the opposite limb as well as tissue texture, presence or absence of fibrosis, oozing of fluid through the skin, and the report of limb decongestion when elevated contribute to a diagnosis (Meek, 1998). Measurements in this technique can vary according to the degree to which the tape constricts the soft tissue (Petrek et al., 2000) or using landmarks that are not equidistant (Gerber, 1998).

The second measurement technique is the Water Displacement Method. In this technique lymphedema is measured by submerging the affected limb in a tank of water; the water displaced is measured to determine the volume of the limb (Brown, 2004). Measurement of the arm volume by water displacement is accurate and results in a single value, but until recently with the ALMANAC trial, the technique has been infrequently employed (Petrek et al., 2000). The third type of measurement is that of tissue tonometer. In this measurement technique, the amount of pressure necessary to depress the skin a specified amount is calculated. The degree of compressibility has been correlated with circumference and thus with the amount of lymphedema (Gerber, 1998). The difficulty with this measurement is the lack of standardized procedure. Other methods for quantitative measurement of soft tissue edema are still experimental and include dichromatic differential absorption, CT scanning, MRI, ultrasound, and optoelectronic scanning (Gerber, 1998; Petrek et al., 2000). The lack of standard measurement protocols, reliability and validity studies, and uniform definition contributes to the dilemma of accurate measures and limits the diagnosis of lymphedema (Armer et al., 2003).

Compounding the difficulty in diagnosing lymphedema, is although 75% of cases occur within the first year after radiation or surgery (Pain & Purushotham, 2000), lymphedema can begin insidiously at any time after axillary treatment for breast cancer. The swelling may range in severity from mild and barely noticeable in the early stages to extreme in later stages, causing a seriously disabling enlargement of the affected limb (Petrek et al., 2000). To help with diagnosis, lymphedema can be categorized as mild, moderate, or severe and staged as Grade I to Grade III (Armer & Fu, 2005). The grades of lymphedema can be categorized as follows: Grade I lymphedema involves soft-pitting edema that reduces with elevation and is without clinical fibrosis; Grade II lymphedema involves non-pitting edema that does not reduce with elevation and demonstrates the presence of fibrosis; Grade III lymphedema involves edema with hardening and hypertrophy of the subcutaneous tissues as well as thickening and changes in the skin (Howell & Watson, 2005).

Treatment for lymphedema is essential because, if left untreated, it has been found to have a significant tendency to increase with time, both in the volume of edema and in stage of tissue fibrosis (McNeely, Magee, Lees, Bagnall, Haykowsky, & Hanson, 2004). Conservative treatment for lymphedema may include complete decongestive therapy (CDT) with manual lymph drainage (MLD) alone or in combination with compression dressing therapy. CDT has two phases, the treatment and maintenance phase. Phase I, or the treatment phase, lasts between one to four weeks with the length of treatment depending on the amount of edema and volume reduction in the affected limb. The treatment phase involves sixty to ninety minute MLD sessions that are accompanied by patient education about skin care and exercise (Muscari, 2004). Immediately following

the MLD, a multilayer low stretch dressing is applied to the limb, which is wrapped from the fingertips to the axilla with the dressing remaining in place until the next day (Muscari, 2004; Petrek et al., 2000). Once the maximum amount of volume reduction is achieved, Phase II or the maintenance phase begins with the goal of maintaining the volume reduction through the use of compression, exercises, and skin care. The maintenance phase is continued indefinitely or until the limb no longer swells (Petrek et al., 2000).

As lymphedema is a chronic, life-long condition, the activities and self-care behaviours the patient needs to engage in with regularity to maintain and continue limb decongestion are ongoing. The tools for maintaining volume reduction include wearing a compression garment daily, bandaging at night, exercise, and self-MLD massage (Muscari, 2004). The goals for lymphedema management are to decrease the swelling, relieve the stress of related physical and psychological symptoms, and to prevent exacerbations and infections (Fu, 2005). The management of lymphedema often requires significant lifestyle changes on the part of patients and families, which is one reason why it can be so challenging to manage. Compounding the challenge of managing lymphedema is the critical importance of adherence to daily care, which has been identified as the most important factor in lymphedema management (Fu, 2005). Patient education to enhance knowledge and self-efficacy is thought to be beneficial in lymphedema management as the ongoing care of the condition falls to patients and their families (Lev, Daley, Conner, Reith, Fernandez, & Owen, 2001).

Self-efficacy

Self-efficacy is people's belief in their ability to accomplish set tasks (Bandura, 1997). Bandura (1997) contends, "people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true" (p. 2). Perceived self-efficacy mediates health behaviours because people must believe they can master and adhere to health-promoting habits before they will devote the time and effort necessary to achieve success (Bandura, 1997; Lev et al., 2001). Previous studies have investigated the impact of self-efficacy on health promoting behaviours and have shown that self-efficacy does not change in the absence of targeted interventions and that understanding patients' self-management behaviours is improved after accounting for self-efficacy perceptions (Lev et al., 2001). In a review article using self-efficacy theory to investigate prevention and adaptation to cancer, Lev (1997) found that increased self-efficacy has a positive impact on health promoting behaviours, such as increased adherence to treatment and self-care behaviours, and decreases in physical and psychological symptoms. The review also found that perceived self-efficacy predicted intention to quit smoking and increased patients' participation in cancer screening programs (Lev, 1997).

Other studies have also demonstrated increased participation in health promotion when self-efficacy is increased (Haas, 2000; Lev & Owen, 2000; Tsay, 2003). In addition to health promoting behaviours, studies have also examined self-efficacy in the context of people with chronic illness. For chronic illness, the physiological and psychological symptoms cannot be completely relieved, however interventions that are effective in increasing confidence for managing the illness are linked to improving self-

efficacy expectations (Tsay, 2003). There is now a growing body of literature suggesting that self-efficacy exerts a causal influence on behaviour (Bandura, 1997). A study investigating patients with end-stage renal disease found patients who received a nursing intervention to increase self-efficacy for controlling mean body weight gains, had significantly increased treatment compliance (Tsay, 2003). Numerous strategies for enhancing self-efficacy in diabetes were examined in a review article, which concluded that patients with high self-efficacy show more compliance with regard to their self-management than patients with low self-efficacy (van de Laar & van der Bijl, 2001). Focussing on disease management, Clark and Dodge (1999) explored self-efficacy as a predictor for patients with heart disease and concluded that enhancing self-efficacy is an important intervention for improving heart disease management behaviours. In another study of patients with chronic illness, the investigators concluded that enhancing self-efficacy improves patients' quality of life and argue that increasing patients' perceptions of self-efficacy can help patients maintain a positive outlook and function at their best within the context of their illness (Krick & Nazaroff, 2000).

Another patient population in which investigators have examined self-efficacy is oncology patients. In a study of self-efficacy and patients' adjustment to cancer, it was found that without a self-efficacy enhancing intervention, indicators of self-efficacy and adjustment to cancer decreased over time and that patients' self-efficacy beliefs directly influenced adjustment (Lev, Paul, & Owen, 1999). In their study on women with breast cancer, Lev and Owen (2000) concluded that self-efficacy has a major impact on adjustment to illness and health practices. A study designed to test a nursing intervention to increase quality of life and self-efficacy for breast cancer patients receiving

chemotherapy found that patients who received the efficacy enhancing intervention had significantly higher quality of life and self-efficacy scores than patients who did not receive the intervention (Lev et al., 2001). Another study on self-efficacy and oncology patients' motivations and expectations found a positive relationship between levels of self-efficacy and patients' beliefs in their ability to change or improve their coping strategies (Edgar & Watt, 2004). Evidence from the above studies examining self-efficacy suggests that a positive relationship exists between increased self-efficacy and improved health promotion outcomes for various patient populations including people with chronic conditions, such as lymphedema.

Quality of Life

For the purposes of this study, quality of life (QOL), a complex, multidimensional concept, is the general overall well-being in a person's physical and psychological life, a satisfaction with current life situations and is dynamic in nature (Haas, 1999; Mast, 1995; Meeberg, 1993). Lymphedema affects breast cancers survivors' quality of life (Hack et al., 1999; Fleissig, Fallowfield, Langridge, Johnson, Newcombe, Dixon, et al., 2006; Fu, 2005; Muscari, 2004; Woods, 1995). Women with lymphedema have greater psychiatric morbidity and greater functional disability than breast cancer survivors without lymphedema (Harris, Hugi, Olivotto, & Levine, 2001). Studies on QOL and lymphedema show patients with lymphedema demonstrate poorer psychological adjustment, greater functional impairment, and increased anxiety when compared to patients without lymphedema (Moffatt, Franks, Doherty, Williams, Badger, Jeffs, et al., 2003; Morgan et al., 2005; Tobin, Hubert, Meyer, & Mortimer, 1993). The physical changes and psychosocial consequences of lymphedema can result in changes to the

person's role within the family, work, and society. This change in status can lead to negative feelings and alterations in body image, sexuality, emotional well-being, and self-perception (Hare, 2000; Muscari, 2004). Despite these consequences, lymphedema has traditionally been viewed as a relatively unimportant and untreatable side effect of life-saving treatment for breast cancer and has been largely ignored by researchers (Morgan et al., 2005). Although there has been a historical lack of research, there is now growing evidence that lymphedema is a significant and complex problem that can present considerable challenges to a person's QOL (Morgan et al., 2005). The growing importance of measuring QOL can be evidenced by the National Cancer Institute of Canada's policy requiring health-related QOL be incorporated into every randomized controlled trial unless there is a stated reason in the protocol outlining why measuring QOL would not be appropriate (Osoba, 2002).

A study examining the psychosocial factors in lymphedema found that for many women the appearance of lymphedema had been unexpected and rapid, generating feelings of fear, anger, and disappointment (Woods, 1995). In examining the lived experience of lymphedema, women discuss the frustration they feel in the lack of available information about lymphedema including both the risks and continuing consequences (Carter, 1997; Hare, 2000). In examining the lived experience of lymphedema, women with the condition expressed frustration about the lack of information received at the time of diagnosis, which continued as the disease and treatment progressed (Hare, 2000). Compounding this frustration, women with lymphedema also experience a great sense of loss and stigmatization.

Another important theme is the disruption lymphedema and its treatment can cause to the social, emotional, and working lives of sufferers and the challenges it can place on relationships with families (Moffatt et al., 2003; Paskett & Stark, 2000). Some women find coping with lymphedema more distressing than coping with the cancer diagnosis (Carter, 1997). This seems to corroborate with Paskett and Stark's (2000) findings that women found coping with lymphedema made them irritable and viewed the condition as a constant reminder of being a cancer patient, which impeded their psychological recovery.

Summary

A review of the literature shows the tremendous physical and psychological toll lymphedema can take on breast cancer survivors with the condition. However, few studies have investigated the direct relationship between self-efficacy training and lymphedema symptom management. Research into the factors motivating breast cancer survivors to participate in lymphedema management behaviours is needed given intention to practice such behaviours is generally low (Bosompra et al., 2002). One way to improve intention to practice health-promoting behaviours is through enhancing self-efficacy. Patients with increased self-efficacy are more likely to engage in self-care activities and adhere to treatment regimes (Tsay, 2003). Patients' confidence in their ability to perform a task, that is their perceived self-efficacy, has a major impact on the performance of health-promoting behaviours (Lev & Owen, 2000).

Chapter III

Theoretical Framework

Introduction

Theory can be defined as “a set of interrelated relational statements about a phenomenon that is useful for description, explanation, prediction, and prescription” (Walker & Avant, 2005, p. 160). Theory analysis is the process of systematically examining a theory by appraising the theory’s origins, meaning, logical adequacy, usefulness, generalizability, and testability (Walker & Avant, 2005). The systematic process of the analysis refers to objectively examining the content, structure, and function of a theory, which results in a non-judgemental and detailed examination of a theory (Fawcett, 2000; Walker & Avant, 2005). As the primary purposes in theory analysis are to understand and draw attention to the strengths and weaknesses of a theory, it provides a way of examining a theory that may lead to new and undiscovered insights and formulations (McEwen, 2002; Walker & Avant, 2005). Theory analysis highlights applicable theories for nursing which help guide efficacious nursing interventions. The ultimate goal of theory analysis is to determine the theory’s potential to contribute to scientific knowledge (McEwen, 2002), specifically nursing knowledge.

The theory that will be analyzed and used to guide this pilot study is Bandura’s (1977, 1997) Self-efficacy Theory (SET), which is a component of Bandura’s (1986) Social Cognitive Theory (SCT). In SCT human functioning is viewed as the product of the relationship between personal, behavioural, and environmental factors (Bandura, 1986). Triadic reciprocity is the dynamic and bi-directional interplay between these three factors and the interactions that result (see Appendix A). In this theory how people

interpret the results of their behaviour informs and alters their environment and the personal factors they possess, which in turn, informs and alters their subsequent behaviours (Bandura, 1986; Pajares, 2002). To better understand the personal factors in triadic reciprocity, Bandura (1977, 1997) developed SET in which self-efficacy beliefs provide the foundation for human motivation, well-being, and personal accomplishment.

To gain a better understanding of SET's potential to provide the framework for developing a nursing intervention for patients with breast cancer related lymphedema, and to determine its potential contribution to nursing knowledge, a theory analysis will be conducted. As theory analysis is an objective and systematic examination of a theory, several frameworks have been developed to assist in the process (Chinn & Kramer, 2004; Fawcett, 2000; Walker & Avant, 2005). For this analysis, Walker and Avant's (2005) theory analysis framework will be utilized. This framework utilizes six steps that will form the basis for the theory analysis and are as follow: (1) identify the origins of the theory, (2) examine the meaning of the theory, (3) analyze the logical adequacy of the theory, (4) determine the usefulness of the theory, (5) define the degree of the generalizability and parsimony of the theory, and (6) determine the testability of the theory (Walker & Avant, 2005).

Theory Origins

According to Walker and Avant (2005), the first step in theory analysis is to determine the origins of the theory because this helps the analyst understand how and why the theory was developed. Bandura's (1977, 1986, 1997) concept of self-efficacy within the framework Social Cognitive Theory will be analyzed. Previously there has been debate about whether self-efficacy is a concept or a theory (Pajares, 2002), however

for the purpose of this analysis self-efficacy will be considered a theory. To begin the theory analysis, this section will explore what prompted the theory's development, the purpose of the theory, and finally the underlying assumptions of the theory.

Theory Development

Walker and Avant (2005) contend that if a theory is developed from another theory, it is deductive in origin. Therefore, Social Cognitive Theory (SCT) is deductive in origin in that it has its origins in Social Learning Theory (SLT). In 1941, Miller and Dollard published *Social Learning and Imitation*, which marked the official beginning of SLT (Pajares, 2002). Miller and Dollard's (1941) SLT incorporated four key principles of learning: reinforcement, punishment, extinction, and imitation of models. The theory's purpose was to explain how animals and humans model observed behaviours, which were then learned through environmental reinforcement. However, SLT failed to account for the creation of novel responses or the processes of delayed and nonreinforced imitations (Pajares, 2002). To broaden the focus of SLT, Bandura and Walters wrote *Social Learning and Personality Development* in 1963. Bandura and Walters (1963) introduced the principles of observational learning and vicarious reinforcement. As the theory progressed, Bandura (1977) wanted to reconcile the divergence between theory and practice by demonstrating that behavioural change can arise from more than just mastery of experience. To explain how behaviour change can be accomplished through different modalities, Bandura (1977, 1997) proposed the concept of self-efficacy. Self-efficacy is derived from four principal sources: performance accomplishments, vicarious experience, verbal persuasion, and physiological / emotional states (see Appendix B).

After his pioneering work on self-efficacy, Bandura published *Social Foundations of Thought and Action: A Social Cognitive Theory* in 1986. Bandura changed the name from SLT to SCT to better distance himself from the prevalent social learning theories and to emphasize the critical role cognition plays in learning (Pajares, 2002). SCT advanced a view of human functioning, which accords a central role to cognitive, vicarious learning, self-regulatory and self-reflective processes in human adaptation, and change (Bandura, 1986). In SCT, people are considered proactive and self-regulating rather than just organisms that react to external environmental stimuli or unconscious inner impulses (Bandura, 1986; Pajares, 2002). SCT views human functioning as a product of the dynamic interplay between personal, behavioural, and environmental factors. The interplay between these three factors is the foundation of Bandura's (1986) conception of triadic reciprocity. Triadic reciprocity is the view that personal (in the form of cognitive, affective, and biological events), behavioural, and environmental factors produce a bi-directional interplay that varies behavioural outcomes (Pajares, 2002) (see Appendix A).

As SCT evolved, self-efficacy theory (SET) emerged to help explain and predict the personal factors of triadic reciprocity (Maddux, 1995). SET examines the effect of cognition on affect, behaviour, and environmental factors and their impact on behaviour. SET maintains that all processes of psychological and behavioural change operate through the alteration of the individual's sense of personal mastery or self-efficacy (Bandura, 1977, 1986, 1995, 1997). Self-efficacy is referred to by different terms, such as self-efficacy expectancies, self-efficacy beliefs, efficacy expectations, and efficacy beliefs. For the purposes of this analysis, the terms self-efficacy and self-efficacy beliefs

will be used. Self-efficacy beliefs are viewed as varying along the three dimensions of magnitude, strength, and generality and are influenced by four principal sources: performance accomplishments, vicarious experiences, verbal persuasion, and physiological and emotional states (Bandura, 1977, 1997). Self-efficacy and outcome expectations (the expectation of success), characteristics of a person, his/her behaviour, and the outcome of that behaviour form the basis Bandura's model of SET (see Appendix C).

Purpose of the Theory

SCT evolved from SLT to address the idea that people are capable of self-reflection and self-regulation and that individuals are active shapers of their environment rather than simply passive reactors to the environment (Maddux, 1995). Bandura's (1986) SCT stands in clear contrast to social learning theories that emphasize environmental factors in the role of human development and behaviour. For Bandura, people make sense of their psychological processes by delving into their own conscious mind. To predict how environmental factors influence human behaviour, it is imperative to appreciate how the person cognitively processes and interprets behavioural outcomes (Pajares, 2002). According to Bandura (1986), "a theory that denies that thoughts can regulate actions does not lend itself readily to explanation of complex human behaviour" (p. 15).

In SCT, people are both proactively engaged in their own development and can make things happen by their own actions. That is, people are both products and producers of their environment (Bandura, 1986; Pajares, 2002). Personal factors, or self-efficacy, enable individuals to exercise a measure of control over their thoughts, feelings,

and actions, in that “what people think, believe, and feel affects how they behave” (Bandura, 1986, p. 25). In SCT, Bandura provided a view of human behaviour in which the self-beliefs people have are crucial components in the exercise of control and personal agency. From this view of human behaviour, SET evolved.

A philosophical underpinning of SCT is that people are born as blank slates and their experiences shape their knowledge and behaviour. People have the power to command control over their environment, shape their own destiny, and the power to regulate their own motivation and behaviour through the positive and negative consequences they produce for themselves (Bandura, 1986). The worldview that people regulate their own motivation and behaviour gives insight into the development of SCT and SET and why personal factors in addition to environmental factors play a key role in behaviour change. SCT views behavioural, environmental, and personal factors as interacting to produce a sum that cannot be explained simply by examining the parts (McEwen, 2002).

Explicitly stated, SCT has the following purposes: (1) to understand and predict individual and group behaviour, (2) to identify methods in which behaviour can be modified or changed, and (3) to develop interventions aimed at personality development, behaviour pathology, and health promotion (Bandura, 1977, 1986; Maddux, 1995). To broaden SCT’s scope, SET was developed and expanded to explore more fully the personal factors in SCT’s triadic reciprocity. Specifically, SET examines the relationship between self-efficacy and outcome expectations (van der Bijl & Shortridge-Baggett, 2002). As the purposes of SET include behaviour change and health promotion, SET can add to nursing knowledge by providing a framework to conduct nursing research and practice.

Underlying Assumptions

SCT is an approach to understanding human behaviour that assumes people are capable of self-reflection and self-regulation and are active in shaping their environment rather than simply reacting to it. SCT also has the following specific assumptions: (1) people have powerful symbolizing capabilities, (2) most behaviour is purposive or goal-directed and is guided by forethought, (3) people are self-reflective and capable of analyzing and evaluating their own thoughts and experiences, (4) people are capable of self-regulation by influencing direct control over their own behaviour, (5) people learn vicariously by observing other people's behaviour and its consequences, (6) physiological and experiential forces interact to determine behaviour, and (7) environmental, personal, and behavioural factors are mutually interacting factors (Bandura, 1986; Maddux, 1995).

In addition to SCT's assumptions, SET also has assumptions. According to Bandura, (1977, 1986) the basic premise underlying SET is that the relationship between self-efficacy and outcome expectations determines whether an individual will engage in a particular activity. That is, people will engage in behaviour they believe will produce successful outcomes. The principal assumption underlying SET is that psychological procedures, whatever their form, serve as a means of creating and strengthening expectations of self-efficacy (Bandura, 1977). Now that the origins of SCT and SET have been examined, the next step in Walker and Avant's (2005) theory analysis framework is to examine the meaning of the theory.

Theory Meaning

The meaning of a theory refers to the theory's concepts and how they relate to one another. The steps in determining the meaning of a theory are: identify the concepts, examine the definitions and use of the concepts, identify the statements in the theory, and examine the relationships among the concepts as used in the statements (Walker & Avant, 2005).

Identify concepts

In identifying the concepts of the theory, all major ideas of the theory and the relevant terms that reflect those ideas are listed. It is then determined whether the concept is primitive, concrete, or abstract (Walker & Avant, 2005). SET is a theoretical framework used to explain and predict psychological changes (Bandura, 1977) and as such, it provides the framework for this study. Consequently, the focus of the analysis will now turn to SET. The theory posits that psychological procedures, whatever their form, alter self-efficacy beliefs. As one of the key concepts in SET, self-efficacy beliefs play a central role in human behaviour and vary along the dimensions of magnitude, generality, and strength. Self-efficacy beliefs are determined by four principal sources: performance accomplishments, vicarious experience, verbal persuasion, and emotional arousal. The four mediating processes of selection, motivation, cognition, and affect also influence self-efficacy beliefs. Another key concept in SET is outcome expectations, which can take the form of positive or negative physical, social, and self-evaluation effects. The relationships between the concepts as posited by Bandura are represented in Appendix D. All the key terms in SET are abstract in that they are not directly measurable (they require situation specific measurement therefore no universal

operational definition has been developed) and are not limited by time or space (Walker & Avant, 2005).

Definitions and use

After identifying the key concepts, the next step is to examine the definitions and uses of the terms. Self-efficacy is defined as “people’s judgement of their capabilities to organize and execute courses of action required to attain designated types of performance. It is concerned not with the skills one has but with judgements of what one can do with whatever skills one possesses” (Bandura, 1986, p. 391). This definition of self-efficacy is consistent throughout SET and shows that people’s self-efficacy beliefs are not of a general nature, but related to specific events. For this reason self-efficacy is defined theoretically. A universal operational definition is not available because general self-efficacy instruments have little explanatory and predictive value in contrast to domain related measures (van der Bijl & Shortridge-Baggett, 2002). Various studies have operationally defined self-efficacy for specific situations (Lev & Owen, 1996; Lev et al., 2001; Spence Laschinger & Tresolini, 1999; van der Bijl & Shortridge-Baggett, 2002) but a general operational definition remains elusive.

Adding to the difficulty of operational definitions, self-efficacy expectations vary along the three dimensions of magnitude, generality, and strength (Bandura, 1977). Magnitude of self-efficacy refers to how difficult a person finds adopting a specific behaviour. Generality of self-efficacy refers to the extent to which success or failure experiences influence self-efficacy. Strength of self-efficacy refers to the resoluteness of a person’s convictions that he or she can perform the behaviour in question (Maddux, 1995).

In addition to the dimensions of self-efficacy are the sources of self-efficacy. The principal sources of self-efficacy are: performance accomplishments (later called enactive mastery experience), vicarious experience, verbal persuasion, and emotional arousal (later called physiological and affective states) (Bandura, 1977, 1997).

Performance accomplishments are the most powerful sources of self-efficacy information because they are based on the person's own experience (Bandura, 1977). Successes at a task or behaviour strengthen self-efficacy whereas failure decreases self-efficacy.

Vicarious experience influences self-efficacy when people observe the behaviour of others (especially role models), see what they can do and the consequences of their behaviour, and in turn use this information to form expectancies about their own behaviour.

The third principal source is verbal persuasion. This source of self-efficacy is less effective than performance accomplishments and vicarious experience but is the most often employed source of self-efficacy due to its ease of use. People try to convince others that they can succeed at a difficult task by giving instructions, suggestions, and advice (van der Bijl & Shortridge-Baggett, 2002). The fourth source of self-efficacy is emotional arousal which includes physiological and emotional states. Physiological states influence self-efficacy because people associate adverse physiological arousal with poor behavioural performance, perceived incompetence, and failure. Conversely, comfortable physiological sensations are likely to lead to confidence in one's ability (Bandura, 1977, 1986). When people are in a positive rather than a negative emotional state, they are more likely to have positive self-efficacy beliefs about their performance of behaviours (Maddux, 1995). In SET, the four principal sources of self-efficacy

(personal accomplishments, vicarious experience, verbal persuasion, and emotional arousal) are descriptively defined and used consistently within the theory.

Mediating processes, which influence self-efficacy beliefs are another component of self-efficacy. The mediating processes are: selection, motivational, cognitive, and affective (Bandura, 1995). In selection processes, activities people pursue or avoid are influenced by judgements of self-efficacy. People tend to avoid tasks they believe exceed their capabilities, while pursuing those they feel competent to perform (Bandura, 1977). Motivational processes include goal setting and persistence. Self-efficacy beliefs influence people's choice of goals and goal-directed activities, expenditure of effort, and persistence in the face of challenges and obstacles (Bandura, 1986). Cognitive processes affect self-efficacy beliefs in four ways. First, they influence the goals people set for themselves. The higher the self-efficacy belief, the higher the goals and the stronger the commitment to those goals. Second, those with high self-efficacy visualize success scenarios while those with low self-efficacy visualize failure scenarios and focus on things that may go wrong. Third, cognitive processes influence the development of rules for predicting and influencing events. Finally, high self-efficacy encourages analytical thought processes in reaction to setbacks and difficulties (Bandura, 1997; Maddux, 1995; van der Bijl & Shortridge-Baggett, 2002).

The last mediating process is affective. Self-efficacy beliefs are powerful determinants of affective responses and can regulate emotional states in several ways. For example: (1) people who believe they can manage threats are less distressed by them, (2) people with high self-efficacy lower their stress and anxiety by acting in ways that make the environment less threatening, (3) low self-efficacy beliefs for attaining

highly desired goals or outcomes can lead to despondency or depression (Bandura, 1986, 1995), which can then influence subsequent coping attempts (Maddux, 1995; van der Bijl & Shortridge-Baggett, 2002). In SET the four mediating processes are descriptively defined and are not used consistently. These processes were not explicitly detailed in the original theory but developed as SET evolved (Bandura, 1977, 1997).

In addition to self-efficacy beliefs, another key concept in SET is outcome expectations. Bandura (1977) defined outcome expectations as “a person’s estimate that a given behaviour will lead to certain outcomes” (p. 193). This is conceptually different from self-efficacy beliefs, which reflect one’s belief in their own ability to successfully execute the behaviour required to create the outcome (Bandura, 1977). The outcomes people expect depend largely on how well they expect to perform (Bandura, 1986) and flow from a given course of behaviour that can take the form of positive or negative physical, social, and self-evaluative effects (see Appendix D). In SET outcome expectations are theoretically defined and consistently used, however, the concept is not operationally defined.

In analyzing SET it becomes apparent that only self-efficacy and outcomes expectations are theoretically defined and consistently used. The other concepts (dimensions, sources, and mediating processes) are descriptively defined with only the sources of self-efficacy being consistently used. This difficulty in operationally defining and measuring SET’s concepts is a weakness of the theory.

Identify statements

After identifying the major concepts and examining their definitions, the next step is to identify the ways the concepts relate to one another (Walker & Avant, 2005). The

main relationship in SET is between self-efficacy and outcome expectancies. Bandura (1977) hypothesized that self-efficacy would determine: whether coping behaviour was initiated, how much effort would be expended, and how long it would be sustained for in the face of obstacles and adverse experiences. Self-efficacy beliefs influence outcome expectations with high self-efficacy beliefs increasing outcome expectations resulting in the person being more apt to initiate and persist in a particular behaviour (Bandura, 1977, 1997).

Other relationships in SET involve the dimensions, sources, and mediating processes of self-efficacy and their impact on self-efficacy. The dimensions, sources, and mediating processes influence self-efficacy beliefs. Ultimately, these variables indirectly affect outcome expectations. All of which have a direct bearing on actual outcomes (see Appendix E).

Examine relationships

Now that the relationships in the theory have been identified, this section will focus on examining those relationships. Analyzing relationships involves determining the types of relationships, the boundaries of the theory, whether the statements are used consistently, and assessing whether there is empirical support for the statements (Walker & Avant, 2005).

Types. Bandura (1986) posited that self-efficacy and outcome expectations have a causal relationship. That is, self-efficacy beliefs directly influence outcome expectations. The dimensions of self-efficacy beliefs (magnitude, strength, and generality) have an associational relationship with self-efficacy. The sources (performance accomplishment, vicarious experience, verbal persuasion, and physiological and emotional states) and the

mediating processes (selection, motivational, cognitive, and affective) of self-efficacy beliefs also have an associational relationship with self-efficacy. Bandura does not explicitly state the associational relationships, but he does argue that by positively influencing the sources and mediating processes of self-efficacy beliefs, self-efficacy will increase (Bandura, 1977, 1986, 1995, 1997).

One of Bandura's (1997) key contentions as to the role of self-efficacy beliefs is that "people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true" (p. 2). This is why, how people behave can often be better predicted by the beliefs they hold about their capabilities, than by what they are actually capable of accomplishing (Pajares, 2002).

Boundaries. Based on theory analysis criteria, SET is a highly abstract grand theory with wide boundaries; it covers a large content area and is applicable to a large number of disciplines (Walker & Avant, 2005). It is necessary for SET to be abstract because it deals with complex behaviours that involve cognitive and social components (Bandura, 1986). SET has emerged as a way to understand and influence behaviour change in all types of behaviours (Bandura, 1977, 1986, 1995, 1997) including those related to health promotion (Haas, 2000; Spence et al., 1999), oncology patients (Lev, 1997; Lev et al., 2001), and chronic illness (Krick & Nazaroff, 2000; Tsay, 2003; Tsay & Halstead, 2002).

Consistency. The relationship between self-efficacy beliefs and outcome expectations is consistent throughout SET. The basic premise that people process and integrate diverse sources of information about their perceived capability, and in turn initiate and continue behaviour accordingly, remains consistent. The sources of self-

efficacy beliefs and that they vary in potency from strongest (performance accomplishment) to weakest (physiological states) remains consistent. Two areas that are not consistent are the dimensions and mediating processes of self-efficacy beliefs. The dimensions of self-efficacy (magnitude, generality, and strength) evolved and expanded from Bandura's (1977) original work. Another area that expanded from the original to more contemporary works is the mediating processes (selection, motivational, cognitive, and affective) of self-efficacy beliefs. In Bandura's original work, the mediating processes are not well developed; however in *Self-Efficacy: The Exercise of Control* an entire chapter is devoted to these processes (Bandura, 1986, 1997). The lack of consistency in the dimensions and mediating processes is a weakness of SET as it has resulted in inconsistent measurements and definitions (Haas, 2000) and exactly how the factors affect self-efficacy (Maddux, 1995).

Empirical support. Bandura's (1995) conviction that "people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively the case" (p. 2) is supported by a number of research findings from different fields. During the literature review examining research that utilized self-efficacy as a theory, numerous studies were found. As discussed in the literature review, SET has provided the theoretical framework for studies on health promotion (Haas, 2000; Lev, 1997; Lev et al., 2001; Lev & Owen, 2000), chronic illness (Clark & Dodge, 1999; Krick & Nazaroff, 2000; Tsay, 2003; Tsay & Halstead, 2002; van de Laar & van der Bijl, 2001), and oncology patients (Edgar & Watt, 2004; Lev et al., 1999; Lev & Owen, 2000). Evidence from the studies examining applications of SET suggests that a positive

relationship exists between self-efficacy and health outcomes contributing to the validity of SET.

The studies reviewed on self-efficacy in health promotion, chronic illness, and oncology patients support SET. The research questions in the studies examined the relationship between level of self-efficacy and outcome expectancies or behaviour change, which reflect SET's concepts. For the research questions being investigated, the studies had appropriate methodology and data analysis. The studies reviewed draw justifiable conclusions and are replicable, which is an important consideration in determining whether studies support a theory or not (Walker & Avant, 2005). Based on the strength of the reviewed studies, they demonstrate empirical support for SET.

Logical Adequacy

The logical adequacy of a theory examines the logical structure of the concepts in a theory and the statements independent of their meanings (Walker & Avant, 2005). The considerations in determining the logical adequacy of a theory include: (1) theory predictions independent of content, (2) agreement of scientists, (3) making sense, and (4) logical fallacies.

Predictions independent of context

To determine if a theory is logical, it is important to assess whether predictions from the theory can be made independently of content. To begin, relational statements from the theory are written and labels assigned. The relational statements for SET are as follows:

1. An increase in self-efficacy beliefs (SE) increases outcome expectations (OE).

2. Self-efficacy beliefs (SE) are dependent on the sources of self-efficacy (SSE).
3. Mediating processes (MP) produce self-efficacy beliefs (SE).
4. Self-efficacy beliefs (SE) vary with the dimensions of self-efficacy (DSE).

Now that the relational statements for SET have been written and labels assigned, the next step is to diagram the relationships in a correlational table. See Appendix F for a correlational table in which all the variables are listed horizontally and vertically and the sign of the relationship is placed in the correct box (Walker & Avant, 2005). After examining the table, it becomes apparent that a positive relationship does exist between self-efficacy beliefs and outcomes expectations. The other three relationships: 1) self-efficacy beliefs and sources of self-efficacy, 2) self-efficacy beliefs and mediating processes, and 3) self-efficacy beliefs and dimensions of self-efficacy, have an implied positive relationship.

Agreement of Scientists

Another element in analyzing the logical adequacy of a theory is to examine the agreement of scientists. In order for scientists to agree, the theory must be sufficiently precise in its representation (Walker & Avant, 2005). There is agreement between scientists that self-efficacy beliefs can predict the initiation and persistence of behaviour in the face of obstacles and challenges (Maddux, 1995; Haas, 2000). Conversely, disagreement surrounds the definition and measurement of the dimensions of self-efficacy beliefs (Shorridge-Baggett, 2002) and outcome expectancy. Kirsch (2002) argued that there is an ambiguity in the definition of outcome expectancy and this has led to confusion in its usage. Maddux (1995) goes further by arguing that SET relies on

poorly defined and unobservable interactions among poorly defined variables such as outcome expectancy. Bandura adds to the confusion by claiming there is a causal relationship between self-efficacy and outcome expectations (Bandura, 1986) and then saying there is no fixed relationship between self-efficacy beliefs and outcome expectations (Bandura, 2002).

Tyron (1981) identified what he thought was a major methodological flaw in Bandura's (1977) study on self-efficacy. Social contingencies rather than self-efficacy beliefs may have lead to the efficacy expectations obtained and thus the study has serious limitations (Tyron, 1981). In spite of these critiques, the vast majority of scientists agree SET has sound theoretical foundations and high predictive value (Bandura, 1997; Haas, 2000; Lev, 1997; Pajares, 2002; Tsay, 2003). Further research on the definition and measurement of the concepts on SET, particularly the dimensions and outcome expectations will augment the self-efficacy literature.

Making Sense

SET makes sense because it provides insight into and understanding about how a person's self-efficacy beliefs affect behaviour. This is evidenced by the numerous studies that have used SET as a theoretical framework to predict and explain behaviour from disciplines as diverse as education, psychology, business management, nursing, and medicine (Bandura, 1995).

Logical Fallacies

According the Walker and Avant (2005) if a theory was developed from another theory, it is deductive in origin. As such, SET is a deductive theory because it evolved out of SCT. In deductive theory, if the premises are true then the conclusions drawn from

the premises are also true (Walker & Avant, 2005). The review of the literature on health promotion (Haas, 2000; Lev, 1997; Spence et al., 1999), chronic illness (Krick & Nazaroff, 2000; Tsay, 2003), and oncology patients (Edgar & Watt, 2004; Lev et al., 2001; Lev & Owen, 2000) previously discussed, supports the premise that self-efficacy beliefs influence outcome expectations and behaviour. Because the premise about self-efficacy beliefs and outcome expectations holds true, the conclusions that increasing self-efficacy increases outcome expectations and positively affects behaviour are also true.

SET is able to make predictions independent of content, has high agreement among scientists, makes sense in numerous disciplines and does not have logical fallacies, all resulting in logical adequacy. Now that the logical adequacy has been determined, the next step in Walker and Avant's (2005) theory analysis is to evaluate the usefulness of the theory.

Theory Usefulness

The usefulness of a theory concerns its practicality and helpfulness to a discipline in predicting outcomes (Walker & Avant, 2005). Usefulness is evaluated by determining (1) the amount of research the theory has generated (amount of volume and new research), (2) the relevant clinical problem, and (3) the theory's influence on nursing practice and research.

Amount of research generated

SET has generated substantial research in various disciplines. A search of the literature produces hundreds of research articles involving SET. The theory has added to scientific knowledge by introducing the concepts of self-efficacy beliefs and outcome expectations. Before SCT and self-efficacy, SLT did not account for people's beliefs in

their capability of performing a task; rather the role of environment or behaviour was overemphasized (Bandura, 1986). SET led to new predictions in how personal factors (such as self-efficacy beliefs) could influence behaviour change. The theory addresses beliefs in capability and how changing those beliefs can change behaviour.

Relevant clinical problem

SET is relevant to numerous clinical problems because it affects the complex and diverse domain of behaviour change. While the theory is relevant to numerous disciplines, it is particularly so for nursing. Nursing involves patient-centred interventions that will ultimately improve patient education and outcome, which is well suited to using SET as a theoretical framework. Nursing interventions that incorporate SET as a framework show an increase in patient quality of life, well-being, treatment compliance (Lev, 1997; Lev & Owen, 2000; Tsay, 2003), and a decrease in depression (Tsay & Healstead, 2002).

Theory's influence on nursing practice and research

SET holds promise as a theoretical basis for nursing practice and research in various patient populations. The theory emphasizes personal factors within the environmental and behavioural spheres, which is why it is congruent with a holistic nursing perspective. Previous work with chronically ill populations (Tsay, 2003; Tsay & Healstead, 2002) and oncology patients (Edgar & Watt, 2004; Lev & Owen, 2000) supports using self-efficacy as a basis for guiding nursing practice and research. To assist patients and to enhance positive patient outcomes, assessment of self-efficacy and psychological status of chronically ill and oncology patients should be an essential part of nursing practice (Tsay & Healstead, 2002).

SET provides an appropriate framework that can guide nursing practice and research, thus contributing to nursing knowledge. SET is a useful theory in that it has generated a plethora of research, is relevant to clinical problems, influenced nursing practice and research, and improved patient outcomes by increasing patient quality of life and well-being.

Theory Generalizability and Parsimony

Generalizability of a theory refers to how widely the theory can be used in explaining or predicting phenomena (Walker & Avant, 2005). Parsimony of a theory refers to the simplicity of a theory even though it may be broad in its content (Walker & Avant, 2005). SET has very wide boundaries and is supported by extensive empirical data (Shortridge-Baggett, 2002). As previously discussed, research on SET is valid and credible. SET is a generalizable theory that is applicable to nursing and diverse patient populations and although generalizable, one of the critiques of the theory is it very complex and difficult to understand (Pajares, 2002). However, the theory is based in behavioural science, which means it cannot be reduced to a simple equation as complexity is to be expected. SET does provide a model (see Appendix E) that helps the reader to visualize the relations of the concepts to each other and given the complexity of the subject (human behaviour and change), SET is a generalizable theory that is as parsimonious as possible.

Theory Testability

For a theory to be valid, it must be testable. That is, it must generate hypotheses, be used to carry out research, and be supported by research evidence (Walker & Avant, 2005). SET fulfills all the above criteria. Bandura (1977) hypothesized that self-efficacy

would determine if behaviour was initiated, the amount of effort that would be expended, and for how long the behaviour would be sustained. This hypothesis has formed the basis for other studies on self-efficacy, which have supported SET (Edgar & Watt, 2004; Kuijer & Ridder, 2003; Lev & Owen, 2000, Tsay, 2003). Finally, SET has predictive value, is empirically supported by evidence and has added to existing scientific knowledge, which results in the theory being testable.

Summary

According to Walker and Avant (2005) theory analysis is a systematic process that objectively examines the content, structure, and function of a theory. A theory analysis was conducted following Walker and Avant's (2005) framework, which allowed a systematic and non-judgemental examination of SET. The six steps used to analyze SET were (1) theory origins, (2) theory meaning, (3) logical adequacy of the theory, (4) theory usefulness, (5) theory generalizability and parsimony, and (6) theory testability. The theory analysis examined what prompted the development of SET as well as SET's major concepts and their relationships to one another. The analysis showed SET to have logical adequacy, usefulness, generalizability, and testability.

The major advantage of theory analysis is it allows for insight into the relationships among the concepts and highlights any strengths or weaknesses of the theory (Walker & Avant, 2005). One of the strengths of SET is it allows for prediction of behaviours based on knowledge of self-efficacy beliefs. From a nursing perspective, another strength of SET is its applicability to nursing practice. The literature reviewed demonstrated SET's positive contribution to nursing knowledge. Research has shown that enhancing self-efficacy through nursing interventions leads to positive patient

outcomes such as increased treatment compliance, quality of life, well-being, and decreased depression (Lev, 1997; Lev & Owen, 2000; Tsay, 2003; Tsay & Healstead, 2002). SET provides a framework to guide the nurse researcher or clinician in promoting healthy behaviour change across patient populations. According to Bandura (1997), perceived self-efficacy impacts on health behaviours because people must believe they can initiate and adhere to health promoting habits in order to devote the time and effort necessary to achieve change. In addition to enabling behaviour change, higher perceived self-efficacy is associated with lower levels of anxiety and despair and higher quality of life. Bandura (1997) theorized that self-management programs based on SET improve patients' level of health and decrease the need for medical services. Ultimately, SET's strength lies in its ability to guide future nursing research into improving patient outcomes and is the reason it was chosen as the theoretical framework for this pilot study.

Chapter IV

Methodology

Introduction

In this chapter the study's research design and methodology will be examined. To begin, an explanation of the study's design, setting, sample, and method will be provided. This discussion will be followed by the ethical implications of the study and a description of the data analysis. Finally, the chapter will end by highlighting how the study's results will be disseminated.

Design

Given the dearth of research investigating the relationship between educational interventions based on self-efficacy and their impact on lymphedema management practices and quality of life, a quasi-experimental, prospective, pre-test, post-test pilot study design was chosen. This type of small study allowed the researcher to explore the feasibility of conducting this type research and to examine the relationships between the study variables. For the purposes of this study the independent variable was the educational intervention based on targeting self-efficacy beliefs. The dependent variables were the quality of life scores as reported by the participants and level of lymphedema in the affected limb.

Setting

The setting for this pilot study was at the Grace General Hospital, a community hospital that houses a satellite lymphedema treatment centre affiliated with the Breast Health Centre in Winnipeg, Manitoba. The Breast Health Centre is a community health site that offers diagnosis and treatment planning for patients facing breast cancer. This

site was chosen because it offers lymphedema treatment with certified therapists, and provided the required space for the study's intervention. The intervention and follow-up focus group took place in a small conference room attached to the hospital.

Sample

The target population for this study was women suffering from lymphedema related to breast cancer treatment. The sample was a non-probability convenience sample of women treated for lymphedema who were recruited from the Breast Health Centre.

Inclusion Criteria

Subjects meeting the following criteria were eligible for the study: breast cancer patients receiving treatment for lymphedema, at least eighteen years of age, living independently, able to read and write English, willing to participate, and ability to provide written consent.

Exclusion Criteria

Exclusion criteria for the study included subjects with an acute illness (such as active cancer or an infection), patients who reported psychological or cognitive disorders, were unable to independently perform self-care (such as arm bandaging or donning a compression sleeve), and patients who were on diuretic therapy or other edema influencing drugs.

Method

Procedure

Before beginning the study or recruiting any participants, written approval to conduct the study was obtained from the Ethical Review Committee, Nursing and Education, University of Manitoba. To begin the process, an email was sent to the

Director of the Breast Health Centre to introduce the researcher and to describe the purpose and details of the study. From this email, a meeting was set to further discuss the study and to get information on what was required to gain site access to the Breast Health Centre. After this meeting an email was sent to update the Director on what was occurring and timelines for when the study would begin. Upon receiving ethics approval from the Ethical Review Committee, Nursing and Education, at the University of Manitoba an additional email was sent to the Director along with a site access letter that detailed the design of the study and the steps that would be taken to conduct the study. Once site access was attained, meetings with the lymphedema therapists at the St Boniface General Hospital and the Grace Hospital, were conducted to explain the purpose of the study and to clarify participant eligibility. The lymphedema therapists were chosen because of their access to lymphedema patients receiving treatment. At these meetings, input from the therapists was sought as to what would be important and appropriate to include in the educational intervention. At this initial meeting, copies of the Invitation to Participate letters were given, as was contact information for the investigator.

Following these meetings with the therapists, participant recruitment was started. At the beginning of treatment, the lymphedema therapists approached the breast cancer survivors meeting the inclusion criteria, to ask if they would be interested in being involved in the study. Eligible participants were given an Invitation to Participate letter (Appendix G). If participants were willing to be involved, the therapist informed the researcher. At the beginning of the lymphedema treatment period, the researcher met with the patients to discuss and obtain informed consent. Two copies of the informed

consent letter (Appendix H) were part of the original package. One copy was signed and given to the researcher to be kept as part of the study's record and the other copy was for the participants. At this initial meeting, the Access to Health Records Consent Form (Appendix I) was also completed. Once informed consent was obtained, the patient demographic data form (Appendix J) and the two pre-test questionnaires, Strategies Used by People to Promote Health (Appendix K) and Functional Assessment of Cancer Treatment – Breast+4 (Appendix L) were completed.

Data collection was conducted at three intervals. Participants completed the self-efficacy (Appendix K) and quality of life (Appendix L) questionnaires at the beginning of the lymphedema treatment period, the day of the educational intervention, and the day of the focus group. A chart review was conducted to determine participants' level of lymphedema in the affected limb on the last day of the lymphedema treatment period. The second time the participants completed the questionnaires was the day of the self-efficacy training session before the educational intervention. Six weeks after this session, the study participants regrouped to complete the post-test self-efficacy and quality of life questionnaires. In addition to the questionnaires, the participants' affected limb was again measured using the Comparative Circumferential Measurement Method (CCMM) to assess the degree of lymphedema. At this follow-up focus group session, participants were invited to discuss the training session and their opinions on the effectiveness of the educational intervention.

Educational Intervention. To test the research questions about whether enhancing self-efficacy would improve quality of life and adherence to lymphedema self-management strategies, the researcher facilitated a structured training program based on

self-efficacy theory. The aim of the self-efficacy training program was to improve patients' achievements and experiences, to use verbal persuasion through praise and encouragement, and to provide a relaxed atmosphere to promote lymphedema management behaviours (Lev et al., 2001). The program was based on Bandura's (1997) self-efficacy theory and incorporates the following components of self-efficacy: performance accomplishments, vicarious experience, verbal persuasion, and emotional and physiological states. The 2 hour training session involved all the participants and occurred after Phase I of the lymphedema treatment period finished. The session consisted of guest speakers, practice and reinforcement of learned concepts, and information on lymphedema management that incorporates recommendations from the National Lymphedema Network. The National Lymphedema Network (2006) developed and recently revised eighteen lymphedema risk-reducing guidelines aimed at decreasing the trauma to the lymphatic system, lessening the damage to the venous system, and preventing infection (Appendix M). Although the guidelines are not evidence-based, they do account for the physiology of the lymphatic system and the pathophysiology of lymphedema, which is why the guidelines were given to the participants at the educational session. Other material given to the participants during the educational session included information on the lymphatic system, lymphedema, causes of lymphedema (Appendix N) and information on managing lymphedema (Appendix O).

To enhance the participants' sense of performance accomplishment, part of the session was dedicated to practicing the self-massage and bandaging techniques learned during the lymphedema treatment period. It was necessary to include a practice session because performance accomplishment is the most important source of self-efficacy since

it is based on the person's experiences (Bandura, 1997). For the vicarious experience component, breast cancer survivors who are successfully managing their lymphedema were invited to speak about their experiences and management strategies. It is important for the participants to observe others successfully managing similar situations, as this is also a source of self-efficacy. For verbal persuasion, the investigator reinforced participants' capability for success and provided encouragement for self-care activities. The investigator invited a lymphedema therapist certified in lymphedema management techniques, to provide instructions, suggestions, and advice to convince participants they can succeed in the difficult task of managing their condition. Finally, for the physiological and emotional states, a quiet and relaxed atmosphere was provided in the training session (Lev, 1997). When people are anxious or tense they have a sense of personal deficiency and feel they will be less successful than when they are not stressed (Bandura, 1997). Participants left with information outlining the techniques discussed for lymphedema management to reinforce the learning that occurred in the training session. To finish the self-efficacy training session the participants set personal goals (Appendix P) to continue with self-care behaviours at home. It is important participants set their own goals because, as Locke (1996) argues, this increases commitment to achieving those goals, which in this study was performing self-care behaviours.

Focus Group. To capture the participants' opinion on the effectiveness of the intervention and to glean information on the lived experience of lymphedema a follow-up focus group was facilitated six weeks after the educational intervention. Before the session commenced, the participants' arms were measured using the CCMM technique. The participants then completed the self-efficacy and quality of life questionnaires. Once

the questionnaires were complete, the focus group session began. The focus group was conducted by the researcher and in attendance were the study participants and the lymphedema therapist. To facilitate the discussion, an informal interview guide (Appendix Q) was developed which provided the opportunity to ask directed questions and use probing technique to elicit further information. The core questions were designed to provide information on key sources of information concerning three main areas. The first area centred on what the participants thought of the intervention, whether they found it helpful and what could be done to improve the intervention. The second main area focussed on the participants' intention to manage their lymphedema, such as what motivates them to manage their condition and what obstacles do they encounter. The third area of discussion centred on how lymphedema affects their quality of life, such as how does lymphedema affect lifestyle, what difficulties has having lymphedema caused, and what are their future expectations of living with lymphedema.

Instrumentation

The measurement instruments for this study are the Functional Analysis of Cancer Treatment – Breast, the Strategies Used by People to Promote Health, and the Comparative Circumferential Measurement Method.

The Functional Analysis of Cancer Treatment – Breast

To measure quality of life, the Functional Analysis of Cancer Treatment-Breast (FACT-B+ 4), a self-report measurement tool was used (Appendix L). The FACT-B questionnaire is adapted from the original FACT-G scale developed by Yellen and colleagues (1987). The tool has been used in previous studies and is well-validated, multidimensional quality of life scale for breast cancer patients (Brady, Cella, Mo,

Bonomi, Tulskey, Lloyd et al., 1997; Coster et al., 2001; Fleissig et al., 2006; Lev et al., 1999; Mansel et al., 2006; Ridner, 2005; Yellen et al., 1987). The FACT-B includes five sub-scales to measure physical, social, emotional, and functional well-being in patients as well as any specific breast cancer related concerns (Coster et al., 2001) and has reported alpha coefficients between 0.62 and 0.90 (Brady et al., 1997; Ridner, 2005). To assess the impact of arm morbidity on quality of life in breast cancer patients post-operatively, Coster et al. (2001) validated the FACT-B+4 scale, which is a four-item subscale specifically addressing quality of life issues for patients with lymphedema. The subscale has an alpha coefficient of 0.83 and a test-retest reliability of 0.97 (Coster et al., 2001). To complete the FACT-B+4, patients indicate using a 5 point scale ranging from 0 (not at all) to 4 (very much), to what degree each statement has applied to them over the last 7 days (Fleissig et al., 2006; Yellen et al., 1987). The scores of negatively framed statements are reversed for analysis and high FACT scores equate with a good quality of life and lower scores equate with a lower quality of life (Fleissig et al., 2006).

Strategies Used by People to Promote Health

An individual's confidence in using strategies to promote health or one's self-care, self-efficacy was measured by Strategies Used by People to Promote Health (SUPPH), a self-report instrument (Lev & Owen, 1996) (Appendix K). The scale contains 29 five-point adjective ratings and includes the dimensions of coping, stress reduction, making decisions, and enjoying life. Participants are asked to rate the degree of confidence they have in carrying out specific self-care behaviours. Each item of the SUPPH is rated on a Likert scale of 1 (very little confidence) to 5 (quite a lot of confidence). Scoring the scale involves summing the responses with higher scores

indicating higher self-efficacy and lower scores indicating lower self-efficacy (Lev & Owen, 1996). Previous studies have validated the SUPPH scale with Cronbach's alpha at 0.94 to 0.96 and test-retest reliability at 0.94 (Lev & Owen, 1996; Lev et al., 1999; Tsay, 2003; Tsay & Healstead, 2001).

Comparative Circumferential Measurement Method

The Comparative Circumferential Measurement Method (CCMM) assessed the degree of lymphedema. In CCMM, measurements are taken at defined points along both limbs. The difference at each point is calculated, and then the sums of the differences are added together to determine the degree of lymphedema (Brown, 2004). Meek (1998) found the intrarater reliability for circumferential measurement was 0.91 to 1.00 and for interrater reliability, the correlation coefficient was 0.81 to 0.98. Studies using the circumferential measurement show the technique to be a reliable and valid tool for measuring the degree of lymphedema (Brown, 2004; Didem, Ufuk, Serdar, & Zumre, 2005; McKenzie & Kalda, 2003; Meek, 1998). Comparative circumferential measurement was chosen because it is a commonly used tool and is the measurement technique currently used at the Breast Health Centre.

The Patient Demographic Data Form

The patient demographic data form (Appendix J) collected information concerning: patient age, education level, marital status, type of breast cancer treatment, number of lymph nodes removed, time since breast cancer treatment, occupational status and current (or previous) employment. If participants were unable to recall the necessary information, the researcher obtained permission to access the participant's charts for clarification and accuracy of demographic data (Appendix I). Information obtained from

participants' medical charts will be kept confidential and maintained in accordance with the Personal Health Information Act.

Ethical Implications

Three committees reviewed and approved this study prior to the commencement of data collection. The thesis committee approved the study in its proposal stage. In the next stage, ethical approval was sought and obtained from the Ethical Review Committee, Nursing and Education, University of Manitoba. Finally, the study was approved and site access granted by the director of the Breast Health Centre.

Informed Consent and Confidentiality

All the participants in the study received a verbal and written explanation of the purpose of the study. Before proceeding with data collection, informed and written consent to participate in the study was obtained including participant consent to access medical chart information where lack of clarity in demographic data existed. Included in the consent letter was contact information for the principal investigator, thesis advisor, and Human Ethics Secretariat. For their own records, participants received a copy of the informed consent letter. Confidentiality and anonymity is assured as the data is being kept in secure storage and no names appear in reports of the study nor will they in any future publications. Instead of names, questionnaires were numerically coded with only the researcher having access to the identifying data. To ensure participation was voluntary, participants were informed they could withdraw from the study at any point without implications for future treatment. At the six-week follow-up focus group, any participants exhibiting lymphedema symptoms were encouraged to follow-up with their

lymphedema therapist. Finally, there was also a commitment to share the results of the study with the interested participants upon completion of the study.

Data Analysis

Due to the small sample size of this study, descriptive statistics such as mean, range, standard deviations, and percentages were used to describe the overall sample characteristics. In previous studies investigating lymphedema with small sample sizes, descriptive statistics have been employed to analyze the data (Erickson, et al., 2001; Turner, Hayes, & Reul-Hirche, 2004). To look for trends in the data and for differences between the pre-test and post-test scores for self efficacy, quality of life and level of lymphedema single case design was used with the results being displayed in line charts. To supplement the quantitative data and to glean information on the effectiveness of the educational intervention, the follow-up focus group was audio-recorded. The recording was transcribed and content analysis was performed on the information with responses being categorized into themes according to similarities.

Communication of Findings

To disseminate the knowledge gained in the research study the plan is to publish the findings of the study in an appropriate nursing journal, and present the information at both an oncology nursing conference and to the staff at the Breast Health Centre. As well, a summary of the study's findings will be provided to those study participants requesting a copy.

Chapter V

Results

Introduction

In this chapter, the results of the pilot study will be discussed. The chapter will start with a description of the demographic data. This discussion will be followed by an examination of each of the three research questions. Finally, the chapter will conclude by examining the themes that emerged from the focus group meeting.

Demographic Data

The recruitment period for this study was four months. In that time, thirteen people who met the eligibility criteria were approached to be involved in the study. Of those thirteen people, two declined to be part of the study leaving eleven participants. One participant developed an infection and was no longer eligible for the study. When contacted about the educational session, three participants were no longer able to attend due to scheduling conflicts and being from a rural area. This left an anticipated seven eligible participants for the educational intervention. On the day of the intervention, one participant did not show and three other people withdrew for personal reasons and time constraints leaving a total of three participants. The mean age was 60.7 years (SD = 10.79), with a range of 53 - 73 years. Among the participants, two worked full-time, one worked part-time and all three women had jobs that included lifting and repetitive arm movements. As for type of surgery, two of the participants underwent mastectomy, with one undergoing a lumpectomy. All three women had twenty or more lymph nodes removed at the time of their surgery, and received chemotherapy and/or radiation therapy as part of their treatment. Two of the three participants had developed lymphedema in

their dominant arm. All of the participants were living independently in the community and able to perform lymphedema self-management. Table 5.1 provides more information about the study participants.

Table 5.1 Participant Demographic Data

<i>Participant</i>	<i>Age</i>	<i>Marital Status</i>	<i>Level of Education</i>	<i>Occupational Status</i>	<i>Lifting and Repetitive Arm Movements</i>	<i>Type of Breast Cancer Surgery</i>
1	73	Widowed	High School	Part-time	Yes	Mastectomy
2	53	Single	High School	Full-time	Yes	Mastectomy
3	56	Married	Community College	Full-time	Yes	Lumpectomy

<i>Participant</i>	<i>Number of Lymph Nodes Identified</i>	<i>Radiation Therapy Treatment</i>	<i>Chemotherapy Treatment</i>	<i>Time Since Finishing Breast Cancer Treatment</i>
1	24	No	Yes	0-6 months
2	22	No	Yes	4-5 years
3	20	Yes	Yes	7-12 months

Research Questions

This study examined research questions concerning the effect an efficacy-enhancing nursing intervention would have on quality of life and level of lymphedema for the participants. The first research question dealt with level of individual self-efficacy, the second research question dealt with quality of life, and the third research question dealt with level of lymphedema. Due to the study's small sample size, analyzing the statistical significance of the results was not possible. However, by using a single case study design, trends in the data can be explored. To capture those trends, a time series design was used using three main time points. Time 1 in this study occurred at the beginning of the lymphedema treatment period. Time 2 occurred at the time of the educational intervention and time 3 occurred at the six-week follow-up session.

Research Question One

The first research question examined whether the participants' self-efficacy scores and thus level of self-efficacy would improve after the educational intervention. Higher scores on the self-efficacy questionnaire correlate with higher levels of self-efficacy. At time 1, the mean score for the three participants on the self-efficacy questionnaire was 131 (range of 120-137 and SD = 9.54). For time 2, the mean score for the three participants was 137 (range of 130-141 and SD = 6.08) and at time 3 the mean score was 140 (range of 137-144 and SD = 3.60). The mean percentage of increase from time 1 to time 2 was 4.58% and the mean percentage of increase from time 1 to time 3 was 6.87%. The mean percentage of increase from time 2 to time 3 was 2.19%, which means that self-efficacy scores increased with the intervention. The change can also be examined individually by looking at the change in ratings in terms of the survey's Likert scale

where 1 is very little confidence, 2 is a little bit confident, 3 is somewhat confident, 4 is confident, and 5 is very confident. On this scale, participant one's overall self-efficacy went from a rating of 4.86 at time 2 to a rating of 4.97 at time 3. Participant two went from a rating of 4.83 at time 2 to a rating of 4.79 at time 3. Participant three went from a rating of 4.48 at time 2 to a rating of 4.72 at time 3. For two of the three participants, self-efficacy scores did increase over the intervention period. Figure 5.1 shows the self-efficacy scores from time 1 to time 2 to time 3. Overall, the trend suggests there is some support for a relationship between the intervention and enhancing self-efficacy for two of the three participants. This offers mixed support for research question one "Will women with breast cancer related lymphedema have improved self-efficacy scores?"

Figure 5.1

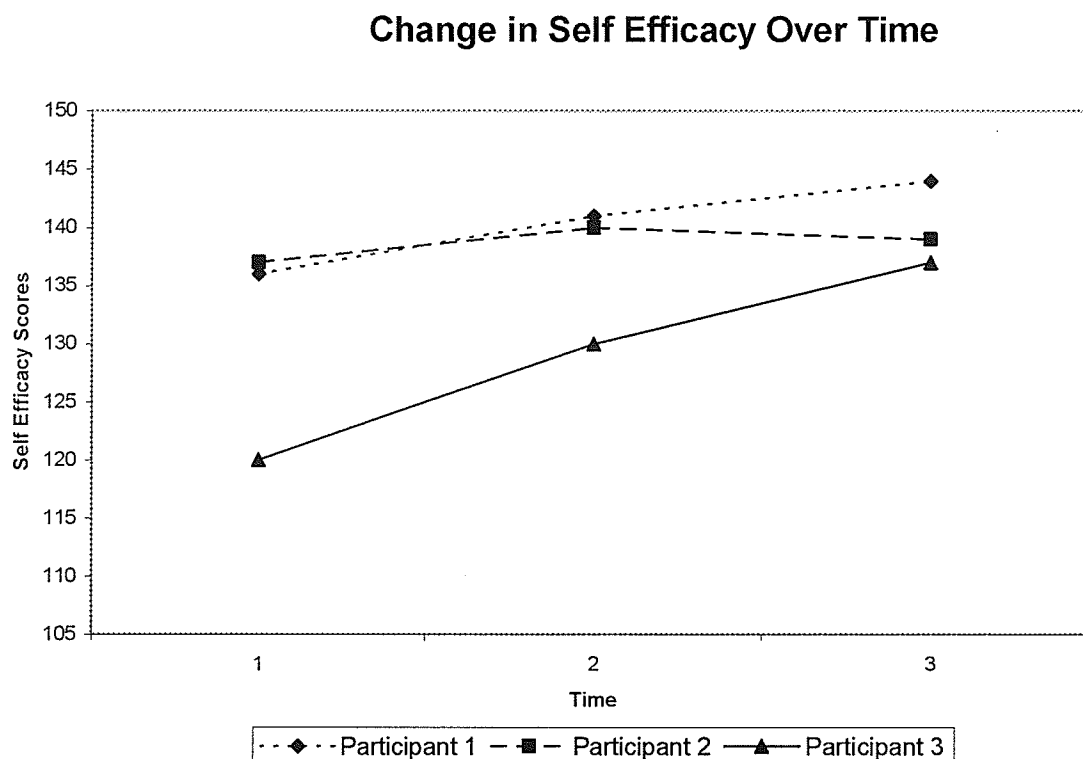


Figure 5.1. Profile of self-efficacy scores for each participant from the commencement of lymphedema therapy (time 1) to the educational intervention (time 2) to the follow-up session (time 3).

Research Question Two

The second research question examined whether quality of life would be improved for the participants with breast cancer related lymphedema. As with the self-efficacy scores, higher quality of life questionnaire scores equate with a perceived improved quality of life. For time 1, the mean quality of life score for the three participants was 113 (range was 102-121 and SD = 9.85). At the time of the educational intervention, or time 2, the mean quality of life score was 128.33 (range was 125-131 and

SD = 3.06) and at the time of the follow-up session, or time 3, the mean quality of life score was 129.33 (range was 124-133 and SD = 4.73). The mean percentage of increase from time 1 to time 2 was 13.57% and the mean percentage of increase from time 1 to time 3 was 14.45%. Finally, the mean percentage of increase from time 2 to time 3 was 0.78%. Just as with the self-efficacy scores, the change in quality of life can be examined individually by looking at the change in ratings terms of the survey's Likert scale where 0 is not at all satisfied, 1 is a little bit satisfied, 2 is somewhat satisfied, 3 is quite a bit satisfied, and 4 is very much satisfied. Participant one went from a rating of 3.21 at time 2 to a rating of 3.41 at time 3. Participant two had no change, having a rating of 3.36 at both time 2 and time 3. Participant three showed a decline in quality of life going from a rating of 3.31 at time 2 to a rating of 3.18 at time 3. Figure 5.2 shows the trend of the quality of life scores from time 1 to time 2 to time 3. While there is a minimal overall increase in quality of life scores from time 2 to time 3 the sheer volume of the change is insufficient to support an improvement in quality of life for the participants in this study after the educational intervention. However, despite the fact that only one of the three participants evidenced a decrease in quality of life at the six-week follow-up, the direction of the overall change does provide an indicator that this research relationship should be pursued in future research studies.

Figure 5.2

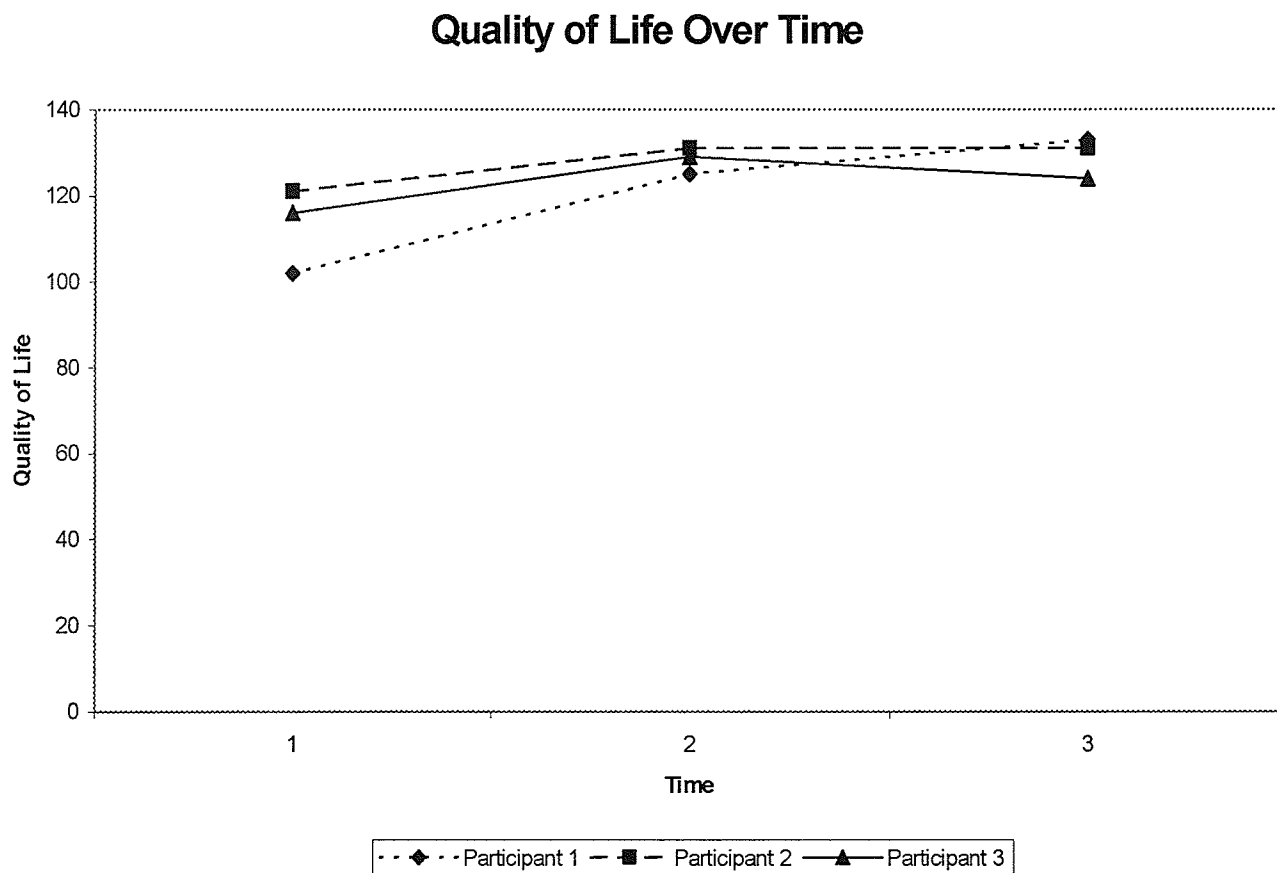


Figure 5.2. Profile of quality of life scores of each participant from the commencement of lymphedema therapy (time 1) to the educational intervention (time 2) to the follow-up session (time 3).

Research Question Three

The goal of lymphedema treatment is a reduction in lymphedema volume over time. Therefore, the third research question examined whether the attained level of reduced lymphedema, achieved during the acute lymphedema treatment phase, would be maintained until the follow-up session. To calculate the amount of reduction in the affected arm a baseline measurement was required. This baseline measure was the size

of the affected arm in millilitres at the time of the initial assessment before receiving any lymphedema treatment, and in this case was time 1. Time 2 was the size of the affected arm upon commencement of the lymphedema treatment. Time 3 was the size of the affected arm at the time of the educational intervention (post-treatment) and time 4 was the size of the affected arm at the time of the follow-up focus group session.

At baseline, the size of the affected arm was 3290 mls for participant one with this number decreasing to 2946 mls at the time of the follow-up session. In terms of percent change compared to the unaffected arm, participant one had a 58.49% decrease in arm size upon treatment completion and maintained a decrease of 47.12% at the follow-up session. Participant two's affected arm measured 2734 mls at baseline with this number decreasing to 2475 mls at the time of the follow-up. In comparison to the unaffected arm, participant two had a 95.16% decrease in the affected arm at the time of treatment completion with the decrease in size improving to 104.44% at the time of the follow-up session. Finally, the affected arm of participant three was 2134 mls at baseline with this number decreasing to 2094 mls at the time of the follow-up session. In terms of percent change to the unaffected arm, participant 3 had a decrease of 78.16% in the affected arm at the time of treatment completion and a 45.98% decrease at the time of the follow-up session. See Figure 5.3 for the level of lymphedema over the four time points of initial assessment, treatment commencement, educational intervention, and follow-up session. From the time of treatment commencement to the time of the educational intervention, all three participants had a decrease in level of lymphedema. Although two of the three participants did have a slight increase in level of lymphedema from the educational intervention to the follow-up focus group, the level of lymphedema for all the participants

did remain lower than at the time of treatment. It is not unreasonable to expect slight increases in level of lymphedema upon completion of lymphedema treatment. In response to research question three, these results indicate providing women with breast cancer related lymphedema with an educational intervention may be beneficial, but more research is required to determine the long term impact of the intervention.

Figure 5.3

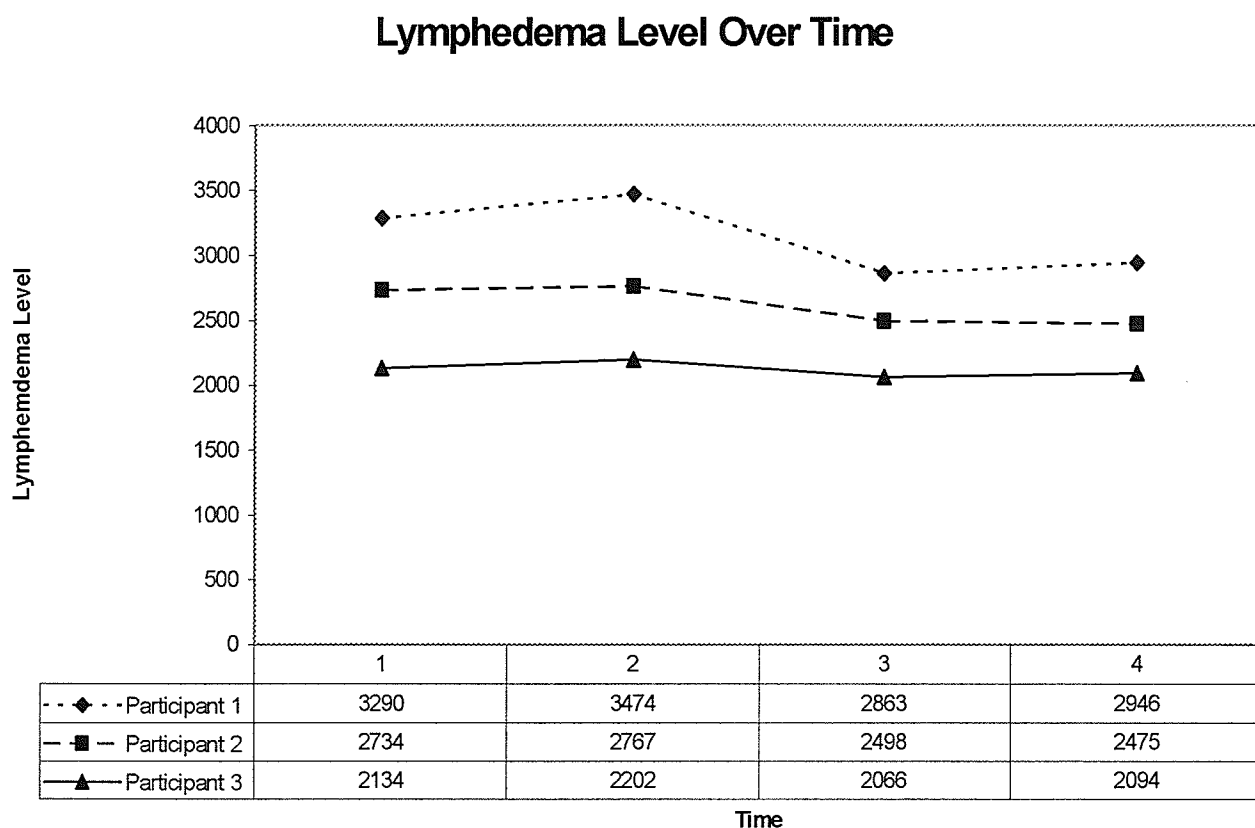


Figure 5.3. Profile of level of lymphedema for each participant where time 1 is initial assessment, time 2 is treatment commencement, time 3 is educational intervention, and time 4 is follow-up session. The table includes actual lymph volume in millilitres by participant.

To determine the change in the affected arm from the beginning of lymphedema treatment to the follow-up session, the affected arm was compared using itself as a control. In other words, the percent change in the affected arm was calculated using the initial assessment measurement and comparing that to the measurement at the beginning of treatment, the educational intervention, and the follow-up session. Participant one's lymphedema was down 10.46% at the follow-up session compared to the initial assessment. Participant two's lymphedema was down 9.47% at the follow-up session compared to the initial assessment and participant three's lymphedema was down 1.87%. After the completion of treatment the mean percent change of all three participants was 8.97% and at the six-week follow-up session, the mean percent change was 7.26%. Figure 5.4 illustrates the percent of lymphedema change for the affected arm. These results suggest a positive dual influence of lymphedema treatment and educational intervention in minimizing level of lymphedema post breast cancer treatment.

Figure 5.4

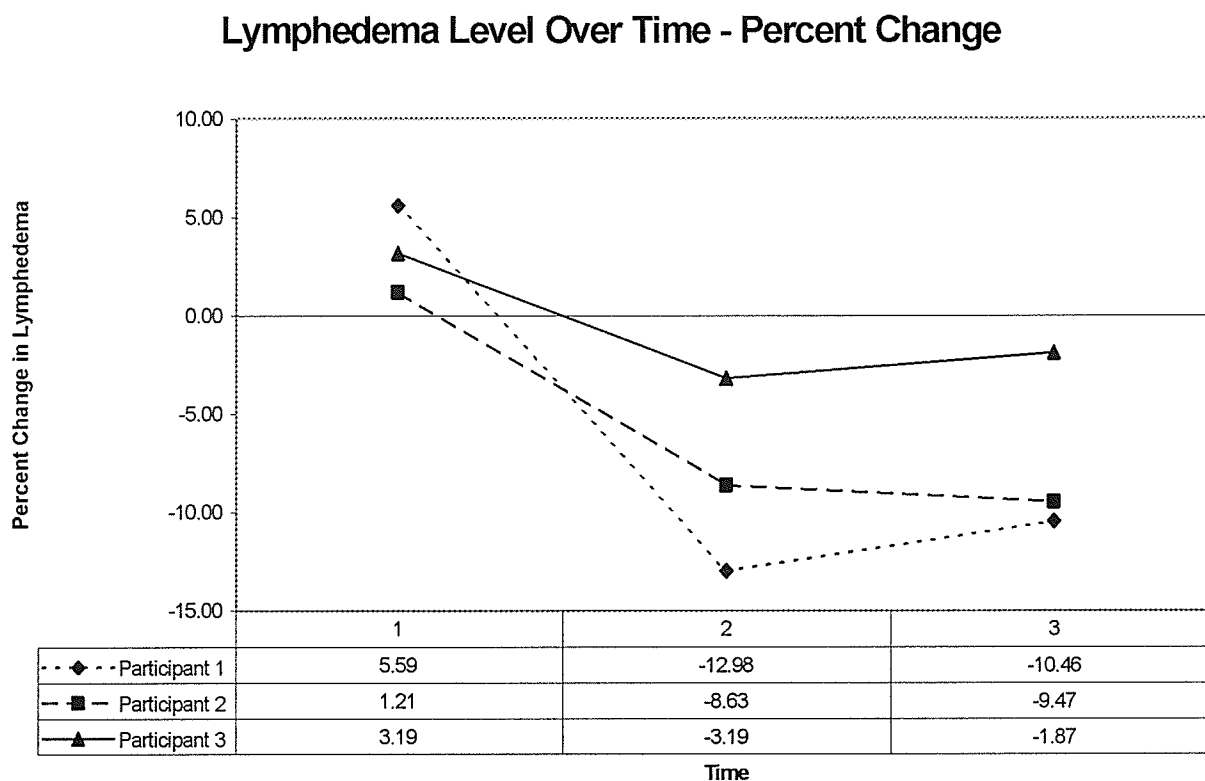


Figure 5.4. Profile of level of lymphedema for each participant using the affected arm as the control where time 1 is treatment commencement, time 2 is the educational intervention, and time 3 is the follow-up session. Table data includes actual lymphedema decrease by participant in percent change.

The final step in the analysis was to examine, whether after the educational intervention the self-efficacy and quality of life scores improved while the decrease in lymphedema from treatment was maintained at the follow-up session. The mean self-efficacy scores for the three participants increased from 131 at time 1 to 137 at time 2 to 140 at time 3, which represents a 2.19% increase from time 2 to time 3. Two of the three participants experienced increased self-efficacy post intervention. For the three

participants, the mean quality of life scores went from 113 at time 1 to 128.33 at time 2 to 129.33 at time 3, which represent a 0.78% increase from time 2 to time 3. However, the individual results are too inconsistent to drive a reliable finding. Finally, the mean percent change in lymphedema level for the three participants was up 3.33% at time 1, down 8.27% at time 2 and down 7.27% at time 3. Figure 5.5 combines the mean self-efficacy and quality of life scores and the mean percent change in level of lymphedema. To recap, the findings presented here offer support for a possible relationship between self-efficacy, quality of life, and lymphedema management. However, further studies with a larger sample size are needed to examine these relationships in greater detail and determine potential statistical significance.

Figure 5.5

Self Efficacy, Quality of Life, & Lymphedema Over Time

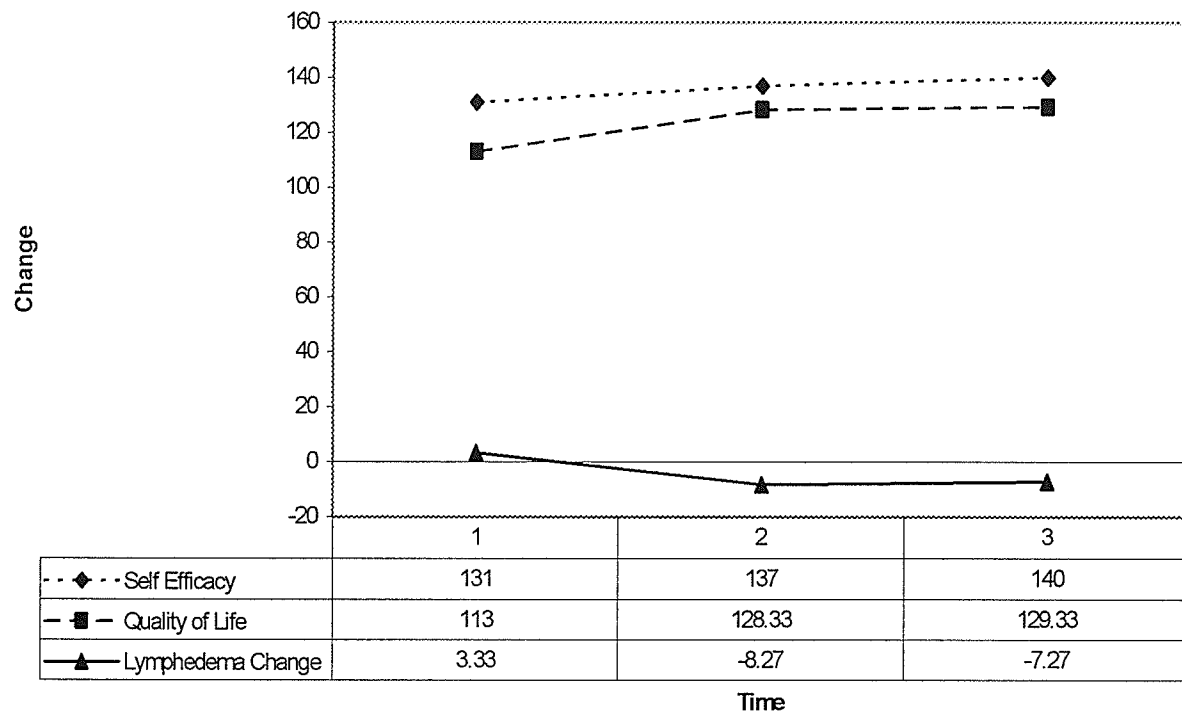


Figure 5.5. Profile of the three participants' mean scores of self-efficacy and quality of life and level of lymphedema where time 1 is treatment commencement, time 2 is the educational intervention, and time 3 is the follow-up session. Table data represents results for each participant per variable.

Focus Group

To supplement the information gathered from the three research questions a follow-up focus group was conducted six weeks after the educational intervention. The purpose of the focus group was to capture the participants' opinion of the effectiveness of the intervention and to glean information on the lived experience of lymphedema. The core questions were designed to provide information on key sources of information concerning: effectiveness of the intervention (What did you think of the intervention? What was helpful? What could be improved?); managing their lymphedema (What are the obstacles and motivators for lymphedema management?); and the lived experience of lymphedema (What was it like to have lymphedema?). With the consent of the participants, the 75-minute focus group was audio-recorded and the recording was then transcribed.

Content analysis of the transcribed text was conducted. This method of analysis was chosen as it allows the researcher to systematically examine large amounts of text and extract overall themes in the data (Streubert Speziale, 2003). The transcribed verbatim texts of the focus group were reviewed and common themes and concerns were identified. To enhance the analysis, categories were identified and entered into the right margins of the text during the readings. As a result of the repeated readings and groupings, categories representing common themes emerged. For the purposes of validation and data triangulation (Adler & Adler, 1988), a trained research assistant with expertise in qualitative data analysis independently reviewed the transcript and categorized the data. The two qualitative data analyses were then compared to verify the findings representing the experiences of the women in the study. These careful and

rigorous means of data analysis were designed to maximize the reliability and validity of the findings (Strauss & Corbin, 1990). From this content analysis, three overarching themes emerged from the data: the survivor experience, the lymphedema experience, and the shared group experience.

The Survivor Experience

One of the first themes to emerge involved “survival”. From their experience of surviving breast cancer, the women in the focus group found their outlook on life had changed. One woman’s comments reflect this change in attitude:

“ Well I think our whole sense of what’s important in life has changed. I mean, our sense of what’s important in life has really changed, I think with this whole cancer thing. All of a sudden your outlook is different. And then you laugh about things, you know, because you just seem to enjoy different things at the moment. Whereas before you didn’t even notice because you were so involved with yourself and stress and all that other stuff.”

Along with this change in attitude, the women expressed the importance of enjoying life, having a positive outlook and being thankful. These sentiments are expressed in the following comments: “I keep telling myself, overall I have just a lot to be thankful for. Everything seems to be going my way, you know I’m very very fortunate.” “I’m very lucky and I keep thinking about it that way... who knows down the line what will be. I’ll cross that bridge when I come to it, for now I don’t worry about it, and just enjoy myself.” “I’m okay with the cancer, it could have been a lot worse you know.”

The group members also shared a sense of empathy for both cancer and lymphedema patients. One comment captured the poignancy of this feeling "...every time I turn around, you hear someone else has been diagnosed (with cancer) and I think they're just getting out of the starting gate. They're just starting their fight and I'm coming to well, down to 5 years now." As to relating to other people with lymphedema, one participant expressed her empathy in this way "I know someone who has it much worse than I do, and she goes to bed with pain. And I have no pain." The experience of having breast cancer appears to have given these women a basis from which to create empathy and understanding for others experiencing cancer and lymphedema.

In addition to the shared "survival" outcomes, lymphedema emerged as a negative survivor experience. One of the difficulties of having lymphedema was it was a constant reminder to the participants of their breast cancer diagnosis and treatment. Each participant expressed the additional worry that lymphedema added to their cancer survivorship. "Lymphedema does kind of remind you of your cancer experience, and it's just you know, I thought I was done with all that. But it brings it all back." "It just doesn't allow you to ever completely forget it." "Normally I don't think about it but if I get the pain in my arm or whatever, it sort of tweaks your brain that there was something wrong and it just kind of gives you, puts you in a funk for a second or two."

The group members shared in the experience of what it means to be a breast cancer survivor. They found a shared meaning in finding the joy in life, learning to laugh more than they did before, and being thankful. Further, having breast cancer appears to foster a sense of belonging to a "cancer survivor community". In contrast to the positive aspects of breast cancer survivorship, the participants also discussed the negative strain

lymphedema can produce; it serves as a constant reminder of the breast cancer experience for the breast cancer survivors. Finally, not only is lymphedema a constant reminder, it presents a new set of challenges.

The Lymphedema Experience

When discussing what lymphedema meant to the group members, the theme of a “lived lymphedema experience” emerged. Within this theme are two main categories; first, lymphedema involves a great deal of frustration and second, the challenges arising from managing lymphedema both physically and emotionally.

Frustration is a major component of the lymphedema experience and the feelings exhibited by the group are captured by the following quote “... most of the time you’re okay with it, but sometimes you do want to put your fist through the wall.” Lymphedema caused frustration for the group members for several different reasons. First, the participants expressed frustration over the general lack of information surrounding lymphedema both before and after its development. When asked if they had been informed about lymphedema before or at the time of their breast cancer surgery all three women said no. However, lymphedema may have been discussed with the women and they might not have remembered, as this was not viewed by the participants as being a priority at the time of diagnosis and surgery. As one woman explained “I didn’t think of lymphedema before my surgery. My surgery was top on my mind. And they thought for sure I had it in my lymph nodes. And this was, all of this was a concern. No, lymphedema didn’t enter my mind at the time.” In addition to not remembering or not being told about lymphedema, the women discussed how they were the ones to first notice a change. One woman noticed her arm started to look and feel bigger than her

other arm, another woman noticed her arm had a feeling of “tightness”, and the third woman had pain and tenderness in her breast. Concern about the possibility of cancer recurrence is what prompted the women to seek medical assistance. One of the women had a family member with lymphedema, which is how she became aware of the condition.

Adding to the frustration about the lack of information is the women’s perception that healthcare professionals appear to have limited knowledge about lymphedema. This second cause of frustration is clearly expressed by the following candid comments. “See my doctor, he downplays lymphedema so much, he thinks it’s overrated. He says he thought there was too much emphasis put on it. I didn’t argue, who am I to argue with the doctor...” “I was told ‘Just elevate your arm.’ Do the doctors tell their wives that they have to have their arm elevated? Are they sitting there doing nothing? Or are you supposed to get on with your life? And move along and do things because we’re not intended to sit on the sofa with our arm elevated.” The women expressed it was not only physicians but also other members of the healthcare team that demonstrated a lack of knowledge about lymphedema. “I went to a family reunion, and three nurses were asking me why I’m wearing a sleeve.” “Like my physiotherapist when I told him, he wasn’t that knowledgeable about it either.” “When the paramedics came, he was insisting, you know, insisting on using my arm...because it’s the first thing they do when the ambulance comes to your house. I said, no, it has to be on this one (pointing to unaffected arm).”

Adding to the perception of a limited knowledge base, the women in the focus group were told contradictory information by healthcare professionals. After their

surgery, some of the women remember being told they were not to allow procedures such as blood pressure readings to be done on their affected arm. No one remembered being told why, just that they were not to use their arms. After being told this information, the women encountered healthcare professionals who then told them it would be okay to use their affected arm. "One time when I was doing my blood work, she said, well yes you can take blood from this arm. I said no, no one touches this arm...but she says, oh yes, you can give blood out of this arm." Due to the lack of consistent information, there was a certain amount of mistrust expressed by the women towards the opinions of the healthcare providers. One woman had an example of a patient developing lymphedema in the hospital after surgery. The woman went on to say the patient had asked that her one arm not be used, but they used it anyway and she developed lymphedema as a result. This prompted another member of the group to comment "Once you go into the hospital, you can tell them not to use your arm, but once they knock you out for surgery, you really don't know if they are going to use it."

Not only does the lack of information about lymphedema frustrate the women, so too do the constant questions about their condition, a third source of their frustration. The women acknowledged they were much more forthcoming with information to their friends and family but it was very annoying when strangers would ask questions. As one person commented "Why does a stranger have to come up and say what's wrong with your arm. You know, I don't explain. I don't tell everybody that I've had breast cancer. I will just say, I have fluid on my arm."

The second major component of the lymphedema experience is that of managing the lymphedema both physically and emotionally. To physically manage their

lymphedema, the women in the group developed routines for themselves. One woman would wrap her affected arm each night before bed, while another woman would do her self-massage exercises and don her compression sleeve each morning.

Another way the women in the group found to physically manage their lymphedema was to protect the affected arm and to modify the way they do things. “I guess nothing has really stopped me...I suspect it’s probably what did this (the lymphedema) in the first place. Before I just did whatever I wanted, but now I’m more aware, I would think twice about doing things now.” “I think about it now, when I’m lifting and carrying my purse. I always used to carry it here (pointing to affected arm) but I don’t anymore.” “I’ll go to and grab something and now I’ll just stop and say ‘can you come and do this’. I used to be very independent but now he can do it.”

In addition to physically managing their lymphedema, the women also found ways to emotionally cope with having the condition. Strategies expressed for coping with lymphedema included not dwelling on it, enjoying life, laughter, and prayer. “Lymphedema is quite copeable, you really don’t dwell on it.” As part of not dwelling on lymphedema, the women felt enjoying life was also important. “At what point do you say no, you can’t do this? I don’t, I’m not planning on saying that. I’m planning on keeping doing things that I enjoy. I’m not planning on sitting in a china cabinet.” “I just carry on what I’m doing and thinking it could be worse.” Laughter and prayer were also considered essential in coping with lymphedema. “I laugh, I think I laugh more now than I ever laughed before.” “I pray a lot, prayer is very powerful.” Clearly, these women express very positive ways they are managing their lymphedema.

As part of managing their lymphedema, the women also discussed their obstacles and motivators for lymphedema care. Part of what motivates the women is they worry about their lymphedema getting worse. "When my family asks what would happen if it didn't do all this stuff (wearing a compression sleeve and wrapping the affected arm) I say well I think the fluid would just increase. And it does, you can feel it some days where you have it more. It's not pain but it is uncomfortable." As well as worrying about the lymphedema getting worse, another factor the women found motivating was to keep in mind the consequences of their actions. "What you have to do is be aware that okay I am going to do this, I may have more swelling but I'm going to do this because you want to live and then I'll do the extra wrapping or exercise to make up for it." Another strategy all the women found helpful in managing lymphedema was to develop a routine. "I haven't missed a morning to do my drainage and put the sleeve on." "The only reason why I do it is I have a routine." One woman put it very simply "Well it has to be done." The financial burden of lymphedema was also found to be a motivating factor for wrapping the affected arm and for doing arm exercises. For one woman her sleeve was not as effective as it could be and she was unable to afford a new one. This meant she needed to wrap her arm every night before bed to keep the swelling down. "There is a financial issue here too, the sleeve is a cost. Replacing it every six months, 2 a year at least. That's a burden. See there's all that extra expense now, the sleeves and other stuff you know. You have to foot the bill until Pharmacare kicks in. It does get expensive. I am just not that rich."

In addition to the above motivators, the women also faced various obstacles to managing their lymphedema. For example, getting out of the routine of wearing the

compression sleeve and performing their arm exercises posed challenges. “On the weekend, there’s more people around at the lake and stuff so I don’t do the happy ball (hand exercise) as much as usual. I do have one at the lake but I don’t do it as much as I do it at home.” “When there’s lots of people around, you get distracted... and then I get carried away. I keep forgetting to put it on (the compression sleeve).” Two of the women shared how their grandchildren posed one of the most difficult obstacles to protecting their arms and managing their lymphedema. “Well, my grandson, I don’t pick him up as often. I do it a little bit different but sometimes I’ll pick him up with both arms.” “Lifting my grandkids, like they want to be hugged and lifted and I really have to make an effort not to lift them up because the minute I do then I get pain in my arm.” These are examples of lymphedema presenting unusual challenges that can affect quality of life.

As part of the lived experience of lymphedema, these women shared the major frustrations they encountered within the limited and contradictory information they had received. None of the woman recalled having heard about lymphedema from the healthcare team before having developed the condition. Nor did they find there was a consensus among healthcare professionals as to what lymphedema was or the precautions to take. The women also discussed the lifestyle changes, both physically and emotionally, that are necessary to manage their condition as well as similar challenges and motivators to lymphedema management.

The Shared Group Experience

The third major theme to evolve from the content analysis of the focus group was that of the shared group experience. Within this theme two categories emerged, the

ability to share and identify with one another's experiences of lymphedema and discussion involving the educational intervention.

During the focus group, discussion turned to how each of the women managed their lymphedema and it became a time to share different management "tricks" that each of the women had developed. One woman talked about how she would do arm exercises while watching TV or while driving when she was stopped at a red light. Another woman explained how she used a paint roller to self-massage her back. The importance of being able to share their experiences is evident in the following. "The whole thing (lymphedema) is so very different. Every person is completely individual. It's so interesting to know what other people go through." One woman raised an interesting point about the difference between this focus group on lymphedema and support groups for people living with cancer. "I'm not a group person and the cancer place offers all these sessions. But there was no way I was going to any cancer counselling session with a group of people. That's just not my thing. I didn't want to sit there and have to discuss all this stuff. That would have been a real funk time for me. And this way, it wasn't really cancer, it was something else...it isn't focussed on the cancer, it focussed on something else and I found that much nicer." Sharing management ideas versus support sessions was viewed differently.

The shared experience theme was also evident during the discussion on the women's perception of the educational intervention. When discussing the intervention, the women found it helpful and useful. While the information was perceived as being interesting, for the participants the most important aspect of the intervention was the shared experience. One woman captured this sentiment by saying, "I appreciate the

information but I also appreciate knowing what somebody else is going through.” During the intervention, seeing other woman managing their lymphedema and discussing their experiences emphasized the significance of the condition to the women in the focus group. “For me to sit there and watch and listen to people and see, it made it more real and that actually made me think I better take better care of myself.” “Like it really does happen, and you know it’s okay you can deal with it but it does happen and you just want to prevent it (the lymphedema) from getting to a certain point.” “You actually saw people (with lymphedema) and I mean I keep thinking, oh gee, you know I’m really lucky, I’ve got horseshoes up my ass. You know what I mean? There’s always someone that’s got it tougher than you have.”

Hearing the women with lymphedema who were successfully managing their condition discuss what motivates them and the obstacles they face made the women in the focus group think about their own condition. The women also found the arm wrapping demonstration, which was part of the educational intervention informative. “It was nice to see how she did it, when she demonstrated how she wrapped her arm.” “She was also a good, a very good influence. She was faithful in how she was doing it all the time (wrapping her arm). And for me, I think my secret of keeping my fluid down is the night wrapping.” “It was very informative...I think she was very diligent, much more diligent than I was.” “It’s good to see someone that’s able to manage their lymphedema and is getting on with their lives, you know you can deal with it.” Seeing and discussing lymphedema with other women had a positive affect on the participants.

Summary

From the data analysis, trends in the data for self-efficacy, quality of life, and level of lymphedema became apparent. Due to the small sample size, it was not possible to complete tests for statistical significance. However, using replicated single case design and charting the data, trends in the data could be analyzed. When compared to baseline, the scores on both the self-efficacy and quality of life questionnaires increased. Specifically with respect to self-efficacy two of the three participants evidenced an increase in self-efficacy scores from the time of the educational intervention to the follow-up focus group. As for quality of life, the results were mixed with one participant having an increase, one participant reporting a decrease in quality of life, and one participant with no change at the focus group. For two of these individuals, there appears to be a positive relationship between the educational intervention and self-efficacy. Unfortunately, the quality of life scores are too divergent to draw any consistent conclusion. On a more positive note, the level of lymphedema for each participant decreased from baseline and this decrease was maintained at the follow-up session. These results offer stronger support for the efficacy of the educational intervention in conjunction with the standard lymphedema treatment. However, these results must be interpreted with caution. Given the small sample size and inconsistent findings, the results are not generalizable outside of this participant group.

Supplementing the quantitative data was the information gleaned from the follow-up focus group. In the focus group discussion three themes emerged in the content analysis: the survivor experience, the lymphedema experience, and the shared group experience. Within the survivor experience the women talked about how having cancer

has given them a positive outlook and made them enjoy life more. However, lymphedema makes this difficult at times, as it is a constant reminder of the breast cancer experience. The second theme, the lymphedema experience, included the feelings of frustration evoked by having lymphedema and strategies for managing the condition. Frustration stemmed from the limited knowledge of healthcare providers, the lack of consistent information, and lymphedema not being taken seriously. Managing lymphedema included the physical and emotional aspects of dealing with the condition as well as motivating factors and obstacles. The third theme, the shared group experience, included the importance of being able to discuss the lymphedema experience and the shared aspect of the educational intervention. Within the focus group, the women were able to discuss and share experiences about their lymphedema. The importance of the shared group experience emerged when discussing the educational intervention because seeing other women with the condition made the lymphedema more real to them, showed them the importance of taking better care of their condition, as well as giving them the confidence that they could care for their lymphedema. The results from this study suggest there may be a relationship between self-efficacy, quality of life, and lymphedema level, as well as presenting an opportunity for further understanding the lived experience. To augment the findings from this feasibility study, more research with larger sample sizes is required before conclusions can be drawn about the efficacy of this educational intervention for women with breast cancer related lymphedema.

Chapter VI

Discussion

Introduction

The purpose of this study was to examine if an educational intervention targeting knowledge level and self-efficacy would influence lymphedema management practices and quality of life in breast cancer survivors with breast cancer related lymphedema. As a result of the small number of women who participated in this research, the study is considered a pilot study and it is meant to suggest directions for future research, data collection, and interventions. In order to facilitate the discussion, the chapter will begin with a brief examination of the theoretical framework. This will be followed by the results of the three research questions and the themes from the focus group. The limitations and recommendations of the study will then be examined, and the chapter will conclude with the implications for nursing practice.

Theoretical Framework

The theory that provided the theoretical framework for this study was Bandura's (1977, 1997) self-efficacy theory. Chapter III provided a detailed discussion of this theory. In self-efficacy theory how people interpret the results of their behaviour informs and alters their environment and the personal factors they possess, which in turn, informs and alters their subsequent behaviours (Bandura, 1986; Pajares, 2002). According to Bandura (1997), perceived self-efficacy impacts on health behaviours because people must believe they can initiate and adhere to health promoting habits in order to devote the time and effort necessary to achieve change.

Self-efficacy theory was an appropriate theoretical framework for this study because it affects the complex and diverse domain of behaviour change, which is what the educational intervention for lymphedema management was targeting. The theory is relevant to nursing and patient-centred interventions that target patient education and ultimately improve patient outcomes through behaviour change. Nursing interventions that incorporate self-efficacy theory as a framework show an increase in patient quality of life and treatment compliance (Lev, 1997; Lev & Owen, 2000; Tsay, 2003). In addition to the current study, previous work with chronically ill populations (Tsay, 2003; Tsay & Healstead, 2002) and oncology patients (Cunningham; Lockwood & Cunningham, 1991; Edgar & Watt, 2004; Lev & Owen, 1996; Lev & Owen, 2000) supports using self-efficacy as a basis for guiding nursing practice and research. Self-efficacy holds promise as a framework for promoting self-management practices for people with breast cancer related lymphedema as it provides guidance for developing nursing interventions that encourage participation in behaviours that promote health.

Demographic Data

Participants in the study were three women who met the following inclusion criteria: breast cancer patients receiving treatment for lymphedema, at least eighteen years of age, living independently, free of an acute illness (such as active cancer or an infection), and not on diuretic therapy or other edema influencing drugs. All the participants either had a mastectomy or lumpectomy with axillary node dissection. Each of the women in the study had more than twenty lymph nodes removed which is consistent with previous studies that have shown that the number of axillary nodes

removed increases the risk for developing lymphedema (Herd-Smith, et al., 2001; Mansel et al., 2006).

The sample characteristics of the participants are similar to other studies examining breast cancer related lymphedema. For example, participants in a study examining a community program for lymphedema consisted of women with a mean age range of 56, who underwent mastectomy or lumpectomy and chemotherapy and/or radiation therapy (Howell & Watson, 2005). In Ridner's (2005) study investigating quality of life in breast cancer related lymphedema, the participants with lymphedema had a mean age of 58, a history of breast cancer treated with surgery and/or radiation and free from other medical conditions that could cause lymphedema. Finally, in yet another study examining breast cancer related lymphedema, the mean age of the study participants was 59 and all had a diagnosis of lymphedema after breast cancer treatment (Fu, 2005). The difference between these studies and the current study is the sample size. With only three participants the ability to generalize the findings from this study to the breast cancer related population is limited.

Research Questions

To add to the knowledge about the relationship between self-efficacy training and lymphedema symptom management, this study examined the effect of a structured nursing intervention for women with breast cancer related lymphedema. The intervention targeted the four sources of self-efficacy: performance accomplishment, vicarious experience, verbal persuasion, and physiological states. As with other types of chronic conditions, changes in behaviour are necessary to manage lymphedema. Interventions based on Bandura's (1977, 1986, 1997) self-efficacy theory show promising results (van

de Laar & van der Bijl, 2001) and the concept of self-efficacy appears to be an integral component in changing behaviour. Several studies have shown that patients with higher self-efficacy show more compliance with their self-management treatment regimes than patients with lower self-efficacy (Brus, van de Laar, Taal, Rasker, & Wiegman, 1999; Edgar & Watt, 2004; Kara & Turkinaz, 2004; Lev et al., 2001; Tsay & Healstead, 2002; Tsay & Hung, 2004). The results of this study also support Lev and colleagues (2001) findings that nursing interventions to promote self-efficacy may increase quality of life and decrease symptom distress (such as lymphedema) for women with breast cancer. In their studies of self-efficacy and people with cancer, Lev and Owen (1996) reported that self-efficacy was positively related to quality of life.

In addition to improving quality of life, psychosocial interventions also improve self-management practices for people with chronic conditions (Lev et al., 2001). Efficacy enhancing interventions may provide women with breast cancer related lymphedema with the means to participate in self-management activities. In a review article, Lev (1997) examined studies that investigated the effect of self-efficacy and found that self-efficacy consistently predicted increased participation in health promotion practices. The data from this study is also consistent with other data suggesting that nursing interventions based on psychosocial frameworks increase self-efficacy perceptions and decrease symptom distress from chronic conditions (Tsay, 2003) such as lymphedema. Studies have found that by facilitating a structured education program on self-efficacy expectations, self-efficacy could be increased through education and this improved self-care activities (Kara & Asti, 2004; Lev & Owen, 2000; Tsay, 2003; Tuner et al., 2004). A study examining a psychoeducational program on coping skills for

cancer patients, found a relationship existed between perceived self-efficacy and quality of life, that is as one increased so did the other (Cunningham et al., 1991). The above studies support the preliminary findings from the current study, however more research is required. For example, longitudinal studies to investigate the effects of nursing interventions on quality of life and lymphedema management would enhance the literature in this area.

Focus Group

Content analysis of the focus group data was conducted to develop themes and capture the women's experiences of lymphedema. To add rigor to the results through data triangulation, having both the researcher and a research assistant, trained in qualitative analysis, independently code and categorize the raw data from the focus group completed validation of the categories and emergent themes. From the content analysis three themes emerged: the survivor experience, the lymphedema experience, and the shared group experience. The discussion will now turn to each of the three themes.

The Survivor Experience

In the research and clinical communities, there is a growing awareness that although the diagnosis and treatment of cancer is distressing and disruptive, the cancer survivor experience often has sequelae that patients view as positive or beneficial (Antoni, Lehman, Kilbourn, Boyers, Culver, Alferi et al., 2001; Carver & Antoni, 2004). As a result of their cancer survivorship experience, which begins at the time of diagnosis and continues throughout the remainder of life (Mellon, 2002), the women in this study talked about how their outlook on life had changed. The women found their sense of what was important to them had changed and that they laughed and enjoyed life more.

There are positive aspects in the cancer survivorship experience that include a new attitude and appreciation for life (Dow, Ferrell, Haberman, & Eaton, 1999; Mellon, 2002; Utley, 1999), as well as a greater empathy for others (Fredette, 1995). The findings of these studies are consistent with the themes that emerged from the focus group, namely that patients had a new more positive outlook on life, they were enjoying and appreciating life more, and they had developed strong feelings of empathy for other cancer patients and especially people with lymphedema. Overall, there was an emphasis on new definitions as to what is important in life and the participants described the many positive dimensions of survivorship. This is supported by previous studies examining the positive sequelae or positive meanings of cancer survivorship (Taylor, 2000; Utley, 1999). For example, Taylor (2000) described the positive sequelae as reappraisal of life, a new attitude toward life, and reordering of priorities. In a phenomenological study of women with breast cancer two to six years post treatment, it was found the women described many positive outcomes of cancer survivorship, such as putting life into perspective, loving life, and finding meaning by helping others (Nelson, 1996). In another study examining women who survived breast cancer for at least five years, Fredette (1995) had similar findings in that long-term survivors find positive meaning including having more concern for others, reconsidering priorities, not taking life for granted, and being thankful. The above studies that explore the positive meaning of breast cancer survivorship are consistent with and support the theme of the survivorship experience that emerged in the current study.

The Lymphedema Experience

The second theme to emerge from the focus group was that of the lived lymphedema experience. Although the women in the study found positive meaning in having survived breast cancer, the development of lymphedema caused additional stress, as it is constant reminder of the breast cancer experience. In her study on women's experiences with breast cancer related lymphedema, Carter (1997) found that the participants in the study viewed lymphedema as a constant reminder of having not fully recovered from the breast cancer which added to their depression and anxiety. In another study examining women's experiences of lymphedema, the authors also found that the women viewed the lymphedema as a constant reminder of being a cancer patient and this additional distress impeded their psychological recovery (Paskett & Stark, 2000). In this study, the dimensions of the lymphedema experience included feelings of frustration and the physical and emotional challenges of lymphedema.

In addition to distress, the women in this study also found lymphedema frustrating. The frustration results from several different reasons such as the lack of available information, limited knowledge of healthcare providers, and contradictory information about their condition. The theme of frustration about the lack of or limited knowledge about lymphedema has been shown in previous studies as being a critical component of breast cancer related lymphedema. In a study examining the lived experience of lymphedema, women with the condition expressed frustration about the lack of information received at the time of diagnosis, which continued as the disease and treatment progressed (Hare, 2000). In other studies investigating the lymphedema experience, women spoke of the distress caused by the limited knowledge about

lymphedema and insensitivity of many healthcare professionals, the difficulty in obtaining information and the contradictions of that limited information (Carter, 1997). For many women, the appearance of lymphedema had been unexpected and rapid, generating feelings of fear, anger, and disappointment, which are key factors of the lymphedema experience (Woods, 1995). The women in this study also discussed their lack of awareness of the risk of lymphedema or its continuing consequences. As in the current study, research has shown that women who are at risk of developing breast cancer related lymphedema do not perceive having received adequate education about lymphedema before developing the condition (Radina, Armer, Culbertson, & Dusold, 2004; Thiadens, Armer, Porock, 2002; Thomas-Maclean, Miedema, & Tatemichi, 2005; Woods, 1993). The lack of information and the surprise of developing lymphedema is a common theme in various studies examining lymphedema (Bosompra et al., 2002; Hare, 2000; Johansson, Holmstrom, Nilsson, Ingvar, Albertsson, & Ekdahl, 2003; Paskett & Stark, 2000; Williams, Moffatt, & Franks, 2004).

Additionally, the women discussed the challenges of managing their lymphedema both physically and emotionally. To physically manage their condition, the women talked about how exercise, self-massage and wearing compression sleeves were necessary. These findings mirror an earlier study on women with lymphedema and their knowledge of their condition, in which it was found that the study participants managed their lymphedema by wearing compression sleeves and having an exercise and self-massage regime (Radina et al., 2004). Other studies also support the importance of continuing daily exercise, performing self-massage, and the wearing of compression

sleeves for successful lymphedema management (Coward, 1999; Fu, 2005; Harris et al., 2001; Klingman et al., 2004; Muscari, 2004).

Further, the women also discussed what motivates them to manage their lymphedema. Common motivation themes that emerged were: the fear the lymphedema would get worse, keeping in mind the consequences of not managing their condition, having a routine, and the financial burden of lymphedema. These women worried their lymphedema would get worse and they did not want to have to go back through treatment or the daily compression dressings. In order to accomplish their intention of not letting their lymphedema get worse, the women kept in mind the consequences of their actions, such as knowing if they did not wear their compression sleeve their arm would swell and cause them discomfort. The women also integrated the management of lymphedema into their daily lives by developing routines so it became like “brushing teeth”. For some of the women, having lymphedema and buying the compression sleeves was a financial burden, which kept them motivated to keep the swelling of their arm under control.

As well as physically managing their lymphedema, the women also found it was vital to emotionally manage their condition through having a positive attitude, laughter, prayer, and not dwelling on their condition. This finding is consistent with other studies that have concluded women with breast cancer related lymphedema and other chronic conditions use both a positive attitude and faith to manage their conditions (Edgar & Watt, 2004; Fu, 2005; Hare, 2000; Krick & Nazaroff, 2000; Radina et al., 2004). Having a positive attitude also meant that lymphedema was not something to dwell on, it just became something that was part of their daily lives. The frustration and the management

of the condition became part of the lymphedema experience and another challenge to overcome.

The Shared Group Experience

The third theme to emerge from the content analysis was that of the shared group experience. From this theme emerged the categories of the significance of sharing information and the opportunity to talk about similar experiences. The women in the focus group expressed how important it was to be able to share their lymphedema experience with other women suffering with the same condition. The women were able to discuss and share experiences with one another that they had not been able to discuss with other people. As part of the sharing of information, having other women discuss their experiences of lymphedema as a component of the educational intervention was also thought to be important because it made the lymphedema more of reality to them. This sharing was viewed as distinctly different from cancer support groups with lymphedema being a separate element of the cancer experience for these women.

Interacting with other women managing lymphedema and sharing the challenges and successes, demonstrated to these women it is a condition that they can manage. Hearing about other women being faithful to their programs was also good influence on the women. In a study examining group support and adaptation to breast cancer, the researchers found the shared group experience had a positive effect by giving the women improved confidence they were not alone and the ability to share their experience with others who understood (Samarel, Fawcett, Krippendorf, Piacentino, Eliasof, Hughes, et al., 1998). Still another theme from the Samarel and colleagues (1998) study that

overlapped with the current study was the appreciation of the women for the information that was obtained from the group.

The women from the focus group found the shared information was beneficial, they learned a great deal from one another, and that it was interesting to hear how other women were dealing with their lymphedema. The women also reported that the information gained from the educational intervention and from one another facilitated their awareness of the importance of managing their lymphedema. Hearing about other women's experiences of lymphedema helped the women in the study to deal with their own lymphedema. Comparing themselves to others made the women realize they were lucky and that their lymphedema could have been much worse, which they found helpful in emotionally managing their lymphedema. Previous studies have demonstrated that educational interventions, which incorporate aspects of both education and support, can prove very beneficial for participants (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Edgar & Watt, 2004; Lev et al., 2001; Lev et al., 1999) and support the findings of the current study.

Psychosocial interventions reveal a positive impact on quality of life for cancer patients (Rehse & Pukrop, 2003) and they may make an important difference for patients suffering from breast cancer related lymphedema. The results from the quantitative analysis of the self-efficacy and quality of life scores, the level of lymphedema and the qualitative analysis of the themes from the focus group are consistent and support the importance of psychosocial interventions. Two of the three participants had improved self-efficacy scores after the educational intervention. The improvement of perceived self-efficacy was also apparent in the comments made during the focus group. The

women talked about having a more positive outlook on life and how their confidence improved after seeing other women managing their lymphedema and it made them realize they too would be able to manage their condition. The women also discussed how hearing about other women being faithful to their treatment regime improved their self-care behaviours. Perceived self-efficacy also improved from the shared experience because to the women it was important to share not only information but also share experiences. The women also maintained a decrease in the level of lymphedema from time of treatment. The successful management of their lymphedema was not only evident in their measurements; it was also obvious in the focus group when they discussed how they managed their condition both physically and emotionally. The final area of consistency between the quantitative measurements and the participants' experiences with lymphedema was in quality of life. The scores on the quality of life questionnaire improved from baseline for all three of the participants. This improved quality of life was also evident in the focus group comments, the women talked about how they had new priorities in life; they laughed and enjoyed life more. Their lymphedema was not viewed as an insurmountable difficulty but rather as another challenge to overcome. In conclusion, this study offers evidence for the promise of nursing interventions that target self-efficacy for positively enhancing the lives of women with breast cancer related lymphedema.

Limitations and Recommendations of Study

This pilot study explored the feasibility of conducting a nursing intervention to improve quality of life and lymphedema management for women with breast cancer related lymphedema. Many of the limitations of this study can be attributed to the small

sample size and the use of a single case study design. One limitation of case study design is focussed on the external validity of study and the generalizability of the findings. In this study, both the sample size and the number of quantitative observations for each case were small. Due to the small convenience sample size, it is difficult to determine if the participants in the study are representative of the general breast cancer related lymphedema population. Another threat to external validity was the lack of control for extraneous variables such as working and living environments. To try and reduce threats to external validity, participants in the study did share similar characteristics with study samples from larger studies on breast cancer related lymphedema. As a result, the participants in this study possessed attributes that are common in the general breast cancer related lymphedema population. In addition to external validity, threats to internal validity were reduced due to the repeated observations across the participants and also the consistent findings between the quantitative and qualitative results. Using both quantitative and qualitative data collection methods was strength of the study. The qualitative data provided a wealth of information that supplemented the quantitative information and allowed for a greater understanding of the lived lymphedema experience.

A second limitation of the study was the recruitment procedure of participants for the study. Although attempts were made to access participants from both lymphedema treatment centres, one contact person did not notify the researcher about eligible participants despite periodic reminders resulting in recruitment from only one site. To increase the number of participants recruited, it may have been beneficial to spend more time with the lymphedema therapists to get their input and suggestions for the educational intervention. Input was sought from the therapists before the intervention

was developed, but it may have been helpful to seek their advice again once the intervention was complete. This may have improved the recruitment potential at both sites. In the recruitment process, too much reliance was placed upon the therapists to involve patients in the study. In future studies, it may be beneficial for the researcher to spend more time being physically present in the lymphedema treatment centres to answer any questions and be available to discuss the study with eligible participants so the process is less time consuming for the therapists. Another way to add to the opportunity for recruiting participants would be to add significance to the study and educational intervention by placing the study information and invitation to participate letter on hospital letterhead. Potential subjects may have viewed the study as more official and made participating in the intervention more of a priority. The length of the recruitment period was likely not long enough, if more time had been available to recruit potential subjects this may have resulted in a larger study sample size. Future studies should include different groups of people with breast cancer related lymphedema to explore the similarities and differences regarding the essential elements of the lymphedema experience.

A third area for improvement was the educational intervention. As previously mentioned, seeking more input from the lymphedema therapists for suggestions on the educational intervention would have strengthened the final product. The therapists may have had ideas and suggestions to improve the intervention and make it more beneficial or more relevant for the participants. In discussing the intervention with the lymphedema therapist after the study was complete, one suggestion was that the time between lymphedema treatment completion and the intervention was not long enough. The

decrease in lymphedema that the participants maintained may not have been due to the intervention, but rather the short period of time between the intervention and the follow-up. This is another aspect to be considered in future studies. Not only may the length of time between the intervention and follow-up been too short, the intervention consisted of only one point of contact with the participants. One of the most important variables in self-efficacy enhancing interventions is duration of the intervention with more than one point of contact is necessary (Rehse & Pukrop, 2003). Future studies may benefit from including more than one session in the efficacy enhancing intervention.

A fourth area for improvement is the instrumentation used to capture quality of life scores. The Functional Assessment of Cancer Therapy - Breast, captured the functional aspect for quality of life but no attempt was made to capture the affective state of quality of life. To capture this missing element, future studies could include the Profile of Mood States questionnaire to measure the affective state of quality of life. The Profile of Mood States has been widely used and validated in general psychotherapy research and has been perhaps the most commonly used instrument measuring outcome of psychological intervention with cancer patients (Cunningham et al., 1991).

The last limitation of the study to be discussed was also one of the strengths of the study. The follow-up focus group provided detailed information about the lived lymphedema experience and this supplemented the information garnered from the quantitative data. However, the focus group could have been used as a tool to capture more pertinent information about ways to improve the educational intervention from the point of view of the participants. This session could have been used to find out more information about what the participants thought of the self-efficacy and quality of life

questionnaires. Did the questionnaires capture their experiences, were the questions difficult to answer, were the questionnaires too time consuming to complete represent some of the questions that could have been explored during the focus group. In addition to the questionnaires, this would also have been an opportunity to discuss with the participants why they agreed to participate in the study and find out any suggestions they may have for improving recruitment strategies for future studies.

Two further factors to be considered in future extensions of this study would be to control for participant's dominant arm (right vs. left) and level of education. With respect to understanding the effect lymphedema has on quality of life, a quota sample could be utilized to account for an individual's the dominant arm. Participant recruitment could divide the potential sample population into left-handed and right-handed categories and a quota could be used to ensure selecting participants allows for accounting of the dominant arm. By recruiting in this way, it would allow for researcher to account for the role of dominant in the lymphedema → quality of life relationship. Furthermore, use of a stratified sample would also help to explore if there is a relationship between level of education and self-efficacy. That is, how does level of education affect self-efficacy? Recruitment of participants into educational categories such as "less than high school", "high school", "university/college education" and "graduate level of education" would provide a broad educational sample that would facilitate an investigation of the relationship between level of education and self-efficacy. As these two areas have been understudied in the literature, investigating the above potential relationships may add to the understanding of self-efficacy and quality of life in women with breast cancer related lymphedema.

During the focus group, questions were asked about what the participants thought of the intervention and what could have been done to improve future sessions. A difficulty with the way the focus group was conducted was the researcher was the person asking the questions. As a result, bias may have been introduced, as the participants may have been reluctant to be forthcoming about their true opinion of the educational intervention. One way to improve the focus group in future studies would be to have an independent moderator facilitate the focus group so the participants are able to openly discuss their opinions about the intervention. Based on the findings of this study and considering both the limitations and strengths, studies using larger sample sizes, longer follow-up periods, additional measurement instruments, and interventions with more than one point of contact may enhance future findings.

Implications for Nursing Practice

Using self-efficacy theory, nurses can develop interventions to promote self-management behaviours in people with breast cancer related lymphedema. The strongest source of self-efficacy is the actual performance of the behaviour. This suggests that nurses are in an ideal situation to develop interventions or provide opportunities for people to successfully perform self-care activities and thus enhance self-efficacy and continuation of health promoting behaviours. For nursing interventions based on self-efficacy theory to be successful, they should focus on all four sources of self-efficacy. Possible interventions for people with breast cancer related lymphedema include support groups (which target vicarious experience and verbal persuasion), providing encouragement and training sessions (verbal persuasion and emotional state) and the opportunity to practice new behaviours (performance accomplishment).

Nurses are also in a position to educate women at risk of developing lymphedema after breast cancer treatment about prevention strategies. Probably one of the most important preventative measures is informing women of their risk for lymphedema both pre and post treatment (Paskett & Stark, 2000; Radina et al., 2004). Women may be taught about lymphedema during the stressful diagnostic and pre-treatment period but may not recall the information. When facing more immediate and urgent decisions about breast cancer treatment, information about lymphedema may not appear to be a priority and therefore not remembered. As a result, it is important to review the information about lymphedema along with continued assessment as part of comprehensive post breast cancer treatment care. Nurses can play an important role in educating breast cancer patients at risk for developing lymphedema that the condition requires specialized treatment, life-long precautions, and ongoing self-management. These patients must receive information about how to identify the signs and symptoms of lymphedema early, the need to report these signs to their healthcare team and be educated as to how to seek out appropriate treatment. Not only are nurses in a position to educate patients, they can also take on the educative role with other healthcare professionals and the public to increase people's knowledge base about lymphedema.

Summary

This study provided quantitative and qualitative descriptions of women's experiences with breast cancer related lymphedema. The findings indicated that as self-efficacy and quality of life trended upwards, the women in the study maintained the level of lymphedema achieved during their treatment. These findings are supported by the focus group findings, namely the three main themes of the survivorship experience, the

lymphedema experience, and the shared group experience. The results of this study provide the basis for future research into not only the physical aspect of lymphedema but also direct nurses to examine the psychological indications of lymphedema. Nurses are in an ideal position to provide nursing interventions that address the need to improve knowledge about lymphedema. Future researchers can build upon this study to improve the outcomes for patients with breast cancer related lymphedema, through targeting self-efficacy, self-management techniques, and ultimately quality of life.

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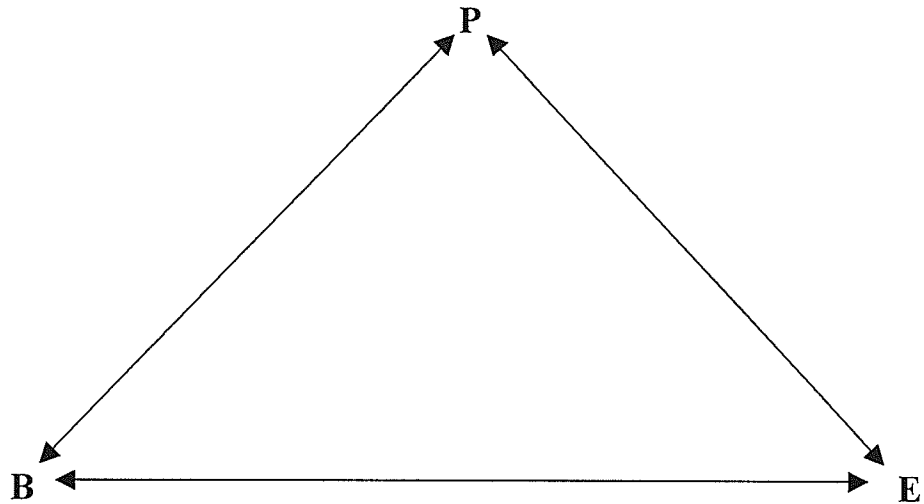
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Appendix A

Diagrammatic Representation of Triadic Reciprocity



The relationships between the three major classes of determinants in triadic reciprocity. All relationships and influences are bi-directional. B represents behaviour; P the internal personal factors in the form of cognitive, affective, and biological events; and E the external environment (Adapted from Bandura, 1986).

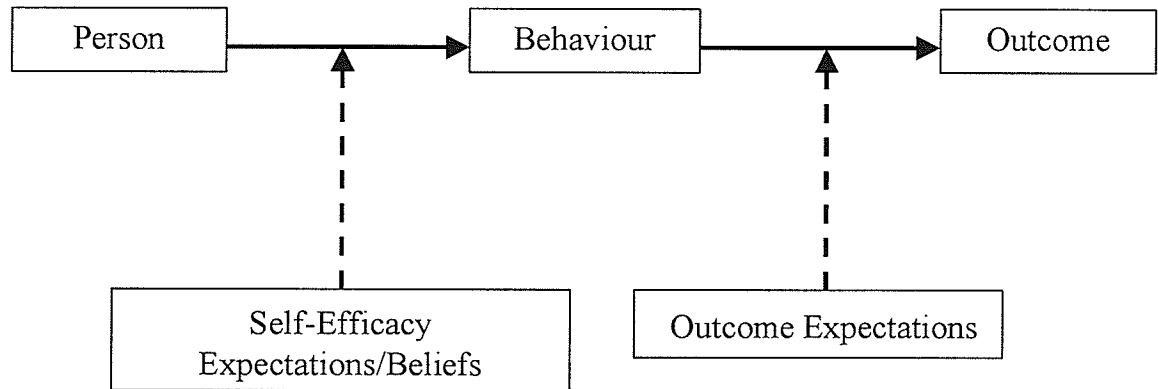
Appendix B

The Sources of Self-efficacy Beliefs and Their Mode of Induction

<i>Source</i>	<i>Mode of Induction</i>
<i>Performance Accomplishments</i>	Participant Modeling Performance Desensitization Performance Exposure Self Instructed Performance
<i>Vicarious Experience</i>	Live Modeling Symbolic Modeling
<i>Verbal Persuasion</i>	Suggestion Exhortation Self Instruction Interpretive Treatments
<i>Emotional Arousal</i>	Attribution Relaxation, Biofeedback Symbolic Desensitization Symbolic Exposure

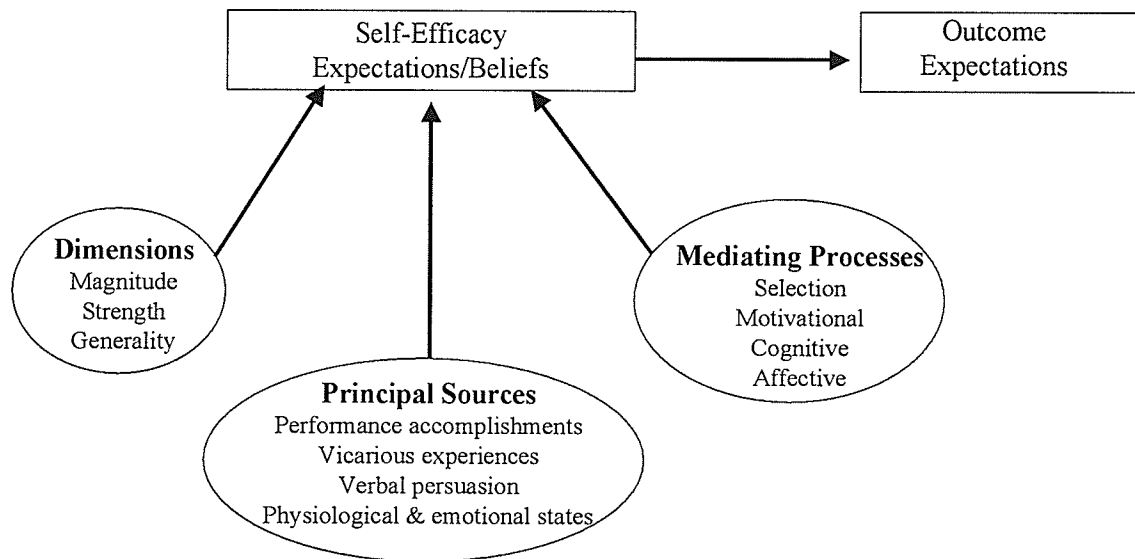
Major sources of efficacy information and the principal sources through which different modes of treatment operate. (Adapted from Bandura, 1977).

Appendix C
Self-efficacy Model



(Adapted from Bandura, 1977, 1995)

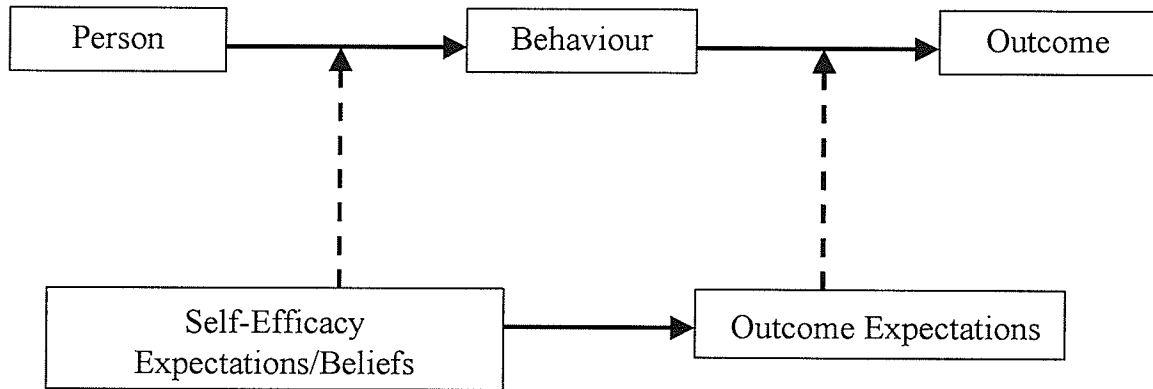
Appendix D

Schematic Representation of Relationship Between
Self-Efficacy and Outcome Expectations

(Adapted from Bandura, 1986, 1997)

Appendix E

Diagrammatic Representation of the Relationships in the Self-Efficacy Model



(Adapted from Bandura, 1977, 1995)

Appendix F

Correlational Table of the Variables in Self-efficacy Theory

	SE	OE	SSE	MP	DSE
SE	+	+	(+)	(+)	(+)
OE		+	(+)	(+)	(+)
SSE			+	?	?
MP				+	?
DSE					+

SE = Self-efficacy beliefs
 OE= Outcome expectations
 SSE= Sources of self-efficacy
 MP= Mediating processes
 DSE= Dimensions of self-efficacy
 + = Positive relationship
 ? = Unknown relationship
 () = Implied relationship

(Adapted from Walker & Avant, 2005)

Appendix G

Invitation to Participate

Gwen McGhan is a registered nurse and graduate student in the Faculty of Nursing at the University of Manitoba. As part of her Master of Nursing degree, Gwen is doing research at the Breast Health Centre. Her research includes investigating ways to help breast cancer patients with lymphedema manage their condition and improve their quality of life.

Whether you decide to participate in the study is entirely voluntary and if you decide not to participate it will in no way affect the care that you receive. Any information that is gathered in the study will be kept strictly confidential.

Would you be willing to speak with Gwen so she may explain the study to you in more detail? You can let your lymphedema therapist know about your decision by indicating whether you would like to speak with Gwen on the bottom of this invitation. You may return this invitation to your lymphedema therapist before the end of your treatment.

Yes, I agree to speak with Gwen

Name: _____

No, I do not agree to speak with Gwen

Appendix H

Research Subject Information and Consent Form

Research Project Title: Enhancing Self Efficacy: Will it Improve Quality of Life and Lymphedema Management for Patients with Breast Cancer Related Lymphedema?

Researcher: Gwen McGhan, RN, BN
Graduate Student
Faculty of Nursing
University of Manitoba

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose

The purpose of this research study is to examine if a person's belief about her ability to perform health care behaviours affects quality of life and self-care practices in breast cancer survivors with lymphedema. All participants will have received lymphedema treatment through the Breast Health Centre. To be included in this study, participants must be breast cancer patients currently receiving treatment for lymphedema, at least eighteen years of age, living independently, able to read and write English, willing to participate, and able to provide written consent. Lymphedema patients not eligible for this study include patients with an acute illness (such as active cancer), patients who report psychological or cognitive disorders or physical limitations in self-care, and patients who are on diuretic therapy or other edema influencing drugs. This research is being conducted to complete the requirements for a Master of Nursing degree at the University of Manitoba, under the supervision of Lesley Degner, RN, Ph.D.

Procedure

You are requested to read and sign this consent form. Once your consent form is completed you will be given three surveys to complete. The first survey will give the researcher general information, such as age and marital status. The second survey will ask questions about how confident you feel in doing self-care activities. The third form will ask questions about your current quality of life. Upon completion of your lymphedema treatment, there will be a session on lymphedema management in which you will have the opportunity to share your experiences, learn more about lymphedema, and hear from other women who are successfully managing their condition. At this session, you will once again fill out the questionnaires about your confidence for doing

self-care activities and your quality of life. One month after this session, the study participants will regroup and fill out the same two surveys about self-care activities and quality of life. Also at this session, the Comparative Circumferential Measurement Method (CCMM) will be used to assess the degree of lymphedema to help determine if the educational intervention was helpful to you in managing the edema in your affected limb. In CCMM, a tape measure is used to take measurements at defined points along both limbs. The difference at each point is calculated, and then the sums of the differences are added together to determine the degree of lymphedema. At the end of this follow-up session, the researcher will ask you questions about whether you found the lymphedema management information helpful or not. Notes will be taken during this follow-up session but your responses will not be tape-recorded. Finally, three months after the lymphedema management session, you will be mailed the same two questionnaires and are asked to return the completed forms to the researcher. In total, your participation in the study will take about 4 hours of your time.

Risks

There are no known risks associated with participation in this study. However, being asked about your feelings and quality of life may cause some distress. If this should happen to you, a list of health care support services in your community will be given to you with your surveys.

Benefits

This study may have benefit to you as it may provide you with additional information about the care and management of lymphedema. The information collected in this study will add to a better understanding of patients' experiences with lymphedema. Information collected in this study will also provide nurses and other health care professionals with a better understanding of how to provide improved care for patients with lymphedema.

Confidentiality

The potential names of participants have been obtained from the staff at the Breast Health Centre. Any medical information collected from your chart will be handled under the guidelines of the Personal Health Information Act (PHIA) of Manitoba. All information will be treated as confidential, and a code number, rather than your name, will be used on all surveys. *Please do not put your name on any survey*, as this will help to ensure confidentiality. The follow-up session will include a focus group discussion in which participants will be invited to share their thoughts and feelings and provide insight into ways to improve the intervention. Due to the open discussion at the session, neither participants' anonymity nor confidentiality of their comments can be maintained from other members of the focus group. As such, it is important that participants in the focus group do not reveal the identity or specifics of anyone else's comments that are shared during the follow-up session. Although information from this study may be published or presented in public forums, your name or any identifying information will never be

revealed. During and after the research all the surveys will be securely locked up, and after seven years the surveys will be destroyed.

Compensation

To compensate for the cost of your transportation, you will receive a stipend of \$8.

Voluntary Participation

Your decision to participate in this study is entirely voluntary. You may choose not to participate or withdraw from the study at any point. A decision to not participate or withdraw from the study will not affect the care you receive at the Breast Health Centre.

Feedback

If you are interested in the findings from this study, please indicate so at the end of the form. A summary of the report will be mailed to you upon completion of the study.

Consent

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Principal Researcher:

Gwen McGhan, RN, BN

Supervisor:

Lesley Degner, RN, Ph.D.
474-6767

This research has been approved by the Education and Nursing Ethics Review Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Printed Name _____

Participant's Signature _____ Date _____

Researcher's Printed Name _____

Researcher's Signature _____ Date _____

I would like to receive a summary of the results of this study:

(Please check one) Yes _____ No _____

If yes, please mail the summary to:

Name _____

Address _____

Appendix I

Access to Health Records Consent Form

Research Project Title: Enhancing Self Efficacy: Will it Improve Quality of Life and Lymphedema Management for Patients with Breast Cancer Related Lymphedema?

Researcher: Gwen McGhan, RN, BN
 Graduate Student
 Faculty of Nursing, University of Manitoba

The purpose of this research study is to examine if a person's belief about her ability to perform health care behaviours affects quality of life and self-care practices in breast cancer survivors with lymphedema. You are requested to read and sign this consent form. The purpose of this form is to authorize the researcher of the study to access your health records. Specifically, your health records will be accessed to obtain the following information, as required: type of breast cancer surgery, number of lymph nodes identified, whether radiation and chemotherapy were part of the breast cancer treatment regime, time since breast cancer treatment finished, and finally, the degree of lymphedema in the affected limb upon completion of lymphedema therapy. Any medical information collected from your chart will be handled under the guidelines of the Personal Health Information Act (PHIA) of Manitoba.

Signing this consent form indicates that you give the researcher for this study the permission to access your health records for specific information as outlined above.

Principal Researcher:

Gwen McGhan, RN, BN

Supervisor:

Lesley Degner, RN, Ph.D.
474-6767

This research has been approved by the Education and Nursing Ethics Review Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Printed Name

Participant's Signature

Date

Researcher's Printed Name

Researcher's Signature

Date

Appendix J

Patient No. _____

Patient Demographic Data Form

Please circle the number of the item that is applicable to you. Please fill in the blanks where further information is required.

1. How old are you?

2. What is your current marital status?

- 01 Single/Never Married
- 02 Married/Common Law
- 03 Divorced/Separated
- 04 Widowed
- 05 Other (Please Specify) _____

3. What is the highest level of schooling or education you have finished?

- 01 No formal schooling
- 02 Elementary school
- 03 High school
- 04 Community/Technical college
- 05 University
- 06 Other (Please Specify) _____

4. What is your occupational status?

- 01 Full-time
- 02 Part-time
- 03 Retired
- 04 Unemployed/Don't work
- 05 Medical Leave
- 06 Student

5. Does your current occupation involve heavy lifting or repetitive arm movements?

- 01 Yes (Please Specify) _____
02 No

6. Did you receive surgery as part of your breast cancer treatment?

- 01 Yes (Please Specify Type) _____
02 No

7. If you received surgery as part of your treatment, how many lymph nodes were identified?

- 01 0-5
02 6-10
03 11-15
04 More than 15
05 Did not have surgery

8. Did you receive radiation therapy as part of your breast cancer treatment?

- 01 Yes
02 No

9. Did you receive chemotherapy as part of your breast cancer treatment?

- 01 Yes
02 No

10. How long has it been since you finished your breast cancer treatment?

- 01 0 to 6 months
02 6 months to 1 year
03 1 to 2 years
04 2 to 3 years
05 3 to 4 years
06 4 to 5 years
07 More than 5 years

Appendix K

Patient No. _____

Strategies Used by People to Promote Health (Lev & Owen, 1996)

Your answers on this questionnaire will help us to learn more about how people deal with illness. Some people use their own methods such as prayer, relaxation techniques, visualization, physical exercise and other techniques, which they feel are helpful. We are interested in what you do. The following questions are answered on a scale from 1 to 5 with 1 being "very little confidence" and 5 being "a lot confident". Please circle the appropriate answer that applies to you.

		Very Little Confidence	Little Bit Confident	Somewhat Confident	A Bit Confident	A Lot Confident
1.	I have confidence in my ability to keep my stress within healthy limits.	1	2	3	4	5
2.	I have confidence in my ability to convince myself I'll be okay.	1	2	3	4	5
3.	I have confidence in my ability to find a way to get me through this time.	1	2	3	4	5
4.	I have confidence in my ability to manage to keep anxiety about my illness from becoming overwhelming.	1	2	3	4	5
5.	I have confidence in my ability to deal with the frustration of illness and treatment.	1	2	3	4	5
6.	I have confidence in my ability to help myself feel better if I am feeling blue.	1	2	3	4	5
7.	I have confidence in my ability to convince myself my treatment is not so bad.	1	2	3	4	5
8.	I have confidence in my ability to believe that I really have a positive attitude about my state of health.	1	2	3	4	5

		Very Little Confidence	Little Bit Confident	Somewhat Confident	A Bit Confident	A Lot Confident
9.	I have confidence in my ability to believe I can find strength within myself for healing.	1	2	3	4	5
10.	I have confidence in my ability to keep my anxiety in check during stressful periods.	1	2	3	4	5
11.	I have confidence in my ability to think myself better off than other people who became ill when they were younger than I am now.	1	2	3	4	5
12.	I have confidence in my ability to manage the side effects of my treatment so I can do things I enjoy doing.	1	2	3	4	5
13.	I have confidence in my ability to exclude upsetting thoughts from my consciousness.	1	2	3	4	5
14.	I have confidence in my ability to be able to refocus on something not associated with my illness as a way of decreasing my anxiety.	1	2	3	4	5
15.	I have confidence in my ability to do things that helped me to cope with previous emotional difficulties.	1	2	3	4	5
16.	I have confidence in my ability to appreciate what is really important in life.	1	2	3	4	5
17.	I have confidence in my ability to do things to control my fatigue.	1	2	3	4	5
18.	I have confidence in my ability to practice stress reduction techniques even when I'm feeling sick.	1	2	3	4	5
19.	I have confidence in my ability to believe that using a technique to manage treatment stress will actually work.	1	2	3	4	5

		Very Little Confidence	Little Bit Confident	Somewhat Confident	A Bit Confident	A Lot Confident
20.	I have confidence in my ability to use relaxation techniques to decrease my anxiety.	1	2	3	4	5
21.	I have confidence in my ability to find ways to alleviate my stress.	1	2	3	4	5
22.	I have confidence in my ability to use a specific technique to manage my stress.	1	2	3	4	5
23.	I have confidence in my ability to do things that helped me cope with previous emotional difficulties.	1	2	3	4	5
24.	I have confidence in my ability to make my own decision regarding treatment alternatives.	1	2	3	4	5
25.	I have confidence in my ability to decide for myself whether or not to have treatment.	1	2	3	4	5
26.	I have confidence in my ability to choose among treatment alternatives recommended by my physician the one that seems right for me.	1	2	3	4	5
27.	I have confidence in my ability to experience life's pleasures since I became ill.	1	2	3	4	5
28.	I have confidence in my ability to do special things for myself to make life better.	1	2	3	4	5
29.	I have confidence in my ability to help other people going through illness and treatment.	1	2	3	4	5

Appendix L

Patient No. _____

Functional Assessment of Cancer Treatment – Breast +4 Questionnaire
(Adapted from Yellen et al. 1987 and Coster et al., 2001)

Below is a list of statements that other people with your illness have said are important. By circling one number per line, please indicate how true each statement has been for you *during the past 7 days*.

During the past 7 days:

PHYSICAL WELL-BEING

	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I have a lack of energy	0	1	2	3	4
2. I have nausea	0	1	2	3	4
3. I have trouble meeting the needs of my family	0	1	2	3	4
4. I have pain	0	1	2	3	4
5. I am bothered by side effects of treatment	0	1	2	3	4
6. In general, I feel sick	0	1	2	3	4
7. I am forced to spend time in bed	0	1	2	3	4

8. How much does your PHYSICAL WELL-BEING affect your quality of life?
Not all 0 1 2 3 4 5 6 7 8 9 10 Very much so

**During the past 7 days:
SOCIAL WELL-BEING**

	Not at all	A little bit	Some- what	Quite a bit	Very much
9. I feel distant from my friends	0	1	2	3	4
10. I get emotional support from my family	0	1	2	3	4
11. I get support from my friends and neighbours	0	1	2	3	4
12. My family has accepted my illness	0	1	2	3	4
13. Family communication about my illness is poor If you have a spouse/partner or are sexually active please answer #14-15. Otherwise go to #16	0	1	2	3	4
14. I feel close to my partner (or main support)	0	1	2	3	4
15. I am satisfied with my sex life	0	1	2	3	4
16. How much does your SOCIAL WELL-BEING affect your quality of life? Not all 0 1 2 3 4 5 6 7 8 9 10 Very much so					

**During the past 7 days:
EMOTIONAL WELL-BEING**

	Not at all	A little bit	Some- what	Quite a bit	Very much
17. I feel sad	0	1	2	3	4
18. I am proud of how I am coping with my illness	0	1	2	3	4
19. I am losing hope in the fight against my illness	0	1	2	3	4
20. I feel nervous	0	1	2	3	4
21. I worry about dying	0	1	2	3	4
22. How much does your EMOTIONAL WELL-BEING affect your quality of life? Not all 0 1 2 3 4 5 6 7 8 9 10 Very much so					

During the past 7 days:

FUNCTIONAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
23.	I am able to work (include work in home)	0	1	2	3	4
24.	My work (include work in home) is fulfilling	0	1	2	3	4
25.	I am able to enjoy life in the moment	0	1	2	3	4
26.	I have accepted my illness	0	1	2	3	4
27.	I am sleeping well	0	1	2	3	4
28.	I am enjoying my usual leisure pursuits	0	1	2	3	4
29.	I am content with the quality of my life right now	0	1	2	3	4

30. How much does your FUNCTIONAL WELL-BEING affect your quality of life?
 Not all 0 1 2 3 4 5 6 7 8 9 10 Very much so

During the past 7 days:

ADDITIONAL CONCERNS		Not at all	A little bit	Some-what	Quite a bit	Very much
31.	I have been short of breath	0	1	2	3	4
32.	I am self-conscious about the way I dress	0	1	2	3	4
33.	One or both of my arms are swollen or tender	0	1	2	3	4
34.	I feel sexually attractive	0	1	2	3	4
35.	I am bothered by hair loss	0	1	2	3	4
36.	I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
37.	I worry about the effect of stress on my illness	0	1	2	3	4
38.	I am bothered by a change in weight	0	1	2	3	4
39.	I am able to feel like a woman	0	1	2	3	4

	On which side was your breast operation?	Left		Right		
		Not at all	A little bit	Some-what	Quite a bit	Very much
41.	Movement of my arm on this side is painful	0	1	2	3	4
42.	I have a poor range of arm movements on this side	0	1	2	3	4
43.	My arm on this side feels numb	0	1	2	3	4
44.	I have stiffness of my arm on this side	0	1	2	3	4

Appendix M

18 Steps to Prevention Revised: Lymphedema Risk-Reduction Practices

I. Skin Care - Avoid trauma/injury and reduce infection risk

1. Keep extremity clean and dry.
2. Apply moisturizer daily to prevent chapping/chaffing of skin.
3. Attention to nail care; do not cut cuticles.
4. Protect exposed skin with sunscreen and insect repellent.
5. Use care with razors to avoid nicks and skin irritation.
6. If possible, avoid punctures such as injections and blood draws.
7. Wear gloves while doing activities that may cause skin injury (i.e., gardening, working with tools, using chemicals such as detergent).
8. If scratches/punctures to skin occur, wash with soap and water, apply antibiotics, and observe for signs of infection (i.e. redness).
9. If a rash, itching, redness, pain, increased skin temperature, fever or flu-like symptoms occur, contact your physician immediately.

II. Activity / Lifestyle

1. Gradually build up the duration and intensity of any activity or exercise.
2. Take frequent rest periods during activity to allow for limb recovery.
3. Monitor the extremity during and after activity for any change in size, shape, tissue, texture, soreness, heaviness or firmness.
4. Maintain optimal weight.

III. Avoid limb constriction

1. If possible, avoid having blood pressure taken on the at risk arm.
2. Wear loose fitting jewelry and clothing.

IV. Compression Garments

1. Should be well-fitting.
2. Support the at risk limb with a compression garment for strenuous activity (i.e. weight lifting, prolonged standing, running).
3. Wear a well-fitting compression garment for air travel.

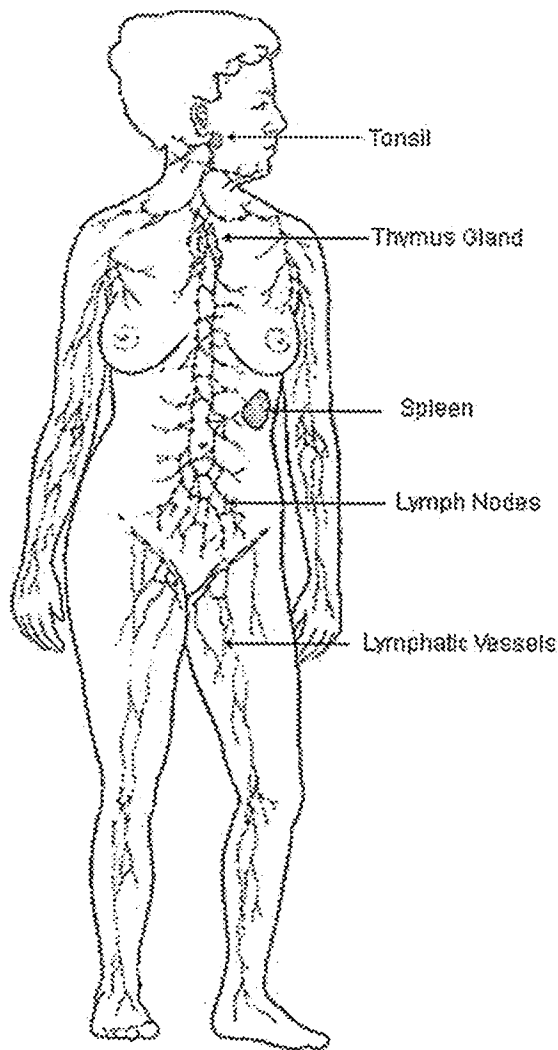
V. Extremes of Temperature

1. Avoid exposure to extreme cold, which can be associated with rebound swelling, or chapping of skin.
2. Avoid prolonged (> 15 minutes) exposure to heat, particularly hot tubs and saunas.
3. Avoid immersing limb in water temperatures above 102° F.

Appendix N

What is the lymphatic system?

The lymphatic system is a system of thin tubes that runs throughout the body. These tubes are called 'lymph vessels'. The lymphatic system consists of bone marrow, spleen, thymus gland, lymph nodes, tonsils, and appendix.



The lymphatic system is like the blood circulation - the tubes branch through all parts of the body like the arteries and veins that carry blood. Except that the lymphatic system carries a colourless liquid called 'lymph'. The lymph system contains a network of vessels that assists in circulating body fluids. These vessels transport excess fluids away from interstitial spaces in body tissue and returns it to the bloodstream.

What does the lymphatic system do?

- Drains fluid back into the bloodstream
- Filters lymph
- Fights infection

Draining fluid into the bloodstream

As the blood circulates, fluid leaks out into the body tissues. This fluid is important because it carries food to the cells and waste products back to the bloodstream. The leaked fluid drains into the lymph vessels. It is carried through the lymph vessels to the base of the neck where it is emptied back into the bloodstream. This circulation of fluid through the body is going on all the time.

Filtering lymph

This is the job of the spleen. It filters the lymph to take out all the old worn out red blood cells. These are destroyed and replaced by new red blood cells that have been made in the bone marrow.

Fighting infection

The lymphatic system helps fight infection in many ways such as:

- Helping to make special white blood cells that produce antibodies
- Having other blood cells called macrophages inside the lymph nodes which swallow up and kill any foreign particles, for example germs

What Is Lymphedema?

Lymphedema is an accumulation of lymphatic fluid in the interstitial tissue that causes swelling, most often in the arm(s) and/or leg(s), and occasionally in other parts of the body. Lymphedema can develop when lymphatic vessels are missing or impaired (primary), or when lymph vessels are damaged or lymph nodes removed (secondary). It is the chronic swelling or feeling of tightness in the arm or hand due to an accumulation of lymphatic fluid in the soft tissue of the arm. The condition occurs when lymph vessels, which normally carry excess fluid out of the limbs and back into central circulation, have had their flow interrupted.

When the interrupted flow becomes so great that the lymphatic fluid exceeds the lymphatic transport capacity, an abnormal amount of protein-rich fluid collects in the tissues of the affected area. Left untreated, this stagnant, protein-rich fluid not only causes tissue channels to increase in size and number, but also reduces oxygen availability in the transport system, interferes with wound healing, and provides a culture medium for bacteria that can result in infection.

What Causes Lymphedema?

Secondary lymphedema, or acquired lymphedema, can develop as a result of surgery, radiation, infection or trauma. Specific surgeries, such as breast, that require removal of lymph nodes, put patients at risk of developing secondary lymphedema. If lymph nodes are removed, there is always a risk of developing lymphedema and it can develop immediately post-operatively, or weeks, months, even years later.

If lymphedema remains untreated, protein-rich fluid continues to accumulate, leading to an increase of swelling and a hardening or fibrosis of the tissue. In this state, the swollen limb(s) becomes a perfect culture medium for bacteria and subsequent recurrent infections. Moreover, untreated lymphedema can lead into a decrease or loss of functioning of the limb(s), skin breakdown, chronic infections and, sometimes, irreversible complications.

(Adapted from the National Lymphedema Network, www.lymphnet.org)

Appendix O

Cool Tips For A Hot Summer

Summertime...and the livin' is easy...maybe.

If you have lymphedema, maybe not. The hot weather, increased number of biting and stinging insects, and many other factors can go into making summer a time of increased risk. Summer fashions make it harder to conceal a swollen limb. You may find yourself sitting out on the sidelines of many of your previous favorite vacation activities. For many people with lymphedema, summer has become a time to dread instead of a time to look forward to. This article is meant to help you take some sensible precautions so that your lymphedema stays under control while you enjoy the summer.

Beat the Heat

Many people with lymphedema find that their affected limb(s) swell more in the summer because of the heat. It's important to stay cool. If possible, be sure that you are in well air-conditioned places while indoors. Try to limit the time you spend outside during the hotter parts of the day, between 11 a.m. and 3 p.m.

If you do get hot, you need to try to cool your whole body as soon as possible. Cool or lukewarm showers or baths work better than very cold water. If you're hot, but it's not possible at that moment to get into a shower or tub, at least cool off your affected limb by wrapping a cold wet towel around it and elevating it with support. To avoid getting your compression garment wet, place a plastic garbage bag between your garment and the towel, encasing either your limb or the towel. Some people prefer to cool off by dampening the garment itself. If you do this, be sure that the garment dries in a reasonable amount of time and that there is no chafing of the skin, especially at the joint creases.

Drink lots of water, even more than you do in the winter, to help keep yourself well hydrated. This makes it easier for your body to regulate its temperature. Even if salty foods don't normally affect your swelling, they may be more likely to in the summer. For crunchy snacks, go for fresh raw vegetables instead of potato chips.

Wear light, loose, non-constricting clothing. Not only will it be cooler; it is also better for the free flow of your lymphatic system. Because of the tendency of lymphedematous limbs to swell more in the summer; clothes and underwear that fit well in the winter may be too tight for summer wear. Check each day to be sure that the edges of your clothing do not leave indentations in your skin. Do

not wear the item if it leaves indentations - it can constrict some of your delicate superficial lymphatic system. Moreover, looser, non-constricting clothing will allow more air circulation so that perspiration and moisture won't be trapped next to your body.

Garment Care

Be sure that your compression garment is well fitted. If your health insurance covers two compression garments per year, get measured for one of them after the hot weather starts and for the other after it has ended. That way, your garments will accommodate normal seasonal changes in edema that can occur.

In the summer, be especially conscientious about washing your compression garment because sweat, body oils and various lotions such as sunscreen can cause the fabric to deteriorate more quickly. Follow the manufacturer's instructions and cautions very carefully about whether lotion can be applied before putting on the garment. Special care must be taken with garments that contain natural rubber.

Summer Hazards

Being outdoors in the summer can pose more problems than just overheating. Sunburn, prickly heat rashes, and insect bites and stings are also potential problems.

An insect repellent is a good idea but some of the more effective ones contain DEET, which you may not want to have on your skin. Health food stores will have natural repellents, usually with citronella as the active ingredient, and these can be less detrimental to your skin. However, you should avoid putting insect repellent on your skin and then wearing a compression garment over it. That may cause skin reactions and can also damage the fabric of your garment.

No matter which repellent you use, some insect bites probably are inevitable. Be prepared to treat them immediately to lessen the histamine effect, which can cause increased swelling in that area. Benadryl or hydrocortisone creams are two treatment options for insect bites. An ointment with aluminum sulfate as the active ingredient can also help decrease the effects of bites and stings. And a tip from my friend Connie: treat bee stings by applying a paste of meat tenderizer and water to the site of the sting. Treat an insect bite like any break in the skin on your limb at risk. Wash and dry the area completely and apply antibiotic cream to the area.

If you are going camping or hiking, be sure to take along a specialized first aid kit. The kit should include alcohol wipes to clean off any skin break, antibiotic cream for application on the skin, and

bandages to protect the area. If your doctor agrees, you may also include antibiotics in your kit so that you can then start on a course of antibiotics without delay if your limb should become infected (hot, red, swollen, and/or painful) while you are away from home.

Avoid excessive exposure to the sun, not only because of the possibility of overheating, but because sunburn will place an extra burden on your lymphatic system and can damage your superficial lymphatics. Skin that has been radiated may remain sensitive to the sun long after radiation treatment has ended. Also bear in mind that you can sometimes get a sunburn even when wearing a compression garment. If your limb is going to be exposed to the sun (for example when you are swimming and do not have your compression garment on) be sure to use a sunscreen with a high SPF (sun protection factor) of 20-30+. And if you are going in water, wear the waterproof kind.

In the Swim

Swimming is a great summer recreation and recommended for people with lymphedema (scuba diving is even better), but there are some risks involved. While the chlorine in the pool is helpful to keep it disinfected, it may be very drying to your skin. Apply a moisture barrier cream before getting in the water (and a sunscreen that is waterproof) and a good moisturizing lotion after you finish swimming.

Although you don't necessarily need to wear a compression garment while swimming, you will need to apply some compression as soon as you are out of the water. Some people wear an older compression garment into the water and let it dry on them when they get out. If you don't want to do this or if you don't have a second compression garment you can use, you may need to have your bandages or your compression garment ready and waiting at the side of the pool or on the beach. If you use an alternative to night bandages such as a CircAid, Reid Sleeve, or MedAssist, all of which are fast and easy to don, you may wish to use the alternative compression device when you first get out of the water. Then you can don your compression garment when you are somewhere more convenient.

After swimming, take a shower or bath with fresh water to wash off. As with any time that you bathe, be sure to dry completely, especially between the toes, under the breasts, and in any skin folds. Using an unscented bath powder or an anti-fungal powder can help prevent fungal infections, which thrive in a moist environment. Powdering the inside of your shoes with anti-fungal powder can be helpful in the summer when your feet may tend to perspire more.

Traveling with Lymphedema

One of the great things about summer is going on vacation. But you don't want to arrive at your destination and find that your edematous limb is more swollen and uncomfortable. Car, train, and bus travel is generally worse for people with leg lymphedema, while airline travel can affect people with either arm or leg lymphedema.

If going by car, use air-conditioning to be sure you do not overheat. When not driving, sit in the back seat so that your limb can be elevated. With arm lymphedema, do not do the driving for long periods of time and be sure to take breaks to rest your arm. If traveling by train, walk in the aisle as much as possible. If traveling by bus, be sure to get off at each rest stop to walk around. If traveling by plane you will need to take more extensive precautions because the lower air pressure in the cabin can trigger or exacerbate lymphedema much more seriously than the inactivity-aggravated lymphedema of car, train, or bus travel. Be sure to have your compression bandage or garment on, including a glove for the hand and fingers, if you have arm lymphedema. Also, if you have arm lymphedema, take only the lightest carry on luggage and use wheeled suitcases (or rent a luggage trolley) for your checked luggage. Drink lots of water during the flight. To make sure you have enough, it's best probably to bring your own water.

Sports

Pace yourself, play for shorter periods of time, take breaks at regular intervals, and make sure you do not wear any constricting clothing. If your affected limb starts feeling tight, achy, bursting, fatigued, or heavy, then stop the activity at once. Those symptoms indicate that your lymphatic system is overloaded. Loosen anything that has become constricting, cool your limb off, and rest with the limb supported in an elevated position until the symptoms subside.

Activities that involve repeated movements against resistance (such as tennis or weight-lifting) or the danger of hard contact of a ball with your limb (soccer or volleyball) put your limb at more risk-but there are definitely people with lymphedema out there enjoying them.

This is really the take-home message: the precautions recommended when you have lymphedema or are at risk for it are not meant to keep you from living your life by hemming you in with all the "don'ts." Instead, these precautions are intended to give you a better chance at keeping your lymphedema under control so that you are free to get on with your life.

Appendix P

Goals for Lymphedema Management

For the next 6 weeks I will do the following to help myself manage my lymphedema:

1. _____

2. _____

3. _____

4. _____

5. _____

Appendix Q

Informal Interview Guide

The questions for the focus group were divided into three main sections: the intervention, managing lymphedema and the impact lymphedema has on quality of life.

The Intervention

1. What did you think of the intervention?
2. Did you find it helpful?
3. What could be done to improve the intervention?
4. What would you add? Take out?

Managing Lymphedema

1. What is it like for you to have lymphedema?
2. What makes you take care of your lymphedema? What motivates you?
3. How do you take care of yourself? Physically? Emotionally?
4. What obstacles did you face in managing your lymphedema? What was the most difficult?

Lymphedema and Quality of Life

1. What has been your general experience of lymphedema?
2. How does lymphedema affect your lifestyle?
3. How do you cope with lymphedema? What do you find helpful?
4. What have been the responses of other people such as family and strangers?
5. What are your future expectations? How do you see your future with lymphedema?