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Preparing for and Coping with Breast Cancer-Related Lymphedema

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1. Introduction

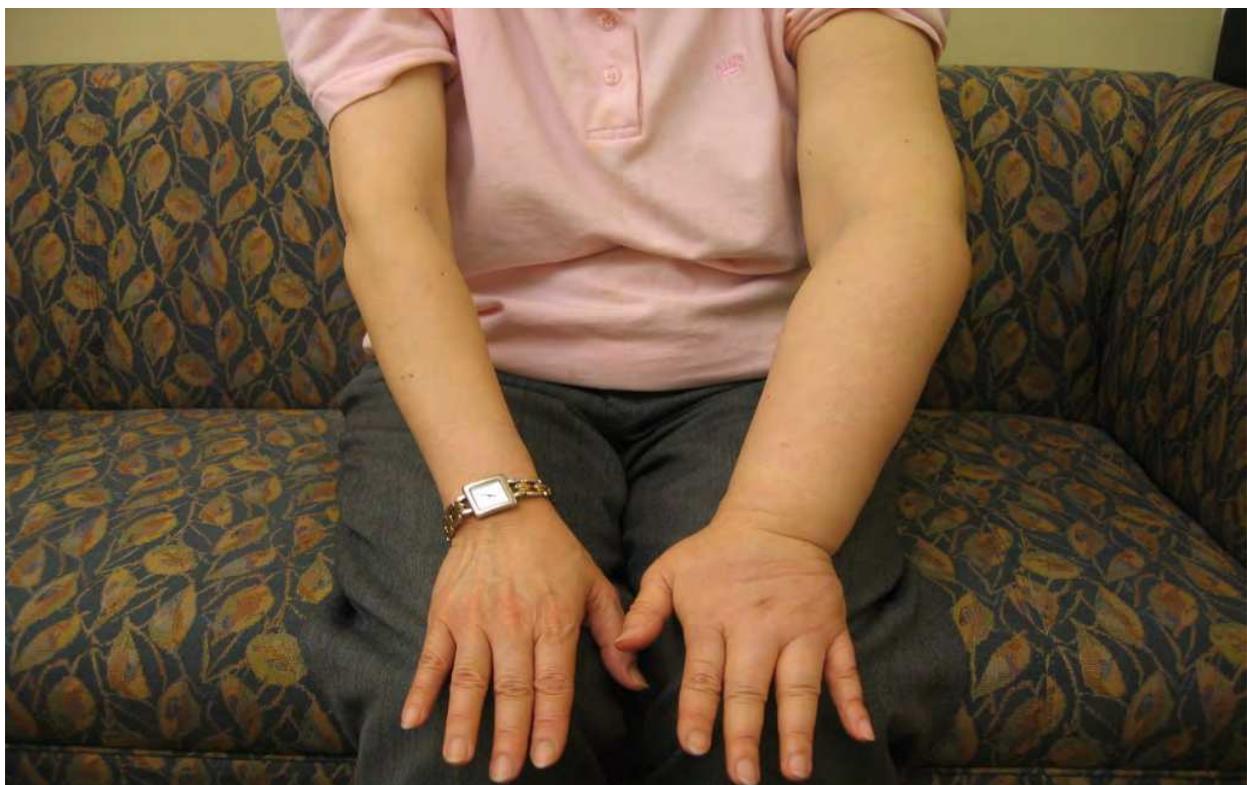
Despite recent trends indicating that new diagnoses of breast cancer have decreased slightly, the American Cancer Society estimates that there will be 207,090 new cases of invasive breast cancer and 54,010 new cases of in situ (i.e., early stage) breast cancer that are likely to have developed in 2010 (American Cancer Society, 2010). Given that the 5-year survival rate for breast cancer is now 90% and that the National Cancer Institute estimates that there were approximately 2.5 million women living in 2006 who had a history of breast cancer (American Cancer Society, 2010; Horner et al., 2009), experiencing breast cancer is increasingly about survivorship. Breast cancer survivors are at lifetime risk for developing lymphedema, a chronic condition that occurs in up to 40% of this population (Armer, Stewart, & Shook, 2009; American Cancer Society, 2007; Ferlay, Bray, Pisani, & Parkin, 2004). Lymphedema involves the accumulation of protein-rich fluid that impacts physical, functional, and psychosocial health and well-being. Second only to breast cancer recurrence, lymphedema is the most dreaded outcome of breast cancer treatment. Research has shown that women with breast cancer-related lymphedema report their most frequent action for management of lymphedema symptoms is no action (Armer & Whitman, 2002). This indicates that patient education about self-care is critical for effective self-management and risk reduction. Given the distressing and chronic nature of breast cancer-related lymphedema, there are both individual and family level psychosocial impacts related to the onset and long-term management.

This chapter is aimed at addressing real and present concerns for both patients and their family members regarding breast cancer-related lymphedema. All too often these individuals are poorly prepared to cope with the potential or actual realities of living with this physically limiting chronic condition. At the same time, many patients and family members report being both unaware that lymphedema was a possible outcome of breast cancer treatment and that medical staff, in particular oncologist and surgeons, are not well informed and/or not helpful in guiding them on how to cope. What is offered in this chapter is an overview of the condition with special attention paid to informing readers (e.g., physicians, nursing, social workers, family therapists, and others who work with patients and their families) so that they might be better equipped to serve patients and the family members. Thus, the focus of this chapter is thus two-fold: 1) patient (and family

member/ caregiver) education regarding strategies for early detection, risk reduction, and management/self-care and 2) individual and family level psychosocial impacts of coping with breast cancer-related lymphedema.

2. Defining breast cancer-related lymphedema

Breast cancer-related lymphedema, a syndrome of abnormal swelling and multiple distressing symptoms, is a major adverse effect of breast cancer treatment (Fu & Rosedale, 2009). Lymphedema is a chronic condition involving accumulation of protein-rich fluid that impacts physical, functional, and psychosocial health and well-being (Beaulac, McNair, Scott, LaMorte, & Kavanah, 2002; Geller, Vacek, O'Brien, & Secker-Walker, 2003; Hull, 1998; Radina & Armer, 2004; Voogd et al., 2003). (Figure 1).



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Fig. 1. Example of Breast Cancer-related Lymphedema.

While the exact cause of breast cancer-related lymphedema is unknown, evidence suggests that some cancer treatments may increase the risk of developing breast cancer-related lymphedema; risks that include the surgical removal of lymphatic vessels and nodes and the development of tissue fibrosis that sometimes follow radiation treatments, infection, or surgery (Kwan et al., 2002). Common breast cancer treatments damage and potentially weaken the lymph nodes and the vessels carrying lymph fluid, which may then compromise the effectiveness of the valves in the lymph vessels (Smith, 1998). The result is the accumulation of lymph fluid in the tissues of the arm, hand, chest, back, and neck (Berne & Levy, 1996). Changes in physical appearance and limitations created by lymphedema can affect physical and psychological health as well as interpersonal

relationships (Casley-Smith, 1992; Passik & McDonald, 1998; Passik, Newman, Brennan, & Tunkel, 1995; Radina, Watson, & Faubert, 2009; Thomas-MacLean, Miedema, & Tatemichi, 2005). Although women with breast cancer-related lymphedema report a variety of physical symptoms (e.g., pain, heaviness, tenderness, numbness, limited range of motion, and stiffness), arm swelling is the most common (Armer, Radina, Porock, & Culbertson, 2003; Coster, Polle, & Fallowfield, 2001; Thomas-MacLean et al., 2005). In addition, those coping with this chronic, sometimes disabling, condition are subject to frustrating physical limitations (e.g., being unable to lift heavy objects; reducing activities that require repetitive motions with the arm; keeping the arm elevated) (Radina & Armer, 2001; Ridner, 2002).

3. Diagnosis of breast cancer-related lymphedema

Early diagnosis of breast cancer-related lymphedema remains a clinical challenge. Traditionally, lymphedema has been clinically diagnosed by healthcare professionals' observations of swelling, and has often arbitrarily been defined in research as a 2-cm increase in limb girth, a 200-mL or more increase in limb volume, or a 5% or greater limb volume change (Armer et al., 2004; Cormier et al., 2009; Stout et al., 2008). Inconsistency in the criteria defining lymphedema and the use of different measures has posed tremendous difficulty in accurately diagnosing lymphedema (Armer & Stewart, 2005). Additional contributing factors to the challenge include failure to precisely evaluate symptoms related to lymphedema, co-existing conditions, insufficient knowledge and lack of awareness among healthcare professionals. Several diagnostic approaches have been used for diagnosing breast cancer-related lymphedema, including the patient's health history and physical examination, measures of limb volume, and lymph vessel imaging.

3.1 Health history and physical examination

Early and accurate diagnosis of breast cancer-related lymphedema is essential to prevent complications and achieve optimal management. A careful review of the patient's health history can promote accurate diagnosis to rule out other medical conditions that may cause similar symptoms. Such medical conditions include recurrent cancer, deep vein thrombosis, chronic venous insufficiency, diabetes, hypertension, cardiac and renal disease. These alternative diagnoses should be ruled out before establishing a diagnosis of lymphedema and referring the patient for lymphedema therapy.

A four-stage system (Table 1) can be used to facilitate physical examination to classify lymphedema in terms of skin condition and swelling (International Society of Lymphedema [ISL], 2003). Within each stage, severity of lymphedema based on volume difference can be assessed as mild (<20% increase), moderate (20-40% increase), or severe (>40% increase). It should be noted that a clinical diagnosis of lymphedema in the current practice patterns is very often made when swelling becomes visually evident and is usually classified as "mild" lymphedema. Mild lymphedema is often defined as an initially reversible. However, by the time lymphedema is visually observable (as described in the Stage 2) it has already evolved into the irreversible advanced stages.

Stages	Presentations
0 Latent or sub-clinical condition	<ul style="list-style-type: none"> • No noticeable swelling • No pitting • A feeling of heaviness • Existing months or years before overt swelling occurs
i. Early accumulation of lymph fluid	<ul style="list-style-type: none"> • Pitting swelling • Visible swelling
ii. Increased or chronic swelling	<ul style="list-style-type: none"> • Pitting swelling • Hardened and thickened tissue
iii. Lymphostatic elephantiasis	<ul style="list-style-type: none"> • Absence of pitting swelling • Enlarged and obvious swelling of the affected limb • Hardness, thickness, and toughness of skin • Lymph leaking through damaged skin

Table 1. Staging of Lymphedema (International Society of Lymphedema ([ISL], 2003)

Symptom assessment is essential since very often observable swelling and measurable volume changes are absent during the initial development of lymphedema, but patients may report such symptoms as heaviness, tightness, firmness, pain, or numbness (Cormier et al., 2009; Fu & Rosedale, 2009). These symptoms may be the earliest indicator of increasing interstitial pressure changes associated with lymphedema (Kosir et al., 2001). As the fluid increases, the limb may become visibly swollen with an observable increase in limb size. Recent research shows that limb volume change (LVC) by the infra-red perometer has significantly increased as breast cancer survivors' reports of swelling, heaviness, tenderness, firmness, tightness, and aching have increased (Cormier et al., 2009). On average, breast cancer survivors reported 4.2 symptoms for survivors with <5.0% LVC; 5.5 symptoms for 5.0-9.9% LVC, 7.0 symptoms for 10.0-14.9% LVC, and 12.5 symptoms for > 15% LVC, respectively ($p < 0.001$) (Cormier et al., 2009). Because early intervention is believed to yield better patient outcomes, the presence of lymphedema symptoms should warrant institution of early interventions (Armer, Radina, Porock, & Culbertson, 2003; Armer et al., 2004; Foeldi et al., 2003). In addition, experience of symptoms has elicited tremendous distress in breast cancer survivors and exerted negative impact on their quality of lives (Fu & Rosedale 2009; Pyszal et al., 2006). Symptoms should be one of the major patient-centered clinical outcomes for evaluating the effectiveness of lymphedema treatment (Armer et al., 2005; Sitzia, Stanton, & Badger, 1997). A symptom checklist (Table 2) may be used for symptom assessment.

The following questions are about symptoms in your affected arm, hand, breast, axilla (under arm), or chest today or in the past three months.					
Have you had ___?	How Severe?				
	No 0	A little 1	Somewhat 2	Quite a bit 3	Very Severe 4
1. Shoulder					
2. Elbow					
3. Wrist					
4. Fingers					
5. Arm					
6. Hand or arm swelling					
7. Breast swelling					
8. Chest wall swelling					
9. Firmness					
10. Tightness					
11. Heaviness					
12. Toughness or thickness of skin					
13. Stiffness					
14. Tenderness					
15. Hotness/increased temperature					
16. Redness					
17. Blistering					
18. Pain/aching/soreness					
19. Numbness					
20. Burning					
21. Stabbing					
22. Tingling (pins and needles)					
23. Arm or hand fatigue					
24. Arm or hand weakness					

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Table 2. Example of Symptom Checklist - Breast Cancer & Lymphedema Symptom Experience Index

Physical examination and symptom assessment can also help to differentiate if the onset of lymphedema following breast cancer treatment is gradual or sudden (Fu et al., 2009). It is still not fully understood why some patients are more prone to fluid build-up than others even with similarity in surgical treatment, numbers of lymph nodes removed, chemotherapy and radiotherapy. With gradual onset, noticeable swelling is often absent initially, but patients may report feelings of tightness and heaviness in the previous year, visible and measurable lymphedema typically occurs two to five years after treatment, but it can also happen as many as 15 to 30 years later (Armer et al., 2003; Petrek, Senie, Peters, & Rosen, 2001). With sudden onset, swelling develops rapidly, usually within 24 hours and often breast cancer survivors are able to identify the triggers, such as air travel, infection, or injuries (e.g., cuts, insect bites, pinpricks, burns) (Fu & Rosedale, 2009; Johansson, et al., 2002; Petrek et al., 2001). With infection (especially cellulitis) or injuries, breast cancer survivors usually experience sudden swelling with redness, elevated white blood cells, or elevated temperature (Foeldi et al., 2003). Very often, immediate administration of oral or IV antibiotics can clear the infection, while elevation of the limb helps to reduce the swelling. It is possible that early stage lymphedema (Stage 1 and 2) may continue to exist in a latent or sub-clinical state even when successfully treated at initial onset, sometimes presenting at later stages ten or more years after initial diagnosis of sudden onset of lymphedema (Brennan & Miller, 1998).

3.2 Measures of limb volume (LV)

Measuring LV is an objective way to quantifying lymphedema. However, quantifying lymphedema is a challenge because various measurement approaches have been used to define lymphedema and certain types of breast cancer-related lymphedema such as breast, shoulder, and truncal lymphedema cannot be quantified with current measurement technology. Methods of measuring limb volume LV include sequential circumference limb measurement, water displacement, infra-red perometry, and bioimpedance spectroscopy (Armer & Stewart, 2005; Petlund, 1991; Tierney, Aslam, Rennie, & Grace, 1996; Cornish, et al., 2001).

3.2.1 Sequential circumferential arm measurements

Measuring circumference is the most widely used diagnostic method. A flexible non-stretch tape measure for circumferences is usually used to assure consistent tension over soft tissue, muscle, and bony prominences (Armer et al., 2004; Petlund, 1991). Measurements are done on both affected and non-affected limbs at the hand proximal to the metacarpals, wrist, and then every 4 cm from the wrist to axilla or at minimum, six measurements are recommended: circumference at the mid-hand, wrist, elbow, upper arm just below the axilla, and at 10cm distal to and proximal to the lateral epicondyle on both arms (Armer et al., 2004; Callaway et al., 1988) The most common criterion for diagnosis has been a finding of ≥ 2 cm or >200 ml difference in limb volume as compared to the non-affected limb or 10% volume differences in the affected limb (Armer et al., 2004; Armer & Stewart, 2005; Mayrovitz, Simms, & MacDonald, 2000; Stanton et al., 2009).

Circumferential limb measurement has limited inter- and intra-rater reliability and costly in terms of training time and clinician's time for measurement (Armer & Stewart, 2005; Gerber, 1998). (Figure 2).



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Fig. 2. Sequential Circumferential Arm Measurements

3.2.2 Water displacement

Water displacement is seldom used in clinical settings because of cumbersome spillover and hygienic concerns (Armer & Stewart, 2005; Gerber, 1998). Patients submerge the affected arm in a container filled with water and the overflow of water is caught in another container and weighed (Figure 3). This method does not provide data about localization of swelling or shape of the extremity (Petlund, 1991; Tierney et al., 1996). The method is contraindicated in patients with open skin lesions. Patients may find it difficult to hold the position for the time needed for the tank overflow to drain.



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Fig. 3. Water Displacement

3.2.3 Infra-red perometry

The advent of infra-red perometry (also called optoelectronic volumetry), such as the perometer 350S (Juzo, Cuyahoga Falls, OH), enables reliable and accurate detection of 3% limb volume change (LVC) (Cormier et al., 2009; Stout et al., 2008). The perometer works in much the same manner as computed tomography but uses infrared light instead of X-rays (Petlund, 1991). There is no toxic effect to the patient. Perometry is performed on each arm as it is held horizontally with the patient standing comfortably (Figure 4). The perometer maps a 3-dimensional graph of the affected and non-affected extremities using numerous rectilinear light beams, and interfaces with a computer for data analysis and storage. A 3-dimensional limb image is generated and LV is calculated. This optoelectronic method has a standard deviation of 8.9 ml (arm), less than 0.5% of LV with repeated measuring (Armer & Stewart, 2005; Cormier et al., 2009). Because the perometer is capable of measuring bilateral lymphedema and localization of swelling as well as detecting a 3% LVC that enables detectable differences in quality of life (QOL) and symptom reporting, the optimal measure for lymphedema is the evaluation of LVC by the perometer (Armer & Stewart, 2005; Cormier et al., 2009; Stout et al., 2008).



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Fig. 4. Infra-red Perometry

3.2.4 Bioimpedance spectroscopy (BIS)

Bioelectrical impedance has been used to detect onset lymphedema and monitor results of lymphatic massage in clinical settings (Cornish, et al., 2001; Ridner, Montgomery, Hepworth, Stewart, & Armer, 2007; Ward, Bunce, Cornish, Mirolo, Thomas, & Jones, 1992; Ward, Essex, & Cornish, 2006). The Imp XCA® (Impedimed, Brisbane, Australia) uses a single frequency below 30 kHz to measure impedance and resistance of the extracellular fluid. The device uses the impedance ratio values between the unaffected and affected limb

to determine arm lymphedema. Ratio means of 1.139 for at-risk dominant arms and 1.066 for at-risk non-dominant arms are indicators of arm lymphedema. The Imp XCA® uses the impedance ratio values to calculate a *Lymphedema Index [L-Dex]*. The L-Dex scale ranges from -10 to +10, which is equivalent to the impedance ratio from 0.935 to 1.139 for at-risk dominant arms and 0.862 to 1.066 for at-risk non-dominant arms, respectively. Each one standard unit in L-Dex is equivalent to the impedance ratio of 0.03. A patient is determined to have arm lymphedema or arm swelling if the patient's L-Dex exceeds the normal value of +10, i.e. exceed impedance ratio means of 1.139 for at-risk dominant arms and 1.066 for at-risk non-dominant arms, respectively (44). Measurement of arms takes less than five minutes when using the Imp-XCA® and results are immediately available to clinicians. However, the Imp XCA® is only capable of assessing unilateral lymphedema, unable to provide data about localization of swelling or shape of the extremity, and cannot be applied to patients with renal or heart failure, cardiac pacemaker or defibrillator, inability to lying down on the exam table, artificial limbs, or pregnancy as accurate measurement of lymphedema may not be possible. Continuous cost for electrodes is needed. (Figure 4).



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Fig. 5. Bioimpedance Spectroscopy (BIS).

3.3 Lymph vessel imaging

Lymphoscintigraphy (isotope lymphography) can ensure definite lymphedema diagnosis (Mortimer, 2003; Cambria et al., 1993). Lymphoscintigraphy employs a nuclear medicine to visualize the lymph vessel. With the patient supine, a radiolabelled macromolecular tracer (Tc-99m filtered [0.22 milli micron] or unfiltered sulfur colloid) is injected intradermally within one of the interdigital spaces of the affected limb using a 25-gauge needle in a 1 ml

syringe (Cambria et al., 1993; Partsch, 1995; Ter et al., 1993). The injection is given between the index and middle finger in the web space for the upper limbs. Both sides are done simultaneously so that the affected limb can be compared to the unaffected limb. The lymphatic transport of the macromolecule is tracked with a gamma camera, and the rate of tracer disappearance from the injection site and the accumulation of counts within the lymph node are both quantified. Typical abnormalities observed in lymphedema include dermal backflow, absent or delayed transport of tracer, cross-over filling with retrograde backflow, and either absent or delayed visualization of the lymph nodes (Cambria et al., 1993; Partsch, 1995; Ter et al., 1993). However, lymphography is now rarely used in patients because of its potential to cause lymphatic injury and its inability to clarify function (Meek, 1998; Mortimer, 2003).

4. Treatment of breast cancer-related lymphedema

Treatment of lymphedema has been and continues to be a major healthcare challenge since no treatment can cure this chronic condition. Lymphedema treatment refers to therapies applied to help to slow the disease progression by reducing or maintaining swelling and relieving symptoms. Lymphedema therapy includes complete decongestive physiotherapy, pneumatic compression therapy (PCT), therapeutic exercises, surgery, and pharmacological therapy (Fu, 2005; Geller, Vacek, O'Brien, & Secker-Walker, 2003; ISL, 2003; Megens & Harris, 1998).

4.1 Complete decongestive therapy (CDT)

Complete decongestive therapy (also known as *complex decompressive physiotherapy*, *comprehensive decongestive treatment*, and *multimodal physical therapy*) is the standard of care for breast cancer-related lymphedema. CDT includes an initial reductive treatment phase followed by an ongoing maintenance phase. The reductive treatment phase involves 2-5 sessions per week for 3 to 8 weeks in a specialized lymphedema clinic until the reduction of fluid volume has reached a plateau. The reductive treatment phase of CDT consists of multiple components, including manual lymph drainage (MLD), multilayer, short-stretch compression bandaging, therapeutic exercise, skin care, education in self-management, and elastic compression garments (Davis, 1998; Megens & Harris, 1998). The reductive treatment phase should be reinstated whenever swelling is exacerbated or whenever symptoms are worsened. Once the reductive treatment phase is completed, the maintenance phase starts in which the patient continues self-management with skin care and exercise, self MLD, and use of a compressive sleeve and gauntlet during the day and arm bandaging at night (Davis, 1998; Megens & Harris, 1998). The maintenance phase of CDT requires a lifelong self-management program with self MLD, exercise, skin care, and compression garments or bandages. Long-term volume reduction is as high as 50-63% in up to 79% of patients who are 100% compliant (Boris et al., 1997; Erickson et al., 2001; Foeldi et al., 2003; Rinerhart-Ayres, 1998). Yet, compliance with the prescribed self-management regimen during the maintenance phase is difficult for breast cancer survivors (Brennan & Miller, 1998; Fu, 2010). From the patient's perspective, the treatment for lymphedema itself is a constant reminder that prevents survivors from living a normal life (Fu, 2005; Fu & Rosedale, 2009).

4.2 Pneumatic compression therapy

Pneumatic compression therapy, also known as compression pump therapy, can be used daily for 30-60 minutes during the maintenance phase of CDT. Acceptable pneumatic compression device (PCD) should have multiple chambers delivering a sequential pressure. Caution must be used, however, because compression pumps can damage the vasculature. Furthermore, compression devices are contraindicated in patients with congestive heart failure, active infection, or deep venous thrombosis (Rockson et al., 1998). The recently developed PCD such as the Flexitouch® system is believed to be safer than the older PCD (Ridner et al., 2010). The Flexitouch® system is an advanced, programmable PCD that is cleared by the Food and Drug Administration for home use. This device is the only PCD designed to emulate the therapeutic techniques of MLD. Published studies and case reports suggest that breast cancer-related limb and truncal lymphedema may be effectively treated with the Flexitouch® system since the device includes garments to treat truncal swelling (Ridner et al., 2010).

4.3 Therapeutic exercises

Therapeutic exercises are individualized remedial exercises that consist of cardiovascular exercises, stretching, aerobic activity, and strength training. Therapeutic exercise is believed to increase lymph flow and protein absorption through repeated contraction and relaxation of muscles. Therapeutic exercise should be initiated by well-trained lymphedema therapists and then continued at home. One randomized controlled trial found that a 6-month intervention did not increase risk or add to symptoms of lymphedema (Ahmed et al., 2006). Other data also indicate that exercise as an individual therapy is neither a contraindication after breast cancer treatment nor does it decrease the risk of developing lymphedema (Ahmed et al., 2006; Schmitz et al., 2009; Johansson et al., 2005). For survivors with lymphedema, compression garments or compression bandages must be worn during exercise to counterbalance the buildup of interstitial fluid (Schmitz et al., 2009; Johansson et al., 2005).

4.4 Surgery

Surgical approaches are performed to debulk tissue or to divert lymphatic drainage (Casley-Smith, 1992; Cormier et al., 2011). Surgical treatment for breast cancer-related lymphedema is rarely performed except in severe and refractory cases to reduce the weight of the lymphedematous region, minimize the frequency of infectious and inflammatory episodes, and improve cosmesis and function. Surgical treatment includes: (1) excisional operations (e.g., debulking, amputation, and liposuction), (2) lymphatic reconstruction, and (3) tissue transfer procedures (e.g., lymph node transplantation, pedicled omentum, bone marrow stromal cell transplantation) (Cormier et al., 2011). For severe lymphedema, excisional operations and debulking procedures have been reported as effective methods to alleviate symptoms by removing fibrosclerotic connective tissue, excess adipose tissue, and excess skin. Various microsurgical techniques for lymphatic reconstruction have been attempted since the early 1960s, including the creation of anastomoses between lymphatic channels and adjacent veins, between lymph nodes and veins, and between distal and proximal lymphatics (Campisi et al., 2001; O'Brien et al., 1990). Lympho-lymphatic anastomosis and

lymphatic grafting have been used as reconstructive techniques that are associated with improved patency over time (Brennan & Miller, 1998). A recent systematic review on surgical treatment for lymphedema revealed that the largest reported reductions were noted after excisional procedures (91.1%), lymphatic reconstruction (54.9%), and tissue transfer procedures (47.6%) (Cormier et al., 2011). Potential complications may occur with surgical management of lymphedema, such as recurrence of swelling, poor wound healing, and infection; thus surgical treatment should be considered only when other treatments fail, and with careful consideration of the benefits-to-risks ratio (Casley-Smith, 1992). It should be noted although these surgical approaches have shown promising results, nearly all the surgical procedures do not obviate the need for continued use of conventional therapies, including compression, for long-term maintenance (Cormier et al., 2011).

4.5 Pharmacological therapy

Pharmacological interventions to treat lymphedema include antibiotics for treatment of infections, benzopyrones, flavonoids, diuretics, hyaluronidase, pantothenic acid, and selenium (Bruns et al., 2003; Rockson et al., 1998; Olszewski et al., 2000). Although not approved by the US Food and Drug Administration (FDA), *benzopyrones* have drawn most of the attention as a pharmacologic approach to treat lymphedema (Rockson et al., 1998). Benzopyrones are believed to encourage protein breakdown and lead to a subsequent decrease in lymph fluid. One randomized controlled trial of benzopyrones and placebo showed a significant decrease in arm swelling after treatment for several months (Davis, 1998). Loprinzi (1999) conducted a controlled study on the effectiveness of coumarin compared with a placebo, and they concluded that coumarin was not effective for managing breast cancer-related lymphedema due to a high risk of hepatotoxicity. A Cochrane review found that it was not possible to draw conclusions about the effectiveness of benzopyrones in reducing and controlling lymphedema due to the poor quality of existing trials (Badger et al., 2004). Flavonoids, hyaluronidase, pantothenic acid, and selenium have also demonstrated limited efficacy (Olszewski et al., 2000; Bruns et al., 2003). Diuretics are not suitable for breast cancer-related lymphedema, as such medications only serve to increase protein concentrations in the interstitium and encourage increase in swelling, inflammation and fibrosis (Davis, 1998; Thiadens, 1998).

5. Risk reduction for and early detection of breast cancer-related lymphedema

5.1 Risk reduction

Breast cancer-related lymphedema is often under-diagnosed and undertreated. The complexity and variability of individual lymphatic system and the unpredictability of risk factors makes it difficult to predict which patients will ultimately develop lymphedema. For decades, to reduce the risk of lymphedema after breast cancer treatment, the focus has been on improving surgical treatment. Such improvements, including sentinel lymph node biopsy (SLNB) in which one to three sentinel lymph nodes are removed, and breast-conserving surgery (BCS) in which only the cancerous part of the breast is removed (Armer et al., 2004), have saved patients with node-negative disease from unnecessary axillary lymph node dissection (ALND) and mastectomy (Boneti et al., 2008; Giuliano et al., 2011).

While lymphedema and symptoms have been reported less frequently in women who underwent SLNB only, lymphedema has by no means become a minor or disappearing problem. Data from recent studies have revealed that lymphedema remains a significant complication of breast cancer treatment, occurring in 20% to 47% of cases after ALND and in 3% to 17% after SLNB (Cormier et al., 2009; Paskett et al., 2007; Langer et al., 2007; McLaughlin et al., 2008). It is very important to note that surgical removal of lymph nodes remains the optimal choice for treating breast cancer with positive cancerous lymph nodes (Boneti et al., 2008; Giuliano et al., 2011, Langer et al., 2007). Each year in the US, more than 190,000 women are diagnosed with invasive breast cancer and many of them undergo removal of positive lymph nodes despite the use of SLNB, predisposing the women to a lifetime risk for lymphedema.

In addition, radiation exposure is associated with trauma to the lymphatic system, and current standard of care includes BCS and SLNB together with radiation therapy to breast and /or axilla. Recent innovative approaches to radiotherapy include the single-day targeted intraoperative radiotherapy delivered by the Targit machine (Enderling, Anderson, Chaplain, Munro, & Vaidya, 2006; Vaidya et al., 2006) and the 5-day accelerated partial breast irradiation using a MammoSite catheter (Benitez, et al. 2006; Berlin, Gjores, Ivarsson, Palmqvist, Thagg, & Thulesius, 1999; Borg et al., 2007; Dragun, Harper, Jenrette, Sinha, & Cole, 2007; Jeruss et al., 2006). Such novel radiotherapies targeting directly on the tumor site while avoiding scattering radiation to the axilla may have a role in reducing the risk of lymphedema in comparison to conventional radiotherapy. Research is needed to evaluate targeted radiotherapies in relation to lymphedema risk reduction. As a result, current surgical approaches for diagnosis of and treatment for breast cancer continue to make patients susceptible to the risk of lymphedema.

Besides unavoidable risk factors, such as breast surgery (mastectomy & lumpectomy), removal of lymph nodes (axillary lymph node dissection and sentinel lymph biopsy), presence of positive nodes, radiation and chemotherapy (Mak et al., 2008; Paskett et al., 2007), risk factors that can be managed or avoided are also identified, including obesity, weight gain after cancer treatment, minor upper extremity infections, injury or trauma to the affected side, overuse of the limb, and air travel (Johansson et al., 2002; Mak et al., 2008). Patient education is vital for implementing risk reduction behaviors targeting on such personal risk and triggering factors. In practice, many women treated for breast cancer have not received any information about lymphedema and risk reduction strategies (Fu et al., 2010; Ridner, 2006).

In a recent research on the effectiveness of lymphedema information provision among 136 breast cancer survivors (Fu et al., 2008; Fu et al., 2010), the researchers revealed that 43% percent of the participants reported that they did not receive any lymphedema information. Significantly fewer women who received lymphedema information reported swelling, heaviness, impaired shoulder mobility, seroma formation, and breast swelling. Regarding the most distressing symptom of arm swelling, 41% of patients who did not receive information reported arm swelling, comparing to 19% of those who received information. In terms of important cardinal symptoms of lymphedema, patients who did not receive information also reported significantly more symptoms of heaviness (27%), impaired shoulder mobility (32%), seroma formation (34%), breast swelling (32%),

firmness/tightness (42%), numbness (39%), tenderness (54%), aching (36%), and stiffness (44%). In summary, patients who received lymphedema information reported significantly fewer symptoms than those who did not ($t=3.03$; $p=0.00$). With regard to risk reduction behaviors, patients who received information reported practicing significantly more risk reduction behaviors than those who did not ($t=2.42$, $p=0.01$). These behaviors included avoiding blood pressure, blood draws, and injections routinely done in the affected limb, wearing compression garments during air travel, treating minor injuries by washing and applying antibiotics, and most importantly, promoting lymph fluid drainage. In terms of cognitive outcome, patients who received information scored significantly higher in the knowledge test ($t=0.49$; $p=0.00$). The researchers developed a multiple regression model to assess the effects of provision of information on lymphedema related symptoms by taking into consideration of treatment-related risk factors. The results demonstrated that provision of information had significant reverse effect ($B= -1.35$; $p<0.00$) on lymphedema symptoms even taking into consideration of treatment-related risk factors. Together, provision of information and treatment-related risk factors account for 13% of variance ($R^2= 0.13$). After controlling for confounding factors, patient education remains an important predictor of lymphedema outcome.

Apparently, patient education is essential to promote risk reduction and early detection. In clinical practice, healthcare professionals could consider taking the initiative to provide adequate and accurate information and engage patients in supportive dialogues concerning lymphedema and risk reduction to improve patients' cognitive, behavior, and symptom outcomes. Healthcare professionals should equip themselves with lymphedema knowledge, including risk identification, early detection, and risk reduction strategies. Pretreatment education should focus on potential risk for lymphedema, brief review of the lymphatic system and pathophysiology of lymphedema, signs and symptoms of lymphedema, and risk reduction behaviors to reduce the risk from personal and triggering factors. Patients should be educated about the need to seek for professional help immediately if they begin to experience feelings of heaviness or tightness in at-risk limbs; or if they notice swelling in the affected area; or if the arm and/or at risk chest or truncal areas becomes hot or red. In the clinical settings, healthcare professionals could use the systematic assessment strategies to help patients to reduce the risk of lymphedema presented in Table 3.

5.2 Early detection

If undiagnosed or not treated effectively, lymphedema can progress into later stages of the condition resulting in a severe form of swelling known as elephantiasis (Figure 5). Early detection of lymphedema is believed to yield better patient outcomes to reduce the risk of the severe stage of lymphedema. To promote early detection, ongoing education should be conducted at each follow-up visit by reviewing the content of pretreatment education and encouraging the patient to report any signs and symptoms of lymphedema such as swelling, tightness, firmness, heaviness, aching, redness, rash, or increased temperature on the affected limb. As certain symptoms, such as tightness, and heaviness are associated with the onset of lymphedema (Armer et al., 2003; Cormier et al., 2009), it is important for healthcare providers to conduct a screening symptom assessment and refer breast cancer survivors with lymphedema to appropriate resources such as lymphedema therapy. (Table 3)



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Fig. 6. Example of severe lymphedema known as elephantiasis

Risk Identification

- Ask the patient about history of cancer treatment
- Identify the affected or at-risk limb

Risk Reduction

- Recommend the patient use the *unaffected* side for blood pressure and blood work.
- If the patient had a bilateral mastectomy, suggest use the lower extremities for blood work and blood pressure.

Rationale: By using the unaffected side or lower extremities for blood draws and blood pressure, the patient will reduce the risk for infection, which lowers the risk of lymphedema.

Early Detection

- Use 3 questions to screen patients who might have developed lymphedema without awareness.
- ? Have you noticed any swelling in the affected hand, arm, breast, or trunk area?
- ? Have you experienced the feeling of heaviness, firmness, tightness in the affected side?
- ? Have you experienced any new discomfort in the affected side?
- Refer patient with early signs of symptoms to the certified lymphedema therapists.
- Assess the patients for signs and symptoms of infections (redness, tenderness, and pain). Administer antibiotics as needed.

Rationale:

- Early symptoms of lymphedema include slight swelling, heaviness, tightness, or firmness. It is important for nurses to assess these symptoms at each patient encounter, since early intervention can sometimes reverse lymphedema symptoms.
- It is important to assess signs and symptoms of infection (redness, tenderness, and pain). Infection, such as cellulitis, is the major predictor for lymphedema.

Table 3. Systematic Assessment Strategies for Lymphedema Risk Reduction

To promote early intervention, it is imperative to implement screening and measurement for early detection of breast cancer-related lymphedema. In a prospective observational study on 196 women with newly diagnosed breast cancer over a five year period (Stout et al., 2008), the women were measured using *infra-red Perometry* prior to their surgery and in three-month intervals following their surgery for up to one year. During that time, researchers were able to identify the development of subclinical lymphedema in 43 women (22%). The women with subclinical lymphedema (defined by the researchers as the limb volume change [LVC] of approximately 100 ml or a 3% LVC compared to the pre-op measure) were treated with an off-the-shelf sleeve and gauntlet, which was worn daily except during sleeping hours. Significant reduction in limb volume was observed that was similar to nearly the women's pre-surgical baseline value in all patients over an average period of 4.4 weeks. It should be noted that pre-treatment baseline measurement of limbs is essential, as this serves as the baseline data to which subsequent measurements can be compared. Healthcare professionals should use a cost-effective measuring method (such as circumferential arm measurement) and a time- and energy-saving measuring method (such as *infra-red perometry*) to monitor LVC in breast cancer survivors. Limb volume measurement should be conducted by the healthcare professionals who treat breast cancer and follow breast cancer survivors at each patient visit. In this way, patients with increased LV in the affected limb can be referred in a timely manner for further assessment and early intervention by specialists in lymphedema treatment.

6. Self-management for breast cancer-related lymphedema

Self-management for breast cancer-related lymphedema focuses on daily activities and strategies undertaken by breast cancer survivors to decrease the swelling, relieve symptoms, and prevent acute exacerbations and infections (Fu, 2005). As discussed previously, CDT requires patients to make a daily commitment by using external compression (sleeve, glove, wrap, bandage, or pump), performing remedial exercise, self-MLD and skin care (Davis, 1998; Rockson, et al. 1998). Self-management is essential for the success of the maintenance phase of the complete decongestive therapy (CDT) (Fu, 2010). Successful self-management of lymphedema also requires breast cancer survivors to initiate and maintain behaviors reduce triggering factors that can lead to severe lymphedema (Fu, 2005).

Limited research has been conducted on effective self-management of lymphedema. Very few exiting research are descriptive in nature yet the studies have delineated the difficulties and barriers that impede the effective self-management of lymphedema. A recent study revealed the major barriers to effective daily self-management include fatigue, lack of sufficient supporting system, insufficient financial resources, insufficient time, occupations involving manual laborious work, employers' misunderstanding, unsupportive working environment, fear of losing job (or stigma, embarrassment or discrimination), irregular working schedules, lack of clear or detailed instructions for self-care, lack of experience of organizing or following a schedule, and lack of experience of establishing or maintaining a routine (Fu, 2010). Currently, no research has been targeting on the identified barriers to promote self-management.

Breast cancer-related lymphedema is a chronic disease that, unlike other chronic illnesses such as arthritis or diabetes, receives little attention from healthcare professionals in clinical settings. To provide an emotional outlet for breast cancer survivors who may be concerned

about developing lymphedema, healthcare professionals should consider asking the survivors if anyone has talked to them about lymphedema risk reduction practices, and if they are concerned about possibly developing lymphedema. For those with lymphedema, healthcare professionals may wish to ask about any problems they are having with swelling, skin integrity, or other problems or concerns they want to discuss related to their lymphedema. These activities, if done in any clinical setting, would begin to address the feelings of abandonment by healthcare professionals verbalized by many breast cancer survivors with lymphedema (Carter, 1997). Management of psychological distress and fatigue associated with lymphedema and self-management may require supportive services from healthcare professionals such as psychologists or conditioning experts (Fu, 2005; Ridner, 2005).

Similar to the self-management for other chronic illnesses, healthcare professionals have a significant role in ensuring effective self-management of lymphedema by motivating breast cancer survivors. Some cognitive, psychological, and social strategies can help breast cancer survivors to promote and maintain self-management behaviors (Fu, 2004). Cognitive strategies refer to breast cancer survivors' ability to understand the need for change of behaviors to implement daily self-management activities and ability to identify and overcome barriers in carrying out such activities. Patient education is the optimal way to enhance breast cancer survivors' knowledge and provide relevant resources.

Psychological strategies include those that help breast cancer survivors set goals for their lymphedema management and motivate them to continue their daily management activities. Fu (2005) identifies four major intentions undertaken by breast cancer survivors to promote effective daily lymphedema management: keeping in mind the consequences, preventing lymphedema from getting worse, getting ready to live with lymphedema, and integrating the care of lymphedema into daily life. The four intentions reveal in detail the way in which breast cancer survivors structure their lives to manage lymphedema daily. Healthcare professionals are in the best position to identify breast cancer survivors' individual needs by assessing the presence or absence of the intentions. In another recent study (Fu, 2010), the researcher described how breast cancer survivors actively and creatively structured their lives to make lymphedema self-management feasible by making conscious decisions about new-fangled limitations, making daily care feasible, and incorporating lymphedema care into daily routine. The study also identified effective and ineffective strategies and barriers to fulfill the intentions of self management (Table 4). Research is needed to develop interventions to test the identified effective strategies for self-management of lymphedema.

Social strategies focus on providing resources or support groups to externally enhance breast cancer survivors' motivation to continue self-management to maintain LV and deal with physical symptoms as well as psychological distress and social anxiety. Internal and external resources, such as programs about lymphedema treatment and reliable internet websites, should be given to breast cancer survivors. Providing social support helps mitigate breast cancer survivors' sense of being singled-out, a perspective that was vividly described by a breast cancer survivors with five years of lymphedema, "You feel that you are on this little island by yourself and just struggling because there is no one else around who knows what lymphedema is" (Fu, 2003, p. 188). Support group in which women can feel free to share their success stories about lymphedema management and the ways of overcoming

Making Self Management Feasible			
Intentions	Effective Strategies	Barriers to the strategy	Ineffective Strategies
Making Conscious Decisions about New-fangled Limitations	<ul style="list-style-type: none"> • Giving up • Letting go • Asking for help • Paying for help • Using the unaffected limb 	<ul style="list-style-type: none"> • Lack of sufficient supporting system of family, friends, and coworkers • Unsupportive working environment • Employers' misunderstanding • Insufficient financial resources • Occupations involving manual laborious work • Impatience 	<ul style="list-style-type: none"> • Ignoring • Forgetting • Neglecting
Making daily Care Feasible	<ul style="list-style-type: none"> • Wearing daytime compressive garments as much as possible • Using <i>Easy Slide</i> or other device to help putting on the compression sleeve • Wrapping the affected arm during nighttime • Using rubber gloves to protect the compression gloves from getting dirty • Performing exercise and massage if time and physical stamina allow • Getting an easy access to the things needed for lymphedema care • Spacing out the household chores • Having someone help • Wearing protective gloves for dish washing, cleaning, and gardening • Using food processor to cut food 	<ul style="list-style-type: none"> • Lack of clear or detailed instructions • Insufficient time • Insufficient financial resources • Insufficient qualified therapists • Fatigue • Fear of losing job, stigma, embarrassment or discrimination • Occupations involving manual laborious work • Employers' misunderstanding • Unsupportive working environment • Lack of sufficient supporting system 	<ul style="list-style-type: none"> • Trying to do all that you were told
Incorporating Lymphedema Care into Daily Routine	<ul style="list-style-type: none"> • Establishing and sustaining a daily routine • Foreseeing the changes in life • Readjusting to the established routine 	<ul style="list-style-type: none"> • Lack of experience of organizing or following a schedule • Lack of experience of establishing or maintaining a routine • Insufficient time • Irregular working schedules • Fatigue • Being a good wife and loving mother 	<ul style="list-style-type: none"> • Following an irregular schedule

Table 4. Intentions, Effective strategies, Barriers and Ineffective Strategies (Adapted from: Fu, M.R. (2010). Cancer Survivors' views of lymphoedema management. *Journal of Lymphoedema*, 5(2), 39-48.)

barriers is an effective way to provide social support (Fu, 2005). Well-designed support groups can also enhance skills for effective lymphedema management through group practice of certain skills such as easier ways of putting on a compression garment, applying bandage or wraps, and performing self-MLD. Group practice allows the opportunity not only for building a community to further promote breast cancer survivors' sense of belongingness, but also for transforming routine lymphedema management activities into fun activities that may elicit interest and enjoyment to sustain the women's motivation. The lifetime commitment to manage lymphedema requires time and effort by both breast cancer survivors and healthcare professionals to insure that quality life is not profoundly impacted.

7. Strategies for personal and family-level care

7.1 Individual-level psychosocial impacts

It has been well documented that psychological health can be impacted by changes in physical appearance and limitations created by lymphedema (e.g., Petrek et al., 2001; Radina & Armer, 2001, 2004; Thomas-MacLean et al., 2005). This includes both mental health concerns and the ways in which patients cope with the physical limitations brought on by breast cancer-related lymphedema in their daily lives.

7.1.1 Mental health concerns

In addition to the physical limitations of breast cancer-related lymphedema, patients are also subject to potential psychosocial problems including depression, anxiety, poor adjustment to illness, and low self esteem (Maunsell, Brisson, & Deschenes, 1993; Thomas-MacLean et al., 2005). Chachaj and colleagues (2010) found that there were several factors that contributed to patients' experiences of negative psychosocial outcomes. These included "pain in the upper limb (mainly shoulder and arm), pain in operated breast, difficulties with arm movement, localization of lymphedema within the hand or in operated breast, a history of dermatolymphangitis and of receiving chemotherapy" (p. Vassard and colleagues (2010) explored the psychosocial outcomes of patients engaged in post-breast cancer surgery rehabilitation. They found that compared with patients who did not develop lymphedema, those with lymphedema reported a greater impact on their psychological well-being. Specifically, patients with breast cancer-related lymphedema were more likely to report lower overall quality of life and perceiving themselves to be in poorer health. These findings are similar to those reported by Heiney and colleagues (2007) who found that both physical and social aspects of quality of life were impacted by breast cancer-related lymphedema. Researchers have also found that the degree to which patients experience negative impacts on their mental health and quality of life is correlated with the severity of the lymphedema symptoms and the degree to which these symptoms are viewed as distressful (Erickson et al., 2001; Kornblith, Herndon, Weiss, Zhang, Zuckerman, Rosenberg et al., 2003). Similarly, Ridner (2005) found that patients with breast cancer-related lymphedema reported higher levels of emotional distress and reduced body confidence than those without lymphedema. Certainly this finding of reduced body confidence has implications for patients' self-esteem as well as sexual intimacy. With regard to addressing psychosocial problems in this population, Hamilton, Miedema, MacIntyre, & Easley, 2011) investigated the use of a positive self-talk intervention. Their findings suggest that such interventions may have a positive impact on patients' coping skills. They argue that further investigations are needed

to determine appropriate psychological interventions that positively impact such mental health concerns as anxiety and depression among patients with breast cancer-related lymphedema.

7.1.2 Coping with physical limitations in daily life

Lymphedema can impose limitations on women's lives in terms of their ability to participate in normal, daily activities (Radina & Armer, 2001; Ridner, 2002). Radina (2009) found that women with breast cancer-related lymphedema experienced a heightened sense of awareness and caution concerning their physical activities, as well as a sense of frustration with the limitations they faced as a result of breast cancer-related lymphedema. At the same time, these women also must engage in time consuming self-care, as described above, in order to reduce and control the swelling associated with lymphedema (e.g., manual lymph draining, CDT). Not only are some of these treatments restricting in terms of range of motion, but they also require the patient to set aside time during the day to perform them and to potentially ask others (i.e., family members) for help. The patient must also avoid getting any wrappings wet and therefore must remove the wrapping and rewrap the arm for bathing or other water activities (e.g., swimming, washing dishes). Lastly, because the compression sleeve is so expensive and must be washed by hand everyday, the patient must be careful not to stain or otherwise damage the sleeve (Casley-Smith, 1992).

7.2 Family/interpersonal relationship-level psychosocial impacts

Given the increasing large population of women living as breast cancer survivors and the understanding that breast cancer impacts the entire family, not just the patient/survivor (Baider, Cooper, & Kaplan De-Nour, 2000; Veach, Nicholas, & Barton, 2002), a growing number of families may be facing the need to navigate survivorship as well. At the same time, given that as many as 40% of women who have gone through breast cancer treatment may develop breast-cancer related lymphedema, there is also a growing number of families who are not only needing to cope with cancer survivorship in general but also coping daily with the chronic condition of lymphedema.

The study of breast cancer survivorship in general has largely centered on the experiences of breast cancer patients and has failed to sufficiently consider the impact that breast cancer diagnosis and treatment can have on family members and family life. The majority of work that considers family members is focused on breast cancer patients' relationships with husbands and young children (e.g., Northouse, Laten, & Reddy, 1995; Radina, 2009; Radina & Armer, 2001; 2004, Radina, Watson, & Faubert, 2009; Rees & Bath, 2000) and the individual quality of life of patients and their family members in the context of breast cancer (e.g., Kim & Given, 2008; Northouse et al., 2002). Only recently have researchers focused attention on how family functioning and adaptation can influence the lives of breast cancer patients and survivors (e.g., Mallinger, Griggs, & Shields, 2006; Radina, 2009; Radina & Armer, 2001; 2004; Radina et al., 2009). The evolution of empirically based understanding of how cancer in general impacts the family continues to evolve. The limited research that explores family dynamics in the context of breast cancer focuses on issues such as participation in treatment decision making (Lacey, 2002; Raveis & Pretter, 2004), family communication patterns both prior to and after the breast cancer diagnosis (Forest, Plumb,

Ziebland, & Stein, 2009; Mallinger et al., 2006), and the family's role as either a supportive or distressing unit (Alfano & Roland, 2006; Spencer et al., 1999). Here we review the research that has been conducted that investigates the specific ways in which breast cancer patients with lymphedema experience their family and interpersonal lives with regard to family work, family play, and sexual intimacy with significant romantic others. We conclude by exploring a theory of health-related family quality of life and how it might be applied to families coping with breast cancer-related lymphedema.

7.2.1 Family work and family play

The daily lives and rhythms of families include both getting the work of the family completed (i.e., housework) and the maintenance of family relationships (i.e., spending quality time together). Researchers have shown that both aspects of family functioning can be impacted by the onset and continued care required of breast cancer-related lymphedema (Radina, 2009; Radina & Armer 2001; 2004). That is, the physical limitations and psychosocial difficulties experienced by women with lymphedema frequently require the individual and her family members to renegotiate family roles and modify how they function as a unit (Radina & Armer, 2001; 2004). With regard to family work, this may include a redistribution of household responsibilities (i.e., asking an adult son to run the vacuum or employing a maid service to do the heavy cleaning) or the modification of how and if such responsibilities are undertaken (i.e., lowering standards of household cleanliness, learning to use the other arm to sweep the kitchen floor) (Radina & Armer, 2001). Women at-risk for developing breast cancer-related lymphedema have been shown to struggle with balancing the needs of others (e.g., family members) with their own needs for self-care that are aimed at reducing their risk of developing or exacerbating breast cancer-related lymphedema (Radina, Armer, & Stewart, under review). Gilligan and others (e.g., Jack, 1991; Ruddick, 1989) have argued that women are socialized within family and community life to embrace this concept of self-sacrifice in the service of others. Caring for others, and doing so in an unselfish way or at the expense of one's own needs, is the currency that women are socialized to deal with in order to create and maintain relationships with others (Jack, 1991). The role women often assume in family life requires some degree of self-sacrifice in order to manage the household and take care of family members (Mederer, 1993), including paid work outside the home. In this sense, what gets put on hold are activities like personal care, medication, exercise, or other activities that are largely for the benefit of the woman alone and not explicitly benefiting the family as a whole or individual family members. Radina and colleagues (under review) found that women at-risk for developing breast cancer-related lymphedema struggled with making their self-care a priority despite being enrolled in an intervention study aimed at teaching them techniques for self-care to reduce their risk of developing breast cancer-related lymphedema. Often the major barrier to self-care was the pull they felt to put others' needs first. Consistent with Ridner, Dietrich, and Kidd (2011) of women diagnosed with lymphedema, Radina et al. (under review) found that these women at-risk for developing lymphedema struggled with finding the time in their daily lives to engage in self-care. Radina and colleagues' findings highlight the important role that social contexts (e.g., family life, gendered expectations) can play as a factor in personal care for breast cancer survivors.

Radina (2009) found that for some women with breast cancer-related lymphedema, lifestyle modifications extend beyond daily activities such as dressing, bathing, cooking, and housekeeping into the realm of leisure. When it comes to leisure activities, wives and mothers who are often responsible for family management, are likely to be the ones creating time and space for other family members' independent leisure activities (e.g., baking cupcakes for her son's football team party, driving children to music lessons). Because of these other responsibilities, women's independent leisure is often sacrificed so that they can accomplish these other tasks for their families (Henderson, Bialeschki, Shaw, & Freysinger, 1999).

For women, their own participation in leisure activities in general, whether engaged in individually or with their families, may act as a buffer against stressful life events such as breast cancer and breast cancer-related lymphedema (Pondé & Santana, 2000). Thus, the continued participation of women with lymphedema in leisure activities appears valuable for sustaining their quality of life after breast cancer treatment. At the same time, family leisure is important for understanding family functioning (Zabriski & McCormick, 2001), particularly in the context of chronic health conditions and health-related disabilities (Jo, Kosciulek, Huh, & Holecek, 2004). Radina (2009) found that breast cancer-related lymphedema can create serious limitations that can impact both family functioning and participation in leisure.

Family interaction in the context of leisure enhances the family's ability to remain stable (Orthner & Mancini, 1990). In fact, researchers have demonstrated that there is a positive relationship between family leisure engagement, family satisfaction, and family quality of life (Zabriskie & McCormick, 2003). The Core and Balance Model of Family Leisure Functioning (Zabriskie, 2000; Zabriskie & McCormick, 2001) suggests that family adaptability (i.e., the family's ability to be flexible and change), cohesion (i.e., closeness, emotional bonding), and communication are facilitated through family members' joint engagement in family-based leisure activities (Zabriskie & McCormick, 2001). These can include both core and balance leisure activities. Core leisure activities are "common everyday, low-cost, relatively accessible, and often home-based activities that families do frequently" (Zabriskie & McCormick, 2003, p. 168) including such activities as playing a game, e-mailing or instant messaging with family members, and making/eating dinner together (Zabriskie & McCormick, 2001). Core leisure activities tend to be associated with the maintenance of family cohesion and thus families who perceived themselves as having high levels of emotional closeness report engaging in more core leisure activities (Zabriskie, McCormick, & Austin, 2001). Balance leisure activities are "less common, less frequent, more out of the ordinary, and usually not home based thus providing novel experiences" (Zabriskie & McCormick, 2003, p. 168) including such activities as family travel, family reunions, and special family events (Zabriskie & McCormick, 2001). Balance activities tend to be associated with maintaining family adaptability (Zabriskie et al., 2001). According to the Core and Balance Model, in order to have healthier family functioning that results from increased levels of family communication, families should participate in both core and balance activities that enhance both family cohesion and adaptability (Zabriskie & McCormick, 2003).

The role that family leisure plays generally also applies to families in which there is a chronically ill or disabled member (i.e., lymphedema). For such families participating in

shared leisure time is associated with enhanced family communication and stability (Guerin & Dattilo, 2001). For individuals with disabilities, the benefits of leisure activities (e.g., increases in self-confidence, social networks, and one's sense of accomplishment and satisfaction) have been well-established (Jo et al., 2004; Lloyd, King, Lampe, & McDougall, 2001). Despite this relationship, families with a disabled member are less likely to participate in balance leisure activities (38%) compared to families without a member with a disability (52%; Jo et al., 2004).

Radina (2009) found that women with breast cancer-related lymphedema approached their participation in family leisure activities in two ways. The first involved continued participation in family leisure activities but with extra care (e.g., purchasing light weight hiking equipment) or being creative about how they participated (e.g., becoming the scout troop treasurer rather than accompanying children on back packing trips). The second strategy involved withdrawing from family activities that according to the Core and Balance Model (Zabriskie et al., 2001) could jeopardize overall levels of family functioning by eliminating opportunities for building or improving family adaptability, cohesion, or communication.

7.2.2 Sexuality and intimacy

Sexuality can be examined as an interaction of biological, psychological, and social domains of life (Lindau, Laumann, Levinson, & Waite, 2003; National Institute on Aging, 2005). How individuals feel about themselves as sexual beings is impacted by a combination of all three of these areas. As women with breast cancer-related lymphedema have already faced breast cancer, their feelings about sexuality and intimacy are intertwined with their breast cancer and lymphedema experiences. Thus, it may not be possible to completely distinguish between body image issues, feelings of sexuality, and the impact on sexual relationships brought about by breast cancer and those resulting from lymphedema.

Researchers have explored the impact of breast cancer on sexuality and sexual relationships (e.g., Henson, 2002). This work has included investigations into the impact of breast cancer and its treatment on hormones and sexual functioning, attitudes of a romantic partner, the impact of fatigue brought about by treatment on sexual relationships, and how an altered body image resulting from (breast) cancer can impact one's sexuality and sexual relationships (Gould, Grassau, Manthorne, Gray, & Fitch, 2006). Research also have focused on how there tends to be a lack of information on how breast cancer and its treatment can impact sexuality that is provided to breast cancer patient and their partners (Gould et al., 2006; Henson, 2002).

With breast cancer-related lymphedema, women may experience changes in their appearance as well as pain and physical limitations due to swelling (Passik & McDonald, 1998). As sexuality is connected to a woman's feelings about herself and her body, not only the experience of breast cancer, but also the development of lymphedema can have a serious impact on her views of herself as sexual and her willingness to be physical with a partner. Having survived breast cancer to now have to contend with breast cancer-related lymphedema can be seen "as a secondary blow to their physical and emotional well-being," which includes their intimate relationships with others (Passik and McDonald, 1998, p. 2818). Research (e.g., Koch et al., 2005; Radina, Watson, & Faubert, 2009; Wiederman &

Hurst, 1997) has highlighted the negative ways in which women with breast-cancer related lymphedema feel about their bodies and how these feeling can take away from their desire to engage in sexual activity with a partner. Radina et al (2009) and Gould et al. (2006) found that the disfiguring aspects of breast cancer as well as breast cancer-related lymphedema made women feel unattractive and self-conscious about their bodies. Radina et al (2009) also found that women with breast-cancer related lymphedema expressed feeling that current or future sexual partners might not find them sexy because of the lymphedema and/or the compression garments that they need to be wear to treat their conditions.

There are numerous studies that explore the connection of sexual satisfaction, self or body image, and physical disability (e.g., Kedde & van Berlo, 2006; Taleporos, Dip, & McCabe, 2002; Galvin, 2005). Lymphedema can be not only be a condition with disfiguring effects but also debilitating ones. Galvin (2005) studied narratives of disabled people with a diverse range of disability and impairment. Based on this research, the term "disabled identity" emerged to reflect a self-perception that is affected by appearance, sexuality, and the negative attitudes of others. Shame and fear of rejection were related to reactions from others for those whose impairment was evident or visible. Feelings of loss of attractiveness, negative reactions of others, and internalized societal messages about the asexuality of disabled people contributed to feelings of loss of sexuality in many of the narratives (Galvin, 2005). Although not a "disability," because of the disfiguring and disabling aspects of the condition of lymphedema, the "disabled identity," which is impacted by an internalization of how others view this condition, can negatively impact sexuality and one's desire to be sexual with others.

7.2.3 Family quality of life

Radina and Armer (2004) explored outcomes for women with breast cancer-related lymphedema within the context of their families using the Resiliency Model of Family Stress, Adjustment, and Adaptation (M. A. McCubbin & H. I. McCubbin, 1996). They found instances where participants described themselves and their families as either adjusting (i.e., making small changes in family patterns of functioning in order to cope with lymphedema), adapting (i.e., making major changes in family patterns of functioning in order to cope with lymphedema), or living in crisis. Specifically, those families who were resilient had shared perception of the limitations brought on by lymphedema as being manageable and something that could be incorporated into patterns of daily living. At the same time, the more resilient families pulled together as a family to make necessary changes (e.g., the entire family focusing on the lymphedema and supporting the patient, the patient or her spouse changing jobs, using humor and inside jokes). The ingenuity and perseverance demonstrated by resilient families suggest that the families of women with breast cancer-related lymphedema can be resilient in coping with lymphedema.

One way to think about family life in the context of breast cancer-related lymphedema is to consider the concept of health-related family quality of life. Health-related family quality of life refers to a state of being for families in the context of one or more family members' illnesses as well as the processes that families use to cope. Below I provide an overview of a theory of Health-Related Family Quality of Life whose purpose is to provide a model of understanding what family quality of life is within the specific context of breast cancer and, by extension, breast cancer-related lymphedema. Below the assumptions, concepts, and propositions of this theory of Health-Related Family Quality of Life are presented.

The first assumption is that families are made up of multiple actors who interact based on established patterns of functioning that are governed by rules that can be both explicit and implicit (Bigner, 1998). Second, new or revised patterns of functioning can result when a stressor (e.g., breast cancer) is encountered by the family (M. A. McCubbin & H. I., McCubbin, 1991; 1996; Olson, Lavee, & McCubbin, 1988). Third, the introduction of that stressor to the family allows for established patterns of functioning to become apparent when they otherwise might not be (Ingoldsby, Smith, & Miller, 2004; Molassiotis, 1997). Fourth, quality of family life is subjective and situation-dependent (McCabe et al., 2008).

As is detailed in Figure 5, the theory of Health-Related Family Quality of Life is made up of three overarching concepts: emotional closeness, family self-efficacy, and family functioning. *Emotional closeness* includes feelings of psychological or affectional closeness toward and/or between family members as well as such feelings toward the family as a unit (Bengtson, 1991; Poston et al., 2003). At the same time, the concept of emotional closeness also includes family communication as a way of facilitating and demonstrating closeness (Bigner, 1998; M. A. McCubbin & H. I., McCubbin, 1991; 1996; Poston et al., 2003). Family communication is made up of family members' feelings regarding the quality, quantity, frequency, and content of this communication (Bengtson, 1991). Lastly, the concept of emotional closeness also includes social support—both among family members and for the family as a unit from those outside the family. Social support can also be considered a resource that the family uses in managing the quality of their family life (Hill, 1949; Patterson, 2002; Poston et al., 2003). *Family Self-Efficacy* refers to the families meaning-making about themselves as a unit and the illness (i.e., sense of coherence), in this case breast cancer. Hill (1949) and others (e.g., Anderson, 1993; Caplan, 1987; McCabe et al., 2008) point to the importance of appraisal of stressors as essential to understanding how the stressor will be handled. That is, if a family considers the stressor to be catastrophic, this may have a negative influence on family quality of life in that it may be seen as irrevocably damaged. As part of this meaning-making, family self-efficacy includes family members' sense of both family strengths (Smith-Bird & Turnbull, 2005) and their ability to cope with challenges (i.e., possibly based on the family's history of how they face challenges and their success with overcoming them; Hill, 1949; M. A. McCubbin & H. I., McCubbin, 1991; 1996; Mellon & Northouse, 2001; Patterson, 2002). Lastly, *Family Functioning* consists of family members' roles and responsibilities (e.g., family care, daily activities, getting help) as well as their satisfaction with how well the family meets individual and family unit needs (Bigner, 1998; Ingoldsby et al., 2004; Park et al., 2003; Rettig & Leichtentritt, 1999).

The theory of Health-Related Family Quality of Life offers three propositions about how health-related family quality of life functions. First, the theory of Health-Related Family Quality of Life is based on family members' perceptions of emotional closeness, family efficacy, and satisfaction with needs being met. Second, changes in family quality of life are based on perceptions of changes in emotional closeness, family self-efficacy, and patterns of functioning. Third, emotional closeness and family self-efficacy are considered resources that families utilize when faced with a stressor.

The application of the theory of Health-Related Family Quality of Life sheds light on the varying factors that can contribute to how a family reacts to and copes with breast cancer-related lymphedema. For some families these factors may already be working well meaning that they will be predisposed to maintain a positive health-related quality of life in the

context of breast cancer-related lymphedema. Others, however, may need coaching from trained professionals in order to enhance or improve their health-related quality of life. The professionals need not be family counselors, family life educators, or social workers alone. Others, including health care professionals, should be aware of the impact breast cancer-related lymphedema can have on family quality of life so that they may also help both patients and their family members thrive.

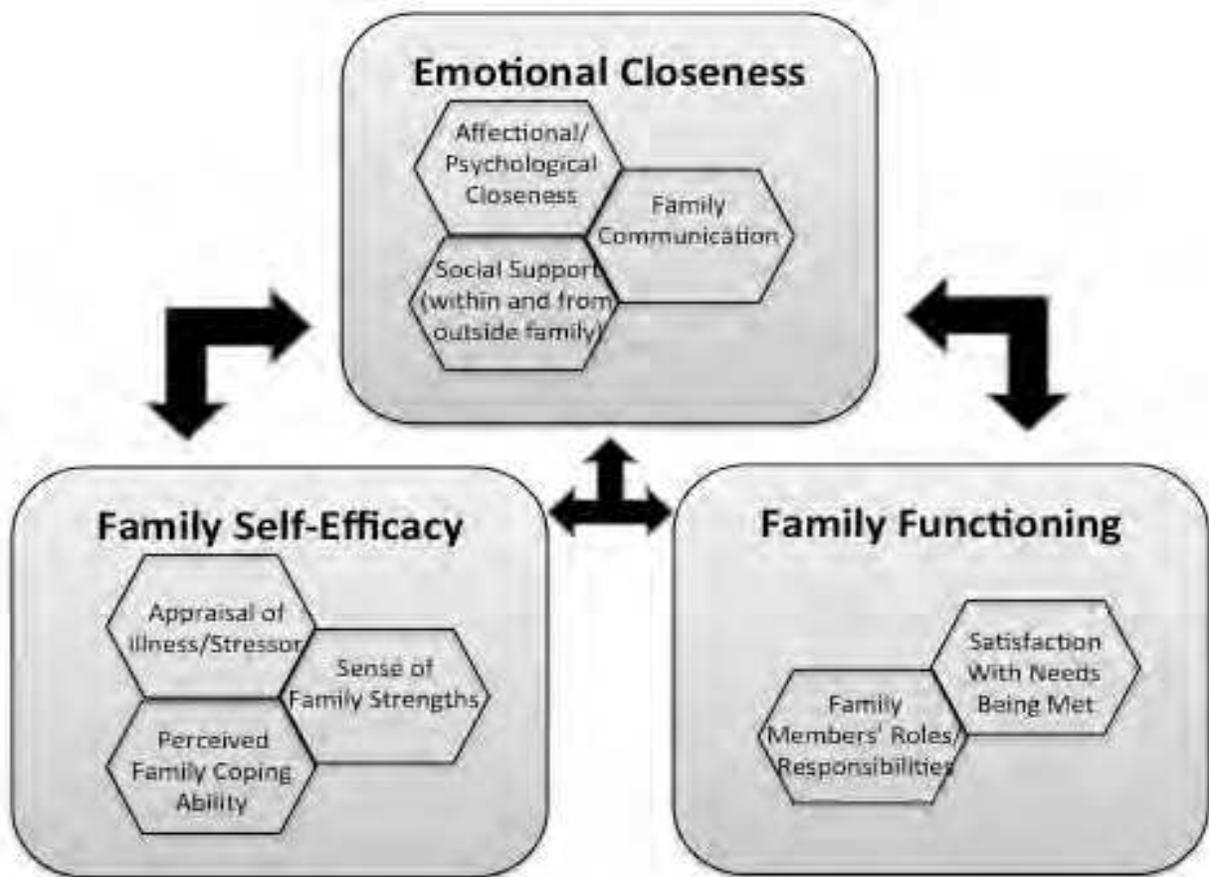


Fig. 7. Theory of Health-Related Family Quality of Life

8. Conclusion

Up to 40% of breast cancer patients are likely to develop breast cancer-related lymphedema. Thus, patients and their family members must learn to not only prepare for but cope with this often disabling chronic condition. Thus, the focus of this chapter was on patient (and family member/caregiver) education regarding strategies for early detection, risk reduction, and management/self-care and the individual and family level psychosocial impacts of coping with breast cancer-related lymphedema. The topics covered in this chapter were chosen with the intention of informing readers (e.g., physicians, nursing, social workers, family therapists, family life educators, and others who work with patients and their families) about the needs of patients and their family members and provide strategies to meet the needs of patients and families. In this way, wide ranging support for patients and their family members would be encouraged and implemented throughout the trajectory of patient care.

9. References

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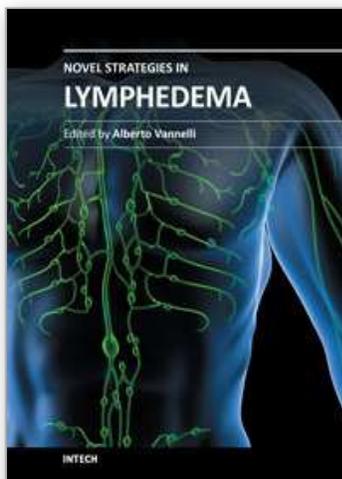
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Lymphedema is a swelling caused by the abnormal accumulation of lymphatic fluid in the skin. Lymphedema can be caused by burns, injury, surgery, radiation therapy or cancer treatment that cancer survivors undergo. Risk of developing lymphedema is high especially in those with breast or prostate cancer. It is hereditary and can appear without warning at any time of life and is related to obesity and circulatory problems. If not treated, lymphedema can be painful and lead to life-threatening infections. This book will help physicians who deal with lymphedema. It will help you understand how the lymphatic system works, how lymphedema is diagnosed, how to cope with the challenges of lymphedema, how to find treatment, and how to deal with insurance issues. Novel Strategies in Lymphedema is for those with, or at risk of, developing lymphedema, and the healthcare professionals who care for them.

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