

■ Article

# Prospective Protocol for Lymphedema Education and Surveillance in a Breast Health Center

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Participation in the ONS Foundation–supported Breast Cancer Survivorship Quality Measures Set pilot study indicated less than optimal assessment and educational practices for lymphedema surveillance at one author’s institution. This finding led staff to expand on nursing practice associated with lymphatic dysfunction and to propose a surveillance tool that is easy to use in a busy clinical setting. Based on current trends in lymphatic surveillance, arm measurements were used to assess for relative percentage differences compared to baseline. The referral threshold for lymphedema diagnosis was set at a 10% relative difference in circumferential measurements, pre- and postoperatively, as well as during the survivorship period. Enhanced education efforts, inclusive of staff and patients, will be established throughout the continuum of care. As lymphedema research and standard of care consensus become established, this surveillance model will be adapted in accordance with evidence-based practice guidelines.

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Lymphedema complications after breast cancer treatment can be an irreversible condition with a negative impact on quality of life (Williams, Vadgama, Franks, & Mortimer, 2002). Lymphedema is defined as a dysfunction in the transport of the lymphatic system, which is unable to accommodate normal lymphatic load. This abnormal accumulation of water and proteins is in the subcutaneous tissues and may present in the extremities and trunk (Zuther & Norton, 2013). Breast cancer survivors have reported dissatisfaction regarding the lack of education provided on this condition by healthcare clinicians (Gray et al., 1998; Runowicz, 1998). According to the American Cancer Society (2014), about 2.9 million breast cancer survivors are living in the United States, with more than 235,000 newly diagnosed cases each year. Secondary lymphedema prevalence has been noted to be as high as 34%–94% in long-term follow-up (Hayes et al., 2011); variances in incidence rates differ on the method of measurement and quantification (Armer & Stewart, 2010). With an improving survival rate for breast cancer, the risk for the development of lymphedema is increasing. Early

assessment, intervention, and education are critical, and hold the greatest promise for successful management of lymphatic dysfunction following breast cancer treatment (Bernas, Askew, Armer, & Cormier, 2010).

## Background

In an era of patient-centered health care with principles based on prevention and early detection, the wait-and-see clinical approach with breast cancer–related lymphedema (BCRL) should no longer be the standard of care. Instead, clinicians should be adopting a proactive approach in the assessment and intervention of BCRL. Through participation in the ONS Foundation–supported Breast Cancer Survivorship (BCS) Quality Measures Set pilot study (Fessele, Yendro, & Mallory, 2014), the authors found the assessment of lymphedema practices at the Springfield Clinic to be less than optimal. The pilot project compelled the authors to look at the current process and workflow related to the care of patients with breast cancer, particularly in the area of lymphedema. Involvement with the survivorship

measures prompted the need to develop a method for appropriate measurement of the upper extremities in the clinic setting, particularly preoperatively. The pilot study findings also indicated a need to expand on nursing education regarding the lymphatic system and associated dysfunction in the development of the lymphedema condition and other sequelae. These findings support the necessity to establish a measurement tool that is efficient, cost effective, reliable, and easily performed in a busy clinic setting. In addition, the tool would provide baseline data of bilateral upper extremities and that information would be readily accessible in the electronic health record. The authors felt that this method would best serve the needs of patients and establish a standardized protocol within the clinic until universal protocols are established.

## Stages of Lymphedema

With the loss of lymph nodes, as with sentinel lymph node biopsy or axillary lymph node dissection, the body has acquired a mechanical insufficiency in the lymphatic system. Symptoms of lymphedema exist when the lymphatic load exceeds the body's ability to transport excess fluid. Stage 0 lymphedema is defined as any loss of lymph node, but no symptoms are present. Stage I lymphedema is when transient symptoms are presenting with days of increased fluid in the affected quadrant of the body, but then resumes the prior level of function. Stage II is when the fluid in the affected quadrant is sustained at a high level and does not resolve and may or may not present with pitting edema and fibrosis. Stage III appears with chronic fibrosis in the tissue and can include a history of repeated infections (Foldi & Foldi, 2006).

With an increased awareness of the lymphatic system and dysfunction by nurses and patients alike, greater attention can be placed on the establishment of a screening tool and its consistent use in surveillance. Expectations can be set for improvements in earlier diagnosis of lymphedema and interventions supporting it being sustained in a stage 0, I, or controlled II level.

## Assessment Criteria and Patient Selection

Assessment tools used in surveillance for BCRL include bioelectrical impedance, water displacement, perometry, and sequential circumferential arm measurement, as well as self-report of symptoms. The authors acknowledge that more accurate measurement techniques exist; however, they require specialized equipment and training. The authors chose circumferential measurement because it offers an easily accessible tool that a breast cancer clinic can incorporate into its work flow. It also is a valuable tool for survivors to easily log their limb measurement in home data collection, particularly because early symptoms can be so variable. Ease of learning to use circumference measurement tapes for the clinic staff as well as the survivor offers an immediate tool for pre- and postoperative limb assessment.

Consensus does not exist regarding the criteria to which clinically relevant lymphedema is made (Armer & Stewart, 2010). Misdiagnosis of having lymphedema causes unnecessary psychological distress, negative quality of life, referral for unnecessary treatment, and increasing cost (Dylke, Yee, Ward, For-

oughi, & Kilbreath, 2012). Current evidence-based surveillance for BCRL uses relative versus absolute measurements in limb changes (Ancukiewicz et al., 2012). In the past, studies have focused on absolute changes for the diagnosis of lymphedema, which does not account for changes in body mass index or normal differences between dominant and nondominant arms (Dylke et al., 2012). Relative arm measurements are independent of body size changes and give a more accurate correlation in quantifying BCRL (Ancukiewicz et al., 2012).

For patients with unilateral breast cancer, a relative difference in limb volume of greater than 10% between the unaffected and affected arm will be the threshold used for lymphedema diagnosis and treatment referral. For patients presenting with bilateral breast cancer, the authors will refer to pre- and postoperative measurements of greater than 10% absolute difference for a diagnostic threshold for treatment and referral purposes. Based on variability in postoperative follow-up, measurements will occur at a minimum of four times per calendar year, separated by at least two-month intervals.

Incorporating the measurement tool offers an early opportunity for patient education and strengthens clinical management of the condition of BCRL. It further allows for relative upper extremity comparative assessment of perioperative and follow-up measurements necessary for earlier identification and intervention in lymphatic system dysfunction. The inclusion of surveillance for BCRL in the authors' clinic will encompass both sentinel lymph node removal as well as axillary lymph node dissection.

## Education

Using the measurement tool plus patient education allowed the focus to be placed on a more holistic approach to lymphedema management. Appropriate education regarding lymphedema is multifaceted. Nursing staff should be well educated on the etiology of lymphedema and the physiologic and psychological impact to the patient diagnosed with lymphedema. Patients should be educated on risk-reduction practices and recommendations of early intervention for reported signs and symptoms of swelling. Fu, Ridner, and Armer (2009) reported that "patients with lymphedema ranked nurses among the most important actual providers of pretreatment education" (p. 39). In addition, they report that nursing knowledge of lymphedema is critical toward educating patients about the condition, and education should begin when breast cancer treatment is initiated (Fu et al., 2009). The inter-relationship between nursing knowledge of the condition and education provided to the patient plays a pivotal role in the successful implementation of the model.

To achieve implementation of the model, the authors plan to offer educational seminars to increase nurses' knowledge of the condition. The education will be offered to any nurse that participates in the care of a patient with breast cancer. In addition to the live seminars, nurses also will be provided with written reference material regarding the stages of lymphedema, signs and symptoms, and risk-reduction practices. In a study by Sherman and Koelmeyer (2011), nurses involved in the care of patients with breast cancer had taken the lead role in the distribution of lymphedema-related information, which seemed to convince women to engage in risk-reduction behaviors.

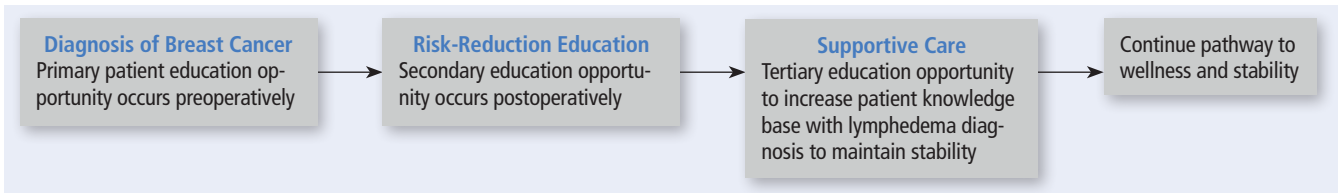


FIGURE 1. Lymphedema Education Opportunities for Patients With Breast Cancer

The authors believed that the seminars and written material provided to the nurses required supplementation to engage nurses in the assessment, intervention, and education cycle. Incorporating the Neuman Systems Model nursing theory (Reed, 1993) allows nurses to integrate individual patient stressors, personal variables with nursing goals, and interventions. The Neuman theory outlines individual stressors that may contribute to a breakdown of the body system or of the patient's lines of defense and protection. Within the context of how BCRL may develop, this theory can be applied to the overall understanding and illustrated as concentric layers of defense with the patient system. If all systems in the body function normally, then lymphedema may not occur. The surgical removal of the lymph node allows for a breakdown in one layer of a patient's defense. A nurse who is unaware of the early signs and symptoms of lymphedema or a patient who is uneducated regarding lymphedema can cause the collapse of yet another layer. When all lines of defense and resistance are broken, the system fails and lymphedema may go undetected. Once these stressors are identified, goals can then be established to evaluate and educate the patient. These goals should be applied at distinct stages of diagnosis and recovery. By prioritizing these goals, successful teaching in a logical framework can be established (Reed, 1993) (see Figure 1).

Nursing education regarding lymphedema should be ongoing and incorporate best practices to disseminate appropriate education to the patients. Fleysler (2010) reported that oncologists, primary care practitioners, community nurses, and/or nurse specialists should be the link between patients and risk-reduction strategies. She further indicated that continuous reassessment of a patient's progress plays a role in prevention and management of lymphedema and its related comorbidities (Fleysler, 2010).

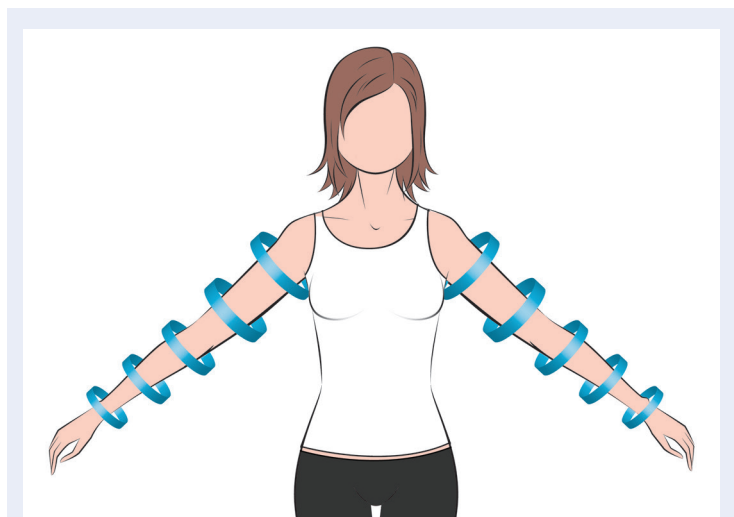
### Surveillance Model

Inter-arm volume differences based on circumferential measurement and using the relative percent difference between arms as compared to baseline was the basis for the authors' surveillance model. The circumferential measurement procedure is done as follows.

- Measurement is conducted on the bare arm (measurements are not reliable if done over clothing).
- Measurements are taken in centimeters verses inches for accuracy in variances.
- The patient is seated with arm flexed to 45 degrees, elbow extended, wrist neutral, and fingers extended.

Joint positions should be documented if they are different (i.e., standing with arm abducted at 90 degrees) for reliability.

- Measurement tape is held secure to tissues with no indent into tissues. Tape is positioned straight and horizontal on the arm.
- The five levels of measurement are the distal wrist crease and at 10, 20, 30, and 40 cm.
- Bilateral arm measurements are documented for relative arm changes in perioperative and follow-up assessments.



Site	Side (circle one)	Date	Date	Date
DWC neutral position	Right (cm)			
	Left (cm)			
10 cm from DWC	Right			
	Left			
20 cm from DWC	Right			
	Left			
30 cm from DWC	Right			
	Left			
40 cm from DWC	Right			
	Left			

DWC—distal wrist crease

FIGURE 2. Lymphedema Measurement Record

Note. Image courtesy of Springfield Clinic. Used with permission.

## Implications for Practice

- ▶ Take an active role as a leader in perioperative assessment and education regarding lymphedema.
- ▶ Incorporate subjective symptoms, as reported by the patient, in the nursing assessment and dispense appropriate and timely information.
- ▶ Positively affect the quality of life of breast cancer survivors with nurse-led, patient-centered discussions about lymphedema.

- Volume is calculated using a truncated cone formula (Caban, 2002).
- Percentage of change between arms as compared to baseline is calculated using a relative volume change formula noted by O'Toole et al. (2013).

To facilitate the ease of locating measurements, the baseline information will be entered on the established tool (see Figure 2) as well as the patient's survivorship care plan at the time of surgical consultation. Follow-up measurements will then be recorded in the electronic health record for easy identification of percentage of relative change.

## Conclusion

Participation in the pilot of the BCS Measures gave the authors the opportunity to analyze current institutional processes and workflow related to lymphedema education and management. With this information, the authors were able to propose a reasonable method to increase patient and staff education, incorporate limb measurements, and establish a referral threshold to a qualified lymphedema therapist. Using a standardized tool of assessment pre- and postoperatively, in addition to follow-up assessments by the nurses and inclusive of patient-reported symptoms, can support vital data gathering to increase earlier awareness of and surveillance for lymphatic dysfunction. At the Springfield Clinic, bilateral arm measurements are obtained at the time of surgical consultation and at follow-up appointments by the nurse navigator. Follow-up measurements are recorded on the established tool and in the electronic health record. Any relative limb changes greater than 10% are reported to the treating physician for consultation, diagnosis, and treatment.

The inclusion of the baseline measurement data in the survivorship care plan provides enduring information for the patient and multidisciplinary team. Establishing a threshold for diagnosis and referral currently remains a relevant concern. The importance in sustaining a stage I level in functional management of lymphedema symptoms is crucial.

Improved documentation of surveillance within the care plan can improve a patient's quality of life as well as reduce cost and use of other healthcare services. Once the model is established in the author's practice, it will provide the opportunity to institute quality performance metrics based on the assessment of lymphedema, treatment-related interventions, and patient education as outlined in the BCS Measures pilot study.

## Implications for Nursing Practice

As breast cancer survivors increase in numbers and longevity, nursing would be well served to emerge as the leader in perioperative lymphedema assessment and education. Subjective symptoms, as reported by the patient, should routinely be incorporated into the nursing assessment and timely education dispensed. A nurse-led, patient-centered discussion about lymphedema has the potential to positively affect the quality of life for many breast cancer survivors, reduce fear of the condition, and empower the patient to self-monitor for changes. The application of the measurement tool combined with a solid foundation in nursing assessment and goal-oriented outcomes will allow for patient-specific education at appropriate phases of recovery and survivorship.

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