Lymphedema: A challenge for caregivers, a burden to patients

Patients with lymphedema may have functional impairment, as well as chronic pain. Preventing the condition is more effective than treating it.



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here is no cure for secondary lymphedema, the chronic, progressive, and frequently debilitating swelling of the arm, shoulder, neck, or thorax triggered by surgical dissection or radiotherapy involving the axillary lymph nodes. Lymphedema impacts the lives of up to 60% of breast cancer patients.¹ Patients with other cancers, such as squamous cell carcinoma of the vulva or metastatic melanoma, may also undergo lymph node dissections, leading to lymphedema in 12% to 69% of this group.² Incidence rate estimates for breast cancer patients vary dramatically between studies, from 5% to 60%, depending on such factors as study length, treatment modality, and diagnostic criteria. A prospective 5-year study of more than 600 patients published in 2009 found a cumulative 5-year incidence of 42%, with 89% of cases appearing within the first 3 years.³ Although risk declines with time since cancer treatment, lymphedema remains a lifelong risk for breast cancer survivors, with onset occurring in rare cases several decades after cancer treatment.4

Among the burdens and challenges faced by lymphedema patients are impaired arm and hand function, chronic pain and discomfort, impaired quality of life and self-esteem, and potentially significant financial effects—including the loss of employment due to the loss of motor dexterity or the ability to lift heavy objects. ^{4,5} Lymphedema-related pain affects more than half of patients (56%, according to one study). ¹ Medical costs for breast cancer patients with lymphedema are up to \$23,000 higher than

those faced by patients who do not develop lymphedema.⁵ Reimbursement rules intended to curb fraudulent outpatient rehabilitation charges to Medicare may force many patients to pay for treatment costs out-of-pocket.6

LIMB MEASUREMENT

Lymphedema may develop gradually or abruptly. Many clinicians are unfamiliar with lymphedema and its diagnosis, and nurses play a pivotal role in the recognition and management of lymphedema and in patient education. Clinical symptoms include patient reports of swelling, pain, heat, or numbness, sometimes preceding physical evidence of lymphedema and possibly explaining the moderate (but reliable) correlation of self-reporting and volumetric methods of detection (r = .65 to .71). While no uniform, widely-accepted diagnostic criteria are available, lymphedema is usually defined as increases in limb circumference or volume exceeding 2 cm or 10%, respectively, as determined by comparison of affected and unaffected limbs, or pre-onset affected limb measurements compared with swollen limb measurements.⁴ After other conditions that may cause lymphedema symptoms are excluded (such as recurrent or secondary cancers, deep-vein thrombosis, diabetes, or heart, kidney, or liver disease), lymphedema of the limb measurements are taken for comparison with quantitative criteria used in lymphedema diagnosis. 4,9 No quantitative standards are available for measuring lymphedema of nonlimb anatomies.

Limb volume can be reliably measured using water displacement, tape measurement, infrared perometry, or electrical impedance measurement. Water displacement volumetry involves the patient's placement of the affected portion of the arm and the equivalent portion of the unaffected arm into a container of water, and displaced water is then weighed for comparison.9 Open skin lesions are a contraindication for water displacement measurement.⁴ Tape measurement of limb circumference can be used instead of water displacement and involves measurement of the hand, wrist, and arm at 4-cm intervals.⁴ Sequential tape measurement can be used to track volume changes over time.

Optoelectronic volumetry using infrared perometry equipment can be used to quantify both the morphology and volume of limbs using infrared light in a manner analogous to CT's use of x-rays. However, the research literature validating this technique, while promising and suggesting measurement reliability comparable to sequential tape measurement, remains scant, and perometric equipment is not universally available. 10,11

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TABLE 1. Extremity positioning for lymphedema patients

Patients should position the affected extremities to avoid constriction or the pooling of blood and fluids. Advise them to

Elevate the arm or leg above the level of the heart.

Avoid rapid movements that could cause centrifugal pooling of fluid in hands or legs.

Avoid heat to limbs (heat can increase blood flow); avoid hot baths

Avoid strain or constrictive pressure that may obstruct lymph flow (but do not avoid using the affected or at-risk limb altogether).

Avoid tight-fitting jewelry and clothing, elastic bandages, clothing with constrictive bands, and blood pressure monitoring equipment on the lymphedemic arm.

Avoid carrying a purse or heavy objects on the affected arm.

Sit smart: do not cross legs while sitting or sit in one position for more than 30 minutes.

Sources: Schmitz KH16 and National Cancer Institute, Lymphedema PDO: health professional version. www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/Health-Professional . Modified May 24, 2010. Accessed June 7, 2010.

TABLE 2. Hygiene: avoiding infection

Daily skin and nail care and inspection are crucial for avoiding opportunistic infections that may trigger cellulitis. **Educate patients to**

Recognize the signs of infection (fever, swelling, warmth, redness, pain), and seek medical intervention immediately if infection occurs.

Avoid intravenous line placement, blood draws, vaccination injections, and finger sticks on the affected limb.

Avoid sunburns.

Apply topical antibiotics to paper cuts and other small cuts.

Wear gloves for gardening, cooking, and dishwashing to avoid cuts and hot water splash or steam burns.

Use the unaffected extremity to test bath water or cooking water for temperature in order to avoid burns (sensation in affected hands may be impaired).

Cut the nails straight across and seek medical treatment for ingrown nails.

Keep feet clean and dry; use cotton socks without restrictive elastic bands; and avoid going barefoot.

Source: National Cancer Institute. Lymphedema PDQ: health professional version. www. cancer.gov/cancertopics/pdg/supportivecare/lymphedema/HealthProfessional. Modified May 24, 2010. Accessed June 7, 2010.

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An accurate and more rapid alternative to perometry is the measurement of the accumulation of lymph fluid in affected limbs. Electrical bioimpedance allows early lymphedema detection and involves the use of electrical currents to measure fluid volumes, which correlate strongly with physical limb and perometric measurements.¹²

RISK REDUCTION

Lymphedema is not curable, so clinical emphasis is placed on prevention and risk reduction, with the goal of avoiding lymphedema entirely or preventing progression or worsening when it does occur. Primary among these approaches is the avoidance of limb constriction or infections that could cause cellulitis and trigger lymphedema (**Table 1** and **Table 2**). Wearing tight jewelry, for example, may increase a patient's risk of lymphedema by more than 700%.³ A 2007 cross-sectional study of 807 patients found early diagnosis, weight control, and limb hygiene to be the primary factors in managing lymphedema severity.¹³

Risk reduction may begin with minimization of treatmentrelated trauma to the axillary lymph nodes through careful targeting of external-beam radiotherapy. The use of lumpectomy instead of radical mastectomy and the removal of only one or two sentinel nodes for staging can also reduce risk.⁴

Behavioral and hygiene strategies also appear to be important in the prevention of lymphedema onset and progression. These include weight loss for obese patients (those with a body mass index exceeding 29 kg/m²) and the avoidance of infection or injury to affected limbs.¹³ At-risk patients should be educated about risk factors such as obesity, constriction, and infection.^{4,14}

MANAGEMENT

Treatment for lymphedema is supportive rather than curative and is aimed at reducing discomfort and functional impairment and slowing or preventing progression. While no uniform standard of care is yet available, the American Lymphedema Framework Project (ALFP), directed by University of Missouri nursing professor Jane Armer, a leading research in lymphedema management, has been created to establish evidence-based best practice guidelines by 2011 (**Table 3**).

The Oncology Nursing Society (ONS) has published evidence-based assessments of management strategies.¹⁵ The use of diuretics or benzopyrenes are *not* recommended, and effectiveness has not been established for compression garments (alone), low-level laser therapy, hyperbaric oxygen therapy, nano-silver treatment for ulcers, simple lymph drainage (alone), pneumatic compression, or surgery.¹⁵

Exercise and prophylactic antibiotics for recurring infection may offer benefits, but these are balanced by potential harms. ¹⁵ Prolonged antibiotic therapy can facilitate the emergence of drug-resistant bacteria, for example, and although exercise can facilitate weight loss and stimulate lymphatic function and lymph drainage, its benefits are unclear and heavy exercise carries the risk of musculoskeletal strain or injury. ¹ However, early concerns that exercise may increase lymphedema risk appear to have been unwarranted, and discouraging even moderate exercise of an at-risk or affected limb may increase lymphedema risk or severity. ¹⁶ A recent systematic review concluded that the risks of progressive resistance training are outweighed by clinical and health-related benefits. ¹⁷

Comprehensive decongestive therapy (CDT) entails manual drainage of lymph node fluids, compression bandaging, and skin hygiene practices. ^{1,15,18} The ONA recommends CDT along with immediate antibiotics treatment for infections. CDT involves patient education and commitment to long-term (lifelong) observance of the recommended practices described here.

TABLE 3. Online resources for nurses and patients

American Cancer Society. Lymphedema: What every women with breast cancer should know.

www.cancer.org/docroot/MIT/content/MIT_7_2x_Lymphedema_and_ Breast_Cancer.asp

American Lymphedema Framework Project www.alfp.org

BreastCancer.org

www.breastcancer.org/tips/lymphedema/

Lance Armstrong Foundation. Lymphedema.

www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Physical-Effects-of-Cancer/Lymphedema

National Lymphedema Network articles database and information on training lymphedema therapists www.lymphnet.org

National Cancer Institute

www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/ HealthProfessional

National Cancer Institute (Information for patients)

www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/

Oncology Nursing Society Lymphedema Putting Evidence into Practice (PEP) Quickview datasheet

www.ons.org/Research/PEP/media/ons/docs/research/outcomes/lymphedema/quickview.pdf

Oncology Nursing Society Putting Research into Practice (PEP) description of evidence-based medicine and lymphedema www.ons.org/Research/PEP/Topics

Lymphedema and Breast Cancer Questionnaire

Available via e-mail from Jane Armer: armer@missouri.edu

The goal of CDT is to reduce congestion of interstitial lymphatic fluid in the limbs in order to decrease pain and functional limb impairment and to improve the range of limb motion. CDT involves two phases of therapy. First, an intensive, therapist-guided phase of patient education, manual lymph drainage, short-stretch compression bandaging, skin and nail care, and remedial exercise is undertaken. Then a maintenance phase begins, involving simple lymphatic drainage, nighttime compression bandaging, daytime use of compression garments, and an exercise and skin-hygiene routine. Specially-trained and certified lymphedema therapists should conduct the manual lymph drainage and bandaging. (For information on training for lymphedema therapists, see the National Lymphedema Network Web site listed in **Table 3**.)

A recent European study of CDT outcomes in 171 patients found that patient adherence to compressive bandaging was the single most important factor in CDT efficacy. The study also found that a history of axillary radiation therapy, venous insufficiency in lower limbs, and greater lymphedema severity at the time of CDT initiation are negatively associated with CDT efficacy; the authors recommended that CDT begin in the early stages of lymphedema. (Warmer ambient temperatures may also matter. Treatment during the autumn in this study conducted in Spain was associated with significant efficacy advantages over CDT initiated during other seasons, though the reasons for this finding are unclear and it has not yet been replicated in other studies. (18)

Patient adherence to compressive bandaging is time-consuming, potentially physically challenging, and costly. Nurses are at the forefront of patient education efforts and must emphasize the key role of compliance with bandaging instructions in successful outcomes.

Nurses also play a crucial role in prevention through presymptom patient education and early detection. Nurses should discuss skin hygiene, limb positioning, and the symptoms and signs of lymphedema with breast cancer patients during follow-up visits. Every breast cancer patient should be routinely assessed for, and questioned about, swelling, impaired range of limb motion, and other lymphedema symptoms. Jane Armer offers a lymphedema questionnaire for periodic posttreatment assessment of breast cancer patients (Table 3).

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