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Lymphedema: Responding to Our Patients' Needs

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Lymphedema is greatly misunderstood in every possible circle—from healthcare providers to patients at risk. Lymphedema is a collection of excess water, interstitial fluid, plasma proteins, bacteria, and cellular waste products in the interstitial tissues as a result of an impaired lymphatic system (Cheville, McGarvey, Petrek, Russo, Taylor, et al., 2003; International Society of Lymphology [ISL], 2003). Ninety percent of interstitial fluid is removed by the circulatory system with the remaining 10% managed by the lymphatic vessels (Ridner, 2002). The lymphatic system is extensive throughout each of us. It begins as a fine network just under the skin surface and converges to become larger vessels deeper in the tissue. Fluid from the lower extremities moves up through the thoracic duct, running up the abdomen, and is affected by diaphragmatic pressures. Lymphatic fluid moves up through the nodal beds and dumps into the vascular system at the entrance of the superior vena cava.

Fluid exchange occurs at the blood capillary-interstitial-lymphatic vessel interface. Fluid exchanges requires blood circulation, tissue channels, proteolytic cells in the tissues, and initial lymphatics. Each of these “systems” interacts with and regulates the others to preserve the extracellular and intracellular environments. Muscular contractions, respiration, and external pressure changes cause pumping and filling of lymph fluid from the tissue into the initial lymphatics via the many openings between the endothelial cell junctions, which, in turn, connect to collecting lymphatics or lymph angions. Lymphatic flow proceeds in the direction of the heart with numerous lymph-venous communications, including the thoracic duct and right lymph duct, with the great veins of the neck.

Causes

Secondary lymphedema results from damage to lymphatic structures leading to congestion when the amount of fluid requiring removal from the tissue exceeds the transport capacity of the lymphangions (ISL, 2003). Transport capacity, the capability of the lymphatics to remove fluid from the tissue, reflects how much fluid volume it can manage.

Altering the lymphatic anatomy through trauma, surgery, radiation therapy, or scarring from infection results in a mechanical problem, in that even the usual amounts of fluid in the tissue are in excess of the transport capacity. In addition to altered mechanics, any activity that causes increased skin temperatures leads to vasodilatation and movement of the fluid out of the vasculature into the tissue. This will lead to a greater

volume needing removal back into the circulatory system (Leitch et al., 1998; Mortimer, 1998; Pressman, 1998). Examples of heat-producing activities are being exposed to direct sun, taking hot showers or baths, soaking in a hot tub, and making repetitive movements to the point of muscle strain.

In people diagnosed with cancer, the two major causes of altered lymphatics and subsequent fluid exceeding the capacity of the lymphatics are lymph node removal or radiation therapy to the lymph nodes. Therefore, in patients with cancer, those diseases most commonly requiring lymph node sampling are at highest risk for lymphedema development. Cancer surgery also results in scarring superficially. Scars inhibit lymphatic flow across them so that fluid collects proximally to the scar. Although sentinel node biopsy is growing in practice, the risk of lymphedema development in patients with breast cancer is still significant if they receive radiation therapy to the nodal basins. It is believed that lymphatic vessels in the radiation field are constricted following radiation because the resultant fibrotic tissue constricts the vessels. Because the risk of lymphedema is lifelong, follow-up is still needed for those patients undergoing limited lymph node dissections, with or without radiotherapy (Hull, 2000; Meek, 1998; Rockson, 1998).

Lymphedema can occur in any quadrant that is drained by the affected nodal bed. Truncal lymphedema is often noted when a patient is examined posteriorly, but it can occur anteriorly as well. Breast lymphedema frequently is accompanied by truncal lymphedema or supraclavicular fullness. Upperlimb lymphedema can be limited to just the arm from wrist to axilla; the posterior side of the elbow, which is dependent and more prone to gravity; or the hand alone. Lower-extremity lymphedema almost always includes the foot but not necessarily the toes and can also be limited to the genitals and buttocks, depending on the extent of the surgery, scarring, radiation field, or past history of compression pump use. There are



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numerous anecdotal reports of compression pump use for leg lymphedema, resulting in enlarged buttocks from fluid being pushed upward but not beyond to draining lymph node beds.

A four-stage classification scale is utilized when describing a patient's lymphadenomatous condition (see Figure 1). Stage 0 or the subclinical condition in which lymph transport is impaired but overt edema is absent can exist for months or years (ISL, 2003). Stage 1 is characterized by soft tissue texture, pitting of the high-protein fluid-filled tissue, and a decrease in swelling overnight. Stage 2 lymphedema has usually been present for greater than one year and no longer decreases with limb elevation. Pitting may not be possible even with excessive pressing as time passes from the first visible signs. Stage 3 lymphedema is the condition that many may remember seeing in someone who died from metastatic breast cancer years ago when treatment was unknown. The limb is grossly enlarged and misshapen, often with added skin folds in the lower limbs, streptococcal rashes, spontaneous open wounds, and seeping areas occurring without breaks in skin integrity. The lymphostatic elephantiasis of stage 3 is not as commonly seen today as in previous decades because it is a progressive condition that occurs over years without treatment. Pitting is nonexistent, and skin thickening with fat deposits and warty overgrowths occurs (ISL).

Contributing Factors

Unfortunately, the lymphedema literature is lacking in a number of areas, including factors that potentially raise the risk of lymphedema development. Empirically, the occurrence of a postoperative cellulitis, hematoma, infection, or seroma seems to raise the risk of lymphedema development because the extremity's workload immediately exceeds the capacity of a newly altered anatomy. Other factors that potentially contribute to risk by raising the tissue temperature and causing more movement of fluid into the extracellular space include using heating blankets or pads, taking prolonged hot and steamy showers, using hot tubs, prolonged exposure to the sun, muscle strain, burns, or infection. Constriction of shoulder collateral lymphatics from thin bra straps or tight waistbands cutting across the superficial lymphatic pathways of the abdomen can obstruct lymph flow as well.

Weight gain and obesity (body mass index [BMI] > 30) are well documented within the literature as major contributors to lymphedema and impedances to successful treatment and management (Meek, 1998; Werner et al., 1991). When asked, patients often correlate a weight gain with the occurrence of limb swelling.

Quality of Life

Lymphedema affects cancer survivors' quality of life. The physical changes potentially alter their role within their family, work, and society. Simultaneously, the presence of lymphedema

can bias a person's body image, sexuality, and emotional well-being (Kwan et al., 2002; Passik & McDonald, 1998). The consequences of lymphedema are numerous (see Figure 2). Although swelling or edema within the tissue is not painful, the stretching of nerve fibers within the skin, presence of a localized infection, or fluid collection that causes compression on top of a nerve bundle can result in discomfort. "Aching," "heaviness," "tightness," and "pulling" are adjectives commonly used by patients to describe their discomfort. Armer, Radina, Porock, and Culbertson (2003) noted that these symptoms are present well before visible signs of swelling are noticed.

Pain can be significant and troublesome, requiring use of a pain scale to adequately measure, monitor, and evaluate a person's report of pain. The comfort alteration typically is described within the context of being deeper than the skin surface, so that touch usually does not instigate more pain unless an infection is present. As lymphedema or the infection is treated, the discomfort resolves. In cases where pain is localized to the back or trunk, muscle tightness or spasms resulting from altered body posturing and positioning will respond to nonsteroidal anti-inflammatory drugs used in conjunction with treatment for the first few days.

Because stagnations of fluid, bacteria, and waste products are accumulating in the tissue, the area is at greater risk of developing localized infection. Bacteria are not being cleared and, when unchecked, can overwhelm the local immune defenses. Because removal of bacteria is altered in an affected lymphatome, bacteria are able to multiply and overpower the immune system response (Brewer, Hahn, Rohrbach, Bell, & Baddour, 2000). Infection, initially localized to the skin tissue where fluid has accumulated, can become systemic, placing the patient at risk for sepsis if untreated or if treatment is delayed. Localized cellulitis is often accompanied by descriptions of heat and is warm to the touch. The resultant infection begins as a pinkish rash progressing to erythematous blotches or streaks and often is preceded by flu-like symptoms of malaise, chills, and fever. The lymphedema-related organism is usually *Beta streptococci*, which responds well to oral penicillin, but treatment beyond the usual 10-day course may be necessary because of the difficulty in achieving adequate tissue penetration with oral agents (Casley-Smith & Casley-Smith, 1997).

Angiosarcoma, a malignancy, is a rare complication of prolonged stage 3 lymphedema. It is more often associated with lower-extremity lymphedema and is another reason for aggressive lymphedema treatment.

The fatigue that can accompany lymphedema can be vague in presentation. Fatigue is dependent upon the limb size, whether the affected limb is an upper or lower extremity, and whether comorbid conditions are present. If a patient is too exhausted to attend daily lymphedema management treatments or carry out any lymphedema treatment recommendations, it is better to treat other underlying fatigue causes to maximize the person's chance of successful lymphedema treatment because compliance is critical (Armer & Porock, 2002).

Swelling of any aspect of an arm can affect manual dexterity, fine motor skills, activities of daily living, and role or job responsibilities. As the swelling increases, a person can withdraw from normal activities because of the cumbersome nature and weight of the limb. Additionally, as the limb size increases and the skin stretches tight, fluid can ooze through the skin without breaks in skin integrity, further causing a person to withdraw socially.

Stage 0: No visible signs despite collecting protein-rich fluid

Stage 1: Soft, pitting tissue; decreases with elevation

Stage 2: Difficult to "pit" tissue; no longer decreases

Stage 3: Lymphostatic elephantiasis

Figure 1. Lymphedema Stages

- Pain
- Altered sensations and function
- Need for nontailored, large-sized clothing and shoes
- Repeated, persistent infections
- Fatigue
- Altered interpersonal relationships
- Functional disability
- Self-image alterations

Figure 2. Consequences of Lymphedema

Body image is challenged because the person's appearance, sense of sexuality, and physical functioning are in a state of flux (Hull, 2000; Passik & McDonald, 1998). Finding suitable clothes can be virtually impossible. Patients buy larger shirts than they need in order to accommodate an increasing arm size. The ability to wear short-sleeved shirts and dresses decreases quickly as people become very self-conscious and attempt to hide the swelling or compression garment. Lower-extremity options are even more limited when long skirts or wide-legged pants are needed to accommodate leg swelling. Costs are increased when patients need two pairs of shoes because they have two different shoe sizes or need hems altered on very large, baggy pants. Hot weather forces patients indoors if they are embarrassed to have their limb seen.

Patients typically do not want to answer questions about their limbs because most people are unfamiliar with the term "lymphedema." Therefore, it is not uncommon for patients to have a reserve of quick comebacks to innocent bystanders who show concern when they see a bandaged limb or compression sleeve on an arm. For example, one woman's response to questions regarding her bandaged arm is "I train Doberman pinschers for a living." This usually stops people very quickly from inquiring further. At the first National Lymphedema Day in Virginia, on March 6, 2001, 60 patients and families came to the celebration. Of the four women with lymphedema posing for a photograph that day, only one was wearing her compression sleeve. If there was an occasion to not feel "different," it would have been at that gathering, yet the three without their compression sleeves said they did not think their sleeves went well with what they were wearing.

Assessment and Diagnosis

Lymphedema is diagnosed according to circumferential size of the affected limb (> 2 cm increase over the opposite limb), tissue texture, and presence or absence of fibrosis as evidenced by the ability to pit the tissue, oozing of fluid through the skin, and the report of limb decongestion when the limb is elevated (Meek, 1998).

The health history begins with learning the patient's chief complaint. The patient's report of the symptoms he or she can recall before visible signs of lymphedema appeared provides the time frame for how long the problem has existed. Inquiring into daily activities and assessing for behaviors that increase tissue temperature and for fluid shifts into the tissue provide insight into risk factors and contribute to the long-term management plan (Armer et al., 2003; Hull, 2000; ISL, 2003; Rockson et al., 1998).

A review of systems with special attention to the integumentary, cardiac, respiratory, and neurovascular systems precedes the focused limb assessment. The presence of cardiac disease,

congestive heart failure, renal insufficiency, active asthma, or an abdominal bruit makes standard treatment difficult to institute because these conditions place the patient at risk for complications from the excess fluid that is mobilized or eliminated possible treatment techniques that are part of the standard of care.

During the physical examination, sensory and motor functions of the limbs are assessed with particular emphasis on vibratory sense, noting differences in affected digits. All scar lines should be recorded in the patient's chart by drawing them on a figure, noting the lengths and widths.

When examining the patient's thorax, make note of any indentations from bra straps, waistbands, kneesocks, or stockings. Collapse of the lymphatic pathways from tight-fitting clothes is a distinct possibility because the vessels are superficial and easily compressed. Educating the patient about this as you find them on the body makes a lasting impression. Additionally, the radiation ports should also be identified and the radiation field recorded on the chart figure so that the practitioner recognizes which lymph node clusters potentially will be fibrosed and therefore unable to contribute to lymph drainage.

Prosthetic weight should be listed on the limb measurement chart along with the patient's height, weight, and BMI. Compression garment manufacturer, type, compression level, and size should be noted. This is also a good time to assess the age of the garment because patients often wear compression garments longer than the six months recommended by manufacturers (Brennan & Miller, 1998).

Bilateral limb circumferential measurements recorded over time should be documented on a special flowsheet. Noted on the flowsheet should be the distances (in centimeters) between measurement points (Brown, 2004; Gerber, 1998) (see Figure 3). Circumferential limb measurements of the unaffected limb at the same equidistant measurement points of the affected limb also should be documented during the initial and subsequent visits. Water displacement and perometry have been used but are more difficult or costly and therefore are used much less than circumferential measuring.

The pathology report of the original cancer tissue diagnosis usually must be requested by the lymphedema practitioner because it typically does not accompany a physician referral. Providing the practitioner with information about the type and



Figure 3. Circumferential Measurement

extent of surgery, histology, and number and level of nodes removed contributes to the practitioner's suspicion level for the possibility of tumor recurrence causing the lymphedema. Ruling out cancer recurrence is indicated in the process of confirming the lymphedema diagnosis.

A Doppler ultrasound of the congested limb and quadrant that the limb drains into assists in ruling out thrombosis as a cause of the congestion. Radiographic confirmation of cancer remission via x-rays or computed tomography scans is also indicated to confirm the lymphedema diagnosis (Rockson, 1998). Reviewing and documenting the report of the most recent scan or test that is used to monitor the patient for recurrence should be routine.

Treatment

Treating lymphedema begins with first managing any comorbid conditions. Because lymphedema is a chronic condition and, in most cases, patients have been dealing with it for a long time, they are weary. People are often worn down by the time they find a well-trained lymphedema specialist because they have spent months and numerous attempts trying to get their care providers to believe that something is not right with their limb. They are frustrated when care providers have dismissed their concerns as cosmetic or have not believed that they are suffering discomfort, altered sleep patterns, and hopelessness over their condition. Therefore, assessing and managing depression, fatigue, pain, and any subclinical infection before or simultaneously as treatment is begun are crucial to successful patient response and lymphedema decongestion. If patients are too tired, too hopeless, or too weary when they are evaluated for lymphedema treatment, they are at risk for not being able to follow through with the daily treatments or compression bandaging. This sets them up for failure to respond because treatment is less than what is required.

Manual Lymph Drainage

Lymphedema treatment is divided into two phases. The acute phase involves daily 60- to 90-minute manual lymph drainage (MLD) sessions for up to 15 treatments over three weeks (Ko, Lerner, Klose, & Cosimi, 1998). During this phase, daily education is conducted and reinforced about topics such as muscle-building exercises, aerobic exercise, abdominal deep breathing, and activities that facilitate abdominal deep breathing (e.g., Pilates, swimming, ballroom dancing).

MLD is movement of fluid from a lymphatome, or drainage area, that is not draining sufficiently to an adjacent functioning lymphatome. In looking at Figure 4, assume that the right axilla, or "point A," is the affected nodal bed. This area, for whatever reason, is not draining, and the limb or trunk has become congested. Experience has shown us that there are connections or anastomoses as depicted by the yellow lines across and down the trunk that lead to functioning, draining nodal beds. Therefore, treatment is designed to identify which nodal beds are not draining as well and to move the fluid manually to nodal beds that do drain well.

In appearance, the technique looks like massage, but in reality, it is a much lighter pressure and technique, causing the collateral lymphatics in the superficial and deep lymphatic networks to carry more lymph to the normally draining lymphatomes (Cheville, McGarvey, Petrek, Russo, Taylor, et al., 2003; Foldi, 1998; Harris & Piller, 2003; Kasseroller,

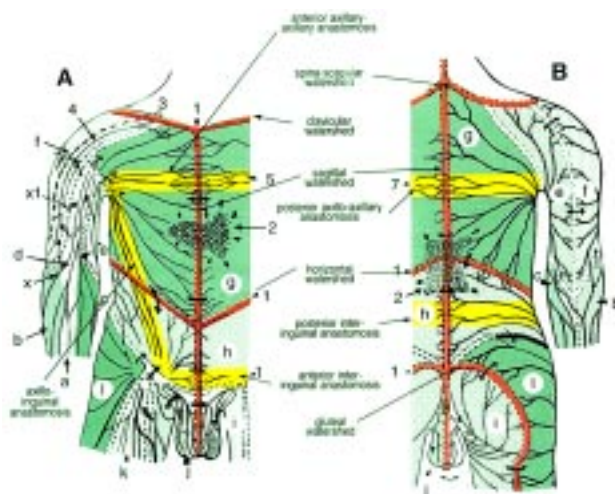


Figure 4. Manual Lymph Drainage via Functioning Lymphatic Pathways and Nodal Beds

Note. Illustration used with permission from the Academy of Lymphatic Studies courtesy of Joachim Zuther.

1998; Leduc, Leduc, Bourgeois, & Belgrado, 1998; Lerner, 1998; Mondry & Johnstone, 2002).

The practitioner's hand is placed flatly on the patient's skin with the fingers perpendicular to the lymphatic pathways. With a very light pressure that does not cause redness or pain, the skin is stretched as far as it can with the hand and then turned at the end of the stretch in the direction of the draining lymph nodes. It is a very slow, deliberate movement, with the hand flush against the skin and without any sliding of the fingers over the skin. This way, the skin is stretched in a direction perpendicular to the flow of the lymph vessels and pathways thereby stretching the vessels and manually causing the lymph fluid to move in the direction of the heart.

In Figure 5, the left axilla is affected because of axillary node dissection and subsequent left arm lymphedema has



Figure 5. Stretching Skin Perpendicular to the Lymph Pathways Running From Elbow to Shoulder

occurred. Early in the treatment hour, the left upper quadrant lymphatic transport capacity is increased by moving the fluid from the axillary area to the inguinal nodal beds. This “clears” the quadrant to then move fluid from the left arm down the trunk to the left inguinal nodes.

With each patient, the order of decongestion begins first with the thorax, front and back (see Figure 6). From there, the practitioner works distally, moving fluid to the area that was just treated. Therefore, the congested areas have an area to move to that can accommodate the volume (see Figure 7).

Compression Bandaging

Upon each MLD session’s completion, the patient’s limb(s) is bandaged immediately (see Figure 8) and remains bandaged until the following day when the patient removes it at home, showers, and comes in for his or her next appointment. Multiple layers are applied with the goal of having the most compression at the most distal points (i.e., at the fingers or toes even if they are not affected) and gradually decreasing compression as you move proximally. This facilitates lymphatic drainage up toward the heart. Compression bandaging requires the use of special bandages with short-stretch fibers. They are not elastic bandages because they do not constrict. Use of compression bandages begins in the acute or intensive treatment period, and the garments are worn the entire time between treatments. Unlike compression sleeves or stockings that do not decrease swelling, bandaging with the specialized short-fiber material assists the muscles in pumping the fluid to the nodal basins, thereby helping with decongestion (Cheville, McGarvey, Petrek, Russo, Taylor, et al., 2003). The bandaging can be cumbersome, depending upon the addition of foams, pads, or cotton underneath the bandage, and may overwhelm patients at first, but this is one of the most helpful tools for patients. Patients see results quickly when they use the bandaging at home. They feel relief from heaviness, aches, or other discomforts when the limb is bandaged. And, ultimately, patients are very empowered and motivated to perform other self-care activities for their condition when they see such response and success with the bandaging. It gives them a sense of control, and their opinions of bandaging change quickly with experience. One



Figure 6. Manual Lymph Drainage Pathways

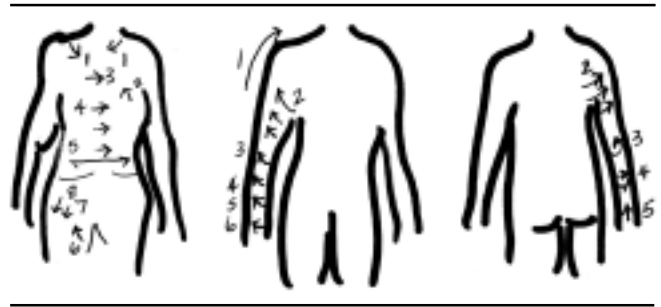


Figure 7. Drainage Progression

82-year-old woman was claustrophobic the first time she was bandaged and did not tell me. As she left my office, I heard her say to her daughter, “I can’t wear these things. Help me rip them off.” I went after her, only to see the 60-year-old daughter tell her that if she took them off, she was going to leave her on the side of the road. And even more shocking to me was the mother’s response of “oh, all right.” I did ask her if we should try something more gradual, maybe one leg rather than two. She said she would try this and, by the next day, admitted that she slept through the night without pain for the first time in months. Compression bandaging can be unilateral, bilateral, or, if the trunk is involved, truncal.

Figure 9 depicts a woman with a 30-year history of lymphedema after radical mastectomy and weeks of radiation therapy. She entered the office carrying her right arm that had constant oozing through the skin without any breaks in integrity. She had been hospitalized for infections more than 10 times over the years and was antibiotic-resistant after two years of various low-dose prophylactic antibiotics in an attempt to ward off systemic infections. In the prior year, she had been in the intensive care unit with sepsis. She had seen numerous practitioners but was very hopeful and almost commanding when she presented her expectations about what I would do for her. She had an extraordinary response despite a fibrotic ridge at the top of her arm from years of pump use. She was treated in 2001 and has had only one infection since that time.

Figure 10 is an example of bilateral lower-extremity lymphedema. The patient experienced a decrease of three shoe sizes, cessation of seeping wounds, and improved skin color after 12 MLD treatments.

The maintenance period of lymphedema treatment is characterized by the activities and self-care behaviors the patient needs to engage in with regularity to maintain the limb decongestion achieved in the acute phase. The tools of achieving this goal include daily compression garment wear, bandaging, aerobic exercise, a muscle-building exercise program, and self-MLD strokes. Although the standard of care is for nightly bandaging and daily compression garment wear, patients may feel overwhelmed at the thought of having to do this for the rest of their lives. Therefore, it is critical that the practitioner understands patients’ goals, life constraints, and motivations to creatively support them in their choices without judgment. This means that patients will choose what to use and when to control their condition, with the appreciation and understanding of the standard of care.

Compression garments are made in a variety of sizes, shapes, lengths, and compressions. They are intended to maintain the



Figure 8. Compression Bandaging

size of the limb at its lowest size following MLD treatment. Standard compressions range from 15–50 mmHg. The greatest compression is at the most distal point(s) of the garment with a gradual decrease moving proximally. Compression garments are intended to prevent increased swelling and should be worn only during the day (Brennan & Miller, 1998; Cheville, McGarvey, Petrek, Russo, Taylor, et al., 2003).

Precautions

Precautionary measures are just that, precautionary and not necessarily preventive. There is a severe lack of supporting research literature for making recommendations about what people at risk for or with lymphedema can and cannot do (Ridner, 2002). Therefore, knowledgeable practitioners become even more critical in the process of empowering at-risk patients because it takes a detailed understanding of the lymphatic pathways in combination with patients' past and current health history. Suggestions for self-care, exercise, hygiene, weight gain or loss, and muscle use should be individualized to each patient.

Patients are commonly told to avoid using the affected arm or lifting anything heavy and to use the other arm. This can be very confusing to people because the recommendations are broad and do not take existing muscle size and strength into account. Another example of the confusion that exists for patients at risk for lymphedema and healthcare providers in general is the question regarding blood tests taken from the affected limb. Traditionally, healthcare providers have avoided phlebotomy in an affected limb, but as bilateral mastectomies and lymph node dissections are presenting with greater frequency, emphasizing

evidence-based recommendations may be more appropriate. The instruction, which is more of a mandate, to *never* have blood drawn in the affected limb turns into the patient's belief that he or she is destined to develop lymphedema if phlebotomy does occur in the limb. Patients can become quite angry and suspicious of any future care providers who suggest or attempt venipuncture in the affected limb, potentially exposing the care provider to a liability suit. Therefore, educate patients that the risk is more likely associated with the tourniquet effect and that they should try to avoid using the affected limb for phlebotomy. This may lessen the burden and alarm that patients feel when they find themselves in this situation with a different care provider. Becoming familiar with the National Lymphedema Network (NLN) position papers on compression garment wear during air travel and exercise of affected limbs is a good way of ensuring consistent education.

Patients should be encouraged to maintain a normal weight for their height because obesity is a known risk factor for lymphedema development. An exercise program is critical to decongestion and long-term control (Brennan & Miller, 1998). Aerobic exercise and muscle building facilitate lymph drainage. These are known factors and areas over which patients do have control. Aerobic exercise increases diaphragmatic breathing, which facilitates movement of lymph through the thoracic duct, thus creating a suction-like effect that pulls lymph fluid from limbs. Muscle building and strengthening of the affected limb work in conjunction with the pumping activity of the heart to move the fluid along. Muscle building decreases the chance for strain, and fluid shifts into the tissue from daily activities such as weeding, carrying groceries, or picking up a gallon container.

Reimbursement

Lymphedema care costs accrue because of the multiple aspects necessary to treat and maintain the condition. Acute care treatment can cost from \$1,500–\$3,000 and is often needed



Note. The left arm is status post modified radical mastectomy and axillary lymph node dissection. The right arm is status post radical mastectomy and lymph node dissection.

Figure 9. Bilateral Lymphedema



Note. The photos on the left were taken pretreatment. The patient underwent 12 manual lymph node treatments and compression bandaging and experienced a 50% reduction in the size of the lower extremities (as depicted in the photos on the right).

Figure 10. Bilateral Lower-Extremity Lymphedema

annually depending upon the person. Garments and bandages need to be changed every six months according to the manufacturer's warranty.

As a result of the Women's Health Care Act of 1998, all patients diagnosed with breast cancer are entitled to care associated with the diagnosis. This includes lymphedema care and is specified in the federal law. Exceptions to this ruling are employees who receive their benefits as part of a small business. Small businesses are not mandated to provide the same coverage. Therefore, unless mandated in the state where the business is located, it is at the discretion of the business as to whether it will cover the care associated with lymphedema.

In the state of Virginia, it was a three-year process to pass a law that mandates coverage for all patients affected by lymphedema, even those whose health care is a benefit offered by a small business. Medicare does not pay for any of the supplies or garments associated with lymphedema unless the patient has previously used a pump, which is covered by Medicare.

The late Senator Emily Couric (D, VA) was an original supporter of the bill that recognized March 6th as National Lymphedema Day in Virginia. She then encouraged me to work with the American Cancer Society to draft, put forward, testify, and pass the current law that provides coverage to all patients with third-party payors. This type of legislation remains to be passed in most other states.

Patient Education

A dedicated amount of time should be allotted to educating patients and their loved ones about the condition of lymphedema

and its causes, risk factors, precautions, current standards of care, and long-term management. People are frightened by the unknown potential of the swelling, which is made worse by the general lack of knowledge among their health-care providers. They feel very vulnerable. It is during this educational period that it should be reemphasized to patients that they can gain control of their swelling limb as opposed to feeling that the swelling is continuing to progress until it overtakes their lives. Providing patients with pictures of the lymphatic system helps contribute to a more detailed understanding of how fluid is accumulating in the tissues, how their individual risk factors are adding to the final result, and how the potential recommended treatment plan will be successful.

Although there is a great deal of information, which can be overwhelming, I have found patients' comprehension and retention to be quite high during the initial educational discussion. Patients always return the following week empowered to commit to an acute period of treatment and, subsequently, lifelong health-promoting behaviors. Education is reinforced in discussion during daily treatments, with written lay materials, in support groups, and at six-month follow-up visits.

The Future

The future of appropriate care for lymphedema lies in the research that needs to be done. There has been so little funding for the problem that lymphedema research is in its infancy. It has been only 10 years since Saskia Thiadens, RN, established NLN and forced healthcare providers to recognize the existence and problematic nature of lymphedema beyond "cosmesis." NLN is a nonprofit patient and healthcare provider organization with a mission to provide patient and professional education while working to set standards of lymphedema care. Thiadens has single-handedly enlisted, cajoled, engaged, and captured the attention necessary for lymphedema care among legislators, care providers, and healthcare organizations.

NLN is working to ask the questions that need answers through research and in guiding clinicians in their daily practices. Fortunately, Jane Armer, RN, PhD, in the MU Sinclair School of Nursing at the University of Missouri-Columbia has provided a significant amount of research to our knowledge base. Her hallmark study regarding symptoms occurring months before visible signs provides oncology nurses with additional assessment parameters. Asking patients whether their arm feels heavy or achy will trigger an earlier referral for intervention that could be much less intensive. Because symptoms occur before swelling, aerobic exercise, muscle building, and weight loss may be all that is necessary for someone to avoid lymphedema development.

It is no wonder that clinicians are struggling in what they should be telling their patients about blood draws or arm use when standards of care about phlebotomy or taking blood pressures are still not research-based. The ability to quantify a patient's risk for lymphedema development has yet to be defined, and grading and staging of lymphedema are still inconsistent across the country (Cheville, McGarvey, Petrek, Russo, Thiadens, et al., 2003). These factors would help tremendously in guiding the recommendations we make to our patients.

We are still at the point of educating all healthcare providers about this problem that continues to exist in this country and will exist for some time despite sentinel node biopsy.

Only after lymphedema has become commonly understood and discussed can movement be made to routinely assess for the problem.

It is my hope that you will help to spread the knowledge and incorporate routine measurement and symptom assessment into your practices. If you do this, we could offer patients earlier intervention, which would mean fewer consequences. We hold

the keys to knowledge, and knowledge is power. I hope that I have “armed” you or given you a “leg up” on the world of lymphedema so that you can empower your practices.

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