CASE STUDY

Home Health Lymphedema Therapy — A Unique and Complicated Case

By: Ruth Moseley, MS, PT, CLT-LANA

The following case illustrates some of the many complications that may be encountered when treating a lymphedema patient in the home health setting. Home health patients represent a very different population from the typical lymphedema patient seen by many lymphedema therapists. In the outpatient setting most patients attend just for lymphedema therapy with few, if any, significant chronic illnesses associated medical problems. In the home health setting, however, most patients have multiple co-morbidities that not only complicate the lymphedema condition, but require treatment along with the lymphedema. In addition, Medicare requires that if therapy is involved in a home health case, the therapist must be able to demonstrate improvement in the patient’s ability to perform daily activities of living, general functioning and mobility as a result of treatment. In other words, the therapist cannot just reduce the lymphedema, but must demonstrate that the patient’s functional mobility is being improved as well.

CASE HISTORY

ML is an 81 year old woman with a more than 50 year history of primary lymphedema, with onset of symptoms in her twenties. She had dealt with symptoms without lymphedema therapy until 2000. Around that time a severe infection in her right leg required radical excision of a great deal of tissue and resulted in severe exacerbation of her right foot lymphedema. Since 2000, ML has had several courses of outpatient lymphedema therapy with limited success due to co-morbidities and complications with compression garmentry. ML is home bound because of left knee arthritis, left foot drop, low back and leg pain, and heavy, bulky lymphedema affecting both lower extremities. As a result, she can only walk short distances with a rolling walker and assistance, and requires a wheelchair most of the time. ML lives in a single family home with her husband. Her two adult daughters alternate responsibility for her daily care and have been very involved in her lymphedema therapy over the years.

MEDICAL HISTORY

ML suffers from multiple co-morbidities complicating her lymphedema condition as well as her functional mobility. These include congestive heart failure (CHF), atrial fibrillation (A-fib), chronic obstructive pulmonary disease (COPD), hypertension, painful multi-joint osteoarthritis, incontinence, lipedema, cellulitis, obesity, and compression fractures in her spine resulting in marked scoliosis and pain. In addition, ML has markedly limited function of her diaphragm, forcing her to use upper chest muscles to breathe, and has left drop foot of unknown origin markedly affecting her gait. These symptoms may be due to amyotrophic lateral sclerosis (ALS), and neurological work-up is in progress.

PHYSICAL/FUNCTION EVALUATION

Upon initial evaluation, ML weighed ~ 229 pounds at 5’ 3” tall. She required maximum assistance (caregiver provides 75% support) to transfer, sit, to stand, and in/out of bed. She required minimal assistance (caregiver provides 25% support) to walk 10 feet with rolling walker, with slow shuffling gait, dragging her left foot because of left foot drop. Upper extremities fatigue very quickly when using the rolling walker, with poor function of respiratory muscles and severe de-conditioning. ML scored 0 on the Timed Up and Go (TUG) because she cannot come from sit to stand and walk independently; 0/12 on the 4-Step Dynamic Gait Index (DGI); and 8/28 on the Tinetti Balance and Gait assessment. Active range of motion (AROM) right shoulder is markedly limited due to painful arthritis; left upper extremity AROM is within functional limits (WFL’s). Both lower extremity AROM is severely limited due to heavy, bulky edema and tight edematous congestion across knee and ankle.
joints. Strength in both lower extremities is grossly assessed as poor across all joints due to tight bulky edema across knee joints and heavy edematous congestion of the limbs. Left foot dorsiflexion strength is no more than a trace, cause unknown. However, ML is able to hold her weight up against gravity for brief periods and walk short distances with assistance using a rolling walker once she has been assisted to stand. Right shoulder strength is poor due to painful arthritis; strength across all other right upper extremity joints is good. Left upper extremity strength is good across all joints and in all planes of motion. ML requires minimum assistance for walking very short distances with a rolling walker, requires maximum assistance for activities of daily living (ADL’s), and is totally dependent for community mobility with a wheelchair.

**LYMPHEDEMA EVALUATION**

ML has bilateral lower extremity primary lymphedema with onset in her twenties. Upon evaluation, physical therapist (PT) finds that ML also has lipedema characterized by extensive bulky, soft fatty tissue on bilateral buttocks, hips, and thighs disproportionate to her upper body. Initial body weight at start of care was 229 pounds at 5’3” tall. ML has extensive lymphedema of both lower extremities characterized by stiff, tight, edematous congestion from toes to knees decreasing from knee to the groin. Stiff tissue changes greater below the knee although both medial thighs exhibit bulky, fibrotic, edematous congestion as well. The right foot is grossly misshapen due to severe lymphedema. The right leg is grossly misshapen due to radical excision of tissue for limb sparing surgery done several years ago. The left foot and leg lymphedema is complicated by L foot drop. Upon initial evaluation, PT made the decision to limit compression bandaging and volume assessment to below the knee because of increased fall risk associated with compression bandaging across the knee. Volume based on circumference upon initial evaluation is as follows: right leg initial volume 6978 ml; left leg initial volume 8957 ml.

**TREATMENT**

ML participated in 20 sessions of lymphexcema therapy for 8 weeks, consisting of manual lymph drainage (MLD), compression bandaging, self/caregiver education, skin care, and exercise instruction. Family caregivers were present for all lymphedema treatments observing, learning and participating in MLD, skin care, compression bandaging, and exercise activities with PT and ML. ML and caregivers were instructed in lower extremity exercises to activate the muscle pump and stimulate lower extremity lymphatics as well as to strengthen lower extremity muscle groups needed for transfers and gait activities. In addition, occupational therapy (OT) was simultaneously working with patient on ADL’s and upper extremity strengthening.

Initially, compression bandaging was limited to the area from toes to knee to avoid limiting knee range of motion with compression bandages across the knee joint and possibly increasing fall risk. However, after 2 weeks of compression bandaging ML noticed increased edema in the thighs causing increased difficulty with ambulation; ML requested compression bandaging above the knee in spite of possible increased fall risk. Compression was taken toes to thighs per ML’s insistence and with the aid of 24 hour caregiver support, though data was not collected for above the knee reduction. By the end of 8 weeks of treatment, circumferential measurements indicated that edema volume had stabilized, ML had been fitted with a mid thigh-high Elvarex compression stocking for the left lower extremity, and a Farrow Wrap was used for the right leg; the thighs were maintained via compression bandaging because the heavy tissue folds above the knees would have made full leg or panty compression garments very difficult to manage, especially considering ML’s problem with urge incontinence.

PT plans to continue treating ML for a second 8 week episode of care to focus on mobility therapy, i.e. gait training, strengthening and transfer training, upon completion of lymphedema therapy.

**RESULTS**

After 8 weeks of active lymphedema therapy ML lost a total of 27 pounds, right leg volume was reduced from 6978 ml to 2157 ml (30.91% reduction) excluding thigh reduction, and left leg volume reduced from 8957 ml to 4146 ml (46.29% reduction) excluding thigh reduction. Transfers from lying down to sitting on the edge of bed improved from maximum assistance to
stand-by-assistance (SBA); sitting edge of bed to lying down improved from maximum assistance to moderate assistance; sit <-> stand transfers improved from maximum assistance to SBA with verbal cues for safety; gait improved from minimum assistance with rolling walker x 10 feet to SBA gait x 30 + feet with verbal cues for encouragement. Tolerance to activity continues to be a problem due to poor respiratory muscle function. However, decreased bulk and weight in addition to improved strength and ease of movement appear to have reduced the strain on ML’s respiratory system.

CONCLUSION

This is a unique case among lymphedema patients as well as among home health patients in that ML’s lymphedema is complicated by a variety of co-morbidities and functional limitations. At the same time, however, the patient has exceptional caregiver support from her adult daughters, who are actively involved in her lymphedema care as well as her mobility therapy and have been trained in basic MLD technique, compression bandaging, and exercise instruction. They ably assist ML in frequent strengthening and range of motion exercises that help to control lymphedema and improve strength and range of motion for improved functional mobility. PT plans to continue mobility therapy with patient/family caregivers to further improve ML’s functional mobility for ease of transfers and gait, and decreased risk for falls and injury to both ML and her caregivers, and to further improve her quality of life. (See photos below)

This is ML before start of care. Note the large area of radical tissue excision on the right anterior, medial and posterior medial leg. This is skin grafted over muscle and bone. There are presumably few if any superficial lymph vessels in this area and thus lymph pathways out of the dorsum of the foot and ankle or the medial and posterior medial ankle are extremely limited.

This is ML after 20 treatments of combined decongestive therapy (CDT). Note that the left foot and ankle reduced nicely, but the right foot and ankle did not progress as well. Also, the fact that the right distal leg is so much narrower than the foot and ankle ruled out the use of a compression stocking for maintenance—a stocking that would fit over the foot and ankle would be too large for the distal leg. Even a zipped stocking would not fit appropriately.

This is ML after 20 CDT visits. The lymphedema reduction had stabilized and we were ready to fit her for compression garments so we could move on to concentrate on mobility therapy. But what garments to use? We already knew we couldn’t put a stocking on the right leg because of the size of the foot and ankle. But the left leg would be straight forward enough, right? Wrong! See the thick folds of tissue at the medial knees—these heavy tissue folds would be a constant drag on any stocking that ML and her daughters tried to pull up over them. Traditional thigh high garments alone would slide down to her knees in no time; she would be fighting to keep a waist-high garment up all day, and pulling a waist-high compression garment up and down all day would just compound her incontinence problem anyway. We considered chaps-style garments but were afraid that anything tight enough keep the stocking in place would cut into the soft fatty tissue at the groin and waist causing a great deal of discomfort if not high risk of friction wounds.

This is ML in compression upon completion of lymphedema therapy, up and walking on her own with a rolling walker!! After a great deal of deliberation and consultation with a very experienced and well trusted compression garment fitter, we finally decided on a mid thigh-high Elvarex compression stocking for her left leg, a knee-high Farrow Wrap for her right leg, and ML’s daughters are continuing to use compression bandages above both knees.