Understanding Lipedema

Guenther Klose, CI, CLT-LANA, and Roman H.K. Strößenreuther, MD

The term "lipedema" was first used in 1974 by Allen and Hinse. Their publication is regarded as "the classical description" of the syndrome.

"We wish to describe a clinical syndrome, lipedema of the legs, which is frequently very distressing. In our experience it affects solely women. The chief complaint is of swelling of the legs and feet...On questioning, the physician may elicit that enlargement of the limbs has always been generalized and symmetrical. The swelling below the knees is accentuated when patients are on their feet much and in warm weather. Aching distress in the legs is common...Occasionally, a patient feels, that her large legs have 'ruined her life.' Many are 'ashamed' of their legs."

This describes the patient's problems very well, but it is difficult to define lipedema precisely because the definition depends mainly on subjective findings. There are no medical or laboratory tests to distinguish local lipo hypertrophy (local fat tissue increase) of the legs or hips from lipedema or general obesity. Consequently, lipedema is not generally accepted as a real disease. We will attempt to describe the current knowledge on the pathophysiology and treatment of lipedema.

Lipedema is a metabolic disorder of the adipose (fat) tissue with unknown etiology, affecting almost exclusively females. The following clinical and pathophysiological findings are of importance for differential diagnosis.

The term "lipedema" was chosen by Allen and Hinse to describe a symmetrical swelling of both legs, extending from the hips to the ankles and excluding the feet, caused by an abnormal amount of subcutaneous adipose tissue. Typically, bulging masses can be found in the proximal thigh region and at the medial aspect of the knees. Occasionally, large, overhanging and hypersensitive fat lobes develop in these areas. In others, contours of the legs are more funnel-shaped, with a decrease of the adipose tissue noted below the knees. Some individuals present with similar changes in the arms especially when patient is also obese.

Most patients report slow onset of symptoms, often in connection with beginning of puberty. In other cases, there is no specific time of onset. Some patients report that other females in the family also suffer from lipedema. Allen and Hinse found a positive family history in 20% (n=119), but epidemiologic studies concerning lipedema do not exist. There is no evidence of a specific genetic disorder or incidence related to race.

Aging causes further loss of skin elasticity and progression of the condition. Problems with normal ambulation (walking) lead to secondary orthopaedic deformities of the knees and feet. The tissue resistance to the contracting calf muscles (calf muscle pump) is too low and results in passive hyperaemia and an increase infiltration of water through blood capillaries, resulting in increased lymphatic water load. Swelling occurs when this fluid load exceeds the transport capacity of the lymphatic system. Blood capillaries are fragile and even insignificant trauma (e.g., hitting the leg on a table corner) can cause the development of small haematomas and a further increase in lymphatic load. Blood continues on page 2

Continued on page 2

In This Issue

President's Message
Case Study: Functional Gains
7th NLN Conference Review
Case Study: Lipedema
Legislation Update
Question Corner
Resource Guide
Support Groups
News & Notes
Scholarship Recipients
Education Corner
Become an NLN Supporter
Understanding...
Continued from cover page

coculation tests for this condition are typically normal. It is not surprising that many patients develop an emotional disorder considering the physical appearance of the legs. ALLEN and Hines pointed out: "Patients with lipedema ordinarily are very sensitive about the appearance of their legs; they wear long skirts, avoid appearance in swimming suits and stand behind chairs at parties...They are likely to be mirror peepers, searching repeatedly in mirrors for evidence that the appearance of their legs is not actually as bad as it seems to be. Evidence of the increased adipose tissue and the enlarged adipose tissue changes contributing to lipedema is possible after elevation treatments. This edema causes an uncomfortable feeling of tension. A reversal of the edema is possible after elevation treatments.

One patient described her situation: "When you become older, you also become a little more overweight and your legs 'go through the roof.' You develop constant rubbing between your thighs; in summer it is itching and becomes sore. With age you also become more lazy—and, because of this constant itching and pain, you don't see any possibility for doing exercises. As the obesity worsens, lower back pain develops, the joints begin to hurt and your friends make silly jokes about your shape—and finally you rest at home, your only consolation is the chocolate in your nightstand and you will be unable to get out of this vicious circle!"

After some years, in cases of coexisting general obesity, lipedema can transform into lipo-lymphedema (Stemmer's sign is now positive) in which fatty tissues begin to hold fluid. Furthermore, there is a correlation between obesity and disturbances of vascular edema protective reflexes, which leads to additional lymphatic water load. Edema is always the result of lymphatic insufficiency and, indeed, the lymphatic system shows typical pathological changes. The pre-lymphatic channels are obstructed and the enlarged adipose tissue and the enlarged adipose tissue structure becomes more and more nodular and tough, developing large deforming fatty lobes, especially at the inner side of the thighs, the knees and above the ankles.

Differential diagnosis
The diagnosis of lipedema can be difficult in the early stage or if a combination form exists. Differential diagnosis of LE and lipedema is, in most cases, possible by taking the medical history and evaluation of the Stemmer's sign. Distinction between primary bilateral lower extremity LE and lipedema can be difficult, although bilateral LE usually presents asymmetrical in contrast to symmetrical presentation of lipedema.

TREATMENT OF LIPEDEMA
While some of the pathophysiological tissue changes contributing to lipedema are identified, the real cause of the disease remains unknown. Therefore, therapy is predominantly symptom oriented. The goal must be to improve the disturbed lymph transport, the pathophysiological changes in microcirculation in the enlarged adipose tissue and a reduction of pain and the fat masses.

The most common therapeutic intervention for lipedema is Complete Decongestive Therapy (CDT). The main constituents of this therapy concept are Manual Lymph Drainage (MLD) and compression therapy. Diet, skin care and remedial exercises are also very important.

At the Lymphologica 1999 in Marburg/Germany, BRENKE reported, a volume reduction of 3.2 liters after a 3-week intensive therapy (mean initial volume of 23.3 liters; the average volume reduction at the thighs was 2.85 liters). In our Department of Lymphology (Freiburg/Germany), the mean volume reduction after 2 weeks of CDT is 14 % on average.

After initial decongestion through MLD and compression bandages, the patients are fitted with custom-made compression stockings. Permanent compression therapy causes significant reduction of adipose tissue, has a positive influence on the disturbed veno-arteriolar response and improves relative insufficiency of the lymphatics.
Lymphedema may develop particularly in patients who are also obese. There are, however, no specific dietary recommendations for lipedema.

Additional therapy with external pneumatic compression is sometimes recommended. Some patients report positive results with pneumatic compression, but controlled studies do not exist. Allen und Hines and others consider the use of diuretics a mistake.

In some select cases, liposuction has been recommended for the treatment of lipedema. Surgeons have shown good results, but problems also exist. After liposuction, some patients develop chronic lymphedema, lymphatic cysts or large haematoma and have problems with wound healing. Moreover, the cosmetic results are not always satisfactory. In recent years, the technique of liposuction has improved, and complications are fewer. Experience with a small number of patients indicates that the combination of surgical techniques with CDT may help to improve the results of liposuction. (Schmeller et al: Dtsch Arztebl 2005; 102:A 1061–1067 [Heft 15]). No definitive studies are available to confirm this finding.

CONCLUSION

Lipedema must be differentiated from local lipohypertrophy, primary LE of both legs and general obesity. Until the real cause of lipedema is known, treatment is symptomatic. With adequate treatment and optimal patient adherence, good results can be achieved, progression of lipedema can be halted and additional health problems prevented.

Guenter Klose, CI, CLT-LANA
Klose Training & Consulting LLC, Boulder, CO—guenter@klosetraining.com

Roman Strößnerreuther, MD
Bavaria, Germany
stroessnerreuther@t-online.de

References available through the NLN office or at www.lymphnet.org.

SECOND BIENNIAL NATIONAL LYMPHEDEMA NETWORK

International Patient Summit
OCTOBER 5-7, 2007

Lymphedema: Sharing Our World Of Knowledge

FOR PATIENTS, THOSE AT RISK, FAMILY MEMBERS, CAREGIVERS, ADVOCATES & THE GENERAL PUBLIC

Registration Available in Mid-January 2007 at www.lymphnet.org
Premier Sponsorship Opportunities Available • Exhibitors Welcome • Call 510-208-3200
Email: 2007patientsummit@lymphnet.org

RENAISSANCE WAVERLY HOTEL, ATLANTA, GEORGIA