

Therapy for lipedema

Incorporating new clinical guidelines

By Guenter Klose

Lipedema, which mainly affects women, is much more complex than its defining characteristics suggest. According to the European Lipedema Consensus Group, the two main criteria for the diagnosis of lipedema are: disproportionate fat accumulation in the legs (and sometimes the arms) and subjective complaints such as pain, heaviness, and tenderness in the area of the affected tissue.¹ However, lipedema is often complicated by a wide range of other physical conditions and emotional and psychological suffering. These complexities can lead to misdiagnosis or treatments that fail to address underlying issues.

Even the root definition of the word lipedema has led to misunderstandings of the condition.^{2,3} The term “lipedema” was first coined by E.V. Allen and E. A. Hines in 1940. “Lipo” means “relating to fat” and “edema/oedema” means “swelling due to the accumulation of fluid.” However, pure lipedema does not consist of fluid edema.³ Nevertheless, lipedema may be combined with other causes of swelling such as orthostatic edema (fluid accumulation in the lower extremities from being in an upright position) or lymphedema (the accumulation of fluid due to lymphatic failure).³

Recognizing the complex nature of lipedema, many articles and guidelines have been published that promote a multimodal

approach for the treatment and management of lipedema, e.g. the Dutch Guidelines 2016 and the United Kingdom Guidelines 2017. Such an approach calls for treatment not only of the physical symptoms but also the psychological issues that are often associated with the condition. However, given how the predominant medical model in North America focuses solely on physical manifestations, implementation of such a multifaceted approach can be challenging. Development of a treatment plan often falls to a lymphedema therapist.

The following considerations are based on new understandings about lipedema published over the last three years in a series of articles entitled *Lipedema – Myths and Facts, Parts 1-5*, by T. Bertsch and G. Erbacher, experts at the Foeldi Clinic in Germany that specializes in treating lymphological disorders.^{1,3,6} Therapists are encouraged to incorporate these new findings into their clinical practice; patients can use them to guide their self-care.

Assessment

Though the number of lymphedema therapists is growing, there are still few physicians in North America who specialize in lymphedema and/or lipedema. This can make it difficult for patients to receive an accurate diagnosis. Non-expert physicians may assign the diagnosis without collecting information critical to successful treatment of the condition. It is

therefore essential that the treating therapist conduct a comprehensive evaluation to establish the patient’s past medical history and to assess their current complaints.

But can a thorough physical evaluation determine the real source of the patient’s suffering?

Lipedema is often associated with emotional and psychological distress.^{1,4} Patients often believe this distress is caused by the physical pain and the embarrassment they feel because of the disproportionate appearance of their legs. However, data collected by the Foeldi Clinic has revealed that in many cases, mental health issues were present before the onset of symptoms typically associated with lipedema and that these issues have an influence on the patient’s perception of pain.⁷ Since mental health issues often precede the manifestation of physical issues, simply treating the physical symptoms, as is typical of traditional lipedema therapy, may not get at the root cause of the patient’s suffering. A referral to a mental health professional will likely prove beneficial.

An additional challenge in diagnosing and treating lipedema is that patients often have comorbidities such as obesity and subsequent obesity-associated lymphedema. Because there is significant overlap between these conditions, clear differentiation may be impossible, even for very experienced professionals. In cases of severe obesity, a consult with a bariatric specialist may prove helpful.^{1,5}

The following specific guidelines pertain only to the treatment of PURE lipedema, which is fairly rare. More often than not, lipedema is associated with various comorbidities.



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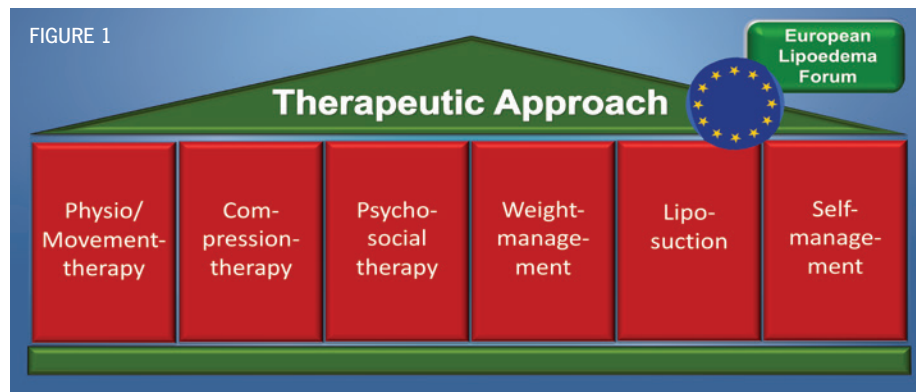


FIGURE 1
Main pillars of the new interdisciplinary therapeutic concept. European Lipoedema Forum

Therapy goals

The main goals of treatment should be to reduce soft-tissue pain and address the psychological vulnerability of the patient with lipedema.¹ Physiotherapists often fail to address the latter because they are trained to focus on the tangible physical and subjective complaints (discomfort and pain) of their patients. Digging deeper to investigate what the patient with lipedema is really suffering from would seem to be out of the scope of practice for therapists entrusted to treat the lipedema. But if a key component of the patient's suffering is due to severe mental stress, depression, and/or poor body image and self-acceptance, limiting treatment of lipedema to physical manifestations is unlikely to be effective in the long term. Although there is no validated lipedema-specific questionnaire available to date, there are a number of other validated tools available to therapists⁸⁻¹¹ that can help them assess whether their patients with lipedema need psychotherapy or psychosocial services. If a need is identified, the therapist should then make the appropriate referral.

Therapists who are treating lipedema are typically trained more specifically in lymphedema therapy. While certain techniques used for treating lymphedema are beneficial for treating the physical symptoms of lipedema, it is imperative that therapists review the latest literature pertaining to lipedema so they understand what lipedema is, and, perhaps more importantly, what it isn't.¹ Armed with this new knowledge, therapists will be able to correct any misperceptions their patients have. As the therapist explores the patient's own subjective beliefs about lipedema, it is critical that the therapist identify the patient's precise

expectations and treatment goals and bring these into alignment with what is possible.¹ Any comorbidities must also be addressed, as appropriate.

Therapy

A multimodal approach is critical to the successful treatment of lipedema. The following information touches on some key points of the new therapeutic concept recommended by the European Lipedema Forum, as illustrated in Figure 1.¹

Physio and movement therapy

Manual Lymph Drainage (MLD)

Since lipedema is not a fluid edema,^{1,3} MLD will not reduce the limb volume but can help to reduce the subjective complaints of the patient. In my own work with patients with lipedema, I have found that the pressure sensitivity of the affected tissues is, quite often, markedly reduced after a relatively small number of treatments, i.e. 6-8 sessions. Although the amount of pressure exerted during MLD must be adjusted to the patient's tolerance, a firmer stroke than is often used by practitioners may offer better results. MLD improves tissue health overall but the soothing, human touch provided by MLD may have additional benefits for a patient with deeply rooted psychological issues as is common with patients with lipedema.

Movement therapy

The benefits of exercise are universally recognized but patients with lipedema may find it difficult to engage in a regular exercise routine because of their size and general deconditioning caused by perpetual inactivity. A graded

activity program that builds strength, flexibility, balance, and general endurance is highly recommended.^{1,2,12} Physiotherapists play a key role in tailoring an exercise program to each individual's needs. As with anyone, patients with lipedema are more likely to maintain a program they find interesting and fun. Patients will likely lose motivation if they are mandated an exercise routine with a set number of repetitions. Aquatic therapy or simply movement in water is very beneficial for patients with lipedema.

Compression therapy

Compression therapy should become part of the daily routine for patients with lipedema.¹ Although there are no scientific studies to date on the effects of compression on pure lipedema, studies examining the efficacy of compression therapy for other conditions have shown that compression reduces inflammation of the tissues, improves microcirculation, and has a positive effect on the hypoxia factor. Hypoxia is insufficient oxygenation of the tissues; it can contribute to the pain in lipedema.¹

Finding a suitable pair of compression tights, comfortable leggings, or a suitable combination of garments to ease with donning and doffing is possible in nearly every case. Depending on the clinical picture, custom-made flat-knit garments are preferred, especially in those patients with a combination of lipedema, lymphedema, and obesity.^{1,12} However, not all patients with lipedema require custom garments. Many women with lipedema prefer a textured material, which can provide a micro-massage on the skin and relieve discomfort (see photo on page 15).

Psychosocial therapy

As mentioned before, many patients with lipedema experience severe mental stress^{1,4} which is particularly relevant because mental health issues can exacerbate pain perception.⁷ Many patients with lipedema have difficulty accepting their own body, especially the shape of their legs, largely because of the prevailing beauty ideal that is constantly promoted in today's media.¹³ It is also notable that an analysis of psychological assessments at the Foeldi Clinic found that a significantly higher number of patients with lipedema reported physical or sexual abuse compared to the general population.¹ Details about an effective therapeutic approach that includes

empathy, education, psychotherapy, and the use of self-help groups is outlined in Part 5 of *Lipedema – Myths and Facts*.¹

Weight management

A high percentage of people in modern societies, including people with lipedema, are overweight or obese. Nutrition education and weight management are important so it is unfortunate that most publications that deal with lipedema state that diet and exercise have no effect on lipedema. This clearly sends out the wrong message to patients and healthcare professionals. It is quite likely that patients with lipedema who are overweight will always have disproportionate fat distribution, even after an appreciable amount of weight loss. However, there are recognizable health benefits to be gained by improving fitness and reducing weight (e.g. pain may be reduced).

Short-term diets must be avoided as they almost always fail in the long term and often result in a yo-yo effect.¹⁴⁻¹⁷ It is important to educate patients with lipedema, especially those with additional visceral obesity, about the inflammatory and anti-inflammatory effects of various foods because dietary choices can help prevent hyper-insulinemia and insulin resistance. However, it is beyond the scope of this article to give specific dietary advice.

Liposuction

There is a common misperception that liposuction can eliminate lipedema and along with it, a

patient's emotional and psychological burdens. Although liposuction can reduce the size of a limb, there are grave risks to the procedure and deep-seated psychological issues cannot be sucked out with the fat. According to the European Lipedema Forum, liposuction should only be considered for patients with considerable functional disabilities whose symptoms persist despite 12 months of comprehensive, conservative therapy, whose weight has been stable for at least 12 months, and for whom a preoperative psychological assessment has been completed. Liposuction is generally not recommended for patients with a BMI >35 who have central obesity.^{1,6} Patients contemplating liposuction are encouraged to scrutinize the qualifications and track record of any surgeon they are considering for the procedure.

Self-management

The Chronic Care Model (CCM) advises that patients should be given a leading role in their treatment.^{2,19} Together, the patient and therapist need to formulate a plan of care that includes reasonable and attainable goals. The therapist should clearly explain the condition, its treatment, and impactful behaviors to the patient. The importance and power of self-management must be emphasized. Motivating the patient to take an active role in their care program will foster compliance and positive long-term results. As therapists, we need to guard against mandating certain actions, rather than collaborating with the patient,

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as inflexibility can sabotage the desired goal. The more we show empathy and support, and the less we (knowingly or unconsciously) comment on behaviors that produce guilt or shame, the more the patient will engage.¹

Final comments

The recent initiatives of the European Lipedema Forum, spearheaded by T. Bertsch and G. Erbacher, provide an invaluable contribution to the understanding of the clinical presentation and treatment of lipedema. Part 5 of the series *Lipedema – Myths and Facts* is a must-read for every healthcare professional involved in assessing and treating lipedema.

It would also be beneficial to create a new term that better describes the condition currently known as lipedema because the condition has very little to do with “edema.” Rather, the condition is a painful, disproportional distribution of fat tissue. Having an accurate term for a medical problem that has long been misunderstood and misdiagnosed and is frequently treated incorrectly could precipitate a paradigm shift in the recognition and treatment of this condition. **LP**

The International Lipedema Consensus Document has now been published as a supplement of the *Journal of Wound Care*. You can find this document as well as the full set of references at www.lymphedemapathways.ca



Editor's Note:

Readers are encouraged to refer back to the Fall 2020 issue of *Pathways* for an interesting interview with Dr. Bertsch about the paradigm shift in thinking about lipedema.



Female patient with lipedema in remission. Pain and pressure sensitivity of the tissues are managed by weight control, healthy nutrition, regular physical activity and textured compression leggings.

Photo: G. Klose