PUBLICATION BY ANDREAS DIETL ON THE TOPIC OF LIPEDEMA

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ABSTRACT

Lipedema, first scientifically documented in 1940, is a chronic progressive and painful fat distribution disorder that predominantly affects women. It is characterized by symmetrical fat deposits on the extremities, along with increased bruising tendency and sensitivity to pressure. Despite numerous publications, lipedema is often underdiagnosed and is mistakenly confused with obesity or lymphedema. Advances in therapy, such as Complex Physical Decongestion Therapy (CPD) and liposuction, have significantly improved the quality of life for affected patients. Early, differentiated diagnosis and multimodal therapy are crucial to slowing the progression of the disease and alleviating symptoms.

Introduction

Lipedema was first scientifically documented in 1940, but evidence of the condition can be found in early civilizations. For instance, a stone statue of the Great Goddess in the Temple of Hal Tarxien in Malta (ca. 3000 BCE) and a bas-relief of the Queen of Punt in the Egyptian Hatshepsut Temple in Deir el-Bahari (ca. 1500 BCE) depict features consistent with the condition. Among the general population, lipedema often goes unrecognized, even among those affected. Despite numerous publications in medical journals, lymphology textbooks, and a German-language monograph, it is frequently overlooked in medical practice or confused with lipohypertrophy, obesity, or lymphedema. Although epidemiological data and key aspects of the pathogenesis remain inadequately understood, significant progress in treatment has been made in recent years (Schmeller & Meier-Völlrath, 2007).

Methodology: Scientific literature and online research.

Results

Lipedema is a painful fat distribution disorder affecting the extremities, manifesting as a striking disproportion compared to the torso. The key symptoms include an increase in circumference due to hyperplasia and hypertrophy of subcutaneous fat tissue, pain from inadequate stimuli, and an increased tendency for bruising in the affected regions. The condition primarily affects women, with a prevalence in this population estimated at around 10 percent (Ghods & Kruppa, 2022). Accurate epidemiological data are lacking, and available figures are derived from specialized clinics. In 1995/96, 15 percent of the 933 patients admitted to a hospital were diagnosed with lipedema. The Baumrain Clinic in Bad Berleburg reported 17 percent for lipedema and 23 percent for mixed forms of lip-, lymph-, and phleboedema in 2003. The Seeklinik Zechlin provided estimates of 8 percent and 20 percent, respectively. The Feldberg Clinic in St. Blasien reported 10 percent and 4 percent, while the Pieper Menzenschwand Clinic recorded 11 percent and 12 percent. These discrepancies make it difficult to determine the exact prevalence (Meier-Vollrath et al., 2005).

Lipedema is based on a genetic predisposition. The visible onset of the chronic progressive disease typically occurs during hormonal adjustments, such as puberty, pregnancy, or menopause. The exact pathogenesis of lipedema is not yet fully understood. Currently, Complex Physical Decongestion Therapy (CPD) is considered the gold standard in treatment. The goal of this therapy is to reduce symptoms and slow the progression of the disease. If conservative therapy does not yield sufficient success, surgical intervention in the form of multi-stage, lymph-sparing liposuction is recommended (Ghods & Kruppa, 2022).

Given its continuous and largely progressive course and the significant burden it places on patients, lipedema has emerged as an important dermatological condition. The introduction of CPD as a standard therapy years ago has enabled significant reduction in the characteristic edema associated with lipedema. Additionally, liposuction under tumescent local anesthesia using vibrating microcannulas has established itself as an effective treatment method. This approach enables targeted and long-term reduction of disproportionate fat tissue, which, when combined with edema reduction and pain relief, leads to a significant improvement in the quality of life for patients (Schmeller & Meier-Völlrath, 2004).

Lipedema is often undiagnosed for years, especially in its early stages when it is easily mistaken for obesity. These misdiagnoses often lead to significant frustration among patients and delay appropriate treatment. Many patients initially consult general practitioners who are often unfamiliar with the condition and therefore unable to make an accurate diagnosis. Experienced specialists in phlebology are the appropriate professionals to provide an accurate diagnosis and develop an individualized treatment plan (von Lukowitz, 2024).

Lipedema manifests as a condition that cannot be influenced by physical activity or dietary changes. To improve patient well-being, early diagnosis, ideally involving multiple specialists, is crucial (von Lukowitz, 2024).

Lipedema is one of the inadequately investigated medical conditions and is gaining importance in plastic-aesthetic surgery. It is resistant to conventional therapies and often progresses, leading to impairments in the lymphatic system and pathological changes in subdermal structures. It is frequently mistaken as a cosmetic issue, complicating diagnosis and treatment. Intensive research, differentiated diagnostics, and interdisciplinary collaboration are necessary to enable proper treatment and alleviate the suffering of those affected (Aliu, 2020).

The condition results in a painful pathological fat distribution disorder. The legs are involved in almost all cases, often the arms as well. Whether other body parts can also be affected is a subject of current research, which will be discussed later in the article (Lymphnetzwerk Lippe e.V., 2024). The belief that it is a purely female condition is widespread among physicians. However, men can also develop lipedema, although the number of cases is significantly lower. In these instances, a pronounced hormonal disorder is usually present, making them rare cases (Kruppa et al., 2020). The exact causes of lipedema are still unknown, although familial clusters have been observed, and the disease can arise spontaneously. Due to the limited number of specialists, many patients experience a long and burdensome journey before receiving a diagnosis. There is no laboratory test for lipedema; the diagnosis is made solely through clinical evaluation, including medical history and physical examination. Symmetrical symptoms are characteristic, with the hands and

feet typically unaffected. Additionally, the affected tissue is sensitive to pain, although the severity varies among individuals. Common symptoms include a feeling of heaviness, fluid accumulation after prolonged standing, and a tendency to bruise. Weight loss does not reduce the fat distribution disorder, and disproportionate differences between the trunk and extremities often persist. Lipedema progresses through several stages. In Stage I, there is increased fat tissue on the hips ("saddlebags"), and the skin is elastic and finely nodular, resembling styrofoam pellets in the subcutaneous tissue. In Stage II, the saddlebags enlarge, and fat accumulates on the inner side of the knees, often accompanied by coarse nodular skin changes. Stage III is marked by severe deformity of the extremities with large, hanging fat tissue lobes. At this stage, lymphedema can also develop, referred to as lipolymphedema. The disease is classified into thigh, lower leg, or ankle types (Lymphnetzwerk Lippe e.V., 2024).

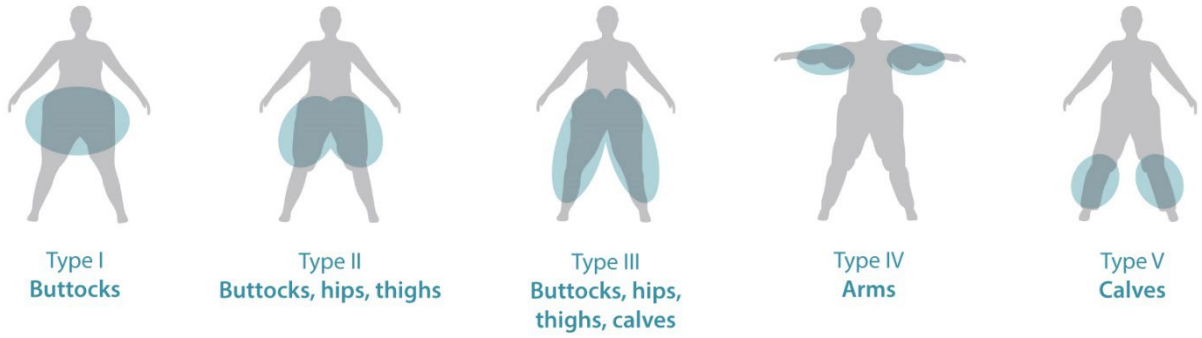

Figure 1: Different types of lipedema. Source: Tactile Medical, 2021.

As described, those affected often face difficulties in finding a qualified doctor for the diagnosis and treatment of their condition. Over 60 years after its initial description by Allen and Hines, lipedema remains largely unknown to many doctors. Compared to lymphological and phlebological diseases, the scientific literature on lipedema is limited (Meier-Vollrath et al., 2005). While the exact triggers of the disease are not yet known, the hormonal connection is clear. For this reason, it is likely that hormonal contraceptives can contribute to the onset or worsening of the disease. This is illustrated by a legal dispute between a patient and her gynecologist. The case involved the potential triggering of lipedema by administering a three-month contraceptive injection. A 28-year-old patient with several risk factors, including obesity (BMI 27) and smoking-related avoidance of the birth control pill, received a Depot-Clinovir® injection after a consultation. After developing painful edema and alleging insufficient information, the patient sued the gynecologist for alleged improper treatment. In court, the discussion revolved around whether contraceptive alternatives and their risks were adequately explained (Greiff, 2021).

Once diagnosed, conservative treatment is applied. The five main pillars of Complex Physical Decongestive Therapy (CPDT) include manual lymphatic drainage, compression therapy, physical activity, skin care, and self-management. Nutrition also plays a key role. A balanced diet not only

promotes overall well-being but is particularly crucial for lipedema patients in maintaining or reducing body weight. Since around 50% of lipedema patients also suffer from obesity, a healthy diet can help prevent obesity and improve symptoms. Unhealthy weight gain often exacerbates edema and mental distress. A strict diet is not the solution; rather, a conscious and balanced dietary adjustment should be adopted for long-term success. According to a study from the Vascular Medicine Center in Hamburg, a long-term dietary change can reduce complaints and pain in obese patients with lipedema or lymphedema by up to 80%, and decrease the number of required treatments. Two specific diets may be particularly beneficial (Medi, 2024):

1. Ketogenic Diet: This low-carb, high-fat diet puts the body into ketosis, where fat is used as the primary energy source instead of carbohydrates. This can have anti-inflammatory effects, reduce pain, and promote significant weight loss.
2. Mediterranean Diet: Based on fresh vegetables, fruits, whole grains, fish, lean meat, and olive oil, as common in the Mediterranean region, it helps inhibit inflammation, improve cholesterol levels, and stabilize blood sugar levels.

Exercise is another way to reduce healthy fat tissue and alleviate symptoms. Physical activity promotes health, but not all types of exercise are suitable for lipedema patients. The choice of activity should be made in consultation with a lipedema specialist, as it depends on the stage, type, and extent of the lipedema tissue. While exercise cannot cure lipedema, sports such as walking, cycling, and swimming are particularly suitable. Water sports like aqua jogging, aqua aerobics, or aqua spinning are highly recommended since water pressure has a lymphatic effect similar to lymphatic drainage. However, many patients avoid public swimming pools. In special classes, often organized by online communities or associations, they can exercise together with others outside regular public hours. In the gym, lipedema patients should focus on endurance training. Muscle building should be avoided to prevent additional stress on the joints. Patients should work with trainers to choose appropriate exercises, preferably those with light weights and numerous repetitions. Running is only recommended in the early stages of lipedema, as it can lead to joint damage in later stages due to the high impact. Yoga and Pilates can be helpful but should be adapted to the specific stage of lipedema and discussed with instructors. Balanced exercise can slow the progression of lipedema and prevent associated conditions such as obesity. Additionally, it promotes blood circulation to the muscles and improves mobility (Reba, 2024).

A holistic therapy approach combining dietary adjustment, exercise, and compression garments is essential. Liposuction also offers an effective option for permanently removing the affected fat tissue, improving appearance, and relieving symptoms. This surgical procedure should be performed by a specialized plastic surgeon with the appropriate experience (Abuagela, 2024).
Since January 1, 2020, liposuction for lipedema in stage III is covered by statutory health insurance under specific conditions. These include (Schmeller et al., 2010):

- Diagnosis of lipedema stage III
- At least six months of unsuccessful physical therapy
- For patients with a body mass index (BMI) over 35 kg/m², a combined obesity treatment (nutritional counseling)
- Women with a BMI over 40 kg/m² are advised against surgery.

This decision by the joint committee of health insurance providers is valid only until December 31, 2024. It remains uncertain whether funding for surgical treatment will continue beyond this date. Future decisions will likely consider research on the effectiveness of liposuction in treating

lipedema, even though the method has been part of medical guidelines since 2005 (Schmeller et al., 2010).

In one study examining this question, 112 women with lipedema were analyzed over a period of eight months to nearly seven years following liposuction with tumescent local anesthesia. The small sample size is typical for studies on lipedema. The analysis was conducted mainly through questionnaires and clinical follow-ups. Results showed significant reductions in circumference and normalization of body proportions. Symptoms such as spontaneous and pressure pain, edema formation, bruising tendencies, and mobility restrictions improved significantly. Additionally, cosmetic concerns and overall well-being were greatly enhanced. Statistical evaluations indicated that improvement was independent of the patient's age. Patients with more advanced stages of the disease (stage II and III) experienced more relief than those with milder forms (stage I). The therapeutic success after one year was comparable to that seen after nearly seven years. Many patients required significantly less traditional treatment such as manual lymphatic drainage and compression therapy when treated by experienced surgeons (Schmeller et al., 2010).

Specialized lipedema surgeons are crucial for successful treatment. In Germany, approximately 250,000 liposuction procedures are performed annually, mainly for aesthetic reasons. However, conventional methods are unsuitable for treating lipedema, as there is a high risk of damaging lymph vessels and causing lipo-lymphedema. Suitable techniques for liposuction in lipedema include tumescent local anesthesia (TLA) and water-assisted liposuction (WAL) under anesthesia or local anesthesia. These methods have been well-established for years and are low-risk when performed correctly. The choice of technique should be individualized and based on the patient’s condition and preferences. Liposuction reduces the number of fat cells and capillaries, resulting in less fluid retention in the tissue. However, the fragility of the remaining blood vessels cannot be corrected, so postoperative fluid retention is still possible, varying from case to case. Since the underlying causes of lipedema are not fully understood, recurrence after liposuction cannot be ruled out with absolute certainty. However, long-term observations suggest that removed fat cells do not regenerate. In rare cases, a repeat liposuction may be needed after many years. The most successful outcomes are achieved in stages I and II of lipedema. Patients with more advanced stages (II and III) report greater personal improvements following liposuction. However, a lasting improvement in quality of life also requires a healthy lifestyle with a balanced diet and sufficient physical activity (Lipedema Portal, 2024).

Conclusion

Lipedema is a chronic progressive disease that primarily affects women, characterized by symmetrical fat distribution in the extremities. Despite its first scientific description in 1940, it often remains undiagnosed and is frequently mistaken for other conditions such as obesity or lymphedema. The pathogenesis of lipedema is not fully understood, and there is no specific lab diagnostic; diagnosis is made clinically through history and examination.

Early diagnosis is crucial in reducing the suffering of patients and slowing the progression of the disease. Conservative treatment, particularly Complex Physical Decongestive Therapy (CPDT), is the gold standard for alleviating symptoms such as pain, swelling, and bruising. When conservative measures are insufficient, liposuction has proven to be an effective surgical option that can lead to long-term improvement in quality of life. Funding is available in advanced stages

under certain conditions through health insurance, although this regulation is only valid until December 2024, with no new guidelines currently in place.

Even 60 years after its initial description, lipedema remains underdiagnosed, often leading to years of patient suffering. Comprehensive interdisciplinary approaches and specialized medical care are necessary to ensure adequate treatment and sustainably improve the quality of life for those affected.

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