

Lipoedema – myths and facts Part 1

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Summary

Lipoedema is far more than just fatter and painful legs! As a disorder, lipoedema is encumbered with many myths. In the first part of this review, we cast a critical glance at two popular statements about lipoedema; statements that found their way into scientific publications decades ago and which have been repeated uncritically and continuously ever since; statements that have since become conventional wisdom for lipoedema patients and, in particular, for lipoedema self-help groups. In our portrayal of the myths surrounding lipoedema, we focus in this article on two aspects in particular that are closely associated with lipoedema: obesity and the psychological situation of lipoedema patients, which, again, is closely linked to the obesity. We examine two frequently publicised statements for their scientific evidence: 1. "Lipoedema is a progressive disorder", 2. "Lipoedema causes mental illness". Both statements largely contradict our many years of daily clinical experience with this specific patient population. At the same time, during our extensive searches of the scientific literature, we also determined that there is no evidence for these claims, which have now become part of the everyday „lipoedema language“. In fact, lipoedema is not usually a progressive disorder! Instead, lipoedema patients often show weight progression (mainly

obesity progression), which can lead to exacerbation of the lipoedema. Our pilot study on the 2nd statement makes clear that it is not the lipoedema that usually causes mental disorders. Our results point in the opposite direction: Pre-existing psychological vulnerability can significantly contribute to the clinical picture of lipoedema. Medicine alone cannot encompass the entire complexity and variety of lipoedema. Psychosocial treatment approaches should be an integral component of an effective multimodal treatment concept. Lipoedema is also wreathed in other myths, besides the two presented in this paper. These will be discussed in further issues of this journal.

Schlüsselwörter

Lipödem, Progredienz, Adipositas, Psychische Erkrankung, Wissenschaftliche Evidenz

Zusammenfassung

Das Lipödem ist weit mehr als einfach nur dickere und schmerzhaft Beine! Die Erkrankung Lipödem ist mit zahlreichen Mythen behaftet. Im ersten Teil dieser Übersicht werfen wir einen kritischen Blick auf zwei populäre Statements zum Lipödem; Statements, die vor Jahrzehnten schon Eingang in wissenschaftliche Publikationen gefunden haben und seither unkritisch und stetig wiederholt werden; Statements, die inzwischen zum selbstverständlichen Wissensallgemeingut von Lipödempatientinnen und vor allem auch von

Lipödem-Selbsthilfegruppen geworden sind. In unserer Darstellung über die Mythen des Lipödems fokussieren wir uns in diesem Beitrag vor allem auf zwei Aspekte, die aufs Engste mit dem Lipödem verbunden sind: auf die Adipositas sowie auf die psychische Situation von Lipödempatientinnen – die wiederum eng mit der Adipositas in Zusammenhang steht. Dabei überprüfen wir zwei häufig publizierte Statements auf wissenschaftliche Evidenz: 1. „Das Lipödem ist eine progrediente Erkrankung“, 2. „Ein Lipödem macht psychisch krank“. Beide Statements widersprechen in hohem Maße unserer seit Jahren bestehenden täglichen klinischen Erfahrung mit diesem speziellen Patientengut. Gleichzeitig haben wir im Rahmen unserer umfangreichen Literaturrecherche festgestellt, dass es auch keine Evidenz für diese in den „Lipödemsprachgebrauch“ eingegangenen Behauptungen gibt. Tatsächlich ist das Lipödem in der Regel keine progrediente Erkrankung! Vielmehr liegt bei Lipödempatientinnen häufig eine Gewichtsprogredienz (meist eine Adipositasprogredienz) vor, in deren Folge sich auch das Lipödem verschlechtern kann. Unsere Pilotstudie zum 2. Statement macht deutlich, dass in der Regel nicht das Lipödem Ursache von psychischen Erkrankungen ist. Hier weisen unsere Ergebnisse in die umgekehrte Richtung: Eine – vorbestehende – psychische Vulnerabilität kann ganz wesentlich zum Krankheitsbild Lipödem beitragen. Um das Lipödem in seiner ganzen Komplexität und Vielfalt zu erfassen, braucht es mehr als nur Medizin. Psychosoziale Therapieansätze sollten integraler Bestandteil eines wirksamen multimodalen Behandlungskonzepts sein. Neben den beiden dargestellten Mythen gibt es weitere, die sich um das Lipödem ranken. Diese werden in weiteren Ausgaben dieser Zeitschrift diskutiert werden.

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Introduction

Lipoedema is far more than fatter, painful legs!

However, and this must be emphasised, not every fat leg means lipoedema (1)!

In the Földi Clinic in Hinterzarten – a European Centre for Lymphology – we provide inpatient and outpatient treatment to approximately 3000 patients annually who have been diagnosed with lipoedema. The vast majority of these patients arrive at our clinic with perceptions and expectations fuelled not only by the media but also by physicians – perceptions of lipoedema far removed from scientific evidence and expectations that are often beyond what is achievable.

One crucial fundamental problem of this disorder is that lipoedema has no objective diagnostic criteria; no parameter, laboratory value or medical imaging exists that allows anything approaching an unequivocal diagnosis of this disorder. According to the 2015 German Lipoedema Guideline, “The diagnosis of lipoedema is based on medical history, examination and palpation with reference to the typical features”. These features can be divided into four symptoms:

- Disproportionate increase in fatty tissue in the legs (and/or arms)
- Sensation of heaviness and/or soreness in the affected limbs
- Tendency to haematoma
- Oedema that increases during the day (2).

This lack of objective and clear diagnostic criteria also means that no reliable figures exist on the prevalence of lipoedema. In the vast majority of cases, the lipoedema is diagnosed either by physicians with little experience in lymphology or, almost more often, by the patients themselves. In our patient population, the diagnosis of lipoedema (and, even more frequently, the diagnosis of “lipolymphoedema”) is by far the most common misdiagnosis that we encounter on a daily basis. All the figures circulating on prevalence, including those in scientific publications, are completely devoid of any evidence and are therefore not presented here (3).



Fig. 1 Patient with lipohypertrophy of the thighs and pelvic region

Despite the absence of objective diagnostic criteria, however, it is clear that the symptoms are absolutely consistent with the diagnosis of lipoedema. The isolated disproportionality of the female leg, without the above symptoms, is called lipohypertrophy (4). The latter is an inherent increase in fatty tissue in the limbs. In some severe cases, this can cause gait impairment with subsequent orthopaedic problems. However, the treatment then required differs from that of lipoedema.

► Figure 1 shows a patient with lipohypertrophy of the thighs and pelvic region. The patient has no further symptoms in the soft tissue of her legs; therefore, no lipoedema is present.

Lipoedema always develops from lipohypertrophy, although only in a very small proportion of patients. The reason why soreness develops in the fatty tissue of some female patients (very rarely, men are also affected) and the underlying pathophysiology of these symptoms is currently still unclear and the subject of ongoing research (5–7).

There are many myths in circulation about lipoedema; statements that have en-

tered into scientific opinion and have therefore also become part of patient knowledge. In this article, we want to examine two of these myths for scientific evidence.

In our clinic, lipoedema is confirmed if the patients describe complaints such as tenderness to pressure (or sensitivity to touch or a distinctly unpleasant sensation of heaviness) as well as an increased tendency to haematoma in the area of the disproportionate soft tissue of the legs (or arms). At the same time, the “pinch test” performed during clinical examination also has to be positive. In this test, a fold of abdominal fat is moderately pinched simultaneously with a fold of fat on the thigh (and subsequently on the lower leg and, if applicable, the arms). In contrast to the patient with lipohypertrophy alone, the lipoedema patient then experiences a marked difference in the perception of pain (limb pain). Confirmation of pitting oedema is not necessary when obtaining the diagnosis, as our clinical experience has shown that relevant oedema is only very rarely present in lipoedema cases. This procedure also corresponds to the diagnostic criteria of both the Dutch and British Lipoedema Guidelines (8–10).

In this first article of our presentation of the myths surrounding lipoedema, we focus mainly on two aspects that are very closely associated with lipoedema: obesity and the psychological situation of lipoedema patients, which, again, is closely linked to the obesity.

The following articles will discuss the scientific evidence supporting further popular statements on lipoedema. The topic of the next presentation is the issue of “oedema in lipoedema” and thus also the role of manual lymphatic drainage.

Myth 1: Lipoedema is a progressive disorder

This statement is found in a variety of scientific publications, as well as in lipoedema portals on the internet and magazines produced by lipoedema self-help groups (11–14). The current German S1 Lipoedema Guidelines also define lipoedema as a “progressive disorder” (15), and the inter-

net portal “Lipoedema Help Germany” [Lipödem Hilfe Deutschland e.V.], which is frequently accessed by patients, even writes: “Lipoedema is ALWAYS progressive, meaning that it gets worse” (16 areas of highlighted text in the original).

It is undisputed that some patients present with a hugely disproportionate increase in fatty tissue – isolated – in the legs. But these patients form a very small minority of our patient population. Nevertheless, images of this small minority often serve as “typical” images of lipoedema patients in both specialist and general publications.

The term “progressive” suggests, however, that this tendency to disproportionate fatty tissue, which is usually genetic in origin (17), increases virtually autonomously, fatefully and independently of general weight gain (18, 19). This increase in fatty tissue occurs in three stages (or four, according to some publications) (20–22). The NDR Health Advice Booklet states: “Fat cells reproduce in an uncontrolled way” (23).

But where is the scientific evidence for this pathophysiological construct?

Data confirming the progression of lipoedema and/or a pathophysiology supporting this assertion do not exist! E.V. Allen and E.H. Hines, who initially described lipoedema and, in their 2nd publication in 1951 (together with E. Wold) first used the term “progressive enlargement of the limbs ...” (24), are often cited. However, even those who were first to describe the disease realised that the progressive course of lipoedema “is ordinarily associated with weight gain”. This weight gain in lipoedema (“gradual increase of body weight”) had already been emphasised in the first publication of 1940 (25).

The question therefore arises, as to whether the leg circumference has increased because the patients have had an overall weight gain. In this case, it would be the body weight that was progressive, not the lipoedema. An increase in leg circumference would then be expected as part of the weight gain. The pathophysiology obviously supports this point of view.

A glance at our patient population makes clear that a close association exists between excess weight and/or obesity and the clinical picture of lipoedema. In our

lymphology outpatient department for non-private patients, we saw over 2300 patients diagnosed with lipoedema in 2015. Only 3% of these patients were of normal weight, 9% were overweight (body mass index [BMI] between 25 and 30 kg/m²) and 88% of our lipoedema patients were obese (BMI >30 kg/m²).

In this context, it should be mentioned that the BMI of lipoedema patients who are overweight (in rare cases, also of patients in the lower obesity range) is only of limited use for evaluation purposes. As shown above, there is the rare patient group with a largely slim upper body and a marked increase in fatty tissue of the limbs. This gives the false impression that the patients are “technically” overweight. As the latter is due to the fatty tissue distribution caused by the lipohypertrophy of the legs, this is not actually the case. For these patients, the waist-to-height ratio (WHtR) is the more appropriate measure. The WHtR describes the ratio between waist circumference and height and is a better indicator of body fat distribution. In the Földi Clinic, both the BMI and the WHtR are determined in all lipoedema patients.

The above figures, which show the close association between obesity and lipoedema, are also confirmed by centres in the Netherlands and Great Britain that treat lipoedema patients (26, 27). The lipoedema patient of normal weight is a rarity!

Why is the question of progression so important and why is the clarification of this statement of such huge practical significance?

In addition to their symptoms, many of our lipoedema patients have one feature in particular: they are afraid; afraid that their lipoedema is progressive. The vast majority of our patients have already read up about lipoedema on the internet (and have thus been given incorrect information!). The internet often shows images of patients with an extreme (but in reality very rare) fatty tissue increase in the legs or arms. Consequently, most of our patients express great concern that their lipoedema could also reach such proportions. For this reason, it is very important to clarify this question.

► Figure 2 and ► Figure 3 show patients diagnosed with lipoedema: Figure 2 with an extensive increase in fatty tissue

isolated in the thigh area, Figure 3 with a massive increase in fatty tissue in both the thighs and lower legs. In lipoedema, the feet are typically unremarkable. Both patients present with extreme findings that we rarely see in our clinical practice. It must be emphasised, however, that the primary disorder in both patients is morbid obesity!

But our daily clinical experience differs radically from the treatment of these extreme findings. We regularly see lipoedema patients, both as inpatients and outpatients, who present with stable lipoedema over many years if their weight has remained stable. We are now seeing courses extending over 20 years of patients with stable – non-progressive – lipoedema; stable, because these patients have stabilised their weight (at varying weight levels).

We have been co-treating the patient in ► Figure 4 as an outpatient for approximately 10 years due to her lipoedema. This patient’s BMI has been stable at 31 kg/m² during this time and her WHtR was 0.53. Leg volumes (thighs and lower legs were measured separately) have remained virtually unchanged during these 10 years. Wearing flat-knit compression hosiery every day and undertaking regular sporting activity 2–3 times weekly, the patient is asymptomatic.

However, the majority of our patients do experience weight progression over the years. This can be continuous; much more frequently, lipoedema patients experience a weight increase that occurs due to regular “dieting” and the subsequent “yo-yo effect”.

With lipoedema, the advice to lose weight conventionally is particularly pernicious. On the one hand, 95% of all people who lose weight with the usual commercial and non-commercial diets regain the weight within 3 years (28–35). At the same time, studies at the University of Hohenheim have shown that women (in contrast to men) regain a disproportionate amount of weight in the lower body after weight loss (36). In other words: every medical recommendation to a lipoedema patient to lose weight increases the risk of exacerbating the lipoedema.

It is thus clear that there is no evidence that lipoedema is progressive. It is, in fact, often the body weight that is progressive



Fig. 2 Patient diagnosed with lipoedema with a severe increase in fatty tissue isolated in the thighs

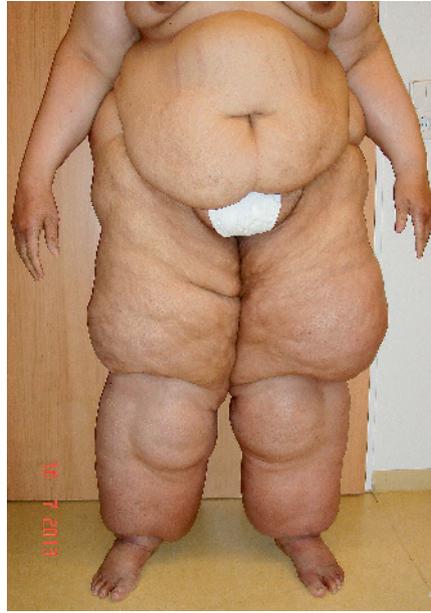


Fig. 3 Patient diagnosed with lipoedema with a massive increase in fatty tissue in both the thighs and lower legs



Fig. 4 Patient with lipoedema whom we have co-treated as an outpatient for approximately 10 years.

and, as a result, the lipoedema also worsens.

If lipoedema is not progressive, however, then the term “lipolymphoedema” makes no sense either. “Lipolymphoedema” suggests that “progressive lipoedema” leads to lymphoedema; it suggests that the lipoedema causes the lymphoedema. In some classifications, the “lipolymphoedema” is also classed as stage IV lipoedema. Karen Herbst from the University of Arizona and a protagonist of the American lipoedema scene writes: “Lipoedema therefore is a pre-lymphoedema condition” (37).

It must be emphasised that there is insufficient scientific evidence for this popular point of view. There are neither histological investigations supporting the construct of “lipolymphoedema” nor medical imaging procedures that have provided any corresponding confirmation. Ultimately, when mentioning “lipolymphoedema”, the vast majority of authors refer to the studies by Amann-Vesti from 2001 and Bilancini et al. from 1995 (38, 39). Only 12 (!) patients were investigated in each of the two studies. Whereas Bilancini, using dynamic lymphoscintigraphy, determined a slowed lymph flow in lipoedema patients, Amann-Vesti, using fluorescence microlymphography in the same patient population,

showed the now frequently cited microaneurysms of the lymph capillaries. However, the transport capacity of the lymphatic system was in no way impaired in the Amann-Vesti study. Further clinical studies using indirect lymphography and lymphoscintigraphy have also shown that lymph transport from the subepidermal compartment functions in lipoedema, in contrast to lymphoedema (40–42).

A major weakness of the data of both Bilancini and Amann-Vesti is the lack of any description of the weight situation of the patients studied. Neither publication gives any details at all of the patients’ BMI. Knowledge of the BMI is, however, essential in order to determine whether the irregularities in the lymphatic system are really due to the lipoedema, as postulated and often cited, or whether they are more likely to be obesity-induced. Amann-Vesti even begins her presentation by stating “Lipoedema is a special form of obesity” (43). It can therefore be assumed that the lipoedema patients she investigated were obese and that some were perhaps severely obese. It seems likely, therefore, that the changes observed in the lymph capillaries were obesity-induced, in the sense of initial obesity-associated lymphoedema.

Our experience with thousands of lipoedema patients in recent years also lends clinical support to this assumption. If a lipoedema patient, who is 165 cm tall and weighs 90 kg, gains a further 20 or 40 kg in weight, lymphoedema can develop in addition to the lipoedema. This lymphoedema is then not lipoedema-induced lymphoedema, however, but rather obesity-associated lymphoedema. The associated pathophysiology was outlined in this issue in the article on obesity-associated lymphoedema.

The term “lipolymphoedema” should therefore be deleted from the vocabulary of lymphology. It should also be deleted because it is frequently misused to allow prescription of manual lymphatic drainage, the treatment most in demand from lipoedema patients. The fact that this misuse is also officially promoted strongly re-

sembles a farcical situation. Manual lymphatic drainage is correctly not listed in the Medicines Catalogue [Heilmittelkatalog] as an indication for lipoedema. This makes sense from the medical point of view, as the evidence for any relevant oedema (oedema in the sense of fluid) is completely absent for lipoedema. (This point is the topic of Part 2 of this presentation). This decision, although medically reasonable, is reduced to absurdity in a joint question and answer catalogue of the Leading Associations of Statutory Health Insurance Funds and the National Association of Statutory Health Insurance (KBV) by the following formulation: “Lipoedema is used synonymously with lipolymphoedema; it can thereby be classified under LY1 or LY2 and treated with MLD” (44).

Of course, the patient forums and self-help groups make many references to this nonsense, which is officially legalised by an administrative act (45).

In other words: two completely different disorders (lipoedema and lymphoedema) are confused with each other to facilitate the eligibility for prescription of a therapy; a therapy that has no proven effect on the one clinical picture (lipoedema), whereas it presents a central therapeutic module for the other (lymphoedema).

In our clinical practice, we mainly see patients who present with these three disorders concurrently: obesity, lymphoedema and lipoedema. Manual lymphatic drainage is essential for these patients, but as treatment of the obesity-associated lymphoedema, not of the lipoedema. ▶ Figure 5 shows a patient treated as an outpatient for years due to lipoedema. In the last 8 years, she has gained approximately 40 kg in weight. In the meantime, distal leg lymphoedema has developed in addition to the lipoedema. The recommended therapeutic approach to this clinical picture is presented in the article on obesity-associated lymphoedema (in this issue).

Conclusion

There is no scientific evidence that lipoedema takes a progressive course. Rather, it is weight gain and obesity that are very often progressive. The WHO is already talking of

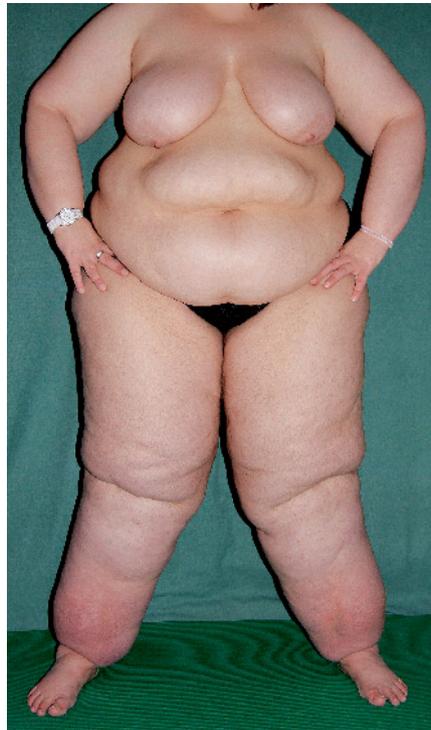


Fig. 5 Patient treated as an outpatient for years due to lipoedema.

an obesity epidemic. An exacerbation of the lipoedema can first occur as part of the progressive weight gain. The term “lipolymphoedema” is thus also incorrect from a medical point of view.

We should understand this perception of lipoedema as good news, which we should share with our lipoedema patients. We can tell our patients that their lipoedema will neither progress nor deteriorate and that it will remain stable – provided that their weight remains stable.

Myth 2: Lipoedema causes mental illness.

Women affected by lipoedema can suffer from a variety of problems. This particularly applies to the experience of lipoedema-related pain and impaired mobility, which leads to a reduction in physical quality of life (46, 47). In addition, many women with lipoedema suffer from dissatisfaction with their body's disproportionality and the associated stigmatisation. They have problems in accepting their own bodies and in self-acceptance, as well as its

consequences (46, 47). Those affected often experience an initial lack of understanding of their problems, even by physicians (50); it often takes several years before the diagnosis of lipoedema is obtained and appropriate therapy given.

Publications repeatedly report mental disorders in lipoedema patients (50–54). Overall, however, data on the relationship between lipoedema and the psyche are currently very sparse. A study in 100 lipoedema patients in the Stutz Liposuction Clinic concludes that 74% suffer from chronic eating disorders (53) and 8% have actually undertaken at least one suicide attempt (54).

In a world-wide, internet-supported survey initiated by Smidt in N=1416 participants in 2015, 39.7% self-assessed themselves as having depression (compared with a prevalence of 3–17% in the general population) and 16.5% cited eating disorders (compared with a prevalence of 1–5% in the general population). However, 30.37% of the participants had not been medically diagnosed with lipoedema (52).

In another internet-based investigation by Dudek et al in 2016 (51) with N=328 participants, 31.8% cited eating disorders in the self-assessment. Depression and anxiety were diagnosed here using the Patient Health Questionnaire (PHQ- 9), whereby 56.8% of participants showed increased to greatly increased scores for depression.

The role of psychological factors in the origin of other somatic disorders, such as cancers, has been taken into account for years (e.g. 55). For example, in rheumatoid arthritis (56), psychological factors, such as stress, play an important role.

To date, with regard to lipoedema, the implicit impression has been given that mental disorders, such as depression or eating disorders, are purely the result of the lipoedema. But – is this really true?

In general, the problems in research mainly appear in two areas: Firstly, there is a risk of overlooking important aspects by reducing the complexity. Secondly, statistical associations in the sense of a correlation are often incorrectly interpreted as a causality. The following questions thus arise: in how many women with lipoedema is it really the lipoedema that causally leads

to the mental disorder, in how many it is merely a comorbidity and in how many does the mental disorder possibly have an important involvement in the development of the pain symptoms of lipoedema?

In order to help clarify these open questions, we conducted a pilot study at our clinic.

Pilot study

Research question: Does lipoedema lead to mental disorders?

Methodology: Patients randomly referred to a certain ward during their inpatient stay in the Földi Clinic in the study period from April to December 2017 were included in the study. The requirement was a diagnosis of lipoedema of the legs, which had been reconfirmed medically in the specialist lymphology clinic, with the typical symptoms of disproportionality, tendency to haematoma and pain due to the lipoedema.

Thereafter, a psychological psychotherapist with specific experience in this patient population conducted semi-structured interviews with the patients. These were usually divided into two sessions and included:

1. Ascertaining the current mental disorders according to the ICD criteria (57) and all mental disorders that had occurred in the patient's medical history
2. The symptoms associated with the lipoedema (cf. 58)
3. The overlapping of both areas.

Questionnaires proved ill-suited to the explorative nature of the study, as they show a too limited range of symptoms (cf. 59–62), overestimate psychological symptoms in somatic disorders, e.g. depression (63, 64), and cannot depict the temporal course. Particularly in the concept of depression, it has been recently shown that, rather than being a unified concept, depression consists of various symptom clusters (65, 66), consideration of which is relevant to a successful psychotherapeutic treatment.

Results

N=45 patients were included in the study (► Table 1). The main results are presented here and, for better legibility, they are rounded up to whole numbers in the text. A distinction was made between subgroup n1 with a BMI <40 kg/m² and subgroup n2 with a BMI ≥40 kg/m².

84% of the total sample show very pronounced psychological symptoms (► Table 2), which preceded the development of lipoedema-related pain. This combines mental disorders, symptoms only slightly less severe than those of a mild depressive episode and burnout syndrome (67). The latter is not considered a mental disorder in diagnostic terms but rather a performance-related work and motivational disturbance. Stressful life events entailing only short-term stress and strain occur in the lives of almost all the participating women but in the pilot study show no effects on the pain symptoms of lipoedema.

The figures show that, at the time of the investigation, 53% of the total sample (n1: 47%, n2: 57%) had at least one mental disorder. The current diagnoses of the study subjects result in the following picture (► Table 3):

Depressive disorders are to the fore, although this category lists only those that reach at least the degree of severity of a mild depressive episode. Dysthymia was classified under Other. In clinical diagnostics, 16% fulfil the criterion of an eating disorder and 18% have an abnormality in their eating behaviour that does not yet fulfil the criterion of an eating disorder according to the ICD. It should also be borne in mind that 7% of the participants had already developed a post-traumatic stress disorder before developing lipoedema.

Only 4% of the women with lipoedema showed an accentuated personality with perfectionist traits – a “variety” of normality that does not represent a personality disorder.

16% of the women in the total sample reported having had specific suicidal thoughts in the past, such as jumping from a bridge or lying down in front of a train. They denied any association with the lipoedema. The main triggers were stressful life events, such as separation initiated by the partner, a life-threatening disorder in a child or serious conflicts at the workplace. One patient had previously undertaken a suicide attempt due to family conflicts.

64% of the women with lipoedema (n1: 59%, n2: 68%) show mental disorders that definitely occurred prior to the development of lipoedema-related pain and thus, in terms of formal logic, certainly cannot be a result of the lipoedema. Both mental disorders that are still current and also those no longer present were taken into consideration here. The period six months prior to the development of the lipoedema-related pain is shown to be of particular significance.

Regarding the question of the development of mental disorders in pre-existing lipoedema, the results show the following: 2% of the total sample show a mental disorder mainly due to the lipoedema; in 9%, an involvement of the lipoedema symptoms is determined in the development of a mental disorder. In 89%, the mental disorders initially occurring after lipoedema were not directly associated with the symptoms of the lipoedema.

Tab. 1 Description of the sample: N=45

	Patients with BMI <40 kg/m ² n1=17	Patients with BMI >40 kg/m ² n2=28	Total sample N=45
Age in years	17 – 62	32 – 62	17 – 62
Mean age	41.06	45.61	43.88
BMI range in kg/m ²	24.01 – 39.48	40.65 – 71.52	24.01 – 71.52
Mean BMI	31.47	48.39	41.99

Discussion

The results show that more precise diagnostic data were acquired in the clinical interview than in the previous online surveys. The patients' spontaneous self-assessment in questionnaires often overestimated the existence of a mental disorder. It is possible to make more nuanced enquiries about many areas in the interview. Whereas in online surveys (68, 69) 56.7% of the women surveyed reported "inexplicable weight gain", in the interview for the present pilot study, various reasons were always given for the weight gain, sometimes accompanied by feelings of shame. This shows the advantages of structured interviews even if they are very time-consuming.

Most of the women with lipoedema had had severe psychological symptoms for several months prior to developing lipoedema-related pain. Purely in terms of formal logic – and this has been verified – something that temporally precedes the development of lipoedema cannot be its consequence.

The results clearly indicate that only in rare cases does lipoedema directly lead to mental disorders and that the traditional view of the case history must be broadened. The statement "lipoedema causes mental illness" is plainly incorrect for the vast majority of women with lipoedema. If the somatic preconditions for developing lipoedema are present, the statement should instead read: "There are many indications that psychological factors can contribute significantly to the development of lipoedema".

In order to work out clear causal associations, interviews with a larger cohort would be desirable, as well as the use of a suitable control group, e.g. women with lipohypertrophy (an increase in fatty tissue in the pain-free leg). Due to the lack of any treatment contract, however, we hardly ever see such women in the specialist clinic.

The two clinical pictures of lipoedema and obesity cannot be investigated independently of each other: 82% of the pilot study participants are obese. This corresponds approximately to the rate in the Földi Clinic: as mentioned above, 88% of

the more than 2300 patients undergoing outpatient treatment for lipoedema at the Földi Clinic were obese. However, the percentage of obese women with lipoedema is also high in the online surveys conducted to date: e.g. 46% (N=120) with a BMI >40 kg/m² (6), or in a further study, a mean BMI of 41.25 kg/m² (N=321) (51).

As Luppino (70) has shown in a meta-analysis, a bidirectional relationship exists between obesity and depression. Thus, the onset of depression increases the risk of obesity by 58%; the onset of obesity increases the risk of depression by 55%. If one considers the fact that weight gain can lead to exacerbation of the lipoedema, it is then not surprising that severe psychological symptoms, often also accompanied by weight gain, precede the development of lipoedema-related pain.

It has now been sufficiently verified that psychological factors modulate the perception and processing of pain (71). To date, no studies exist on pain in lipoedema, but there are some studies on pain in orthopaedic (72) or rheumatic disorders (56). Negative influencing factors on pain intensity are withdrawal behaviour, helplessness and hopelessness, unhappy, dejected mood (71) or catastrophising (72). The associations between psychological factors and pain perception are bidirectional here.

The underlying problems often start well before the development of a mental disorder or lipoedema. An ideal of beauty that already describes women who are of normal weight and clothes size 38 as "plus size" (representative of several: 73,74), leads many women to feel dissatisfied with their own bodies. Attempts to lose weight by means of numerous diets, usually followed by a yo-yo effect, result in a vicious circle for women with a corresponding disposition with exacerbation of the disproportionality.

Even the initial and frequently cited papers on lipoedema by Allen and Hines in 1940 (25) and 1951 (24) point out the significance of the ideal of beauty: "Indeed, it is quite probable that much or all of the distress (both emotional and physical) associated with lipoedema would not occur were "fat legs" considered a manifestation of beauty." (24).

Tab. 2 Occurrence of mental disorders or psychological vulnerabilities prior to the development of lipoedema in % of the subgroups divided according to BMI

Psychological disturbances or vulnerabilities prior to lipoedema	Patients with BMI <40 kg/m ² n1=17	Patients with BMI >40 kg/m ² n2=28	Total sample N=45
yes	94.12	78.57	84.44
no	5.88	21.43	15.56

Tab. 3 Current mental disorders (without other psychological vulnerability) in % of the subgroups divided according to BMI or % of the total sample N=45, sometimes with multiple diagnoses

	Patients with BMI <40 kg/m ² n1=17	Patients with BMI >40 kg/m ² n2=28	Total sample N=45
Depressive disorders	23.53	39.29	33.33
Eating disorders	5.89	21.43	15.56
Anxiety disorders	5.89	10.74	8.89
Post-traumatic stress disorders	5.89	7.14	6.67
Pain with somatoform elements	11.76	3.57	6.67
Other	5.89	7.14	6.67

Conclusion

Lipoedema is not a mental disorder, but rather a somatic one. Currently, however, there is some evidence that psychological factors can play a decisive role in the perception of lipoedema-induced pain.

Prospects

In addition to the two myths presented, there are others surrounding lipoedema that urgently require investigation. However, their discussion would have exceeded the scope of this presentation. They will be considered in further issues of this journal.

One example to mention here is the assumption that lipoedema is an “oedema problem” and that manual lymphatic drainage is thus also an essential treatment component to be performed regularly. The statement that weight reduction has no effect on the lipoedema is also popular.

At the end of this short series of articles on lipoedema, a multimodal treatment concept for lipoedema will be presented, one that will help to ensure a more sustainable and comprehensive improvement in our patients' symptoms.

Conflict of interest

The authors declare that no conflicts of interest exist.

Ethical guidelines

No studies in humans or animals were conducted for this paper.

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