

Lipoedema – myths and facts, Part 5*

European Best Practice of Lipoedema – Summary of the European Lipoedema Forum consensus

Lipödem – Mythen und Fakten Teil 5

Streitschrift für eine European Best Practice of Lipoedema – Zusammenfassung des Konsensus des European Lipoedema-Forums

Authors

Tobias Bertsch¹, Gabriele Erbacher¹, D. Corda², R. J. Damstra³, K. van Duinen³, R. Elwell⁴, J. van Esch-Smeenge³, G. Faerber⁵, S. Fetzter⁶, J. Fink⁷, A. Fleming⁸, Y. Frambach⁹, K. Gordon¹⁰, D. Hardy¹¹, A. Hendrickx³, T. Hirsch¹², B. Koet³, P. Mallinger¹³, A. Miller¹⁴, C. Moffatt¹⁵, N. Torio-Padron¹⁶, C. Ure¹⁷, S. Wagner¹⁸, T. Zähringer¹

Affiliations

- 1 Foeldiclinic Hinterzarten – European Center of Lymphology, Germany
- 2 Polimedica San Lanfranco, Pavia, Italy
- 3 Center of Expertise for Lymphovascular Medicine, Nij Smellinghe, Drachten, The Netherlands
- 4 University-Hospitals of North Midlands, UK
- 5 Zentrum für Gefäßmedizin, Vascular Medicine, Hamburg, Germany
- 6 Patient self-help organisation Lipoedema UK
- 7 Department of General and Visceral Surgery at the Medical Center – University of Freiburg, Germany
- 8 Rehabilitation-Centre Reade, Amsterdam, Netherlands
- 9 Hanse-Klinik, Clinic for Liposuction, Lübeck, Germany
- 10 St.-George's-Hospital, London, GB
- 11 Kendal-Lymphology-Centre, UK
- 12 Praxis für Innere Medizin und Gefäßkrankheiten, Vascular Medicine, Halle, Germany
- 13 Klinikum Klagenfurt, Austria
- 14 Dermatologische Praxis, Berlin, Germany
- 15 Nottingham-Trent-University, UK
- 16 Praxisklinik für Plastische Chirurgie, Freiburg, Germany
- 17 Lymphklinik Wolfsberg, Austria
- 18 RehaClinic Bad Zurzach, Switzerland

Additional attendee who agreed to the consensus: J. Dudek, SWPS University of Social Sciences and Humanities, Warsaw, Poland

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Correspondence

Dr. med. Tobias Bertsch
 Földiklinik GmbH & Co.KG, Rösslehofweg 2–6,
 79856 Hinterzarten
 Tel.: ++ 49/76 52/12 40
 Fax: ++ 49/76 52/12 41 16
tobias.bertsch@foeldiklinik.de

ABSTRACT

The four previous articles in this series addressed the myths and facts surrounding lipoedema. We have shown that there is no scientific evidence at all for the key statements made about lipoedema – which are published time and time again. The main result of this “misunderstanding” of lipoedema is a therapeutic concept that misses the mark. The patient’s real problems are overlooked.

The national and especially the international response to the series, which can be read in both German and English, has been immense and has exceeded all our expectations. The numerous reactions to our articles make it clear that in other countries, too, the fallacies regarding lipoedema have led to an increasing discrepancy between the experience of health-care workers and the perspective of patients and self-help groups, based on misinformation mostly generated by the medical profession.

Parts 1 to 4 in this series of articles on the myths surrounding lipoedema have made it clear that we have to radically change the view of lipoedema that has been held for decades. Changing our perspective means getting away from the idea of “oedema in lipoedema” – and hence away from the dogma that decongestion is absolutely necessary – and towards the

* All authors share the first authorship.

actual problems faced by our patients with lipoedema. Such a paradigm shift in a disease that has been described in the same way for decades cannot be left to individuals but must be put on a much broader footing. For this reason, the lead author of this series of articles invited renowned lipoedema experts from various European countries to discussions on the subject. Experts from seven different countries took part in the two European Lipoedema Forums, with the goal of establishing a consensus. The consensus reflects the experts' shared view on the disease, having scrutinized the available literature, and having taken into account the many years of clinical practice with this particular patient group. Appropriate to the clinical complexity of lipoedema, participants from different specialties provided an interdisciplinary approach. Nearly all of the participants in the European Lipoedema Forum had already published work on lipoedema, had been involved in drawing up their national lipoedema guidelines, or were on the executive board of their respective specialty society.

In this fifth and final part of our series on lipoedema, we will summarise the relevant findings of this consensus, emphasising the treatment of lipoedema as we now recommend it. As the next step, the actual consensus paper "European Best Practice of Lipoedema" will be issued as an international publication.

Instead of looking at the treatment of oedema, the consensus paper will focus on treatment of the soft tissue pain, as well as the psychological vulnerability of patients with lipoedema. The relationship between pain perception and the patient's mental health is recognised and dealt with specifically. The consensus also addresses the problem of self-acceptance, and this plays a prominent role in the new therapeutic concept. The treatment of obesity provides a further pillar of treatment. Obesity is recognised as being the most common comorbid condition by far and an important trigger of lipoedema. Bariatric surgery should therefore also be considered for patients with lipoedema who are morbidly obese. The expert group upgraded the importance of compression therapy and appropriate physical activity, as the demonstrated anti-inflammatory effects directly improve the patients' symptoms. Patients will be provided with tools for personalised self-management in order to sustain successful treatment. Should conservative therapy fail to improve the symptoms, liposuction may be considered in strictly defined circumstances.

The change in the view of lipoedema that we describe here brings the patients' actual symptoms to the forefront. This approach allows us to focus on more comprehensive treatment that is not only more effective but also more sustainable than focusing on the removal of non-existent oedema.

ZUSAMMENFASSUNG

Die Mythen und Fakten des Lipödems waren das Thema der vergangenen 4 Teile dieser Artikelserie. Wir konnten zeigen, dass für die zentralen – und immer wieder publizierten – Statements zum Lipödem keinerlei wissenschaftliche Evidenz vorliegt. Wesentliche Folge dieses „Fehlverständnisses“ der Erkrankung Lipödem ist ein Therapiekonzept, welches an den tatsächlichen Beschwerden der Patientinnen weitgehend vorbeigeht.

Der nationale, aber vor allem auch der internationale Zuspruch, auch der in Englisch zu lesenden Reihe, war immens und übertraf all unsere Erwartungen. Die zahlreichen Reaktionen auf unsere Artikelserie machten eines deutlich: Auch in anderen Ländern führen die Stilblüten des Lipödems zu einer zunehmenden Diskrepanz zwischen den Erfahrungen der Behandler und der durch – meist ärztlich verursachten – Fehlinformation geleiteten Perspektive der Patientinnen und Selbsthilfegruppen.

Die Teile 1 bis 4 der Artikelserie über die Mythen des Lipödems haben deutlich gemacht, dass wir diese seit Jahrzehnten tradierte Perspektive auf die Erkrankung Lipödem verändern müssen. Veränderung der Perspektive heißt: Weg vom „Ödem im Lipödem“, damit auch weg vom Dogma der notwendigen „Entstauung“ und hin zu den tatsächlichen Beschwerden unserer Lipödem-Patientinnen. Ein solcher Paradigmenwechsel eines seit Jahrzehnten auf immer gleiche Weise beschriebenen Krankheitsbildes kann nicht Aufgabe Einzelner sein, sondern muss auf breite Füße gestellt werden. Aus diesem Grund hat der ärztliche Erstautor dieser Artikelreihe renommierte Lipödem-Experten aus verschiedenen europäischen Ländern zu einer Diskussion über das Lipödem eingeladen. Ziel der beiden „European Lipoedema-Foren“, an denen Experten aus 7 Ländern teilnahmen, war die Erstellung eines Konsensus. Dieser Konsensus spiegelt unter Sichtung der zur Verfügung stehenden wissenschaftlichen Literatur – bei gleichzeitiger Berücksichtigung der jeweils langjährigen klinischen Arbeit mit diesen Patientinnen – die gemeinsame Sicht der beteiligten europäischen Experten auf diese Erkrankung wider. Der Komplexität des Krankheitsbildes Lipödem angemessen war auch die Struktur der Teilnehmer interdisziplinär. Nahezu alle Teilnehmer des European Lipoedema-Forum haben in der Vergangenheit entweder über das Lipödem publiziert bzw. an ihren nationalen Lipödem-Leitlinien mitgearbeitet oder sind in Vorständen ihrer Fachgesellschaften vertreten.

In diesem fünften und letzten Teil unserer Artikelserie über das Lipödem sollen vorab die wesentlichen Ergebnisse dieses Konsensus kurz zusammengefasst werden, wobei der Fokus auf der empfohlenen Therapie des Lipödems liegt. Das eigentliche Konsensus-Papier, „European Best Practice of Lipoedema“, wird dann in einem zweiten Schritt im Rahmen einer internationalen Publikation veröffentlicht.

Statt einer Ödem-Behandlung wird im Konsensus-Papier auf die Behandlung des Weichteilschmerzes ebenso fokussiert wie auf die psychische Vulnerabilität der Lipödem-Patientin. Zusammenhänge zwischen der Schmerzwahrnehmung und der psychischen Situation der Patientin werden anerkannt und gezielt behandelt. Hierbei wird auch das Problem der Selbstakzeptanz thematisiert und spielt im neuen Behandlungskonzept eine herausragende Rolle. Eine weitere Therapiensäule stellt die Adipositas-Behandlung dar. Adipositas wird somit als mit Abstand häufigste Begleiterkrankung – und wesentlicher Trigger – des Lipödems akzeptiert. Bei schwer adipösen Lipödem-Patientinnen sollte daher auch die bariatrische Operation erwogen werden. Kompressionstherapie und gezielte Bewegungsaktivität wurden von der Experten-gruppe deutlich aufgewertet, da durch die nachgewiesenen antiinflammatorischen Effekte die Beschwerden der Patienten

direkt verbessert werden. Durch ein individualisiertes Selbstmanagement werden den Patientinnen Tools mit an die Hand gegeben, die den Therapieerfolg nachhaltig stabilisieren. Sollte die konservative Therapie zu keiner relevanten Beschwerdeverbesserung führen, kann die Liposuktion unter Einhaltung klar definierter Vorgaben erwogen werden.

Die hier beschriebene Veränderung der Perspektive auf das Lipoedem stellt die tatsächlichen Beschwerden der Patientinnen in den Fokus. Dies ermöglicht eine umfassendere, damit bessere und auch nachhaltigere Behandlung als die Fokussierung auf ein nie nachgewiesenes Ödem und dessen Entstauung.

Introduction

This is the fifth and final part of our series on the myths and facts surrounding lipoedema.

In these articles, the two lead authors have critically addressed statements on lipoedema that have existed and been propagated for decades, and have reviewed them for supporting scientific evidence. Many of these statements have become “lipoedema dogma” – deemed to be guiding principles whose validity is no longer in doubt. And, as a result of this dogma, an understanding of this disease has developed that has very little to do with the patients’ actual problems. In addition, research has shown that there is no scientific evidence at all for the pathophysiology previously thought to underlie lipoedema.

To briefly recapitulate the myths discussed in parts 1 to 4, it is clear that there is no evidence at all for the presence of oedema in lipoedema [1]. Neither clinical examination nor diagnostic imaging has ever shown there to be a significant accumulation of fluid in the tissues of patients with lipoedema, which makes “decongestion of the tissues” by manual or automated lymphatic drainage techniques obsolete. The term “lipoedema” is therefore outdated and should be reconsidered.

Although it is often said that lipoedema is a progressive disease, there is no evidence to support this assertion [2]. On the other hand, obesity is often progressive and lipoedema may worsen as the patient’s weight increases. For this reason, the (frequently misused) term of “lipolymphoedema” is also obsolete. Progressive obesity rather than lipoedema is the cause of additional lymphoedema. Many patients, therefore, have three diseases that need to be treated: obesity, lipoedema, and obesity-related lymphoedema.

Our data (now of 150 cases) also show a high level of psychological vulnerability in the great majority of our patients with lipoedema [2]. But mental health issues were present before the onset of the typical lipoedema symptoms and have therefore an influence in the patients’ perception of pain.

Our data have reduced to absurdity the claim that losing weight has no effect on lipoedema – a view widely shared by many of our colleagues, especially those offering liposuction – and also the belief, often fueled by the media, that “lipoedema makes you fat”.

In fact, the opposite is true: obesity makes you fat. Speaking in purely physiological terms, weight gain includes an increase of adipose tissue in the legs. Also speaking purely physiologically, weight loss therefore includes a reduction of adipose tissue in

the legs [3]. The dramatic improvement in lipoedema which patients experience after bariatric surgery is the subject of an ongoing doctoral research project being carried out in conjunction with University Hospital in Freiburg, Germany. We already have the preliminary results [4].

And finally, we have shown that the current situation regarding available studies on liposuction is disastrous. The claim that “liposuction cures lipoedema” is just wishful thinking on the part of “lipoedema surgeons” and many patients, and in no way reflects reality [5].

Current status of reimbursement for liposuction by healthcare insurance

Despite this lack of reputable studies, the current German Minister of Health has been effectively campaigning for liposuction to be covered by healthcare insurance [6].

And despite this lack of reputable studies, the Federal Joint Committee (G-BA) has capitulated. The situation now (July 2019) is such that it should be possible to prescribe liposuction for “stage 3 lipoedema” under statutory healthcare insurance from 1 January 2020 onwards [7].

Nevertheless – and this is crucial – there is no even remotely meaningful staging of lipoedema. The current classification depends upon a subjective (and therefore arbitrary) assessment by the examiner and is based on morphological criteria alone, without taking the patient’s actual symptoms into consideration. These “stages” therefore completely ignore the clinical reality. In the so-called stage 3, there are women with highly disproportionate adipose tissue in the legs (or arms) who have only mild symptoms or none at all. At the same time, physicians treating lipoedema see women with mild disproportion – and de facto allocated to stage 1 – who have intense pain in the soft tissues of the leg.

The classical “patient with stage 3 lipoedema” referred to our outpatient clinic is a severely overweight woman whose main disease is obesity. In our opinion, carrying out liposuction on these often morbidly obese patients constitutes malpractice, a malpractice which is possibly reimbursed, starting January 2020, at the expense of the statutory health insurance (and thus of all premium payers). Faerber and Bertsch have therefore submitted a comprehensive statement on this wrongful decision to Prof. Josef Hecken of the G-BA in Germany. This statement can be accessed on the website of the German Society of Lymphology [8].

Lipoedema – a necessary paradigm shift

Parts 1 to 4 in this series of articles on the myths surrounding lipoedema have made it clear that we have to radically change our view about lipoedema. Changing our perspective means getting away from the idea of “oedema in lipoedema” – and hence away from the dogma that decongestion is absolutely necessary – and towards the actual problems faced by our patients with this condition. Such a paradigm shift in a disease that has been described in the same way for decades cannot be left to individuals, but must be put on a much broader footing. For this reason, the lead author of this series invited renowned lipoedema experts from various European countries to discussions on the subject. The first European Lipoedema Forum was held in Hamburg in June 2018, with participants from five countries. The second forum in March 2019 included experts from seven countries. The goal was to establish a consensus that would reflect the view shared by these European countries, following scrutiny of the available literature and at the same time taking many years of clinical practice with these patients into consideration. Appropriate to the clinical complexity of lipoedema, the participants provided an interdisciplinary approach: psychologists, physiotherapists, nutrition and obesity experts, lymphoedema/lipoedema nurses (common in the UK), doctors treating conservatively, surgeons, and the chair of Lipoedema UK, a British patient support group. Nearly all of the participants in the European Lipoedema Forum had previously published work on lipoedema, had been involved in drawing up their own national lipoedema guidelines, or were on the executive board of their respective specialty society. The consensus drawn up in Hamburg was established using open space technique (OST) and the formation of interdisciplinary working groups which then presented their results to the entire expert group for reaching a consensus.

In the fifth part of our series on lipoedema we will summarise the relevant findings of this consensus, focusing on the new treatment recommendations for Part 5 is therefore a combined effort between the previous lead authors and the participants of the European Lipoedema Forum. In a second step, the final consensus paper “European Best Practice of Lipoedema” will be issued as an international publication.

We would like to state explicitly, however, that the European Lipoedema Forum experts listed as co-authors are responsible only for the consensus statements and the subsequently developed therapeutic concept, while the two lead authors are responsible for the article in its entirety.

Consensus statements from the European Lipoedema Forum

Before we address the therapeutic concept for the treatment of lipoedema in depth, we would like to present the key consensus statements on the “Scientific Background” and the question of the “Diagnostic Approach” to lipoedema. To avoid misinterpretations in translation, we are using the original statements that appear in the Hamburg consensus paper [9].

Consensus agreement for “Scientific Background”

There is **no** scientific evidence:

- that Lipoedema is an “oedema problem”
- that MLD is reducing the patients’ complaints due to its drainage effects
- that Lipoedema is a progressive disease
- that weight loss is not effective
- that Lipoedema is the cause of Lymphoedema
- that 11 % of the female population suffer from Lipoedema
- that onset of Lipoedema is during puberty

Consensus agreement for “Diagnostic Approach”

Re oedema

- Orthostatic oedema does not have to be present for Lipoedema
- Oedema is only present in a small subgroup of Lipoedema patients
- Conclusion: Oedema is not pathognomonic for Lipoedema

Re the distribution of adipose tissue

- Disproportional fat distribution must be present for Lipoedema
- Differential diagnosis:
 - Obesity: “global” visceral and subcutaneous fatty tissue increase
 - Lipohypertrophy: subcutaneous fatty tissue increase in legs and sometimes in arms but no pain/complaints in soft tissue
- Obesity is often progressive, usually not Lipoedema. If obesity is progressive, Lipoedema can get worse.
- Conclusion: Disproportional fat distribution is a major symptom of Lipoedema

Re pain/symptoms in the soft tissues

- Pain/complaints in the soft tissue of the legs (sometimes arms)
- Other diseases must be excluded as the cause of pain
- Pain must be further differentiated:
 - Heaviness
 - Discomfort
 - Spontaneous pain or pain on pressure
- Pain must be assessed as objective as possible: Visual Analogue Scale (VAS) 0–10, pain questionnaire, Central Sensitization Inventory (CSI)
- Conclusion: Pain/complaints in the soft tissue of the legs or arms are a major symptom of Lipoedema

Re overweight and obesity

- Overweight/obesity is an aggravating factor of Lipoedema
- Majority of Lipoedema patients are obese (62–88 %)
- Lipoedema patients usually suffer from their weight gain
- Majority of patients try “diet and exercise” and experience yo-yo effect
- Weight gain can impair Lipoedema
- Obese Lipoedema patients often experience a lack of fitness and mobility
- Conclusion: Obesity/weight gain must be focused on

Re the mental health of patients with lipoedema

- Psychological issues are an additional aspect of Lipoedema
- Impact of psychological distress is underestimated
- Psychological vulnerability contributes to the amount of pain perception
- Eating disorders are often present and need to be treated
- Lack of self-acceptance because of current beauty ideal
- Conclusion: Psychological assessment is a must

It is clear that a substantial change in perspective has taken place, not only in the scientific understanding but also in the diagnostic approach to the disease. The consensus of the European expert group is that there is no scientific evidence to support the lipoedema dogma which has been published and propagated for decades. There has also been a shift in focus: while the disproportionate increase in adipose tissue in the limbs and the symptoms associated with this fatty tissue increase are considered to be major symptoms, oedema (and also the tendency to developing haematoma) is now considered to be only a very minor symptom in the diagnosis of lipoedema. Instead, great importance is given to both obesity and the patient's mental health (which has a significant effect on pain perception).

Pathophysiological considerations

The two lead authors have proposed a pathophysiological model to explain the symptoms associated with lipoedema to the patients; this model is also used by their colleagues at the Foeldi Clinic.

When patients present with a history of being diagnosed with lipoedema, routine practice at the Foeldi Clinic is now to ask not only about any changes in weight but also about the time of onset of the pain.

In this context, we know that one of the main complaints in patients with lipoedema regularly consists of weight gain – some patients put on only six kilograms, some gain 40 kg or more – with a disproportionate increase in the legs (and less commonly in the arms). An increase in weight basically means an increase in adipose tissue. A hormonal pattern may develop in the expanded adipose tissue, resulting in low-grade inflammation and hypoxia of the fat cells [10]. An increase in adipose tissue leads particularly to a local increase in proinflammatory hormones (adipokines) [11, 12]. In the second part of our series of articles, we already cited Pou, who wrote that the subcutaneous fatty tissues “appear to be associated with chronic inflammation” [13]. At the same time, Rutkowsky et al. stated, “Adipose expansion results in tissue hypoxia” [10]. Fat cells are only able to expand with increased vascular growth. The vessels' inability to keep pace with the expanding adipose tissue may lead to hypoxia. Hypoxic conditions in this tissue lead to an increased expression of hypoxia-inducible factors (HIF1a) [14]. HIF1a in turn induces inflammation of the adipose tissue [15].

Earlier findings by Kayserling also pointed in the same direction: in the histology of patients with lipoedema he observed an increase of crown-like structures that were nothing other than a step in the elimination of dying fat cells [16]. More recent data from Karen Herbst's research team in the USA confirm the inflammatory processes in the subcutaneous adipose tissue of patients

with lipoedema. One study showed an increase in the sodium content of the skin in these patients. The authors wrote, “Skin sodium accumulation is an emerging hallmark of inflammatory diseases” [17]. A study published in 2019 confirmed the inflammatory processes in the adipose tissue. The authors found a greater increase in macrophages in the fatty tissue of patients with lipoedema than in the control group [18].

Like the hypoxia, this low grade chronic inflammation may contribute to the patient's perceived pain [19].

► **Fig. 1** depicts these complex pathophysiological processes.

► **Fig. 2** shows the first part – the somatic aspects – of the model that we use in our clinic to explain to the patients how the pain develops.

However, this somatic view of lipoedema is just one side of the coin.

In the past, the medical profession has viewed pain exclusively as a warning signal for tissue or nerve damage. More recently, we have come to understand that chronic pain can also be (co-) triggered by stress or personal conditions. The mechanism of stress-induced hyperalgesia (SIH) is also of importance in patients with lipoedema, especially when they experience intense pain. The – absolutely genuine – pain that patients suffer is less related to the extent of tissue damage, but has more to do with the way in which the brain and nervous system interpret the stimulus as “danger” [21].

A pilot study carried out by the lead authors [2] (now including 150 cases) showed that patients who had suffered mental stress over a long period gave higher estimates of the severity of the lipoedema pain (7–8 and even up to 10) on a visual analogue scale (VAS) from 0–10, while 10 was considered by the investigators to be “amputation pain”. If there were no pronounced mental stress factors, the severity of the pain was usually rated 2–3 and only rarely 5–6.

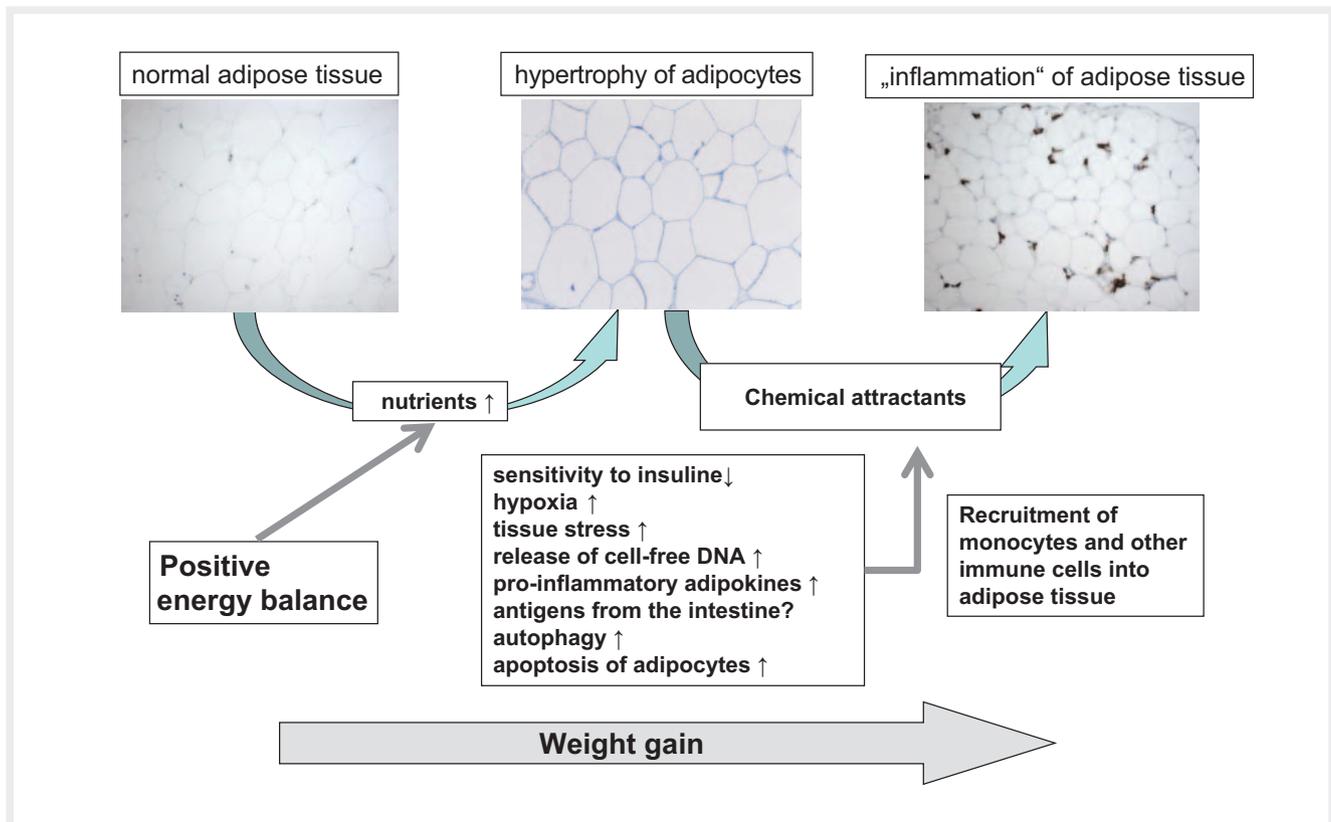
Chronic stress, but also anxiety and depression [22, 23], lower the pain threshold and lead to a significant increase in pain. Catastrophic thinking [24], focusing attention on the pain, negative assessments and helplessness reinforce the pain and can cause it to become chronic [23].

Patients with pain often avoid movements that may trigger the pain, which restricts everyday activities even more and brings about feelings of helplessness and subjection [23].

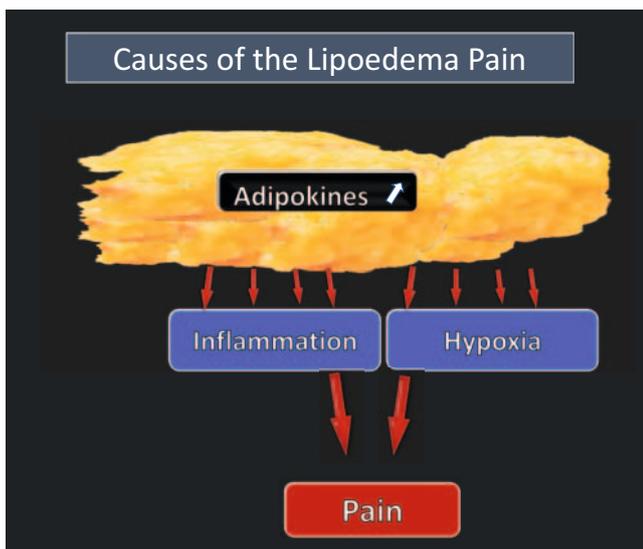
In addition, and the available studies are in agreement on this point, chronic stress in turn causes the inflammatory markers to rise. Results from recent studies show this to be the case in patients with rheumatoid conditions [25], in whom a stress-induced increase in inflammatory mediators can be seen, irrespective of their disease activity.

At the same time, patients with depression [26], social stress [27] or post-traumatic stress disorder [28] also show an increase in inflammatory markers that is unrelated to any underlying somatic disease. Given the high psychological vulnerability in the majority of our patients with lipoedema, a vicious circle may ensue. A vicious circle where chronic stress and psychological symptoms intensify the pain through inflammatory mediators, which in turn may lead to a situation of increased mental stress.

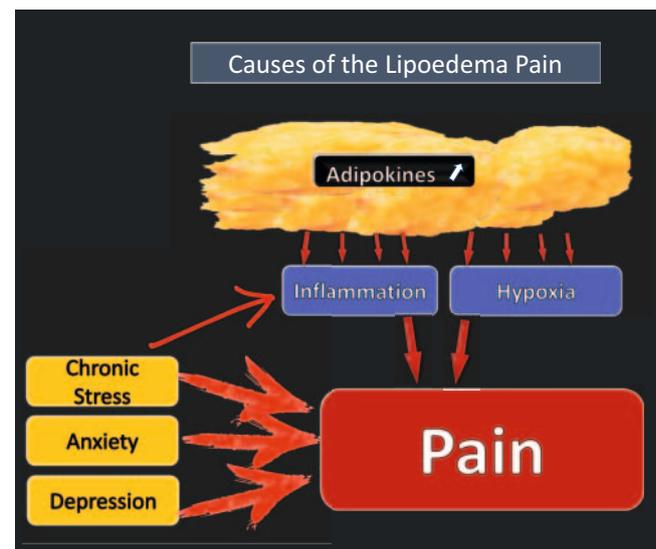
► **Fig. 3** adds the psychosocial factors to the somatic aspects shown in ► **Fig. 2**.



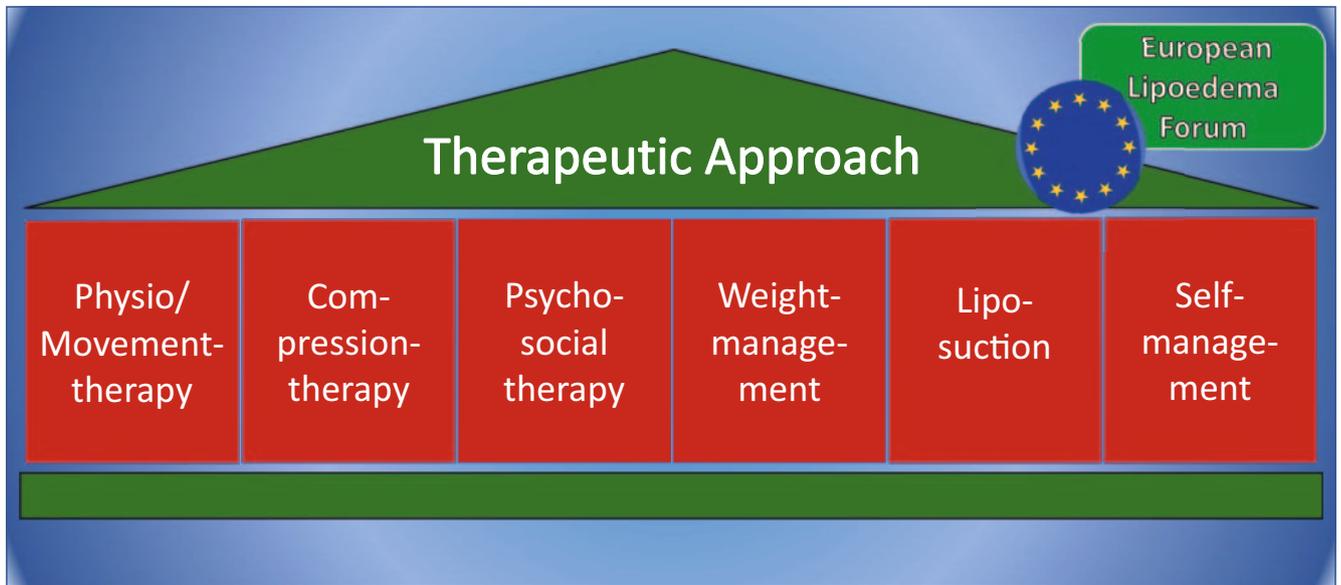
► **Fig. 1** Mechanisms of adipose tissue dysfunction and inflammation. Long-term increased energy intake and little physical activity lead to weight gain and an increased flow of nutrients into the adipose tissue. This increased supply causes hypertrophy of the fat cells with subsequent hypoxia in the adipose tissue, activation of stress signalling pathways, autophagia, apoptosis, and other mechanisms. These processes may also be potentiated by increased antigens from the intestines (leaky gut hypothesis) or the release of cell-free DNA. In turn, the adipose tissue secretes chemical attractants and endothelial adhesion molecules that bind integrins and chemokine receptors on monocytes and recruit them into the adipose tissue. Inflammation may then result. Source: Blüher M. Adipokine & klinische Bedeutung. Adipositas – Ursachen, Folgeerkrankungen, Therapie 2019; 13(01): 6–13. doi:10.1055/a-0804-6353.



► **Fig. 2** The increase in adipokines in the expanded fatty tissue leads to an inflammatory reaction (low grade inflammation) and hypoxia, which may cause mild pain.



► **Fig. 3** Effects of psychosocial factors on pain perception.



► Fig. 4 Main pillars of the therapeutic concept.

To summarise, and emphasise it again at this point, lipoedema is not a mental illness. Psychological factors do, however, play a key role in connection with the associated complaints. It is therefore extremely important for us to be open to the complex interactions between body and mind. This perspective makes it easier to develop effective long-term treatment strategies. Labelling, an additional stigmatisation that many patients with lipoedema have already experienced because of their disproportionality or their existing obesity, is very damaging to mental health, hinders effective therapy, and should therefore be avoided at all costs.

There are still some questions that need to be answered in the future:

Why do patients with lipoedema experience pain only in the subcutaneous fatty tissue of the limbs (usually the legs) and not in the subcutaneous fatty tissue over the abdomen or back? And why do treating physicians repeatedly see women with advanced disproportionate fat distribution who do not complain of pain (by definition, lipohypertrophy) and at the same time patients with less disproportionality but intense pain in this adipose tissue?

Treatment of lipoedema

The key element of the therapeutic concept was the question about the complaints of our lipoedema patients. This question alone represents a basic paradigm shift in our view of lipoedema. The traditional approach was focussing on an – scientifically untenable – “oedema” in lipoedema which is closely associated with “decongestion”. The crucial questions in the new treatment concept are as follows:

- “What do our patients with lipoedema really SUFFER from?”
- “What is the therapeutic goal from the patient’s point of view?”

Serious scientific data on the patient’s perspective do not exist. The questions were therefore answered from the extensive clinical experience of the experts participating in the European Lipoedema Forum, crystallising into the following key aspects:

Patients with lipoedema suffer to varying degrees of:

- pain/other symptoms in the soft tissues of the legs or arms
- greater psychological vulnerability, which may in turn potentiate the pain
- a lack of self-acceptance, mainly because of today’s ideal of beauty
- overweight or obesity with numerous attempts at dieting
- a lack of physical exercise and fitness, especially in obese patients

Starting from this constellation of suffering, the forum participants defined the main components of treatment (► Fig. 4). Interdisciplinary expert groups compiled the content of the individual therapeutic modules. The results of the working groups were then subjected to plenary sessions in order to reach agreement and allow a consensus statement.

Summaries of the reports from each working group are given in the following. We would like to comment on some national differences. For example, physiotherapists working in the Netherlands have greater responsibility and a wider scope of practice than is usual for those in Germany. It may therefore not be possible for all European countries to follow the consensus recommendations in an identical manner.

Physio- and movement therapy

Managing expectations

Prior to treatment it is of great importance to know the patients’ precise expectations and treatment goals, as well as their subjective illness beliefs.

If the patient's expectations or convictions are unrealistic or inappropriate, it is important that these will be discussed with the patient in order to avoid that the treatment is starting off on the wrong foot. Begin the conversation with a mutual exchange of expectations.

Health profile

Patients with lipoedema should receive a holistic assessment which does not just focus on the diagnostic and medical aspects of the disease but also takes the impact on daily functioning into account.

In order to establish this overall picture, you can draw up a patient health profile that includes data on (repeated) clinical measurements to provide a more objective personal history and identify specific individual needs. The International Classification of Functioning, Disability and Health (ICF) [29] may be a useful tool for establishing this health profile and determining a detailed picture of the patient's problems, abilities, and goals in all areas.

The ICF model offers a fundamental framework for determining human functioning and a classification system based on the biopsychosocial model [29, 30]. It consists of two parts (► Fig. 5): Part 1 describes functional ability and disability based on three components:

1. The physical body (body structures and functions)
2. Activities
3. Participation

Part 2 is concerned with specific contextual factors and has two components:

1. Environmental factors
2. Personal factors

All parts of the ICF model show interdependence.

In order to establish a comprehensive health profile, basic data should be recorded from each patient with lipoedema before they start treatment. The Dutch guidelines [31, 32] suggest measuring the circumference of the limbs, the body mass index (BMI), abdominal girth, and the Dutch standard of normal activity [33]. In addition, the European experts recommend recording the waist-to-height ratio (WHR) to determine the body fat distribution.

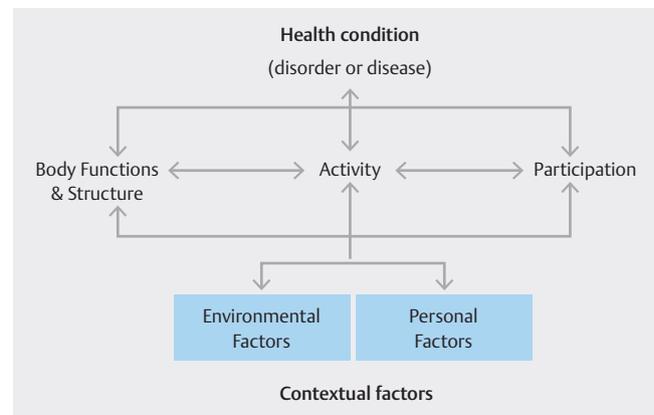
Depending on the individual patient's history, clinical assessment should be supplemented with additional tests and questionnaires e. g. on tiredness, pain, quality of life (QoL) and stress.

Use of the ICF in combination with clinimetric tools offers the possibility of establishing an individual health profile and drawing up an optimally personalised treatment plan.

This should lead to an improvement in function and quality of life [29, 30, 34, 35]. Monitoring the measurements at regular intervals allows us to analyse treatment progress and adapt the treatment plan as necessary.

Treatment

Physiotherapy focuses on reducing the subjective complaints and restrictions as well as preventing the condition from becoming worse. Each treatment session should consist of a selection of interventions that can be combined according to the patient's needs. Any unnecessary modules can be left out.



► Fig. 5 The ICF model.

1) Education

It is important for the patients to know and understand what lipoedema is and, perhaps even more importantly, what it isn't. It should also be made clear that lipoedema is a chronic disease that can be negatively impacted by increasing body weight and a lack of physical activity.

Patients should also be aware that it is their own responsibility to deal with the lipoedema, not only physically but also mentally. As the treating physician or therapist, it is important to realise that you can coach patients but not solve their problems. A step-by-step approach to behavioural changes (starting with realistic goals and slowly building upon them) and motivational interviewing may be beneficial in the treatment of patients with lipoedema. As with the self-management of lymphoedema, education at an early stage is crucial [36].

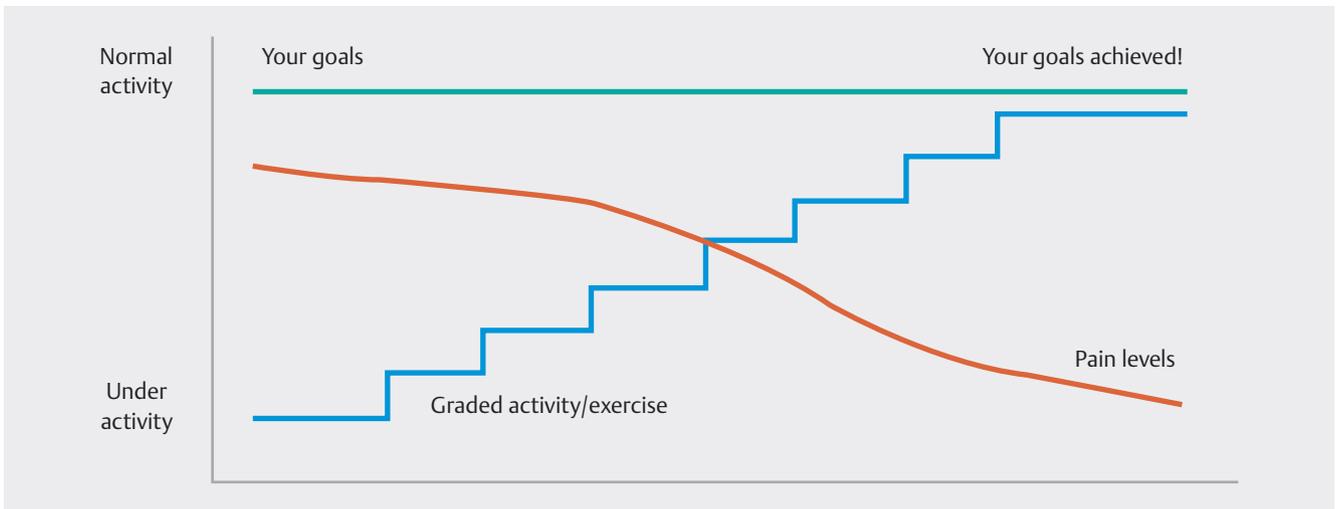
2) Optimising daily functioning and physical capacity

In many cases, patients with lipoedema have a lower level of activity as well as diminished physical capacity, including reduced muscle strength [37]. Graded Activity is a structured treatment that is based on cognitive behavioural therapy combined with physiologic principles of training. The goal of gradual increased activity is to augment everyday functional ability; the key training elements are building up muscle strength and aerobic exercises [38–40].

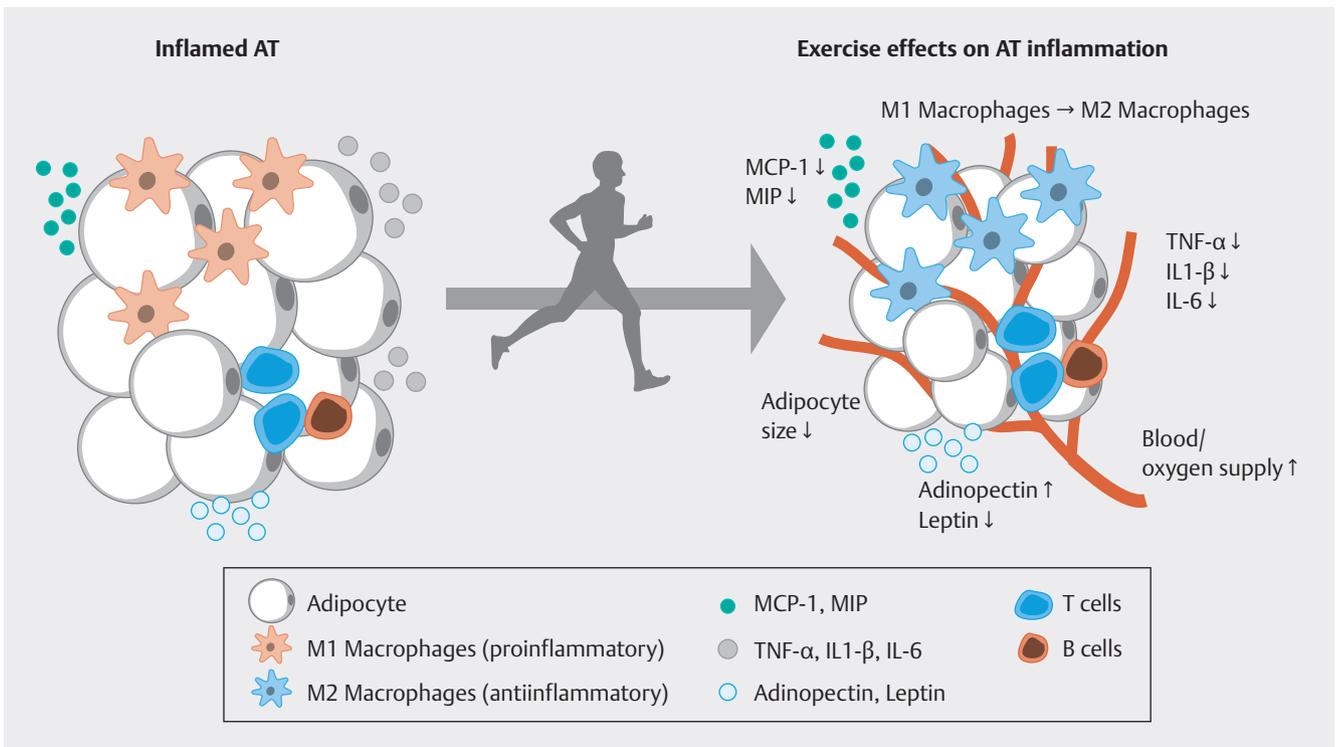
The programme starts by determining the baseline based on measurements of pain, activities of daily living (ADLs), physical performance and psychological status. It is incrementally increased, which ensures greater patient compliance [41]. The method aims to change behaviour in such a way as to increase the patient's level of activity irrespective of their complaints. Gradual increase in activity improves physical function without increasing pain levels. In a subgroup of patients, Graded Activity decreases pain levels in the long run [42] (► Fig. 6).

The key element of this programme is the setting of personal goals, which can be used as the base for determining patient-appropriate physical activities, always bearing in mind the necessity of a sustainable healthy lifestyle.

The importance of physical activity cannot be overstated. As mentioned previously, inflammatory processes in the adipose tis-



► **Fig. 6** Stepwise increase in physical activity.



► **Fig. 7** The effects of physical activity on inflammatory processes in adipose tissue.

sue are the most likely cause of the somatic base of the pain. It has recently been shown that regular physical training leads to a decrease in proinflammatory adipokines and macrophages [43]. In addition, physical exercise increases blood flow and thus counteracts the hypoxia in the adipose tissues [44].

Physical activity reduces the inflammatory processes in fatty tissue and contributes considerably to pain relief.

► **Fig. 7** illustrates the effects of physical activity on the inflammatory processes in adipose tissue that we mentioned above.

Exercise can, however, do even more. Physical training acts like a natural antidepressant [45]. This is of great relevance in patients with lipoedema, most of whom have an increased psychological vulnerability or suffer from chronic mental stress. Sporting activity in conjunction with basic psychotherapy is more effective in persons with a depressive tendency than a more sophisticated psychotherapy alone [46].

3) Manual lymphatic drainage

Manual lymphatic drainage (MLD) has no effect on the lipoedema itself, as it can only influence oedema and not the distribution of fat or the size of fat cells.

Lipoedema neither includes any relevant oedema nor impairs the lymphatic system [1, 120]. Furthermore, the efficacy of MLD has not been demonstrated in this condition [47, 48]. Perceived pain reduction through the application of MLD may be helpful in the initial stages of treatment. If so chosen, it is essential to combine this treatment with adequate information for the patient about the neuro-physiology of pain (as explained above). In addition this kind of therapy should be restricted to the maximum of one month because it is of greatest importance to preserve the patient from dependency on the therapist. The widespread and over years applied German practice of regular weekly MLD has no scientific basis whatsoever and therefore, from the medical and economical point of view, it is more than questionable.

4) Self-management

Following the chronic care model (CCM) [49], patients should be given a leading role in their treatment in order to achieve behavioural changes.

Self-efficacy, the extent of one's belief in one's own ability to complete tasks and to reach goals, is one of the pillars of self-management [50].

These relationships are described in depth in the section on "Self-management". As self-management is so important, the consensus considers it a mainstay of treatment in its own right.

Compression therapy

Compression therapy has always been and still is an important element of Best Practice in the treatment of patients with lipoedema. Nevertheless – and this point is crucial to our understanding – the change in the pathophysiological view of lipoedema presented above alters the indication for wearing compression stockings. The basis for prescribing compression therapy is no longer the fictitious "oedema in lipoedema" but rather the frequently demonstrated anti-inflammatory effect in the subcutaneous tissue. Currently, no data exist on the effects of compression in lipoedema. However, studies in phlebology and sports medicine have shown that compression has an impressive effect on the inflammatory processes in subcutaneous tissue [51, 52]. Confocal laser scanning microscopy has been used to show a significant reduction in pro-inflammatory cytokines and a simultaneous rise in anti-inflammatory mediators in the compressed tissue of patients with venous disease [53]. Ligi et al. highlighted these effects in their review entitled "Inflammation and compression: the state of art" [54]. Beidler et al. likewise demonstrated a decrease in proinflammatory cytokines and macrophages after four weeks' compression therapy in patients with chronic venous insufficiency [55]. Other studies have reported an improvement in the subcutaneous microcirculation from wearing compression stockings [56, 57]. One noteworthy study on healthy industrial workers and surgical nurses (who spend most of their working life on their feet, stand-

ing and walking) showed that wearing compression stockings resulted in a significant "reduction of oxidative stress", a finding that also points to improved microcirculation in the subcutaneous tissues [58].

All the studies that we know and have mentioned previously are concerned with compression of the legs in patients or healthy volunteers when standing or walking. There is much to be said for considering the positive effects of compression as synergistic with the effects of active movement (when standing or walking). Both these therapeutic options have an anti-inflammatory effect and both of them have a positive impact on the hypoxia factor. We therefore consider wearing compression sleeves on the arms (for lipoedema) to be less meaningful. We see the synergistic effects of compression and movement particularly with physical activity in water. So far, we have not come across a single patient with lipoedema who has said that her symptoms have not improved with swimming or water aerobics.

Consequently, the central importance of compression now lies in the reduction of pain and other symptoms due to inflammatory processes. It seems to us that getting this point across to the patient is a key task in doctor-patient communication.

In addition, discussions with the patient should emphasise the delusory nature of the much-cherished hope that compression will reduce the amount of fatty tissue. Nor does compression prevent an increase in fat in the legs if the patient puts on weight.

Depending on the clinical picture, custom-made circular-knit or flat-knit compression garments can be used. Flat knit is clearly to be preferred, not only because it is more comfortable to wear (and hence encourages compliance) but also because the Forum participants have observed that it is more effective. There is no alternative to flat-knit stockings in severely obese patients with lipoedema who have deep skin folds in their fat lobes.

Besides providing symptomatic relief, compression also supports the soft tissues, reduces the mechanical impairment of movement from skin lobes rubbing against each other, and improves mobility [47, 48].

The patient's acceptance of compression as a necessary tool to reduce the symptoms of lipoedema increases with appropriate patient education. Aesthetic criteria with respect to the quality, colour, and pattern of the material, as well as the contouring effects of the compression can also increase patient compliance.

The extent of the lipoedema in the individual case determines whether compression pantyhose, leggings, Capri length compression garments or below knee stockings are required and which compression class is necessary; the decision is always personalised accordingly. The success of compression therapy in the treatment of lipoedema can be established with appropriate tools for measuring biometric, psychological, and social parameters.

Psychosocial therapy

Introductory remarks

The crucial question to ask is: What do women with lipoedema really suffer from? If we keep the relevant problems and symptoms in focus, we can identify those patients who are suffering

from severe mental stress. This is particularly relevant for patients with lipoedema, as mental health issues and pain perception are closely related [59].

The treatment options and supportive services are as many and varied as the psychosocial problems of our patients with lipoedema. The one psychosocial or psychotherapeutic option to fit all patients therefore does not exist. But there are general factors that significantly affect all patients, including those with lipoedema. And, at the same time, there are “lipoedema-specific” issues that can be found in the great majority of patients with this condition.

Nearly all of our patients with lipoedema express difficulties in accepting their own bodies, especially the shape of their legs. In this respect, the media has an enormous influence on self-perception. The greater a woman’s media consumption (a media consumption that almost exclusively promotes a slim, long-legged beauty ideal), the greater her dissatisfaction with her own appearance and the more she craves a slim body [60]. The beauty ideal amongst teenage and young adult women is already far below the normal weight for their own age groups [61]. But the media suggest that this ideal can be achieved. And this achievability puts pressure particularly on those girls and women who think that they have to conform to this ideal and may set off a vicious circle of dieting and subsequent weight gain. Furthermore, psychological assessments at the Foeldi Clinic found a clearly higher proportion of patients with lipoedema who reported physical or sexual abuse in comparison with the general population [62], and these experiences also impact body awareness and increase the risk of chronic pain [63].

The consensus discussions also identified other problem areas in our patients with lipoedema, in particular a diminished feeling of self-esteem, difficulties in coping with stress and, of course, the typical lipoedema pain whose perception depends so greatly on the patient’s mental health.

Diagnostic screening

But how can we identify patients with lipoedema who need psychotherapy or other psychosocial services? Since it is usually difficult to make an appointment for psychological assessment quickly, apart from exceptional cases, the European Lipoedema Forum consensus proposed the use of questionnaires to encompass the most important psychological symptoms. All healthcare professionals should be able to use these questionnaires to screen for the most common mental health issues or problem areas in patients with lipoedema. If the scores are remarkable, the patient should be referred to a licensed psychotherapist or counselling service for a psychological evaluation. Further treatment can be planned and the necessary services initiated.

Until such time when a validated lipoedema-specific questionnaire becomes available, questionnaires that have already been validated and proved their worth in both clinical practice and research should be used. ► **Table 1** in the Annexe gives an overview and proposes appropriate tools.

Screening does not, of course, replace a full mental health assessment. However, the use of screening questionnaire provides the outpatient physician with an indication of which patients

with lipoedema must definitely be referred for further psychological assessment. A comprehensive view of the patient’s symptoms is essential, especially when the pain intensity score is high.

Therapeutic approach

Empathy

Taking all the therapeutic options into account, the relationship between the patient and the treating physician or therapist has an important impact. The ideal relationship is based on empathy and an understanding of what the patient is going through; it acknowledges the burden of suffering felt by the patient but also strengthens the patient’s resources to cope [64].

Education

Information and education on how pain develops in lipoedema may start to modulate the patient’s perception of pain. There is evidence that education on the neuronal basis of pain has a positive effect in various types of pain [65–67]. When patients attribute severe pain entirely to severe tissue damage, they will be more likely to try to protect themselves and possibly be even more sensitive to pain. A comprehensive understanding of pain, seeing it also as a dysregulated reaction or an overreaction of the stress system, allows patients with lipoedema to develop further strategies for pain relief by relieving stress; they can then employ these strategies themselves.

Psychotherapy

If anxiety, depression or severe psychological distress can be lessened by psychotherapeutic intervention, it has a positive effect in reducing pain [68, 79].

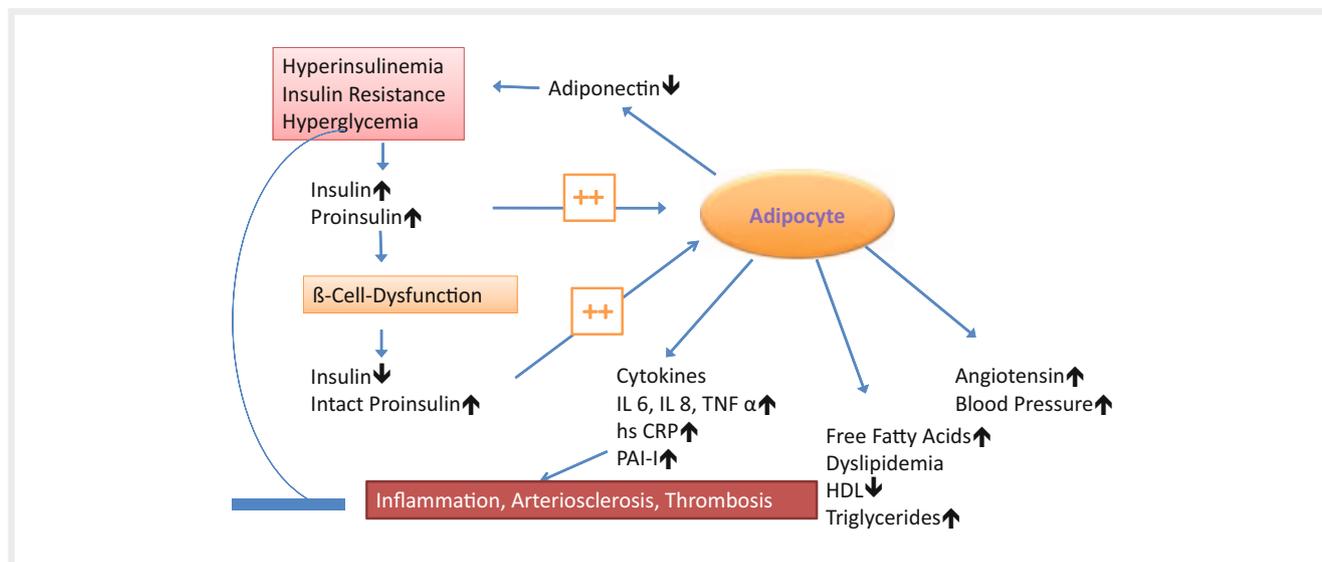
Non-disorder-specific interventions include mindfulness techniques or acceptance and commitment therapy (ACT), based on mindfulness, which improve mental well-being and increase psychological flexibility.

According to the German Association for Psychiatry, Psychotherapy and Psychosomatics treatment guideline, evidence-based disorder-specific psychotherapy may be used when there is a psychological disorder such as depression, an eating disorder or an anxiety state [70].

Additional procedures: Psychotherapy in patients with lipoedema seems to reduce pain more effectively when used in combination with physically oriented techniques such as embodiment-focused procedures. This may be attributed to a calming effect on the stress system taking place in addition to the effect of the words at the neuronal level. Under the new ICD-11 terminology, much of the psychological vulnerability found in patients with lipoedema can be described as a stress-related disorder [64]. However, this initial experience needs to be reinforced by the results of research.

Self-help groups

Experiencing self-efficacy and optimism as well as social support – from positive like-minded people in a self-help group – increases resilience. According to a review article by Faerber and Rosendahl, well-developed resilience (i. e. the psychological power of resist-



► Fig. 8 Metabolism of adipose tissue expansion.

ance) is associated with better mental health in people with physical health problems [71]. This aspect is addressed in greater depth in the section of “Self-management”.

Weight management

Obesity is often progressive, usually not lipoedema. If obesity is progressive, lipoedema can get worse. In tertiary referral centres, 80–88% of patients with lipoedema are obese [72–74]. In order to treat lipoedema effectively, obesity therefore must be focused on. Weight management therefore plays a major role in the treatment concept. The recommendation for conservative management or additional surgical treatment depends on the patient's weight and the patient's wishes. Nevertheless, the basic precepts of conservative treatment (weight management) must still be followed after surgery.

Recommended conservative approach

There has also been a change in perspective regarding weight management. The European Lipoedema Forum consensus does not put weight loss per se as the first concern for the moderately obese patient. Instead, both therapist and patient should focus on achieving a state of well-being and fitness.

Weight management is absolutely mandatory whenever severe obesity-related disease already exists or threatens to develop.

The European expert panel has drafted a nutritional medicine concept:

1. Short-term diets must be avoided by all means. They almost always fail and often result in a yo-yo effect [75–83]. Instead, patients should be educated as soon as possible on how to change their eating habits towards an individually appropriate and adapted healthy diet that they can follow for the rest of their lives.

2. The concept of energy balance has to be accepted. This must not imply mere calorie counting since it is by now evident that the

different nutrients have different metabolic effects – “a calorie is not a calorie” [84]. Instead, emphasis must be put on intake and expenditure of energy.

3. Patients should be informed about the pro- and anti-inflammatory effects of their dietary habits and food choices. In this context the reduction of hyperinsulinemia and the reduction of insulin resistance, which is present in most cases with additional visceral obesity, is of great importance for lipoedema patients. Hyperinsulinemia and insulin resistance are associated with visceral obesity but are also extremely important for patients with lipoedema [85]. Hyperinsulinemia is the main cause of chronic inflammation; the vicious circle of obesity and gradually increasing hyperinsulinemia leads to a further increase in adipose tissue [86, 87].

The following graph by G. Faerber illustrates the complex relationships (► Fig. 8).

The following measures to reduce hyperinsulinemia should be recommended:

- Sufficiently long intervals between meals. Recommended are four to six hours during daytime, and at least twelve hours during the night [90–92]
- Strict avoidance of constant “grazing” (many small meals spread throughout the day), especially eating sweets and other snacks that raise blood glucose levels.
- Reduction of foods containing refined carbohydrates or sugar. The fewer of refined carbs consumed the better [85, 93, 94].
- Preference for “real food” instead of processed foods.
- Consumption of healthy fats (olive oil, wild oily caught fish, pasture raised meat and milk products and avoidance of industrial trans-fats) [95–97].

4. For long term weight stabilisation support and coaching are mandatory during and after nutrition therapy in order to prevent relapses [98].

Recommended surgical approach

1. Bariatric surgery is recommended for patients with lipoedema and a BMI of $\geq 40 \text{ kg/m}^2$.
2. Bariatric surgery may be considered for patients with lipoedema and a BMI of $35\text{--}40 \text{ kg/m}^2$.

It has been shown that bariatric surgery is the most effective treatment for losing weight. A comprehensive meta-analysis with 25 prospective studies showed significantly better weight loss after surgical procedures, irrespective of the type of operation, the duration of follow-up care or the severity of the obesity [99]. The BMI threshold for recommending obesity surgery is based on historical developments and is in line with the European and American interdisciplinary guidelines for bariatric surgery [100, 101]. Preoperative examination and preparation for bariatric surgery should be carried out in accordance with the European guidelines [100]. The bariatric surgery itself should also be carried out within the framework of this interdisciplinary guideline. When patients have a BMI of $35\text{--}40 \text{ kg/m}^2$, the WHtR should also be taken into consideration to identify overproportional fat distribution in patients with lipoedema. Patients with lipoedema and a WHtR < 0.5 probably do not have a metabolic risk, so that bariatric surgery is not absolutely necessary [102].

Liposuction

As mentioned earlier, the Federal Joint Committee (G-BA) in Germany considers that liposuction has the potential to be an alternative treatment option for lipoedema. On the basis of the available scientific findings, however, the G-BA does not consider that it is yet possible to make a definitive decision on whether the statutory health insurance should bear the costs of this operation [103]. This stance has also been largely confirmed by the Federal Social Court in Germany [104]. Nevertheless, as explained above, the G-BA followed the wishes of the German Minister of Health. In Germany patients with lipoedema in “so-called stage 3” may be treated by liposuction at the expense of the health insurance.

In the view of the European Lipoedema Forum experts, the benefits of liposuction depend strongly on a clearly defined patient selection. Not every patient with lipoedema would benefit from liposuction. In order for patients to really benefit from this procedure, the participants agreed on the following criteria.

Liposuction may be considered in patients with lipoedema if:

1. The symptoms persist despite at least 12 months of conservative treatment as presented above
2. The patient has considerable functional disabilities (e. g. restricted mobility)
3. The patient’s weight has been stable for at least 12 months. This reduces the risk of the effects of liposuction being cancelled out by postoperative weight gain (or by a yo-yo effect after weight loss) [5].
4. A preoperative psychological assessment is available. This assessment should rule out any eating disorders or relevant mental health issues that might stand in the way of sustained treatment success.

Liposuction is not a treatment option in patients with a BMI $> 35 \text{ kg/m}^2$ and simultaneous central obesity (WHtR > 0.5). If there is no central obesity, liposuction can also be carried out in patients with a higher BMI – although this constellation occurs extremely rarely.

A Lipoedema/Liposuction Task Force comprising members of the executive committee of the German Society of Phlebology (DGP) and the German Society of Lymphology (DGL) has issued a statement to the G-BA, in which they include criteria that should be met by physicians treating lipoedema. According to this Task Force, the diagnosis of lipoedema (and lipolymphoedema) is frequently found to be a mistaken diagnosis on referral. For this reason, the physician referring patients for liposuction should also have an additional lymphology or phlebology qualification. A further statement from the Task Force says “If the doctors who have been treating the patient for six months do not have such qualifications, the diagnosis should be confirmed by an appropriately qualified physician who does not himself/herself perform liposuction” [105].

It is obvious that clear requirements on the qualification of surgeons also have to be formulated. To ensure the necessary quality standards, we propose specialist certification for doctors performing liposuction, similar to that which in Germany already exists for bariatric surgeons [106]. Patients will then have the possibility of finding a surgeon who meets the defined quality criteria.

Self-management

Successful self-management is necessary for patients with lipoedema to reduce their symptoms in the long term. The available studies on self-management are very consistent: good self-management improves the state of health, everyday functioning, and the quality of life in patients with chronic diseases [107, 108]. We now regularly see patients with lipoedema who have achieved a considerable long-term reduction in their symptoms with successful strategies to improve their self-esteem, and some even describe themselves as symptom-free.

As experts, we have high expectations of our patients with lipoedema – old and relatively unhealthy habits should be relinquished as soon as possible and replaced by new healthier self-management strategies. Following the chronic care model (CCM), patients should be given a leading role in this treatment concept [49, 109].

Nevertheless, the feasibility of establishing new habits is overestimated. Old habits die hard and change has nothing to do with a low IQ or “laziness” but depends on the basic principles of motivation, the “Maths of Motivation” so to speak.

Neurobiology offers a basic insight as to why people adhere to unhealthy habits: unfavourable behaviour often reduces stress quickly and easily. From the neurobiological aspect, binge eating can be viewed as a coping method for frustration which lowers stress levels in the short term [110] – and which the brain interprets as a reward.

When we tell our patients about these relations, they are likely to offer confirmation: “Yes, stress eating makes me feel better in the short term, but it hardly helps in the long run, does it!”. In mo-

tivational interviews, the patients themselves start to talk about the disadvantages of their old automatic behaviour and/or the advantages of the new favourable healthier behaviour [111, 112].

Many treatment models wrongly assume that imparting information and education alone are sufficient for patients to change their patterns of behaviour. As practitioners, however, we have found that even the most excellent advice often has hardly any effect in changing behaviour. When we give our patients direct advice, they are most likely to reply in a “Yes, but...” mode and explain why they themselves are unable to change things. This even tends to reinforce their old habits. The more we, as treating physicians or therapists, show empathy [113] and the less we (knowingly or unconsciously) comment on behaviour that produces guilt or shame, or the less we try to shock the patient into changing (“If you go on like this, you’ll be dead within five years.”), the more the patient can get involved with the new approach [114].

Patients often fail to meet their own demands. If they do not reach a set goal (e. g. more physical activity with compression therapy three times a week) they often give up totally.

Studies have shown, however, that if you deviate from the new habit on a single day, it has no measurable influence on your long-term success. It depends on the average speed, not the top speed. Our advice has more effect when we use the inclusive “we” and treat our patients on equal footing. We can therefore say “None of us eats only healthy meals every single day, and that really isn’t a problem. But studies have shown that it isn’t a good idea for us to fail in our good intentions twice in one day. If we eat a healthy meal after having an unhealthy one, we’re back on track. We don’t have to be perfect. Good enough is good enough.”

And similarly, with respect to physical activity “None of us takes enough exercise every day...” [111].

Not having to feel ashamed or guilty if something does not immediately go according to plan unburdens the patient, reduces stress, and increases the likelihood of establishing new healthier habits.

The “Maths of Motivation”

Motivation is an essential ingredient for changing behaviour. Any amount of knowledge multiplied by zero motivation will not change a thing. We can also look at this as a motivational matrix: motivation = importance (of the goal) × self-efficacy (belief in one’s own ability to achieve the goal), as shown in ► Fig. 9.

Take a patient with lipoedema who is hardly moving about on a daily basis due to her complaints. Allow her to rate each self-management strategy that she should use (in this case regular physical exercise under compression) on a scale of 0 to 10:

- How important is it for you to use the self-management strategy of X in your everyday life (e. g. on a scale of 0 to 10, how important is it for you to exercise with compression for half-an-hour, three times a week from now on)? and
- How much do you trust your own ability to carry out this strategy (e. g. how do you estimate the chances of your being able to exercise for half an hour, three times a week? And what sort of exercise would you enjoy the most)?



► Fig. 9 The “Maths of Motivation”.

If the goal is important to the patient, and she is sure that she can achieve it, then she is already highly motivated (green area). If the patient’s score lands in the other three fields, then we need to use motivational interviewing.

If a patient says that her goal is not important – even though it is greatly relevant to her health – and rates it, for example, as 3 out of 10, our instinct is to ask “Why only a three? I’ve told you about the advantages of X several times!” Instead of why, we can ask in a more motivational manner, “What (already) makes it a three?” Then she will think about it and explain why – she is now called upon to be the expert. The patient now does the work, not the treating physician or therapist. And then we can ask, “What do you need to make it a four or a five?” (Give her enough time to think it over). “Is there anyone who could help you in any way?” [111], “Would you like me to tell you what I know about X?”. Wait until she answers in the affirmative. Don’t give any unsolicited information but allow the patient to make active requests. Studies have shown that the effects of such motivational interviews last for a long time after the end of treatment [112].

In summary, the best way for us to support our patients with lipoedema is to help them develop new self-management strategies by meeting them on an equal footing – as experts on themselves.

Final comments

Exactly two years have passed since part 1 of the article series on the myths and facts of lipoedema appeared. The resulting and urgently needed paradigm shift in lipoedema has been gaining ever greater acceptance since then. Originating from the largest lymphology clinic worldwide, the Foeldi Clinic [115], large sections of the executive committees of the professional associations in Germany “responsible” for lipoedema have adopted this altered perspective. The previously mentioned Lipoedema/Liposuction Task Force with committee members from the German Society of Phlebology (DGP) and the German Society of Lymphology (DGL) has issued the Statement: “The view that lipoedema includes oedema has been abandoned” [105]. Many members of the executive committee of the Society of German-speaking Lym-

phologists (GDL) and of the DGL have actively been involved in the European Lipoedema Forum and promoted the altered perspective on this affliction.

The European Lipoedema Forum, with 25 renowned experts from seven European countries, has developed the “European Best Practice of Lipoedema” outlined here and thus also supports the overdue paradigm shift in lipoedema. After reading the Consensus, numerous other national and international experts and opinion leaders have also pledged their support for the change of perspective in lipoedema e.g. Dr. M. Oberlin, General Secretary of the Society of German-Speaking Lymphologists and Prof. L. Perbeck, President of the Swedish Society (Svensk Förening för Lymfologi, SFL). Prof. H. Brorson, former President of the International Society of Lymphology (ISL), and also a board member of the Swedish Society (SFL) is certainly one of the internationally most experienced and well-known surgeons for liposuction. In a letter to the lead author, Prof. Brorson expressly supports the paradigm shift and supports the consensus. Leading Belgian lymphologists like Prof. N. Devoogdt, board member of the Belgian society (OEDEMA.BE) and Dr. S. Thomis, head of the lymphoedema centre Leuven are backing the consensus and will be part of the European expert group. Together with the colleagues from Sweden the European Lipoedema Forum now consist of experts from 9 European countries. Lymphological societies and national lymphoedema schools from other countries such as Sweden or Australia have linked the series of articles on the myths and facts of lipoedema to their websites and draw attention to it in newsletters [116, 117]. Guenter Klose, founder and CEO of Klose Training in Denver/Colorado, one of the largest and most renowned training institutes for lymphoedema therapy in the world, also is greeting the new perspective on lipoedema and will integrate the new treatment concept into its training catalogue. Thereby it is hoped that the new way of seeing and treating lipoedema will also become established in the USA. So far, the topic has been dominated exclusively by financially strong patient organizations. Last but not least – at the Congress of the German Society of Phlebology (DPG) in September 2020 in Leipzig and four weeks later at the World Lymphology Congress (International Lymphoedema Framework, ILF) in Copenhagen, the paradigm shift of lipoedema will be one of the central issues [118].

As always when things change, there is resistance to the changes. In a notable article published in *LymphForsch* in June 2019, the chairman of the professional association of lymphologists in Germany acknowledged the effects of obesity on lipoedema. Since the nineties, he has held “the notion that, in the long run, lipoedema and lipohypertrophy are primarily a problem of weight” [119]. The great influence of psychological vulnerability is also not contested in this *LymphForsch* article and lipoedema is “without doubt a psychosomatic illness” [119].

But at the same time, the author is vehement in his response to the first four parts of the present series, insisting that “Lipoedema is a condition regularly accompanied by oedema” [119]. This apodictic statement not only conflicts with the European Lipoedema Forum experts’ consensus but also with the Task Force of phlebologists and lymphologists, which has established that “Neither clinical examinations nor imaging procedures such as CT, MRI or high-resolution soft tissue ultrasonography have provided any evidence of oedema in “pure lipoedema” within the past decades. In

addition, histological examinations have never found a relevant “accumulation of fluid” in the adipose tissue” [105]. The chairman of the professional association ignores these facts and bases his divergent view on personal experience with ultrasound scanning, in which “apart from isolated exceptions”, he has “always” found oedema in “women with a regional increase in adipose tissue” [119]. This personal experience of the *LymphForsch* author has, however, never been published and therefore cannot be verified! A recent multicentre registry study published in 2018 by Hirsch and co-workers stands in clear opposition to this personal ultrasound experience. This article, which is well-worth reading, concerns high resolution ultrasonography in lipoedema and the authors conclude from their findings that “The accumulation of fluid could not be detected in patients with “painful lipohypertrophy”, which means that the designation of lipoedema for this condition is misleading and should be reconsidered” [120].

In line with his traditional take on lipoedema, “freedom from oedema” is one of the treatment goals of the chair of the professional association. He therefore considers MLD to be as equally important as the other components of complete decongestive therapy (CDT).

This indifference to scientific facts is also reflected in his personal approach to obesity surgery: bariatric medicine “is the declaration of surrender of nutritional medicine” [119], and furthermore, “Weight loss is achieved at the expense of mutilation of the digestive tract, an enforced lifelong alteration of dietary habits, and even unappeasable hunger” [119]. Greater misinformation on the subject is hardly conceivable. This declaration by the *LymphForsch* author is not only factually incorrect, it also contradicts the consistent findings of the available studies mentioned previously – studies that show a rare unanimity in the largely sustainable success of this therapeutic option [99, but also 121–129]. The chairman of the lymphologists’ association also ignores the experience gathered since 2007 by colleagues at the Foeldi Clinic (doctors, therapists, nurses and psychologists) working with patients who have undergone bariatric surgery. For 12 years, this specialist clinic has offered a surgical procedure to numerous patients with a BMI > 40 kg/m² as part of its multimodal obesity programme. After a bariatric surgery, patients with lipoedema experience considerable relief of the typical complaints (many even say they are symptom-free), improved mobility, an improvement in other obesity-related diseases and, last but not least, often a dramatic improvement in their quality of life. These findings are currently being evaluated as part of a doctoral dissertation at the University Hospital Freiburg, Germany. We already have the preliminary (confirmatory) results, which will be presented at the German Lymphology Congress 2019 in Bad Krozingen [4].

Ultimately, however, this adherence to “the old lore” must also be understood as concern, as concern about change, as concern that the established doctrines of many decades are suddenly proving to be wrong. It is always painful to question your own beliefs and position. It is also associated with a fear of loss: a loss of acquired expertise, a loss of familiar certitude, a loss of control.

Patients who have lipoedema face a completely different concern when confronted with this change in the perspective of their disease. At a time when people are stigmatised and discriminated against because of being overweight or because of the shape of

their legs, it is easier to believe that a medical condition is responsible for all the past adversity. Instead, it would be more helpful to look into the complex background of lipoedema. Only at first glance is it easier to believe in the “accumulation of fluid in the body”, in an “oedema”, and receive MLD sessions rather than undergo regular enforced physical activity under compression. Only at first glance is it easier to have fat removed from the legs by liposuction than to deal with one’s own – biographically founded – psychological vulnerability or problems of self-acceptance.

But even so, we are now seeing patients with lipoedema who are changing their way of thinking – away from the passive attitude of being a “victim” – to an active, positive and self-aware approach to the condition, and hence to themselves. Natalie Stark and her lipoedema podcast [130] and Isabel Garcia with her courageous book “Lipödem – ich bin mehr als meine Beine” [Lipoedema – I am more than just my legs] [131] serve as good examples of a differentiated approach to their own medical conditions.

Conclusions

In our opinion, there is no alternative to the paradigm shift in lipoedema! The view is progressively gaining acceptance on both a national and an international level.

Our hope is that the opportunities inherent in this paradigm shift will be seen more and more, despite the concerns of some treating physicians and patients. The change in perspective on lipoedema that we have described in this article brings the patient’s real symptoms to the forefront. This focus allows more comprehensive and therefore better and more sustainable treatment than focusing on non-existent oedema and its decongestion.

Physicians and therapists treating outpatients with lipoedema should gain an idea of the direction in which to guide and accompany their patients from the treatment strategy presented above. As experts in compression therapy, physical activity, and fitness, physiotherapists have a major role in our treatment concept.

For specialist lymphology clinics, this paradigm shift means a significant change from their previous therapeutic approach. If they have been treating patients with lipoedema virtually in the same way as patients with lymphoedema, using CDT, the new perspective requires clearly more differentiated treatment. The European Center of Lymphology, the Foeldi Clinic in Hinterzarten, has therefore radically altered its treatment concept for patients with lipoedema and adapted it to the patient’s individual symptoms [115]. Nevertheless – and this also needs to be emphasised – many of the patients referred to the specialist clinic with a diagnosis of lipoedema also suffer from two further diseases in need of treatment: obesity and obesity-related lymphoedema. Treatment of the obesity and CDT are, of course, still the mainstays of treatment for these two conditions – but they are by no means enough to treat the complex disease of lipoedema adequately.

Our greatest desire is to make this absolutely clear!

Conflicts of interest

The European Lipoedema Forum was sponsored by Essity, but the authors declare that they do not have any associated conflicts of interest.

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