

Der Lipödemschmerz, seine Folgen auf die Lebensqualität betroffener Patientinnen – Ergebnisse einer Patientenbefragung mittels Schmerzfragebogen

Pain in lipoedema, fat in lipoedema and its consequences: results of a patient survey based on a pain questionnaire

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ZUSAMMENFASSUNG

Bei 640 Patientinnen einer Fachklinik für operative Lymphologie erfolgte mittels Fragebogen der Deutschen Schmerzgesellschaft e. V. eine Befragung. Neben Fragen zum Schmerz und zur Schmerzcharakteristik wurden gleichzeitig noch demographische Daten miterhoben. Es ergab sich, dass nur bei etwas über 50 % eine echte Adipositas nachgewiesen werden konnte. Lipödem und Adipositas müssen als unabhängige Krankheitsbilder gewertet werden. Der Schmerz wurde überwiegend als

drückend und ziehend empfunden. Attribute wie klopfend oder pochend, passend zu einer akuten Entzündung, erfuhr die Wertung „nichtzutreffend“. Die Beschwerdesymptomatik war unabhängig vom BMI, der bei der Lipohyperplasie dolorosa nur bedingt verwertbar ist. Insgesamt ist das Leitsymptom „Schmerz“ sehr facettenreich, das angeborene, nicht erworbene Lipödempett der Extremitäten führt zu einer deutlichen Beeinträchtigung der Aktivitäten allgemein, als auch im Freizeitbereich. Die durch den GBA initiierte Studie muss daher kritisch gesehen werden. Da bislang keine objektivierbaren Befunde beim Lipödem erhoben werden können, ist eine subtile Befragung betroffener Patientinnen zur Diagnosestellung notwendig.

ABSTRACT

640 patients from a specialist clinic for operative lymphology were surveyed with the help by a questionnaire issued by the German Society of Pain Therapy (Deutsche Schmerzgesellschaft e. V.). This survey collected responses to questions about pain and pain characteristics as well as demographic data. It revealed that only a little more than 50 % of respondents were genuine cases of obesity. Lipoedema and obesity must therefore be regarded as clinical pictures unrelated to one another. The pain was mostly described as pressing and tearing in nature. Attributes such as throbbing or pulsing, consistent with acute inflammation, were rated as “not applicable”. Symptoms were independent of the BMI, which is only useable to a limited extent in lipohyperplasia dolorosa. On the whole, the main symptom “pain” is multi-faceted. The study initiated by the German Federal Joint Committee (G-BA) must therefore be viewed critically. Congenital (as opposed to acquired) lipoedema fat on the extremities significantly impairs a person’s ability to undertake activities in general as well as leisure activities. Since no objectively verifiable findings in lipoedema can be ascertained thus far, the diagnosis should be based on a careful patient survey.

Introduction

Lipedema is a chronic, progressive disease occurring almost exclusively in women and is caused by aberrant fat distribution resulting in significant disproportion between the mid/ upper body and the extremities [1].

This condition was first described by Allen and Hines in 1940 [2]. Initially given little attention, it was only in the 1990s that doctors and patients started focusing on it [3]. Although the manifestation of this disease is multifaceted, it can be characterized by the following criteria (► Tab. 1):

Despite increased research, there still exists to date many unverified information on the cause and objective diagnostic findings about lipedema [4]. Even in more recent literature, it is still difficult to find reliable information on its pathophysiology and diagnosis [5, 6, 7]. This is especially true for stages I and II, where examination of patients using ultrasound, and visualization of lymphatic vessel by dye injection and infrared light prove too unspecific for diagnosis. Even regular functional lymphoscintigrams just depict a well-functioning orthologous lymphatic system. Quantitative measurements of lymph flow indicate high volume transport [8]. This led to the derivation of the term "high volume transport insufficiency", described by Marsch and Cornely as the basic pathophysiological process leading to lipohyperplasia dolorosa [9], another name for lipedema [10, 11, 12]. Cornely later coined the term "March'en theory". However, the diagnosis of lipedema still primarily depends on its clinical appearance. One of the characteristic symptoms of this disease is pain. Using a self-created questionnaire, Schmeller and Meier-Vollrath [13] investigated the characteristics of pain in lipedema in 2008. In this investigation, 50 patients with lipedema in stage II were treated. The pain was primarily described as dull and pressing. In a variety of publications, efforts were made to characterize the pain, as well as to determine the cause of pain in lipedema. An overview of the literature on this topic was published by Brenner in 2017 [14]. He concluded that neither a description nor an explanation for the pain was possible. The characterization of pain in lipedema patients could also not be undertaken.

Despite the existing uncertainty on characterizing pain in lipedema, the Joint Federal Committee of the Statutory Health Insurance Funds (GBA) has decided that one of the ultimate criteria for deciding whether surgery would be a valid option for treating lipedema, would be its influence on pain in patients. This is with regards to its resolution to temporarily cover costs [15] in conjunction with a multicenter study assessing the surgical treatment of lipedema which was decided on in 2017. The directive for conducting the study [16] was passed by the GBA in January 2018. This resolution was then confirmed by the Federal Ministry of Health in April 2018 [16]. In this resolution, guidance on disease symptoms are described, and includes symptoms stated in the

► **Tab. 1** Diagnostic criteria, modified based on the S1 guideline of the AWMF [3].

Beginning with puberty, pregnancy, or menopause

Familial clustering/aggregation
Symmetrical changes
Disproportionate increase of adipose tissue (extremities>trunk)
„Inverse shouldering“ in joint regions
Heaviness and swelling of affected extremities
Spontaneous pain or upon palpation – increase during the course of the day
Tendency to bruise
Symptom-free hands and feet, negative Stemmer's sign

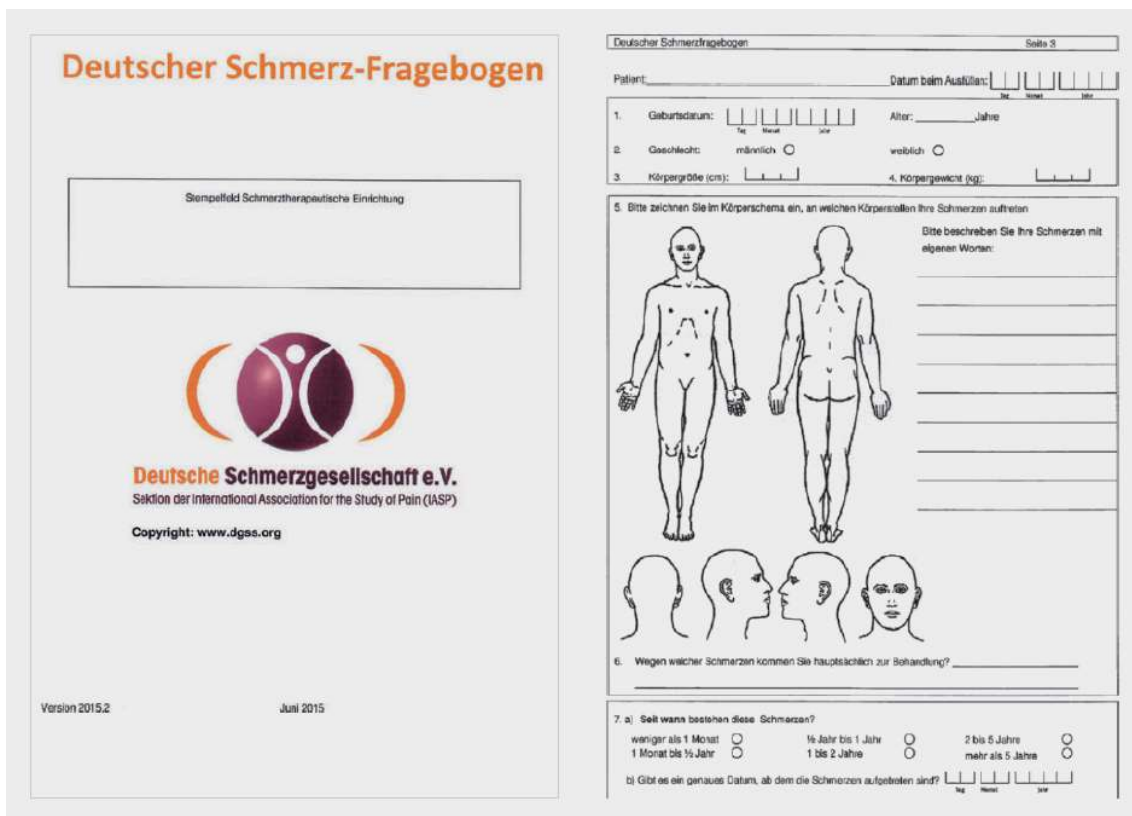
ICD-codes E88.20 - 22, which has been available since 2017. The endpoint for the investigation should be the symptom of "pain".

Quote from the G-BA trial The aim of the trial is to accurately assess the potential advantages and disadvantages of liposuction compared to complex decongestive therapy (CDT). On the other hand, the aim of treating lipedema is to reduce impairments due to the symptoms of the disease. Analogous to the main symptoms of lipedema reported in previous studies, pain was selected as the primary end point [16].

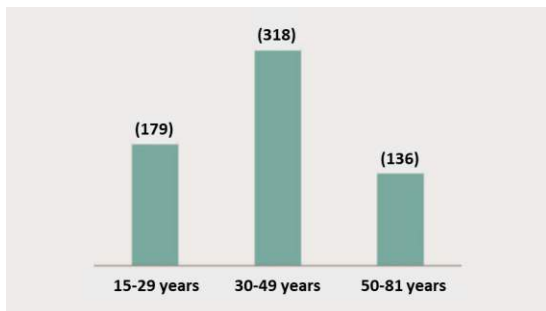
The aim of the present study was not only to characterize pain more precisely, but also to investigate how symptoms interferes with a patient's life, from everyday life up to the ability to work.

Methodology/Patients

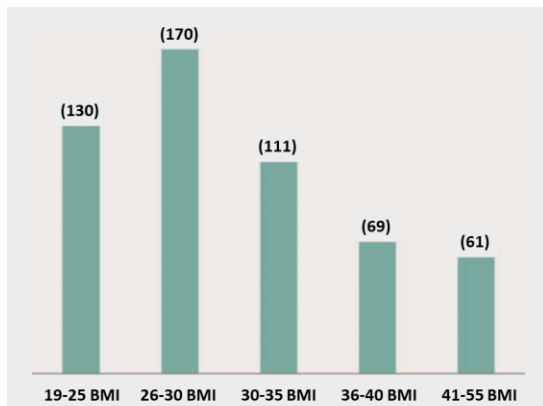
From January to July 2017, clinic patients suspected of suffering from lipedema were requested to complete the long version of the pain questionnaire (DSF) [17] provided by the German Pain Society. Details of the pain questionnaire are described in a publication by the German Pain Society which can be found online at <https://www.dgss.org/schmerzfragebogen/> (► Fig. 1). All investigations were performed exclusively by the author and co-author. It should be noted that only questionnaires for patients confirmed with the diagnosis of lipedema were evaluated for this publication. However, it was not taken into consideration whether patients were already undergoing conservative treatment or intended to undergo surgical therapy. Both conservative and surgical treatment are provided at our clinic. This study also did not take into account the type of follow-up therapy administered. The evaluation was carried out using software from Akkaya Consulting. A total of 640 questionnaires were evaluated



► Fig. 1 Questionnaire cover sheet, exemplary page 3 of 14.



► Fig. 2 Categorization of patients by age.



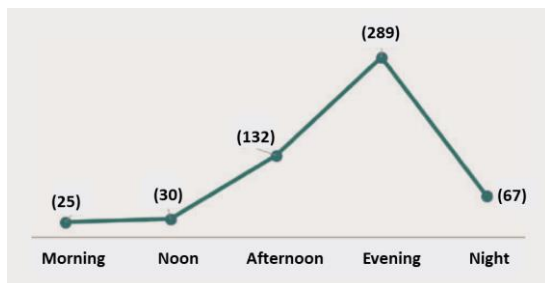
► Fig. 3 Categorization of patients by BMI.

However, not all questions were answered by all patients, leading to different numbers observed in the presentation of the analyzed results (see figures).

Results

More than half the patients surveyed were between 30 and 49 years of age. The youngest patient was 15 years old. The oldest patient had reached the age of 80 (► Fig 2).

Obesity, which has repeatedly been associated with lipedema was observed in just over 50% of the patients surveyed. The remaining patients – and of great importance here – had completely normal weights or were just slightly obese (BMI < 30) (► Fig. 3). More than 20% of the patients had a BMI that was completely in the normal range. **The lipedema-associated pain symptoms studied by the authors appeared to be independent of weight.**



► Fig. 4 Maximum pain sensations in the course of a day.

Nearly 50% of the patients surveyed have had pain symptoms for more than 5 years. The pain is subject to a circadian rhythm with maximum symptoms during the evening (► Fig. 4).

The questionnaire used has made it possible to characterize the symptoms of pain in a variety of ways. The following is an overview diagram of the observed descriptions (► Fig 5).

Descriptions of the various pain symptoms were obtained by ticking boxes from “exactly applicable” to “not applicable”. Well over 50% of the patients described the pain as pressing, while the second most described pain was pulling. In contrast, the majority of patients indicated that the pain could in no means be described as throbbing, which is often associated with inflammatory reactions. The details are displayed graphically in the following two graphs. (► Fig. 6, ► Fig. 7)

Around 90% of patients reported daily pain. Approximately 50% of patients describe a mean pain intensity between 2 and 6 on an intensity scale from 0 to 10. A large proportion of patients felt hindered in the execution of their everyday activities. The impairment was mainly in the range between 2 to 8 (► Fig. 8).

A similar distribution and impairment was also found for leisure activities. These findings do not indicate in any way that 21% of the patients (► Fig. 8) do not experience pain, rather that they do not feel impaired by the pain. Consistent with our own observations, complex decongestive therapy (CDT) could reduce the level of pain [18].

In a small minority of around 3% of patients, the ability to work was completely impaired.

Due to the pain, more than 80% of patients stated that they took pain medication at irregular intervals. This was mainly non-steroidal anti-inflammatory drugs, in particular ibuprofen at a dosage of 600 mg. Regular medication intake was the exception, especially since these medications did not lead to permanent pain reduction.

Despite the impairments, over 50% of the patients surveyed rated their general condition as at the very least good, very good or even excellent

Discussion

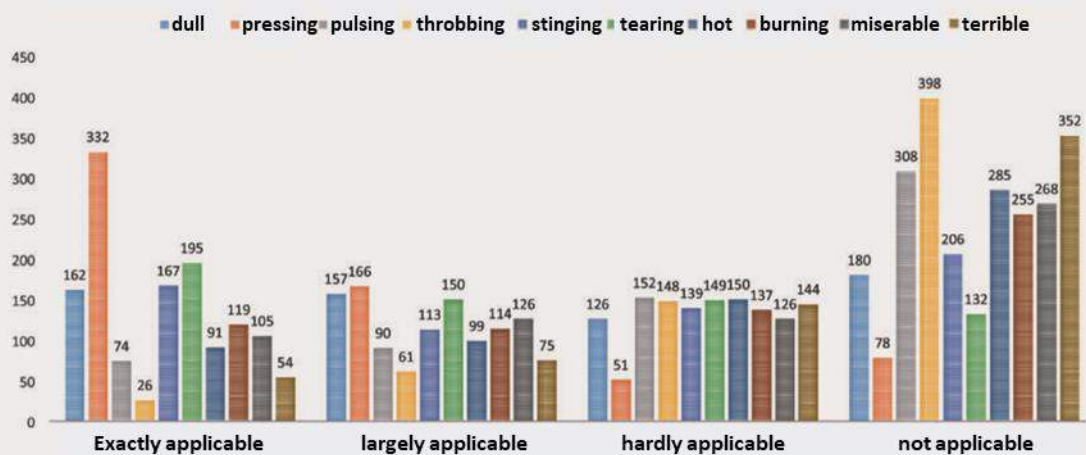
The DSF questionnaire should enable a better understanding of the test results, and facilitate further examinations. However, the evaluation showed that a whole series of questions could only be used to a limited extent in lipedema patients. This also meant that some patients did not complete the questionnaires completely. Some questions such as the correlation between the stages of lipedema and the listed changes in quality of life could not be assessed by the evaluation software used. For further investigations, the authors believe that it makes sense to develop a modified questionnaire that is more relevant to lipedema.

The questionnaire also did not reflect the observation that by no means do patients with a higher BMI show more pronounced pain symptoms.

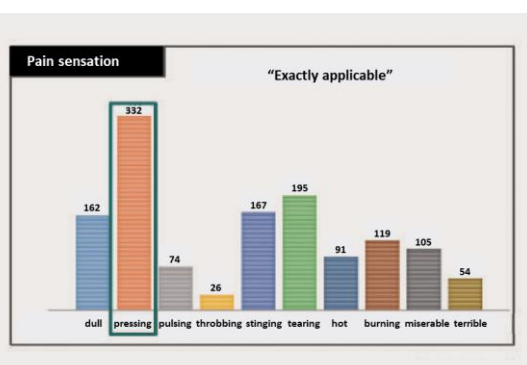
The data shows that the diagnosis of lipedema is not necessarily associated with obesity, even if the current views are biased in this direction. According to a study by the German Nutrition Society, 74.2% of men are overweight at the end of their working lives, compared to 56.3% of women of the same age [19]. BMI assessment has limited use in lipedema patients. Although lipedema patients can very well reduce their weight if they are obese, the weight reduction does not significantly influence the enlarged extremities and pain caused by lipedema. During the consultation hours at our clinic, we repeatedly see lipedema patients with morbid obesity whom have lost 50 – 60 kg after bariatric surgery, but still retain excess fat at their extremities. The patient statement of “I cannot lose weight” should thus rightly be “I cannot lose my lipedema fat”. This is in accordance with the estimates in the AWMF guidelines that only about 6-8% of the female population in Germany are affected by this disease [20].

These data indicate that the symptom of pain is extremely multifaceted. Taking this into consideration, the GBA-initiated study, in which the end point of pain is designated as the main criterion for determining the success of either the conservative or surgical treatment, should be viewed critically. The aim of treatment should be to achieve freedom from pain or at the very least significant pain reduction. Furthermore, there should be no need for subsequent therapy, whether it be lymphatic drainage or compression therapy. If possible, the goal must be a cure and thus a relapse-free treatment. The planned period of the GB-A study is hardly conducive towards assessing these criteria.

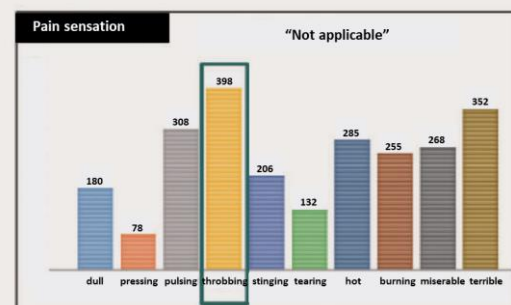
Characteristic words used to describe pain by lipedema patients



► Fig. 5 Overview: subjective characterization of lipedema pain.



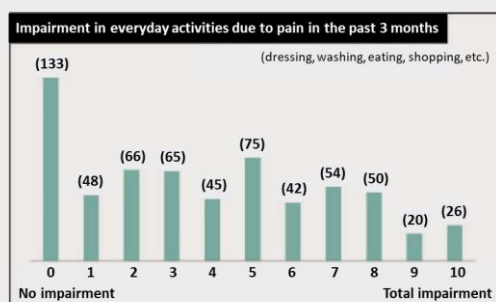
► Fig. 6 Detailed view: subjective characterization of Lipedema pain.



► Fig. 7 Detailed view: subjective characterization of Lipedema pain.

Most patients described the pain as dull, pressing, pulling and stinging. Nevertheless, there were also other attributes for the sensation of pain. The attributes throbbing and pulsing, usually associated with inflammatory reactions, occurs less often in lipedema patients, and are thus mentioned more frequently in the "not applicable" section. This leads to the conclusion that the pain symptoms of lipedema are not an inflammatory process. Although no formally planned laboratory tests were performed in the course of this study, these suggestions agree with our laboratory values on ESR (erythrocyte sedimentation rate), leukocyte count and CRP (C-reactive protein), which are regularly collected as part of the preoperative

blood tests of the patients operated on in our clinic. The inflammation markers appear generally unremarkable. What is striking however is the differences in the intensity of pain. The pain can occur spontaneously, but can also be triggered by external stimuli. Thus, in the context of diagnosis, a very subtle questioning of the patients is required to sufficiently and correctly assess the key symptom of Lipohyperplasia dolorosa – pain. A careful, targeted analysis of a patient's medical history is therefore an integral requirement for correct diagnosis. Suggestive questions should however be avoided. Demographic data collected during the survey clearly show that the repeatedly mentioned obesity was only demonstrated as a co-morbidity in 50% of the patients surveyed [21].



► **Fig. 8** Detailed view: subjective impairments due to Lipedema pain.

In this respect, it is more than questionable that current discussions on lipedema at congresses almost exclusively describe it as an obesity-related disease. Even if the number of lipedema patients also suffering from obesity is approximately 50%, lipedema and obesity must be considered as two separate diseases. The repeated claims that lipedema patients cannot lose weight is thus untrue. Lipedema patients can indeed lose weight, just not the pressure-sensitive, painful lipedema fat at the extremities, which is potentially due to genetically hereditary defects. Concomitantly, this leads to impairments in daily life, both in terms of general mobility as well as the quality of life. The data show that 85% of lipedema patients are affected by minor impairments in daily life, which can influence the work process – including household chores – and leisure activities. Due to the considerable impairments of lipedema on a patient's life, the primary aim of treatment, whether it be conservative or surgical, should be to reduce the symptoms or to cure it through surgery. Even if objective findings not subject to patient bias are not currently available, patients with these symptoms should be taken seriously.

Conflict of interest

The authors state that there is no conflict of interest

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