Lipedema: no man's land

Amato ACM

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Lipedema is a chronic condition marked by abnormal accumulation of subcutaneous fat, mainly in the legs and arms, and it affects almost exclusively women. This fat accumulation can be painful and often causes a sensation of swelling. First described in the 1940s, lipedema is still underdiagnosed and poorly understood, which results in inadequate treatment.

Many physicians disregard its existence, attributing the symptoms to common obesity and thereby blaming the patient herself. Recognizing lipedema implies not only the correct diagnosis but also the need to adopt a specific treatment, one that goes beyond simply placing the responsibility on the patient.[1]

The absence of precise clinical guidelines and the insufficient recognition of lipedema in medicine have created an unusual situation. Professionals from other fields, and even laypeople, feel qualified to diagnose and treat this disease. Meanwhile, less experienced physicians, influenced by the Dunning-Kruger effect, venture to create their own treatment protocols and present them as effective solutions. In some cases, these laypeople and professionals from other fields do in fact manage to support patients better than their own physicians did.

I want to make it clear that I am not generalizing; there are dedicated physicians who understand and study lipedema in depth. Nevertheless, it is essential to recognize that the treatment of lipedema is a multiprofessional task. Physicians, physical therapists, psychologists, nurses, physical educators and other professionals focused on human well-being must collaborate and share knowledge constructively. The main goal must always be the patient's well-being, and the exchange of information between professionals from different fields enriches and enhances treatment outcomes.[2]

Lipedema, in its neuroendocrine complexity and vascular manifestations, challenges the conventional boundaries of medicine and demands a multidisciplinary and collaborative view for its effective treatment. Isolated practice, especially that of the plastic surgeon without integration with endocrinology and other specialties, is a limited approach that may ignore critical *nuances* of the disease. It is a neuro-immuno-endocrine disease, with an exuberant vascular symptom, that is being treated by the plastic surgeon. It is a bomb waiting to explode.

Individuals with a more commercial outlook, interested in marketable novelties, are capitalizing on the growing interest on social media. They exploit patients with lipedema who seek reliable information and do not find it with the physicians they trust. There is a worrying lack of effort in research and scientific validation of these proposed solutions. The commercial focus is exclusively profit, without considering the real or potential benefits of these treatments for patients.

When cellulite (the non-medical kind? Is there such a thing? Well, the non-infectious kind) was being addressed with countless miracle techniques, serious physicians simply ignored this market trend; after all, it had nothing to do with them or their specialties. However, with the medical diagnosis of lipedema, the whole aggressive market aimed at the aesthetics of cellulite perceived the need and the possibility of addressing lipedema in the same way. And doctors have not yet realized that they need to embrace this cause for the sake of their patients' health. So what is happening?

Translator's note: in Portuguese, *celulite* means both cellulite (the dimpled skin of aesthetic concern) and cellulitis (the skin infection); the author's parenthesis plays on this ambiguity.

Each profession tries to pull lipedema into its own specific field:

- Nutritionists claim that it can be treated by adjusting the diet alone.[3,4]
- Physical therapists develop and sell multiple protocols of their own creation without scientific validation.
- Aestheticians perform a variety of applications, often without a scientific basis.
- Personal trainers say that physical exercise is the definitive solution.[5]
- Psychologists identify problems resulting from long-standing lipedema, but some oppose drug treatment, even when it is necessary.

Are they wrong? I understand the tendency of each to overvalue his or her own knowledge. In this scenario there is a clear conflict of interest, in which each one tends to overestimate the importance of his or her own knowledge. For example, a surgeon may firmly believe that surgery offers the patient more benefit than a diet simply because surgery is the service he is qualified to provide and has incentives to provide.[6,7]

At a large international congress on lipedema, as I was leaving the module on diet, I came across a group of plastic surgeons chatting animatedly. I asked them what they had thought of the presentations, which had shown symptomatic benefits of more than 40% with proper nutrition. They answered that they had not attended, because they were interested only in the surgical module, believing it to be the only way to treat lipedema. They only wanted to learn about different surgical techniques and equipment. I was speechless.[8]

At the same time as this trend, we see, on the other hand, several traditional medical specialties tending to distance themselves from lipedema, either because they do not believe in its existence or because they do not want to be associated with the problem. Or, worse still, I suspect that many are afraid of having to revise a great deal of established knowledge now that the existence of lipedema must be taken into account. What do I mean? I will explain with vascular surgery, my own specialty.

Vascular surgery, for example, holds that the problem does not lie in the arteries or veins, ignoring that lipedema involves microangiopathy, hypoxia, edema and lymphatic stasis as part of its pathophysiology.[9] I spent years being criticized and judged for trying to draw the specialty's attention to this disease. I still believe that, because of the typical leg symptoms, vascular surgeons are the first to be sought for help, in both early and late cases.

I understand that it may be uncomfortable to have to study in depth a topic that was not covered during medical school or residency. I believe that even those who do not wish to study the subject in depth could help in the diagnosis and treatment of the venous comorbidities common in patients with lipedema, but without losing sight of the treatment perspective and of the causal link between the symptoms and the identified disease.

But do you know what significant problem I perceive? The need to revise all prior knowledge on venous insufficiency and to acknowledge past mistakes. I believe that much of that knowledge would have to be reviewed from the perspective of lipedema. One example: the CEAP classification for varicose veins, adopted worldwide, does not include symptoms such as pain, heaviness and fatigue in the legs. This is due to their poor correlation with the stage of the varicose veins. Could it be that this was the underdiagnosis of lipedema and, therefore, the absence of a causal link with venous insufficiency?

In other fields, I see the situation as an observer and, although I cannot be entirely assertive, I notice significant discomfort. I hope no one takes this personally; this is indeed a generalization, intended to understand the problem at a macro level in order to point toward a systemic solution. I have no intention whatsoever of offending or accusing anyone.

Endocrinology tends to see lipedema as obesity, without justifying the need to differentiate the two problems. This happens despite the pain and swelling that are present in lipedema but absent in obesity.

Recently, at a congress I attended, a participating endocrinologist told me that a small segment wishes to classify lipedema as a subset of obesity. I believe this will be an inevitable discussion in the future. Only in the last year did I begin to notice sessions on lipedema included in the major congresses of the field. Hormonal changes, such as those associated with leptin, hypothyroidism and Hashimoto's thyroiditis, are often neglected and treated as coincidences. However, if they were taken into account, endocrinologists could assess and manage these hormonal imbalances related to the problem, contributing to a more comprehensive management of this condition.

Immunology and allergology do not associate lipedema with allergy and various symptoms, considering them mere coincidences or comorbidities. To this day I have not found an immunologist talking about this association; however, I can state that the greatest advances with my patients occurred when I decided to study our immune system in depth. Lipedema is definitely associated with chronic inflammation in adipose tissue.[9] Immunologists could help identify and monitor inflammatory markers, and could also help contain this inflammation. I am certain they would be protagonists in this disease; however, patients do not seek them out for leg pain and swelling.

Gastroenterologists are sought out because a large proportion of women with lipedema have altered bowel habits; however, symptomatic treatment that does not consider the possible causes and the correlation with the problem ends up preventing significant improvement. I do not know how many of them bother to examine their patients' legs and ask about them. Some, when they hear "cellulite", simply dismiss the complaint, classifying it as aesthetic. Many patients end up undergoing surgery of the gastric system, for reasons that may be related to the same inflammatory origins. From a scientific point of view, gastroenterologists could certainly add a great deal to the understanding of endotoxins in lipedema.

It is essential that oncologists not neglect the existence of lipedema, even though it may be considered an aesthetic condition. Even when facing serious diseases such as cancer, it is crucial to take into account complaints such as pain, leg swelling and aesthetic appearance. Several of the biological processes associated with lipedema also correlate with oncological processes: systemic inflammation.

Although I cannot state it on the basis of scientific evidence,[10,11] there is a hypothesis that, just as the peripheral fat of lipedema helps protect the cardiovascular system, it may also reduce oncological risk. I have noticed that many patients, after surgical removal of this fat, develop some type of cancer — could this be a correlation? We need oncologists committed to research that takes these possible risk factors into account. I look forward to research in this area.

Rheumatology usually diagnoses fibromyalgia before considering lipedema,[12] even though the latter may play a significant role in the control of concomitant inflammatory conditions such as arthritis. I believe there is a reluctance to reassess fibromyalgia and other similar diseases in light of current knowledge about lipedema. To do so, it is necessary to admit the possibility that we made mistakes in the past, diagnosing one condition instead of another. Confronting this idea can be challenging, and it inhibits deeper reflection. It takes great humility to question and abandon beliefs so deeply rooted in, and so intrinsic to, a medical specialty.

Dermatologists are often consulted for the treatment of skin lesions and dermatitis, which may share an inflammatory origin with lipedema. However, how many of them are concerned with pain and swelling in the legs? Certainly, many would be concerned and willing to offer a variety of aesthetic treatments for cellulite. Most of these aesthetic procedures promote more inflammation in the treated area,[13] which may be beneficial for individuals without excessive inflammatory sensitivity, since it aids tissue regeneration and repair.

In lipedema, inflammation has a dual effect. It can harden the fat, improving the superficial appearance. However, it can also worsen the symptoms and cause internal scarring, known as fibrosis.[2] Dermatology could play a crucial role in helping to manage skin problems such as capillary fragility, urticaria, rash and livedo reticularis, thereby contributing to the early diagnosis of lipedema.

Orthopedists see many patients with lipedema, particularly in advanced cases that have caused gait impairment and joint damage. Although correcting joint damage is crucial, it does not address the root cause of the problem. I notice that some orthopedists refuse to treat certain patients, advising them to lose weight first, but without providing guidance on how to do so. It is worth stressing that orthopedists can be very helpful in managing musculoskeletal and joint pain. They can recommend specific exercises to strengthen the muscles and improve joint stability, and prescribe assistive devices to improve mobility. Here, physical medicine and rehabilitation is also very important, as it often deals with gait difficulties, often without considering that lipedema itself is the initial cause of these difficulties.

Psychiatrists may believe that they do not play an important role in lipedema therapy. However, our studies point to a high prevalence of depression, anxiety[1] and ADHD[14] in patients with this disease. Ignoring these comorbidities can result in inadequate clinical and surgical management. Patients with these comorbidities have been observed to adhere less to the routines required in both clinical and surgical treatment.[15] The psychiatrist's contribution is therefore crucial for comprehensive and effective treatment of lipedema.

Nutrition physicians (*nutrólogos*), especially those who do not prescribe hormones indiscriminately, can play a significant role in the dietary guidance of these women. Some professionals understand that there is a correlation with female hormones and believe that by altering the hormonal profile they will solve the problem. However, a correct nutritional approach is much more effective and healthy. I believe that all medical specialists should study more about the impact of diet on health. We overvalue complex care and neglect simple measures that could make all the difference. An example I like to cite is that of Parodi, who in 2018[16,17] demonstrated the improvement of intermittent claudication, a limb pain characteristic of arterial ischemia, through simple adequate hydration. Despite being a brilliant study, it

has so far been cited only 12 times; after all, surgical treatment with *stent* implantation has much greater financial appeal. For industry, the surgical implantation of an expensive device is more profitable than encouraging water intake. Who will fund research on the importance of drinking water? And whose ego will be massaged by something as basic as hydration?

The field of plastic surgery quickly identified a financial opportunity in liposuction, promoting it as an effective solution. This happens mainly because the procedure is not covered by health insurance plans, under the rules of the ANS (Brazil's National Supplementary Health Agency), so it is charged separately to treat a disease. Most surgeons have good intentions and genuinely believe they are improving their patients' self-esteem. However, the metabolic complexity of the disease is often set aside, with the focus only on the details of surgical technique. There are 450 documented cases of liposuction to treat lipedema in the medical literature.[18] Nevertheless, even without rigorous scientific studies, the practice is often presented as a definitive cure. I believe that the medium- and long-term metabolic impact of these procedures on patients does not justify indiscriminate intervention. The initial improvement in pain reported by patients and mentioned in these studies usually ignores the return of visceral fat accumulation, physiological changes and other unmeasured symptoms. Before prioritizing self-esteem, the proper correction of immunometabolic health must be ensured.

Yet, in the end, no one is to blame: lipedema is, in fact, a disease without a specific field of practice. This disease touches on several specialties but is the focus of none of them. The tendency is for each to stick to the symptom related to its own field and ignore the rest, treating the disease but not the patient as a whole. Thus, with each specialty addressing one aspect of lipedema but not taking the patient into account as a whole, none feels fully responsible, and each transfers the responsibility to another. We must actively decide to take ownership of the problem in order to change this perspective.

The solution will only emerge when it is understood that joint, multiprofessional work involving several specialties can lead to a complete understanding and resolution of the problem. I believe we are still at an early stage, still trying to make the medical community aware that the problem exists, and at this moment self-assessment is indispensable. I did it myself, reviewing medical records to see how many times I had failed to diagnose lipedema before I was aware of its existence and high prevalence. I found many cases, and to those patients I can only offer my most sincere apologies. Unfortunately, at the time, I was not prepared to help them.

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