

Letter to Editor: Series of articles by T. Bertsch and G. Erbacher culminating in Lipoedema – myths and facts, Part 5*: European Best Practice of Lipoedema – Summary of the European Lipoedema Forum Consensus published online 2020-01-31

Present authors represent a non-profit that provides online education and support to people with lipoedema, educational opportunities for clinicians, and fosters knowledge and research into lipoedema. Our current world-wide membership is 21 500. Three writers are women with lived experience of lipoedema. The goals of our organization align with the stated goals of the European Lipoedema Forum Consensus (Consensus).

We are grateful for the research and deliberation that has gone into the Consensus and background papers. We agree that lipoedema literature has made and repeated unsubstantiated assumptions. The fault though lies in the lack of research into basic questions. Clarification of what has not been validated points to the need for further research. Lipoedema has been marginalized in the social and medical worlds. It is heartening that the Consensus proposes to attend to the lived concerns of women with lipoedema.

We endorse the Forum's proposal to provide multimodal services for women with lipoedema. Since 2018 our programs have followed a similar model which is geared to five domains: physical, social, psychological, emotional and spiritual. We actively promote weight management, appropriate physical therapies, resources for social, psychological and emotional concerns. We offer personalized coaching on all aspects of living well with lipoedema.

We have some concerns with the Consensus paper. First, we agree that lipoedema is a complex condition. It is likely that the causes for lipoedema are also complex and not identical in all cases. We agree with setting aside unsubstantiated claims and assertions from the past but we caution against adopting new hypotheses that have not themselves been scientifically validated, and treating them as established or proven. We prefer to acknowledge comorbidities with lipoedema addressing them in the present without ascribing causal relations. This approach more accurately reflects the current state

of knowledge, or unknowing, about the etiology of lipoedema. An open approach to causation allows for respectful and compassionate interactions with women who already suffer from social shame and blame. It avoids compounding suffering with intimations of fault. We acknowledge that women often present with comorbidities. In any one woman these comorbidities might, or might not, entail: obesity, actual lymphedema, lack of social understanding and support, emotional and/or psychological difficulties, other medical, and even spiritual/existential conditions. We agree that all comorbidities present ought to be respectfully addressed.

Second, we are concerned that in a field where there is so much uncertainty, the Forum members were forced to admit that "Serious scientific data on the patient's perspective do not exist." This is even more worrying in that "crucial questions" the Forum members articulated were: "What do our patients with lipoedema really SUFFER from?" and "What is the therapeutic goal from the patient's point of view?" We agree that women with lipoedema are called to be "experts" in doing the work of rehabilitation. But they are already "experts on themselves" and are in fact the only experts in their lived experience of suffering from lipoedema. (All quotations are reference 1, p. 37)

Each woman with lipoedema presents at a clinician's office aware of the areas of her suffering and of her therapeutic goals. With thousands of women seen every year at clinics worldwide, it is astonishing that information about how they suffer and what they want, which can so readily be obtained and compiled scientifically, is not available to guide treatment protocols. For instance, it is almost universal that women with lipoedema suffer from dysmorphia of the legs. Yet the series articles have deemed dysmorphia to be pathologically insignificant [2]. Dysmorphia is real, observable, and persistent, despite successful obesity treatment, as is evident in the before and after pictures of bariatric surgery [2]. Women with lipoedema do not

want to have the legs of Vogue cover models, but legs like their neighbours and like the other women in their exercise classes. Additionally, lipoedema alters biomechanics. The weight of lipoedema on the levers of the legs makes participation in exercise more strenuous, challenging stabilizing muscles far more than legs of peers with normal morphology. This and the stigma of having morphology different from anatomical normal can be barriers to community exercise and social participation. In expecting body acceptance, the Consensus asks women to accept the socially, anatomically and even functionally abnormal. Dysmorphia acceptance may be a necessary goal for individual patients. However, clinical persuasion has to be undertaken with the *clinicians' acceptance* of the real suffering that accompanies dysmorphia, rather than with the clinician's dismissal of women's lived experience of dysmorphia as pathologically insignificant. Dysmorphia is not a cosmetic issue, but a divergence from the anatomically normal that has real, verifiable musculoskeletal consequences in everyday life and in rehabilitation. That said, self-love, compassion and acceptance are the cornerstone and heart of our program.

Given our understanding of biomechanical and psychological problems associated with dysmorphia, we cannot agree with the division of associated dysmorphia into two diagnostic categories: lipoedema and lipohypertrophy [2]. Lipoedema is distinguished from lipohypertrophy by the patient's pain perception, rendering lipoedema primarily a chronic pain condition. The assumption seems to be that lipoedema, the pathological condition, is in remission when pain is managed and then is transformed into lipohypertrophy. Given that understanding of causation and development of lipoedema is in early stages of research, it is premature, in our opinion, to divide characteristic dysmorphia into two categories based principally on pain perception.

Third, contrary to the view of this series, evidence of an edema component in

lipedema continues to mount. Several imaging studies have shown damaged lymphatics in a significant proportion of women with lipedema independent of severity of their condition [3–5]. In 2017, a research group at Vanderbilt University Medical Center led by Rachelle Crescenzi found higher levels of sodium and water in the subcutaneous fat in women with lipedema [6]. Most recently, a biomarker for lymphatic impairment was identified and levels were elevated in lipedema but not in obesity [7]. Ignoring evidence for lymphatic dysfunction in lipedema can potentially wrongfully disallow needed valuable treatments such as manual lymph drainage and pneumatic compression.

Fourth, we find that hormonal theory is integral to treating obesity in women with lipedema. By addressing hyperinsulinemia we have reduced a vast array of symptoms, even independent of weight loss. Therefore, we focus all of our dietary recommendations on reducing both fasting insulin and insulin response. We agree that, “short term diets must be avoided by all means” [1]. Indeed, dietary intervention must constitute a life-long change. We disagree that, “It has been shown that bariatric surgery is the most effective treatment for losing weight” [1]. This is not our experience. Many women with post-bariatric surgery complications and weight regain achieve relief and weight stabilization with insulin-lowering therapies [8, 9]. In our experience, women wish they had known about metabolic treatments for obesity *before* weight loss surgery. They often say, had they known, they never would have risked surgery given their subsequent challenges. Therefore, we concur that metabolic therapies should be fully exhausted before bariatric surgery is considered, even “for patients with lipedema and a BMI of ≥ 40 kg/m” [1].

In the absence of scientific data on either the inflammatory or the neuromodulation theories of pain in lipedema, we prefer the inflammatory model as presented in the Consensus; it is less open to interpretations of blaming and shaming women with lipedema. The inflammatory model has sound physiological bases that tie together diet, exercise, compression,

stress reduction and conceptual practices. Neuromodulation can be viewed, as is illustrated in the fifth article in the series [1], as impacting inflammatory processes. We think understanding the effect of stress on inflammation is persuasive enough to induce women with lipedema to continue the sometimes daunting journey of tackling emotional, psychological, spiritual and social concerns.

We believe that our approach is evidence-based. Best practice protocols must be living documents regularly updated to incorporate new research and knowledge. Most importantly, women with lived experience of lipedema need to be heard, recorded, and scientifically studied. Results from these studies can then form the rationale for updated best practice treatment.

Conflict of Interest

The authors declare that they have no conflict of interest.

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