What if it’s not Obesity?
Shaida Vossough

She was crying. “I’ve tried everything I can. I barely eat and I really do exercise. I don’t know what else to do. And I feel like no one believes me.” She looked defeated. She presented to clinic for evaluation of pain and weight loss; and, before even seeing the patient, I heard remarks like “maybe if she lost weight, she wouldn't be in pain” after providers saw the BMI of the patient. Most of us have heard similar comments, and we all know the effects weight can have on the body, but something was different with this patient.

She had an interesting distribution of fat on her body, predominantly from her hips to her knees and from her shoulders to her elbows, bilaterally and symmetrically. Her waist, however, was much narrower than you would expect with her elevated BMI. She told me how the fat deposits felt like “bags of frozen peas” and were tender to palpation. When I examined her I noticed significant striae over her thighs, torso, and upper arms with bruises in various stages. “I bruise like a peach,” she said. “I barely bumped the coffee table and turned black and blue.” The fat seemed to stop at her ankles, sparing her feet. The attending talked with her about lifestyle changes and she left.

It was in endocrine clinic later in the year that I was reminded of that patient. Dr. Herbst told me about lipedema, an adipose disorder which affects subcutaneous adipose tissue to cause what appears to be edema of fat. The disorder predominantly affects women in the third decade of life and is often misdiagnosed as obesity. Patients typically present with bilateral and symmetrical fat distribution from the iliac crest to the malleoli with visible involvement of the arms in 30 percent of patients. Patients also experience pain, tenderness, and easy bruising. “These poor women can work out all day long and eat a piece of lettuce and they still won’t lose the weight because it’s a disease of fat cells. No amount of diet and exercise will change that,” Dr. Herbst told me. It was one of those light bulb moments you have in your third year clerkships, only 8 months too late.

Lipedema is often misdiagnosed as obesity, with lifestyle changes such as caloric restriction and increased energy expenditure being ineffective treatment methods. The disorder is likely due to vascular and lymphatic dysfunction leading to edema. Decreased elasticity of skin and fascia causes capillaries to become more permeable as the skin can no longer contribute its support to the skeletal muscle venous pump. The fluid leaking out of these vessels results in the fluid accumulation in fat cells, which is lipedema. Subcutaneous adipose tissue also develops increased compliance, worsening the edema. Lymphatic vessels are quickly overrun by the severity of the extravasation of fluid and lymph eventually leaks out of the lymphatic system, resulting in lymphedema. Coupled together, these patients can develop lipolymphedema, further worsening the edema.

Patients are often depressed, struggling with their weight and feeling left without support by their healthcare providers. They can also experience anxiety, skin changes such as dryness, fungal infections, cellulitis, and slow wound healing. One study found patients with lipedema were more depressed than patients with paralysis (Fife et al. 2010). We, as the next generation of physicians, owe it to our patients to improve our understanding of lipedema and rare adipose disorders, treat them appropriately and improve the lives of those affected. Treatment options include lymphatic decongestive therapy, pool hydrotherapy, psychological support, and even liposuction to improve pain, among other options. The
The purpose of this article is not only to share information with you, my colleagues, concerning lipedema, but also to encourage you to further explore the rare adipose disorders so that we may better support and treat our patients.

Editor’s Note: Lipedema is not a rare disorder but is similar to rare diseases that have atypical fat distribution such as Dercum's disease, lipodystrophies, primary lymphedema, Madelung's disease and familial multiple lipomatosis. It is important to recognize that atypical fat distribution can be a medical condition distinct from common obesity.

Resources:


Learn more about lipodystrophies and fat disorders:

Fat Disorders Research Society, Inc.
PO Box 3014
Ridgefield, NJ 07657 USA
Phone: (203) 769-1267
Email: info@fatdisorders.org
Website: http://www.fatdisorders.org

**NORD Physician Guide to the Lipodystrophy Disorders**