Abstract

This study consisted of an open-ended questionnaire and survey that was conducted online through survey monkey. The sample consisted of 65 women with lipoedema who participate in online support groups on Facebook: Lipoedema Ladies, UK & Europe; Lipoedema Sisters, USA; and LASS, Australia. The purpose of these interviews was to conduct a grounded approach in eliciting narratives of the experience of lipoedema in their lives and their interactions with healthcare.

Definition: Lipoedema

Lipoedema, an inherited genetic “fat disorder,” affects 11% of women of all sizes, from extremely thin to the morbidly obese, resulting in localized fat, often painful, that is bilateral, symmetrical and usually from the waist to just above the knees. There is visible disproportion between upper and lower parts of the body. Unlike “normal” fat of obesity, lipoedematous fat cannot be lost through diet and exercise. Conservative estimates: 17 million women in the USA, 3.5 million in the UK, and 370 million worldwide.

Onset or exacerbation of the condition correlates with critical hormonal disturbance periods:

1. Puberty
2. Pregnancy
3. Peri-menopause

and as a result/complication of surgical general anesthesia.

In light of the obesity epidemic and the anti-fat bias that seems to proliferate the culture, it is common for there to be a lack of knowledge among healthcare professionals leading to great difficulty for women to be diagnosed and to receive quality care (Puhl & Brownell, 2006).

Research Methodology

Stages of Lipoedema

Stage 1 – Normal skin surface; increased fat

Stage 2 – Uneven skin with indentations in the fat; larger mounds of tissue grow as unencapsulated masses, lipomas (benign soft tissue subcutaneous tumors consisting of adipose/fat tissue) and angiolipomas (subcutaneous nodule with vascular structure, having all other features of a typical lipoedema that are commonly painful)

Stage 3 – Large extrusions of tissue causing deformation especially on the thighs and around the knees

Stage 4 – Lipolymphedema

Lipoedema with lymphedema (localized fluid retention and tissue swelling caused by a compromised lymphatic system)

Experience with Healthcare Professionals

What was your experience in attempting to get diagnosed, treated or to receive support for your condition of lipoedema from healthcare professionals?

“Awful, for years I was told I was obese, told to diet, exercise and lose weight, was even told by one doctor that I had large legs because I drank too much tea and coffee! When my new GP did finally agree that something was wrong, he was very supportive and put me in the right direction. My GP now says there is no use me going back to the surgery as there is nothing more they can do and to research it myself online and keep going to the clinic!”

“I was told to lose weight by GPs. A friend in England (I live in South Africa) had Lipoedema and she told me I had it. It took 8 years to get a medical diagnosis.”

“The reason I was doing my own research was that for my entire adult life I asked doctors WHY my legs were such an abnormal shape, and getting more so. I was repeatedly dismissed with ‘it’s just a weight issue’ which translated to me, ‘it’s your own fault’. Once diagnosed, I was able to get treated with MLD and compression leggins.”

“I spent 16 years going from doctor to doctor in Eastern Idaho, trying to find out what was wrong with my legs. Some said lymphedema and some said I was just fat. After I got the diagnosis from the Mayo Clinic I tried explaining to my doctors about lipoedema but they weren’t very interested, as there wasn’t even a diagnosis code for it if they couldn’t accept it as a valid condition.”

Treatment for Lipoedema

• Manual lymphatic drainage massage (MLD)
• Compression garments (arm, leg, etc.)
• Anti-inflammation diet – elimination of wheat & sugar
• Supplements can be helpful to stop progression
• Liposuction surgery – specialized medical not cosmetic treatment eliminating localized lipoedematous fat tissue

Contact Information

Anti-Fat Bias: Media’s Influence on Obesity Stigma, Lipoedema, and Its Impact on Receiving Quality Healthcare

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