

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

Catherine Seo, M.S., Ph.D. (candidate), Joanne Bird, Michelle Ellis, Karen E. Dill-Shackleford, Ph.D.
Fielding Graduate University, U.S. /Lipoedema Ladies, U.K.



Abstract

Media's influence is far reaching. Nowhere does it have more impact than on the internalized and externalized images the culture projects about women's bodies. Perfect idealized images of women, impossible to attain and maintain, are disempowering and lead to widespread stigma and discrimination.

Anti-fat bias is common and along with a lack of knowledge about lipoedema among healthcare professionals generally results in misdiagnosis for women with the disorder. Despite its medical vs. cosmetic nature, lipoedema is often confused with obesity and women are judged, shamed and blamed by healthcare professionals, either implicitly or explicitly.

Women learn a sense of powerlessness in the face of anti-fat bias, and fail to advocate for themselves in healthcare situations. Cognitive understanding about lipoedema and mindfulness meditation are two interventions that can increase self-efficacy and self-caring, especially for women with lipoedema, allowing them to advocate for themselves in receiving appropriate quality 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 ankles. There is visible disproportion between upper and lower parts of the body. Unlike "normal" fat of obesity, lipoedemic 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

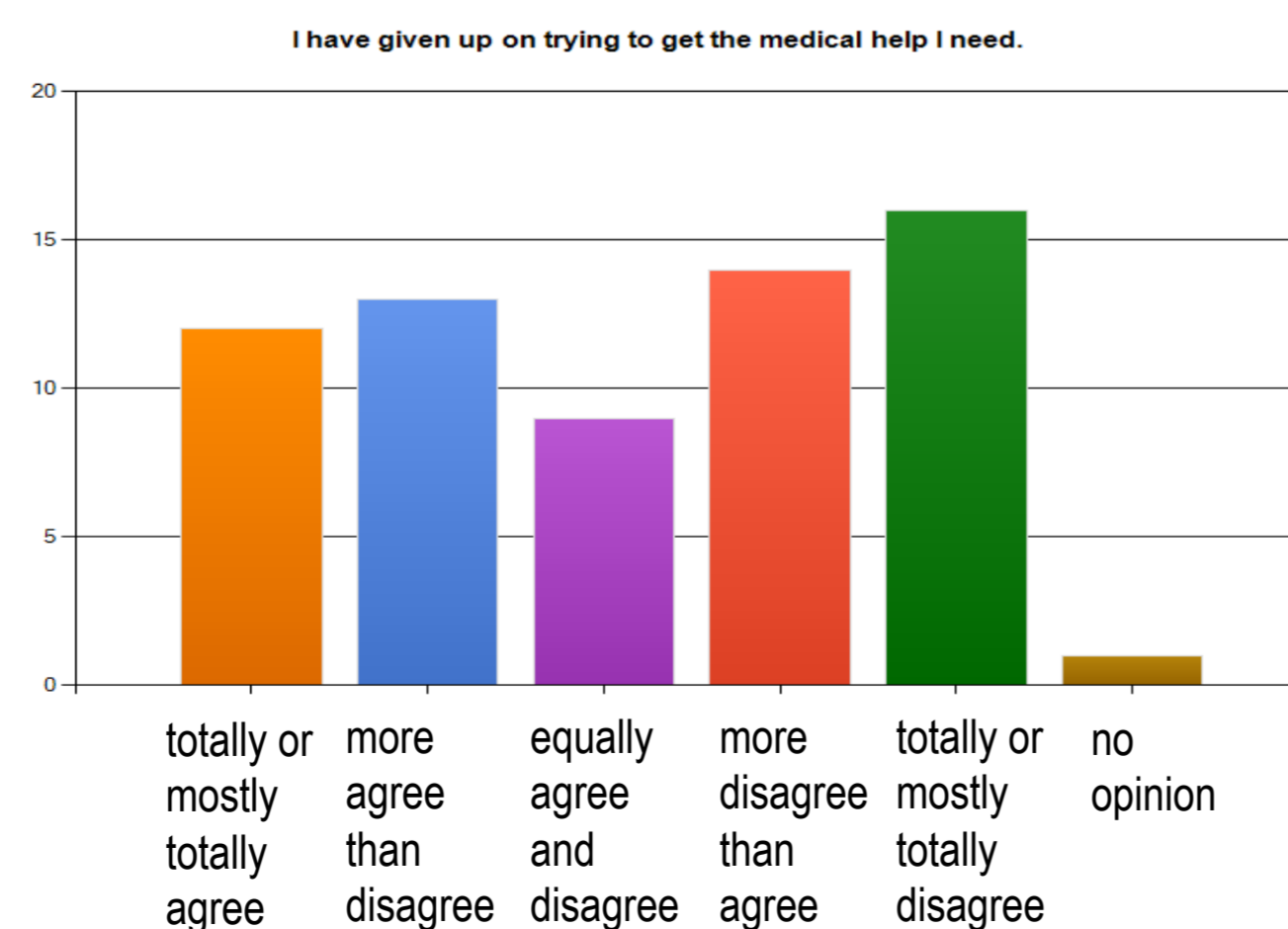
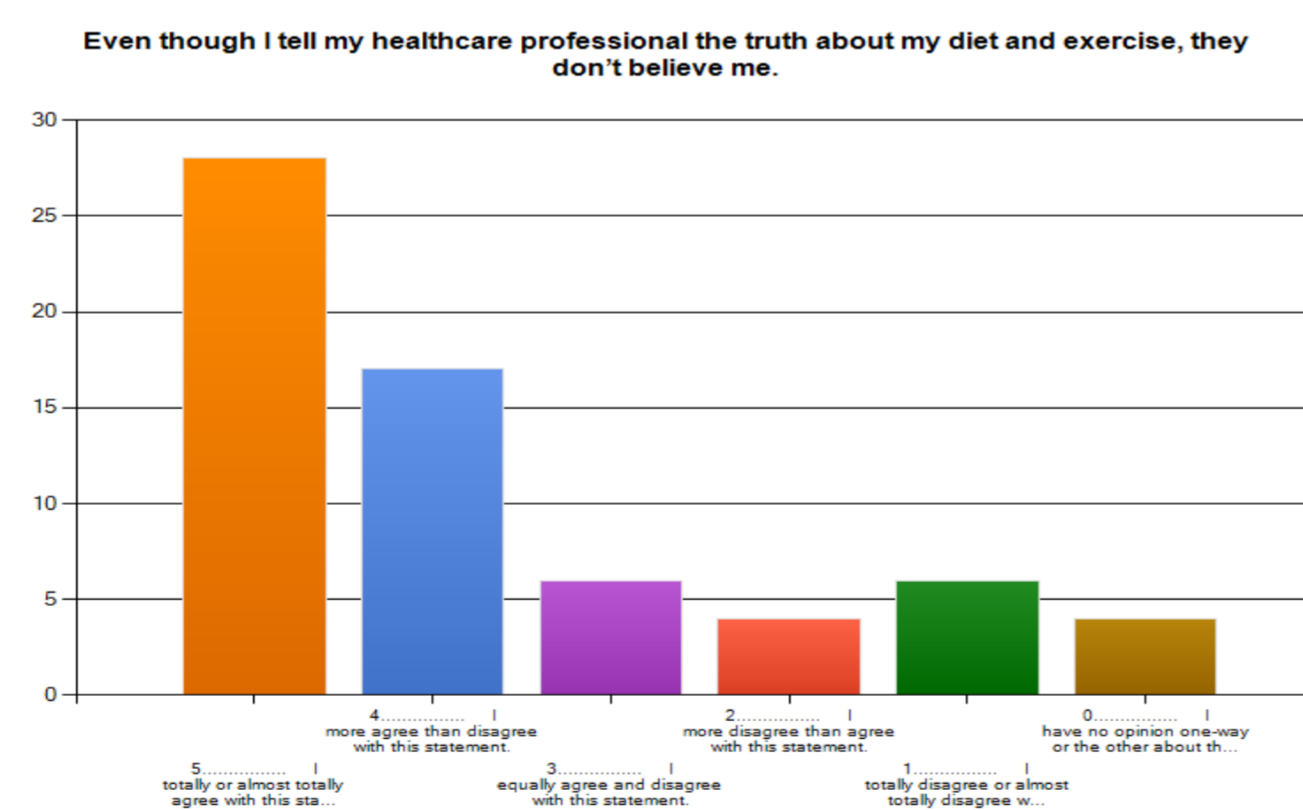
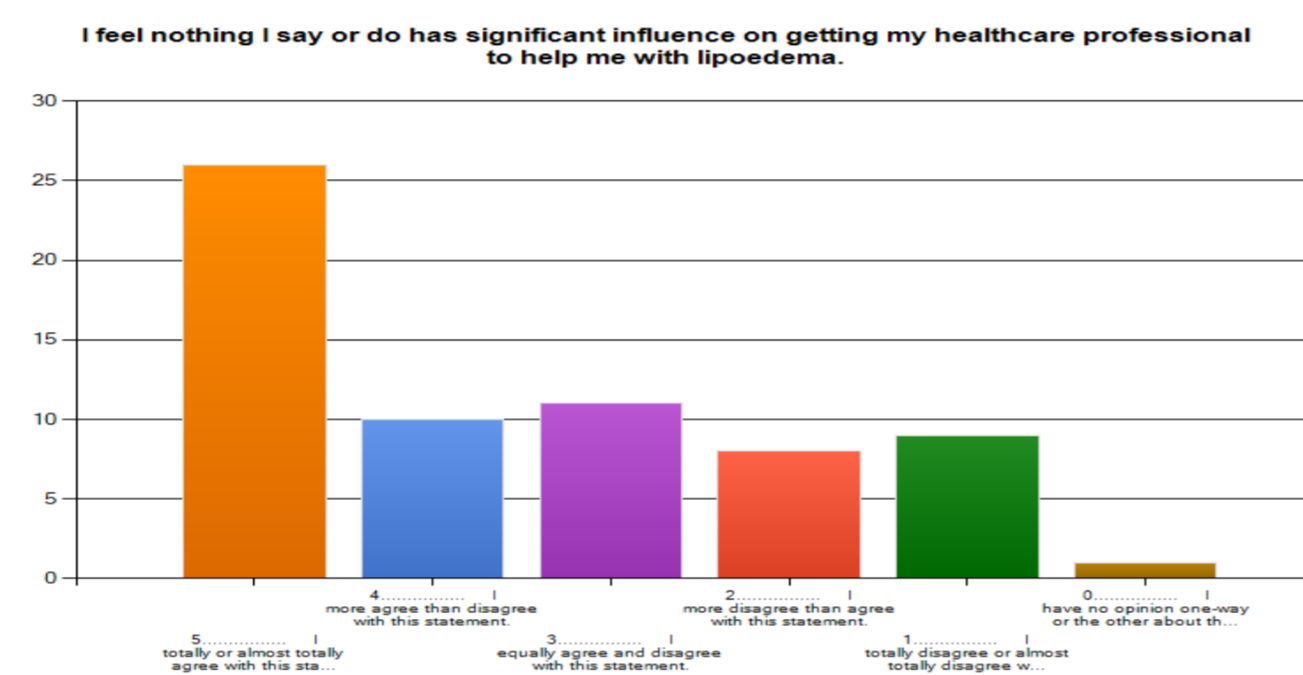
and as a result/complication of surgical general anesthesia.

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

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.

Interacting with Healthcare Professionals



Stages of Lipoedema



Stage 1

Stage 2

Stage 3

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 angioliomas (subcutaneous nodule with vascular structure, having all other features of a typical lipoma 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)



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 lipoedemic fat tissue

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 for 5+ years that my legs were just where I carried my weight. I was just fat & needed to lose weight. When Lipoedema was first mentioned to me none of my doctors knew who to refer me to. I had to go home and research it on the Internet and find out myself who to see to get diagnosed."

"Shocking. First three attempts, I was smiled at patronizingly, not examined and given leaflets on dieting...I tried again with a different GP, who also refused to examine me and said "Face facts, you're FAT. Stop wasting my time and yours and go to a gym". He turned back to his computer and left me to do the walk of shame out of his office...I still have problems as when I explain to healthcare professionals in hospitals that I have lipoedema, they act as if I'm so far in denial that I'm 'fat', I've 'made up' a condition to explain it...The gynecologist who carried out my hysterectomy was downright rude and said, 'God, you're carrying a lot of weight on your legs!'"

"I was always told to lose weight by GP's. 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, to "it's your own fault." Once diagnosed, I was able to get treated with MLD and compression leggings."

"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 they couldn't accept it as a valid condition."

Contact Information



lipoedema simplified

Catherine Seo, M.S., Ph.D. (cand.)
Karen Dill-Shackleford, Ph.D.
Fielding Graduate University
T: 1.617.721.9463
cseo@email.fielding.edu
www.lipoedema-simplified.org



Lipoedema Ladies UK
Joanne Bird
Michelle Ellis
T: 07968 590530
info@lpladies.co.uk
www.lipoedemaladies.com