

Williams A, MacEwan I (2019) A qualitative study of the experiences of women with lipoedema in Scotland. Oral Presentation, International Lymphoedema Framework Conference, Chicago, 13-15th June 2019

Introduction:

Lipoedema is a fat and connective tissue disorder associated with symmetrical proliferation of diet-resistant inflammatory fat tissue, mainly in the limbs and buttocks. Effective self-care is key to improving symptoms, and minimising lipoedema progression (Wounds UK 2017).

Evidence from online surveys has shown that living with lipoedema presents many challenges (Fetzer and Fetzer 2016). There has been limited exploration of the qualitative experiences of living with lipoedema, how women perceive and self-manage their condition, and what support is required.

Aims:

To explore the perceptions and self-care experiences of women living with lipoedema of different stages.

To identify self-care outcomes and support strategies relevant to women with lipoedema.

Methods:

The study, informed by social constructionism, was undertaken in partnership with Talk Lipoedema, with recruitment via Talk Lipoedema social media. Ethical approval was obtained from the university ethics committee. Semi-structured interviews with women living with lipoedema were undertaken by an experienced researcher. A focus group was also convened to further explore the data from the interviews. Interviews and focus group were recorded and transcribed verbatim, and thematic analysis undertaken.

Results/Findings:

A total of 24 women were interviewed, including those with lipoedema of: stage 1 (n=3); stage 2 (n=8); stage 3 (n=7); stage 4 (n=6). Eight women took part in the focus group, including seven of those already interviewed, and an additional woman (stage 1 lipoedema). Their ages ranged from 28-74 years and most had developed lipoedema around puberty. Key themes that will be presented include: the lipoedema trajectory/being different; the wasted years; emotional baggage/managing the spiral of self-loathing; 'you have lipoedema but there is nothing we can do for you'; trigger moments and crisis points; how much more do you want me to do?; sod you kind of attitude; family support; professional supported self-care after the diagnosis; strengths of peer support; those who went before and the future generations.

Conclusions:

The findings further illuminate the devastating impact that lipoedema may have on women as they manage the demands of their family and working lives. Women predominately find support and information through third sector organisations. Professional NHS support services for women in Scotland are inequitable and inadequate, but the research findings provide directions for future developments.

Fetzer A, Fetzer S (2016) *Lipoedema UK Big Survey 2014 Research Report*.

Wounds UK (2017) *Best Practice Guidelines for the Management of Lipoedema*. London.