

# Women in dire need: the far-reaching impact of lipoedema on women's lives

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Lipoedema, an adipose tissue disorder, is an invisible, often unrecognised condition, which has wide-reaching impacts on patients' lives (Wounds UK, 2017). These range from pain and reduced mobility to poor self-esteem and working prospects (Fetzer and Fetzer, 2014; Wounds UK, 2017).

Treatment options, such as compression or liposuction, are limited and come with challenges, including poor ease of use and service provision (Wounds UK, 2017). To foster a greater understanding of the significant and debilitating impacts faced by women living with lipoedema, the charity Lipoedema UK conducted four focus group interviews, and the findings were published in a series of reports under the umbrella title 'Women in dire need' (Fetzer, 2019).

The reports identify the numerous negative effects of lipoedema on the everyday lives of affected women, including patients' experiences with compression garments, the effects of liposuction surgery (many of which are not positive) and the considerable challenges faced by women with late-stage lipoedema, which can even render them immobile.

These reports, notably the focus group interviews about compression, also capture recommendations to assist health professionals and patients with early diagnosis and treatment of the condition, which are of paramount importance. Also essential is information on treatment to help mitigate the effects of this condition.

## What is lipoedema?

Lipoedema is a chronic fat disorder that mostly affects women and causes an abnormal build-up of painful fat cells predominately in the legs, thighs and buttocks, although it can also be present in the arms (Damstra et al, 2014; Wounds UK, 2017). Typical onset occurs during periods of hormonal change, such as puberty, pregnancy or menopause.

Lipoedematous fat cannot be significantly reduced by exercise or dieting (Herbst, 2012; Fetzer and Fetzer, 2014, Wounds UK, 2017) and is frequently misdiagnosed as obesity (Todd, 2010; Fetzer and Fetzer, 2015), although obesity and lipoedema can coexist (Wounds UK, 2017). As well as being painful and potentially disabling, the condition can take a huge toll on patients' mental health and quality of life (Fetzer and Fetzer, 2014, Wounds UK, 2017).

Although there is some debate in the medical community, lipoedema staging tends to be characterised as follows (Wounds UK, 2017).

- ◆ Stage 1: the skin appears smooth. On palpation, the thickened subcutaneous tissues are found to contain small nodules
- ◆ Stage 2: the skin has an irregular texture that resembles orange peel. Subcutaneous tissues nodules vary in size between a walnut and an apple
- ◆ Stage 3: the indurations are larger and more prominent. Deformed lobular fat deposits are formed and may cause considerable distortion of the affected limb
- ◆ Stage 4: lipoedema accompanied by lymphoedema (referred to as lipolymphoedema).

## Focus group methodology

To gain insights into the impact of lipoedema and the two most commonly used treatment options (compression and liposuction) on women's lives, Lipoedema UK conducted four 90- to 120-minute focus group interviews at the charity's annual conferences in 2017 and 2018.

## ABSTRACT

Lipoedema, an adipose tissue disorder, is a poorly visible, often unrecognised condition. To foster a greater understanding of the significant and debilitating impacts faced by women living with lipoedema, the charity Lipoedema UK conducted four focus group interviews, the findings of which were published in a series of reports under the umbrella title 'Women in dire need'. The reports identified the substantial and numerous negative effects of lipoedema on the women's everyday lives, including the patients' experiences with compression garments, the effects of liposuction surgery (many of which were not positive), the everyday impacts ranging from pain and reduced mobility to poor self-esteem and working prospects, and the considerable challenges faced by women with late-stage lipoedema which can render them immobile.

## KEY WORDS

◆ Lipoedema ◆ Compression ◆ Symptoms ◆ User experience

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The topic for the focus groups were:

- ◆ The everyday impacts of lipoedema on life
- ◆ The challenges of obtaining the correct-fitting garment on prescription
- ◆ Life after liposuction
- ◆ The challenges of late-stage lipoedema.

Between 11 and 16 participants were involved in each focus group. Participants either volunteered or were invited to attend. The majority were patients, but health professionals also attended (typically one or two per session), and, in the case of the compression focus group, two representatives from garment manufacturers attended as well.

Industry professionals were included to facilitate discussion around solutions, as well as to increase industry awareness of the patient perspective. After participant introductions, the researcher introduced a series of questions or talking points and made notes of the discussion that ensued.

Key findings were published in a series of reports on Lipoedema UK, 2019. These bring together patient experiences with practical advice for patients and health practitioners.

## Key focus group findings

The key findings across the four focus groups could be summarised as follows:

- ◆ Lipoedema is a poorly visible, under-recognised condition
- ◆ Discrimination and judgements are as debilitating for patients as physical symptoms are
- ◆ Patients have poor mobility, and the impact that lipoedema has on patients' financial health blights lives
- ◆ Patients have poor mental health, including poor body image, self-esteem and self-confidence
- ◆ Compression garments can improve quality of life but patients struggle to get the right prescription
- ◆ Surgery can improve quality of life and pain, and can have a positive mental impact, but it is not without its challenges and can be financially crippling.

## Everyday impacts of lipoedema on life

The women affected by lipoedema who participated in the focus group interviews were aged between 22 and 67 years. The far-reaching impacts of lipoedema that they reported included significant effects on mobility, careers, relationships, mental health, social interactions and participation in daily activities.

Everyday activities are severely impacted and/or restricted as a result of several factors, which include:

- ◆ Mobility constraints, including the challenges of finding accessible toilets and getting in and out of vehicles
- ◆ Size constraints, including finding clothing and footwear that fit
- ◆ Psychological constraints, including issues such as low self-esteem, low self-confidence and crippling self-consciousness as a result of their size or shape.

The women reported having poor mental health (anguish) as a result of factors such as a lack of understanding and

control of their bodies; frustration, guilt and blame; and poor body image, self-esteem and self-confidence.

They also found being active and exercising difficult because they faced challenges in wearing suitable kit; wearing swimwear (they were embarrassed); accessing an exercise centre or facility; finding the time or making the effort to remove compression garments; gait; and getting the right advice over suitable exercise.

Many reported that they experienced painful legs and bruising, and poor relationships with food or eating disorders. They also found it difficult to engage in romantic and sexual relationships, find career paths and job prospects, and felt a lack of control and the need to 'plan every minute'.

The following comment from a patient summarised the wide-ranging and damaging impact of lipoedema on her everyday life:

*'I lost my career as I didn't know what was wrong with me and I couldn't physically do the work anymore. So we got into debt. We're now in rented accommodation, with nothing to show for our careers. Lots of older ladies are almost homeless—and their condition makes them housebound.'*

## Challenges of obtaining the correct-fitting compression garment on prescription

The focus group study revealed the serious challenges faced by patients in getting the correct-fitting compression garments on prescription. Potential solutions that could help overcome these challenges were also discussed, although some of these solutions require funding to be made available.

Compression is a conservative therapy that aims to reduce the volume of interstitial fluid (Schmeller, 2008) by promoting venous and lymphatic drainage. It is a frequently recommended treatment option for lipoedema patients. It is not a cure: its purpose is to reduce discomfort by supporting tissues, streamlining limbs, improving mobility, reducing oedema and decreasing the risk of progression (Wounds UK, 2017). However, many women struggle to be assessed by a specialist who is trained and able to prescribe compression garments, as service provision is not routine throughout the UK. Compression garments can be purchased privately or prescribed through the NHS. However, the cost, especially for customised items, can be a barrier given the already stretched NHS budgets.

Very few women were successful in getting well-fitting garments on prescription, and compression recommendations from practitioners were often not reflected in the products received. Commonly, made-to-measure recommendations were not followed, with patients provided with off-the-shelf products instead. A possible solution for this problem is for patients to request that their GPs handwrite prescriptions to ensure accuracy, so that practitioner recommendations can be followed and they receive exactly what they have been prescribed from the pharmacy.

Another problem is that patients are not routinely taught how to use garments and identify a good fit. A recommended

solution for this if the budget were made available was for Lipoedema UK and garment manufacturers to conduct education programmes for therapists and practitioners to train their patients in garment use, and for patients to request guidance from their therapists.

Often, patients wait a long time to receive their garments, and, to overcome this, they could directly contact their prescriber (usually their GP) to ensure that their garments (once it is confirmed they are the correct ones) are put on repeat prescription.

Lives can be improved by well-fitting garments but these can be difficult to access. For this, patients, practitioners and manufacturers should work collectively to ensure all patients are measured correctly and receive the correct garments. Off-the-shelf products have limited effectiveness for patients with moderate to severe lipoedema. Patients must be guided by the practitioner in finding the best possible garment, and they should be open to trying new garment types. Further, manufacturers must invest in research and development to improve the range of off-the-shelf garments.

The next problem discussed in the focus group was regarding the inconsistency of measurement techniques and findings. As a potential solution, it was proposed that Lipoedema UK and garment manufacturers run practitioner education programmes on measurement, although again budgets would have to be found to fund this solution. Practitioners also need to ensure that they are up-to-date with the appropriate measurement techniques and how to interpret or use the findings of these techniques.

Wearability is an important barrier to compression use, as many patients find putting on compression garments difficult and time-consuming. Further, once on, garments are restrictive or uncomfortable, discouraging patients from wearing them. Lipoedema UK and garment manufacturers need to invest more in research and development to design and produce more comfortable garments that are easier to put on and specifically designed for those with lipoedema.

Lastly, to encourage patients to be proactive in obtaining the garments and advice they need, Lipoedema UK and garment manufacturers will work jointly to create a checklist that explains what patients are entitled to and includes advice and tips on the prescription system and identifying whether a garment is the correct fit.

### Life after liposuction

This group comprised 14 people: 12 lipoedema patients (11 of whom who had undergone liposuction surgery and one who wanted to learn about liposuction surgery), one therapist and one researcher. The patients in this focus group had undergone between one and five surgical procedures for their lipoedema. Patient ages ranged from 19 to 53 years. Most had more procedures planned—an additional one to five operations—to complete their treatment.

The discussion highlighted that, while almost all the women agreed that liposuction surgery had improved their symptoms and quality of life, it was not a cure, and challenges remained. The women also experienced new

challenges as a result of the procedure, such as guilt over spending so much money on themselves.

All but one patient in this group reported that liposuction surgery had vastly improved their quality of life. With regard to pain, the group agreed that, while not eliminated entirely, pain was lessened after liposuction surgery. This was irrespective of age or lipoedema stage. However, liposuction surgery was not seen as an ‘easy option’. The women talked about recovery being ‘a long, hard road’ and ‘tough going’ but mentioned that it was worth it to ‘get their life back’, as the surgery, even if they still had more planned, had already ‘made a huge difference’.

Liposuction surgery was reported to have positive mental impacts, ranging from fostering a positive self-image to the patients gaining confidence and feeling proud of themselves for undergoing a serious procedure to gain control of their lives and their bodies. However, equally, feelings of guilt were common and considerable. All except one patient had to fund their surgery privately. The women felt guilty about the money the operation required and the support needed during recuperation.

Feelings of frustration and anger were also common. Several of the women noted how their postoperative experience made them realise how lipoedema shaped their life and held them back. They also acknowledged feeling disappointed in the extent to which liposuction had helped. Patients acknowledged a need to ‘be realistic—because even though surgery significantly improves it—we’re always going to have lipoedema. But we can have the surgery—and it won’t be so uncomfortable, and we can try and stop progression’.

Compression was still important, but less of a priority. Although many women still wore compression, and some indicated that were still were reliant on it, several noted they could do without it more easily.

Lastly, the group cited Lipoedema UK as a catalyst. Some patients explicitly mentioned the charity, in particular its annual conference, as a source of finding treatment information, surgeons and support/inspiration from other members.

### Challenges of late-stage lipoedema

Patients in this group categorised themselves as having late-stage lipoedema. This definition was assumed to encompass severe stage 3 lipoedema and stage 4 lymphoedema secondary to lipoedema (lipolymphoedema). The discussion highlighted that patients with late-stage lipoedema have a specific set of needs, from having significant mobility issues to ill-health-related debt and discrimination.

Lipoedema restricts all areas of life and mobility is a primary concern. Many women used mobility aids, and navigating simple elements of everyday life, such as walking, shopping or working, was often prohibitively hard. Going to the toilet is extremely difficult for women with late-stage lipoedema. This is primarily because of compression (the difficulties of getting it on and off in confined toilet spaces) and access issues around public toilets.

Discrimination and public judgements can be as debilitating as some physical symptoms. The women shared stories of negative comments they had received from friends, family and members of the public and the detrimental impact of these.

Lipoedema is a poorly visible, under-recognised disability. Improving awareness of this debilitating condition among the general public would help patients access treatment and improve public perception of patients.

Financial health and debt were major issues reported. The potent combination of mobility issues, pain, comorbidities, low self-esteem and low confidence dramatically affected the financial health of patients with late-stage lipoedema, limiting previous and current income and their prospects. Retirement is a looming concern, as most women had already used up savings during periods of ill-health or to pay for treatments such as liposuction.

Compression was cited as a help as well as a hindrance, evoking strong responses. When measured correctly and when the garments were well-fitting, it was seen as a life-saving tool for patients with late-stage lipoedema. However, the challenges in obtaining well-fitting garments and putting compression garments on and the discomfort caused were seen as near-insurmountable barriers.

Swimming can be hugely effective at managing pain and in reducing size. The six women who went swimming said it was 'amazing' and that they 'loved it'. The rest said they would love to swim if they could get in or out of the pool—this was a mobility and confidence issue.

Pain management treatments can improve symptoms and quality of life. However, the high costs of these treatments, such as manual lymphatic drainage or physiopod, made them inaccessible. Many patients mentioned the difficulties they had in accessing treatment, especially NHS treatments via lymphoedema clinics. Lastly, the patients said that guidance on filling in medical paperwork would be hugely helpful. They found filling in reports and referrals in order to access treatment on the NHS a challenge.

## Conclusion

The qualitative research presented in this article provides valuable documentation on the impact of lipoedema on patients' lives. It also provides useful insights into ways that some of the challenges, for example, those around compression, can be overcome.

Understanding the full spectrum of experiences among women with lipoedema is vital to enable health professionals meet the needs of these individuals effectively. This research demonstrates the need for appropriate psychological support and mobility advice, as well as the importance of helping patients access relevant therapies, such as well-fitting compression.

It would be worthwhile to validate these insights by taking a quantitative approach. The focus group research also identifies areas ripe for further investigation, such how compression can be made more effective and user-friendly; how women can access better psychological support; and

how liposuction is best approached to manage expectations and limit psychological impacts. **BJCN**

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## KEY POINTS

- ◆ Lipoedema is an invisible, often unrecognised condition that has wide-reaching impacts on patients' lives
- ◆ Discrimination and judgements are as debilitating as physical symptoms, and poor mobility and financial health blight lives
- ◆ Patients suffer poor mental health, including poor body image, self-esteem and self-confidence
- ◆ Compression garments can improve quality of life but patients struggle to get the right prescription
- ◆ Surgery can improve quality of life and pain and can have positive mental impacts, but it is not without its challenges and can be financially crippling

## CPD REFLECTIVE QUESTIONS

- ◆ Patients report that the psychological and social impacts of lipoedema often outweigh the physical symptoms. Why do you think this is so?
- ◆ What kind of psychological support would be beneficial for women with lipoedema?
- ◆ How can nurses help lipoedema patients to ensure they receive the correct prescription for compression garments?
- ◆ What kind of support and information would be beneficial for a patient considering liposuction?

