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Understanding the challenges of lipoedema.

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Abstract

Lipoedema is a challenging condition for patients, health and social care professionals. Lack of understanding about the condition leads to delayed diagnosis and poor support with self-management. This paper draws on key evidence, Best Practice Guidelines for the Management of Lipoedema, and a case study, to provide insights into the presentation, diagnosis, impact and management of the condition. It also identifies key points for practice for community nurses.

Keywords

lipoedema; best practice; pathophysiology; compression therapy; self-management

Introduction

Lipoedema presents many challenges for women living with the condition, and for health and social care professionals. Limited public and professional awareness and understanding of lipoedema frequently results in misdiagnosis of the condition, often as lymphoedema or obesity (Fetzer & Fetzer 2015). Women with lipoedema may therefore wait several years for a correct diagnosis, with limited access to support and treatment services in many areas of the UK. The lack of definitive diagnostic tests for lipoedema (Wounds UK 2017), means that prevalence data are limited. There are also no apparently curative surgical or pharmacological treatments for lipoedema. Furthermore, psychosocial issues, emotional distress and co-morbidities experienced by women with lipoedema may significantly impact on the woman's health and wellbeing, influencing their quality of life (Fetzer and Fetzer 2016; Wounds UK 2017).

This paper will draw on best practice guidelines (see practice point box below) (Wounds UK 2017) to discuss current evidence regarding the pathophysiology underpinning the signs and symptoms experienced by a women with lipoedema. It will provide key points for practice relating to the diagnosis and assessment of women with lipoedema, and management approaches, including the use of compression therapy and surgery. The patient story illustrates some of the challenges of living with lipoedema, and highlight the role of community nurses in supporting this patient group with self-management to achieve optimal health and wellbeing.

Practice point: Best Practice Guidance
The first UK Best Practice Guidelines for the Management of Lipoedema were published in 2017. These evidence-based, peer-reviewed guidelines were developed by an expert working group, including three women living with lipoedema, specialist nurses and physiotherapists, a consultant in Dermatology and Lymphovascular Medicine, and a dietician. They aim to be accessible and useful to professionals, women living with lipoedema, and those who commission services. The guidelines are available at: http://www.wounds-uk.com/best-practice-statements/best-practice-guidelines-the-management-of-lipoedema

Lipoedema presentation

Lipoedema (literally meaning ‘fat swelling’) mainly affects women and is a disorder of the fat and connective tissue (Fife et al 2010, Langendoen et al 2009). Prevalence is suggested to be around 1 in 72,000 (Child et al 2010) but this is likely to be greatly underestimated, and further epidemiological studies are required. Typically, women present with a disproportionate body shape, due to proliferation of diet-resistant fat (Fife et al 2010). This leads to enlargement of the lower body, including thighs, buttocks, and lower legs above the ankles (Figure 2). The upper body and arms may also be affected, although the feet and hands are generally spared, at least in early stages (Table 1) (Langendoen et al 2009).

The most common symptoms reported to health professionals include:

- feelings of heaviness in the legs
- painful legs
- difficulty in losing weight
- swollen and bruised legs (Fetzer and Fetzer, 2016).

Commonly, on examination, the skin in the early stages of lipoedema feels soft, smooth and cool to touch (Fetzer & Fetzer 2015). Subcutaneous tissue nodules, and larger deformed lobular fat deposits at the thighs and knees develop in more advanced stages (see patient story) (Wounds UK 2017). Some individuals also develop a secondary lymphoedema, sometimes referred to as lipo-lymphoedema (Wounds UK 2017) as a result of inflammation, poor mobility and reduced lymph drainage in the enlarged tissues. This may lead to tissue fibrosis and a risk of cellulitis (Williams and MacEwan 2017).

Stage 1	Skin is smooth although small nodules may be palpated in the subcutaneous tissues
Stage 2	Skin become irregular and ‘mattressing’ is evident where the skin looks uneven, and larger subcutaneous nodules or lipomas may be evident on palpation
Stage 3	Prominent indurations develop in the tissues, particularly above and below the knees; this distorts the limb profile and influences the gait
Stage 4	A secondary lymphoedema develops, often referred to as lipo-lymphoedema.

Causes and pathophysiology

The exact causes and pathophysiology underlying lipoedema (Table 2) are not absolutely clear, and it is likely that several factors may be involved (Okhovat & Alavi 2014). Currently, genetic studies are ongoing in the UK as some predisposition to develop lipoedema has been recognised within families but specific genes have not yet been identified (Child et al. 2010, Schmeller & Meier-Vollrath 2007). Different patterns of fat distribution occur and may indicate different lipoedema phenotypes (Fife et al 2010). There also appears to be a significant hormonal influence related to the influence of oestrogen on fat cells, as lipoedema commonly first presents around puberty (Lipoedema UK 2016). Many women also report worsening symptoms during and after pregnancy, and around the menopause (Fetzer & Fetzer 2015).

Inflammation may also be a key factor in lipoedema, contributing to pain and hypersensitivity even when gentle pressure is applied to the tissues (Lontok et al. 2017). Some women with lipoedema have obvious varicose veins, indicating some associated risk of chronic venous disease (Peled and Kappos 2016). There is also evidence that lymphatics undergo structural and functional changes in lipoedema (Amann-Vesti et al 2001). This may be associated with 'leaky lymphatics' and increased interstitial fluid accumulation within the enlarged fat tissue, triggering the development of secondary lymphoedema, and various inflammatory changes (Szél et al 2014).

Table 2: Possible pathophysiological changes in lipoedema

- Reduced elasticity of the skin and connective tissue (Herbst 2012)
- Hypertrophy (increase in size) of fat cells leading to tissue enlargement
- Inflammation and hypoxia of fat cells (Suga et al 2009)
- Growth of new (and fragile) blood capillaries in fat tissue – leading to easy bruising (Fife et al 2010), and increased capillary permeability and filtration
- Reduced lymph drainage when the lymphatic system becomes overloaded due to inflammation and enlarged tissues

Impact of lipoedema on the person

Lipoedema can have a significant and longstanding impact on physical and mental health and wellbeing as shown in the case study (Figure 4). Young women who develop lipoedema after puberty may face comments from others about their

changing body shape, becoming focused on dieting and exercise, often with a frustratingly limited influence on their weight and body shape (Fetzer & Fetzer 2015). An online survey of women with lipoedema revealed that 45% of women reported eating disorders, while 98% had tried to lose weight, and 95% experienced difficulties with buying clothes due to their size (Fetzer and Fetzer, 2016). The same survey reported over 60% of women being told to lose weight and/or exercise more regularly by health professionals. Sadly, anecdotal reports from peer support organisations such as Talk Lipoedema, often provide evidence that women with lipoedema are often wrongly accused by health professionals of poor eating habits, potentially undermining the patient:professional relationship.

Physical symptoms such as swelling, pain, unsteadiness, hypermobility and joint problems also restrict daily living activities and movement, and may be unpredictable for the individual (Lontok et al 2017). An online survey of 120 women with lipoedema indicated that pain and tenderness were particularly problematic, and associated with lower quality of life (Dudek et al 2016). Gait is often affected by changes in limb shape and size. Lipoedema has been shown to be associated with reduced muscle strength and poor exercise capacity (Smeenge 2013) which impact on mobility, and compromise home, family and work commitments. In the online survey, 87% of respondents reported a negative effect on their life as a result of lipoedema, with 60% reporting social restrictions as a result of lipoedema, 51% identifying an impact on their work and career, and 50% reporting changes in their sex life (Fetzer and Fetzer, 2016).

There are also clear mental health implications with 60% of women taking part in the survey reporting feelings of hopelessness, and 86% reporting low self-esteem (Fetzer and Fetzer 2016). In another online survey of 60 women with lipoedema, 30% reported depression as a problem (Dudek et al 2016). It is likely that changes in body image and social isolation may influence mental wellbeing and compromise health related behaviours. Dudek et al (2016) reported associations between higher levels of social connectedness and improved quality of life, and showed that those reporting higher psychological functioning were more likely to adhere to self-care actions such as using compression therapy, or going swimming.

Practice points

As lipoedema appears to worsen for many women at particular life stages, around puberty, pregnancy and menopause, there are clear opportunities for key professionals such as community nurses, practice nurses, midwives and health visitors, to recognise lipoedema, and provide support to women and their families through:

- Holistic assessment and listening to their story of lipoedema
- Identifying and addressing physical symptoms and problems
- Encouraging women to seek help with mental health challenges
- Signposting to appropriate services
- Avoiding activities such as taking blood pressure on the enlarged and painful upper arm.

Holistic assessment and diagnosis

There are currently no diagnostic markers or investigations that provide a definitive diagnosis of lipoedema (Wounds UK 2017). This can make it challenging for primary care professionals (Goodliffe et al 2013) who may not be familiar with the unique and often highly variable characteristics of lipoedema. Diagnosis is based on clinical examination, patient history, and exclusion of other conditions such as lymphoedema or obesity. Referral to a lymphoedema clinic, or vascular services may be useful, and other conditions such as treatable venous disease should be addressed. Key areas to consider in the assessment are identified in Table 3.

Age of onset	Usually presents or worsens around puberty or times of hormonal change such as starting the contraceptive pill, experience of pregnancy or menopause
Family history	Genetic research is ongoing, as patients often report family members (women or men) with similar body shape or apparent weight problems
Areas affected	Commonly lipoedema is bilateral, with symmetrical enlargement of the legs, thighs, hips and buttocks, with sparing of the feet; this often leads to a 'pear-shape'
Effect of dieting	Patients may describe years of dieting with little or no effect
Pain/ hypersensitivity particularly under pressure	This can be debilitating, and may be due to changes to nerves and/or inflammatory processes

Skin changes such as bruising, cold to touch, ulceration	The skin may feel very soft, easily bruised due to capillary fragility, and cold due to the insulating properties of fat. In later stages, when lymphoedema has developed, chronic ulceration may develop
Impact on daily living activities and gait	Activities such as standing for long periods may exacerbate pain and swelling; a swinging gait may develop due to fat bulges at the knees
Impact on personal relationships	Lipoedema may influence family relationships through, for example, difficulties in lifting children, or challenges with body image. Living with and understanding lipoedema can also strengthen relationships
Other medical and surgical history	Various co-morbidities may exist, and many women identify problems such as fibromyalgia, allergies, cellulitis. Exclusion of other conditions such as polycystic ovary syndrome, growth hormone deficiency or Madelung's disease is also important (Fife et al 2010).
Anthropometric measures	This may include limb circumference, and hip:waist measurement; however, weight and BMI may be less useful as they are skewed by the presence of lipoedema fat
Person's understanding of the disease and expectations of treatment outcomes	Some may have negative experiences of past investigations and treatments. As with all long term conditions, exploring expectations is key to working in partnership with women who have lipoedema and their families, to identify their priorities and develop a realistic treatment plan.

Management

Working with a person living with a long-term condition such as lipoedema, requires a partnership approach, sensitivity and good communication. Community nurses are in a strong position to identify lipoedema early and initiate support (see 'Useful resources' box). The key principles of lipoedema management are identified (Wounds UK 2017) as:

- Facilitation and enhancement of the patient's ability to self-manage
- Optimisation of health and prevention of progression of the condition
- Management of symptoms.

Self-management support should begin from the first assessment (Fetzer & Wise 2015), and many people with lipoedema will have already researched their condition, and have clear ideas of what they need to effectively manage their condition over the long term. Peer and online support groups are very active in relation to lipoedema,

but are not accessible to many patients. Optimising health is key, and lifestyle measures such as dietary changes, weight management, and use of compression therapy can all enhance mobility (Fetzer & Wise 2015). This may be key to preventing long term problems such as osteoarthritis of the knee or hip joints, lymphoedema, ulceration, and mental health problems.

The main components of lipoedema management include:

Psychological support

The aim is to identify emotional and mental health issues that are problematic for the person, enhance self-efficacy, and provide individualised long term support with psychological adjustments. For some, this may require referral to psychology services. Potential barriers to self-management should be discussed with the person; advice with family planning and genetic counselling may be required.

Healthy eating and weight management:

As indicated earlier, many women with lipoedema experience eating disorders linked to fruitless attempts at weight management. Weight loss programmes appear to have limited influence on lipoedema fat, but will reduce 'normal' fat, which often compounds lipoedema. The Best Practice Guidelines provide a critical review of diets used in lipoedema (Wounds UK 2017). Although there is no robust research evidence, many women report food sensitivities; and diets rich in processed foods, wheat and inflammatory foods such as those high in sugar, are generally thought to exacerbate lipoedema symptoms (Ehrlich et al 2015).

Physical activity

Individualised exercise can enhance lymph drainage, build muscle tone and help with maintaining a healthy weight (Fetzer & Wise 2015). Low impact exercise reduces joint strain, and water-based exercising is often favoured by women with lipoedema as it allows free and supported movement of the joints, while the water exerts pressure on the tissues, enhancing lymph and venous return. The excess fat tissue means that the women may float easily in the water! Specialist advice should be sought for those with falls risk, gait problems, and foot deformities such as plantar fasciitis, which may develop in women with lipoedema.

Skin care and prevention of skin damage

As with lymphoedema, maintaining intact, healthy skin through daily cleaning and moisturising is essential (Wounds UK 2017). This will help to reduce the risk of ulceration and cellulitis (Williams & MacEwan 2017). Women should be encouraged to use emollients that suit their skin, and additional wound care products initiated as required, for example, to protect skin folds or treat problems such as fungal infections.

Compression therapy:

Compression therapy is used in lipoedema to:

1. Provide containment and support to the tissues, reducing discomfort, aching and pain, and enhancing movement
2. Improve limb shape and body image
3. Reduce interstitial fluid formation and encourage venous and lymphatic return, so minimising oedema formation.

Many women with lipoedema, even in the early stages of the condition, derive benefit from wearing compression garment, provided these are well fitting and comfortable. Those with secondary lymphoedema should certainly be fitted with garments, and some may require compression bandaging to reduce oedema content or heal ulceration, before moving to wearing a garment. Skilled measuring and fitting of garments is required, and customised made-to-measure garments are often more effective due to the unusual shape of the legs and buttocks (Wounds UK 2017). It is often judicious to start with lower compression, due to the pain and hypersensitivity associated with lipoedema. Some women prefer footless leggings, or Bermuda-style garments in a flat knit style (Picture from medi uk?). Below knee stocking may be unsuitable due to fat bulges at the knees. Circular knit garments are mainly suitable in the early stages when shape distortion is minimal. Time should be spent discussing how the garments will be applied, and prescribing a suitable applicator if required. (or this could be in a Points for Practice table)

Referral for additional support

Referral to lymphoedema, vascular services, dietetics, plastic surgery or a manual lymph drainage therapist may be important for additional investigations, specialist

advice and treatment. Manual lymph drainage may be indicated to manage pain and oedema, but is not readily available on the NHS (Wounds UK 2017). Third Sector organisations such as Lipoedema UK and Talk Lipoedema are key sources of peer support and self-management advice, and information can be accessed online about local and national activities.

Surgical management

This includes liposuction and bariatric surgery, although opportunities for NHS treatment are limited and many women attend private clinics in the UK or abroad for liposuction as shown in Angie's story (Figure 3). There is evidence that liposuction can improve quality of life and reduce symptoms such as pain, poor mobility and oedema (Schmeller et al 2012; Baumgartner et al 2016). Clinics providing liposuction must take a multi-disciplinary approach, as conservative management, such as regular wearing of compression therapy after surgery, is also essential.

Conclusion

Lipoedema is a poorly understood long term condition that creates many challenges for women, their families and professionals. Best Practice Guidelines are helpful in increasing awareness of how the condition is diagnosed and managed. Further research is required to identify the most appropriate approaches to supporting women with lipoedema to deal with the physical and mental issues associated with lipoedema.

Patient story- Angie

I was diagnosed as having lipoedema in 2007, at the age of 45. I had always had bigger legs from around the age of 13 and always felt that there was something different about me but had no understanding of the condition or the long journey ahead of me. I was shocked that the GP had never heard of lipoedema, when the vascular surgeon made the diagnosis. I was then referred to my local lymphoedema clinic.

Initially, I was offered liposuction in 2008, and I had to go to a private clinic in England (I am from Northern Ireland) to have the treatment which was funded by the NHS. The clinic also prescribed compression garments and administered manual lymphatic drainage. Soon I began to realise that there was more to lipoedema than I realised.

However, not long after, I was diagnosed with depression. I feel it is important to remember that depression and anxiety can be caused by pain; and lipoedema is a

painful condition. There is often a low level of pain present and this drains your energy, both physically and emotionally.

A year after my surgery I was referred to a plastic surgeon locally in Northern Ireland, who had a particular interest and expertise in lipoedema. He was very honest and explained that further surgery was not necessarily the answer, and that dieting could also be limited help as it would not remove the lipoedema fat. He said he could lock me in a room for a year and feed me on lettuce leaves and sadly I would still have lipoedema.

These days I manage and control my condition as best I can by wearing compression garments. I now also have to pay privately to have manual lymph drainage (MLD) as this is no longer available to me on the NHS. The MLD has made a vast difference to my overall health and, in fact, reduced the size of my legs on the areas that have not had liposuction by up to 9cm in places!

My focus these days is on advocating the public and medical professionals and I do this with the help of Talk Lipoedema which is an online support group and which currently has around 2,000 members. My hope for the future is that someday every healthcare professional will recognise the signs and symptoms of lipoedema, and know the difference between lipoedema and lymphoedema.

I also hope eventually that the future generations such as my own daughter who has also received a diagnosis of lipoedema will have access to the much needed medical care they deserve. The lack of recognition is probably leading to many cases of severe lipo-lymphoedema that might have been prevented by having more awareness and earlier treatment of lipoedema.

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Signpost to Royal College of GPs online course?

Provide Talk Lipoedema website