

LIPOEDEMA: POOR KNOWLEDGE, NEGLECT OR DISINTEREST?

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At the 3rd International Lymphoedema Framework (ILF) conference in Toronto, an attempt was made to begin to try to address this issue. Over thirty people attended a lipoedema workshop run by the author. In this workshop, I had the opportunity to talk to this international group (Canada, USA, Netherlands, Australia, UK, Germany) who shared their experiences from across the world. One of the goals of the workshop was to create an initial broad consensus about the worldwide diagnosis and management of lipoedema. The outcomes of that workshop are presented in the following report.

Background

Lipoedema is a fat distribution disorder that almost exclusively occurs in women and is infrequently recognised. Both hormonal impacts and genetic predisposition are assumed with lipoedema. However, statistics vary widely. Lipoedema usually develops during puberty or pregnancy. It is characterised by symmetrical enlargement of the legs, pain, tenderness, easy bruising and persistent enlargement after elevation of the limbs, or weight loss. The swelling and pain gets worse during warm weather and exercise. The disorder has a chronic

and progressive character that may result in a lipolymphoedema. There are some views that lymphoedema may precede lipoedema (Piller, personal communication). Several types have been described according to the location of fat deposits:

- ▶▶ Type 1: mainly buttocks
- ▶▶ Type 2: buttocks to knees
- ▶▶ Type 3: buttocks to malleoli
- ▶▶ Type 4: mainly arms
- ▶▶ Type 5: Lipolymphoedema.

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Schmeller and Meier-Vollrath (2007) defined three stages of lipoedema:

- ▶▶ Smooth skin with a thickened subcutaneous layer with evenly distributed small nodules in stage 1
- ▶▶ Enlarged nodules with an uneven, orange-like skin surface in stage 2
- ▶▶ Increasingly indurated subcutaneous tissue with bulging protrusions of fat in stage 3.

Diagnosis can be made by patient (family) history and clinical examination. The back of the hands and feet remain free of swelling. 'Stemmer's sign' is always negative in lipoedema. Also, the typical distribution of fat nodules clearly indicates lipoedema. To date, no reliable diagnostic test for lipoedema is available

(Schmeller and Meier-Vollrath, 2007; Langendoen et al, 2009).

Epidemiology

A range of prevalence/incidence numbers are mentioned in the literature. However, the incidence of lipoedema in the general population is not known. Several specialty clinics support the general healthcare professional's suspicion that the incidence of lipoedema is more frequent than indicated. Figures from a specialised lymphoedema clinic in Spain revealed that lipoedema was diagnosed in 22.9% of the patients referred (Forner-Cordero et al, 2006). A German clinic indicated 15% of their patients were diagnosed with lipoedema (Herpertz, 1995). In Hungary, one epidemiology study was conducted by Szolnoky et al (2008) regarding concomitant disease. 34% of the patients were diagnosed with pure lipoedema. All other lipoedemas had other concomitant diseases (venous oedema, lymphoedema). Földi described 11% prevalence of some degree of lipoedema among postpubertal girls (Foldi and Kubik, 2005). Since several women in one family often have lipoedema, a genetic predisposition is assumed in 16–64% of the cases (Schmeller and Meier-Vollrath, 2007). *Table 1* outlines the differences between lymphoedema and lipoedema.

Those attending the lipoedema workshop during the 3rd ILF conference were generally not aware of the prevalence numbers in their country, despite often seeing and treating the condition when it presented as a misdiagnosis of lymphoedema, or when it was clearly associated with lymphoedema. Overall, the group

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Table 1
Differences between lymphoedema and lipoedema

| Lymphoedema | Lipoedema |
|-------------------------|-------------------------|
| Both female and male | Mostly female |
| All age groups | Mostly puberty |
| Asymmetrical | Symmetrical |
| Not painful | Painful |
| Feet involved | Feet not involved |
| No haematomas | Haematomas |
| Erysipelas | No erysipelas |
| Responds to dieting | No response to dieting |
| Positive Stemmer's sign | Negative Stemmer's sign |

concluded that lipoedema is probably more common than most physicians realise. However, there is a great need for epidemiology studies to support this conclusion.

Treatment

Combined decongestive therapy (CDT) is widely accepted as standard therapy for lipoedema based on clinical experience. Compression is part of this treatment regimen. Compression may prevent the progression of the lymphatic component of lipoedema and partly improve the symptoms. It has been suggested that with early detection of lipoedema, compression should be enough to stay in stage 1. However, there is no worldwide consensus about the compression class to be used. The most widely used classifications are:

- ▶▶ Class 1: 20–30mmHg
- ▶▶ Class 2: 30–40mmHg
- ▶▶ Class 3 40–50mmHg
- ▶▶ Class 4 50–60mmHg.

However, there are also the British standard and RAL (German classification) (Table 2; Lymphoedema Framework, 2006).

Although international recommendations advise to use class 1

or 2, the department of dermatology and allergology at the University of Szeged, Hungary prefer class 3 garments.

Seventeen of the group attending the conference advised looking at the individual patient and fitting a garment according to experience from pain tolerance during bandaging. Others suggested that limb shape and garment stiffness play an important role in deciding which compression class to use. Patients with lipoedema generally have more fat deposition on the lateral side of the thighs and the medial side of the knees. Also, the 'cuff sign' at the ankles makes it difficult to measure a proper fitting compression garment.

CDT consists of manual lymph drainage (MLD), physical exercise, multilayered compression bandaging and skin care. In some cases it can be combined with intermittent pneumatic compression (IPC). IPC may improve venous flow and decrease lymph production upon reduction of capillary afterload (Szolnoky et al, 2008). During the ILF conference, the group debated whether IPC is a useful addition to the treatment of lipoedema patients.

The general group opinion (30) was that there is no conclusive data. It was felt that IPC may not be well tolerated and there were doubts as to its effectiveness on patients with lipoedema, due to the absence of fluid components. On the other hand, the group agreed that in some cases it might be useful, for example, in lipolymphoedemas, but always under strict supervision and in combination with MLD. In a clinical study (n=23) conducted by Szolnoky et al (2008), MLD-based CDT was compared with MLD plus IPC-based CDT. Each treatment resulted in significant limb volume reduction (P=<0.05). However, the trial did not reveal a difference (P=0.07) between the two therapeutic modalities. It is safe to use IPC in addition to other treatments (Szolnoky et al, 2008).

Exercise is one treatment modality that is recommended to patients. But, what kind of exercise and how intensive?

Table 2
UK and German RAL classifications of hosiery

| | British standard | RAL (German classification) |
|---------|------------------|-----------------------------|
| Class 1 | 14–17mmHg | 18–22mmHg |
| Class 2 | 18–24mmHg | 23–33mmHg |
| Class 3 | 25–35mmHg | 34–46mmHg |

During the ILF conference, the majority of the group had no answer to this question. They all agreed that patients should control their weight, strengthen their muscles and improve their endurance, but what is the effect on the lymphatic system or blood vessels? Does high intensity exercise worsen micro aneurysms of blood vessels and make bruising worse? The group could not reach agreement, and no consensus was reached on exercise being based upon graded activity.

Surgical intervention for patients with lipoedema has become more common in recent years. The historical picture of liposuction shows thick and sometimes sharp suction cannulae that damage the lymphatic system (Schmeller and Meier-Vollrath, 2007: chap 7). This resulted in a clear judgement during the ILF conference: the whole group decided that liposuction was not the right course of treatment for lipoedema.

However, the development of new surgical techniques and better anaesthesia has led to a turnaround in this picture. During the super-wet technique, 2–8 litres of fluid get infiltrated subcutaneously. Tumescence local anaesthesia (TLA) eliminates the need for general anaesthesia, increases the safety for the patient, contributes to a low rate of infection, and, following surgery, patients remain pain-free for 18 hours (Schmeller, personal communication). During suctioning, a thin mixture of solution and a maximum of 4 litres of fat are removed. Depending on the degree of lipoedema,

between one and five operations may be required with intervals of several months (Schmeller and Meier-Vollrath, 2007; Schmeller et al, 2010). The results of a study conducted by Schmeller et al (2010) in Germany (n=112) show that spontaneous pain, pain upon pressure, oedema, haematomas and restriction of movement were improved. In addition, there were reductions in fat volume, improvement in quality of life, self-assessment and cosmetic appearance.

Greer (1974) suggested that people with lipoedema do not inherently have obesity, but about 50% are overweight. In recent years, populations have grown to include many different ethnic and cultural groups, resulting in diverse food preferences and eating habits. Considering this pattern alongside today's fast pace of life, the group came to the agreement that this has contributed to an almost 70–80% incidence of patients with lipoedema being overweight. It has been suggested that increased fat deposits of the lower limbs in women is caused by obesity (60%), lipoedema (20%) or a combination of both (20%) (Herpertz, 1995). Questions that arose among the group included:

- ▶▶ Do eating habits contribute to a higher incidence of lipoedema?
- ▶▶ Does this explain the differences between, for instance, women in Japan and Brazil in terms of body shape?

Most importantly, it is vital that we all continue to raise awareness and recognition of lipoedema among doctors, therapists, politicians and those

who manage the public and private healthcare systems. Lipoedema is a chronic progressive condition and early diagnosis and targeted intervention may prevent or slow down its development,

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thereby resulting in cost-savings for healthcare systems.

If you would like to be updated and contribute to consensus about the management of lipoedema, or you have experience with one of the above mentioned topics that you would like to share, please send an email to lipoedema@live.com, or add a discussion point on the JoL website (www.lymphormation.org), the author will coordinate and include your responses in a follow-up paper.

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Key points

- ▶▶ Lipoedema is probably more common than most physicians realise.
- ▶▶ Look at the individual patient and use your experience in pain tolerance during bandaging when fitting a proper compression garment for lipoedema patients.
- ▶▶ There is agreement that patients should control their weight, strengthen their muscles and improve their endurance.

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www.lymphormation.org

A one-click site for keeping abreast of up-to-date lymphoedema-related resources, events and developments, both nationally and internationally.