Survey of lipoedema symptoms and experience with compression garments

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**Abstract:**
Lipoedema is an incurable chronic disease causing limb deformity, painful skin and excessive ecchymosis. Compression garments are frequently recommended to manage symptoms but existing compression garments are designed for other medical conditions. A structured questionnaire was prepared to investigate lipoedema symptoms and the use of compression garments to manage symptoms. The survey was available on ‘Online Surveys’ in October 2018. 279 people with lipoedema completed the survey, 70% wore compression garments in all 4 compression classes, class 2 was most common (58% of wearers). The top 3 reasons for wearing compression garments were to feel supported (73%), reduce lipoedema pain (67%) and improve mobility (54%). Most people with lipoedema who had compression garments, found compression helpful in managing their symptoms but overall satisfaction was low. Problems with existing compression garments were so severe in some cases that garments were not worn at all or used less often.

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**Additional Information:**

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<th>Question</th>
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Survey of lipoedema symptoms and experience with compression garments

Ilka Paling and Lisa Macintyre

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Acknowledgement: Many thanks to the staff at Jobskin, especially Debbie Wright, Sharie Fetzer of Lipoedema UK and Denise Hardy. Jobskin sponsored some of the time associated with this work, covered expenses for promoting the survey at BLS and supplied a free compression garment to one of the survey participants. Sharie and Denise proof read the questionnaire and Lipoedema UK helped to promote the survey via their website.

Conflicts of interest: No conflict of interest to report. However, in accordance with my ethical obligations as a researcher I wish to disclose that Jobskin commissioned this survey as part of a wider study. Complete academic freedom was maintained throughout data analysis and writing and Jobskin have encouraged the dissemination of this work without interference.
Abstract

Lipoedema is an incurable chronic disease causing limb deformity, painful skin and excessive ecchymosis. Compression garments are frequently recommended to manage symptoms but existing compression garments are designed for other medical conditions. A structured questionnaire was prepared to investigate lipoedema symptoms and the use of compression garments to manage symptoms. The survey was available on ‘Online Surveys’ in October 2018. 279 people with lipoedema completed the survey, 70% wore compression garments in all 4 compression classes, class 2 was most common (58% of wearers). The top 3 reasons for wearing compression garments were to feel supported (73%), reduce lipoedema pain (67%) and improve mobility (54%). Most people with lipoedema who had compression garments, found compression helpful in managing their symptoms but overall satisfaction was low. Problems with existing compression garments were so severe in some cases that garments were not worn at all or used less often.

Keywords: Lipoedema; compression; symptoms; experience; survey

Key points

• Lipoedema is an incurable chronic disease causing tissue pain, abnormal shape, reduction in mobility with significant impact on quality of life, its prevalence is reported as between 0.003% and 11% of women.
• Reduction in self-confidence was reported by 86% of people with lipoedema and 71% said that it has reduced their ability to exercise.
• Compression garments are often recommended to manage lipoedema symptoms but none were specifically designed for lipoedema and ideal compression level is not known.
• The top 3 reasons for wearing compression garments were to feel supported (73%), reduce the pain associated with lipoedema (67%) and improve mobility (54%).
• Although most of the people with lipoedema who had compression garments wore them regularly to alleviate their symptoms, a number of problems with existing compression garments were reported that led to overall satisfaction being low.

Reflective questions

1. What level/type of compression works best for lipoedema in your experience?
2. What are the biggest difficulties encountered when wearing compression?
3. What factors have the biggest impact on compliance with compression?

Introduction

Lipoedema is a distinct medical condition of the adipose tissue (Shavit et al, 2018), with misdiagnosis commonplace (Peled and Kappos, 2016). Lipoedema is commonly confused with obesity or lymphoedema (Allen and Hines, 1940) but has some distinctive characteristics:

• It affects lower limbs but spares feet (Allen and Hines, 1940; Child et al, 2010; Buck and Herbst, 2016; Shavit et al, 2018).
• Some believe it can affect upper limbs but spare hands, (Shavit et al, 2018) while others believe this to be rare (Schmeller et al, 2012).
• There is often a clear demarcation between normal and lipoedemous tissue known as the “cuff sign” (Shavit et al, 2018).
• It is bilaterally symmetrical but disproportionate to the rest of the body (Allen and Hines, 1940; Bilancini et al, 1995) and people with lipoedema often have comparatively slim waists.
• Excessive and frequent ecchymosis that is disproportionate to trauma (Herbst, 2012) reported by 86% of patients (Romeijn et al, 2018).
• Tissue pain in limbs, particularly lower limbs (Allen and Hines, 1940; Herbst, 2012; Shavit et al, 2018) and pain upon pressure reported by 88% of people with lipoedema (Romeijn et al, 2018).
• Pendulous tissue (or ‘cuffing’) and lumps of fat particularly on the legs at ankle, knee and thigh (Schmeller et al, 2012; Shavit et al, 2018) at stage 3.
• It affects (almost) only women and may be hereditary (Allen and Hines, 1940).
• Onset, and progression, of lipoedema is often associated with significant hormonal change such as puberty, pregnancy or menopause (Child et al, 2010; Dudek et al, 2016).
• Dieting and exercise have limited impact on lipoedema (Dudek et al, 2016; Peled and Kappos, 2016).

Some authors report the incidence of lipoedema as low/rare (Child et al, 2010), while others claim 11% prevalence of lipoedema among hospitalised women (Dudek et al, 2016) and rarely in men with hormonal imbalance (Shavit et al, 2018). Birkballe et al (2014) believe that 10-20% of people attending lymphoedema clinics actually have lipoedema.

Lipoedema reduces quality of life and is commonly reported as affecting patient’s mental health (Dudek et al, 2016). In the later stages of lipoedema, lymphoedema can develop (called lipolymphoedema), venous disorders can also co-develop (venolipedema) (Shavit et al, 2018). Early diagnosis and effective treatment can minimise the progression and impact of the condition, which can be debilitating.

Compression for lipoedema

Lipoedema tissue does not respond to compression therapy, but compression garments can reduce pain, limit progression of symptoms and development of complications (Reich-Schupke et al, 2013; Coppel et al, 2017; Shavit et al, 2018). Despite the lack of clinical evidence many believe that compression can minimise lipoedemous symptoms (Romeijn et al, 2018) and report its common use as a conservative treatment (Schmeller et al, 2012). Compression should be introduced at the early stage of the disease to control oedema. However, non-compliance with compression is associated with discomfort, and difficulties have been reported in getting compression garments on (donning) (Fetzer, 2016). Compression is reported to shape and support lipoedemous limbs and prevent progression to lipolymphoedema (Szolnoky and Kemény, 2010) but there is limited evidence for this.

Lipoedema pain is associated with touch or pressure (also prolonged standing or end-of-day) and therefore high compression products are not well tolerated. This is problematic if the lipoedema is associated with venous or lymphatic disorders where treatment with high-level compression is necessary (Shavit et al, 2018).

Compression class 3 garments (exerting distal pressures of 30-39 mmHg) are recommended for reversible lymphoedema patients (Dumbleton and Clift, 2008) and it is likely that lipolymphoedema
patients should wear this level of compression. Coppel et al (2017) recommend class 1 or 2 compression hosiery for lipoedema patients (dependent on symptom severity) with the addition of compression wraps and bandaging where severe lipolymphoedema is present. However, the earlier ‘buyers guide to compression hosiery’ recommends compression of over 50mmHg for lipoedema (Dumbleton and Clift, 2008). There is currently no specific compression level guideline for lipoedema or lipolymphoedema published by NICE. It is likely that lower levels of compression may be suitable for lipoedema but explicit evidence for this is not currently available.

Methods

Questionnaire

A questionnaire containing 41 questions on lipoedema symptoms and compression garments was prepared. Most questions used a 5-point Likert scale with space for comments, measurements or additional information. Feedback was given by Fetzer (chair of Lipoedema UK charity) and Hardy (Lymphoedema/lipoedema nurse consultant) to ensure the questionnaire met the needs and experience of people with lipoedema. Wright and Holmes (Jobskin) ensured that wording on garment types complied with commercial norms. Ethics approval was granted by Heriot-Watt University Ethics Committee.

Setting and participants

The questionnaire was distributed through Online Surveys and collected all data anonymously. The survey was publicised via Lipoedema UK website and British Lymphology Society conference. A plain language statement explaining the survey was provided at the start of the questionnaire. Questionnaires were self-administered and completed anonymously. Payment was not offered for completing the questionnaire but respondents were invited to enter a prize-draw for a Jobskin compression garment designed for lymphoedema treatment or post liposuction oedema control (118 people entered the prize-draw by emailing Jobskin).

Statistical analysis

Descriptive statistics, including means, variation (SD and SE), 95% confidence intervals (CIs) and percentages were calculated in Microsoft Excel (2016). Pearson’s correlation coefficients and p-values were calculated from original data using Minitab 18. Missing values were not included in calculations. Correlations and significant differences between data/responses will only be highlighted if significant at ≥95% confidence.

Results and discussion

Symptoms and impact

A total of 279 lipoedema patients responded to our survey. Figure 1 shows the mean and mode age of our respondents was in the 48-57 age range. Our respondents (n=266) reported an average height of 164.4cm (SD=6.9cm, CIs=163.6-165.2). Approximately 30% of our respondents did not know their lipoedema ‘stage’. There was no correlation between age and reported Lipoedema stage.
Figure 2 shows that 39% of our stage 1 and 2 lipoedema respondents reported having lipolyphoedema, this is more than would commonly be reported in the literature. This may reflect:

- a lack of clarity on what constitutes ‘stages’ of lipoedema;
- that lipoedema in some respondents did not cause their lymphoedema;
- that some respondents incorrectly believe they have lipolyphoedema;
- or a response bias with this group of respondents, possibly due to the fact that 82.5% of respondents with compression garments were prescribed and measured by a ‘lipoedema or lymphoedema nurse or therapist’. Given that lipoedema is a relatively newly recognised condition, most people with lipoedema are treated in lymphoedema clinics, leading to possible confusion about their diagnosis.

There was no statistically significant difference in the mean age of people reporting lipoedema versus lipolyphoedema. However, respondents reporting lipolyphoedema wore significantly larger dress sizes than those reporting lipoedema ‘only’.

Figure 3 shows that whilst most respondents reported lipoedema tissue in their lower bodies and upper arms. Lower arms, waist and stomach were also reported at lower rates. This description of lipoedema tissue location does not match the literature perfectly, these discrepancies may reflect:

- that people cannot always distinguish between their lipoedema and normal adipose tissue;
- some over-diagnosis of lipoedema, identified as a risk by Reich-Schupke et al. (2013), note 12% of respondents self-diagnosed;
- literature does not yet perfectly reflect the lipoedema respondent’s lived experience.

We also asked people if they had pendulous or large lumps of lipoedema and where this tissue was located. People reporting lumpy lipoedema (n = 160, 58%) gave an average of 2.3 locations, with knees (n = 94, 34%) and thighs (n = 89, 32%) being the most common sites of lumpy lipoedema tissue. 135 people (49.5%) reported pendulous lipoedema with an average of 2.2 locations reported per person, with knees (n = 78, 29%) and upper arms (n = 72, 26%) being the most common locations of pendulous lipoedema. Upper arms are a common location of pendulous tissue in women and there may be some over-reporting of this as lipoedema. 34% (n = 96) of respondents reported having both pendulous and large lumps of lipoedema. There was no correlation between presence of lumpy or pendulous lipoedema and age and no significant difference in age between those with and without lumpy and/or pendulous lipoedema.

The following relationships were noted during the data analysis:

- Respondents reporting pendulous or large lumps of lipoedema wore significantly larger dress sizes than those without.
- Respondents with lumpy and/or pendulous lipoedema reported significantly later stage lipoedema.
- Around half (49%, n = 66) of people reporting pendulous tissue reported having lipolyphoedema while only 29% (n = 40) without pendulous lipoedema reported having lipolyphoedema.

Of the 5 impacts surveyed, and shown in Figure 4, the biggest impact of lipoedema was on self-confidence: 86% of our respondents reported lipoedema reducing their self-confidence ‘always’ or ‘frequently’ and 76% said lipoedema reduced their self-confidence ‘badly’ or ‘severely’. However, there was no significant correlation between the impact of lipoedema on self-confidence and reported lipoedema stage or body size and no significant difference in self-confidence between
respondents reporting lipoedema or lipolymphoedema. Thus although a reduction in self-confidence was the most commonly/severely rated impact of lipoedema it did not appear to be directly related to the severity of the respondent’s current symptoms.

Increasing dress (body) size and lipoedema stage had increasing negative impact on mobility, ability to exercise, work and attend social events (all p<0.001). Respondents with lipolymphoedema reported significantly higher impact, in both frequency and severity, of their symptoms on their mobility, ability to work and socialise than those with lipoedema alone. When asked to score the overall impact of lipoedema on their lives from ‘no impact=1’ to ‘life changing=5’, 73% said lipoedema’s impact on their life was 4 or 5 and only 8% rated its impact as 2 or 1 (little or no impact). The overall impact of lipoedema on people’s lives correlated positively and significantly with both lipoedema stage (p<0.001) and body size (p=0.001).

Large lumps of lipoedema and pendulous lipoedema both had a significantly bigger impact on respondent’s lives than lipoedema without these features. Means and confidence intervals for all these are provided in the supplementary information associated with this paper.

Impact was significantly worse on all factors shown in Figure 4, and overall impact on the respondent’s lives, if they had large lumps of lipoedema tissue compared to no lumps, and were worse if they had pendulous lipoedema compared to not having pendulous lipoedema. Stage 3 lipoedema respondents reported significantly greater impact of their condition on their lives on all counts than stage 1 or 2 respondents. Stage 2 respondents tended to rate the impact of their condition on their lives as worse than stage 1 respondents and most, but not all were statistically significant.

Figure 5 shows that lipoedema respondents wore significantly larger sized garments on their lower body than upper body. There were significant positive correlations between lipoedema stage and body size (p<0.001). Stage 3 respondents were significantly larger than stage 2 (at 95% confidence) but stage 2 respondents were not significantly larger than stage 1. The garment size worn correlated positively with age range mid-point on both upper (p=0.001) and lower body (p=0.002).

Pressure garments

Most (82%, n=229) respondents had pressure garments, normally prescribed by a lipoedema/lymphoedema nurse/therapist (n=188). Of the 229 respondents with pressure garments, 85.5% (n=195) of our respondents wore them with 57% (n=130) wearing them 5-7 days/week, which is similar to previously reported 55% wear frequency (Fetzer and Fetzer, 2016). 14% (n=33) of respondents with pressure garments never wore them.

Figure 6 shows why people wear compression with ‘support’ and ‘pain reduction’ being the most important reasons. 13% (n=26) of all compression wearers thought their garments made little (rating=2) or ‘no difference’ (rating=1) to their symptoms, and a further 33 respondents had compression garments but did not wear them. 33% (n=64) gave a ‘neutral’ ‘3’ rating while 54% (n=106) of respondents thought their garments made a difference (rating=4) or ‘huge difference’ (rating=5) to their symptoms. The compression garments worn by these respondents were not designed explicitly for people with lipoedema and all compression classes were worn, this is likely to impact on wearer experience and satisfaction.

Figure 7 shows that 65 people did not know what class of compression they wore, they may be wearing unclassified compression, may not have been informed or forgotten. Class 2 was the most
commonly reported compression class worn. The differences in overall satisfaction between compression classes were not statistically significant.

The mean compression class worn by stage 3 lipoedema respondents was significantly higher than that worn by stage 1 respondents, but the differences in mean compression worn by stage 2 compared to stage 1 or 3 respondents were not significant. Respondents reporting pendulous lipoedema wore a significantly higher mean class of garments than those without pendulous lipoedema. There were no significant differences in wear experience between respondents with different stages of lipoedema or between those with and without pendulous lipoedema. There were no significant differences in the garment types, level of compression, wear times or wearer experience reported between the group of respondents with lipoedema and the group with lipolymphoedema, nor between those reporting large lumps compared to no lumps of lipoedema.

Figure 8 shows that 84% of compression garments owned by our respondents were for lower body and most were compression stockings or tights. Note that seamed/flat knit tights and stockings are normally made-to-measure from thicker fabric than circular knitted tights and stockings (no seams on legs). The differences in satisfaction ratings between garment types were not statistically significant.

Figure 9 shows that most people wore their compression garments regularly, the same number of people wore their garments every day as the total who wore them less regularly and some wore their garments every day and night. There was no significant difference between the wear time of any of the different groups of respondents based on their lipoedema stage, compression class worn, presence/absence of: lumps, pendulous lipoedema or lymphoedema. However, there was a significant correlation between increasing wear frequency/time and increasing impact on symptoms of lipoedema/lipolymphoedema (both p<0.001) as might be expected. However, it was not clear whether people who found their garments more useful wore them more frequently, or whether frequent use of compression increased the beneficial impact on symptoms.

We asked people to rate their garments on a 5-point Likert scale for a range of ‘wearer experiences’ where 1 was a negative statement and 5 was the positive opposite. For example ‘the garments I have are uncomfortable’ (=1), ‘the garments I have are comfortable’ (=5). Table 1 shows that the biggest problems with existing garments were that they are difficult to get on and off, can be too hot and are unattractive. Unattractive garments may seem superficial but as a visible therapeutic device for women with low self-confidence this is a potentially important issue in relation to quality of life. In a separate question: ‘Do you struggle to get the compression garment on?’ 61.2% of respondents answered ‘yes’ and associated comments indicated donning can take some people 30 minutes and sometimes the pain of donning prevents or limits use. There were significant correlations (all p<0.001) between overall satisfaction and the individual ‘wearer experience’ questions shown in Table 1. Overall satisfaction with compression garments correlated with reported wear time (p=0.015) and wear frequency (p<0.001).

There were no statistically significant differences in ‘wearer experience’ or overall satisfaction with pressure garments for people reporting lipolymphoedema compared to lipoedema ‘only’, those reporting large lumps of lipoedema compared to those without or pendulous lipoedema compared to people without pendulous lipoedema.

**Conclusions**
People with lipoedema responding to this survey most commonly wore class 2 compression garments for the lower body, most commonly compression hosiery. Respondents most commonly wore compression to feel supported, reduce pain and improve mobility. The biggest problems reported with compression were getting garments on and off, being too warm and compression garments being ugly. These issues frequently prevented or limited respondent’s use of their compression garments.

This survey has shown that garments giving positive wearer experiences were worn more often and for longer than garments that were too tight, uncomfortable, ugly, too warm, etc. Wearers reporting longer wear times/frequency also reported greater beneficial impact on symptoms and by implication better mobility and reduced pain. This survey indicated that more severe symptoms had less impact on garment use than whether or not the garments were comfortable and easy to use. Thus, it is important to determine the properties of compression garments that would be comfortable for different stages of lipoedema and lipolymphoedema as compression is not currently designed specifically for these conditions. Whilst most of these garments should be for the lower body, there is a smaller need for upper body compression. Many respondents expressed a desire for non-medically styled compression, in a wide range of colours and garment options.

References


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Figure 1 – age range and reported stage of lipoedema reported by survey respondents (n=278)
Figure 2 – number of respondents with lipoedema who also report having lymphoedema (lipolymphoedema) and those who report having lipoedema alone
Figure 3 – breakdown of where lipoedema tissue is believed to reside by respondents identifying with a particular stage of lipoedema (respondents ticked all locations of their lipoedema tissue)
Figure 4 – Impact of lipoedema on patient’s lives. Bars show the percentage of respondents rating the impact from ‘never’ to ‘always’. Respondents also rated how much lipoedema affected them on a scale of 1-5 where 1 was ‘not at all’, 2=‘slightly’, 3=‘moderately’, 4=‘badly’ and 5=‘severely’, mean rating is given in parenthesis and most closely associated term is stated before the impact statement.
Figure 5 – garment size worn on upper body and on lower body by Lipoedema patients (n=276)
Figure 6 – reasons why respondents (n=195) wear their compression garments (mean 3.6 reasons selected/respondent) cross-referenced to respondent’s overall rating of how much compression garments help to alleviate their symptoms.
Figure 7 – compression class of garments worn compared to average improvement in symptoms, $r$ = the mean rating of improvement made to symptoms by garments.
Figure 8 – Types of compression garments worn by respondents and their overall rating of how much difference compression garments make to alleviate their symptoms, n = number of respondents with that garment type, r = mean rating for overall symptom alleviation.
relationship between how long compression garments are worn and symptom alleviation

n=5 wear less than once a month, r=3.0
n=12 wear less than once a week, r=2.58
n=11 wear 1-2 days a week, r=2.91
n=30 wear 3-4 days a week, r=3.47
n=24 wear 5-6 days a week, r=3.75
n=82 wear every day, r=3.93
n=11 wear every day and at night, r=4.18

Figure 9 – how long compression garments are worn compared to the rating given for the impact that garments had in ‘help(ing) to alleviate symptoms’. n gives the total number of respondents wearing the garment for the stated time and r gives the average respondent rating.
Please rate the way you feel about compression garments you have worn: **A rating of 1 being:**

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<td>The garments I have are too hot</td>
<td>N= 50 (26%)</td>
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<tr>
<td>The garments I have are ugly</td>
<td>N= 49 (25%)</td>
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<td>The garments I have cut into my skin</td>
<td>N= 31 (16%)</td>
<td>3.127</td>
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<td>The garments I have are uncomfortable</td>
<td>N= 29 (15%)</td>
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<td>The fabric irritates my skin</td>
<td>N= 28 (15%)</td>
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<td>The fabric is scratchy on my skin</td>
<td>N= 25 (13%)</td>
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<tr>
<td>The garments I have don’t fit properly</td>
<td>N= 23 (12%)</td>
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<tr>
<td>The garments I have, have a negative effect on how I feel about body appearance</td>
<td>N= 21 (11%)</td>
<td>3.142</td>
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<tr>
<td>I find the pressure hard to tolerate</td>
<td>N= 16 (9%)</td>
<td>3.495</td>
</tr>
<tr>
<td>The garments I have are too tight</td>
<td>N= 14 (8%)</td>
<td>3.543</td>
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</table>

Table 1 – Mean satisfaction ratings for ‘wearer experience’ of existing compression garments and the number (and percentage) of respondents giving the worst rating to garments
Click here to access/download **Dataset**
**supplementary data.xlsx**