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Lymphoedema management at night:
views from patients across
five countries

Justine C Whitaker

Nurse Consultant and Senior Lecturer (Uclan), Northern Lymphology Ltd

justine@northernlymphology.com

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Lymphoedema is a debilitating lifelong, progressive illness affecting a reported 200 000 people in the UK alone (NHS, 2016). Any part of the body can be affected, but lymphoedema mostly presents in the lower or upper limbs (Rankin and Cooper, 2016). Lymphoedema occurs as a result of the lymphatic system failing to drain (Nazarko, 2015), leaving an excessive accumulation of lymph fluid in the superficial tissues. Lymphoedema can have either a primary or secondary cause (Cooper and Bagnall, 2016). Cooper (2014) identifies primary causes as congenital abnormalities with secondary lymphoedema caused by damage; this could include cancer, trauma, disease or infection. Venous complications, increased age and obesity are also contributory factors to lymphoedema (Jones, 2014).

Lymphoedema is often diagnosed late, misunderstood and inappropriately managed (Hampton, 2015). A lack of research and absence of knowledge in this area is

widely acknowledged to be a concern (Davies et al, 2012; Cooper, 2014). Patient self-management is encouraged at the time of diagnosis, empowering the patient to make informed decisions with support from clinicians about his/her 24-hour-a-day care and treatment. Improved health outcomes have been recorded in patients who have undertaken self-management (Hibbard and Greene, 2013).

Skin care, exercise and compression are key features of effective management of lymphoedema (Wigg and Lee, 2015) together with lymphatic drainage (Honnor, 2008). The International Lymphoedema Framework's (2012) position document on compression stated that successful management of lymphoedema requires a two or three phased multi-faceted approach. Phase 1 focuses on intensive management for the first 1–4 weeks and involves skin care, remedial exercise, manual lymphatic drainage and multilayer lymphoedema bandaging; there may be a transition phase from intensive to long-term management. Phase 2 consists of long-term management strategies to gain control of the condition involving skin care, regular exercise, the use of compression garments, and continued education and encouragement of the patient in his/her self-management.

The use of compression therapy to manage lymphoedema as a long-term strategy is widely documented, with various types of compression garments discussed (Nazarko, 2015; Wigg and Lee, 2015; Whitaker, 2016), although none of these articles refers to specific garments for night wear.

Clinical guidelines and consensus statements for the management of lymphoedema identify armsleeves and short stretch bandages for night-time use (Herpertz, 2004; Lee et al, 2011; National Lymphedema Network, 2011; International Society of Lymphology, 2013). The compression delivered claimed for the products cited was from 12–14 mmHg to 20–30 mmHg.

Literature offering support to health professionals can be confusing; Cooper (2014) describes how compression is removed in the evening to undertake skin care but does not specify when compression therapy should be re-applied either in the evening or only the next morning. With limited published information relating to compression

ABSTRACT

The aim of this study was to gain a comprehensive insight into the use of night-time compression in the management of lymphoedema in patients who had been suffering from chronic lymphoedema for over 12 months. Data were collected and analysed from 94 patients, across five countries. Understanding user characteristics provided insight and understanding into how night-time compression regimens were initiated, products were used and benefits to the patient were reported. In addition to gaining an insight into user habits and night-time compression benefits, unmet needs were also identified. Positive outcomes from the use of night-time compression were reported, with all patients identifying benefits of using night-time compression. An increase in swelling was documented in 89% of all patients in this study group when night-time compression was not used. The study provided an opportunity to explore how lymphoedema affects patients, and how night-time compression can form part of a beneficial regime.

KEY WORDS

- ♦ lymphoedema ♦ night-time compression ♦ swelling
- ♦ product experience ♦ oedema

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therapy usage and outcomes during rest or night periods, this study was planned to provide an insight into the patient experience, identifying benefits, drawbacks and any unmet needs in the use of night-time therapy.

Method

Patients were recruited for interview from Germany, Sweden, USA, UK and Australia through lymphoedema support networks and clinicians. The Code of Conduct of the European Pharmaceutical Market Research Association (2016) was followed in protecting patients' rights and obtaining their written permission for the anonymised use of their data. Inclusion criteria stipulated that the patient had to have been diagnosed with lymphoedema at least 12 months before the start of the study and should be using night-time compression a minimum of once a week in addition to the use of daytime compression. Patients suffering from either primary or secondary lymphoedema were included. A mix of anatomical locations of lymphoedema were included. Inclusion criteria stipulated that all recruited patients must be beyond the decongestion phase of management, i.e. phase 1 (International Lymphoedema Framework, 2012).

Quantitative and qualitative data were collected: comparable quantitative data were gained through set interview questions, which were answered in a 45-minute telephone conversation. The severity of oedema of the affected limb, assessed by the patient, was recorded pre- and post-compression. *Figure 1* shows the guidance given for assessment. Qualitative data were obtained through participants keeping a diary over a 3–5-day period, thus ensuring the patient's experience of night-time compression benefits, drawbacks and unmet needs were identified on an individual basis.

Results

Ninety-four patients were recruited. Patients were 90% female, with an average and median age of 53 years.

Severity of oedema

Sixty per cent of patients described their swelling as moderate to severe. Patient self-categorisation is shown in *Figure 2*.

Table 1 illustrates the distribution of patients: 80% of respondents came from three countries because there was a low response rate in the UK and Sweden.

Severe	No pitting, tissue is hard (fibrotic). Distorted shapes of the limb, often with increased skin folds and skin changes
Moderate	Pitting is manifest. Limbs are misshapen, yet not severely distorted
Mild	Slight pitting possible (when you press your finger on the tissue it leaves a dent that slowly 'fills' up again). No or low distortion of limbs

Figure 1. Guidance to the patient for assessment of oedema. Based on the International Society of Lymphology's (2003) staging

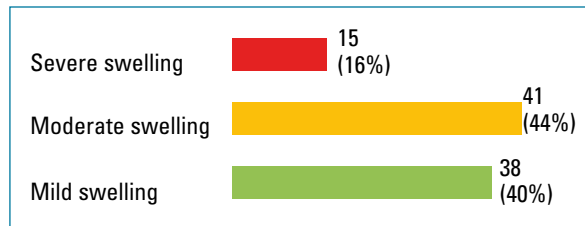


Figure 2. Patients' usual extent of night-time swelling

Night-time compression therapy is widely recognised and recommended as common practice in three of the five countries involved in the study (Australia, USA and Sweden). Over 50% (47) of night-time compression therapy usage was recommended by a health professional. Data were collected on 207 nights within these three countries, and 108 nights from Germany and UK. *Table 2* shows which clinicians by country were the cause of patients starting night-time compression, *Figure 3* shows the clinical reasons that patients initiated night-time compression distributed between those who self-initiated and those who responded to advice from a health professional.

Location of lymphoedema

The location of lymphoedema is shown in *Figures 4* and *5*: 63 (67%) participants experienced lymphoedema of the leg, 28 (30%) in the arm or hand and the remaining 3 (3%) in both arm and leg.

A total of 84 (89%) patients reported increased swelling overnight when night-time compression was not worn

Table 1. Patient distribution by country					
Australia	USA	Sweden	Germany	UK	
25	25	9	25	10	

Table 2. Who recommends the use of night-time compression?						
	Australia (n=25)	USA (n=25)	Sweden (n=9)	Germany (n=25)	UK (n=10)	Total (n=94)
Total % of patients receiving advice from health professional	19 (76.0%)	13 (52.0%)	8 (88.8%)	12 (48.0%)	4 (40.0%)	56 (59.6%)
Physician	5 (20.0%)	3 (12.0%)	3 (33.3%)	10 (40.0%)	–	21 (22.3%)
Lymphoedema specialist	6 (24.0%)	2 (8.0%)	3 (33.3%)	1 (4.0%)	2 (20.0%)	14 (14.9%)
Therapists or physiotherapist	7 (28.0%)	7 (28.0%)	2 (22.2%)	1 (4.0%)	2 (20.0%)	19 (20.2%)
Others: type of health professional not specified	1 (4.0%)	1 (4.0%)	–	–	–	2 (2.2%)

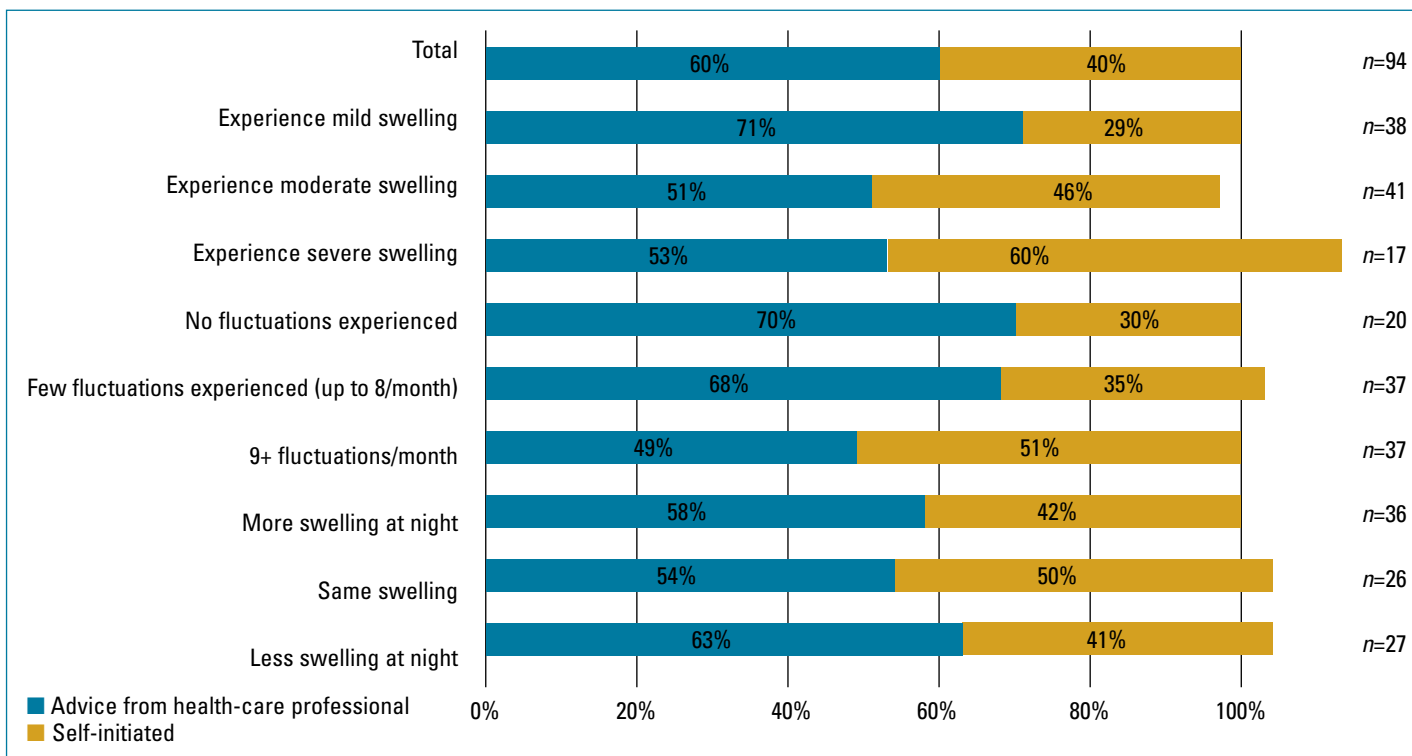


Figure 3. Responses to the question: What made you start using night-time compression? Distributed by receiving health professional advice or self-initiation (percentages may not add to 100%; multiple answers possible)

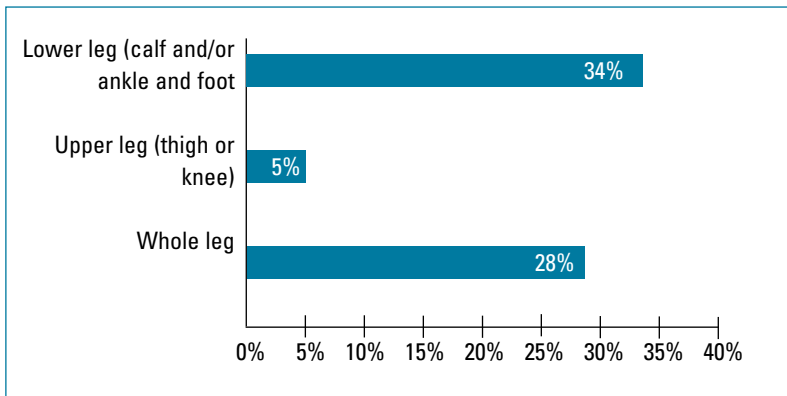


Figure 4. Location of lymphoedema in the lower limb (multiple answers possible)

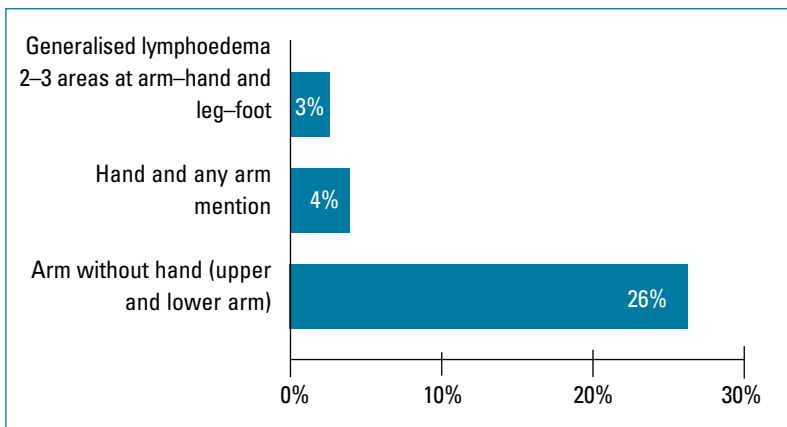


Figure 5. Location of lymphoedema in the upper limb and generalised lymphoedema

(Figure 6), which in 41 (49%) persisted for 24 hours.

A higher proportion (20%, n=25) of those with solely upper limb oedema reported ‘no difference’ than of those with solely lower limb oedema (8%, n=62) (Table 3).

Night-time problems

This study found that 18 (19%) of patients experience sleep problems associated with their lymphoedema. Sixty-six per cent of patients (62/94) reported oedema during the night was the same or greater than that experienced in the daytime. Terminology used by patients to describe the worst thing about night-time swelling included ‘aching’, ‘pain’, ‘tight’, ‘uncomfortable’ and ‘heavy’.

One patient described what night-time swelling feels like:

“a lot heavier, a lot fuller if you like, and I can wake up and its aching”

Andrew: 34, primary lymphoedema, lower leg, UK

Seventy-nine per cent of patients experienced fluctuation in the extent of their oedema (Figure 7). Those reporting ≥9 fluctuations a month (37/94) also had the highest proportion reporting increased oedema at night (Figure 8).

Triggers of oedema

Eighty seven (93%) study participants reported that increased activity or too much activity was a trigger for night-time swelling, but 56 (60%) patients also reported inactivity or sitting too much as a trigger for night-time swelling. These contrasting causes emphasise why the creation of individual care plans based on a holistic

assessment is essential. Overall outcomes stated that 60 (64%) patients link daily activities to their night-time swelling, whether this was too much or too little activity or linked to temperature.

Treatment options

Fifty seven (61%) patients surveyed started using night-time compression later than daytime compression. Thirty eight (40%) used two different products at night. Table 4 shows the types of product mentioned. Multiple answers from one interviewee were possible.

Of the respondents, 38 (40%) used two or more different products simultaneously at night. Three (3/15; 20%) of those with upper limb oedema using two products at night had swelling of over 30% compared to their other limb, compared to 8 (8/23; 34.6%) of those with lower limb oedema.

The specific night-time compression products and classic compression products were not used alone but in 97% (91/94) of cases supplemented by creams, moisturisers, padding, donning aids and the use of intermittent pumps to soften the limb. Of the 91 patients using more than one product, 74 (81%) used a moisturiser in addition to compression therapy; only 9% (5/58) of those who used skin care products used a prescribed skin care product, with the remainder purchasing over the counter products with little or no guidance. Use of additional products by country is shown in Table 5.

Benefits of compression therapy

Data on limb circumference at three points were collected, once at night and once in the morning, for a total of 315 nights from 66 patients, of which 214 nights (68%) recorded leg circumference and 101 nights (32%) recorded arm circumference.

In 86% of measurements of the thigh and 87% of the ankle, oedema was reduced or maintained at the same level; similar results were achieved at the upper arm with 83% oedema reduction or maintenance and 86% at the wrist (Figures 9 and 10).

Forty-five per cent of patients reported a reduction in oedema from using night-time compression and all patients could spontaneously name two or three benefits of it; the top three being the better management of their oedema, reduction in pain and a sense of relief continuing into the daytime. Half of all night-time compression users felt a 24-hour benefit; 60% said they noticed a negative difference all or most of the day when they did not wear night-time compression (Figure 11) and 65% felt that using night-time compression helped them to manage their oedema better. Night-time compression was worn all night long for 73% of nights. Those using a product specifically for night-time wear were more concordant with the therapy; 53% used a specific night-time product every night vs 31% using the same product at night that they had worn during the day. Of those saying a product was easy to self don, 59.3% (19/32) reported a reduction in swelling; of those only 15.8% (3/19) used a true night-

time compression product.

Drawbacks and unmet needs

Twenty five (27%) patients cited being too exhausted or tired to put on night-time compression (Table 6) and 24

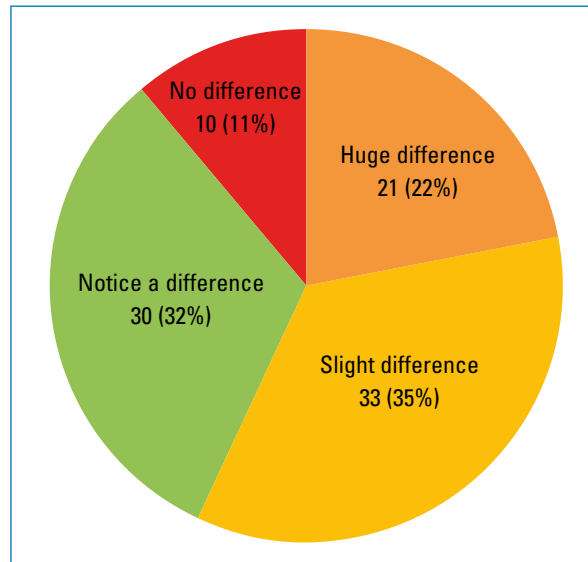


Figure 6. Negative difference experienced as increased swelling if night-time compression not worn (n=94)

	Notice a huge difference	No difference	Notice a difference	Notice a slight difference
Hand/arm (upper limb) (n=25)	n=5	n=5	n=9	n=6
Leg (lower limb) (n=62)	n=13	n=5	n=17	n=27
Hand/arm and leg (n=7)	n=3	–	n=4	–

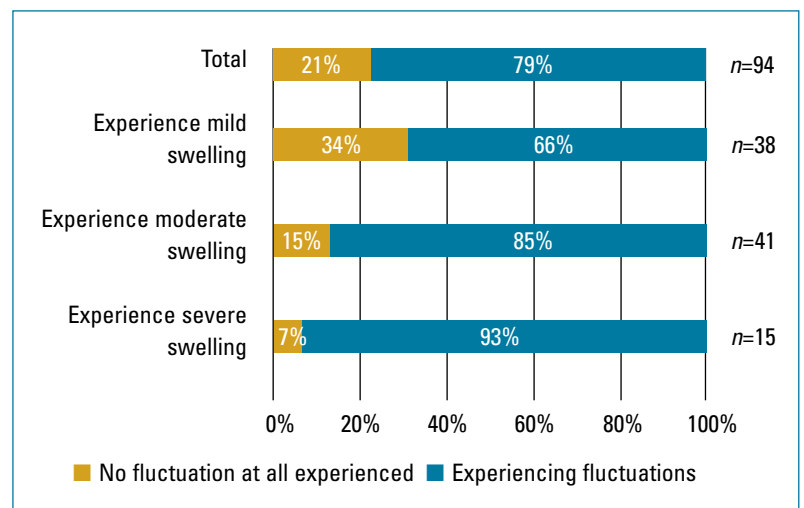


Figure 7. Extent of experiencing fluctuations in lymphoedema swelling at any time

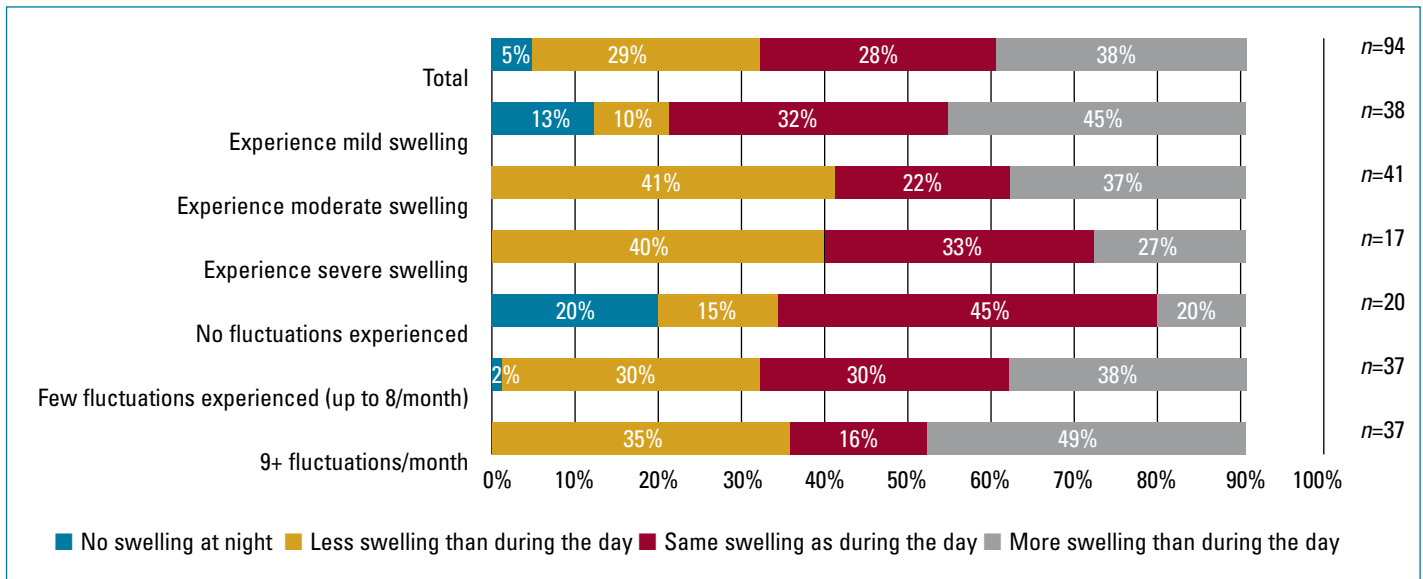


Figure 8. Lymphoedema swelling experienced at night (in general – not as an effect of using a night care compression product) (multiple answers possible)

Table 4. Types of product used at night						
		Australia	USA	Sweden	Germany	UK
Compression products/garments	78%	80%	44%	100%	96%	70%
Wrap	26%	–	56%	11%	32%	10%
Bandage	26%	8%	46%	33%	8%	50%
Fabric with foam fill	18%	12%	48%	11%	–	10%
Foam liner with straps	10%	–	28%	11%	–	10%
Short stretch binders	12%	–	32%	11%	4%	10%
		n=25	n=25	n=9	n=25	n=10

Table 5. Use of additional products with night-time compression by country (n=91)						
		Australia	USA	Sweden	Germany	UK
Use of moisturiser in addition	81%	92%	84%	78%	70%	80%
I massage the affected area	68%	58%	88%	56%	61%	70%
I use a cream in addition	29%	29%	44%	22%	17%	20%
I use a wrap in addition	23%	4%	60%	33%	9%	–
I use a pump to soften/loosen tissue	22%	13%	44%	67%	–	–
I use a donning aid	22%	38%	16%	–	26%	10%
		n=24	n=25	n=9	n=23	n=10

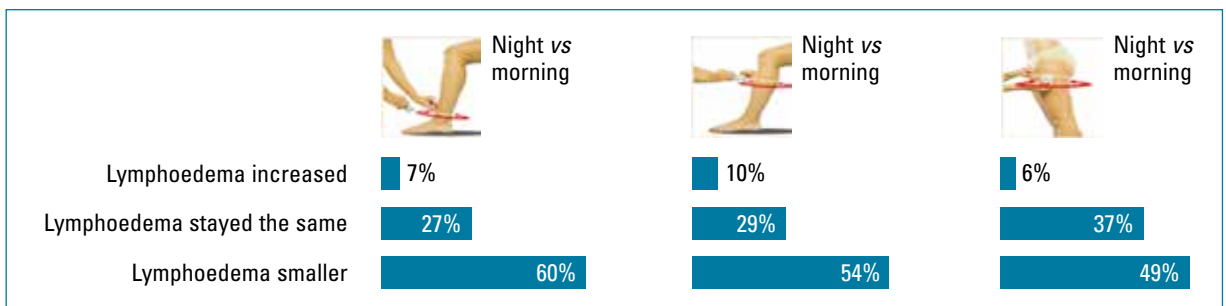


Figure 9. Impact of using night-time compression for lower limb oedema on 214 nights, 45 respondents

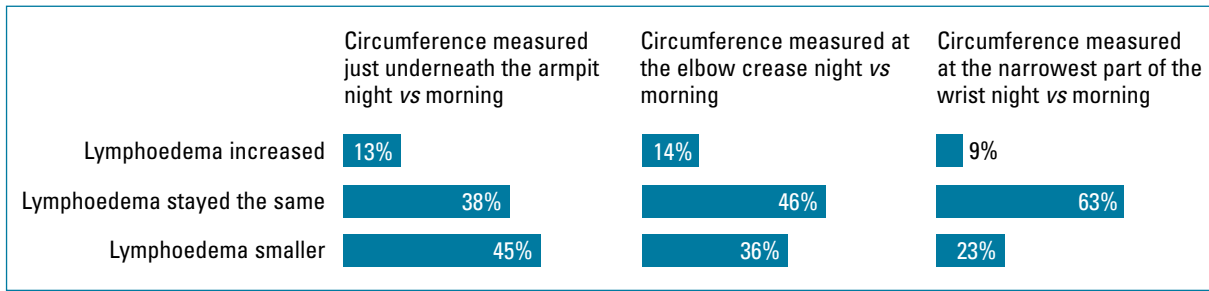


Figure 10. Impact of using night-time compression for upper limb oedema on 101 nights (21 respondents)

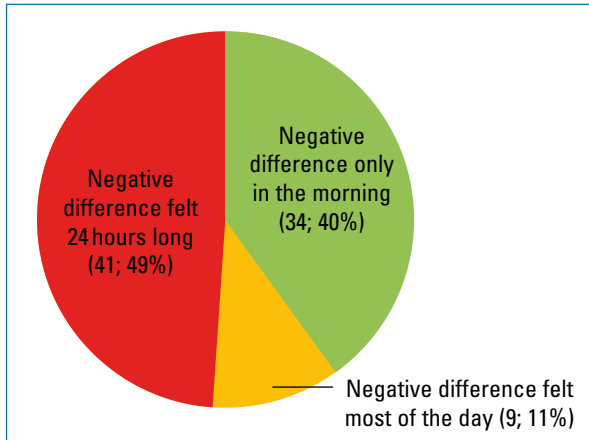


Figure 11. Duration of the negative difference felt by patients after not using night-time compression (n=84)

(26%) (Table 7) identified their biggest problem was that it was uncomfortable to wear.

The patients were asked to identify how their unmet needs could be addressed with a focus on how they would improve the compression therapy garment.

The feedback prioritised addressing issues of comfort with 26 (28%) asking for a change of material and a further 18 (19%) directly identifying required improvements in comfort. Ideally the product would be less tight, would not cut into the skin and would be free of any slippage. Easier application of the product (doffing and donning) would be beneficial for 13 (14%) patients – these data concur with the study’s finding that 14 (15%) participants required help applying their compression therapy garments. Thirteen per cent agreed that a breathable, less warm product would help to address the issue of the product being too hot to wear.

Discussion

The findings from this study involving 94 patients, accumulating data over 315 nights, clearly highlight that lymphoedema and its associated swelling is problematic at night as well as during the day for many patients. The use of night-time compression therapy is clearly supported with the study identifying both psychological and physical benefits. Just under two-thirds of patients said that they started using night-time compression because of advice from a health professional.

The study found that when night-time compression was not worn 89% of patients noticed an increase in

Table 6. Reasons not to wear night-time compression	
Feeling exhausted and too tired	25 (27%)
Heat or temperature	19 (20%)
Stable oedema	17 (18%)
Giving myself a break	13 (14%)
Hard to get into or had huge swelling	11 (12%)
More discomfort than usual	
Travel or staying away from home	7 (8%)
Skin problems	5 (5%)
Wrap or bandage put on by the clinic	3 (3%)

swelling. Patients listed their reasons for not using night-time compression as tiredness, heat or that their oedema was stable. The resolution of these will be fundamental to supporting concordance with night-time compression.

Night swelling impacts the patient’s life, especially causing pain and sleep disturbance. Patients using night-time compression reported benefits of reduced swelling, improved pain management and better sleep. One diary entry during the study illustrates night-time compression’s overall benefits:

“when I wake up in the morning it is not swollen, it looks better, it feels better, it does not call attention and I can put on my day garment easier”

Table 7. Drawbacks to the use of night-time compression*			
	Total (n=94)	Upper limb only (n=28)	Lower limb only (n=63)
Uncomfortable to wear	24 (26%)	7 (25%)	17 (27%)
Sweating or too hot	20 (21%)	6 (21%)	14 (22%)
Too tight or a lot of pressure	9 (10%)	3 (11%)	6 (10%)
Skin gets itchy or dry – additional skin care	9 (10%)	2 (7%)	7 (11%)
Slips down	4 (4%)	1 (4%)	3 (5%)
Difficult or time consuming to get them on	7 (7%)	2 (7%)	5 (8%)
Embarrassing or ugly design	5 (5%)	1 (4%)	2 (3%)
Not fashionable	3 (3%)	1 (4%)	2 (3%)
Disturbs sleep	3 (3%)	3 (11%)	-

*Multiple answers were possible

KEY POINTS

- ◆ Patients experience a positive effect from using compression for lymphoedema for up to 24 hours.
- ◆ Sixty-six per cent of all patients reported oedema during the night was the same or greater than that experienced in the daytime.
- ◆ More than 80% of patients experienced a reduction in or a maintenance of their level of lymphoedema when using night-time compression.
- ◆ Patients reported both increased activity and inactivity as triggers for oedema, reinforcing the need for an individual and holistic assessment of the patient when designing a lymphoedema management plan.
- ◆ The top three reasons given for not using night-time compression were fatigue, heat and the oedema being stable.
- ◆ Patients use a variety of products to supplement their night-time compression, from donning aids and pumps to creams and moisturisers.

Laura: 58, secondary lymphoedema, arm, USA

The study noted the persistence of a negative difference to oedema throughout a 24-hour period. Varying degrees of pain and swelling were reported during the evening or night period. Issues of how poor night management impacts on the patient's day were also reported through both interview and patient diaries, with mobility issues, pain and even choice of day wear proving problematic. Patients with upper or lower arm oedema reported it being worse at night than during the day. It is not clear whether this is an issue associated specifically with lymphoedema of the arm or simply a result of poor compliance with management regimes; further research is needed as this may represent an opportunity to improve the management regimen as well as product design.

All of the patients surveyed felt they had received benefits from night-time compression. Areas for improvement focused on product design improvements; designing a product that did not feel so tight, did not slip or dig in and did not feel so hot to wear. Making application easier would prove a great benefit as 15% of users currently require assistance to apply product. As the incidence of lymphoedema increases with age easier means of application need to be available.

While the findings from this study support the use of night-time compression therapy, they also make clear that the development and refashioning of new and existing products are required to meet the needs of the patient over a 24-hour period. Many patients currently use old hosiery at night-time as it is easier to apply and causes less discomfort which may indicate the need to explore lower degrees of compression for use at night. A high proportion of patients is already motivated to explore the most effective and comfortable means of night-time compression so the delivery of garments addressing the key drawbacks should increase concordance with night-time management disproportionately.

Further studies and analysis are required to support a greater understanding of lymphoedema processes during rest and at night, and what opportunities they offer for improving care. The lifestyle of the individual needs to be taken into account when understanding why day time and night-time management regimes may differ greatly. Any

work carried out will benefit from the appropriate staging of lymphoedema (International Society of Lymphology, 2013) as the tissue type and extent of the disease will impact on the change in limb size overnight.

In a relatively small cohort the study has recorded positive clinical outcomes from night-time compression and high levels of patient motivation to manage their condition. Further data are now required to understand what product characteristics and performance are appropriate. The provision of garments specifically for night wear needs to be investigated, in particular for the lower limb and allowing a degree of customisation.

Research is needed into therapies and products targeted on specific limb locations. The current use of classic compression garments designed for the day and also worn at night requires further study.

The fact that half of all the patients surveyed saw a 24-hour benefit to wearing night-time compression is a positive challenge to address this opportunity both in terms of clinicians' awareness and garment design. **BJCN**

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