

Lymphoedema Management at Night: Views from Lymphoedema Patients across 5 Countries

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Introduction

Lymphoedema is a debilitating lifelong, progressive illness that is mostly present in the lower or upper limbs¹. Despite the known burden for the patient, lymphoedema is often diagnosed late, misunderstood and inappropriately managed². Patient self-management is required to enable a continuous management of lymphoedema in today's multi-faceted approach³. The use of compression therapy to manage lymphoedema is well acknowledged but there is limited published information relating to compression therapy usage and outcomes during periods of rest or at night. The aim of this study was to gain a comprehensive insight into the use, drawbacks, challenges and benefits of night-time compression in patients suffering from chronic lymphoedema⁴.

Method

Data was collected by structured interviews using set questions and patient diaries with 94 patients (90% female; median age 53 years) across Germany (25), Sweden (9), USA (25), UK (10) and Australia (25). The Code of Conduct of the European Pharmaceutical Market Research Association (2016) was followed to protect patients' rights. Written permission for the anonymised use of the data was obtained. Patients diagnosed with primary or secondary lymphoedema, of over a 12 month duration, that were beyond the decongestion phase and wore night-time compression at least once a week as part of their management regime were included. Patients assessed their oedema based on the staging of the International Society of Lymphology (2003) (Figure 1).

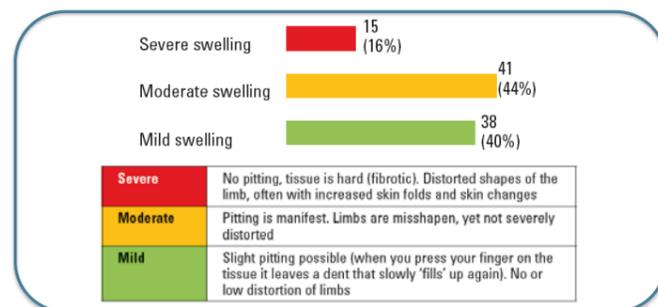


Figure 1. Extent of patients' night-time swelling based on the International Society of Lymphology's staging (bottom)

Results

Two thirds of surveyed patients perceived their swelling as moderate to severe during the night compared to the day. (Figure 1). Night-time compression was widely recognised as common practice in Australia, USA and Sweden and mostly recommended by a healthcare professional. Oedema was usually located at the leg (67%) whereas oedema in the arm and hand (30%) or at both arm and leg (3%) was less common. An increase in swelling was documented in 89% of all patients when night-time compression was not used (Figure 2 left) which persisted for 24 hours in 49% of the observed patients (Figure 2 right). Among the night-time problems reported were sleep problems (19%) and fluctuations in the extent of the oedema (79%). Triggers of oedema were either too much activity (93%) or prolonged inactivity such as sitting (60%).

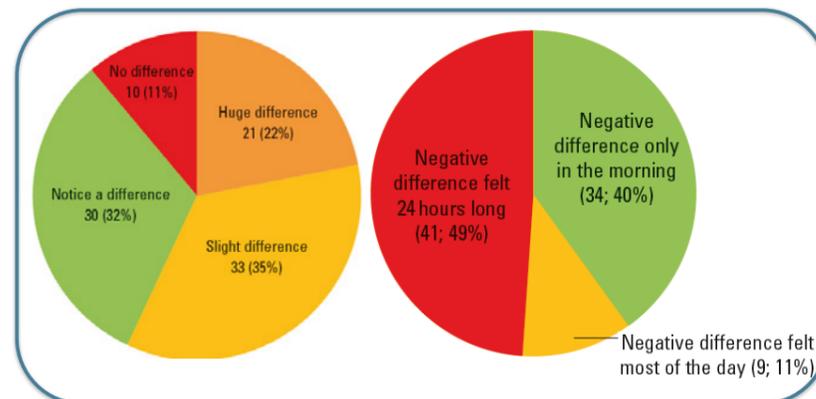


Figure 2. Negative difference reported with regard to increased swelling when night-time compression was not worn (left) and persistence of negative difference for 24h (right).

Although the landscape of night-time compression differed between the countries involved, compression garments were widely used in all countries. In addition, in 97% of patients night-time compression was supplemented by creams, moisturizers or intermittent compression pumps.

Benefits of wearing night-time compression were assessed and limb circumferences were recorded. 45% of patients reported a reduction in oedema from using night-time compression affecting both lower and upper limbs (Figure 3). Positive experiences from using night-time compression were reported by all patients including better management of oedema, reduction in pain and a sense of relief. Despite the considerable impact of night-time compression typical drawbacks were identified that may restrict the use of night-time compression (Table 1).

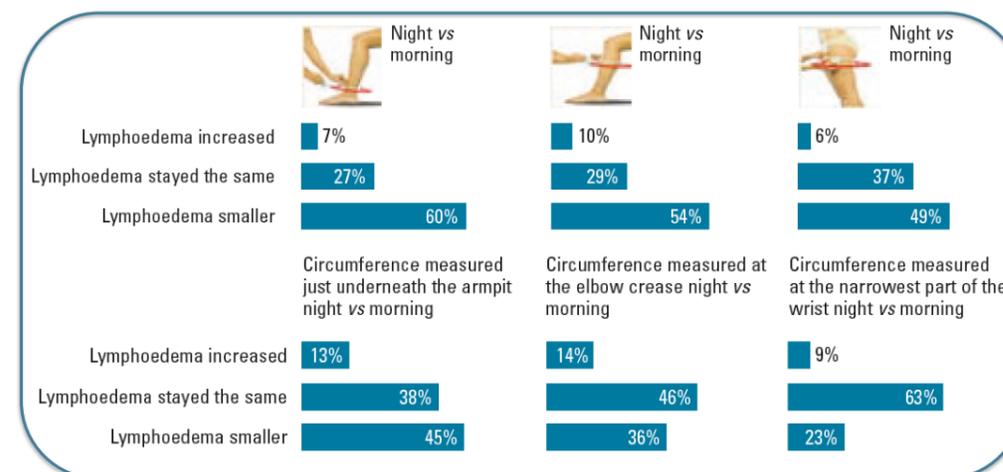


Figure 3. Impact of night-time compression on lower limb oedema (top) based on 45 patients reporting on 214 nights and upper limb oedema (bottom) based on 21 patients reporting on 101 nights. Maintenance or reduction of oedema was achieved for lower and upper limb by using night-time compression.

"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"

Comment by Laura (58 years, USA) with secondary lymphoedema in the arm after wearing night-time compression

Discussion

This study documented patients' experiences and views across 315 nights and revealed the challenges of lymphoedema related swelling. The striking impact of night-compression on oedema at night and day clearly demonstrates the benefits of additional night-time compression. Given the many requirements (Table 1) for convenient and effective night-time compression, specific products that sufficiently address the patients' unmet needs over a 24-hour period are required.

Feeling exhausted and too tired	25 (27%)
Heat or temperature	19 (20%)
Stable oedema	17 (18%)

Table 1. Top three reported reasons for not wearing night-time compression

Conclusion

- Two thirds of the patients reported oedema to be worse or comparable to daytime
- Over 80% of patients reported a reduction or management of their oedema when wearing night-time compression
- Night-time compression has a positive effect for up to 24 hours
- Main reasons for not wearing night-time compression were fatigue, heat and stable oedema
- Specific night-time products that meet patients' needs are required to increase concordance with lymphoedema management at night.

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Declaration of interest:

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