

# Selected abstracts from the 8<sup>th</sup> Joint International Lymphoedema Framework Conference, Rotterdam, 2018

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These abstracts have been selected because we believe they represent a combination of leading edge information or are likely to be of current interest generally or represent a unique solution to a particular problem or issue. We hope you enjoy reading them.

## Ultrasonography and thermography as new methods of assessing cellulitis with lymphoedema

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Recurrent cellulitis (and erysipelas) is a cause of worsening lymphoedema. Therefore, cellulitis should be prevented as part of lymphoedema management. In patients with lymphoedema, lymphatic circulation is abnormal and protein-rich lymph accumulates. We previously used high-frequency ultrasonography in a case-control study of patients with lymphoedema and a history of cellulitis. We found that dermal structure differed between the patients with history of cellulitis and without. Comprehensive assessment of the skin, including the structure of the subcutaneous tissue and immunological function, is required to prevent cellulitis. Such assessment is suggested as part of a management strategy to prevent recurrent cellulitis. Therefore, we established a new project that aims to prevent recurrent cellulitis in patients with

lymphoedema. We applied ultrasonography and thermography to reveal some risk factors of cellulitis in such patients. Here, we will present the results of this case study using these non-invasive, safe, and clinically useful modalities.

## A mixed method study to explore the perceptions of self-management in children, adolescents parents and professionals: an ifl research initiative

Aimee Auberluck

This presentation will disseminate the initial findings from a mixed methods study exploring the practice of self-management of Lymphoedema (LO) among children, young people (CYP) and professionals. Our primary objective was to establish the perceived barriers and facilitators to self-management of LO. We wanted to begin to understand what self-management in LO looked like to patients, families and professionals; how LO is managed and the impact of this. We also wanted to explore any cultural differences and establish whether a week-long summer camp could provide support and agency to all those involved in the self-management of LO. Utilising a mixed methods design, focus groups, questionnaires, observations, drawings and photographs captured the lived experience of those self-managing LO. Initial findings would suggest that children are robust in self-managing their condition, employing a variety of coping mechanisms, but that parents and professionals would sometimes benefit from additional support.

## Liposuction in lymphedema patients — a 25 years' prospective study without recurrence

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Lymphoedema leads — already within the first year — to deposition of subcutaneous adipose tissue. Liposuction for non-pitting chronic large lymphoedemas is useful when patients have been optimally managed with conservative treatment, in order to transform a pitting oedema to a non-pitting oedema. If the excess volume — now comprising of excess adipose tissue — is still bothering, liposuction is an excellent option leading to complete reduction. Just as after conservative treatment compression garments are needed postoperatively. Microsurgical reconstructions, although attractive as a physiological concept, cannot provide complete reduction in chronic large non-pitting lymphoedemas because they do not eliminate the newly formed subcutaneous adipose tissue collections.

**Introduction:** Patients with chronic non-pitting lymphoedema do not respond to conservative treatment or microsurgical procedures because the diminished lymph flow and inflammation result in the formation of excess subcutaneous adipose tissue, which cannot be removed by these methods. All patients had received conservative treatment before surgery without further reduction. All were wearing

compression garments before surgery. Aspirate and leg volumes were recorded.

**Materials and methods: arms:** 158 women with non-pitting oedema, a mean age of 64 (range, 39–89) years and a mean duration of arm swelling of 9 (range, 1–38) years underwent liposuction. Mean age at breast cancer operation, mean interval between breast cancer operation and lymphoedema start, and duration of lymphoedema were 52 years (range, 33–86), 3 years (range, 0–32), and 9 years (range, 1–38), respectively. Aspirate and arm volumes were recorded.

**Materials and methods: legs:** 96 patients with an age of 52 years (range, 17–76) and a duration of leg swelling of 14 years (range, 2–50) underwent liposuction due to non-pitting, chronic lymphoedema. There were 29 primary (PL), and 27 secondary lymphoedemas (SL) following cancer therapy. Age at cancer treatment and interval between cancer treatment and lymphoedema start were 43 years (range, 20–65), and 3 years (range, 0–26), respectively. Age at onset of PL was 32 years (range, 4–63).

**Results: arms:** Aspirate mean volume was 1,768 ml (SD 634) with an adipose tissue concentration of 95% (SD 10) in the tourniquet fraction. Preoperative mean excess volume was 1,528 ml (SD 734). Postoperative mean reduction was 103% (SD 27) at 3 months and 115% (SD 28) at 1 year, and more than 100% during 23 years' follow-up, i.e. the lymphoedematous arm was somewhat smaller than the healthy arm. The preoperative mean ratio between the volumes of the oedematous and healthy arms was 1.5 (SD 0.2), rapidly declining to 1.0 (SD 0.1) at 3 months, and less than 1 after 6 months.

**Results: legs:** Aspirate volume was 3,672 ml (SD 1,675) with an adipose tissue concentration of 93% (SD 10) in the tourniquet fraction. Preoperative excess volume was 3,775 ml (SD 1892). Postoperative mean reduction was 80% (SD 24) at 3 months and 101% (SD 22) at 1 year, and more than 100% during 13 years' follow-up, i.e. the lymphoedematous leg was somewhat smaller than the healthy one. The preoperative mean ratio between the volumes of the edematous and healthy legs was 1.4 (SD 0.2), rapidly declining to 1.0 (SD 0.1) at 1 year and less than 1 after one year.

**Conclusion:** These long-term results demonstrate that liposuction is an effective method for treatment of chronic, non-pitting lymphoedemas in patients who have failed conservative treatment. Because of adipose tissue hypertrophy, it is the only known method that completely reduces excess volume at all stages of arm

lymphoedema. The removal of hypertrophied adipose tissue, induced by inflammation and slow or absent lymph flow is a prerequisite to complete reduction. The newly reduced volume is maintained through constant (24-hour) use of compression garments postoperatively Mean pre- and postoperative excess volume reduction following liposuction of leg lymphedema [AQ: there seems to be missing text in this bit?].

## Revision of the lymphedema functioning, disability and health questionnaire for upper limb lymphedema (Lymph-ICF-UL): validity and reliability

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**Background:** Lymphoedema is a dreaded and frequent (DiSipio et al, 2013) complication, affecting a patient's life in various ways. The 'Lymphedema Functioning, Disability and Health' questionnaire for upper-limb lymphoedema (LymphICF) is a valid and reliable tool to assess lymphedema-related problems in functioning after breast cancer treatment (Devoogdt et al, 2011). However, simplification of the scoring system was warranted. Therefore, a revised version implementing a numeric rating scale was tested for its clinimetric properties.

**Aim:** Investigation of reliability and validity of the LymphICF-UL.

**Methods:** The Lymph-ICF-UL was completed twice within 24 hours by 56 participants with objective lymphoedema. Additionally, the 36-item Short Form Health Survey (SF36) was completed. Approval was obtained by the Ethical Committee of the University Hospitals of Leuven, Belgium (EudraCT Number 2015-004822-33).

**Results:** Intraclass correlation coefficients for test-retest reliability ranged from 0.79 to 0.95. Cronbach's alpha coefficients for internal consistency were higher than 0.80. There were no systematic changes from the first test to the second test, and measurement variability was acceptable. Face and content validity was good. Finally, construct validity was established. 4 out of 5 expected domains of the Lymph-ICF-UL showed a

moderate correlation with expected corresponding domains of the SF-36, showing good convergent validity. Furthermore, divergent validity was also good, since seven out of nine hypotheses were accepted.

**Conclusion:** The Lymph-ICF-UL is a reliable and valid questionnaire using a simplified scoring procedure to assess impairments in function, activity limitations, and participation restrictions of patients with arm lymphedema after breast cancer treatment. Investigation of the responsiveness of the Lymph-ICF-UL is ongoing.

## Hypothesis of total management of the patient affected by secondary and primary lymphedema, during a week "lymphedema village"

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**Introduction:** Our idea is that it is not enough to think about the loneliness of complex decongestive physiotherapy, but rather a holistic approach that cares for the person as a whole, considering the particular impairment of the social, psychological aspect that the pathology involves. We, therefore, conducted research, control and research. This is a study conducted by a group of experts on psychological problems.

**Patients and methods:** Affected by primary and secondary lymphoedema, contacted in a social way, throughout the Italian national territory, the only common element is the lymphedema pathology. From the literature we have identified correlates such as anxiety, particularly present in lymphedema patients, then at the beginning of the event we gave the test for anxiety. Description of the treatment "Lymphedema Village". These include water aerobics, physiotherapy sessions, health coach sessions, round tables with the doctor, guided tours in the mountain area, evening entertainment activities, involvement of the host territory with a popular day on the pathology with the participation of patients and citizens. . Statistic analysis: Random sampling methodology, group of 12 patients, with primary and secondary, male / female. Data collection technique with questionnaire S.T.A.I -Y (Y scale, scale of state) intra-group administration before / after treatment, quantitative analysis.

**Conclusions:** The first data readings confirm a significant reduction in the state of anxiety, after the treatment understood as an experience of the week Lymphedema Village, where the hypothesis is that the

patient with lymphoedema need a complete approach.

### Do adjustable velcro compression wraps enhance patient care and quality of life, as part of supervised self-management?

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**Aims:** The aim of this case report is to evaluate the effectiveness of one adjustable velcro wrapping device when used as part of self-management strategies for managing lymphoedema and lipoedema.

**Description:** Three patients were asked to share their personal experience of living with lymphoedema and lipoedema and feedback on the impact and experiences of self-managing using adjustable velcro compression devices. They were asked to complete an evaluation of the product and document personal experiences in relation to using the device and how this impacted on day to day activities and quality of life. Data relating to limb volume was taken to ascertain if the device helped to maintain or reduce limb volume.

Outcome: Limb Volume data shows oedema is maintained or reduced. Patient reports demonstrate that introducing a velcro wrapping system as part of selfmanagement, improved quality of life and had a positive impact on daily living.

**Evaluation:** The case studies discussed demonstrate the impact of living with lymphoedema and lipoedema, mentally, emotionally and physically. The patients have been empowered to self-manage their condition through access to specialist services. This impacts positively on how patients cope with the day to day aspects of their care, such as compression therapy, by promoting patient choice with garments and velcro wrapping devices, enables patients to individualise their care based on their personal goals. From the case studies it can be concluded that the introduction of velcro wrapping devices into the patients' daily routine has enhanced quality of life and the ability to self-manage.

### Patient empowerment by increased knowledge and practice

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**Aims:** Patient empowerment by increased

knowledge and practice of self-management of lymphoedema/lipoedema.

**Description:** SÖF has once a year, for four years, conducted a two-day workshop and a series of lectures to increase the knowledge of what the patients can do themselves to gain better control over their lymphoedema/lipoedema. It comprised engagement from several different stakeholders: a lymphoedema clinic, industry, lymph therapists and instructor of qi gong. Follow up with evaluation questionnaires. The workshops covered:

- Basic knowledge about the lymphatic system and instructions how to perform an effective self MLD
- Compression alternatives and how to judge for yourself if the compression fits correctly.
- Physical exercise assisting the lymphatic flow, skin care and diet.
- A "try-for-yourself-introduction" to other methods supporting the lymphatic flow such as pneumatic compression, laser, lymph taping, deep oscillation and qi gong.
- An introduction to research about lymphatics, lymphedema and different treatment methods.
- Informal meetings with fellow patients and lymph therapists.

**Evaluation of impact:** Evaluation showed that 73% of the participants marked very satisfied and 18 % satisfied (no one marked not very satisfied or dissatisfied) and 9% did not participate since they had no lymphoedema/lipoedema (accompanying family members). SÖF has noticed an increasing demand for workshops like this to be held more frequently and also in different parts of Sweden.

### Group care for filariasis in an endemic area

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**Introduction and Methods:** In mid-2015 Sangtin, a community organization working with farmer-labourers in Sitapur district, realized that there were a huge number of people suffering Filariasis and its after effects in the region and contacted SATHI (Society for Administration of telemedicine and Healthcare Informatics –www.sathi.org). SATHI offered help, and as a result, two major Filaria camps were organized on November 2015 and January 2017. In these camps patients were examined by specialists from SATHI, who also initiated the treatment, which included treatment with penicillin (injectable in 2015, oral in 2017), training in limb hygiene, and

application with training for, compressive bandages for patients with advanced lymphoedema. Volunteers from Sangtin were trained to continue, later long term care. There were later telemedicine supported camps where outcomes were evaluated and further instructions provided as per need. Psycho-social support was provided for people with disabling conditions through group learning and counselling during initial as well as follow-up sessions.

**Results:** Among the total 147 patients who had undergone treatment in these camps, there was 40% reduction of limb volume immediately, which increased to 70% with continued care at home through selfcare, leg washing and continued use of compressive bandages. Patients still continue to come for follow up every 22nd of each month to Pisawan CHC – declared as Filarais day. The project has helped in;

- Estimation of cases
- Provision of simple management guidelines for different morbidities for all levels of care.
- Training for different levels of health care staff
- Support activities - Capacity building • - Monitoring and evaluation
- Management of acute attacks

**Conclusion:** Camp based group care is useful in remote locations. Continued maintenance is the key.

### Case report: usage of kinesiology taping for management of lower extremity lymphoedema in singapore

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There has been a global growing trend on the usage of Kinesiology Taping (KTaping) for various conditions. Research on its usage for the management of oedema is also emerging. While most of the research done proves its effectiveness in the West, there is little research to show its effects in Asia where the climate is warm and humid; and the risk for developing secondary bacterial and fungal infections may be more prevalent. A 75 year-old female of Malay ethnicity was referred to our Lymphedema Physiotherapy Clinic for management of her right leg lymphedema. Initial bioimpedence results showed a difference of 1.18 litres (right leg 4.59 litres, left leg 3.41 litres) with fibrotic skin changes to the webs of toes and dorsum of foot. Initial management involved application of Manual Lymphatic Drainage (MLD) and regular compression bandaging. Patient was also taught self-bandaging. However, she reported

difficulty bending over for prolonged periods as this would aggravate her back pain. Subsequent reviews showed that she applied too much tension at the toes during self-bandaging, which resulted in worsening of swelling. KTaping was used on her toes with the aim of reducing swelling and the need for frequent re-bandaging. Regular KTaping to patient's toes proved to reduce swelling effectively. Initial fibrotic changes to the skin were also reversed. The patient self-reported better compliance to KTaping for the toes as it was less bulky, less likely to slip out from the toes or get hooked to other materials, more convenient, climate-friendly, aesthetically tolerable and comfortable.

## A study of incidence of and risk factors for breast cancer-related lymphedema in Ghana

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**Purpose/objective:** To determine the incidence of and risk factors for lymphoedema after breast cancer treatment at the oncology unit of KATH, Kumasi, Ghana, between January 1, 2005 to December 31, 2008.

**Methods:** Breast cancer and lymphoedema-related variables were collected from the medical records of breast cancer patients. Data were analysed using descriptive statistics and chi-square tests.

**Results:** Among 313 patients treated for breast cancer between 2005 and 2008, 31 (9.9%) developed lymphoedema after treatment. A chi-square test showed that axillary lymph node dissection was a statistically significant risk factor of lymphoedema (Chi-square test value = 7.055, *P* value = 0.008). Radiation and late-stage breast cancer diagnosis may have contributed in development of lymphoedema, despite having *P* value >0.05. Age, BMI and hypertension were also not found to be associated with lymphoedema.

**Conclusion:** This study provides evidence that the incidence of lymphoedema was 9.9% in this medical record review, with axillary lymph node dissection found to be a statistically significant risk factor associated with lymphoedema.

**Implication for practice:** With the majority of breast cancer patients in Ghana presenting with late-stage disease and also undergoing axillary lymph node dissection, lymphoedema will continue to be a problem in Ghana. Knowing the incidence and risk factors for lymphoedema not only helps in the early detection and effective management of lymphoedema, but also provides baseline data for further research on lymphoedema in Ghana.

## Using telehealth to support people with lymphoedema in a remote and rural area

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NHS Highland

Supporting self-management across a sparsely populated, large geographical area presents challenges. During 2017, NHS Highland piloted the use of the Florence text messaging service to provide ongoing support to people with lymphoedema. The aim of the pilot was to evaluate the acceptability and usefulness of texts as a means of providing information and self-management tips to enhance the information provided to patients at their clinic appointment. Florence is a simple, automated interactive NHS telehealth service using mobile phone text messages to support people with a wide range of long term conditions. It can be used to monitor symptoms and provide information, advice and support to help patients manage their condition. The Florence protocol, including its length, content of the messages and their frequency was developed by the lymphoedema team with patient input. The protocol included monitoring questions regarding the size of the affected limb and frequency of garment use. Texts were sent twice weekly initially, reducing in frequency over the 20 weeks of the protocol. Links to video clips covering garment application, simple lymphatic massage and exercise were included. Formal feedback from text and written questionnaires is limited at present, due to the small number of patients completing the protocol so far but has been positive. Informal feedback from patients has been positive and has led to proposed changes to the protocol. In particular, the monitoring questions were felt to be unhelpful and will be reduced in future versions.