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Chair: Isabelle Quéré

Jane Armer
American Lymphedema Framework Project (ALFP) systematic reviews - Revues systématiques American Lymphedema Framework Project (ALFP)

The American Lymphedema Framework Project (ALFP) continues to pursue the mission of improving the management of lymphedema and related disorders in the United States, while contributing to the global advancement of lymphedema treatment. The 25 ALFP systematic review authors continue their work to summarize the evidence base for the best practices for management of lymphedema. To date, four systematic review articles have been published: surgical management led by Dr. Janice Cormier; exercise led by Marilyn Kwan and Joy Cohn; palliative care led by Marcia Beck and Ausanee Wanchai; and intermittent pressure devices led by Dr. Joseph Feldman and Nicole Stout. Self management and complete decongestive therapy reviews are in press. Other articles have been submitted to various professional journals or are in final stages of development. These will be announced as they come in press.

Christine Moffatt

Saravuru Narahari
Experience of using compression bandaging in India - Expérience d'utilisation des bandages de compression en Inde

Compression therapy is recourse poor villages face special challenges. This chapter explains the practice of compression bandaging over 2500 lower limbs disabled by Lymphoedema. Long stretch bandages are used routinely as short stretch bandages are not available in the market. Locally available materials such as sponge and micro-cellular rubber are used to prepare moulds. Sandwich moulds and chalky bags are used to achieve dekinking of lymphatic vessels by unfolding large crevasses. Recommendations of Foldi clinic and Moffat are followed in routine practice. Large sized limbs (>7 liters of volume) presenting with different shapes, associated with co- morbidities and recurrence after post debulking surgeries are most difficult to manage. Slipping and rolling back of bandages into crevasses causing constriction, moulds inducing friction blisters and folliculitis in tropical climates are common side effects of bandaging. There is a need to improve the products used in tropical climate. Patients and their family members are trained to practice self bandaging at home. Total cost of bandaging in the supervised phase of integrated treatment ranges from Rs. 1523 to 5871 i.e. 66% - 74% of the total cost on medicines. This is 71% to 81% (Rs. 900 to Rs. 3500) of the total cost monthly thereafter. All patients do not follow compression therapy during day time as it comes in the way of their above. The bandage usage hours range from zero to 10 hours during day.
10.30 – 12.00 – Concurrent sessions - Sessions concurrentes

BS1 - Towards a new clinical pathway for lymphoedema in France - Session 1 - Vers une nouvelle organisation des soins du lymphoédème en France - Session 1

Chair: Loïc Vaillant

Alain Corvez
Introduction by the President of «Agence Régionale de Santé» Languedoc-Roussillon - Introduction par le Directeur de l’Agence Régionale de Santé (ARS) Languedoc-Roussillon

Isabelle Quéré
Why a new clinical pathway in France for lymphoedema? - Pourquoi une nouvelle organisation des soins en France pour le traitement du lymphoédème ?

Nicole Stout
Patient pathway in USA - Organisation des soins pour les patients aux Etats-Unis

Pierre Brantus
Patient pathway in developing countries - Organisation des soins pour les patients dans les pays en voie de développement

Christine Moffatt
The Wandsworth study - L’étude Wandsworth

BS2 - Abstracts session 1 - Session résumés 1

Chair: Neil Piller

Robert Damstra
Prospective, randomised controlled trial comparing the effect of CircAid® Juxta-Fit™ versus Trico bandages in the initial treatment of leg lymphoedema

**Background:** Inelastic multicomponent bandages (IMCB) are the standard of compression in the initial treatment phase of lymphoedema. The inelastic Juxta fit™ device (JFD), which can be easily adjusted by the patient to the circumference of the limb and was originally developed to maintain the effect of a lymphedema treatment but not for initial treatment.

**Aim:** To compare the efficacy of JFD with IMCB concerning volume reduction and interface pressure loss in the initial treatment phase.

**Material and methods:** Thirty hospitalized patients suffering from moderate to severe lymphedema (stage 2-3) of the leg were randomized in 2 groups of 15 patients each. The group receiving the new JFD, was trained how to adjust the device by themself as soon as the patients sensed the therapeutical pressure became ineffective. The control group was treated with IMCB. Bandages were removed and reapplied after 2 and after 24 hours. Bilateral lower leg volume was measured by means of classic water displacement volumetry before bandage application, at 2 after 24 hours. Sub-bandage pressures were measured at the B1 location at several moments during the study. Primary outcome parameters were volume reduction of the affected leg and interface pressure loss after 2 and 24 hours.

**Results:** A preliminary evaluation of 26 patients showed a mean volume reduction after 24 hours of 11.3% in the JFD group compared to 7.3% in the IMCB group (n.s.). The interface pressure dropped significantly after two and 24 hours in the IMCB group, but much less in the JFD group due to self-adjustment.

**Conclusion:** The JFD is very effective in the initial treatment phase compared to IMC bandages. The possibility of self-adjustment of JFD enhances the efficacy of the clinical outcome.
Robert Damstra
Dose finding for an optimal compression pressure to reduce chronic edema of the extremities

**Aim:** The optimal pressure to reduce chronic extremity swelling is still a matter of debate. The aim of this study was to measure volume reduction of a swollen extremity depending on the amount of pressure exerted by compression stockings and inelastic bandages.

**Methods:** Thirty-six patients with unilateral breast cancer related arm lymphedema were investigated in a lymphedema clinic in the Netherlands, 42 legs with chronic edema of the lower extremities were examined in a phlebological center in Italy. The arm-patients were randomized to receive inelastic arm bandages with a pressure between 20-30 mmHg or 44-68 mmHg. The leg patients were either treated with compression stockings (23-32 mmHg) or with inelastic bandages (pressure 53-88 mmHg). Inverse water displacement volumetry for the arms and measurement of leg circumference was performed before and after compression.

**Results:** In the arm-patients low pressure after 2 hours achieved a higher degree of volume reduction (-2.3%, 95% CI 1.0-3.6) than high pressure (-1.5%, 95% CI 0.2-2.8) (n.s.). In patients with leg edema compression stockings in the range between 20 and 40 mmHg showed a positive correlation between exerted pressure and volume reduction, bandages applied with an initial resting pressure of more than 60 mmHg resulted in a decreasing volume reduction.

**Conclusion:** There is obviously an upper limit beyond which further increase of compression pressure seems counterproductive. For inelastic bandages this upper limit is around 30 Hg on the upper and around 50-60 mmHg on the lower extremity.

Tanja Planinsek-Rucigaj
Lymphoedema treatment with two short stretch bandages - which pressure do we need?

T Planinsek Rucigaj, N Kecelj Leskovec
Dermatology Dept., University Clinical Centre Ljubljana, Slovenia

**Aim:** To compare the effect of compression therapy in oedema reduction (leg, arm) for two different short-stretch bandage system in lymphoedema patients st. II according to sub-bandage pressure and stiffness.

**Methods:** We measured circumference reduction of lower/upper extremities in one week period and sub-bandage pressure in standing and supine position with both bandages immediately after bandage application, after one hour and after one week of application. Static stiffness index (SSI) was calculated accordingly.

**Patients:** Prospective randomised study includes at the end 13 patients with arm lymphoedema (8 treated with Coban Lite™ bandages for one week and 5 treated with Porelast/Panelast™ bandages for one week) and 39 patients with leg lymphoedema (23 treated with Coban Lite bandages for one week and 16 treated with Porelast/Panelast bandages for one week). In the group with Porelast/Panelast bandages treatment 5 patients with arm lymphoedema and 7 patients with leg lymphoedema were excluded because of missing visits.

**Results:**

<table>
<thead>
<tr>
<th>Patients</th>
<th>Leg ankle circ.</th>
<th>calf circ</th>
<th>wp(mmHg)/SSI 0</th>
<th>wp(mmHg)/SSI 1h</th>
<th>wp(mmHg)/SSI 1 week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coban Lite</td>
<td>1 cm</td>
<td>1,5 cm</td>
<td>39/17</td>
<td>44/9</td>
<td>26/5</td>
</tr>
<tr>
<td>Porelast/Panelast</td>
<td>2 cm</td>
<td>1,5 cm</td>
<td>73/18</td>
<td>55/15</td>
<td>27/8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patients</th>
<th>Arm wrist circ.</th>
<th>forearm circ</th>
<th>wp(mmHg)/SSI 0</th>
<th>wp(mmHg)/SSI 1h</th>
<th>wp(mmHg)/SSI 1 week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coban Lite</td>
<td>1 cm</td>
<td>1 cm</td>
<td>53/5</td>
<td>42/4,5</td>
<td>25/4</td>
</tr>
<tr>
<td>Porelast</td>
<td>1 cm</td>
<td>2 cm</td>
<td>59/9</td>
<td>54/11</td>
<td>35/8</td>
</tr>
</tbody>
</table>

**Discussion:** There were no statistic differences in leg/arm circumference reduction with both bandages systems after one week of treatment despite of higher working sub-bandage pressure and SSI with Porelast/Panelast comparing to Coban Lite.

Coban Lite™; 3M
Porelast/Panelast™; Lohmann & Rauscher
**Renate Roeterink**  
*How to treat the patient with lipedema, «food for thought»*

**Background**: The patient with lipedema suffers from varying degrees of extremely big lower extremities known as “fat legs”, pain, overall fatigue, limited activities of daily living and subsequently a reduced quality of life. Therapeutic options are non-curative, complex and therefore require a multifactor and interdisciplinary approach based upon chronic disease management. Conservative therapy programs often consist of a combination of manual lymphatic drainage therapy and compression therapy, although good clinical evidence is lacking.

**Objective**: Present an overview of the diagnostic and (physical) therapeutic processes in the Expert Centre for Lymphovascular medicine Drachten, The Netherlands.

**Methods / Results**: The need for adequate medical examination in order to determine lipedema, lymphedema, combinations of both, or other causes of “fat legs” is obvious. At the same time, the medical background of other existing symptoms, such as overall fatigue, must be determined. Less common in current treatment programs, but in our opinion absolutely necessary, is the search for factors which negatively influence lipedema, such as decreased muscle strength, deconditioning, inactivity, ineffective illness beliefs and weight gain.

To determine these factors, we use weight measurements (BMI and abdominal girth measurement), questionnaires for daily activities and fatigue, muscle strength measurements and cardio/pulmonary performance tests. The combination of these outcomes helps to develop a “health profile” as well as a personalized therapy program for the patient with lipedema.

This program includes physical training, in combination with elements of cognitive behavioural therapy. The main focus of the treatment program is active patient participation (physically and mentally) with the aim of gaining and maintaining an active lifestyle.

**Conclusion**: The combination of a medical diagnostic process and the search for factors (negatively) influencing lipedema enables the health care professional to develop an optimal therapy program.

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**Javorka Delic**  
*Secondary lymphoedema - A complication of genital clamydia trachomatis infection*

**Angiology Department, City Institute of Dermatology, Belgrade, Serbia**

Secondary lymphoedema (SL) is five time frequent in comparison with primary one. SL is caused by trauma, tumor, infection and veins thrombosis and present 10% of all disturbance of the periferal circulation.

The aim of this study is to present SL developed in course of genital infection by Clamydia Trachomatis (CT). We present a woman, aged 32 years, with lymphoedema, erythema and skin plaqual infiltration on the left limb. She had chronic infection upper genital tract by CT, in subclinical form, during two years. Lymphoedema was the first sign of the disease and the starter for examination.

The diagnosis is confirmed by the presence of CT in genital and urethral tract- colpitis, cervicitis, urethritis (Chlamydia Cel IF Test). The culture of the lymph nodes tissue was positive. Ultrasound (US) is showed ovarian cyst, ovarian tube obstruction, paraovarial adhesiones on the left. MRI is showed enlargement of the paraaortalis and ingvinalis lymph nodes on the left side. US of the leg soft tissue is confirmed oedema and chronic cellular inflammation. Color duplex scan of the legs veins and arteries had normal. CT is confirmed a chronic postinfective inflammation of the lymph nodes, with fibrosis. The serum antichlamydial antibodies were positive (MIF test).

**Discussion,Conclusion**: The first sign of disease was oedema on the leg. The patient had asymptomatic genital CT infection. CT exists in 10% of the health female but in non-gonorrhoic and gonorhoic urterhrirs in 50-75% of the cases. The sequelae are urethritis, pericarditis, arthritis, salpingitis, ectopic pregnancy, infertility. The finding of antichlamydial antibody is an indication of ascending form CT infection. The risk factors for sequelae is unsafe sex, subclinical and chronic form of disease and inadequate or late treatment. The complications were often the first signs of CT infection. This case indicates that lymphoedema may be a sequelae of chronic genital infection by Clamydia.

**Key words**: Chlamydia trachomatis, secondary lymphoedema
Alexandre Pissas
Prévention du lymphoédème secondaire

Pathophysiologic and anatomo-surgical aspects explain the main complications of axillary lymphonodal resection and radiotherapy for breast cancer treatment : the role of the very precise knowledge of anatomy and the lymphatic vicariant ways explain the less importance of the concept of sentinel lymphnode although that technique remains a real progress in lymphology. Concerning the lower limb the authors underline that the suppletive pathways are very rare and the wound of inguinal or femoral lymphocenter always occur of a secondary lymphedema. The experience of the authors is based upon thirty years of oncologic treatment, lymphological and anatomical research.

Françoise Dubois
Contribution de la lymphoscintigraphie et importance du temps de transit dans le diagnostic d’insuffisance vasculaire des membres inférieurs. Analyse de 92 cas

Une lymphoscintigraphie a été pratiquée chez 92 malades souffrant de jambes lourdes et de cellulites. 

Lymphoscintigraphie : Après une période de repos de 30 minutes, allongés sur une table d’examen, la lymphoscintigraphie a été pratiquée par injection de nanocolloïdes marqués au Technetium 99m dans le 1er espace interdigital du pied.

Des études dynamiques (pendant les 30 premières minutes post injection) et statiques (4 heures après l’injection) ont été réalisées.

Analyse des 92 lymphoscintigraphies : Etude Dynamique au repos

Le Temps de Transit entre le point d’injection et les ganglions inguinaux était

- Normal dans 16 cas (8 – 11 minutes)
- Augmenté dans 13 cas
- Diminué dans 37 cas
- Asymétrique dans 19 cas
- Echec technique dans 7 cas

Etude Statique : Des voies de dérivation profondes ont été visualisées dans 66 cas. La stase était présente dans 84 cas. Un reflux dermique a été observé dans 3 cas. Des anomalies anatomiques ont été détectées au niveau des collecteurs lymphatiques dans 76 cas.

Conclusion : Les implications du système lymphatique dans les pathologies vasculaires des membres inférieurs sont beaucoup plus importantes que généralement admis.

La lymphoscintigraphie avec détermination du Temps de Transit est une méthode d’investigation intéressante pour un diagnostic précis des composantes vasculaires chez les patientes souffrant de jambes lourdes et de cellulites des membres inférieurs.

Jean-Paul Belgrado
Lymphofluoroscopie associée à un traitement physique

Background: Lymphoscintigraphy supports scientists to study the efficiency of manual lymphatic drainage and persists being the reference imaging for lymphatics, but we can’t ignore its minimal ionizing effects on patients and physicians. Subcutaneous injection of Indocyanine green and the observation of its diffusion under the skin by a specific camera, seems to be an interesting new way of imaging in the study of lymphoedema and their treatment.

Objectives : To verify the efficiency of such technique composed the physical treatment of lymphoedema, ie "A.Leduc technique of manual lymphatic drainage" on resorption of oedema and acceleration of the lymphatic flow inside the collectors. To verify the possibility of mapping the functional lymphatic superficial network of patients with lymphoedema in order to indicate the best way to apply the physical treatment

Method : Lympho-fluoroscopies applied on 30 voluntary patients presenting an unilateral secondary lymphedema of the upper limb after adenectomy for breast cancer.

- Injection of a diluted solution of Indocyanine green in the second interdigital space.
- "passive" period of 10 minutes : observation of the progression of the tracer in the subcutaneous area.
- 20 minutes protocol of manual lymphatic drainage and permanent observation of the tracer's progression under the skin. Completed by a second injection in the root of the arm if no fluorescence is visible the axilla or the retroclavicular space after the 20minutes of MLD.

Results : During the passive stage, we have repeatedly observed contractions of lymphangions and a slow diffusion of the tracer inside of lymphatic collectors.

During the manual lymphatic drainage, we visualized systematically an increase of the lymph flow mapping progressively the functional lymphatic network of the edema, even areas of dermal backflow. When the dermal back flow was important and no fluorescence was visible in the axilla or in the retroclavicular space, the second injection in the root of the limb, followed by MLD, show progressively the substitutions pathways, give us the mapping of the superficial lymphatic network reaching the contra-lateral axilla.

Conclusions: Dynamic lymphofluoroscopy completes the arsenal of imaging tools in lymphology. It might help to verify the efficiency of manual lymphatic drainage. It allows a mapping of the functional superficial lymphatic network.
Marlène Coupé
Enquête auprès de patients porteurs d’un lymphœdème avant rédaction d’un programme d’éducation thérapeutique du patient

M.Coupé, F. Mourgues, M.F. Magne, L ; Porthié, V. Bouys, F. Delseny, S. Mestre, V. Soulier-Sotto, I. Quéré.
Service de Maladies Vasculaires, Hôpital Saint-Eloi, CHU Montpellier.

Introduction : L’Éducation Thérapeutique du Patient (ETP) fait partie intégrante de la prise en charge d’une maladie chronique. Elle est individuelle ou collective et doit être proposée à chaque patient mais elle n’est pas obligatoire. Le succès de l’ETP dépend de la connaissance des besoins des patients.

Objectif : Recueillir les besoins des patients pour construire un programme d’ETP adapté au lymphœdème.

Méthode : Un questionnaire de 16 questions a été adressé en décembre 2010 avec enveloppe de retour à 619 patients suivis régulièrement dans le service entre 2000 et 2010. Les patients, âgés de 0 à 80 ans sont des enfants, des hommes et des femmes. Ils sont atteints d’un lymphœdème primaire ou secondaire avec une ou plusieurs localisations. La question sur les besoins des patients a été libellée ainsi : quelles sont vos attentes d’un programme d’ETP ?

L’évaluation est qualitative avec un choix multiple de réponses entre 7 propositions.

Résultats : 40% des patients ont répondu soit 248 réponses. Les résultats sont exprimés en pourcentages de réponses en tenant compte des choix multiples.

<table>
<thead>
<tr>
<th>Besoins des patients</th>
<th>nombre de réponses</th>
<th>pourcentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Informations administratives sur la prise en charge</td>
<td>139</td>
<td>56</td>
</tr>
<tr>
<td>2. Informations en diététique</td>
<td>134</td>
<td>54</td>
</tr>
<tr>
<td>3. Quels sont les exercices physiques adaptés</td>
<td>121</td>
<td>49</td>
</tr>
<tr>
<td>4. Apprentissage de gestes techniques</td>
<td>119</td>
<td>48</td>
</tr>
<tr>
<td>5. Connaissances théoriques sur le lymphœdème</td>
<td>91</td>
<td>37</td>
</tr>
<tr>
<td>6. Soutien psychologique</td>
<td>45</td>
<td>18</td>
</tr>
<tr>
<td>7. Autres demandes (explications des traitements, intérêt des cures thermales, nouveautés en recherche, informations sur les orthèses, le chaussage...)</td>
<td>29</td>
<td>12</td>
</tr>
</tbody>
</table>

Conclusion : Nous avons été étonnés par l’ordre de fréquences des réponses et en particulier par l’inquiétude manifestée par les patients quant à la possibilité de se faire soigner et rembourser. Ceci confirme qu’il est important de recueillir les besoins des patients avant de construire un programme d’ETP si l’on veut être efficace car les préoccupations des patients semblent différentes de celles des professionnels.

Véronique Bouys
Evaluation des ateliers d’auto-bandage et d’auto-drainage


Objectif : L’objectif de ces ateliers est de créer un échange d’une part entre patients et d’autre part entre patients et soignants, d’améliorer la prise en charge de leur lymphœdème, d’éduquer les patients afin de leur donner un maximum d’autonomie et de les accompagner dans leur recherche de soignants spécialisés près de leur domicile.


Leur rôle est d’apprendre aux patients des gestes simples et efficaces d’auto-drainage et d’auto-bandage. L’atelier se termine par la remise de documents d’auto-soins aux patients.

Sylvie Dubois
Développement d’un contenu éducatif pour les femmes diagnostiquées d’un cancer des organes génitaux, à risque de lymphoédème secondaire des membres inférieurs : étapes et limites

Le risque de développer un lymphoédème suite à un cancer gynécologique est estimé entre 5 et 49% selon les études (INESSS, 2012) et peut représenter un coût annuel de traitement approximatif de 2 500 $ pour la patiente (Donovan et al., 2002). Face à cette situation, il a été suggéré de développer des pratiques d’autogestion pour permettre aux patients de gérer les symptômes et maintenir une vie active. Or, à notre connaissance, il existe peu d’informations organisées et consacrées aux femmes atteintes d’un cancer des organes génitaux (ex., vulve, col de l’utérus), à risque de développer un lymphoédème des membres inférieurs. À cet effet, peu d’interventions éducatives ont été développées et évaluées en termes de savoirs et de satisfaction du soutien éducatif reçu. Or, plusieurs études ont montré que le développement et l’évaluation de nouvelles approches éducatives utilisant les technologies de l’information via le Web étaient souhaitables tant pour la promotion de la santé que pour les changements de comportements.

Cette communication présente les étapes d’élaboration de la phase A d’un projet pilote consistant à développer et évaluer une stratégie éducative Web auprès des femmes atteintes d’un cancer des organes génitaux. Les étapes de développement et de validation du contenu de formation, d’élaboration et de validation des algorithmes et de la bibliothèque des messages et de transposition du contenu clinique développé dans l’application Web avec l’utilisation de la plateforme informatique VIH-TAVIETM (Côté et al., 2011) sont détaillées. Les limites de la réalisation de ces principales étapes sont aussi présentées.

Sylvie Dubois
Évaluation et implantation d’une intervention éducative pour les femmes en attente de chirurgie d’un cancer du sein, à risque de lymphoédème

La chirurgie mammaire en mode ambulatoire est documentée comme un traitement de choix pour les femmes atteintes de cancer du sein. Néanmoins, on estime que de 15 à 20% des femmes qui subissent une chirurgie avec lymphadénectomie seraient à risque de développer un lymphoédème. Plusieurs études révèlent que les femmes ne sont pas suffisamment informées de cette complication, de sa prévention et de son traitement. Le développement d’interventions infirmières pour soutenir ces patientes à risque permettrait de favoriser le sentiment d’auto efficacité et l’anxiété.

Le but de ce projet, réalisé entre 2009 et 2011, était donc d’implanter une intervention infirmière éducationnelle structurée, en préadmission, et d’évaluer ces effets sur le sentiment d’auto efficacité et l’anxiété des femmes atteintes d’un cancer du sein et ayant à subir une chirurgie. Un devis quasi expérimental comparatif de type prétest-postest a été utilisé auprès de deux groupes de femmes en attente de chirurgie mammaire avec lymphadénectomie, soit celles qui recevaient l’intervention (n = 56) comparativement à celles qui recevaient les soins usuels (n = 57). L’intervention consistait en une séance de formation de groupe de 90 minutes (incluant information, manipulation de matériel et période de questions). Des questionnaires étaient complétés au moment de l’annonce de la chirurgie (T0), après l’enseignement (T1) et lors du premier suivi postopératoire (T2). Les résultats de l’effet de l’intervention éducative, les éléments d’implantation (leviers et obstacles) en milieu de soins, ainsi que les retombées cliniques seront présentés.

BS4 - Duplex scanning patients - Echo-doppler pour les patients
Jean-Pierre Laroche, Dominique Brisot

BS5 - Breast oedema - Œdème du sein
Wouter Hoelen, Joyce Bosman

BS6 - Volumetry - Volumétrie
Sandrine Mestre-Godin, Thomas Behar, Michel Dauzat
12.45 - 13.45 - Thuasne Symposium - Symposium Thuasne
Polit Study & Mobiderm - Etude Polit & Mobiderm
Chair: Isabelle Quéré, Alain Leizorovicz
Alain Leizorovicz, Isabelle Quéré, Maryvonne Chardon-Bras, Marlène Coupé

14.00 - 15.30 - Lymphoedema and disability (in partnership with Handicap International) – Lymphœdème et handicap (en partenariat avec Handicap International)

Chairs: Stan Rockson, Patrick Carpentier

Pierrette Castelein
Handicap production process - Processus de production du handicap

En 2011, l’OMS définit dans la Classification Internationale du Fonctionnement du handicap et de la santé (CIF –ICF) que « l’état de fonctionnement et de handicap d’une personne est le résultat de l’interaction dynamique entre son problème de santé et les facteurs contextuels de son environnement ».

En 2006, l’ONU adopte la Convention internationale relative aux droits des personnes handicapées (signée par 153 pays et ratifiée actuellement par 114 pays) qui définit ainsi le handicap dans son article 1 : « Par personnes handicapées on entend des personnes qui présentent des incapacités physiques, mentales, intellectuelles ou sensorielles durables dont l’interaction avec diverses barrières peut faire obstacle à leur pleine et effective participation sociale sur la base de l’égalité avec les autres.»

Dès 1998, le Processus de Production du Handicap (RIPPH Québec) met en évidence que le handicap ne peut pas se réduire à un attribut de la personne en le réduisant à la dimension de ses atteintes organiques, mais plutôt à un ensemble complexe de situations de réduction de sa participation sociale du fait de l’interaction entre ses déficiences et les obstacles de son environnement physique et social.

L’intervention auprès d’une personne atteinte de filariose lymphatique nous impose également de ne pas se limiter aux seules manifestations cliniques mais de prendre également en considération les conséquences sur sa participation sociale (travail, éducation, …) ainsi que l’impact de son environnement pour orienter les priorités thérapeutiques.

Pierre Brantus
Practical applications of this model - Applications pratiques du modèle
16.00 – 17.30 - Concurrent sessions - Sessions concurrentes

BS7 - International Patients Initiatives - Initiatives internationales de Patients

Chair: Anna Kennedy

Marie Ponce, Véronique Bouys
Association Vivre Mieux le Lymphoedème (AVML) self management classes - Ateliers AVML

Rachel Pritzker
Initiative from Lymphedema Association of Quebec - Initiative de l’Association Québécoise du Lymphoédème

Anna Kennedy
National Lymphedema Network’s (NLN) Lymph Science Advocacy Programme - Programme de promotion de la connaissance sur le lymphoédème (NLN)

Joana Pradas
Spanish Manifesto - Manifeste espagnol

Margareta Haag
Swedish patients conference in 2011 - Conférence suédoise de patients en 2011

Ayelet Albala
Israel primary lymphedema support group - Association de patients Israéliens pour le lymphoédème primaire

BS8 - Abstracts session 3 - Session résumés 3

Chair: Margaret Sneddon

Lachlan McFetridge
Photogrammetry for limb volume measurement

Measuring and monitoring limb volume is an effective method for assessing the efficacy of treatments for lymphoedema. The ideal tool for limb volume measurement should be non-invasive, inexpensive, portable and hygenic, while also providing accurate and repeatable results. Using photographic imaging techniques, such as photogrammetry, is a move toward the ideal limb volume measurement device. In addition, photography provides both the clinician and patient with a visual record of their treatment progression.

Objectives: To demonstrate the progress made towards extracting limb volume and shape data from photographs using automated computer-imaging techniques on mobile devices.

Methods: The volume of a range of artificial limbs as well as lymphoedema limbs will be measured with imaging techniques and compared to the results from the traditional measures, such as perometry, water displacement and circumference measurement.

Results: The application is currently in the testing phase. The results to be presented will report the current findings at the time of the meeting(including data such as accuracy and speed).

Conclusions: Photographic imaging techniques provide quantitative and qualitative indications. It allows us to monitor changes in limb volume and shape for lymphoedema patients over time. Running the application on mobile devices also allows easier access to patients that are either unable to leave home or live too far from their specialist centres (e.g. rural communities).
### Nele Devoogdt

**Test-retest reliability of the lymphoscintigraphy of the upper extremity**

The purpose of this study was to examine test-retest reliability of the lymphoscintigraphic examination of the lymphatic system of the upper extremity. 10 breast cancer patients with unilateral axillary lymph node dissection, more than one year ago, were included. 5 patients had arm lymphedema and the other patients had no lymphedema. All included patients underwent two lymphoscintigraphic evaluations with identical protocol. The time interval between both evaluations was one week. The lymphatic system of 20 upper extremities was evaluated. The protocol consisted of different parts: 15 minutes of rest, 15 minutes of squeezing rhythmical in a ball, 10 minutes of rest, 70 minutes of normal activity. Following quantitative parameters were determined: % clearance from the hands 45 minutes and 120 minutes post-injection; % uptake in the axilla 45 minutes and 120 minutes post-injection; time post-injection of arrival at the axilla; velocity of uptake in the axilla; and % uptake in the liver. Following qualitative parameters were determined: axillary, humeral and cubital lymph nodes, lymph collectors, dermal backflow, collaterals and liver.

In conclusion, the lymphoscintigraphy is a reliable measurement tool to evaluate the lymphatic system of the upper extremity quantitatively and qualitatively.

### Alice van den Wijngaard

**Experimental study comparing interface pressure and static stiffness index of four types of compression systems**

**Aim:** The study aimed to compare interface pressure and Static Stiffness Index (SSI) of four different compression systems that are currently in use for venous leg ulcer and lymphedema treatment of the lower limbs.

**Methods:** For the experimental study fifty-two ambulatory adults with healthy legs, were recruited at random in the study center, after they had given informed consent. The evaluated systems were: *Short Stretch Bandage system (SSB), multi-layer bandaging (LSB), Vari-stretch bandage (VSB) and tubular compression (CS).* Interface pressure (3 cm ø probe was placed at the B1 point) was recorded on application of the compression systems and every 15 minutes for 4 hours, in supine, standing, while sitting and during walking.

**Results:** The mean interface pressure of SSB, LSB and VSB was significantly higher (p<0.05) in each position measured over 4 hours, compared to CS. In supine VSB showed high pressure levels, up to 60 mmHg, which remained high. The other systems had more tolerable levels of 30 mmHg. Measurements in sitting showed similar trends. All compression systems maintained pressure levels in walking of at least 40 mmHg. The SSI was the highest for SSB with 20 and remained 19 throughout the study period. LSB followed with an SSI of 18, reduced to 15, where the SSI for VSB went from 17 to 12 and CS with an SSI of 6 lagged behind.

**Conclusion:** The study results showed different patterns of interface pressure and SSI, which may enable clinicians to predict the frequency of bandage application, supporting an adequate and safe choice of bandage system.

### Susanne Birkballe

**Differentiating lymphoedema from lipoedema using tissue dielectric constant measurements**

**Aim:** To test whether measurements of skin Tissue Dielectric Constant (TDC) can differentiate chronic lower extremity swelling caused by lymphoedema from swelling caused by lipoedema.

**Methods:** Nine newly referred patients with lymphoscintigraphy-verified lower extremity lymphoedema, 10 patients with diagnosed lipoedema and 10 healthy controls volunteered for the study. TDC-measurements were performed prior to treatment initiation on predefined locations on the foot, ankle and lower leg using a new handheld device. A 300 MHz electromagnetic (EM) wave is transmitted non-invasively into the skin via a coaxial probe (M25) placed on the skin surface. TDC is calculated from the reflected wave and is directly proportional to tissue water content ranging from 1 (vacuum) to 78.5 (pure water).

**Results:** In the lymphoedema group TDC was 46.2±6.6 (mean±SD) on the foot, 48.7±4.0 on the ankle and 51.4±3.9 on the lower leg. In the lipoedema group and the control group corresponding values were 36.0±5.6, 26.9±3.6, 25.7±2.9 and 37.3±6.9, 29.3±2.0, 30.2±3.4 respectively. Lymphoedema values were significantly higher than lipoedema values and control values in all locations (p < 0.001, two-way ANOVA). The greatest difference was demonstrated on the lower leg measurements. Applying a cut-off-value of 39 (determined by ROC-curve) results in a sensitivity and specificity of 100 % for ankle and lower leg measurements.

**Conclusion:** TDC-measurements can become a reliable aid in distinguishing chronic lower extremity swelling caused by abnormal fatty tissue deposition from swelling caused by tissue fluid accumulation. If introduced in the initial clinical evaluation costly and cumbersome diagnostic examinations may be spared.
**Ellen Kuipper-Kuip**  
*A new treatment regimen evaluated in twenty lymphoedema patients*

**Introduction:** In The Netherlands 350.000 patients suffer from lymphedema. In combination with obesity and or lip- edema it may pose complex problems.  
**Aim:** Improvement of treatment outcome using a new debrider, a short stretch compression system and tubular under padding.  
**Method:** Case ascertainment was used in patients with lymphedema of the legs or combined venous lymphatic leg ulceration. Twenty patients aged 25 - 80 years were successfully treated with short stretch cohesive bandages (a) using tubular Terry under padding (b). The toes were included in the compression bandage using a fixation bandage (c). Patients received manual lymph drainage at the skin therapy clinic, twice weekly. Ulcers and skin lesions received a bio-cellulose dressing (d) covered with a super absorbent pad (e). Depending on exudate production dressing changes took place on average 2 x weekly in the first 2 weeks of treatment. Skin and wound cleansing was conducted using a microfiber debridement (f) product and PHMB, a moisturizer was used to treat the dry skin condition.  
**Results:** Skin lesions and ulcers were closed within a mean of 12.5 days and the reduction of edema was a mean of 12 cm (measured at the calf) per week for the first 3 weeks. After 4 months of treatment all patients were fitted ready to wear compression stockings for maintenance therapy. To prevent recurrence, concordance with maintenance therapy is key.  
**Conclusion:** Wound healing and reduction of edema was achieved in a patient-friendly and effective manner within 4 months of treatment in all included patients, improving their quality of life significantly.

**Andrew Nathanson**  
*Validation of the digital indurometer as a cost effective tool for evaluation of lymphoedema in any setting*

**Introduction:** Lymphoedema remains a global problem whose treatment is hamstrung by limited availability of tools for objective quantification of its severity. Whilst tools exist for measurement of fibrotic changes (CT, MRI and US) they are large, expensive and require trained clinicians. Tonometry/Indurometry can measure subtle changes in superficial fibrotic induration. What is needed is a reliable, portable, inexpensive, user friendly device that provides objective measurements of key changes in the oedematous limb, usable in rural/remote areas by untrained persons. This study is aimed at identifying whether the digital indurometer is capable of filling this gap.  
**Methods:** 28 volunteers who had never used the indurometer were presented with written instructions on use and asked to take three measurements on three phantoms (Soft, Medium, Hard) in flat and incline configurations. The data were captured to a laptop whilst video of the volunteer’s technique was simultaneously captured to the same laptop. The data were split into ≥500ms and <500ms groups. Statistically significant differences were identified in the Soft Flat (p < 0.001), Soft Inclined (p < 0.0012), Medium Flat (p < 0.001) and Medium Incline (p < 0.0025) groups. No statistically significant differences were identified in either Hard group. All measurements in the ≥500ms Medium and Soft groups were +/- 10% of control.  
**Conclusion:** Once modified to display an error if measurement is too rapid, the indurometer will provide an affordable, portable, user friendly device that obtains reliable objective measurements of the oedematous limb in the clinic or rural/remote areas.

**Karin Johansson**  
*Breast oedema during and after radiotherapy to the breast – preliminary results*

Breast lymphedema (BLE) after breast conserving treatment is an often overlooked side effect and very rarely documented.  
**Patients:** Two hundred breast cancer patients with breast conserving surgery including axillary node dissection (AND) or sentinel node biopsy (SNB), and radiotherapy (RT) to the breast only or to the breast and the axilla will be included.  
**Measurements:** Local lymphedema is evaluated using a MoisterMeter where an electrical parameter, Tissue Dielectric Constant (TDC), directly proportional to tissue water content in the tissue, is calculated. Lymphedema is defined as &gt;30% (2SD) difference in TDC compared to non-affected breast and values are expressed as ratio between the breast.  
**Design:** Measurements are performed pre-RT and once a week during RT treatment (3-5 weeks), 2 and 4 weeks, 3 and 6 months, 1.2 and 3 years post-RT. Patients with BLE at 3 months post RT will be included in a RCT where controls will get no treatment and intervention group will get treatment with compression (sport-bra) and self-MLD.  
**Results:** So far 62 patients have been included (11 AND, 51 SNB). At pre-RT, end of RT, 4 weeks and 3 months post-RT mean values of TDC for affected breast was 35/ 37,8/ 39/ 43,1 with mean ratio 1,35/ 1,46/ 1,51/ 1,67. So far 13 patients have been included in the RCT.
**Mads Radmer Jensen**  
The peripheral circulation in breast cancer-related lymphoedema

**Authors:** Mads Radmer Jensen, MD1,2; Lene Simonsen, MD, DMSc1; Tonny Karlsmark, MD, DMSc2; Jens Bülow, MD, DMSc1  
**Affiliations:** 1) Department of Clinical Physiology and Nuclear Medicine, 2) Department of Dermatology and Venereology. Bispebjerg University Hospital, Copenhagen, Denmark  
**Background:** Breast cancer related lymphoedema - defined as a chronic swelling of the ipsilateral upper extremity - is a frequent and debilitating complication to breast cancer treatment. The pathophysiology of BCRL is complex and poorly understood; however, data suggest that changes in the peripheral circulation may contribute to oedema formation.  
**Methods:** In 13 volunteers diagnosed with BCRL the following aspects of the upper extremity peripheral circulation were examined; 1) Muscle microvascular volume; 2) Capillary filtration Coefficient; 3) Central sympathetic vascular reflexes; 4) Local sympathetic vascular reflexes; and 5) Forearm blood flow and vascular resistance at rest. This was studied by: 1) Realtime contrast enhanced ultrasound, 2-3) Venous occlusion strain gauge plethysmography, non-invasive beat-to-beat blood pressure measurements, and Lower body negative pressure; and 4) Skin 99mTc-pertechnetate washout. All measurements were when possible performed bilaterally and simultaneously using the healthy arm as a control.  
**Results:** The Capillary filtration coefficient was 7.98 ± 2.52 μL 100 g tissue-1 mmHg-1 min-1 (mean±SD) on the swollen forearm and 6.09 ± 1.83 μL 100 g tissue-1 mmHg-1 min-1 on the control forearm. This difference was highly significant (p < 0.001). No significant differences could be demonstrated concerning muscle microvascular volume, forearm blood flow, central - or local sympathetic vascular reflexes.  
**Conclusion:** Capillary filtration is increased in arms with BCRL, while the vascular control mechanisms seem to be preserved. We hypothesize that increased capillary permeability may be due to low-grade inflammation promoted by a reduced lymphatic removal of inflammatory cytokines.

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**Amy Baker**  
Impact of radiation therapy on lymphatic function

**Background:** Radiation therapy associated with surgical breast cancer treatment is known to be a significant and independent factor in the development of lymphedema. However the primary damage to the lymphatic system induced by radiation remains unclear.  
**Goal:** The purpose of this study was to determine the impact of radiation upon lymphatic system.  
**Methods:** In rabbits, the popliteal lymph node within the popliteal fossa received 8gy on 4 subsequent days. Lymphatic functionality was assessed by the ability to transport FITC-dextran through the afferent/efferent popliteal system to blood. Examination of the popliteal fossa was conducted using fluoroscopic and histological methods and extracellular water content of the limb was monitored utilizing biimpedance. Animals were sacrificed at 7 and 30 days post radiation. Additionally, cell culture was used to examine morphology, proliferation, survival and apoptosis of lymphatic endothelial cells following radiation (0-20 Gy).  
**Results:** Radiation impaired lymph transport by more than 50% at 7 and 30 days compared to non-treated controls with concurrent elevations in tissue water by 30 days. While some degree of fluid continuity was demonstrated in the treated animals, the vessels were very leaky at both time points. Fibrosis and thickening of the node capsule and trabeculae were observed at 30 days. Despite the functional deficit, ongoing studies suggest that lymphatic cells may be more resistant to radiation than their arterial or venous counterparts based on morphology and apoptosis studies.  
**Conclusions:** Radiation has a significant negative impact on the lymphatic system. The mechanisms responsible for this effect are under investigation.

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**Robert Dinniwell**  
Impact of local regional nodal radiotherapy on the incidence of extremity and truncal lymphedema in women with locally advanced breast cancer

**Background:** Radiotherapy (RT) is a key component in the multi-modal management of women with locally advanced breast cancer (LABC).  
**Purpose:** An analysis of the frequency and patterns of lymphedema following comprehensive regional nodal irradiation (RNI) in women with LABC provides insight for this at risk population.  
**Material/Methods:** An REB approved review of a prospective LABC database at a tertiary care centre was undertaken to identify women having RNI. RNI encompassed the axillary level I, II and III nodal basins in tandem with the infra- and supraclavicular fossae. The onset and distribution of lymphedema was recorded in a prospective manner.  
**Results:** From 2006-2009, 112 LABC patients with clinical stage IIA-IIIC were treated with adjuvant (105) or neoadjuvant (7) RT. The median age was 51 years (27 to 94); 64 patients with left-sided and 48 right-sided primaries. All patients received second or third generation chemotherapy regimes, 95% were treated in the neo-adjuvant setting followed by definitive surgery. The median follow-up was 3.7 years. Over this period 42 women (38%) developed lymphedema. Their median BMI was 24.4 (19.9-31). Twenty one had breast and or truncal, 38 proximal extremity and 32 distal extremity involvement. Twenty three (55%) reported associated pain with a median intensity of 5 (2-10) and 13 (31%) reported some degree of functional compromise.  
**Conclusions:** Following treatment for LABC, truncal and upper extremity lymphedema is common. Given the use of comprehensive RNI to the dissected axilla and supraclavicular fossa, this population would benefit from directed interventions for prevention and management of lymphedema.
Primary lymphoedema syndromes; identification of two new causative genes using whole exome sequencing

Fiona Connell

F Connell, P Ostergaard, M Simpson, G Brice, S Jeffery, S Mansour, P Mortimer
Guy’s and St Thomas’ Hospital NHS Trust, St George’s University of London, King’s College London School of Medicine

Careful phenotyping has enabled the recognition of specific syndromes in which lymphoedema is a characteristic feature. Together with utilisation of next generation sequencing, progress in the understanding of the genetics of lymphatic disorders has been achieved.

The co-occurrence of primary lymphoedema with myelodysplasia progressing to acute myeloid leukaemia (AML), termed Emberger syndrome (MIM614038) was first described in 1979. Over thirty years later we have been able to show that haploinsufficiency of GATA2, a transcription factor that plays an essential role in gene regulation during vascular development and hematopoietic differentiation, underlies this potentially lethal condition.

Microcephaly, primary lymphoedema and chorioretinal dysplasia syndrome (MLCRD, MIM 152950) and the chorioretinal dysplasia, microcephaly and mental retardation syndrome (CDMMR, MIM 156590) present with an overlapping, yet variable, spectrum of central nervous system (CNS) and ocular developmental anomalies. Again these conditions were first described over twenty years ago but with modern techniques we have identified mutations in KIF11 as one causative factor in autosomal dominant forms of microcephaly that are variably associated with congenital lymphoedema and/or chorioretinopathy, demonstrating that MLCRD and CDMMR are allelic disorders. The main features of this condition can so far be summarised as: primary microcephaly with characteristic but subtle dysmorphic facies and variable degree of learning difficulties, congenital lymphoedema of the dorsum of the feet, and/or chorioretinopathy (with or without hypermetropic astigmatism) with marked inter- and intra-familial variation.

Identification of new genes involved in causing primary lymphoedema is essential in understanding pathogenesis of lymphatic disorders and will hopefully ultimately assist in the way these conditions can be diagnosed and managed.

BS10 - ILF Health Service Evaluation DataSet - Base de données d’évaluation d’un service de santé

Chairs: Susan Nørregaard, Neil Piller

International Lymphoedema Framework Japan (ILFJ)
Health Service Evaluation Dataset (HSED) tool

Susan Nørregaard
HSED tool use feedback

BS11 - Footcare - Chaussage

Pierre Brantus, Claire Fuller
Gail Davey

Background: Podoconiosis (non-filarial elephantiasis) is a common cause of lymphoedema among barefoot farmers in areas of red clay soils in highland Ethiopia. Untreated, patients are at risk of frequent episodes of acute cellulitis. The aim of this study was to compare stratum corneum (SC) hydration and barrier function in podoconiosis patients and controls.

Methods: 54 patients were recruited from a podoconiosis clinic, and 21 unmatched controls from a community leaders meeting and a general hospital outpatients in northern Ethiopia. Ethical approval was obtained from Bahir Dar University. Demographics and foot and leg circumferences were recorded. Trans-Epidermal Water Loss (TEWL) and hydration measurements were taken using ‘VapoMeter’ and ‘MoistureMeterSC’ probes, respectively, at 3 points on both lower limbs.

Results: Foot circumferences and foot/leg circumference ratios were significantly greater in podoconiosis patients than controls (p<0.05). TEWL values were similar among patients and controls, however, strikingly lower SC hydration values were seen at all sites in podoconiosis patients relative to controls (foot 6.0 vs 15.0, p<0.001; calf 7.0 vs 11.4, p=0.013; thigh 8.6 vs 12.1, p=0.014). A negative correlation (r=0.38; p<0.05) was observed between foot/leg circumference ratio and foot SC hydration values.

Conclusions: While TEWL values were similar, SC hydration values were significantly reduced on the lower limbs of podoconiosis patients relative to controls. This breach in protection is critical as it may allow ingress of bacteria and red clay soil particles, believed to be central to the induction and propagation of both cellulitis and podoconiosis.
BS12 - Towards a new clinical pathway for lymphoedema in France - Session 2 - Vers une nouvelle organisation des soins du lymphoedème en France - Session 2

Chair: Loïc Vaillant

PFL
Plan d’action du PFL

PFL
Présentation de la proposition de plan d’action national

PFL
Identification des modules action et discussion

17.45-18.45 - Therapeutic innovation symposium - Symposium innovation thérapeutique

Chair: Neil Piller
FRIDAY JUNE 29 - JEUDI 29 JUIN

08.30-10.00 - Skincare and lymphoedema - Soins cutanés et lymphoedème

*Chairs: Hiromi Sanada, Loïc Vaillant*

Loïc Vaillant
Lymphatic Insufficiency and cellulitis - the chicken and egg situation - Insuffisance lymphatique et erysipèle - l’exemple de la poule et de l’œuf

Mieke Flour
Skin problems - Problèmes cutanés

Michel Dandurand
Lymphoedema and skin cancer - Lymphoédème et cancer de la peau

10.30 - 12.00 - Concurrent sessions - Sessions concurrentes

BS13 - National Lymphœdema Frameworks Initiatives - Initiatives de Partenariats Nationaux du Lymphœdème

*Chair: Susan Nørregaard*

Cristina Papadopulu
Identification of the need for a National Lymphoedema Framework - Reconnaissance du besoin d’un Partenariat du Lymphœdème

Robert Damstra
The Netherlands: Core team to Foundation Meeting - Pays-Bas : création de l’équipe exécutive et événement fondateur du Framework

Mieke Flour
Belgium: Foundation Meeting - Belgique : événement fondateur du Framework

Jane Armer
USA Open Space meeting - Etats-Unis : Réunion open space


A National Stakeholders Conference was held by the ALFP in March 2009 to share perspectives on the current state of LE, establish priority issues, and recommend actions to move the field forward. Seventy-one LE stakeholders participated in the day-long conference: patients/advocates (15%), therapists (26%), physicians (9%), industry representatives (17%), researchers (16%), nurses (4%), and educators (3%). Initially facilitators guided participants to create multi-disciplinary working groups to elucidate the biggest issue in LE management. Topic-based groups brainstormed about solutions, resources needed, and action plans required to address these issues. Summary sheets were collected over the course of the day which indicated that diagnosis, education, awareness, reimbursement, and establishing ALFP credibility were among the most significant LE issues. Open Space meetings are an effective format to solicit input from multiple constituencies. The results and outcomes of the National Stakeholders Conference will enable the ALFP to achieve its mission to improve LE management in the US and globally.

Loïc Vaillant
France: PFL structure - France : structure PFL

Christine Moffatt
UK: Drug Tariff - Royaume-Uni : inscription du traitement pour le lymphoedème au registre des médicaments
**BS14 - Abstracts session 5 - Session résumés 5**

**Chair: Karin Johansson**

**Peter Viehoff**

**Development of ICF Core sets for lymphedema: Qualitative study**

**INTRODUCTION** The International Classification of Functioning, Disability and Health (ICF) offers a system to describe the functioning of the patient. Since the ICF is too comprehensive for daily practice, Core Sets can be composed for easier use. **PURPOSE** The research is part of the development of ICF Core Sets for lymphedema. The purpose of the research is to get clear the patients' point of view concerning meaningful concepts which can be classified by the ICF. **METHODS** Focus group meetings were organised and audiotaped. These were transcribed verbatim and analysed. Meaningful concepts were classified according the ICF. **RESULTS** The research is not yet concluded. At the time of the congress provisional data can be delivered. **CONCLUSIONS** With ICF Core Sets for lymphedema the health care professional can work faster (no need to describe the patient in words) and gets a better overview of the patient with lymphedema. The Core Sets can give direction to treatment goals. The codes of the ICF can also be used to formulate outcome measures. Once there are ICF Core Sets digital registration in terms of the ICF of the patient with lymphedema can be faster and more compact. Registration generates data which can be used for research (getting to know more about the patients) and policy making (e.g. insurance companies, governmental).

**Ad Hendrickx**

**The use of clinimetric instruments according to the International Classification of Functioning (ICF), disability and health**

**Background:** Patients with lymphedema suffer from varying degrees of severity from swelling, limited range of motion, pain, loss of muscle strength and fatigue. Related to these problems, activities of daily living are limited, e.g. personal care, walking, housekeeping, sports activities as well as working. Subsequently, the overall quality of life for people with lymphedema is significantly affected.

With the utilization of the ICF, based on the bio-psycho-social model, influences upon a patient's functioning, including body functions and structures, activities and participation in relation to personal and environmental factors, can be described.

In the management of lymphedema monitoring of activity of disease parameters as well as results of treatment and follow-up is mandatory. Health care professionals and the patient perform monitoring. Such checks require validated measurements, in a protocolled schedule on all domains of the ICF.

**Objective:** Present an overview of the process of clinical measurements and reasoning on all domains of the ICF in the Expert Centre for Lymphovascular Medicine Drachten, The Netherlands.

**Methods / Results:** We use several clinical instruments for all the phases of treatment for the patient with or at risk for developing lymphedema. The phase after oncological surgery, when the lymph system is impaired, secondary prevention consists of volumetry and Body Mass Index and is regular measured during oncological follow-up.

When a patient has been diagnosed with lymphedema and the treatment has started, the initial measurements are aimed at the edema itself, but also at the presence of risk factors, pain, loss of joint mobility, strength, physical capacity and emotional distress. In this phase, the frequency of measurement is high.

In the maintenance phase the desired level of activity and participation are leading for the therapy itself, but also for the instruments and the frequency of measuring. For example, the DASH (Disabilities of the Arm, Shoulder and Hand) and objective questionnaires regarding Health Related Quality of Life are utilized.

The frequency of measuring decreases and the role of self-monitoring becomes more important.

**Nele Devoogdt**

**The lymphoedema functioning disability and health questionnaire: reliability and validity**

The purpose of our study was to investigate reliability and validity of the Lymphoedema Functioning, Disability and Health (Lymph-ICF) questionnaire.

Lymph-ICF consists of 29 questions about the impairments in function, activity restrictions and participation problems of patients with breast cancer and arm lymphoedema. Lymph-ICF is divided into five domains: physical function, mental function, household activities, mobility activities and life domains and social life activities. Reliability and validity was examined on 60 patients with and 30 patients without lymphoedema.

Intraclass Correlation Coefficients for test-retest reliability ranged from 0.65 to 0.93. Cronbach’s alpha coefficients for internal consistency were more than 0.70. There were no systematic changes from the first to the second test occasion and measurement variability was acceptable. Content validity was good, because all the questions and the scoring system were understandable and all the patients’ complaints due to arm lymphoedema were mentioned. Construct validity was good. First, there was good convergent validity, because five expected domains of the Lymph-ICF had the strongest correlation with five expected domains of the SF-36. There was acceptable divergent validity, because three of five hypotheses assessing divergent validity were accepted. Second, there was good known groups validity, because patients with lymphoedema had a higher total score on the Lymph-ICF and had a higher score on each domain and on each question than patients without lymphoedema.

In conclusion, the Lymph-ICF is the first reliable and valid questionnaire to assess the impairments in function, the activity restrictions and participation problems of breast cancer patients with arm lymphoedema.
Beverley De Valois
Using traditional acupuncture to promote well being and improve quality of life for cancer survivors with upper body lymphoedema

**Background**: Using acupuncture in lymphoedema management is controversial, with assumptions it will introduce infection or exacerbate swelling.

**Aims**: The National Institute of Health Research (NIHR) Research for Innovation, Speculation and Creativity (RISC) programme funded this exploratory study to assess acceptability, impact on quality of life, and adverse events of using traditional acupuncture as an adjunct to usual maintenance for people with lymphoedema secondary to breast and head and neck cancers.

**Methods**: The Hertfordshire Research Ethics Committee approved this three-step, patient-centred, mixed-methods study.

- **Step 1**: Focus groups with patients and clinicians assessed acceptability.
- **Step 2**: In a single-arm observational study, participants chose 7 (S1) or 13 (S2) acupuncture treatments, with the Measure Yourself Medical Outcome Profile (MYMOP) and SF-36 administered at baseline, end of S1 and S2, and 4 and 12 weeks after end-of-treatment.
- **Step 3**: Participants discussed their experiences of acupuncture in focus groups.

**Results**: Step 1: Eight focus groups (n=39) found acupuncture acceptable, providing affected areas were not needled.

Step 2: 30/35 participants completed 13 treatments. Change in MYMOP profile score for S1 was 1.51 (SD=0.96, p<.0001, n=32); for S2 was 1.32 (SD=0.94, p<.0001, n=30) points improvement on a 7-point scale. SF-36 scores remained significant for Bodily Pain and Vitality 4 weeks after end-of-treatment. No serious adverse events were reported. Step 3: Qualitative data from six focus groups (n=23) supported quantitative results.

**Conclusions**: Acupuncture can adhere to best practice for avoiding skin puncture to manage the symptom burden for cancer survivors with upper-body lymphoedema. It may improve patients’ concordance with long-term management.

Maho Takeuchi
Development of a Quality of Life Measure for Limb Lymphoedema (LYMQOL) Japanese version

**Background/Aim**: The aim of this study was to describe the reliability and validation of LYMQOL, a condition-specific quality of life assessment tool in Japan.

**Methods**: We conducted a preliminary study of 129 patients in a lymphoedema clinic. Original LYMQOL was translated into Japanese. Criterion-related validity was assessed by comparison with European Organization for Research and Treatment of Cancer Quality Life Questionnaire-Core 30 questions (EORTC QLQ-C30) Japanese version; reliability by method of internal consistency (Cronbach’s Alpha) and split-half-test; construct validity by factor analysis (maximum likelihood estimation and promax rotation) and comparing LYMQOL score with the staging of ISL (one-way ANOVA).

This study was approved by Ethics Committee of Tohoku University Graduate School of Medicine.

**Results**: In total, 67 patient questionnaires returned. All of the patients had lower limb lymphoedema. All domains from the original LYMQOL (‘function’, ‘symptoms’, ‘mood’, ‘appearance’ and ‘over-all’) showed good correlation with the scores from EORTC QLQ-C30. Cronbach’s alpha was >.73 for all domains. Reliability was adequate by split-half-test (>.80). LYMQOL Japanese version were consisted by five domains as same as the original version. Two items, however, were not included to any of the domains. The LYMQOL score in all domain except mood was significantly different among the staging of ISL (P<.01).

**Conclusions**: LYMQOL is a validated condition-specific QOL assessment tool which can be widely used as both clinical assessment and an outcome measure in Japan. Two of the 27 items did not reflect any of the domains therefore further revisions are required.

Kyra Sierakowski
The impact of sporting compression clothing on normal and lymphoedema limb volumes and composition after exercise; A pilot study

**Background**: Lymphoedema affects between 10 and 30% of those receiving treatment for cancer. Exercise is encouraged by lymphoedema specialists and research suggests it is beneficial in improving lymphatic drainage by utilising muscle pump action; however it is also known that excessive exercise may increase the lymph load on the vulnerable limb. Many practitioners recommend the use of sporting compression during exercise, and sporting compression companies promote their value in the treatment of lymphoedema. This study aims to examine these claims and establish whether low level sporting compression is a valid recommendation for those at risk of developing lymphoedema and those with early manifestations.

**Objectives**: To establish whether sporting compression garments (SCGs) decrease lymphatic fluid load and/or improve lymph flow in lower limbs following exercise. To compare this effect on those with normal lymph drainage and those that have early lymphoedema to see if sporting garment compression levels are effective at reducing lymph load.

**Methods**: A group of normal subjects and a group of lymphoedema patients were selected for the program. All were measured using Bioimpedance spectroscopy (BIS) before and after exercise both with and without sporting compression garments. The exercise regime was standardised and involved treadmill walking at increasing rates within each person’s activity limitation.

**Results and Conclusions**: SCGs were shown to decrease the fluid build up caused by exercise in both healthy and to a lesser degree lymphoedema affected lower limbs. SCGs pose a potentially cost effective means of lymphoedema control for early or latent lymphoedema management.
**Chair: Stéphane Vignes**

**Marta López Martin**
Présentation et développement d’un essai clinique

**Background**: Lymphoedema is a common and troublesome condition that develops following breast cancer treatment. The aim of this study is to analyze the effectiveness of Manual Lymphatic Drainage in the treatment of postmastectomy lymphoedema in order to reduce the volume of lymphoedema and evaluate the improvement of the concomitant symptomatology.

**Methods**: A randomized, controlled clinical trial in 58 women with post-mastectomy lymphoedema. The control group includes 29 patients with standard treatment (skin care, exercise and compression measures, bandages for one month and, subsequently, compression garments). The experimental group includes patients with standard treatment plus Manual Lymphatic Drainage. The therapy will be administered daily for four weeks and the patient’s condition will be assessed one, three and six months after treatment.

The primary outcome parameter is volume reduction of the affected arm after treatment, expressed as a percentage. Secondary outcome parameters include: duration of lymphoedema reduction and improvement of the concomitant symptomatology (degree of pain, sensation of swelling and functional limitation in the affected extremity, subjective feeling of being physically less attractive and less feminine, difficulty looking at oneself naked and dissatisfaction with the corporal image).

**Discussion**: The results of this study will provide information on the effectiveness of Manual Lymphatic Drainage and its impact on the quality of life and physical limitations of these patients.

**Trial registration**: NCT01152099

**Current Status of study**

**KEYWORDS**: Breast cancer, Manual Lymph Drainage, Lymphoedema, Complex Physical Therapy

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**Isabelle Quéré**
Etude multicentrique d’observation prospective de la prise en charge du lymphoedème

**Le traitement du lymphoédème et ses modalités d’application ne sont pas connues en France. Un observatoire multicentrique de l’efficacité et de la tolérance des traitements décongestifs du lymphoedème en phase aiguë et d’entretien a été réalisé (Observatoire POLIT). L’objectif principal est de décrire les traitements de la phase décongestive intensive en enregistrant la variation volumétrique du lymphoedème entre J1 et la fin du TDI puis pendant les six premiers mois du traitement d’entretien. Un total de 306 patients ont été inclus entre Juillet 2009 et Aout 2010. Résultats : L’observatoire décrit une médiane d’excès de volume à J1 de 38,7% par rapport au membre sain pour l’ensemble de la population. Elle varie selon la durée du TDI : 24,4% entre J1 et J5 chez les patients traités au moins 5 jours, 12,8% entre J5 et J12 chez les patients traités au moins 12 jours et 8,0% entre J12 et J19 chez les patients traités 19 jours. Lors du traitement d’entretien, le volume du lymphoédeème augmente et la réduction volumétrique médiane diminue de 31,0% en fin de TDI à 18,3% en fin de suivi, pour les 242 patients pour lesquels la donnée est disponible. Cet observatoire des pratiques est la première étude multicentrique Française d’évaluation prospective des pratiques dont les résultats serviront de base de réflexion aux travaux du Partenariat Français du Lymphoédème.

**KEYWORDS**: Breast cancer, Manual Lymph Drainage, Lymphoedema, Complex Physical Therapy

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**Sandrine Mestre-Godin**
Evaluation des facteurs prédictifs de l’extension anatomique des lymphoédèmes primaires familiaux et sporadiques

**Le potentiel évolutif en terme d’extension anatomique et d’augmentation de volume des segments de membre est source d’inquiétude voire d’angoisse légitime pour les parents des enfants atteints de lymphoédème. C’est une question centrale des échanges au cours de la consultation diagnostique qui fait souvent suite à une erreur diagnostique de plusieurs mois ou années. En l’absence de données disponibles dans la littérature, il n’est souvent pas possible à ce jour de prévoir et d’informer les patients et leur famille sur l’éventualité de leur maladie que ce soit de façon générale ou spécifique, à l’échelon individuel. En effet, cette pathologie est responsable d’importantes déformations de membre ou de segments corporels à l’origine d’un handicap à la fois physique et psychologique, de troubles du développement moteur et du schéma corporel qui altèrent profondément la qualité de vie des patients. Nous nous proposons dans une étude historico prospective portant sur 151 patients d’évaluer le risque d’extension du lymphoédème en fonction de la localisation initiale et les facteurs prédictifs de cette extension en cas de lymphoédème primaire familial (génétiquement caractérisé ou non) et sporadique. L’étude se déroule actuellement dans l’unité de Médecine Vasculaire du CHU de Montpellier qui est un centre de compétence pour la prise en charge du lymphoédème. L’objectif principal est la détermination des facteurs prédictifs du risque d’extension du lymphoédème primaire dans ses formes familiales et sporadiques pour pouvoir informer au mieux les patients. L’extension sera définie d’un point de vue anatomique comme l’atteinte d’un nouveau segment de membre, non préalablement atteint lors de l’apparition initiale du lymphoédème et évalué entre le début de l’apparition du lymphoédème (données d’interrogatoire) jusqu’au jour de la consultation selon une méthode standardisée. Les premiers éléments de cette étude associent à la maladie de Milroy une atteinte d’emblée bilatérale des membres inférieurs qui reste souvent infra gonale...**
Lors du diagnostic et du suivi des patients présentant un lymphoédème primaire ou secondaire l’évaluation du volume du segment atteint est un élément clinique majeur. Elle permet de guider la prise en charge et d’évaluer de façon objective son impact (orthèse, drainage, bandage) notamment pour le traitement hospitalier intensif. En effet, celui-ci ne sera réalisé quand cas d’échec des mesures prises en ambulatoire et/ou dans le cas où l’excès de volume du membre atteint est supérieur ou égal de 20% au volume de la jambe controlatérale. Pour l’estimation volumétrique, les recommandations prône l’utilisation de la botte à eau qui mesure le déplacement d’eau correspondant au volume du segment étudié. Cette technique paraît simple au premier abord mais est peu utilisée en pratique quotidienne (disponibilité de la botte, entretien, temps de mesure, utilisation difficile pour le membre supérieur). Cette technique a été remplacée en pratique quotidienne par les mesures de périmétrie réalisée au mètre ruban tous les 10 cm à partir du coude pour le membre supérieur ou à partir de la pointe de la rotule pour le membre inférieur (5 cm pour les enfants). A partir de ces mesures, le volume peut être approximativement calculé en utilisant la formule des troncs de cônes car elle ne permet pas de connaître le volume des extrémités (mains, pieds). Cette technique est utilisée quotidiennement lors des consultations et des prises en charge en unité de lymphologie du service de médecine vasculaire du CHU Montpellier. Mais d’autres méthodes doivent être développées afin d’évaluer le volume complet du lymphoédème. Celui-ci peut être évalué après reconstruction d’image TDM ou IRM des membres inférieurs mais ces examens ne peuvent être utilisés quotidiennement pour évaluer le volume dans le lymphoédème. La solution est sans doute dans le développement de nouvelle technologie. L’utilisation d’une caméra portative, auto positionnée, avec reconstruction 3D immédiate déjà utilisé dans certains domaines industriels et médicaux (chirurgie, semelle orthopédique) permet un calcul rapide et complet du volume du membre inférieur étudié. Cet examen non vulnérant peut être renouvelé autant que nécessaire et permet donc d’évaluer les différents traitements mis en place. Cette technique actuellement à l’étude sur le CHU de Montpellier doit être validée avant de permettre une utilisation pratique régulière dans le cadre du lymphoédème.

Amer Hamadé
La place des médicaments veinotoniques en lymphologie

**Background :** Veinotonics drugs are normally indicated in the treatment of lymphovenous insufficiency. Is it necessary to treat lymphorrhea and lymphedema of lower limbs by these drugs ?

**Methods :** We report the case of 6 patients, five men and one woman who presented lymphatic fistula with lymphorrhea on the inguinal region. All patients underwent a clinical examination and lymphoscintigraphy. The first group (3 patients) had been treated with high dose of Diosmin : 4 g/die for the first 5 days, 3 g/die for 10 days and after 2 g/die during 30 days associated to local medical care and an elastocompressive dressing at the level of the affected inguinal region. The second group (the remaining 3 patients) was only treated by elastocompressive dressing and local medical care. Also we studied 8 patients, 5 men and 3 women who presented lymphedema of lower limbs. These patients had been treated by Diosmin 3 g/die for 30 days. Doppler ultrasound did not identify venous complaint in any of the 14 patients.

**Result :** In patients with lymphorrhea : in both groups, the closing time of the lymphatic fistula was identical in the 2 groups.

In patients with lymphedema of lower limbs, no clinical improvement was noted after the treatment by veinotonic.

**Conclusion :** Taking into consideration these partial results, we consider the treatment of lymphorrhea and lymphedema of lower limbs using lymphoveinotonic drugs not to be justified.
En résumé, le renforcement musculaire avec des haltères ou des poids est une approche controversée mais prometteuse en particulier pour les femmes qui ont subi un traitement pour le cancer du sein et qui souffrent de lymphoedème. Les résultats de l'étude PAL suggèrent que ce type d'activité physique peut non seulement améliorer l'apparence et le bien-être, mais aussi réduire la fréquence et la gravité des complications liées au lymphoedème. Cette approche s'inscrit dans une pratique émergente qui vise à mieux comprendre et gérer le lymphoedème, et à la fois à promouvoir une activité physique adaptée et bénéfique pour ces femmes."
BS18 - Towards a new clinical pathway for lymphoedema in France - Session 3 - Vers une nouvelle organisation des soins du lymphoedème en France - Session 3

Chairs: Isabelle Quéré, Geneviève Roblès, Nadine Deshormiere

PFL
Le parcours de soin : approche qualitative
Définition et objectifs d’un parcours de soin
Validation des parcours de soin hospitaliers
Conception des parcours de soin libéraux
Nouveau parcours de soins en France : groupe de travail patients

12.45 - 13.45 - CNETH symposium - Symposium CNETH

Thermal medicine and lymphoedema - Médecine thermale et lymphologie

Chair: Patrick Carpentier

Christian F. Roques, président du conseil scientifique de l’Association Française pour la Recherche Thermale AFRET
Thermal vascular medicine offer in France – general presentation - L’offre française en médecine thermale vasculaire – présentation générale

Monsieur Jacques Burille, Directeur des Thermes de Balaruc-les-Bains
Thermal vascular medicine techniques: the exemple of Balaruc les Bains spa centre - Techniques de soins en médecine thermale vasculaire : l’exemple des Thermes de Balaruc-les-Bains

Professeur Patrick Carpentier, médecine vasculaire, CHU Grenoble
Management of vascular circulation dysfunctions in thermal medicine - La prise en charge des troubles de la circulation de retour en médecine thermale

Docteur Patrick Bergugnat, médecin thermal à Aregeles-Gazost (Hautes-Pyrénées)
Our experience in the management of breast cancer related lymphoedema - Notre expérience de la prise en charge en milieu thermal du « gros bras » post-mammectomie

Monsieur Rachid Aïnouche, Directeur des Thermes de La Roche-Posay (Vienne)
Thermal management of breast cancer related lymphoedema follow-up: the experience of La Roche-Posay spa centre - La prise en charge thermale des suites du cancer du sein : l’expérience des Thermes de La Roche-Posay
14.00 – 15.30 - Therapeutic education of children with lymphoedema and their families - Education thérapeutique des enfants porteurs de lymphœdème et leurs familles

Chairs: Isabelle Quéré, Christine Moffatt

Penny Sanderson
Teenagers with lymphoedema - Adolescents porteurs de lymphoedème

Fabienne Mourgues
Towards an education programme in lymphoedema - Vers un programme d’éducation sur le lymphoedème

Christine Moffatt
Qualitative analysis in children with lymphoedema (study) - Analyse qualitative réalisée sur des enfants porteurs de lymphoedème (étude)

Isabelle Quéré
Film youth camp - Film sur le camp enfants

16.00 – 17.30 - Concurrent sessions - Sessions concurrentes

BS19 - National Lymphoedema Frameworks Achievements - Réalisations de Partenariats Nationaux du Lymphoedème

Chair: Deborah Glover

Patrick Carpentier
France: Survey on current practices - France : enquêtes sur les pratiques courantes

Kerryn Shanley
Australia: Practitioner Repository - Australie : référentiel professionnel

Anna Kennedy
Canada Magazine - Canada Magazine

Junko Sugama
Japan: ILF Dataset implementation - Japon : exécution de l’ILF Dataset

Susan Nørregaard
Denmark: setting up centre of excellence - Danemark : création d’un centre d’excellence
BS20 - Abstracts session 7 - Session résumés 7

Chair: Isabel Forner-Cordero

Rhian Davies
Lymphoedema: Not only hidden but buried and a cause of professional impotence

Lymphoedema is an unrecognised problem for which delayed management is associated with significant costs to patients and services. National disparities in specialist service provision for people with lymphoedema exist, and the need for education of health care professionals was confirmed by a recent national survey. However, the nature of these educational needs for different health professionals has not been previously explored. The study aimed to determine the nature of the educational needs of health care professionals within the context of their working lives.

Method
Focus group discussions were held with representatives from medical, nursing and allied health professionals from Scottish hospital and community-based care settings. A framework approach to data collection and analysis was used in order to identify themes pertinent to the research enquiry.

Results
The identified themes were the rewards of managing lymphoedema; lymphoedema as a hidden and sometimes intentionally buried problem; professional impotence due to knowledge and skill limitations or service boundaries causing inequity in accessing services; lymphoedema specialist resource scarcity, and educational constraints in current financial climate.

Conclusions
Health care professionals who have not undertaken education specifically relating to lymphoedema do not have the knowledge or skill to effectively manage their affected patients. Both generalists and specialist health care professionals feel impotent and frustrated by the inability to transfer patients to adequately skilled providers across care settings. Limited educational opportunities within the current financial climate compound these concerns.

Robert Damstra
A comprehensive lymphedema service according the chronic care model in the Netherlands

Aim: For long time the approach of diagnosis and treatment of lymphedema was segmented. As medical doctors made the medical diagnosis, paramedical healthcare professionals often delivered the conservative treatment and the focus was on reducing swelling or another symptom. As lymphedema should be considered as a chronic disease it needs another approach with integrated care.

Description: The chronic care model (CCM) refers to medical care, which addresses long-term illness with a scope on prevention, self management and self efficacy, an active participation of the patient, coaching and hands-off attitude of the professional, using clinimetry and guidelines and a mutual electronic communication system. CCM offers integrated care and prevents unnecessary costs.

The ICF, international classification of functioning, disability and health focus on an integrated bio-psycho-social model that allows a standardized description of functioning and disability based on individual and contextual factors. With the utilization of the ICF, influences upon a patient’s functioning in three domains of (1) body functions and structures, (2) activities and (3) participation in relation to personal and environmental factors, can be described. In the management of lymphedema monitoring of activity of disease parameters as well as results of treatment and follow up is mandatory.

Evaluation: In 1995 the expert center for lympho-vascular medicine in Nij Smellinghe hospital Drachten (NL) organized all healthcare workers around the patient to work multidisciplinary, improve and standardize diagnostics, early recognition of lymphedema in the cancer department, start early treatment programs and stimulate self-management and awareness to the patients. Since 2005 the CCM and ICF approach was gradually introduced in the lymphological care. This included intensive (non) operative treatment provided at an inpatient ward with 12 beds. Since 2009 the center is certified and financed by the healthcare authorities as expertise center for end stage clinical care, secondary and tertiary referral, education and research. We constantly improve and adjust the new concept of CCM and ICF to the field of lymphology.

Domenico Corda
The conservative treatment of lower limb lymphoedema: from decongestion to hosiery. Ten years of experience in our Rehabilitation Centre

National and International guidelines of the Lymphome-Angiological, Vascular and Rehabilitation Scientific Societies state that the conservative approach to lymphoedema requires a personalised combined decongestive physiotherapeutic programme. The approach to a patient with a lymphoedema-related disability requires a personalized rehabilitation project, with short, medium and long term programmes.

We define as a short term programme what in fact is identified with the attack phase, or CDP 1, of the Lymphologists’ combined decongestive physiotherapeutic treatment. The medium term program is the stabilitation phase or CDP 2 and long term programme is identified with CDP3, the phase of maintenance and optimization of the results obtained.

In CDP2 and in CDP3, elastic, contensive hosiery (garments) plays an essential role in contrasting interstitial hypertension and in maintaining a balance between lymph production and lymph transportation. Naturally, in these phases, the patient should also undergo therapeutic decongestive sessions, with a frequency to be evaluated at each check, in relation to his/her individual variable difficulty to maintain this balance.

A last concept is that there is a very tight relationship between results and the preparation and experience of the rehabilitation-lymphology expert team that treats, and cares for, the lymphologic patient. With this presentation, we will present our results of ten years of lymphedema outpatient management.
Rachel Pritzker
Lymphedema education initiative

INTRO: According to a recent CLF national survey of Canadian health professionals, approximately 40% of nurses and physiotherapists treating lymphedema patients have no basic lymphedema education. Rehabilitation programs that have been published in recent years have shown successful results in reducing the incidence of lymphedema. Knowledge translation of these studies is essential and can change the landscape in our country.

AIM: To create a self-sustaining educational initiative in lymphedema risk reduction and management for health professionals across Quebec.

RATIONALE: Together, the MUHC Lymphedema program and the Lymphedema Association of Quebec initiated an education program in hospitals and community clinics to fill this knowledge gap. The goal was to provide health professionals with tools for early detection and referral. This basic knowledge can be delivered in a one hour lecture that can fit into a busy hospital and clinic schedule.

DESCRIPTION OF THE EDUCATION PROGRAM:
Phase I: Based on recent literature, a module on risk reduction was created and tested on 600 nurses, physiotherapists, physicians, and radiology technicians in 4 hospitals.
Phase II: Fifteen Physiotherapists specialized in lymphedema treatment from across Quebec attended a full day training on teaching risk reduction to health professionals. Lectures are being delivered in different venues across the province and through electronic conferencing.

EVALUATION: This education initiative has been well received. Evaluation comments stress the program’s pertinence to health professionals’ work. It is a first step in education on lymphedema risk reduction across the province.

Martina Reddick
Transforming the management of lymphoedema in Canada

Lymphedema is a chronic debilitating condition that manifests as a swelling and results in the accumulation of protein rich fluid in the tissue spaces. It causes edema and can cause skin breakdown predisposing patients to cellulitis. Lymphedema arises from congenital malformation of the lymphatic system or damage to lymphatic vessels and/or lymph nodes. Despite its long history in the literature lymphedema remains a challenge and often leaves health care professionals and the medical community frustrated and searching for answers.

Dr. Emil Vodder is considered the originator of Manual Lymph Drainage (MLD). The method was first made known to the public in 1935. His first publication appeared in Paris in 1936. In the 80’s Dr. Michael Foeldi advanced lymphedema therapy considerably by combining MLD compression bandaging, exercise and skin and nail care into what is now known as Complete Decongestive Therapy (CDT).

This presentation will highlight an exciting new 2 layer cohesive short stretch bandaging system that is transforming the management of lymphedema in Canada. Its ease of application, low profile with clinically effective reduction without the bulk is improving patient’s mobility and function and in turn improving their quality of life. This presentation will discuss the benefits of this new short stretch bandaging system to patients and clinicians and the significantly lower overall cost of care. In one patients words “You’ve changed my life five hundred percent.”

BS21 - Patients session: preparation for «MLD debate» and «Surgery session» - Session patients : Préparation pour «Débat sur DLM» et «Session chirurgie»
Chair: Loïc Vaillant
Loïc Vaillant, Stéphane Vignes

BS22 - Palliative care and lymphoedema - Soins palliatifs et lymphoedème
Chair: Anna Towers
Anna Towers, Hubert Vuagnat

BS23 - Prescribing & fitting garments for children - Prescription & essaiage des vêtements de compression pour les enfants
Fabienne Mourgues, Marlène Coupé
BS24 - Towards a new clinical pathway for lymphoedema in France - Session 4 - Vers une nouvelle organisation des soins du lymphoedème en France - Session 4

Pierre Aubas, Grégoire Mercier
Identifying ressources / estimation of costs - Identification des ressources / estimation des coûts

PFL
Estimation of current cost - Estimation du coût actuel

PFL
Identifying the limit of access to treatment - Identification des défauts d’accès aux soins

PFL
A better management of the budget in place / provision of treatment - Optimisation de la ressource financière / administration des soins

17.45 - 18.45 - Debate on Manual Lymph Drainage - Débat sur le Drainage Lymphatique Manuel

Chair: Vaughan Keeley

Neil Piller, Isabel Forner-Cordero, Loïc Vaillant, Vaughan Keeley
What is the place of MLD in the management of lymphoedema? - Quelle est la place du DLM dans la prise en charge du lymphoedème ?

Chair: Anna Towers

Robert Damstra

Janice Cormier
Systematic Review - Revue systématique

A systematic review of the literature was conducted under the guidance of the American Lymphedema Framework in 2010 to examine the contemporary peer-reviewed literature (2004 to 2010) evaluating the surgical treatment of lymphedema. A total of 20 studies from 11 major medical indices were identified. Surgical procedures were categorized as excisional procedures (n=8), lymphatic reconstruction (n=8), and tissue transfer (n=4). The reported incidence of volume reduction in these studies varied from 118% reduction to a 13% increase. The largest reported reductions were noted following excisional procedures (91.1%), lymphatic reconstruction (54.9%), and tissue transfer procedures (47.6%). The majority of these reports, however, are based on small numbers of patients, use non-standardized or inconsistent measurement techniques, and lack long term follow-up. The proposed benefits of any surgical approach should be evaluated in the context of the potential morbidity and surgical expertise. In addition, while these surgical techniques have shown promising results, in general they do not obviate the need for continued use of conventional therapies including compression for long-term maintenance.

Håkan Brorson
From lymph to fat - complete reduction of lymphedema with liposuction - Réduire un lymphoédème avec une liposuccion

Robert Damstra
Surgery with lymphoedema - nodes transfers and anastomoses technique results - Chirurgie et lymphoédème - les résultats des techniques de transferts ganglionnaires et anastomoses

Stéphane Vignes
Role of Repairing Surgery - Rôle de la chirurgie réparatrice

10.30 - 12.00 - Concurrent sessions - Sessions concurrentes

BS25 - Early Detection accurate detection, improved treatment outcomes? - Détection précoce, évaluation précise, meilleurs résultats ?

Chair: Neil Piller

Neil Piller
Harry Voesten
Circumferential suction-assisted lipectomy in end-stage primary or secondary lower limb lymphoedema: a prospective study in 75 patients

**Background:** The incidence of secondary leg lymphedema ranges from 40 to 60% in patients who underwent inguinal or para-iliac lymph node dissection with or without radiation therapy. In addition to this, primary lymphedema of the leg has a prevalence ranging from 1/100,000 to 8/100,000. Although in the early (pitting) phase complex decongestive therapy is the treatment of choice, this therapy is not effective in end-stage lymphedema as hypertrophied fatty and fibrotic tissue do not respond to compression.

**Objectives:** to demonstrate the long term results of CSAL in end-stage primary or secondary irreversible lymphedema of the leg.

**Methods:** A prospective study of 75 patients with end-stage lymphedema of the leg. After initial conservative treatment CSAL was used to reduce the volume difference. Compression was resumed at the recovery room with short stretch bandages, followed by flat-knit garments later in the week. Leg volumes were measured pre-and postoperatively after 1, 3, 6, and 12 months and then twice yearly.

**Results:** the mean preoperative volume difference was 4965 ml (range 1520-19.137 ml). The mean aspirate volume using CSAL was 6996 ml containing 74 percent adipose tissue. After one year the mean volume difference reduction was 93 percent.

**Conclusion:** Circumferential suction-assisted lipectomy combined with a multi-disciplinary approach including pre-and postoperative compression therapy and afterwards wearing of compression garments is an effective in the treatment of irreversible lymphedema of the leg.

Corradino Campisi
Lymphatic microsurgery for effective and long-lasting prevention and therapy of lymphatic disorders

Authors’s wide clinical experience in the treatment of patients with peripheral lymphedema by microsurgical techniques is reported. Microsurgical methods included derivative lymphatic-venous anastomoses and lymphatic reconstruction by interpositioned vein grafted shunts.

In all patients lymphatic and lymphnodal tissues were sent for histological assessment, together with specimen of the interstitial matrix. Diagnostic investigations consisted in venous duplex scan and lymphoscintigraphy. Results were assessed clinically by volumetry performed pre-operatively and post-operatively at 3-6 months and 1-3-5 years. The outcome obtained in treating lymphedemas at different stages was analyzed in terms of volume reduction, stability of results with time, reduction of dermatolymphangioadenitis (DLA) attacks, necessity of wearing elastic supports and use conservative measures post-operatively.

Volume changes showed a significant improvement, till over 80% volume reduction comparing pre-operative conditions. Among patients with lymphedema at earlier stages (stage I and stage II A), over 85% could progressively give up the use of conservative measures and of elastic supports, and 30% of patients with late stage lymphedema (stage II B and stage III) could decrease the use of physical therapies. DLA attacks reduced of about 90%. Histological findings showed poor lymphatic and lymphnodal tissular changes in early stage lymphedemas, whilst significant fibrotic lesions were demonstrated in late stage lymphedemas.

Microsurgical lymphatic derivative and reconstructive techniques allow to bring about positive results in the treatment of peripheral lymphedema, above all in early stages when tissular changes are slight and allow almost a complete restore of lymphatic drainage.
Noriko Kobayashi
The effectiveness of the patient education for lymphoedema prevention in the early postoperative period for gynaecological cancer

**Introduction/Background:** Although the patient education for lymphoedema is one of the important factors to improve lymphoedema, it is not clear whether the early postoperative patient education is effective for the prevention of lymphoedema.

**Aims of the study:** The aim of this study was to examine the effect of early preventive patient education for lymphoedema after lymphadenectomy in patients with gynecological cancer.

**Methods:** 529 gynaecological cancer patients who received lymphadenectomy after 1995 were enrolled to this study. Three main risk factors (suprafemoral node dissection, radiation therapy and patient education), surgery years and the presence of lymphoedema in each patient were checked. Surgery years were divided into three periods (A: before 2005, B: from 2006 to March, 2008, C: from April, 2008 to present). Patient education for lymphoedema has been performed for some patients tentatively in a gynecological ward since 2006. According to the introduction of lymphoedema instruction management charges as a new system in Japan, patient introduction has been routinely performed for early postoperative cancer patients since April 2008. The onset frequency of lymphoedema in each period was analyzed.

**Results:**
1) There was a significant relation between the number of risk factors and the onset of lymphoedema (P<0.05).  
2) The overall lymphoedema onset was 21.2% and lymphoedema onset by surgery year was as follow: A 23.9%, B 18.4%, C 11.0%, showing significantly decrease (P<0.05) in proportion to an improvement of patient education.

**Conclusions:** The patient education in the early period after gynecological surgery was suggested to be effective for prevention of lymphoedema.

Janice Cormier
Melanoma and lymphoedema: prospective assessment following lymph node surgery

**Background:** Limb volume change (LVC) and associated symptoms were assessed in melanoma patients undergoing sentinel lymph node biopsy (SLNB) or lymph node dissection (LND).

**Methods:** Limb volume measurements were collected preoperatively and at 9-12 months using a perometer (JUZO 1000M). LVC was calculated by subtracting baseline measurements and adjusting for weight change. Patients were categorized into LVC groups: <5%, 5-10% and >10%. A 19-item lymphoedema symptom assessment questionnaire was administered with scores reflecting affirmative responses. Mixed effects logistic regression models were used to identify significant risk factors for LVC.

**Results:** 115 patients had measurements at 9-12 months. Limb volume changes were influenced by limb and type of surgery (Figure 1). The median (range) change in symptom scores for axillary LND patients with LVC >10% was 9 (1,11) compared to 1 (-1,7) for patients with <5% LVC (p = 0.03). The median change in symptom scores were 0 (-1,5) and 9 (8,10) for those with <5% and >10% LVC for patients undergoing inguinal SLNB (p = 0.02), and 7 (0,11) and 6 (-1,12) for those undergoing inguinal LND. The odds ratio for developing >5% LVC was 1.97 for inguinal LND compared to axillary LND and 2.4 for SLNB compared to LND.

**Conclusions:** LVC >5% is common occurrence melanoma patients following lymph node surgery. Inguinal LND is associated with a 2-fold increase in LVC compared to axillary LND. Symptom scores were significantly increased for patients with LVC >10%. Informed consent should include a discussion of the risks of postoperative lymphoedema.

Els Brouwer
Early diagnostics of lymphoedema and self management after oncological surgery

Breast cancer patients and those having an axillary lymph dissection and patients receiving an inguinal/abdominal dissection in particular, have a legitimate concern for developing LE. Healthcare providers should keep in mind that LE involves more than just a swollen limb.

Until true prevention strategies are developed or a cure is found, early identification of swelling and prompt referral for treatment remain the best hope for achieving optimal patient outcomes. In this process the patients play an important role themselves.

In this process we have two stages: primary prevention in those who don’t have LE yet but are at risk and secondary prevention in those who already experiencing LE or just found a small swelling. In this second group self-assessment and self-treatment is very important.

Many articles are published about patient independence, encompassing the concepts of the expert patient and self-management in which the nurse-patient relationship is based on partnership.

Well designed, quality lymphoedema education must be offered to cancer survivor’s to reduce dissatisfaction with educational information. It serves as the foundation from which coping decisions and strategies are generated should LE develop later. This awareness education exists of knowledge and practical skills. The psychological issues on LE and cancer are being discusses in the course, but are not the main topic, because it is all about prevention and awareness. If possible, family members/friends are included in the training in order to help encourage compliance with this part of the program.
Malou Van Zanten

The importance of scar tissue and skin assessment post-surgery/radiotherapy for patients with cutaneous melanoma

**Background:** The integrity of the skin contributes to health. Cutaneous melanoma is normally surgically removed with a wide margin. The post-operative site shows scarring which can block lymphatic drainage, slow capillary re-growth, and result in pain, tension and immobilisation. Many treatments are implemented to improve lymphatic drainage and skin condition but no measure of the status of the skin prior to and during treatment is made, so outcomes can be optimised. Such measures could include scar site, direction, visco-elasticity and induration. These influence wound healing, skin health and lymphatic drainage. Therapist actions and patient education will help manage immobilisation, pain and reduce infection risk and wound breakdown.

**Objective:** To improve awareness of the key parameters of lymphatic, skin and scar tissue conditions in post-surgery cutaneous melanoma patients and to indicate key objective measurements, and though improved knowledge, reduce the risk of developing lymphoedema.

**Method and Results:** A critical review of the literature and a selection of case studies of melanomas has shown patients and practitioners may not be gaining optimal outcomes possibly due lack of assessment of the location, direction and condition of the scar, surrounding skin and effects of radiotherapy. Initial findings of skin and subcutaneous tissue changes from key case studies using estimates of fluids, elasticity and induration will be presented to indicate their impact on treatment outcomes.

**Conclusion:** Collecting more evidence for our treatment actions and measuring their impact may help to gain better patient outcomes through improving skin condition, facilitating lymph flow, reducing wound infection and subsequent lymphoedema risk.

BS27 - Patients session: Debriefing from surgery session and MLD - Session patients : Discussion sur la session chirurgie et DLM

Stéphane Vignes, Isabel Forner-Cordero, Stanley Rockson

BS28 - Education Focus Group - Groupe de discussion éducation

*Chair: Maree O’Connor*

Maree O’Connor, Margaret Sneddon

**Aims:** To discuss issues arising from the ongoing consultation on minimum requirements for education within programmes leading to registration as a non-specialist healthcare professional, thereby contributing to refinement of benchmark statements. This will explore whether to include learning outcomes (or benchmark statements?) related to: Identifying critical findings associated with oedema that may indicate a more extensive disease process
Compression therapy
To identify examples of successful strategies in integrating effective lymphoedema education into non-specialist healthcare programmes
Participants are asked to consider the aims of the session and contribute to discussion. The discussion will be audio recorded and transcribed. The workshop leaders will analyse the transcript and provide a summary for the education and ILF committees. Key points will be reported in a plenary session of the final day of the conference. Themes identified from the discussion, with anonymised quotes may be included in a paper submitted for publication. Participants will be asked to sign a consent form at the start of the session.

BS29 - Foot and hand strapping – Strapping du pied et de la main

Maryvonne Chardon-Bras, Véronique Bouys
**BS30 - Towards a new clinical pathway for lymphoedema in France - Session 5**

Cécile Zinzindohoue
Prévention et dépistage après cancer du sein, réflexion autour d’une structure de soins libérale

**PFL**
Plan d’action du PFL : décision et répartition des tâches

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**BS31 - Open session for National Lymphoedema Frameworks – Session ouverte pour les Partenariats Nationaux du Lymphoédème**

**NLFs**

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**12.45 - 13.45 - Breast cancer symposium - Symposium cancer du sein**

**Chair: Jane Armer**

Nicole Stout
The prospective surveillance model in the US - Le modèle américain de surveillance préventive

Katie Riches

**Introduction:** The significance of the early detection of lymphoedema following treatment for breast cancer has been reported. Pre-treatment limb volume assessment by Perometer and extracellular fluid volume measurement by bioimpedance can be used as a baseline against which post-treatment measurements can be compared, to allow "subclinical" lymphoedema to be detected. Pre-treatment assessments have been offered to women being treated for breast cancer by the Derby Breast Unit since February 2010. An audit of these is reported here.

**Aim:** To identify the proportion of patients willing to attend for post-treatment re-measurement. To identify the proportion of patients with abnormal measurements and subsequent referrals to the lymphoedema service.

**Methods:** All patients were offered pre and post-treatment arm volume and bioimpedance measurements. Follow up measurements coincide with other hospital appointments and are undertaken at 1, 3, 6, 12 months post operatively and then yearly.

**Results:** To date over 800 patients have undergone pre-treatment assessments. Fourteen patients have declined follow up assessment. Abnormal results have been demonstrated in both pre and post-treatment assessments. Some patients present clinically with lymphoedema despite having measurements within the normal range. 35 patients have been referred to the lymphoedema service for further assessment.

**Conclusions:** Pre and post-treatment assessments are acceptable to patients undergoing treatment for breast cancer. Abnormal measurements and clinical signs of lymphoedema have been detected in patients who have undergone axillary node clearance (ANC) and also sentinel node biopsy (SNB). A more detailed evaluation of these methods and the results will be undertaken.
14.15 - 15.45 - **New/future developments in the management of lymphoedema** - **Nouveaux/futurs développements dans la prise en charge du lymphœdème**

*Chair: Christine Moffatt*

Vaughan Keeley  
*Primary lymphoedema - Lymphoédème primaire*

Michel Dauzat  
*A glimpse at the future of the vessels ultrasound - Le futur de l’ultrason des vaisseaux*

Stanley Rockson  
*Emerging and future treatments - Traitement émergents et futurs*

15.45 – 17.00 - **Managing Lymphoedema: the way forward - Prise en charge du lymphœdème : la voie à suivre**

*Chair: Vaughan Keeley*

Margaret Sneddon  
*ILF education committee report - Résumé du comité éducation de l’ILF*

Chi-Ren Shyu  
*ALFP Minimum Dataset - Base de données de l’ALFP*

Junko Sugama  
*Health Service Evaluation DataSet report - Base de données Health Service Evaluation DataSet*

Vaughan Keeley  
*ILF Strategic meeting report - Rapport sur la réunion stratégique de l’ILF*
Anneke Andriessen
Clinical efficacy of a monofilament fibres containing debridement product evaluated in lymphedema patients with skin lesions, scales, rhagades and hyperkeratosis

Objective: The study evaluated debridement efficacy of a monofilament fibre product when used in lymphedema patients with skin lesions, erythema, scales, fissures, rhagades and or hyperkeratosis.

Methods: Case ascertainment was used, looking at debridement efficacy, time for the procedure, safety of use, patient comfort and users' satisfaction. For debridement the study product was wetted with saline or Polihexanide. Clinical outcome was scored by a trained clinician. Additionally before and after photographs were assessed by one and the same clinician, who was blinded for the treatment given.

Results: Debridement was shown to be effective in 93.2 % of the DB sessions (p<0.01), while the product remained intact in 95.2 % of sessions. The average time for the session was 2.50 minutes, significantly shorter than with current methods (p<0.000). Visible debris and scales were successfully removed with the debridement product. Patients reported no pain during the procedure.

Conclusion: The results indicate the potential of the monofilament fibre product to not only provide effective wound debridement but also to remove scales, fissures, rhagades and hyperkeratosis. This is particularly important in the treatment of patients with lymphoedema.

*Debrisoft® Lohmann & Rauscher

Joyce Bosman
High intensity exercise program in lipoedema patients

Background: Physical exercise has consistently been identified as a central element of rehabilitation for many chronic diseases and has been successful in improving quality of life and reducing all-cause mortality. Physical exercise has the potential to be a useful addition to the treatment of lipoedema, but currently its potential benefits have not been fully investigated.

Aims: To investigate the potential of high intensity exercise in the treatment of lipoedema.

Methods: One patient who was diagnosed with lipoedema was referred for exercise training. The training program consisted of high-intensity strength and interval training for 14 weeks and is divided in 3 phases of respectively 2, 6 and 6 weeks. The patient trained individually on specialized strength and cardio training equipment. The focus is on time, instead of pain.

Results: The statistics revealed an overall pain reduction of 73%. After 14 weeks of high intensity exercise training, substantial changes were found in leg circumference, weight, BMI and fat percentage.

Conclusions: This case study has demonstrated that high intensity exercise training might be a useful addition to the treatment of lipoedema patients.

Jillian Bracha
Massive Localised Lymphedema – A Treatment Challenge

Objective: A case presentation illustrating the treatment for lower limb lymphedema which was complicated by development of a massive localised lymphedema in a patient with morbid obesity.

Method: Various compression bandages and modified techniques for reduction of unusual swelling were applied to the lower limbs followed by a fitted garment.

Results: The massive localised lymphedema reduces rapidly when using a combination of compression bandaging for lymphedema with limb amputation stump bandaging. Long term swelling reduction depends on patient and caretaker competency and adherence to compression.

Conclusion: Morbid obesity is a multifaceted condition in which physical therapy using compression bandaging technique for lymphedema treatment may be useful in relieving the discomfort of massive localised lymphedemas in dependant fatty lobules.

Marita Dahl
Follow-up program for early detection and treatment of breast cancer related arm lymphedema

The follow-up program started 10 years ago, as a result of a 2 year prospective study. This study identified patients having axillary dissection and axillary radiotherapy as being at risk of developing arm lymphedema.

The results also showed that patients at risk of developing arm lymphedema had a greater decrease in shoulder abduction, flexion and external rotation.

Thus the follow-ups not only contain measuring for armlymphedema but also scanning for impairment in shoulder mobility and factors associated with the decreased mobility.

Early discovery and treatment of arm lymphedema after breast cancer treatment is important as it increases the possibility to stabilize the lymphedema whilst still relatively small.

Equally important is the discovery and treatment of post treatment impairment.

With this poster we want to show an example of a follow-up program and also enhance the importance with results from the study mentioned above as well as a second study which shows the result of the follow-ups 10 years after they started.
Case study

Description of Case: A 54 year old lady, single, self employed. Longstanding asthma, severe atopic dermatitis/eczema, high body mass index. Diagnosed May 2007: intraductal carcinoma and lobular carcinoma in situ, right breast. June 2007: right total mastectomy and axillary node clearance. March 2008 lymphoedema right arm. March 2012 no evidence of disease recurrence. Reason for Report: A complex case of late stage II secondary lymphoedema, affected right arm 102% larger than contralateral side, BMI 52.1, problematic eczema and history of recurrent cellulitis. These factors affect quality of life: including activities of daily living, employment opportunities and income, body presentation, relationships and mood. Patient accepts the need to re-address weight management strategies. General Practitioner has been requested to review eczema management and antibiotic prophylaxis, thereby reducing risk of recurrent cellulitis. Lymphoedema clinic to provide intensive lymphoedema treatment: aiming at improved skin condition to affected arm, softening of subcutaneous tissues, improved limb shape and size. Additionally, ongoing patient education and support. Case Description: A three week course of bandaging treatment, two appointments per week for review, skincare, manual lymdhatic drainage, re-application of bandages and ongoing encouragement and advice on exercise and function. Discussion: Were the following challenges overcome?

- Overcoming anticipated bandage slippage due to adipose nature and increasing girth of upper arm
- Proceeding with treatment without exacerbating current eczema symptoms
- Patient maintaining independence and productivity during course of treatment
- Effectiveness of treatment with concomitant high body mass index
- Achieving goals of treatment

Prise en charge kinésithérapique du lymphœdème dans les soins de support en cancérologie

Objectif : améliorer la prise en charge kinésithérapique du lymphœdème sur un territoire de santé dans le cadre des soins de support en cancérologie. Description : en 2003, un travail de réflexion sur la prise en charge globale des patients atteints de cancer a été mis en place en amont de la publication du premier Plan cancer. Une équipe transversale a vu le jour (psychologue, diététicienne, kinésithérapeute, assistante sociale et infirmières) pour aider le patient tout au long de son parcours de soins. Un état des lieux mené auprès des kinésithérapeutes libéraux concernant la pratique du drainage lymphatique du membre supérieur après curage axillaire, a révélé une disparité d’accessibilité aux soins et de qualité de prise en charge. D’où la mise en place d’une consultation externe pour :
- procéder à des bilans de lymphœdème pour des patients opérés d’un cancer du sein avec curage ganglionnaire
- proposer des cures de drainage et bandage pour les cas rebelles.
L’évaluation menée auprès des patients et des professionnels de santé concernés a permis d’identifier des perspectives d’action :
- Harmoniser les pratiques et mettre en place un référentiel commun
- Permettre une gestion autonome du lymphœdème en tenant compte des besoins spécifiques des patients.
La mise en place d’ateliers d’éducation thérapeutique est le prolongement du développement des soins de support. L’engagement que prendra le patient à être acteur de sa prise en charge sera le résultat d’un travail pluri professionnel.

"Today I understand it better": Evaluating Breast Cancer Patients’ Success in Learning Lymphatic Self-Massage at a Tertiary Academic Hospital Lymphedema Clinic

A lymphedema clinic, supported by an annual fundraising event, was established in 2005 to bridge patient-identified gaps in breast cancer-related lymphedema management and care. This hospital clinic provides patients with comprehensive care plans and training in self-management and self-care skills based on Combined Decongestive Therapy guidelines (CDT). Manual lymphatic drainage (MLD) is a component of CDT. Patients are taught lymphatic self-massage by a CDT-trained therapist using techniques adapted from MLD. This mixed methods study evaluates the clinic's lymphatic one-on-one self-massage instruction interventions and its effect on patients’ knowledge and adherence to regular self-massage practice. Pre- and post-knowledge tests, structured demographic and self-massage questionnaires and semi-structured patient-feedback interviews were developed, administered and analyzed using basic descriptive statistics and descriptive thematic analysis. Pre/post test results (n=23) indicate that self-massage understanding improved (p&l;t:0.0001). Factors promoting the integration of self-massage into daily life included health literacy and establishing a routine; identified barriers included physical limitations. Patients reflected on their experiences with the learning environment and made recommendations for improvement. Quantitative data collection (currently n=47) is ongoing; trends include higher adherence to daily self-massage among older patients and those who see an MLD therapist in the community. Data are providing a more comprehensive understanding of patients’ needs and experiences of lymphatic self-massage instruction and adherence. Findings will drive program changes to address patients’ unmet needs, improve patient-centered lymphedema care and provide insight for similar programs in this field.
Terumi Iuchi
A comparison of the Japanese and English versions of the ILF Health Service Evaluation Data Set and assessment of their content-related validity and operability

**Purpose:** ILF and ILF Japan developed the ILF Health Service Evaluation Data Set (HSEDS) to promote and document best practice. This study aimed to evaluate and compare the content-related validity and operability of the Japanese and English versions of HSEDS.

**Method:** The data were collected from six lymphoedema clinical practitioners from Japan, 4 from the UK, one from Canada and Denmark. They were asked to input information regarding five patients into the Japanese or English versions of HSEDS. This was followed by a questionnaire about HSEDS. Following collection and analysis of the answers to the questions posed, we evaluated the content-related validity and operability of HSEDS. This study was approved by the Kanazawa University Medical Ethics Committee.

**Result:** In both of versions, the content-related indexes were 0.8 or greater for all sections. From the free comments, we realized there were aspects of HSEDS that were not necessary in the English version because of differences in medical systems. In terms of operability, more than half of the participants found it easy to input the data with all sections. The median inputting times were less than 8 minutes for all sections.

**Discussion/conclusion:** We found that the content-related validity was sufficient. We believed that HSEDS could be a common resource worldwide; however, the different medical systems in each country have proven to be a barrier. In terms of operability, HSEDS was easy to use as confirmed by the short time required for data input despite the numerous questions that are posed to participants.

Nina Linnitt
Managing exudate and wound healing in lymphoedema - an innovative approach

This study highlights an inspirational case of a man with a long standing lymphovenous oedema complicated by non-healing wounds over 10 years. The distress of the odour, exudate and daily management had led to depression and the need for maximum daily pain relief in order for him to function at all. The dressings had to be changed up to 4 times daily during work hours in order to manage the exudate. He had regular episodes of cellulitis. There was also a risk that his job would have to change due to the management of his leg and socially he was becoming more isolated.

After evaluating a new self-care regime using an innovative - simple compression device, his need for pain relief reduced rapidly within the first week and continued to diminish altogether. The exudate reduced significantly over the first 2 days and stopped altogether within 4 days. His motivation improved with each dressing change as he could see the wounds healing each time. He began to regain a socially interactive life because there was no longer an offensive odour to his legs. His lymphoedema and recurrent cellulitis were also controlled.

Originally he was such a complex case, it was thought that nothing would help resolve his issues, however, with some very simple guidelines and the use of a device that was easy for him to manage at home he became a happy, motivated and inspirational person. His leg is wound free, the skin is hydrated and intact, and even the discolouration of long standing chronic inflammation has significantly reduced.

Shizuko Okajima, Gojiro Nakagami
Comparison of coping style between patients with primary and cancer-related lower limb lymphoedema in an out-patient clinic in Japan

**Purpose:** Coping style among lymphoedema patients could be different because primary lymphoedema and cancer-related lymphoedema have distinct pathogenesis. Reinforcing patient’s own coping style would encourage self-directed behavior toward lymphoedema management. The purpose of this study was to compare coping style between primary and cancer-related leg lymphoedema.

**Methods:** A short version of the Coping Orientation to Problems Experienced scales (Brief-COPE) Japanese version was used to evaluate the coping style of patients with primary and cancer-related leg lymphoedema in an out-patient clinic from November 2009 to November 2010. Analysis of covariance was used for statistical analyses for adjusting the effect of age. Since there was an interaction between age and classification of lymphoedema in some domains, age-stratified analyses were conducted.

**Results:** Seventy eight patients with primary leg lymphoedema and 63 patients with cancer-related leg lymphoedema were included in this study. Mean ages were 42.5±14.0 and 61.5±11.9, respectively. In the domains of Brief-COPE, the score of active coping and self-blame coping in primary lymphoedema patients were higher than those of cancer-related leg lymphoedema. Besides, positive reframing coping tended to be higher score in primary leg lymphoedema. Planning coping and acceptance coping styles showed higher score in the primary leg lymphoedema in aged group (≥48 years old).

**Conclusion:** There were significant differences in coping style between primary and cancer-related leg lymphoedema after adjusting age. The higher score of active coping and self-blame coping were distinctive in the patients with primary lymphoedema and those might be related to the cognition of lymphoedema.
INTRO: According to a recent CLF national survey of Canadian health professionals, approximately 40% of nurses and physiotherapists treating lymphedema patients have no basic lymphedema education. Rehabilitation programs that have been published in recent years have shown successful results in reducing the incidence of lymphedema. Knowledge translation of these studies is essential and can change the landscape in our country.

AIM: To create a self-sustaining educational initiative in lymphedema risk reduction and management for health professionals across Quebec.

RATIONALE: Together, the MUHC Lymphedema program and the Lymphedema Association of Quebec initiated an education program in hospitals and community clinics to fill this knowledge gap. The goal was to provide health professionals with tools for early detection and referral. This basic knowledge can be delivered in a one hour lecture that can fit into a busy hospital and clinic schedule.

DESCRIPTION OF THE EDUCATION PROGRAM:
Phase I: Based on recent literature, a module on risk reduction was created and tested on 600 nurses, physiotherapists, physicians, and radiology technicians in 4 hospitals.
Phase II: Fifteen Physiotherapists specialized in lymphedema treatment from across Quebec attended a full day training on teaching risk reduction to health professionals. Lectures are being delivered in different venues across the province and through electronic conferencing.

EVALUATION: This education initiative has been well received. Evaluation comments stress the program’s pertinence to health professionals’ work. It is a first step in education on lymphedema risk reduction across the province.

Hiromi Sakuda
Structure of “professional autonomy” acquired by nurses through “lymphedema specialty outpatient activities”

Hiromi Sakuda1), Mika Nishiyama2), Momoko Sakaguchi1), Satou Miyuki3), Yukiko Miyakoshi4), Tsuyoshi, Kataoka4), Emiko Kimura5)
1) Osaka City University, 2) Hiroshima Bunkyo Women’s University, 3) Ube Frontier University, 4) Hiroshima University, 5) Aomori University of Health and Welfare

Background: Patient outcomes in lymphedema specialty outpatient clinics in Japan have been previously reported, but outcome evaluations of the nurses who perform these activities have not been made. Clarification of the structure of the professional autonomy of nurses involved in specialty outpatient care may provide basic data that will contribute to human resources development of nurses.

Purpose: The aim of this study was to inductively elucidate the structure of “professional autonomy” in lymphedema specialty outpatient clinic nurses.

Methods: A qualitative descriptive study design was adopted. The subjects were five attending nurses in a lymphedema specialty outpatient clinic at A University Hospital. Data were collected from a semi-structured interview conducted using an interview guide prepared based on a previous study of professional autonomy, and analyzed qualitatively and inductively.

Results: Episodes related to professional autonomy of nurses told by the subjects were classified with 86 codes, from which they were divided by type into 20 subcategories. Finally, the five themes of “interest in one’s technical skills,” “interest in one’s ability to understand others,” “goal of patient satisfaction,” “awareness of responsibility as a professional,” and “confidence in one’s ability as a nurse” were taken to form the structure of professional autonomy of nurses.

Hiromi Sakuda
Formulation of a lymphedema section path using the Patient Condition Adaptive Path System

Authors: Hiromi Sakuda1), Kaoru Kitamura2), Satoko Tsuru3), Yukiiyo Kuroda3)
1) Osaka City University, 2) Nagumo Clinic Fukuoka, 3) The University of Tokyo

Background: Lymphedema patients continue to be neglected in Japan, and understanding of lymphedema patients and symptoms remains poor even today. The presence of “lymphedema section” in the Patient Condition Adaptive Path System (PCAPS) developed in Japan is promising for improvements in the quality of lymphedema medical care and raising the quality of life of lymphedema patients. Purpose: To create a “lymphedema section” in PCAPS.

Methods: A lymphedema section was prepared within the content for breast cancer. This section was prepared through discussion by breast cancer and lymphedema medical and nursing specialists and engineering experts who were PCAPS development members, revolving around previous study and documents on lymphedema.

Results: The subjects were all patients following breast cancer surgery. “Lymphedema assessment” was performed in parallel with outpatient follow-up, and was also included in postoperative and pretreatment evaluation of chemotherapy. Observation and education items were incorporated into the unit sheet. Investigation was initiated upon the receipt of a complaint from a patient, objective discovery, worsening of symptoms, or inability to perform self-care. Patient goals were independent self-care and maintaining the present state. Transition classifications were improvement or stage deterioration; there was no transition if the current stage was maintained.

Discussion: We would like to apply this lymphedema section clinically in the future.
Maho Takeuchi
Morphological changes in the lower limb assessed by Ultrasonography and Bioelectrical Impedance Analysis before and after sever cellulitis: A case report

Introduction: Morphological findings of the affected limbs are rarely monitored until the diagnosis of lymphedema. Here we report the time-course of development of lymphedema after the cellulitis by showing the morphological examinations of the affected limb either before or after the diagnosis.

Case description: A 72-years-old female have underwent a gynecologic surgery including lymph-node dissection. She had no edematous episode or venous disorders on basis. She was referred to the outpatient clinic of lymphedema six weeks after the surgery. More than 4 cm increase in circumference and 1.70l increase of the body fluid was observed in her right lower limb. Developed fibrosis was also recognized by the images from ultrasonography. Also, she had tenderness and burning sensation in her right lower limb. We looked into all the clinical episodes and changes in her lower limb. There were no specific changes in her lower limb before and seven days after the surgery. Fourteen days after the surgery, she had a severe fever, and lower limb cellulitis was diagnosed. She had an antibiotic treatment for two weeks and her general condition had recovered, though the edematous condition in her lower limb continued.

Discussion: Secondary lymphedema is generally considered to be worsening gradually, and finally be an irreversible state. Cellulitis is noticed as a trigger of worsening the condition in lymphedema. This report strongly assists the importance of intensive prevention of cellulitis after surgery in lymphedema care.

Janneke van der Zee
The nursing approach of Podoconiosis treatment in Bahir Dar Ethiopia

Description of original/rare case: Population-based surveys suggest that one million people in Ethiopia are suffering from podoconiosis. The cause of podoconiosis is not completely resolved but long-term walking barefoot on red soil is related to it. In Ethiopia approximately 18% of the surface of the land contains the red soil that causes the irritating in the lymphatic vessels of the legs and leading chronic infections. Often podoconiosis is confused with filariasis.

Reason for report: Morbidity among podoconiosis patients is large. There is much misconception among community members and patients are stigmatized.

Case description: Ethiopian man, 34, suffers from podoconiosis stage II both legs for 17 years. He lived in the rural area 37 kilometres from Bahir dar until the swelling below the knee exacerbated. He stopped farming because of the swelling and the side affects from this disenable disease.

The patient divorced his wife because he was embarrassed of his outcasting disease and moved to Bahir Dar.

The dermatologist treats this patient since October 2011 with compression therapy and 4 nodularectomy operations.

Because of this treatment the patient is able to wear proper sized shoes again and slowly the patient regains his dignity.

Discussion: One dermatologist and one specialized nurse in Bahir Dar diagnose and treat podoconiosis patients for the whole rural area. The role of the nurse is raising awareness, educating patients in skincare, applying compression therapy to the legs and woundcare. Early diagnosis and treatment is mandatory. Education of patients and healthcare workers contribute to this goal.

Anna Loskotova
The influence of myofascial – manual lymphatic drainage and proteolytic enzymes on wounds healing

INTRODUCTION: The number of new findings about the role of lymphatic system in a relation to pathogenesis, treatment of primary and secondary lymphedema and in a relation to wound’s healing – especially in traumatology, i.e. also a burn trauma, has risen dramatically in last 20 years.

AIM OF THE STUDY: This study would like to present our experience with area of burn trauma complex therapy. Influence of functional changes in the area of lymphatic system (LS) and soft tissues (ST), preferably with per oral administration of proteolytic enzymes is also included into the complex therapy. This complementary therapy reduces not only the development of edema but also a secondary inflammation reaction in the wound area, thus reducing the need of antibiotics administration. At the same time the study points out significance of syndrome of immunocomplexes (Sy IMK), which is closely related to wound healing.

CONCLUSIONS FROM PRACTICE: Application of both M-MLD and proteolytic enzymes had unequivocally anti-edem effect and in the same time they played role in lowering the risk of development of secondary inflammation. Best results were achieved in cases of early treatment while combining both methods. Dynamic of level of circulated IMC was in accordance with clinical symptomatology.

DISCUSSION: Laboratory tests of circulated IMC are unspecific, however, they gain on importance in cases of monitoring the dynamics of levels during the sickness. With its help it was possible to indirectly verify effectives of medical treatment methods, which lead to effect on functional pathology of lymphatic system and secondary inflammation reaction.

CONCLUSION: Within complex approach to the wound therapy in traumatology, the above mentioned combination of healing methods can be appropriate supplement to basic surgical treatment. Application of these methods leads to accelerated healing, prevention of scar hypertrophy, lower economic costs, shorter sick-leave and prevention of medical-law disputes.