



INTERNATIONAL  
LYMPHOEDEMA  
FRAMEWORK

**3<sup>rd</sup> ILF  
CONFERENCE**  
**June 16 - 18, 2011**

*Marriott Eaton Centre, Toronto, Canada*

## **Towards Global Implementation of Best Practice Opportunities and Challenges**

3<sup>rd</sup> ILF Conference  
June 16-18, 2011  
Toronto, Canada

### **ABSTRACTS BOOKLET**



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**09.30-10.30 – Plenary Session – Progress on ILF Best Practice Document 2<sup>nd</sup> Edition – Chair: A. Towers**

J. Armer – The process and outcomes of the systematic review for the BPD 2<sup>nd</sup> edition

A series of systematic reviews by expert researchers and clinicians in the field of lymphology and lymphedema are being conducted to summarize and discuss current data in the published lymphedema literature (2005-2009) and implications for practice and research. In support for an update for the Best Practices for the Management of Lymphedema guide, a partnership was developed through collaboration between the International Lymphoedema Framework (ILF) and the American Lymphedema Framework Project (ALFP) based at the University of Missouri. The ALFP performed all searches and article retrieval from 11 key databases in consultation with a reference librarian. Systematic review processes, timeline, findings, and implications for lymphedema practice will be summarized by topical areas.

C. Moffatt, D. Glover – The current position of the document and the way forward

The current position of the document and the way forward  
The progress on editorial work on the BPD 2<sup>nd</sup> edition

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**11.00-12.30 – Concurrent sessions**

**Abstract Session A1 – Practice 1 – Chair: J. Feldman**

K. Riches – The use of measuring plasma B-type natriuretic peptide (BNP) in screening patients for heart failure

**Clinical Audit:** There should be confirmation that approval was granted by an appropriate committee. The use of measuring plasma B-type natriuretic peptide (BNP) in screening patients for heart failure.

**Introduction:** Patients with chronic leg oedema may be suffering from heart failure as the sole cause or as a component of a mixed aetiology chronic oedema. The use of the measurement of B-type natriuretic peptide has been introduced in the UK to aid the diagnosis of heart failure. We have been using BNP measurements in our lymphoedema clinic to assess patients with complex aetiology oedema.

**Aims of the audit:** To calculate the percentage of patients who have had abnormal BNP levels and determine the cause.

**Methods:** Patients who have had BNP measurements either before referral or following assessment in the lymphoedema clinic have been included. In those who have had abnormal BNP measurements, echocardiography has been performed and the results of these analysed.

**Results:** Since 2006, BNP levels have been measured in 51 patients after assessment, with 37 (72.5%) being abnormal. In the majority of these echocardiography confirmed heart failure, often with a normal ejection fraction. In some patients, treatment of the heart failure resolved the oedema.

**Conclusion:** The use of BNP measurements has helped in the management of patients with complex aetiology chronic oedema. It seems that in our population heart failure with normal ejection fraction (HFNEF) is more common than that with reduced ejection fraction (HFREF). This distinction is helpful in the further management of patients with chronic oedema.

V. Keeley – The use of arterial Doppler wave forms in screening for peripheral vascular disease prior to compression in patients with lymphoedema

**Clinical Audit:** There should be confirmation that approval was granted by an appropriate committee. The use of arterial Doppler wave forms in screening for peripheral vascular disease prior to compression in patients with lymphoedema.

**Introduction:** Peripheral vascular disease (PVD) is considered a contra-indication to full compression treatment. In the UK the ankle brachial pressure index (ABPI) is a commonly used screening tool for PVD. However, there is evidence that in patients with chronic oedema, this is inaccurate. Examination of the Doppler wave form in peripheral arteries may be more reliable in this group.

**Aims of the audit:** To review the prevalence of abnormal Doppler wave forms in our clinic population and to examine the causes of these.

**Methods:** Doppler wave forms are recorded routinely in new patients with chronic leg oedema attending our clinic using a “Vascular Assist” (Huntleigh, UK). Biphasic or triphasic wave forms in the dorsalis pedis and the posterior tibial arteries are considered normal, whereas monophasic wave forms suggest arterial disease and merit further investigation. The audit looks at the percentage of patients who had monophasic wave forms and what further investigation of these patients revealed.

**Results:** Doppler wave forms were recorded for 320 new patients in 2010. 29 (9%) patients demonstrated at least one monophasic waveform. Further investigation and assessment confirmed PVD in a significant proportion of patients including one patient who had normal ABPIs.

**Conclusion:** Patients with monophasic wave forms do have arterial pathology, which may be asymptomatic. The results have influenced our subsequent management of patients with compression.

C. Vukotich – Use of a laser scanning system to measure limb volume in chronic edema

**Introduction/Background:** There are many ways to assess disease progress in lymphedema. Volume measurement is the most common, but is often time consuming, inaccurate, and improper for patients with mobility impairment or for irregular body parts.

**Aims of the study:** The investigators are evaluating a hand-held laser scanner currently being used to provide accurate measurements of body segments for fabrication of prostheses as a possible replacement for measurements obtained with a tape measure.

**Methods:** (including statistics, whether ethics committee approval has been given) Seven healthy subjects were measured using two separate water volumeters, with each measurement repeated three times. Following this, the subjects were scanned using the Insignia™ laser scanner to create a three dimensional shell. The water levels were marked and outline exported into Microsoft Excel as a point-cloud. The shell was analyzed as a series of frustums. The measurements of both limb segments were analyzed using Pearson’s correlation coefficient between the water volumetry measurement and the laser scanning volume.

**Results:** The results of the study showed a high correlation between measurements for the limb segments. For the leg, the average difference between the measured tank and the insignia was 11.3 mL or 0.87% normalized volume with a Pearson’s correlation coefficient of 0.985. For the foot, the average difference between the measured tank and the insignia was 119 mL or 11% normalized volume with a Pearson’s correlation coefficient of 0.962.

**Conclusions:** (what does the study add to existing knowledge)

The laser scanning system performed better than current clinically used measurement protocols. Although care should be taken to avoid interference from any stabilizing devices, the device can be used to measure anybody segment.

H.N. Mayrovitz – Biophysical Assessments for Lymphedema Detection in Patients with Breast Cancer before and One Year after Breast Cancer Surgery

**Introduction/Background:** In breast cancer (BC) treatment-related lymphedema (BCRL), tissue dielectric constant (TDC) values, reflecting local skin water, are reportedly greater in affected than contralateral arms. However, the magnitude of side-to-side differences before and sequentially after surgery is unclear. Pre-surgery evaluations with follow-ups are the best approach for early BCRL detection, but patients often are initially evaluated after surgery. So, it is useful to know if BC presence or natural variations between affected and contralateral body sides alter biophysical parameter values that are possibly useful for detecting BCRL.

**Aims of the Study:** To determine body side differences in lymphedema assessment parameters before and one year after surgery.

**Methods:** With IRB approval, 70 newly diagnosed BC patients were evaluated before surgery and 30 re-evaluated 12 months after surgery. Bilateral TDC values (2.5 mm probe<sup>1</sup>) were determined at forearm, biceps, axilla and lateral thorax. Arm volumes and bioimpedance<sup>2</sup> values were concomitantly determined and [affected-side/contralateral-side] ratios determined for all parameters.

**Results:** Pre-surgery values (mean±SD) for affected and contralateral sides and [ratios] are as follows; TDC<sub>forearm</sub>: 25.2±3.7 vs. 24.9±3.7 [1.019±0.117], TDC<sub>biceps</sub>: 22.1±3.1 vs. 22.0±3.6 [1.019±0.139], TDC<sub>axilla</sub>: 35.1±7.0 vs. 34.8±8.1 [1.037±0.203], TDC<sub>thorax</sub>: 26.4±4.6 vs. 26.7±5.2 [1.001±0.115]. Bioimpedance values were 290.9±41.6 vs. 290.4±42.8 [0.999±0.052]. All pre-surgery side-to-side differences were statistically insignificant. Twelve months after surgery a significant increase only in the thorax TDC-ratio was detected (0.998±0.010 vs. 1.072±0.022, p=0.004).

**Conclusion:** Similar pre-surgery side-to-side values suggest that if pre-surgery measurements are unavailable, subsequent differentials between sides that exceed predefined thresholds may be diagnostically useful. Further, the first indication of incipient lymphedema may occur in thorax tissue.

R. Davies – What is the education need of health care professionals regarding lymphoedema and what is the preferred method of delivery? A national education research project

**Introduction:** As funding for education reduces there is anxiety among specialists and patients that gains made in raising awareness and knowledge of lymphoedema will be lost. Information regarding content and preferred delivery would enable better targeting of lymphoedema education.

**Aims:** To establish the specific education needs of different HCPs across a nation and their preferred method of accessing education. To compare the lymphoedema specialists' opinion of the needs of generalist HCPs with the needs identified by the generalists themselves.

**Rationale:** Early identification and management of lymphoedema prevents undue suffering and saves costs. There is little evidence that generalist HCPs recognise an education need regarding lymphoedema, however it is a common complaint from specialists and patients. Evidence of the specific content of education need and preferred method of accessing education is lacking. Current education is often designed by lymphoedema specialists with little input from the generalist; greater understanding of the generalist perception of need may enhance provision.

**Description:** An electronic survey was distributed nationally to generalist HCPs via national hubs. A different electronic survey was distributed to lymphoedema specialists.

**Evaluation:** Survey results were analysed using SurveyMonkey software and SPSS. Analysis of over 450 responses across more than 8 professions produced descriptive and comparative data which could be broken down by profession & geographical region.

Preliminary results show some unexpected findings while confirming some previous thinking.

## Abstract Session A2 – Service – Chair: P. Franks

P. Hodgson, A. Kennedy – Lymphedema Landscape study – Canada phase I

**Aims/Rationale:** This online survey of lymphedema care providers aimed to document: 1) the level of lymphedema training and certification of health professionals; 2) the profile of care settings; 3) treatments and services provided; and 4) patient characteristics.

**Description of initiative:** Lymphedema care providers were contacted through community and professional organizations that forwarded the online survey link to their memberships.

**Outcome/Impact:** 239 respondents (47% massage therapists, 29% physiotherapists, 13% nurses, 11% other) completed the survey. 90% of massage therapists, 70% of physiotherapists and 50% of nurses had received specialized lymphedema training; overall 32% had not been trained in Complete Decongestive Therapy (CDT). 60% of care (intensive and maintenance CDT) is provided in private clinics; hospitals offer mainly evaluation and education. Over 50% respondents provide patient education on exercises, risk reduction, self-bandaging, and self lymphatic drainage. 70% of patients had cancer-related lymphedema, 13% had primary lymphedema and 17% had non-cancer related secondary lymphedema.

**Evaluation:** Massage therapists provide more than half of all lymphedema care, primarily in private clinics, thus limiting access to those who can pay for treatment. The focus of lymphedema care in hospitals is on education, assessment and self-management, yet many providing education lack specialized knowledge and training. That many patients self refer for treatment may reflect lack of diagnosis and lack of knowledge among physicians. The need for standardization of training and treatment across Canada is evident. Phase II will investigate funding issues through qualitative interviews with CDT schools, insurance and government representatives.

S. Okajima – Health-related quality of life and associated factors in patients with primary lymphoedema

**Introduction/Background:** Primary lymphoedema requires continuous conservative treatment over patients' life, which may affect their health-related quality of life (HRQOL). Physical and psychosocial characteristics related to lymphoedema would be associated with their HRQOL.

**Aims of the study:** To assess HRQOL in patients with primary lymphoedema undertaking conservative treatment and to reveal the factors associated with their HRQOL.

**Methods:** (including statistics, whether ethics committee approval has been given)

A cross-sectional, observational study included 83 patients with primary lymphoedema at an out-patient clinic for lymphoedema. HRQOL were assessed with SF-36 and EQ-5D.

Lymphoedema status/complications and psychosocial status were evaluated by medical records, physical assessment and self-administrative questionnaires. The study protocol was approved by the Ethical Committee of the University of Tokyo.

**Results:** General health perception score in the SF-36 was lower than the age- and sex-stratified national norms ( $p = .001$ ). In the EQ-5D, the proportions of patients with some/moderate or severe problems were 42.2% for pain/discomfort, 21.7% for usual activities and 20.5% for anxiety/depression. By multiple regression analyses, a lower physical component summary score in the SF-36 was associated with a higher lymphoedema stage ( $p = .021$ ), cellulitis within 30 days ( $p = .003$ ), exercise ( $p = .010$ ) and more substance use coping ( $p = .012$ ). A lower mental component summary score was associated with skin lesions over edematous limbs ( $p = .008$ ), less humor coping ( $p = .005$ ) and more self blame coping ( $p = .014$ ).

**Conclusions:** (what does the study add to existing knowledge). These patients had problems in some domains of HRQOL; health perception, discomfort, usual activities and anxiety/depression. Cellulitis, skin lesions and humor coping may be notable factors to improve their HRQOL.

#### K. Johansson – The Lymphedema Quality of Life Inventory (LQOLI)

**Aims of the study:** The purpose of this study was to measure the quality of life in patients with different types of lymphedema.

**Methods:** (including statistics, whether ethics committee approval has been given)

The Lymphedema Quality of Life Inventory (LQOLI), an instrument developed in Australia for assessment of quality of life, and adapted to Swedish, was used. The Swedish version of the LQOLI (SLQOLI) consists of 61 items and was found valid with a moderate reliability (kappa rang 0.25-0.83) in the physical, emotional, social and practical dimensions. It can be used in the clinic to describe quality of life in patients with lymphedema, a low score indicating better quality of life (items range from 0-3). The responses in the reliability test, from 58 patients with lymphedema, were analyzed.

**Results:** The highest scored items were found in the physical dimension and emotional dimension. In the physical dimension, feelings of swelling and heaviness were the highest scored. In the emotional dimension, anxiety of whether or not the lymphedema would get worse, was the item most highly scored.

**Conclusions:** Lower quality of life scores in lymphedema patients is more influenced by items in the physical and emotional dimensions than the social and practical dimensions of the SLQOLI.

#### D. Willson – Devising clinical notes for the future

**Aims/Rationale:** Synoptic reporting systems have been shown to improve the delivery of care in pathology and surgery. This project explores the feasibility and impact of utilizing a synoptic reporting system, the eCancer Survivorship Program (ESP), for the management of lymphedema care.

**Description of initiative:** ESP is designed to standardize data collection during the lymphedema clinic visits by using a series of easy-to-use click-boxes, drop downs, and open text fields. This setup allows clinicians to simultaneously record data and generate clinical notes tailored for both the clinicians and the patient. Templates for the clinical notes have been developed through an iterative process, including an inter-professional (OT, PT, RN) consensus building exercise. A visual timeline feature allows for easy tracking of clinical activities. ESP has undergone formative and summative evaluation through a simulated implementation with clinicians and a preliminary cost analysis.

**Outcome/Impact:** Just in the past year alone over 1,500 lymphedema clinic visits have been captured and over 1,000 notes generated using ESP. Each of these appointment events contains multiple data and this data has already been used to guide development and research in lymphedema clinic.

**Evaluation:** Preliminary evaluative results suggest that by using the ESP, both the clinical encounter and the patient experiences have improved. Clinicians and patients report high level of satisfaction with the tool that saves time, allows for immediate e-communication and enhances standardisation of data collected and their notes. The implementation of synoptic reporting in the hospital clinical setting has yielded significant cost savings by averting transcription and saving clinical time.

#### E. Quinlan – Lymphedema Trajectories Among Breast Cancer Survivors

Over 22,000 Canadian women will be diagnosed with breast cancer in 2011. Increased screening and more effective treatments have led to improved survival rates; however, treatment often has arm morbidity effects, including lymphedema. Lymphedema has been evaluated using increased arm volume thresholds of 10%, 5%, and most recently, 3%. These changing thresholds create diagnostic dilemmas.

**Objective:** To model changes in arm lymphedema, pain, and disability in breast cancer survivors based on our Canadian cohort study of arm morbidity in breast cancer patients over a five year period. Design: The study's longitudinal data are from over 745 breast cancer survivors collected in four geographical locations across Canada. Participant inclusion criteria are women over 18 years old with unilateral Stage I-III breast cancer, English or French speaking. Data are collected from physical examination and four standardized questionnaires including the McGill Pain. Volume measurements of both arms provides the basis for a continuous lymphoma variable. Analysis uses Latent Growth Curve Modeling (LGCM) to evaluate the starting values, rates of change over time, and their association, of lymphedema, pain, and a disability index. The models of each of these three dimensions of arm morbidity are tested and comparisons between resulting model parameters and fit statistics are analyzed.

**Conclusions:** A continuous lymphedema variable, used in conjunction with appropriate statistical techniques, provides a more sophisticated analysis to better support evidence-based diagnoses. LGCM analyses offers greater understanding of the healing trajectories for breast cancer survivors and thereby makes a contribution to the emerging surveillance literature.

#### S. Rockson – Lymphedema International patient registry and biorepository for lymphatic disease

**Introduction/Background:** The authors have inaugurated a Patient Registry and Biorepository (PRB) for Lymphatic Diseases.

**Aims:** The PRB will provide researchers with much-needed clinical data to study the impact of diseases of the lymphatic system, in order to develop improved treatments a find a cure for lymphatic diseases, lymphedema and related disorders.

**Methods:** (including statistics, whether ethics committee approval has been given)

The PRB is a comprehensive, multi-center U.S.-based program designed to stimulate and support lymphatic research. It will eventually serve as a clinical trial recruitment mechanism as therapeutics and technologies are developed. The registry incorporates the broad spectrum of lymphatic diseases, including primary and secondary lymphedema, vascular anomalies, and visceral lymphatic derangements. Enrollment occurs through a web-based interface. The comprehensive case report form features interactive fields that encompass the broad disease spectrum, both subjectively and objectively. Objective clinical data is entered and validated directly by the patients' affiliated health care professionals. Future developments will include the creation of DNA and tissue banks directly linked to this registry.

**Results:** A comprehensive patient registry and tissue/cell bank program paves the way for future clinical trials of therapeutics as they are developed. The design and early analysis of the registry experience will be presented.

**Conclusions:** The inauguration of the PRB represents a milestone for the patient lymphatic community. Lymphatic investigators throughout the world will have the opportunity to gain access to this invaluable dataset to further the cause of human lymphatic research. In future, the link between the registry and relevant samples of human tissue and DNA will stimulate much-needed progress.

## Workshop A3 – Implementing best practice clinical reasoning

D. Tidhar – Implementing the Best Practice Document: experience of a workshop method in Canada and Israel

**Introduction:** The diagnosis and management of patients with lymphedema has evolved considerably in recent years, driven by empirical evidence from observational as well as randomized control trials. Adherence to evidenced-based medicine (EBM) has been shown to be associated with improved clinical outcomes; however EBM implementation remains sub-optimal.

**Aims:** We aimed to assess the implementation of the “Best Practice for the Management of lymphedema International Consensus” International Lymphedema Framework (ILF) document among lymphedema therapists from Canada and Israel.

**Rationale:** Worldwide surveillance of guideline-driven practices is a vital step toward improving health care. Furthermore, assessment of performance skills from different countries may advance the quality of patient care on both a local and a global scale.

**Description:** 45 therapists from Maccabi Health Care Services in Israel, and from Quebec, Canada attended 4-hour workshops (2009- 2010) discussing lymphedema assessment, classification, diagnosis, measurement techniques, and management in accordance with the Best Practice document.

**Evaluation:** The performance skills of therapist were evaluated from 9 case studies presented at the end of the workshop. Intra-class correlation coefficient (ICC) test was used for assessment of reproducibility and consistency of lymphedema classifications. ICC was very good for both groups (Israeli group: severity ICC=0.754, staging ICC=0.824, Quebec group: severity ICC= 0.924, staging ICC=0.822), signifying high agreement rates among the therapists for lymphedema classifications at the end of the workshop. We suggest that a 4-hour workshop may provide the opportunity to optimize adherence to EBM and to improve overall lymphedema patient’s health.

## Workshop A4 – ICF Core Set

P. Viehoff – Development of core sets for lymphedema: review of the literature / The use of ICF core sets for lymphoedema in daily practice

**Introduction/Background:** 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.

**Aims of the study:** The review is part of the development of ICF Core Sets for lymphedema. The purpose of the review is to get clear the researchers point of view concerning meaningful concepts which can be classified by the ICF. "Methods (including statistics, whether ethics committee approval has been given)". "Databases were searched and then two researchers selected the articles. These were read and meaningful concepts were classified according the ICF. This was also done by two researchers who had to come to consensus."

**Results:** "A total of 149 articles were selected according to the in- and exclusion criteria. 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).



## Education Initiatives

**Introduction:** the use of icf core sets for lymphedema in daily practice.

The International Classification of Functioning, Disability and Health (ICF) offers a system to describe the functioning of the patient complementary to the medical problems described with the ICD-10. Since the ICF is too comprehensive for daily practice, Core Sets can be composed for easier use.

**Aims:** The purpose of the presentation is to make the audience more familiar with the ICF and to make clear the benefits of using the ICF.

**Rationale:** 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).

**Description:** An oral presentation will be given with explications and examples of the use of Core Sets for patients with lymphedema.

**Evaluation:** Not Applicable

## Workshop A5 – Team Building Skills

J. McFarland – How to enhance the team building skill set of those working to create local, national and international multi-disciplinary partnerships in lymphedema frameworks

**Aims/Rationale:** This abstract is to propose a workshop designed to enhance the team building skill set of those working to create local, national and international multi-disciplinary partnerships in lymphedema frameworks. Stakeholders in these frameworks need to have excellent skills in communicating, taking collective responsibility for finding solutions, fostering inter-professional cooperation and visioning together.

**Description of initiative:** Information will be presented from current research in neuroanatomy and positive psychology as an evidence base for new relational models which are currently being used successfully in lymphedema management. When we think of a framework, a geometric structure comes to mind. By studying the geometry that is the framework for the natural world, the human body and efficient physical structures we discover valuable information on how to design social structures that are equitable and harmonious allowing people to relate communicate and co-create cooperatively. In the experiential component of the workshop, participants will have the opportunity to work with these models to collectively find solutions and to create a dynamic vision of how a collaborative and multi-disciplinary partnership between all stakeholders (including patients who are at the heart of this work) can change the face of lymphedema worldwide.

**Outcome/Impact:** Participants will gain a theoretical and applied understanding of how to create frameworks that are effective and empowering. When stakeholders can effectively work together, solutions will emerge collectively that would not emerge from any one person alone thus frameworks can provide leadership, vision and motivation for those working in the field of lymphedema.

## **Workshop A6 – Education Focus Group**

M. O'Connor, M. Sneddon – Focus discussion on Education

**Aims:** To define the parameters for a shared international curriculum for lymphoedema education for non-specialist health professionals by exploring:

- What are the priorities for lymphoedema education?
- What will make the biggest difference to people with, or at risk of, lymphoedema?
- What education is required and by whom?
- To identify the challenges faced in delivering effective lymphoedema education to health care professionals.
- To identify examples of successful strategies in delivering effective lymphoedema education.

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.

## **Workshop A7 – Yoga**

A. Guruprasad – Integrating Yoga into Lymphoedema management - experiences from Kerala – Practical session

These workshop objectives are to explore the role of Yoga within Ayurvedic treatment of patients with lymphoedema. This will be a practical session and will include a demonstration and video of the pioneering work in Kerala.

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## **14.00-14.45 – Plenary Session – Psychosocial Aspects of Lymphoedema – Chair: C. Moffatt**

R. Thomas-MacLean – Qualitatively understanding lymphedema: Canadian perspectives

This presentation addresses the qualitative findings from two Canadian studies of lymphedema after breast cancer. Results from a national, cohort study of arm morbidity are shared, along with a model for understanding the impact of disability. Preliminary findings from an arts-based study are also discussed, as are the implications of the data for health care practices.

M. Fu – The psychosocial impact of living with Lymphoedema

This session will focus on the overview of psychosocial impact through concise critical analysis of existing research to bring detailed daily impact of lymphedema. Dimensions and contents of psychosocial impact will be identified and described. Available quantitative measures for psychosocial impact will be discussed and challenge for quantitative measurement and future directions of how to measure such impact will be discussed. In addition, interventions targeting lymphedema-related psychosocial distress will be discussed.

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**14.45 -15.30 – Plenary Session – Obesity and Lymphoedema by M. Flour – Chair: C. Moffatt - The challenges of managing obesity and lymphoedema**

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**16.00-17.30 – Concurrent sessions**

**Abstract Session B1 – Practice 1 – Chair: C. Pike**

M.J. Geyer – Legs to Stand On™ an international effort to develop integrated lower limb care (LLC) programs for prevention of disability (POD) in the developing world

Education Initiatives

**Introduction:** In diabetes, neglected tropical diseases, and other chronic conditions, increased morbidity, premature death and disability are the result of common secondary complications affecting the lower limbs (swelling, wounds, joint limitations, weakness, immobility). Developing countries disproportionately bear the disease burden from these conditions. LLC programs can potentially provide an effective low-cost solution but integrated technical tools are needed.

**Aims:** This initiative aims to develop and publish technical tools (modular format) for easy replication in various countries and to conduct operational research to evaluate the tools.

**Rationale:** There is an urgent need to scale up lower limb care programs. To date, POD activities have not focused on strategies that address common problems across diseases. No integrated approach to building the capacity of low-resource health systems to provide LLC programs currently exists.

**Description:** This initiative has evolved over the past few years from the efforts of key international stakeholders in diabetes and neglected tropical diseases. In May 2010, an international conference was held to explore the development of an integrated approach to POD. Subsequently a taskforce prepared a preliminary draft of guidelines and technical tools. Draft documents will be finalized and published in May 2011.

**Evaluation:** The Legs to Stand On™ project has been endorsed and is supported by numerous multilateral organizations and international non-governmental organizations. Funding has been secured for the completion of the technical tools and partners are currently in the process of planning operational research projects.

M.J. Geyer – Telerehabilitation (TR) Tools for Self-Management of Chronic Limb Swelling

**Introduction/Background:** Persons seeking care for chronic limb swelling often encounter barriers to critical early treatment (few qualified therapists, long distances to travel, inability to perform self-care, and high costs). Telerehabilitation, use of information technologies for remote delivery of therapy to affected persons where they live, work & play, may aid in overcoming these barriers. However, widespread adoption will depend on the validity and reliability of the method and the usability of the technology.

**Aims of the study:** To determine the content validity of the tools and estimate the effectiveness (usability) of the technology developed for a TR study (real-time videoconferencing) for self-management of chronic swelling of the lower limb(s).

**Methods:** (including statistics, whether ethics committee approval has been given)

Three expert lymphedema therapists produced 10 patient education videos for use in a standardized 6-week TR intervention for self-management of chronic lower limb swelling. Eight additional expert lymphedema therapists evaluated the content via a questionnaire designed to

assess content clarity, accuracy, and completeness as well as the effectiveness domain of usability. Responses were scored on a 5-point Likert scale.

**Results:** Likert scale scoring was: 5= strongly agree; 4= strongly agree; 3= neither agree nor disagree; 2=disagree; 1=strongly disagree. Greater numerical values indicate higher content validity and effectiveness. The mean score for all videos was 4.5 (range 4.1 to 4.91; SD +/- 0.35).

**Conclusions:** Lymphedema experts validated the content of the videos and found high estimated effectiveness. Therefore, the videos are appropriate for use in a TR research study of self-management for chronic swelling in persons with limited mobility.

#### J. O'Toole – Transient and Persistent Lymphedema Following Treatment for Breast Cancer

**Introduction/Background:** The optimal management of lymphedema following treatment for breast cancer (BC) often depends on early identification and intervention. Although some authors suggest not all lymphedema is permanent, this phenomenon is not well documented in the literature

**Aims of the study:** The purpose of this study was to determine the incidence of breast cancer related lymphedema that resolves without treatment (transient) versus persistent lymphedema that requires intervention.

**Methods:** (including statistics, whether ethics committee approval has been given) 578 women treated for unilateral BC were measured on the perometer prior to surgery and followed for serial measurements after surgery with a mean time to follow up of 24 months. Lymphedema was defined as a relative volume change (RVC)  $\geq 5\%$  above the baseline measurement. If edema persisted  $> 4$  months it was classified as persistent. If edema fluctuated back to  $< 5\%$  without intervention, it was classified as transient.

**Results:** 25% of this cohort had an edema that crossed the 5% threshold. 56% of this group had transient lymphedema, and 44% were persistent. Among lymphedema cases, 38% had lymphedema within the first 3 months post surgery. 60% of this group had transient and 40% had permanent lymphedema.

**Conclusions:** This data demonstrates that after the initial identification of lymphedema, a verification measurement should be performed to confirm that the lymphedema is not transient. Intervention without this confirmation could potentially bias the results of clinical trials and initiating treatment for edema that resolves without intervention could subject patients to unnecessary burden. Patients should be counselled about the possibility for transient edema.

#### A. Chafranskaia – Hospital-Based Lymphedema Clinic: taking Interdisciplinary Care to the Next Level

##### **Service Development Initiatives**

**Aims:** Lymphedema is a chronic condition that affects patients physically, emotionally and psycho-socially. Effective treatment requires a skilled and diverse team of health care providers trained to address patients' evolving needs. Choosing an optimal team composition and a model of care (e.g., traditional multidisciplinary, interdisciplinary or innovative trans-disciplinary) is important in order to meet patients' needs within the organization's cultural context and available resources.

**Description:** The Lymphedema Clinic has opened for breast cancer (BC) patients in April 2005. The ongoing challenge has been to provide care and support to increasing numbers of patients with limited resources. Based on evidence-based guidelines and research on chronic disease management a self-management/self-care approach was adopted to enhance patient empowerment through education, coaching and support. Overtime, the care model has evolved from Multidisciplinary to Interdisciplinary to Transdisciplinary: the scope of practice for clinicians (RNs, PT, OT, and RMT-s) started to overlap going through 5 role changes (extension,

enrichment, expansion, release, and support). Novel collaborations with external agencies were developed to help patients who needed more intense lymphedema management leading in turn to an Interagency model of care.

**Evaluation:** (indicate any patient involvement)

Ongoing education, coaching and support are currently provided to over 1,000 lymphedema patients. The Lymphedema Clinic team is cohesive and strong, members express high job satisfaction, and there was no team member turnover in the past 5 years. Semi-structured staff interviews will be conducted to obtain more feedback on the benefits and the challenges of the Transdisciplinary team model.

## **Abstract Session B2 – Surgical Approach – Chair: N. Piller**

N. Kobayashi – Preventive intervention for lower- limb lymphedema at early postoperative period in gynecological cancer

**Introduction/Background:** The treatment of the lower-limb lymphedema (LLL) is not easy because of various factors such as the age, the complication, the patient background, and so on. Therefore, the management of LLL at the early period after gynecological surgery is very important for patients to improve the quality of life.

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

**Methods:** (including statistics, whether ethics committee approval has been given)  
From June, 2002, 623 LLL patients after lymphadenectomy for gynecological cancer were diagnosed lymphedema stage according to the criteria of the International Society of Lymphology. Self-management techniques based on Complete decongestive physiotherapy (manual lymphatic drainage, compression, exercises, and skin care) were guided for the postoperative patients with gynecological cancer in hospital.

**Results:** 1) Ninety of 623 patients (14.4%) were diagnosed stage I of lymphedema, and 533 (85.6%) were more than stage II. Although 55.7% was aware of the edema within 1 year after the operation, patients took  $5.0 \pm 6.7$  years ( $M \pm SD$ ) to a diagnosis of LLL.

2) In stage I, 81 of 90 patients (90.0%) didn't turn worse of LLL (non-progress group), while 9 of 90 patients (10.0%) had a progression to stage II from stage I (progress group) in treatment follow up period  $4.3 \pm 2.1$  years.

3) The occurrence of cellulitis were 6/9 (33.3%), 5/81 (6.2%) in the progress group and non-progress group, respectively. In the progress group, cellulitis occurred significantly higher than the non-progress group ( $p < 0.05$ ).

**Conclusions:** It was suggested that the self-care management and the infection prevention at the early stage of lymphedema would be effective to prevent progression of lymphedema.

P. Lievens – The short time effect of radiation therapy on the lymphatic system and on the newly formed lymph vessels

In this study we have tried to understand the influence of radiotherapy on the lymphatic system and on the regeneration of lymphatic vessels.

**Method and results:** In the first part we irradiated the main lymph vessels of the abdomen of mice with Brachytherapy and inspected the interior of the skin after different intervals after the irradiation. In the second part 3 groups of mice were selected: one normal group, one group where the lymph vessel was cut and one group where the lymph vessel was cut and irradiated afterwards. At intervals (4 to 9 weeks) the lymph flow (from the inguinal to the axillar lymph node) was evaluated. To do so we used two complementary techniques. The first technique was the lymphoscintigraphy on mice in order to compare the lymph flow between the three groups. Here we came to the conclusion that even in the group where we made an incision

together with an irradiation of the lymph vessels the flow between the inguinal and axillary lymph made seemed to be restored completely. The second technique that we have used is the dissection. In this way we could see how the lymph flow was restored. The transillumination technique allowed us to observe that there were many complementary lymph vessels who were formed to restore the lymph flow but not in the original pattern.

**Conclusion:** We could not observe a damage of the irradiated normal lymphvessels. We could observe an inhibition of the regeneration of lymphatics after irradiation. We could observe many supplementary lymph vessels who appeared and who are of great importance for the physical therapy treatment.

#### J. Maegawa – Technique, results, and late patency of lymphaticovenous side-to-end anastomosis in peripheral lymphedema

**Introduction/Background:** Although there are reports on complex decongestive physiotherapy and surgical treatment for chronic lymphedema, only a few detailed descriptions on treatment protocols that combine the two exist. In recent years, several facilities have been established for lymphaticovenous anastomosis (LVA). However, the statistical analysis of the direct effects of LVA on edema has not been thorough.

**Aims of the study:** The aim of this study is to reveal true effects of LVA on changes of circumference on the affected limbs.

**Methods:** The subjects were 55 patients with lower limb lymphedema; 39 had secondary lymphedema and 16 had primary lymphedema. The patients were divided into three groups; early (SA) and late (SB) phase of secondary lymphedema according to preoperative lymphoscintigraphy, and primary lymphedema (P). We calculated the mean circumference of the lower limb during the initial examination as well as 100 days before and after surgery.

**Results:** The results identified a significant difference between in the mean values during the initial examination and 100 days before surgery in SA and SB. A significant difference was observed in the mean values 100 days before and after surgery in SA, but no significant difference in the mean values 100 days before and after surgery was identified in SB. In the P, a significant difference was observed in the mean values 100 days before and after surgery.

**Conclusions:** We believe that LVA needs to be performed before lymphatic functions worsen. LVA was shown to be effective in patients with primary lymphedema in whom lymph ducts can be identified.

#### C. Campisi – L.Y.M.P.H.A.: a New Proposal to Prevent Breast Cancer Related Lymphedema

**Introduction/Background:** The prevention of lymphatic complications caused by breast cancer treatment is a central topic concerning the high incidence of secondary lymphedema.

**Aims of the study:** The purpose of this manuscript is to prospectively assess the efficacy of LYMPHA (Lymphatic Microsurgical Preventive Healing Approach) to prevent lymphedema following axillary dissection (AD) for breast cancer treatment.

**Methods:** Among 49 consecutive women from March 2008 to September 2009 addressed to complete AD, 46 were randomly divided in two groups. Twenty-three underwent LYMPHA technique for the prevention of arm lymphedema (LYMPHA group – LG). The other 23 patients had no preventive surgical approach (control group – CG). LYMPHA procedure consisted in performing lymphatic-venous anastomoses (LVA) at the same time of AD. All patients underwent pre-operative LS. Patients were followed up clinically at 1, 3, 6, 12 and 18 months by volumetry. Lymphedema was diagnosed when a difference in excess volume was of at least 100 ml. Post-operatively LS was performed after 18 months in 41 patients (21 LG and 20 CG). Arm volume and LS alterations were assessed.

**Results:** Lymphedema appeared in 1 patient in the LG after 6 months from the operation (4,34 %). In the CG lymphedema occurred in 7 patients (30,43 %). No significant difference in the arm volume were observed in LG during follow-up, while the arm volume in CG showed a significant

increase after 1, 3 and 6 months from operation. There was significant difference between the two groups in the volume changes with respect to baseline after 1, 3, 6, 12 and 18 months from operation (every timing p-value<0.01).

**Conclusions:** LYMPHA represents a valid technique for primary prevention of secondary arm lymphedema with no risk of leaving undetected malignant disease in the axilla.

### C. Campisi – Lymphatic Microsurgery Treat and Prevent Lymphatic Complications Due to Melanoma Treatment

**Introduction/Background:** The prevention of lymphatic lesions caused by melanoma treatment is a main topic concerning the balance between the radical treatment and its complication profile.

**Aims of the study:** Aim of the study is to evaluate the efficacy of diagnostic and microsurgical procedures in the prevention and management of lymphatic complications in melanoma treatment.

**Methods:** The study includes 21 patients who underwent complete iliac and groin dissection and 14 axillary lymphnodal dissection for the treatment of skin melanoma. They underwent lymphoscintigraphy to assess superficial and deep lymphatic circulation of the limb and Duplex Scan to rule out the presence of any venous thrombotic complications. Therapeutic strategies consisted in bandages and compression garments as non-operative treatment of lymphatic stasis. In the group of patients with melanoma at the trunk, microsurgical lymphatic-venous anastomoses were performed at the groin (10) and at the axilla (6) simultaneously with lymphnodal dissection.

**Results:** Non-operative techniques allowed to control the evolution of lymphedema and to reduce the stage of already advanced cases. Microsurgical preventive approach allowed to prevent the appearance of secondary lymphedema in all patients and no compression garment was used. Those patients operated on after proper oncological follow-up had significant (about 80% averagely) reduction of edema. Post-operative lymphoscintigraphy demonstrated the patency of anastomoses at over 5 years from operation.

**Conclusions:** Proper preventive and early therapeutical strategies of secondary peripheral lymphedema that include lymphoscintigraphy, non-operative procedure and microsurgery demonstrated to be able to reduce the incidence of lymphedema after melanoma treatment and to successfully manage already stabilized lymphedema.

### Workshop B3 – Treatment of Lipoedema associated with obesity

#### J. Bosman – Lipoedema: the challenges of diagnosis and management

Lipoedema is a frequently unrecognized and evolving disorder. The fact that lipoedema is such a small part of this conference shows that attention and understanding of lipoedema is in development. Lipoedema is more common than most physicians realize.

Usually lipoedema presents itself in combination with other types of oedema, such as CVI or lymphoedema. The diagnostic and therapeutic approach of these types of oedema are globally similar. With the Best Practice Document of the International Lymphoedema Framework in 2006, practitioners all over the world give similar treatments to their patients. The methods of assessment and treatment develop through exchanging experiences and learning from each other. Not just for lymphoedema patients, but also for lipoedema patients. It's about time we got to know each other, because knowing each other is learning from each other!

After this workshop you will have more insight in the challenges of diagnosis and treatment of lipoedema globally. We will talk about the approach in Spain, Austria, USA, Canada, Australia and Japan. And possible by sharing your experience we can learn from you!

## Workshop B4 – Hosted by Haddenham – LymCalc

J. Wigg – Presentation of the Lymcalc Software for Clinical Notes and outcomes measures

**Aims/Rationale:** One of the aims of the International Lymphoedema Framework (ILF) is to develop an International Minimum data set. LymCalc has been available for the last decade but has now been developed with enhanced user benefits. LymCalc 4Pro will be presented providing a demonstration of its uses.

**Description of initiative:** LymCalc 4Pro can collect patient data from patient assessment and assist in the evaluation of treatment. LymCalc 4 Pro provides information for therapists and managers to audit services looking at a range of data from types of referrals and treatment outcomes. Following the launch of the new version it is hoped that LymCalc 4 will form the basis of an international tool for MDS. Highly secure and developed to integrate with the NHS security systems it can connect to multiple LymCalc databases and can be LAN networked and hold a remote database.

**Outcome/Impact:** With new security designs and unlimited patient numbers, LymCalc 4 is designed to ensure the secure collection of confidential information and allow for the users to provide evidence of outcomes and costings. It is able to produce GP letters, store images and produce graphs and charts to ensure good practice and produce reports.

**Evaluation:** The use of a MDS programme will assist with the development of services and statistics providing essential information to ensure the continued provision of care in an under resourced field.

## Workshop B5 – Patients with Wounds and Lymphoedema

C. Moffatt – Clinical cases of patients with wounds and lymphoedema

**Background :**Traditionally wound healing and Lymphoedema management have been considered as two separate clinical specialities. However there is growing recognition that the two are intrinsically linked and that failure to address both aspects results in delayed healing and poor control of Lymphoedema. Although the true prevalence and incidence of the problem remains poorly elucidated there are some studies that highlight the magnitude and these suggest the following:

- 40% of patients with leg ulceration have clinically severe signs of Lymphoedema
- 44% of a population of patients with Lymphoedema in London had concurrent wounds
- 34% of patients following panniculectomy had wound healing post-op complications
- 45% patients had wound healing problems that delayed healing after vulvectomy

**The aim** The aim of this workshop is to consider the range of wounds associated with Lymphoedema and the challenges of management.

### Objectives

- to define the range of wounds and the size and complexity of the problem
- to examine why wounds develop
- to explore the assessment issues
- to consider the impact on patients and families
- to explore strategies for conservative management and symptom control

The workshop will be interactive and small groups will be asked to consider the management of patients with different wound problems associated with Lymphoedema .



## Workshop B6 – Head & neck lymphoedema

### D. Squire – Managing head and neck lymphoedema

Overview/statistics

Evaluation:

- Parameters
- Measurements
- Documenting with photos

Compression options

Exercises

- Neck
- Face
- Shoulder

MLD

- Lymphotomes of head/neck
- Pathways

Risk reduction/skin care

Literature overview

Handouts:

- Evaluation sheet
- Bibliography

**08.30-10.00 – Plenary Session – Diagnostics – Chair: V. Keeley**

**N. Piller – New developments in diagnostics for the clinic**

The use of a technique will depend on their availability and whether you work as a sole practitioner or in a multi group practice. Apart from Lymphoscintigraphy, (which is the only tool for measuring the functional status of the lymphatic system) all other techniques are about measuring the signs of failure of the lymphatic system to remove its load, in what ever stage the limb or area is in be that latent, early stage fluid through fatty to fibrous. Most basic techniques have a quantitative and qualitative element to them, but we often miss out on detail due to lack of an attempt to quantify.

For the early detection of subtle failure there is Bio-Impedance Spectroscopy (Single and multi frequency) which can tell us about segmental and whole limb fluids and body composition by looking at resistivity to current flow (generally its only the accumulated ECF we are interested in), there is EM waves looking at dielectric constants to measure fluids specifically under the instrument head (lymphatic territories) and the pitting test. But it's got to be repeated for each territory!

For the detection of excessive epifascial adiposity, BIS and EM can be used (as water and fats are mutually exclusive), and there is Ultra sound. Using a skin fold calliper is a good idea at all stages of lymphoedema as it does give an objective measure of epifascial thickness as can a simple pinch and roll test between the skin and fore finger.

For the measurement of the build-up of fibrous tissue we have the traditional Stemmer sign. It's generally only used at the base of the toes and fingers but it can be used elsewhere. More objectively, we have the techniques of Tonometry and Indurometry, which measure the resistance of the tissues to compression over a specific area such as a mid point or watershed of a lymphatic territory.

For the measurement of limb volumes, either total or segmental, we have Perometry, and a range of forms of traditional or reverse plethysmography. The former can be very accurate but only over short periods of time since limb volumes change not only due to fluids, but fats and muscle and it (nor circumferential or phethysmography) can distinguish between these.

Each technique has some benefit no matter what the stage of the lymphoedema, even if its not clinically discernable by circumference measurement or observation.

Accurately staging a lymphoedema by using as much objectivity as possible is crucial if we are to obtain good outcomes as only then can we target and sequence treatment and measure its outcomes. This session will elaborate on these techniques.

**M. Bernas – Lymphoscintigraphy and new technological developments for clinical practice and research**

The phrase “lymphatic system imaging” is often used, but does it mean the same to everyone? It can raise an appreciation of the power and utility that imaging can bring to disorders of the lymphatic system, it may bring thoughts of something distant or unknown, or it can as easily be dismissed as not useful to some. So what is lymphatic imaging and why is it useful? Beginning with some of the earliest historical images and techniques, this session will explore lymphatic imaging with a focus on the current gold standard as well as peek into the future of imaging. We will explore questions such as: Is lymphatic imaging useful in the diagnosis of lymphedema? What can you see? How can you see it? Can imaging provide clues to some “secrets” in lymphedema and treatment? Most importantly, what does it mean? Put on your seat belts and don't fall asleep for this quick, exciting, and thoughtful overview. It is sure to give some clues, but more importantly- generate more questions for the future.

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## 10.30-12.00 – Concurrent sessions

### Abstract Session C1 – Diagnostics – Chair: M. Bernas

J. Iivarinen – Quantitative diagnostics of soft tissue consistency

**Introduction/Background:** Soft tissue oedema induces variations in the tissue consistency. Therefore, pathological development may be diagnosed by monitoring tissue mechanical properties.

**Aims of the study:** The aim of the study was to evaluate feasibility of mechanical indentation and suction devices to diagnose non-invasively changes in the forearm soft tissues after tissue swelling.

**Methods:** Eleven healthy volunteers (age =  $31 \pm 7$  years, weight =  $84 \pm 9$  kg) gave their informed consent for the study. Two hand-held devices, based on mechanical indentation and suction were used to measure forearm soft tissue stiffness in vivo at rest and under venous occlusion (VO) by pressure cuff. The measurements were conducted 4, 8 and 12 minutes after VO. A layered, hyperelastic finite element (FE) model was matched with the experimental indentation data to determine biomechanical properties of each tissue layer before and after VO.

**Results:** The mean indentation load, measure of tissue stiffness, increased by 14.0 % after VO. Tissue stretch, caused by 13.3 kPa suction, was reduced by 7.6 % after VO. Swelling equilibrium of soft tissues was typically reached 4 min after VO. The FE model showed that changes in the indentation stiffness after VO were explained by the changes in the properties of skin and fat.

**Conclusions:** The indentation and suction devices could diagnose in vivo changes in the biomechanical properties of soft tissues. Further, we could evaluate the mechanical role of different soft tissues in oedemic human forearm. Therefore, the present devices are useful for diagnosing changes in soft tissues following tissue swelling.

A. Newman – Assessment of breast cancer-related lymphedema using dual energy x-ray absorptiometry and multi-frequency bioelectric impedance spectroscopy

**Introduction/Background:** The composition of breast cancer-related lymphedema (BCRL) has been shown to evolve from the initial accumulation of fluid to the development of fibrotic lesions and abnormal fat deposition. Therefore, precise and reliable assessments of BCRL are needed to develop accurate staging and management.

**Aims of the study:** To assess fat, fat-free mass and fluid volume differences between the lymphedema (LE) and unaffected (U) arms of women with BCRL using dual-energy x-ray absorptiometry (DXA) and multi-frequency bioelectric impedance spectroscopy (MFBIS).

**Methods:** Approval was obtained from the McGill University Health Center's Research Ethics Board. Duplicate bilateral arm measurements of fat mass and fat free mass obtained from total body DXA scans were performed on thirteen women with BCRL. Similarly, measurements using MFBIS were performed to determine extracellular fluid volumes for both arms. Statistical analysis included paired t-tests and Spearman's correlation coefficients.

**Results:** Using DXA, significant differences were found in fat mass ( $p=0.003$ ) and fat-free mass ( $p=0.036$ ) between the LE and U arms. Using MFBIS, extracellular fluid (ECF) volume was significantly different ( $p=0.005$ ) between the LE and U arms. There was no significant difference in the precision of the DXA measurements between LE and U arms. While no relationship existed between fat mass and ECF in either arm, there was a significant relationship between fat-free mass and ECF in the LE ( $r=0.754$ ;  $p=0.007$ ) and U ( $r=0.587$ ;  $p=0.044$ ) arms.

**Conclusions:** These findings suggest DXA and MFBIS can be used to determine differences in limb composition and fluid volumes. DXA fat mass measurements do not appear to be influenced by BCRL.

#### M. Takeuchi – Assessment of Lower Limb Lymphedema with Ultrasonography

**Introduction/Background:** Ultrasonography is one of the tools for assessing lymphedema objectively. However, there are few studies in this regard.

**Aims of the study:** To validate ultrasonography as an assessment tool of Lower Limb Lymphedema (LLL).

**Methods:** (including statistics, whether ethics committee approval has been given)

An observational study of 54 women (44 LLL cases and 10 healthy volunteers as controls) was conducted at an outpatient clinic from September 2010 to February 2011. Around 7.5MHz ultrasound was used to visualize whole skin and subcutis. Ultrasound images of lower limb were recorded on 9 region of each lower limb. 972 images were obtained in all, and categorized according to region. The images from LLL cases were compared with the images from corresponding region of the controls. Each image from LLL cases were compared with subjective data, such as their complaints and other conventional methods. This study was approved by Ethical Committee of Tohoku University.

**Results:** Four assessment points in LLL region became apparent with ultrasound, 1) increased thickness of subcutis; 2) increased echo-genicity of the whole subcutis; 3) less distinctive subcutaneous fibers; 4) widening of echo-free space.

Point 4), or both 2) and 3) appeared in remarkable edema region, which can be also clearly identified with the subjective data. In midline edema region, which is difficult to determine the existence of edema from the subjective data, either point 2) or 3) appeared from the ultrasound images, which was apparently different from the images of the controls.

**Conclusions:** Morphological assessment with ultrasonography is applicable as an objective measurement tool for assessing LLL. Further study would be required.

#### J. Rasmussen – Assessing Lymphatic Architecture and Function in Health and Disease Using Near-Infrared Fluorescence Imaging

**Introduction/Background/Aims:** The use of near-infrared fluorescence (NIRF) imaging to non-invasively image lymphatic architecture and contractile function in both control subjects and subjects with lymphedema was recently demonstrated in an IRB and FDA approved clinical study.

**Methods:** Following off-label, intradermal administration of microgram amounts of indocyanine green (ICG, total dose  $\leq 400 \mu\text{g}$ ) in bilateral limbs, a custom NIRF imaging system was used to illuminate the limbs and to acquire images of fluorescent lymphatics. 200 ms exposure times enabled the acquisition of near-real-time image sequences of the uptake and peristaltic propulsion of ICG from injection sites toward the regional nodal basins. The apparent lymphatic propagation velocity and period between propulsion events were quantified.

**Results:** Control lymphatics generally presented with well-defined, linear architecture, while diseased lymphatics were characterized by extravascular fluorescence, dense networks of fluorescent lymphatic capillaries, tortuous lymphatic vessels, and lymphatic backflow and/or reflux. Fewer propulsion events were generally observed in diseased limbs, however, when propulsion was observed, the average apparent lymphatic velocities were 0.7 cm/s in arms and 0.8 cm/s in legs irrespective of disease. The period varied from 28.3 s to 37.7 s between symptomatic and control arms and from 40.5 s to 58.6 s between control and symptomatic legs respectively.

**Conclusions:** These results demonstrate that NIRF imaging can detect architectural and functional lymphatic abnormalities and may provide a means to diagnose lymphatic disease and measure efficacy of lymphatic treatments. Supported in parts by the American Cancer Society, the Longaberger Foundation, and the National Institutes of Health.

#### I-C. Tan – Lymphatic imaging for guidance of therapy in head and neck lymphedema

**Introduction/Background:** Treatment of lymphedema (LE) could be controversial due to the limited understanding of the lymphatics. Head and neck lymphedema (HNL) is especially debilitating because of the limited options for treatment. Complicated geometry and complex lymphatic structure in the H&N region make managing HNL difficult.

**Aims of the study:** Herein, we describe the compassionate use of near-infrared (NIR) fluorescence imaging together with 3-dimensional photogrammetry (3DP) to understand the lymphatic anatomy and function, and to help better manage the disease in a subject with HNL.

**Methods:** Immediately after 9 intradermal injections of 25 µg indocyanine green each in the face and neck region, skin surface was illuminated with a diffused excitation light, and NIR fluorescence images were collected using a custom-built imaging system. Manual lymphatic drainage (MLD) therapy was performed through the guidance of the images. Also, 3DP of the face was used to monitor response to therapy.

**Results:** NIR fluorescence images revealed some abnormal lymphatic structures in the H&N region, and helped identify some functioning vessels and draining lymph nodes. Using 3DP, precise geometry of facial structure was obtained, and detection of small changes in edema between therapy sessions was achieved.

**Conclusions:** Effective HNL therapy was achieved through the guidance of the map of lymphatics in the H&N region using NIR fluorescence imaging. 3D photogrammetry allowed longitudinal assessment of LE to evaluate the effect of therapy.

#### Workshop C2 – Diagnostics

##### N. Piller – A practical guide to use diagnostics methods in clinical practice

This workshop will examine the different techniques available. This is a practical demonstration and discussion.

#### Workshop C3 – Palliative Care

##### A. Towers – The management of lymphoedema in advanced disease based on ILF Position document

This workshop will present the key findings from the ILF Palliative Position Document. Symptom management, effective communication, modification of lymphoedema treatment.

#### Workshop C4 – Hands on bandaging Techniques with 3M Coban 2 System

**This is a workshop open to Canadian therapists.**

#### Workshop C5 – Diagnostics 2: Bio-impedance

##### K. Riches – A practical guide to use of bioimpedance in clinical practice

The importance of the early recognition of lymphoedema and the significance of pre-treatment measurements has been established. Bioimpedance Spectroscopy (BIS) is a non-invasive technique that measures the opposition of the body to an applied electrical current passed through the limbs being compared.

When lymphoedema is present, lymph builds up in the interstitial spaces of the tissues. This results in an overall increase in the total amount of extracellular fluid in the limb, causing swelling.

When compared to standard measurement techniques, such as limb volume measurements, change in BIS has been found to occur earlier in the development of lymphoedema. These

findings have supported the application of BIS has in the identification of early, sub-clinical lymphoedema and monitoring of treatment outcomes.

The objective of this skills workshop is to provide an overview of how BIS can be used to assess unilateral arm and leg oedema. This will include when BIS measurement is indicated and how to undertake BIS using the U400 device (Impedimed). An overview of how this is used clinically in current practice and some examples of how BIS measurement has aided clinical assessment and track extracellular fluid change over time will be given.

## **Workshop C6 – Aqua Lymphatic Therapy**

D. Tidhar – Aqua Lymphatic Therapy for leg and arm lymphedema – workshop for lymphedema therapists

**Workshop Aims:** The therapists will be able to understand the rationale of Aqua Lymphatic Therapy (ALT) which differs from other types of aquaform regimes, and be able to choose this option of treatment in their therapy decision-making processes

**Background:** ALT is a method that uses the physical properties of the water to achieve the same goals as Complex Lymphatic Therapy. ALT was studied in two randomized control trials and was found to be a safe method with an immediate positive effect on edema and long term positive effects on pain, grip strength, quality of life and disability in women who suffer from mild breast cancer related lymphedema. ALT for the lower extremities was found to be effective only in case series.

**Description of the workshop:** This one hour workshop includes 15 minutes of theory regarding the principles of ALT and 45 minutes of practicing a full session of ALT for leg lymphedema in a 4 feet height pool (participants should bring swimsuits).

The session is comprised of gentle exercises, which are performed in a slow rhythm. Breathing exercises are performed at first to clear the reservoirs followed by exercises of the shoulder girdle, abdomen, and back extensors muscles. Self-massage is performed from the affected lower limb lymphotome to the healthy chest lymphotome. The use of floating aids during the second half of the session helps to create distal-to-proximal exercises that involve the hips, knees and ankle joints.

Demonstration of leg measurements will be done before and after the session in order to emphasize the importance of monitoring the patient especially in a group situation.

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## **12.15-13.15 – Lunch Symposium – Breast Cancer Survivors and Lymphoedema**

M. Fu – Work-related Impact of Post-Breast Cancer Lymphedema

**Introduction/Background:** With the higher survival rates of individuals diagnosed with breast cancer, further study needs to be directed toward the changes in life style and the experiences of survivors. One area which has received little attention has been the impact of lymphedema on breast cancer survivors' work experience.

**Aims of the study:** As part of the four-part symposium on breast cancer survivorship which includes: Long-term disability after breast cancer: Expanding an empirical foundation for education, prevention and rehabilitation; and Characteristics and lymphedema occurrence among breast cancer survivors followed for five years after initial treatment; and Lymphedema management from the breast cancer survivor's perspective, this research aimed to describe the experience of work of breast cancer survivors with lymphedema.

**Methods:** A descriptive phenomenological method was used. Sixty-six in-depth interviews were completed with 22 participants in the United States.

**Results:** Three essential themes illuminating the meaning of working for breast cancer survivors with lymphedema emerged, namely: having a visible sign of disability or a need for

help; having physical limitations that made some women handicapped, while others felt inconvenienced; and, finally, some women had constant worries while others felt fortunate. Women endured emotional distress at work. Women whose jobs required heavy lifting and constant use of the affected limb, suffered profoundly from the physical and functional impact of having lymphedema. Qualitative data supporting the major themes will be reported, along with recommended directions for further research

**Conclusions:** Future research should focus on interventions that help employers to understand breast cancer survivors with lymphedema and improve their working conditions.

#### A. Towers – Long-term disability after breast cancer: Expanding an empirical foundation for education, prevention and rehabilitation

**Introduction/Background:** Increased screening and more effective treatments have led to higher survival rates (86%) and longer survival times for women diagnosed with breast cancer. Treatments can have long-term, negative effects on arm function. Arm morbidity can be extremely devastating for women and is the main cause of disability after breast cancer treatment.

**Aims of the study:** The purpose is to create interdisciplinary knowledge about the impact of arm morbidity after breast cancer treatment, through the generation and testing of hypotheses about arm morbidity and its relationship to overall health and psychosocial well-being.

**Methods:** A cohort study with a sample size of 745 breast cancer patients who are followed for 5 years. The project began in January 2005. Participant accrual concluded in 2008, and data collection will end in September 2013. Ongoing data analysis will conclude in 2014. .

**Results:** According to literature, the occurrence rate for surgery-induced arm morbidity is estimated at 30-50%. However, our longitudinal research indicates those figures may be too conservative; 76% of our participants (n=719) experienced arm morbidity in some form at 6-12 mos. post-surgery. Twelve months later (i.e., 18-24 mos. post-surgery), 62% (n=476) experienced arm morbidity.

**Conclusions:** (what does the study add to existing knowledge)

Our findings show that aspects of arm morbidity require a long study period before the natural history and psychosocial impact can be fully documented and analyzed. Longitudinal data demonstrating incidence rates, etiology, disability, psychosocial impact, and access to treatment will aid policy makers in the development of multidisciplinary rehabilitation programs to address problems in a holistic fashion in a timely manner.

#### J. Armer – Characteristics and Lymphedema Occurrence Among Breast Cancer Survivors Followed for Five Years After Initial Treatment

**Introduction/Background:** Breast cancer (BC) survivors present for treatment with many differences which may impact treatment options. BC survivors are at lifetime risk for developing lymphedema. Physical and psychological aspects of lymphedema impact patients' daily lives and quality of life. More than 40% of BC survivors may develop lymphedema, potentially affecting one to five million survivors.

**Aims of the study:** To explore the risk factors related to the development of lymphedema, other co-morbid conditions, and long-term survivorship. Occurrence of lymphedema by treatment factors and patient characteristics were examined and associations of lymphedema occurrence with functional and psychosocial outcome were examined.

**Methods:** Participants were enrolled following BC diagnosis before treatment and followed every three months for 12 months, then every 6 months to five years. Limb volume changes were measured using circumferences, infra-red perometry, and symptom experience via interview. Additional information was collected through medical chart review and interviews. Psychosocial and functional data were collected through the Functional Living Index-Cancer,

MOS SF-36, and Psychosocial Adjustment to Chronic Illness-Self Report. Data were analyzed with descriptive statistics and multivariate analysis.

**Results:** Data were available for 248 survivors. Average age at diagnosis was 57. Over half were from rural counties. Nineteen were single, 25 were divorced, 31 were widowed, and 173 were married. A total of 58 had another primary cancer, 64 had a second surgery, 155 received radiation, and 162 were placed on hormone therapy.

**Conclusions:** These preliminary descriptive findings provide evidence that BC survivors present for treatment with many differences which may impact survival, as well as treatment options.

#### M. Fu – Lymphedema Management from the Breast Cancer Survivor's Perspective

**Introduction/Background:** The compliance paradigm is based on the concepts clinicians use to characterize the ways in which patients manage their lymphedema on a daily basis. Rarely have any of the studies done to date investigated daily management and compliance from the breast cancer survivors' perspectives.

**Aims of the study:** Our study aims were to identify experiences of breast cancer survivors in managing lymphedema and to identify effective strategies and possible barriers

**Methods:** Using three racial/ethnic groups a qualitative design was developed based on Husserlian descriptive phenomenology. 102 interviews were conducted with the 34 participants over a five year period

**Results:** The perspectives of breast cancer survivors indicate that they consider managing lymphedema as more than following treatment plans. Rather it is a daily effort to manage the lymphedema as it fits into their life style. They also indicated that their life styles had changed and they had to come to terms with what they could and could not do.

**Conclusions:** For clinicians it is important to understand the perspective of the breast cancer survivor in determining how best to effectively manage lymphedema with regard to the daily life of the survivor.

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### 13.30-15.00 – Plenary Session – ILF Lymphoedema Dataset – Chair: H. Sanada

#### P. Franks – Concept and design for the ILF Minimum Dataset: the UK experience

This presentation will consider the following issues in relation to the development of a Minimum Dataset (MDS) for use in patients with lymphoedema.

Aims and objectives

- What we want to achieve, and why

**Methods:**

- How we aim to achieve it
- Development of the ILF dataset
- Review and expert opinion on the MDS
- Gaining additional support from the MDS meeting at the ILF in Brighton
- Looking to the future

#### J. Sugama – Launch of ILF Lymphoedema Dataset in Japan

**Aims/Rationale:** The study of Health Related QOL in patients with lymphoedema at Japanese outpatient clinic has launched at five representative facilities in Nov 2009. We chose minimum data set for lymphoedema as a main questionnaire and added other inquiry forms as Japanese original version. The data base soft ware for the exclusive use of this study was programmed in order to collect and analyze the clinical data more easily. The data base was written on the Compact Disc-Recordable (CD-R) and then these CD-Rs were provided to each facility. The



CD-Rs included the data of each facility were brought together in the chief researcher's university and the data were analyzed.

After completion of collecting the data, we addressed key problems of the data base and revealed improvements. In 2011, International Lymphoedema Framework (ILF) · Japan round table meeting launched to develop the internet data base system for English and Japanese version.

To promote and document best practice with the development of an international minimum dataset is one of the ILF objectives. We will introduce the contents and making process in the development of the data base as a means of spreading minimum dataset world-wide in this session. The objectives of this session are to discuss the possibility of application of this trial data base for international settings and to identify any problems when it is used globally.

### C. Shyu – The ALFP dataset and informatics framework

This session will present:

How the dataset was designed. What do we hope to achieve.

The Informatics tools to help all levels of stakeholders.

The experience sharing with participating sites.

The progress to date.

The future developments

The demonstration of the data set and process of development of this collaboration between the practice setting and the research/MDS architecture.

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## 15.30-17.00 – Concurrent sessions

### Abstract Session D1 – Evidence for treatment – Chair: H. Partsch

#### J. Bosman – Managing Seroma

**Introduction/Background:** The most common complication of breast cancer treatment is seroma formation. Persistent seromas have traditionally been treated with repeated aspirations, however, the use of aspiration can be problematic and may produce additional inflammation and oedema. Lymph taping has the potential to prevent or reduce seroma formation, but currently its potential benefits have not been fully investigated.

**Aims of the study:** To investigate the potential of lymph taping to combat seroma formation.

**Methods:** Nine women treated for breast cancer were recruited to this randomised clinical trial; four developed seromas requiring aspiration. Bio-impedance spectroscopy of the breast was used to assess intra- and extra cellular fluid levels in each of the four quadrants of the breast. Participants also filled out a Quality of Life questionnaire. From day one postoperatively, lymph taping was applied over the watershed between skin territories on the posterior thorax between the spine and axilla on those allocated to the treatment group. Measurements were repeated at five, nine and sixteen days.

**Results:** The extra cellular fluid value at t16 was  $0.1037 \pm 0.0324$  (15.3% decrease) over t1 in the lymph taping group and  $0.1066 \pm 0.0227$  (4.6% decrease) in the current best practice group (n=4 in each group). After 16 days of treatment, substantial changes were found in burning sensations, tightness and heaviness in favour of the lymph taping group. In particular, pain perception in the lymph taping group improved.

**Conclusions:** This study has demonstrated that lymph taping has the ability to reduce extra cellular fluid accumulation and improve a range of Quality of Life measures. Lymph Taping has the potential to become a non invasive method to manage seroma.

### J. O'Toole – The Natural History of Cording Following Treatment for Breast Cancer

**Introduction/Background:** Cording is a painful condition that can occur following surgery for breast cancer, and is not well understood.

**Aims of the study:** The purpose of this study was to determine the incidence of cording and its relationship to lymphedema.

**Methods:** From August 2009 to December 2010, 135 women with unilateral breast cancer were evaluated as part of a large prospective breast cancer related lymphedema funded trial. Participants were assessed with volumetric arm measurements using the perometer and with patients completing an electronic survey, the Lymphedema Evaluation Following Treatment for Breast Cancer (LEFT-BC). The LEFT-BC addresses upper quarter symptoms, cording, physical function, and quality of life. This cohort was assessed preoperatively, at the first post surgical visit, with 86/135 patients having an additional third measurement. Edema was quantified mathematically as the relative volume change (RVC) in arm volume compared to the baseline measurement, with lymphedema defined as an  $RVC \geq 5\%$  above baseline. Groups were compared utilizing the Fisher exact test.

**Results:** Post-operative cording was reported in 37.38% (51/135) of the patients at their first post-operative visit, with a mean time to follow up of 3.6 weeks (1.6-5.6 weeks). 15.69% (8/51) of the patients also had an  $RVC > 5\%$ . 34.8% (30/86) measured the third time, at a median of 4.3 months (0.9-12.1 weeks) still reported cording with 17.9% (8/30) reporting cording for the first time. Of the patients who reported cording at this point, 30.23% (26/30) had an axillary lymph node dissection and 17.39% (8/30) had a mastectomy. Cording at this data point was associated with axillary node dissection ( $P < 0.0001$ ) and mastectomy ( $P = 0.0041$ ). 33.33% (10/30) also had an  $RVC > 5\%$ . Thus the presence of cording at data point 3 was strongly associated with lymphedema ( $P = 0.007$ ).

**Conclusions:** This data reveals that cording following treatment for breast cancer is not an infrequent event, and that cording can develop and persist beyond the early post operative period. It demonstrates that at least in this cohort, there is an association between lymphedema and cording when measured several weeks following surgery, with patients who have had a mastectomy and axillary dissection. Understanding the natural history of cording related to treatment for breast cancer will enable clinicians to educate patients and provide them with early intervention.

### I. Dayes – DELTA: A Multicentre Randomized Trial of Decongestive Therapy for Women with Breast Cancer-related Lymphedema

**Introduction/Background:**

Arm lymphedema remains a complication of breast cancer treatment. While decongestive therapy is often recommended, randomized trials have demonstrated little additional benefit over more conservative measures.

**Aims of the study:**

DELTA was the first multicentre trial to compare the benefits of massage and bandaging to elastic compression sleeve in a randomized setting.

**Methods:**

Women treated for breast cancer with arm lymphedema were enrolled from six Canadian institutions. Patients with a minimum 10% arm volume difference were randomized to immediate sleeve or four weeks of daily manual decongestive therapy and bandaging. Primary outcome was percentage reduction in excess arm volume at completion of massage and bandaging. Quality of life and arm function measures were also collected.

**Results:**

A total of 103 patients were randomized. Mean baseline excess arm volume was 27% (684 ml) in all patients. Eight patients withdrew immediately following randomization, leaving 95

evaluable patients. Analysis demonstrated a reduction of excess volume of 29.8% from decongestive therapy and 22.6% from elastic sleeve alone ( $p=0.28$ ). Absolute volume loss was 256 ml and 143 ml respectively for an additional benefit of 113 ml ( $p=0.019$ ). The proportion of patients with less than 200 ml of remaining excess fluid was not significant (17.9% vs. 10.2%;  $p=0.38$ ). Quality of life and arm function did not differ between the two groups.

#### Conclusions

The DELTA study evaluated the role of decongestive therapy for lymphedema in breast cancer survivors. Treatment benefit appears modest at best and is in keeping with estimates from previous trials.

#### R. Harris – The use of the Vodder Method of MLD for Primary Lymphoedema in a client with Intellectual Disability - Overcoming Obstacles

**Description of original/rare case(s):** 48 Year old Female presenting with a diagnosis of severe/profound intellectual disability, paranoid schizophrenia and bilateral lower limb primary lymphoedema. Confounding conditions include incontinence, dermatitis, obesity and challenging behaviour.

**Reason for report:** The case outlines the story of success in the face of adversity, and is an example of how perseverance and dedication to a treatment technique can lead to rewards. There is a vast lack of documented research in the area of Intellectual Disability, especially regarding the use of MLD with these clients. Hopefully this case report will encourage further research with this client group.

**Case(s) description:** This case describes the application of the Vodder Method of MLD with a client with intellectual disability, and the challenges that her condition presented. These obstacles to treatment included decreased understanding of her condition and poor tolerance to the physical aspect of the treatment; poor compliance with compression bandaging and garments; self injurious behaviour; therapist resource constraints; parental interference with treatment due to Munchausen by Proxy, and poor compliance with exercise program. Methods of treatment used were MLD, compression bandaging and custom compression garments, but all of these had to be adapted in response to the challenges in treating this client. After 2 years of treatment, and perseverance, a 13cm circumferential reduction in lymphoedema was achieved at the ankle joints. The client is now compliant with compression garments being worn on a daily basis, and is participating in a weekly exercise regime. Consent has been given to present this case report.

**Discussion:** The intended message of this case study is to stress the importance of perseverance and belief in our treatment techniques. There are always challenges that present with each new lymphoedema client, but we can be assured that our treatment can be successfully adapted to face these challenges which still adhering to the basic Vodder Method of MLD. This case also shows the importance of therapist's hands on interaction with clients presenting with an intellectual disability who would not tolerate mechanical interventions to address their lymphoedema.

#### Abstract Session D2 – Exercise – Chair: C. Pike

B. Miedema – Do post breast cancer difficulties with recreational activities improve over time? A longitudinal follow-up study of participants 8 and 43 months (3.6 years) post surgery  
A longitudinal follow-up study of participants 8 and 43 months (3.6 years) post surgery.

**Background:** Many breast cancer patients have difficulties resuming recreational activities post cancer treatment.

**Objective:** To examine the difficulties with recreational activities experienced by a sample of women at 8 and 43 months post-breast cancer surgery.

**Method:** A longitudinal national study tracked 178 women every six months over 3.6 years to examine arm morbidity post-breast cancer surgery. The study has been approved by all participating institutes Research Ethics Boards.

**Analysis:** Hierarchical Multiple Regression analyses were conducted to predict which variables were responsible for recreational difficulties at 8 and 43 months post-surgery.

**Results:** Between 8 months (T1) and 43 (T2) months post- breast cancer surgery, women reported a slight increase in lymphedema rates. Conversely, they reported significant improvements ( $p < .001$ ) in range of motion (ROM) of the affected arm and less “pain when using arm.” These improvements resulted in fewer difficulties with recreational activities. However, a number of women still suffered from moderate “pain when using arm” and ROM restrictions. Pain and ROM were statistically significant ( $p < .001$ ) predictors, with pain accounting for the greatest proportion of variance, for recreational difficulties. Demographics, treatment modalities were not predictive of “pain when using the arm” nor recreational difficulties.

**Conclusion:** The women who still experience pain years after breast cancer surgery also report difficulties with recreational activities. Pain was not related to any treatment modality. To better understand pain’s causes and prevention, it is important to further study this aspect of arm morbidity longitudinally.

K. Johansson – A randomized study of the effect of swimming and water aerobic exercise on breast-cancer-related arm-lymphedema

**Introduction/Background:** The health benefit of exercise for cancer patients are well established and safety has been shown in those with lymphedema.

**Aims of the study:** The purpose of this study was to determine the impact of swimming and water aerobic exercise on arm volume, shoulder range of motion and perceptions of body image in women with breast cancer-related arm lymphedema.

**Methods:** Twenty-nine women, previously treated for unilateral breast cancer, and had subsequently developed arm lymphedema participated in this study. Lymphoedema needed to be chronic (present for at least 6 months), stable (no exacerbations requiring a change in treatment in the previous 6 months) and was clinically verified at the time of enrolment. Women were randomized in blocks of 4 to a control group with no intervention or an intervention group performing swimming and water aerobic exercise for 30 minutes, 3 times per week for 8 weeks. Participants were able to choose whether they swam, did water exercises or a combination of both, and recorded details of their session in an intervention log. Arm volume was measured by perometer, arm fluids by bioimpedance spectroscopy (BIS), local tissue water by Tissue dielectric constant (TDC), and shoulder range of motion by goniometer and body image by the Body Image and Relationship Scale. The protocol has been approved by IRB, University of Pennsylvania.

**Results:** Data collection will be completed in March, 2011. Women participating in the study have a mean age of  $64 \pm 10$  years and BMI of  $31 \pm 6$ . Baseline lymphedema relative volume was median (min, max) 20.6(5.2, 71.1)%. Results will be available for presentation at the conference.

J. Bracha – Advantage of proximal Arm Exercise for arm volume reduction in women with breast cancer related lymphedema

**Introduction/Background:** Advantage of Proximal Arm Exercise for Arm Volume Reduction in Women with Breast Cancer Related Lymphedema.

BCRL is commonly treated by Complete Decongestive Therapy (CDP) or Complex Lymphatic Therapy (CLT). These include similar arm exercise but sequence differs. CDT arm exercise is performed from lower to upper arm; in CLT upper arm exercise precedes hand and forearm

**Aims of the study:** The goal was to assess volume change following upper arm exercise, lower arm exercise and combination of both in lymphedematous and contra lateral arms.

**Methods:** Design: self control, multiple intervention clinical trial. Participants: women with unilateral BCRL. Inclusion criteria: completed cancer treatment, maintenance phase of lymphedema treatment. Exclusion criteria: cancer recurrence, concurrent arm disease, lack of understanding of Hebrew. Measurement: arm circumference measurement and volume calculation. Intervention: 5 weekly sessions. First and fifth session: arm volume calculation. Second and third sessions: random order upper or lower arm exercise. Fourth session: upper arm exercise followed by lower arm exercise. Arm volume measured before, immediately following and an hour after exercise. Assessors blinded to exercise performed. Repeated measures ANOVA was performed for each exercise type. Ethics committee approval by Hillel Yaffe Medical Center and Tel Aviv University.

**Results:** Exercise resulted in forearm volume reduction. Upper arm exercise caused a significant immediate reduction (33.5ml,  $p < 0.05$ ), a smaller effect after hand exercise (18.9ml,  $p < 0.05$ ). The lymphedematous arm responded immediately; the contra lateral arm an hour later.

**Conclusions:** Upper arm exercise caused larger arm volume reduction than hand and forearm exercise. Information from the study can be helpful for exercise instruction to women with BCRL.

#### D. Tidhar – Aqua Lymphatic Therapy (ALT) for Post Surgical Lymphedema

**Introduction/Background:** Breast cancer related lymphedema is an adverse effect of breast cancer surgery. Aqua lymphatic therapy (ALT) is a novel treatment for limb volume reduction.

**Aims of the study:** To examine whether ALT is a safe method and whether there are differences in adherence to self management treatment (SMT), limb volume, and quality of life between women who participate in ALT and women who perform only SMT

**Methods:** Forty eight women were randomized in a single-blind controlled trial to a control group of SMT alone vs. a study group of weekly session of ALT for 3 months in addition to SMT. Limb volume assessed by a water-displacement tool, adherence, by self-reported diaries, quality of life by the Upper Limb Lymphedema Questionnaire (ULL27), Analyses were performed by paired t-test and a repeated measures analysis of variance. The study was given ethics approval by the Asuta Hospital Ethics Committee in Israel.

**Results:** There was no episode of arm infection or aggravation in limb volume during the study period. ALT had a beneficial effect on limb volume immediately post treatment (a reduction of  $75.0 \pm 53.5$  ml after the first treatment  $P = 0.02$ , and a reduction of  $45.1 \pm 98.2$  ml after the last treatment  $P < 0.01$ ). Quality of life improved in the study group but not in the control group.

**Conclusions:** ALT was found to be safe with high adherence rate, and improves quality of life. It is reasonable to offer ALT within the frame of treatment methods that are offered today.

#### Workshop D3 – ILF Minimum Dataset

##### P. Franks, J. Sugama – ILF Minimum Dataset

This workshop will review the minimum data set within its web based form. Practical session on the use of the systems using computers

## Workshop D4 – Laughing Therapy

R. Kelly – Laughter, Movement & Lymphedema

**Format:** This is an interactive hands-on fun workshop with movement, music and some props.

**Objective:** Laughing Lymphercise classes have been held for several years at Hope Spring Cancer Support Centre in Waterloo Ontario. Though no formal study has been undertaken, anecdotal evidence suggests that participants feel some benefit after just one class and that long-term adherence to the program shows a reduction in swelling. Laughing Lymphercise is not a stand alone program. A vital component is the provision of up to date Lymphedema risk reduction information and contact details for the region's MLD therapists. Education is a key part of Laughing Lymphercise and this exercise program is an integral part of C DT. In most cases, in the cancer support context, newly diagnosed patients will learn of Lymphedema and possible risk for the very first time through this program.

**Structure:** This presentation will begin with a short talk and brief explanation (possible Power Point Presentation) of how laughter and simple movement benefit the lymphatic system. There will be handouts, exercises will be demonstrated in a casual and amusing atmosphere and everyone will be encouraged to participate, move and laugh.

**Audience Suitability:** This presentation will be deceptively simple and disarmingly fun and is appropriate for all attendees. It can be tailored according to the audience's physical capabilities as well as their prior knowledge of Lymphedema.

## Workshop D5 – What's your criteria for change?

We don't seem to be gaining better outcomes for our patients, (well at least not as good as the results from controlled research would suggest). Given we have early detection, new treatment options, fine tuning of older ones, best practice programs and more accurate measurement ability why is this so? Is it the relative homogeneity of the clinical trial and that we can't see our current patient as being represented by it or is the level and volume of evidence not enough to encourage us to change treatment, measurement or practice?

Is it right that we are not getting better outcomes? Are we not adopting new ideas and techniques for treatment or are we not using accurate and appropriate measurement techniques to determine changes related to treatment, are we not using the right criteria at the right time or are we making errors in our assumptions and interpretations of the data?

This workshop will briefly explore the range of new treatments but concentrate on techniques that can be used by sole practitioners or small group practices to assess the stage of lymphoedema, help in differential diagnosis and determine the impact of treatment with an emphasis on their accuracy, discriminative ability and applicability.

These techniques include tools to assess local and segmental fluids such as Bio-impedance spectroscopy, EM and dielectric constants, opto electronic and similar tools to assess limb volume changes, stemmer sign and pinch tests, tonometers and indurometers to measure fibre levels and changes. Other techniques used by larger clinics will be touched on.

Many of the techniques are not new but they are uncommonly used still be many except in larger research groups. Cost may be an issue initially but time saved, accuracy gained, and targeted treatment in the longer term can result in reduced treatment and better outcomes. How might you be able to use them for your and your patient's benefit? Come and see how at the workshop!

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**08.30-10.00 – Plenary Session – Developments in Compression – Chair: C. Moffatt**

H. Partsch – Overview of what we know about compression and its effects in lymphoedema and chronic oedema management

Compression is the basic treatment modality in lymphoedema. Its most obvious effect is oedema reduction, which is initially achieved by inelastic bandages and maintained by custom made compression hosiery. Intermittent pneumatic compression pumps can be used in addition.

Oedema reduction is mainly achieved by two mechanisms of action:

1. Reduction of capillary filtration (= lymphatic load) by increasing the tissue pressure.
2. Promotion of lymphatic drainage, mainly by increasing the lymphatic absorption in the initial lymphatics and by promoting the peristaltic contractions of the lymph collectors.

These points determine the optimal “dosage” of compression, which can be assessed by measuring sub-bandage pressure and volume reduction and which is higher on the lower and lower on the upper extremity. The frequency of bandage changes depends mainly on the compression material and on the initial pressure. There is a lack of randomized controlled trials comparing compression versus no compression or evaluating different compression modalities without any additional adjunctive treatment modalities.

N. Stout – ICC paper Consensus Document: “Chronic edema of the lower limb extremities: international consensus recommendations for compression therapy in chronic edema”

S. Rockson – An overview of the role of IPC in lymphoedema

Review of the evidence for use of IPC with Lymphoedema. Physiological and clinical effects and differentiations for different devices

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**10.30-12.00 – Concurrent sessions**

**Workshop E1 – How compression works**

H. Partsch – A practical guide to how compression works in lymphoedema management

Measuring the sub-bandage pressure under different kinds of compression material applied to the legs of voluntary attendants several important features of effective compression will be shown:

- Resting pressure
- Working pressure
- Massaging effect
- Stiffness
- Pressure loss

The rationale for using short stretch bandages for the initial treatment phase specifically in lymphoedema patients is based on these points. Advantages and disadvantages of different compression materials concerning efficacy and comfort will be discussed.

E. Albrecht – Compression therapy is more than decongestion – Supported by an educational grant from BSN Medical

## **Workshop E2 – Hosted by Haddenham/Farrow – Adapting compression for clinical challenges**

G. Armstrong – Using devices to solve complex compression problems in lymphoedema

## **Workshop E3 – Advanced measurement and fitting of compression hosiery**

D. Hardy – A practical guide to advanced measurement in compression hosiery

Compression hosiery plays a vital role in the successful management of lymphoedema and is deemed to be the mainstay of treatment.

It is therefore essential that clinicians appreciate not just the diverse range of garments available, but that they also have an understanding of the relevance of the technical aspects of hosiery construction as well as the science behind it.

However, for success to be achieved and objectives/ treatment goals to be met, then patients actually have to wear them. It is therefore essential that clinicians provide suitable garments that address the often wide ranging and complex needs of the patient, whilst ensuring that it is a correct fit, that it is comfortable to wear, and that it encourages long-term use.

This workshop will:

1. Briefly discuss the basic construction of compression garments and how the different types of knitting and yarn can affect the type of garment produced
2. Discuss the use and relevance of custom made and ready to wear garments within a lymphoedema programme
3. Facilitate a holistic approach to garment selection ensuring the complex needs of the patient are taken into account
4. Offer a guide to help in the selection of the most appropriate compression level for the garment selected
5. Provide a practical guide on measuring for custom made fit garments and the various options available for patients with complex needs
6. Provide a forum for discussion of the fitment/removal/care of compression garments.

## **Workshop E4 – Managing Genital Oedema**

C. Pike – A practical guide to managing genital lymphoedema

This workshop will explore practical strategies for the treatment of different presentations of genital lymphoedema

## **Workshop E5 – Intermittent Pneumatic Compression**

E. Maus – A practical guide to managing IPC in lymphoedema – Supported by an educational grant from Tactile Technologies

Pneumatic Compression Devices in Lymphedema

History of the development of compression devices Mechanisms of action Indications

Controversies regarding contraindications Dosing Improving Compliance



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## 12.15-13.15 – Lunch Symposium – Focus on Global Issues

N. Stout – Presentation of a paper on global issues

M. Sneddon – Key results from ILF Education Committee surveys

This session will outline the development and work of the ILF Education Committee and explain the background and rationale for two pilot surveys undertaken by the ILF Education Committee. Extracts from the preliminary findings of each will be presented and the next steps outlined. During the conference there will be a meeting of National Lymphoedema Framework Educational Representatives and a focus group meeting of interested participants. These will endeavour to capture the international perspective and ensure that the work of the committee reflects the key issues for global lymphoedema education. The main points from these discussions will be shared. The future direction of the Education Committee, which will be informed by the discussions at the conference, will be presented with an opportunity for delegates to comment.

A. Guruprasad – Challenges, realities and outcomes using western and traditional approaches to lymphoedema in India

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## 13.30-15.00 – Plenary Session – Children with Lymphoedema – Chair: M. Sneddon

I. Quéré and S. Mestre – Clinical features of constitutional lymphoedema in children and young adults: what is progression related to?

**Purpose:** Primary or constitutional lymphoedema results from abnormal development of the lymphatics. The purpose of this study was to determine the main clinical characteristics and morbidity of constitutional lymphoedema according to the age of onset of the lymphoedema.

**Methods:** Our Vascular and Lymphatic anomalies database was reviewed between 2009-2010 for patients with constitutional lymphatic anomalies. Cystic lymphatic anomalies were excluded. Lymphoedema was determined based on history, physical examination, and imaging. Family history, gender, age of onset, in utero data, location, examination data, measurement and syndromic association were recorded.

**Results:** Primary lymphoedema was confirmed in 133 children and young adults. Diagnosis was made in infancy [21% (28/133)], childhood [16,5% (22/133)], or adolescence and later [63% (83/133)]. Males most commonly presented in infancy (68%) whereas females were most likely to develop swelling in adolescence (86%). Lymphoedema was always in a limb and bilateral in 35%, genitalia [17,3% (23/133)], trunk or head. Three patients had isolated upper limb lymphoedema. Nine percent (12/133) of patients were syndromic. Up-turned toenails, prominent veins were more frequent in congenital lymphoedema ( $p=0.0009$ ). Cellulitis was equally distributed between congenital and later-onset disease.

**Conclusion:** Constitutional lymphoedema involves the lower extremities, and is commonly bilateral. Males are more likely to manifest lymphoedema at birth, females more often during adolescence. Up-turned toenails and prominent veins are more frequent in congenital lymphoedema whereas cellulitis are equally distributed and correlates with the duration of observation.

F. Connell – Recent advances in the genetics of primary lymphoedema

**Introduction/Background:** Primary lymphoedema is a chronic oedema caused by a developmental abnormality of the lymphatic system. In recent years there has been

considerable progress made in understanding the molecular pathways underlying lymphangiogenesis but knowledge of the genetic causes of human lymphatic disease was limited to VEGFR3, FOXC2 and SOX18. There are many different phenotypes of primary lymphoedema and with the use of conventional molecular analysis techniques and new next generation sequencing we have identified two further genes that cause different primary lymphoedema phenotypes; CCBE1 and GJC2.

**Aims of the study:** The aim of our work has been to improve phenotyping of primary lymphoedema patients in order to facilitate the identification of well defined patient groups for molecular studies that would lead to the discovery of genetic causes of primary lymphoedema in humans.

**Methods:** Patients were ascertained from the joint Lymphoedema/Genetics Clinic at St George's Hospital, London.

Linkage and sequence analysis was carried out to identify the genetic cause of recessively inherited generalised lymphatic dysplasia/Hennekam syndrome. A large, non-consanguineous family with three affected siblings with generalised lymphatic dysplasia was studied.

Linkage analysis was used to determine a locus in a large multigenerational pedigree in which four-limb lymphoedema segregates in an autosomal dominant manner. Exome sequencing was employed to look for causative variants within the predetermined locus. Ethical approval for the study was granted.

**Results:** A homozygous change in CCBE1 was identified as the causative mutation for autosomal recessive generalised lymphatic dysplasia/Hennekam syndrome. Mutations in GJC2 were identified to cause autosomal dominantly inherited four-limb/bilateral lower limb lymphoedema.

**Conclusions:** Notable advances in the understanding of the genetics of primary lymphoedema have been achieved and the implications of these discoveries will be discussed. The role of CCBE1 and GJC2 in lymphatic disease has been reported by Alders et al (2009) and Ferrell et al (2010) respectively, and our work adds supportive evidence to these studies. Understanding the molecular mechanisms that result in lymphatic disease will hopefully ultimately translate into improved therapies for patients.

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## 15.15-16.30 – Plenary Session – Infection in Lymphoedema – Chair: A. Towers

### V. Keeley – Cellulitis and the UK national audit

Although cellulitis is a clearly recognised common complication of lymphoedema, there is little evidence in the literature to guide management. Furthermore, patients often report that healthcare professionals do not recognise the problem and are unsure how to treat it.

As a result of this, a group of healthcare professionals in the UK was brought together by the British Lymphology Society and the Lymphoedema Support Network to produce a consensus document on the management of cellulitis in lymphoedema.

The guidelines are based on the concept that Beta haemolytic streptococci are the predominant cause and therefore anti-biotic treatment aimed at these organisms is recommended. The full guidance is available on [www.thebls.com](http://www.thebls.com) or [www.lymphoedema.org](http://www.lymphoedema.org)

Following production of the guidance and information for healthcare professionals, an audit was carried out in the UK to determine how patients are being treated and whether the guidelines are being followed.

396 responses were received during an 18 month period in 2007/08. In those treated at home, a large number of different drug combinations and doses were used and the most frequently prescribed was Flucloxacillin alone. This is despite the recommendation in the guidance that Amoxicillin is the antibiotic of choice for home treatment.

Time to recovery and the need for a second course of antibiotics were used as “proxy” measures of the effectiveness of the antibiotics and from this audit there was no obvious difference in outcome depending upon whether Flucloxacillin or Amoxicillin was used as the primary antibiotic.

A better understanding of the microbiology of cellulitis would facilitate future guideline production.

#### P. Brantus – Acute attacks (cellulitis) prevention, impact on lymphoedema patient in Handicap International project in Madagascar

One of the two main goals of the Global Programme to Eliminate Lymphatic Filariasis (LF) is to provide care for those suffering from the devastating clinical manifestations of this filarial infection. Among the 120 million infected people worldwide, up to 16 million have lymphoedema. The WHO strategy for managing lymphoedema is based on rigorous skin hygiene, exercise, surelevation, adapted footwear. The aim is to reduce acute attacks of adenolymphangitis and cellulitis responsible for lymphoedema progression and disability. The objective of the presentation is to address the effectiveness of home-based lymphoedema management implemented by the national health system and Handicap International in Madagascar through a cohort study (sample 68 patients from 800) carried out in 2009. Any patient was eligible to participate in the study if suffering from LF-related lymphoedema of a lower limb at any stage, and receiving care as part of the health education and washing project. Impact analysis of activities shows a significant improvement of health status from 51.6% to 87.5% of persons reporting having a good health status, evolution of stage with an occurrence of 15.6% of stage 1 (WHO classification), absent at the start of the study and reduction of stage 2. As it is reported in other international studies, frequency of acute attack significantly decreased from 47.7% to 20.3 % of patients or observed by the care-giver reporting occurrence of an acute attack in the month preceding the consultation. Our results suggest that the home-based lymphoedema management programme in the primary health care system of Madagascar is effective in reducing morbidity due to LF. The lymphoedema management requires no additional human resources, but whether its effect can be sustained remains to be seen. The presentation address also the issue of pathogenesis of acute dermatolymphangioadenitis related to lymphatic filariasis versus erysipelas/cellulitis.

## POSTERS

### A. Baker – Evaluation of potential therapies for post-surgical lymphedema: the sheep model

**Introduction/Background:** Sheep possess a lymphatic system, which is similar in complexity and size to humans. This species is ideally suited for analysis of therapeutic approaches designed to mitigate the impact of post-surgical lymphedema in cancer patients.

**Aims of the study:** The objective of this study was to utilize the sheep to compare the effectiveness of autologous lymph node transplantation and delivery of lymphangiogenic factors in reducing edema in a lymph node excision model.

**Methods:** In this species, all the afferent vessels of the hind limb pass through the popliteal lymph node and removal of this node induces lower limb edema. In one study, the popliteal node was removed and replaced with an autologous, lymph node transplant. In a second study, the prolymphangiogenic growth factors VEGF-C and ANG-2 were introduced into the nodal excision site. Lymphatic function was assessed by injecting radiolabelled albumin into a prenodal popliteal lymphatic and monitoring its recovery in blood. Edema was assessed using circumferential measurements.

**Results:** Lymph node removal impaired lymphatic function and resulted in edema in all animals. In limbs receiving vascularized lymph node transplants, functionality was found to be similar to the SHAM controls and edema resolved over an 8-week period. In limbs receiving growth factor therapy, functionality levels were also similar to SHAM controls. While, edema in the growth factor treated limbs was significantly reduced, limb swelling did not resolve over a 12-week period.

**Conclusions:** In sheep, both transplant and lymphangiogenic therapies demonstrate potential for future utilization in the prevention of lymphedema.

### S. Bowles – The lymphedema outpatient nursing team

**Introduction:** The lymphedema outpatient nursing team has provided group based lymphedema education to the nurses recruited to the oncology program at a university teaching hospital since 2007.

**Aims:**

- To increase the knowledge base of nurses coming on staff to the oncology program pertaining to lymphedema
- To make new recruits aware of the lymphedema resources available to patients in this hospital and outpatient area
- To expose the nurses to the lymphedema clinic

**Rationale:** It was hoped that there would be earlier diagnosis of lymphedema and better management of this condition.

**Description:** Content for the teaching session was developed by the lymphedema nursing team and a one hour power point presentation was made as part of the orientation for the recruits to the oncology program. The nurses also attend a lymphedema clinic, during their orientation period.

**Evaluation:** No formal evaluation has been made. The number of new patient referrals has been increasing.

**Introduction:** A lymphedema group based patient education class in an outpatient cancer centre was developed in November 2009 that all patients were asked to attend before their initial assessment in the nurse led lymphedema clinic, that has existed for 10 years. Prior to this, the basics of lymphedema management were taught at the initial assessment.

**Aims:**

- To increase the capacity to see more new consults
- To make the patient teaching consistent

**Rationale:**

- There are now 3 nurses in the lymphedema clinic, and it is felt that having a consistent teaching program would mean that all patients were receiving the same accurate information.
- Preparing the patients before their initial visit means that the patient has time to reflect, and there is the opportunity to reinforce teaching at the clinic appointment
- We now would have a program to evaluate and thereby improve

**Description:** The breast cancer nurse educator and the lymphedema nurses developed the content for the teaching session. The classes are 1 hour in length, and patients and family/friends attend. The three lymphedema nurses rotate and share the teaching duties. The class is held in a small lecture theatre and Power Point is used.

**Evaluation:**

- An after class paper evaluation was requested to be done and handed in and plans are for a Phase II evaluation that we would hope to use to develop better outcomes.
- A database was kept of attendees

**E. Chan – Exploration of treatment in patients with lymphoedema and breast or gynaecological cancer**

**Introduction/Background:** An exploration of the types and effectiveness of treatment in patients with lymphoedema and breast or gynaecological cancer not only provided unconvincing evidence, but also exposed methodological inconsistencies.

**Methods:** A critical literature review of 30 current studies was undertaken to appraise the treatment of lymphoedema in patients with breast or gynaecological cancer.

**Results:** Only one longitudinal study focused on patients with gynaecological cancer. Methodological concerns included design issues of unspecified randomisation methods, lack of blinding and poor study power. There were also large variations in the inclusion criteria for the duration and staging of lymphoedema. Consequently, it was inconclusive which intervention was most effective according to chronicity. Limb size through volumetric or circumferential measurements was the most popular, yet diverse method used to measure the presence, severity and changes of lymphoedema, making comparisons and the pooling of data difficult. Subjective assessments of symptoms and quality of life were increasingly utilised to provide a holistic measure of patients' experiences. However, there was a lack of formally structured and tested tools used specifically with lymphoedema patients. Although subjective symptoms may appear before visible changes in limb sizes, it is debatable if these are sufficient to monitor and justify changes brought about by treatment.

**Conclusions:** More studies on patients with lymphoedema and gynaecological cancer are needed. In view of the difficulties in the methodological qualities of studies, future studies need to acknowledge these and address them. In so doing, it will improve the strength of evidence in this important area of patient care.

**G. Collins – Feet First – How MLD prevented limb amputation**

**Description of original/rare case(s):** Mr B was admitted to Hospital after he had a stroke which affected the right side of his body. During his stay in Hospital he was first treated for his stroke injury and wound on his other leg. As there was no lymphoedema service based at the Hospital, an external service was contracted to help with the lymphoedema of the left lower leg. Frequent episodes of cellulitis worsened the lymphoedema affected leg during his stay in Hospital. At one stage it was feared that Mr B might have osteomyelitis and maggot debridement therapy was applied for wound treatment. This presented a difficult challenge to

manage. Lack of mobility restricted exercising needed to encourage lymph flow. Amputation below the knee was considered and leg was marked for amputation, this in turn caused tremendous emotional stress for the patient. Combined wound care and lymphoedema treatment assured continues improvement. Results: Regular MLD reduced the re-occurrence of cellulitis greatly, restored the limb shape, assisted in wound healing and improved the immune system. Mr B's started to gain his independence gradually, as the left leg was restored to function.

**Reason for report:** To inform other MLD specialist that MLD can save limbs even at the point of amputation, where surgeons are possibly not aware of the ability of MLD for limb recovery.

**Case(s) description:** I hereby confirm that written consent had been given by patient to use his case for educational purpose. Case description as above.

**Discussion:** Cost of MLD/CDT versus cost of surgery and supply of a care team. A full understanding of lymphoedema management using specialist knowledge and resources is the key to successful treatment of complex cases, such as this case.

#### R. Dinniwell – Feasibility of ultrasound registration to three-dimensional structured-light surface scanning measurements for the serial assessment of lymphedema

**Introduction/Background:** Ultrasound echogenicity provides a non-invasive means of monitoring lymphedema tissue fluid alterations and fibrosis of the dermis and subcutis. Structured-light illumination is a non-contact optical means of obtaining three-dimensional surface volumetry. Both measures would be of use in serially assessing lymphedema.

**Aims of the study:** The aim of this study was to determine the feasibility of anatomically co-registering ultrasound echographic images with structured-light volumetry.

**Methods:** A calibrated depth image enabled infrared camera (monochrome CMOS sensor) with an infrared laser projector (Microsoft, Redmond, WA) was used to obtain 3-dimensional surface data points (x,y,z) in Matlab (MathWorks, Natick, MA) for three phantoms (sphere, head, and head/torso). Surface reconstructions of the point clouds were undertaken in Meshlab (ISTI - CNR, Italy) and exported in the STL data format for measurement in 3D Doctor (Able Software Corp, Lexington, MA). At fixed locations on each phantom a SONIX CEP ultrasound system (Ultrasonix Medical Corporation, Richmond, BC) with a 58mm linear transducer was used to obtain an image. A series of graduated external fiducials (5, 10, 15, 20mm) were placed to demarcate the locations of these sites.

**Results:** Volumetric surface and ultrasound data were obtained and registered for all regions of interest on the phantoms. A minimum fiducial marker size of 15mm was required for detection in the point cloud to allow for co-registration.

**Conclusions:** Image fusion between volumetric surface scans with ultrasound is possible with an appropriate external fiducial marker. Anatomic co-registration of these non-invasive measurement tools provides a useful means for volume and tissue monitoring.

#### C. Hammond – Compression therapy: reflecting the individual needs of the patient in lymphoedema

**Description of original/rare case(s):** Three cases will be presented to demonstrate the versatility of a new compression bandage system in the treatment of complex lymphoedema management. All patients had lymphoedema with complications including: veno-lymphoedema, neuropathy, Charcot's, ulceration, recurrent cellulitis, paraplegia, loss of independence and pain.

**Reason for report:** To demonstrate how the implementation of a new compression bandage system improved patient outcomes and quality of life in the management of lymphoedema.

**Case(s) description:** The three patients have granted consent for presentation. They were all challenging for clinicians due to gross limb/foot shape distortion, neuropathy, loss of foot/calf

muscle pump action, the need to use Negative Pressure Wound Therapy as an adjunct to compression and because previous therapies had been unsuccessful in controlling their lymphoedema. The compression system, made up of two low profile cohesive bandages, provided adequate compression, allowed the patients to wear appropriate footwear, permitted ankle mobility, allowed for limb shape distortion and were easy to apply. There was no bandage slippage and patients found them comfortable.

**Discussion:** Compression therapy has transformed lymphoedema management by preventing recurrent cellulitis, healing ulcers, improving quality of life and providing cost effective treatment. Short-stretch bandages can be bulky and restrictive leading to inappropriate footwear, reduce the effectiveness of the foot and calf muscle-pump, thus reducing lymphatic and venous return. Bandage slippage, particularly with large and distorted limb shapes, is a common problem and can lead to pressure damage and non-concordance. The introduction of a low profile cohesive bandage system has improved patient outcomes providing effective, comfortable compression that reflects individual patient needs.

#### D. Hardy – Longstanding venous leg ulceration

**Description of original/rare case(s):** A 53 year old gentleman presented at clinic with a history of longstanding venous leg ulceration. He had been treated with 4 layer compression bandages but had consequently developed severe, distorted swelling above and below the bandages. The proximal swelling was 4798mls (63%) greater than the contra lateral limb.

The consequences of this became more troublesome than the ulcerated areas, including reduced function/mobility, clothing difficulties, poor skin integrity and recurrent Cellulitis. Moreover, it added to his pain/ discomfort associated with arthritis of the knees and added to the venous hypertension in the lower limb.

**Reason for report:** Oedema reduction was paramount to improve quality of life and prevent further complications, but the use of traditional Multi Layer Lymphoedema Bandaging was difficult to implement as the bulkiness of the system added to his reduced mobility and ability to maintain his independence.

An alternative approach was to use an innovative bandage system using just 2 layers over the entire limb.

**Case(s) description:** The bandages (applied twice weekly for 3 weeks within a lymphoedema programme) demonstrated enhanced patient comfort, created less bulk (allowing use of normal clothing/footwear), provided more freedom of movement, generated less slippage, and resulted in a vastly improved limb shape and size, with excellent skin condition. (consent given).

**Discussion:** The success of this new system within the management of lymphoedema will challenge the rationale of our practice. However, there is no disputing the benefits of treatment and the improvements made to patient quality of life. Moreover, the ease of, and less frequent application saves the clinic time, money and resources.

#### L. Hawkins – Investigating the effect of socioeconomic status and social support on compliance to self-massage lymphedema management in breast cancer patients at a tertiary academic hospital: an evaluation of the lymphatic self-massage instruction program

**Introduction/Background:** Combined Decongestive Therapy (CDT) is an established approach for management of lymphedema secondary to treatment of breast cancer. Manual lymphatic drainage (MLD), a component of CDT, uses gentle skin massage to promote lymphatic drainage from areas of stasis and edema to functioning lymphatic vessels and nodes. Adapted from MLD, lymphatic massage is taught to patients for condition self-management. This study evaluates the lymphatic self-massage instruction program at a tertiary academic hospital, which offers group classes and one-on-one self-massage training.

**Aims of the study:** This mixed methods study examines the effect of one-on-one sessions on patient knowledge and the impact of socioeconomic status and social support on patient compliance.

**Methods:** Pre- and post-knowledge tests, structured questionnaires and semi-structured interviews were developed, administered and analyzed using biostatistics and descriptive thematic analysis. Study approval was granted by the hospital's Research Ethics Board.

**Results:** In a pilot study (n=10), understanding of lymphatic self-massage improved (p=0.016) with the one-on-one refresher session. No significant association existed between social support and self-massage adherence. Factors promoting integration of self-massage into daily life included establishing a daily routine; identified barriers were detrimental physical symptoms and limitations. Individual sessions were preferred to group classes.

**Conclusions:** Ongoing data collection (N=50) will provide a more comprehensive understanding of these patients' needs and experiences of lymphatic self-massage instruction and adherence, as related to socio-economic status and social support. Findings will drive program changes addressing patients' unmet needs, improve patient centered lymphedema care and provide insight for similar programs in this field.

H. Janlöv Remnerud ; M. Haag – Lympho-Logical thinking in self management of lymphoedema

**Aims:** To survey, describe and simplify the concept of self management of lymphoedema.

**Description:** The Kaiser Permanente Triangle healthcare model for chronic conditions indicates that 70-80% of all people with long term conditions such as lymphedema could be managed using supported self care. Consequently it is very important how the knowledge of self care is presented and taught to the patient. The question is: What makes a difference? In analyzing the concept of how to convey the knowledge of self care to the patient to the extent that the knowledge becomes a natural, integrated part of the patient's daily life a patient and health professional teamwork is essential. This presentation is a product of such teamwork and will cover what is important to learn and teach and what it takes to learn and teach. The 4 steps of learning, the important things to learn and metaphors to simplify the understanding – tools for Lympho-Logical thinking.

**Outcome(s):** Patients who have a solid knowledge of how to handle their lymphoedema problem can live a near to normal life.

**Evaluation of Impact:** Things that you never heard of are hard to understand however easy and logical they are. By simplifying and comparing with well-known things it is easier to learn. To own the knowledge about how to self manage a long term disease – and use this knowledge as a routine way of life without thinking - (adds to) improves quality of life.

N. Hodgkinson – 2- Layer, Inelastic Compression Therapy for Post-Op Lower Limb/Scrotal Lymphedema in a Person with Arterial Disease

**Description of original/rare case(s):** Unilateral, non-cancer related, lower extremity and scrotal lymphedema in a person with moderate arterial disease in the foot. Lymphedema was primarily managed with a 2-layer compression bandaging system which is safe for use in persons with compromised arterial status.

**Reason for report:** The actual prevalence of non-cancer related lymphedema is unknown<sup>1</sup>. Some risk factors for non-cancer related, lower limb lymphedema are surgery with inguinal lymph node dissection, recurrent soft tissue infection at the same site, obesity, vein harvesting, orthopaedic surgery, and prolonged limb dependency among others.<sup>2</sup> Because lymphedema is commonly associated with breast cancer, persons with this condition are often faced with the challenge of finding a diagnosis and receiving client-centered, specialised care. Currently, the large municipality where this case was treated is faced with challenges in maintaining funding for the only clinic providing non-cancer related lymphedema care.



Compression therapy is recommended as a tool to help reduce limb size in both cancer and non-cancer related lymphedemas<sup>2</sup>. Modified levels of compression forces exerted on a limb with peripheral, arterial occlusive disease (ABPI <0.5) are provided. Traditional compression therapy involves the use of a multilayered, inelastic bandaging system which can be applied using a variety of techniques to accommodate for arterial insufficiency. This method, although proven effective, is bulky and limiting in terms of patient mobility as well as clothing and footwear selection. It also requires frequent, and in many cases, daily re-wrapping to maintain its compression

This report explores the use of an innovative 2-layer bandaging system (Coban 2 Lite<sup>®</sup>) which is safe for use in persons with moderate arterial disease in the lower limb. Prolonged wear time, thinner bandage profile and comfort of the overall bandaging system enabled a person with unilateral lower extremity and scrotal lymphedema to maintain excellent quality of life with minimal interruptions to his activities of daily living while receiving compression therapy.

**Case(s) description:** Patient has consented for use of all relevant information and photographs for this abstract.

**Consult process:** 75 year old male admitted to acute care neurology unit for multiple TIAs (December 3, 2010.) While in his hospital room, he overheard the occupational therapist, wound consultant assessing the patient in the adjacent bed. This patient stopped the consultant as she was leaving the room “do you know anything about this?”.

Past Medical History- Hypertension, benign prostatic hypertrophy, recurrent UTI, recurrent cellulitis in left lower limb, benign neoplasm of rectum, kidney stones

Surgical history- Colonoscopy (21 May, 2011), Transurethral resection of the prostate TURP (10 Feb 2011)

Lymphedema onset- August 2010. Exacerbated by recurrent cellulitis in left limb (IV antibiotics September 23- October 9, 2010 and November 26- December 2, 2010). Multiple ultrasounds negative for DVT.

**Arterial assessment:** Dependent rubor, cool (not cold) to touch, reduced hair growth

ABI (right) 1.2, (left) 1.3 TBI (right) 0.4, left (0.4)

Angiogram Summary: “No significant stenosis of the main lower extremity arteries from the aortic bifurcation to the ankle with below marked atherosclerosis of the anterior tibial artery and posterior tibial artery bilaterally.

Clinical symptoms: Pitting lymphedema to left leg, scrotum also involved, present for 6 months.

Compression Therapy Treatment:

Coban 2 Lite wrapped from base of metatarsal heads to above thigh and near groin:

Modified or “loose” application at the foot to accommodate for arterial disease

Figure-8 used around flexed (~45 degrees) knee joint to minimize bandage bulk and allow for maximum mobility.

Double layer, spandex “bike shorts” used to manage lymphedema in scrotal area.

\*\*\*Bandages changed twice per week. This minimized burden of care as the patient had ~55km trip to hospital and was unable to drive his own vehicle.

\*\*\*Multidisciplinary services were utilised in the care and treatment of this patient. Including but not limited to: family physician, dietician, PT/OT, nursing

Treatment time from initiating bandaging to measurement and arrival of custom pressure gradient stockings: December 8, 2010 – January 21, 2011. (44 days total).

**Implication for Practice:**

- Safe and easy compression therapy for managing edema extending above the knee in a patient with moderate arterial disease in the foot
- Reduced frequency of bandage changes: decreased time and travel burden on the patient and enhanced efficiency and effectiveness of lymphedema service
- Enhanced patient mobility while wearing compression

- Minimal disruption to activities of daily living including not having to modify shoe and pant choices because of thin bandage profile.

#### E. Kimura – Quality of Life in Lymphoedema Patients, Part 1 and Part 2

##### **Research Framework for Investigating Quality of Life in Lymphoedema Patients at Out Patient Services in Japan <Part-1>**

**Introduction/Background:** Since 2000, growing awareness of lymphoedema management has been occurring by research presentations or widespread media coverage. However, there was no longitudinal study of QOL in lymphoedema patients at out patient services in Japan.

**Aims of the study:** The purpose of the research is to investigate for QOL of patients and to evaluate care outcomes at lymphoedema outpatient services.

**Methods:** The data collection period is from Nov 2009 to Sep 2010. The participants answered the questionnaire including Minimum Data Set (demographic information, EuroQol), HADS, Brief-COPE and The Medical Outcomes Study short form-36 in every 2 or 3 months, total 3 times. This research was approved by Ethical Committee of the University of Tokyo.

**Results:** In total, 15 patients completed to answer the questionnaire for three times. They were all female, The mean age was 54.9/y(SD9.6), the mean swelling duration was 7.9/y, the number of each classification of ISL :stage I(n=3),stagell-(n=7),stagell late-(n=5), and the mean time of care was 58.3/min by therapists. No any key person(n=2). Overall, the size of the limbs has reduced, although the reduction rate was different individually. The mean of circumference difference between 1st and 3rd measurement was 1.1cm(5.5) in the lower extremity, and 0.43cm(2.2) in the upper extremity.

**Conclusions:** For six months for follow-up, the mean size of the limbs has reduced without any complications by appropriate care. It is suggested that we should continue this lymphoedema-management. Besides, we need to follow-up to the patients who do not have any key person and to introduce some resources to them.

##### **Research Framework for Investigating Quality of Life in Lymphoedema Patients at Out Patient Services in Japan <Part-2>**

**Results:** The types of self-care of which frequency decreased were garments, self-massage and skin-care for 6 months follow-up. On the other hand, the frequency that increased were bandage and IPC. In Brief COPE, Active coping, Acceptance, Positive reframing showed higher score (5.91, 5.76,5.62 , respectively). Whereas, Substance use, Religion, Denial showed lower score (3.0,3.42,3.73). Regarding HAD scale, the number of patients at different anxiety status were None (n=10), Moderate (n=4), severe (n=1) and similarly, None (n=13), Moderate (n=1), severe (n=1) at depression status. In SF-36, the mean score for each domain was PF44.3(SD11.6)、RP44.7(11.8)、BP47.0(9.91)、GH47.1(4.36)、VT50.5 (10.1) 、SF47.8(9.59)、RE46.4(9.85)、MH50.5 (9.17) . The mean score for Index and Health condition (VAS) in the EQ-5D, were Index :0.82,VAS :64.7(SD17.8) in the first period, 0.88,70.2(13.9) , 72.9(12.7) in the third period. There were no significant differences in the mean score for each item between 1st and 3rd measurement in each scale (Wilcoxon,Friedman).

**Conclusions:** Although Brief COPE score was no remarkably high, they could use active coping and seemed to have accepted chronic condition. Moreover, as their QOL scores showed no change score throughout 6 month follow-up, the patients could have stable daily life with regular care and kept their QOL. However, as there were fluctuations in the number of patients at severe level in HAD, we need to continue psychological support for them.

#### M. E. Letellier – Drugs and lymphedema

**Introduction/Background:** Drugs are not effective for lymphedema; therefore, research into physical treatments and methods of self-management are of primary importance.

**Aims of the study:** This study investigated the feasibility of conducting a larger RCT aimed at assessing the effectiveness of aqualymphatic exercises in the control of lymphedema.

**Methods:** This is a randomized controlled pilot study. Participants were evaluated prior and following a 12-week intervention period. At each assessment, women were asked to complete four questionnaires and to perform an arm function evaluation. Ethical approval was provided by the McGill University Institutional Review Board. T-test was performed.

**Results:** Twenty-five women with chronic breast cancer related lymphedema were allocated into an exercise program (control, n=12) or exercise program plus aqualymphatic exercise (pool, n=13). Prior to intervention, the pool group had greater volume excess (p=0,05). Post intervention, only the grip strength improved in the control group (p=0,0076). In the pool group, pain intensity reduced (p=0,015), quality of life improved (FACT-B p=0,02), arm disability reduced (DASH p=0,02), as well as the grip strength increased (p=0,008). Of the 13 participants, 10 adhere to 81% of the pool session (range from 6-12 sessions).

**Conclusions:** Aqua lymphatic therapy did not change arm volume over time. However, only the pool group showed significant changes in the pain, disability and QOL. Further pilot studies with women having moderate lymphedema are required to justify a full RCT to assess the method's effectiveness. This study has given us valuable information that will help design future studies that will outline the potential place of this type of therapy in cancer rehabilitation programs.

J. Maegawa – Statistical evaluations of the effects on lymphaticovenous anastomosis and complex decongestive physiotherapy for treatment of peripheral lymphedema

**Introduction/Background:** Although there are reports on complex decongestive physiotherapy and surgical treatment for chronic lymphedema, only a few detailed descriptions on treatment protocols that combine the two exist. In recent years, several facilities have been established for lymphaticovenous anastomosis (LVA). However, the statistical analysis of the direct effects of LVA on edema has not been thorough.

**Aims of the study:** The aim of this study is to reveal true effects of LVA on changes of circumference on the affected limbs.

**Methods:** The subjects were 55 patients with lower limb lymphedema; 39 had secondary lymphedema and 16 had primary lymphedema. The patients were divided into three groups; early (SA) and late (SB) phase of secondary lymphedema according to preoperative lymphoscintigraphy, and primary lymphedema (P). We calculated the mean circumference of the lower limb during the initial examination as well as 100 days before and after surgery.

**Results:** The results identified a significant difference between in the mean values during the initial examination and 100 days before surgery in SA and SB. A significant difference was observed in the mean values 100 days before and after surgery in SA, but no significant difference in the mean values 100 days before and after surgery was identified in SB. In the P, a significant difference was observed in the mean values 100 days before and after surgery.

**Conclusions:** We believe that LVA needs to be performed before lymphatic functions worsen. LVA was shown to be effective in patients with primary lymphedema in whom lymph ducts can be identified.

S. Matsubara – MR lymphangiography for the assessment of the lymphedema

**Introduction/Background:** A major obstacle in understanding the lymphedema has been the difficulty of visualizing lymphatic vessels in human beings. On the other hand, microsurgical reconstructions of lymphatic vessels were performed and good results were reported in some cases.

**Aims of the study:** The one aim of our study was to evaluate the feasibility of MR lymphangiography with subcutaneous injection of contrast agent for the visualization of lymphatic vessels in patients with primary and secondary lymphedema. Another was to make clear the indication of microscopic lymphatico-venous anastomosis (LVA).

**Methods:** Between April 2007 and February 2011, 105 patients with lymphedema of the extremities were taken care in our hospital. (eight primary, 15 upper and 90 lower extremities). 10 of them, good controlled by the CDT, were evaluated by MR lymphangiography and 2 patients were evaluated to exclusion diagnosis. After preparation with local anesthesia, each 5ml gadolinium contrast agent was injected to subcutaneous tissue of each extremity. MRI was performed with a 1.5-T scanner. A half hour and one hour later from injection, 3D images were constructed.

**Results:** In 8 out of 9 patients of lymphedema of lower extremities and one of upper extremity, enlarged lymphatic vessels were detected. Only one lower extremity has just only reticular network of lymphatic vessels. In tow patients without lymphedema, lymph node were demonstrated on inguinal area, but not lymphatic vessels.

**Conclusions:** MR lymphangiography is safe, is technically feasible. It has the potential to become a diagnostic imaging tool for patients with lymphedema and to determine the indication of LVA surgery.

N. Matsuda – Investigation of manual lymphatic drainage based on visualization of lymph flow with ICG lymphangiography for peripheral lymphedema

**Introduction/Background:** There is little evidence of the efficacy of manual lymphatic drainage. The lymph in superficial lymph vessels and the dermal backflow (DBF) region can be visualized on ICG fluorescence lymphangiography. We have confirmed the direction of superficial lymph flow in the trunk during lymphaticovenous shunt operations by the lymphangiography.

**Aims of the study:** This study aims to determine the direction of lymph flow drainage, which was previously difficult, and to verify the outcome following the drainage using ICG lymphangiography.

**Methods:** We conducted conventional drainage on lower limb lymphedema patients several days after they underwent ICG-assisted LVA surgery. We observed the direction of lymph flow in the vessels and changes in the subcutaneous backflow region using a special camera for ICG fluorescence lymphangiography during the procedure.

**Results:** Although drainage performed via the trunk was directed toward the ipsilateral axillary lymph nodes, the lymph flowed toward the contralateral inguinal lymph nodes. No changes were observed in the DBF regions unless these regions were loosened by massaging, rather than by applying pressure. The pattern of flow observed was almost identical to that observed intraoperatively with ICG lymphangiography.

**Conclusions:** ICG fluorescence lymphangiography has simplified the visualization of superficial lymph vessels during lymphatic drainage, which is usually difficult. It is also useful in the evaluation of a therapeutic value.

H. Moore – A New Bandage System and a New Technique for Managing Lower Limb Oedema

**Description of original/rare case(s):** Mrs H, a 57 year old mother of 2 was referred by her G.P, due to bilateral lower limb oedema. This had been present for years but, had begun to impede her movement and affect her ability to do her part time job. It also affected her body image and her husband had urged her to seek treatment.

Her co morbidities included hypertension, ulcerative colitis, lipoedema and a BMI of 50.7.

On examination, Mrs H exhibited soft pitting oedema below the knees, a positive Stemmer sign and skin folds at the ankles. This indicated late Stage 2 Lymphoedema 1.

**Reason for report:** The patient agreed to have intensive lower limb compression but, did not want individual toe bandaging. A new 2 layer compression bandage was being trialled in the clinic. It offered maintenance of limb function as well as having a 'moccasin' technique for the feet which reduced swelling without the need for conventional toe application.

**Case(s) description:** the bandage system was applied five times in week 1 and then three times a week for 2 weeks, in addition to intensive skin care. After 3 weeks the limb volume had reduced 1464mls on the right and 1869 mls on the left. The patient was more comfortable and the legs felt 'lighter'.

**Discussion:** Clinical studies have now shown that this system delivers best results when applied just twice weekly. The bandage proved low profile and maintained mobility. It also offered an alternative technique for oedema reduction on the toes and feet which was both effective and comfortable.

#### C. Pike – Pioneering Bandage Solves Challenging Clinical Presentation

**Description of original/rare case(s):** Mrs P is an 83 year old lady who lives alone. She enjoys walking her dog and keeping mobile to maintain her independence. She is awaiting a right total hip replacement but, surgeons are reluctant to operate due to severe lower limb Lymphoedema and a history of Cellulitis.

She presented with bilateral soft pitting oedema from feet to mid thigh.. She also had a left shoulder dislocation, making use of walking aids challenging.

**Reason for report:** Reduction of the lymphoedema was paramount in order for surgery to take place. However the compression treatment chosen needed to optimise her current mobility. Mrs P lives 50 miles from the clinic and relies on her son for transport. It was therefore decided to trial a new biweekly treatment for Lymphoedema. It consists of a 2 layer bandage that bonds together to give stiff compression and maintains a good range of motion.

**Case(s) description:** The advantages of the bandage were discussed with Mrs P who consented to this case report. She was treated twice weekly for 2 weeks with the compression bandage along with skin care, exercise and aids to daily living.

Total volume reduction over 15 days was 2,432ml for the left leg and 1,994ml for the right.

**Discussion:** The treatment proved successful as it provided excellent volume reduction. The patient was able to wear her normal footwear and maintain her independence; and the reduced clinic visits meant that there were cost savings for both the patient and the clinic.

Sadly, the surgery remains on hold due to cardiac issues.

#### N. Piller – Diet and lymphoedema: facts and fallacies in the grey and popular internet literature

**Introduction:** A range of medically related magazines and health sites on the internet provide patients with numerous options for the management of lymphoedema. With the introduction of the www there is an ever increasing volume of grey and popular literature available to a patient, much of which is not peer reviewed or evidence based. Patients, unless well educated about their lymphoedema, may not be critical consumers. This review summarises the current recommendations for conservative treatments in lymphoedema related to diet and exercise and critically analyses their real value in clinical practice.

**Background:** Despite lacking evidence, the grey literature on the www is abundant with recommendations for lymphoedema management. Schwartz et al. (2006) found 48% of respondents had used the internet to find information on health issues or medical conditions, and 98% felt the information was trustworthy. The great concern is that many uneducated patients may lack the ability to critically appraise and separate the facts from the fallacies.

**Aims:** To provide practitioners and patients with a report of conservative lymphoedema therapies (particularly focusing on diet and exercise) currently recommended on the www. Through being informed, encourage better communication between patient and practitioner through the provision of more credible advice to patients who approach them with information they have gathered from the internet.

**Methods:** Search strategies: google was used to find websites and the first 20 valid results from each search were investigated for claims about lymphoedema strategies targeting diet/exercise. E-books were purchased from some sites. Search terms: general terms used for this search

included: lymphoedema, lymphedema, lymphatic dysfunction, diet, exercise, cure, management. Search results: eight topics/themes were identified as diet related management options for lymphoedema: diet to achieve and maintain a healthy weight, low carbohydrate diet, low protein diet, alkalisng diet, low salt diet, drinking distilled water, abstanance from alcohol and caffeine, oil pulling.

Each was then investigated in the peer reviewed literature for evidence that supported or refuted the claims made. The topics/themes categorised into the following: safe and effective: management strategies that are both safe to the patient and supported by peer reviewed evidence, no harm but no evidence: recommended strategies that are not supported by peer reviewed evidence but that are of no harm to the patient, no evidence and potentially dangerous: recommended strategies that are unfounded and can potentially cause physical, mental and financial harm to the patient.

**Results:** Although some sites contained inaccurate information, this often accompanied accurate information, which may make elucidating right from wrong even more difficult for an uninformed patient.

**Discussion:** The search of the grey literature on the www has revealed some concerning information about what is available to patients. In the area of lymphoedema this is perhaps more of a problem, since its profile is only just increasing and there is often inadequate peer reviewed evidence available for conservative treatments for practitioners and patients. Patients should not be discouraged from taking the initiative in their own health. It is, however, crucial that they are aware of the importance of being critical of any information they may gain from the www, and that they discuss any potential treatment strategies with their aware health professional or doctor before commencing a new intervention.

#### R. Pritzker -Education Initiatives

**Introduction:** Patients have limited access to lymphedema treatments under Quebec's health care system and knowledge about lymphedema risk reduction and management is lacking among health professionals. Patients and their families need accurate, evidence-based information as well as training in self care and autonomy in managing a chronic condition and ensuring their quality of life.

**Aims:** To create a self-sustaining educational initiative in lymphedema risk reduction and management for health professionals and patients, and continuing evidence-based education for lymphedema therapists.

**Rationale:** Education of health professionals in recognition, risk reduction practices and principles of lymphedema treatment will result in improved patient assessment, access to care and treatment outcomes. Early diagnosis, education, and treatment will reduce costs of hospitalization due to infections and complications of untreated lymphedema. Providing patients with information on prevention, and treatment choices will reduce the consequences of their untreated lymphedema and its financial burden and improve patient quality of life.

**Description:** Lectures, workshops and courses were designed and offered to health professionals (oncology nurses, physiotherapists, occupational therapists, radiation oncology technicians, physicians) in Montreal hospitals and the private sector (physiotherapists, lymphedema specialists) on various subjects such as introduction to lymphedema, rehabilitation, exercise, minimizing risk, best practices, clinical decision making, self management and more. This pilot educational project was pilot-funded through charitable donations by the Lymphedema Association of Quebec and the Foundation of the Royal Victoria Hospital in Montreal.

**Evaluation:** Over 600 participants attended the pilot workshops. Pooled data from common questions on completed evaluation forms rated the relevance of the workshops as excellent. Many commented on the need for longer sessions and further workshops.

**Conclusion:** Educational programs on lymphedema are well received by health professionals and patients and demonstrate the need for this kind of initiative. Our next challenge is to ensure a cadre of adequately trained teachers for such a program, thus ensuring sustainability. We will also continue to advocate for the Ministry of Health to subsidize this type of educational endeavor.

### **Service Development Initiatives**

**Title:** A program of self bandaging instruction for patients of the McGill University Health Centre (MUHC) lymphedema clinic: a key to independence

**Aims:** This program aims to give patients self management tools with which they will be able to treat and control their chronic condition. It targets those who cannot afford treatments, or those who cannot, or do not want to commit to treatment.

**Description:** Patients have no access to lymphedema treatments under the Quebec provincial health care system. Treatments and compression materials are expensive and often patients will not get a full series of intensive Complex Decongestive Therapy (CDT) due to financial difficulties.

The McGill University Health Centre (MUHC) Lymphedema Clinic provides services that include diagnosis, assessment and advice regarding treatment options to patients with lymphedema. Education on self massage, exercise, skin care and risk reduction are provided in the lymphedema clinic but these modalities are insufficient to treat moderate and severe lymphedema where compression therapy is essential.

Therefore, the MUHC Lymphedema Clinic began a parallel service that teaches patients and their care givers how to bandage.

**Evaluation:** At the beginning of the intervention, each patient's limb is measured. Using a measurement flexible tape, the circumferences of the limbs are taken, and the volume of the limb is calculated using the truncated cone method. During each session, measurements are taken and a graph is drawn. The patient and the therapist decide together when to order a garment, depending on when the graph plateaus.

Twenty-five patients participated in this program in 2010. Updated results with graphs and photos of will be presented.

**Conclusion:** Patients need independence in treating lymphedema, especially since the treatments are not covered by the Quebec health care system. Learning how to bandage is a good way of giving the control back to the patient.

M. Reddick

**Aim:** 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. This case study will explore a new treatment option for lymphedema using a two layer cohesive short stretch bandaging system.

**Method:** There are many treatment options available for lymphedema however none can repair the damaged lymphatic system or return it to normal. This case study is a 45 year old male with significant chronic primary lymphedema with multiple medical problems. On this patients initial assessment his leg circumference measurement was taken at 20 centimeters proximal to right lateral malleoli and measured 89centimeters. He was immobilized and disabled from work. Treatment options were presented and patient opted to try the new two layer cohesive short stretch bandaging system. Initially the bandages were applied three times a week and then decreased to biweekly and weekly and subsequently patient was fitted with a custom compression stocking.

J. Semple – Lymphedema associated with cancer surgery

**Introduction/Background:** In North America between 3 and 5 million people suffer from lymphedema and most cases are associated with cancer surgery. While the sentinel node technique in breast cancer has undoubtedly reduced the incidence of lymphedema, 23% of patients will still develop lymphedema with the combination of lymph node biopsy and radiotherapy.

**Aims of the study:** Taking all patients and treatment regimens into account, up to 40% of breast cancer patients will develop lymphedema depending on the criteria applied and all survivors are at risk for this condition. The quality of life for lymphedema patients is significantly compromised with the patient suffering impaired limb function, psychosocial problems and in extreme cases malignant complications and life- threatening infections.

**Methods:** Treatment options are very limited. Most individuals are offered compression garments, the use of intermittent or sequential pneumatic compression devices and/or massage therapy. Several surgical techniques have been used clinically and in experimental studies in an attempt to restore fluid drainage after tissue injury. These include lymphatic-venous anastomoses, lymphaticovenular bypass, lymphatic vessel transplantation, omental grafts that contain lymphatics, implantation of lymph node fragments, liposuction (Brorson) and vascularized lymph node transplantation. In many cases some degree of lymph continuity was re-established and the lymphedema status improved to variable degrees.

**Conclusions:** An overview of the different surgical techniques will be presented along with intra operative details of newer techniques including micro vascular transfer of lymph nodes. Outcomes and appropriate methods of assessment of lymphedema including standards of circumferential limb measurement and bioimpedance techniques will be discussed.

R. Thomas-MacLean

Basic Science or Clinical Research Study (quantitative or qualitative)

Studies should preferably be completed before presentation at the conference

**Introduction/Background:** Capturing the Landscape of Secondary Lymphedema Using Visual Methods INTRODUCTION: Visual methods, such as photography, are increasingly recognized as both important forms of qualitative data collection, but also as potential psychosocial interventions or creative practices. Through these creative practices, a rich understanding of



the impact of lymphedema after cancer may emerge. This presentation shares the preliminary findings of two studies – one involving drama and the other, photography.

**Methods:** (including statistics, whether ethics committee approval has been given)

Both studies were approved by our university's research ethics board. The first study included the creation of collages and installations of items depicting the impact of lymphedema after breast cancer (n=7). The second study, which is ongoing, uses photovoice to document experiences of secondary lymphedema.

**Results:** A variety of themes emerged, some of which include: the need to adapt to a new landscape, a search for information and understanding, and movement toward self-compassion.

**Conclusions:** While related studies by the authors of this presentation have utilized qualitative methods, the data from the two projects discussed are much richer in comparison. Visual methods have great potential to further understanding of the impact of secondary lymphedema. In addition, the feedback from participants indicates that these approaches to research are also promising creative practices (interventions).

#### A. Tilley – Multilayered inelastic lymphedema bandaging

**Introduction/Background:** Multilayered inelastic lymphedema bandaging (MLLB) alone or in combination with manual lymphatic drainage massage, exercise and skin care, has long played a part in the effective management of lymphedema. Traditionally, MLLB consists of multiple rolls of short stretch cotton bandages applied to the edematous limb over custom-cut foam of varying densities. Traditional MLLB, while effective, can be awkward, heavy and hamper joint range of motion. It often does not fit normal footwear or ordinary clothing. MLLB needs to be replaced every 2 days or more due to loosening and slippage. The application technique can be difficult for patients to learn and apply.

**Aims of the study:** An evaluation was conducted to assess the effectiveness of a new 2 layered cohesive short stretch bandage system as a substitute for traditional MLLB for treatment of chronic lymphedema within the Complete Decongestive Therapy (CDT) model.

**Methods:** After Research Ethics approval was received, an 8 patient case series was conducted using the new MLLB system. Subjects were included as they presented to our active, hospital-based, lymphedema treatment program, and only if they required compression bandaging to reduce the limb prior to fitting with compression garments. Subjects were treated, and bandages were replaced 2-3 times per week for 3 weeks. Some required Manual Lymph Drainage (MLD) massage, bandaging, exercise and skin care, while others did not require MLD. Subjects were not required to re-bandage their limbs on weekends. Bandages were worn 24/7 throughout the 3 weeks. Patients were assessed throughout using digital photography, limb volume, skin condition, and comfort.

**Results:** ISL stage 2 and 3 lymphedemas were reduced. Skin remained intact. Patients wore normal shoes and clothing. They reported greater comfort than with traditional MLLB. Following the intensive phase, bandages remained in place for up to 7 days and maintained limb size comfortably. Bandaging application time was reduced to one half of that required for traditional MLLB. With virtually no slippage in the lower leg and arm, fewer visits were required.

**Conclusion:** The new 2 layer cohesive short stretch bandage system may be an excellent option for the treatment of Lymphedema. The new cohesive short stretch bandage system provides similar effectiveness to traditional MLLB in reducing lymphedema but with better patient comfort, mobility and ease of application in fewer visits. Larger studies using this system would be of benefit."

#### A. Tosaki – Evaluation of tissue hardness in peripheral lymphedema by ultrasound imaging device with a sensor to measure pressure

**Introduction/Background:** During physical therapy for treating lymphedema we often observe a change in skin hardness; however, we have not yet been able to quantify the change in

hardness of edematous skin. We used the ultrasound imaging device with a sensor for measurement of pressure to evaluate treatment efficacy by assessing the change in skin hardness in lymphedema-affected areas, which is not indicated by circumference measurement.

**Aims of the study:** The aim of this study is to evaluate tissue hardness of lymphedema by the special equipment.

**Methods:** Subjects included 10 outpatients with lymphedema of the lower extremities from our hospital. The ultrasound imaging device developed for evaluation of tissue hardness includes a sensor to measure pressure in its probe. We can measure tissue hardness by pressing the probe to the skin of the patients and evaluate thickness change of the tissue at the same time. We performed an ultrasound imaging of the patients' front thighs of the affected limbs both at the time when we started physical therapy and at the maintenance phase when the circumferences were stable. We also performed the same study on the contralateral limb as a control.

**Results:** By comparing the displacement value at the time of starting treatment with that during the maintenance phase, we observed that all patients had experienced an increased displacement when receiving a pressure on subcutaneous tissues, which meant that their skin became soft.

**Conclusions:** Change of subcutaneous tissue in lymphedema could be a useful indicator for severity assessment and treatment evaluation if no circumference change can be confirmed.

#### J. Wong – Utilization of a Single Use 2 Layer Short Stretch Compression System to Promote Rapid Limb Volume Reduction in Patients with Secondary Lymphedema

**Description of original/rare case(s):** Short stretch, reusable bandages with 30-40 mmHg compression has been the industry gold standard and a key component in providing treatment for patients with chronic lower extremity secondary lymphedema. Plan was to evaluate the effectiveness of a single-use 2 layer compression system\* with these patients.

**Reason for report:** With two times per week application, the single-use 2 layer compression system resulted in rapid limb volume reduction in patients with secondary lower extremity lymphedema.

**Case(s) description:** Six patients with diagnosed Stage II secondary Lymphedema were treated with manual edema mobilization techniques, utilization of an intermittent sequential compression pump & the application of a 2 layer short stretch compression bandage. Comparison circumferential measurements were taken and limb volume calculation was performed 7 -10 days from initial evaluation. A significant volumetric reduction was achieved in each case. Treatment was well tolerated by all six patients without development of skin irritation or breakdown. Patients reported decreased discomfort (per the visual analog scale).

**Discussion:** Utilization of the 2 layer compression system with twice weekly application significantly achieved successful and rapid limb volume reduction in all six patients and maintained the reduction until the patient could be fit into a compression garment for long term management of their condition. The rapid reduction in limb volume (average of 6.67 days) allowed for quicker completion and discharge from therapy services. This could possibly equate to a more cost effective treatment in both time & financial savings.

#### S. Xu – Associations among Population at Risk for Cancer and Lymphedema, Distribution of LANA-certified Lymphedema Therapists, and ALFP Therapist Survey Respondents Using Geographic Information Systems

**Aims/Rationale:** The primary study aim was to examine associations among location of LANA-certified Lymphedema (LE) therapists and population centers with persons at greatest risk for cancer and treatment-associated LE. Secondarily, we examined associations among location of 2009 ALFP survey respondents with LANA-certified therapists and population centers. Further,

we examined associations between Missouri LANA-certified therapists and zip codes of Missouri breast cancer survivors. A geographic information system was used to identify distribution of certified therapists by zip code, after which cross-mapping techniques were used to compare population distributions.

**Description of initiative:** The American Lymphedema Framework Project mission is to increase awareness, education, research, and care for persons with lymphedema in the United States and around the world. This study aims to better understand geographical availability of trained LE therapists in relationship to the population in need of LE therapists. The National Library of Medicine-funded G08 web-based portal will allow seamless access to critical information on geographical proximity of certified therapists and support evidence-based planning for program development and improved access.

**Outcome/Impact:** Findings point to a relative lack of correspondence between population density and LE therapist availability. Results provide information for planning training programs to prepare LE therapists in areas of greatest need. Findings will be shared with third-party payers, health-policy analysts, and advocates to inform future coverage and policy planning.

**Evaluation:** Similar methodology can be applied by other national frameworks and globally to assess availability of and need for trained LE therapists, as a step in improving access to optimal care for persons with and at risk for lymphedema.

#### Y. Yabuki – An Examination of Post-operative Patency and its Regulating Factors in Lymphaticovenous Anastomosis

**Introduction/Background:** Lymphaticovenous anastomosis (LVA) has become established as a typical method for the surgical treatment of chronic lymphedema. However, there are few reports on long-term anastomotic patency and its clinical effects. We have previously identified long-term patency by fluorescein angiography using ICG postoperatively.

**Aims of the study:** We report an attempt to evaluate the clinical effects of long-term patency and examine factors that regulate it.

**Methods:** From among 65 cases in which LVA was performed, 32 cases of lower limb were underwent fluorescein angiography after a minimum of six months had passed after the operation. The items examined were the presence or absence of patency, general statistical items, and the amount of volume reduction in the diseased limb, and the detail status of anastomosed site.

**Results:** Among 32 cases, patency was identified in 18 cases. No statistically significant difference was identified in general statistical items, but a greater tendency toward volume reduction was identified in which patency had been identified. Next, we examined the each sites; 41 were able to judge clearly, and 25 were identified as patent. Consequently, the long-term patency rate was about 60%. We performed a detailed evaluation by using the surgical records, but we can only detect that patency in which the size of anastomosed venous is less than 0.8 mm tended to be greater.

**Conclusions:**

We have previously used fluorescein angiography to evaluate the postoperative anastomosis directly. The volume reduction in which patency was identified tended to be greater. We also examined the factors that regulate long-term patency, but more detailed examination is required.