Notes from Canadian Lymphedema Conference

November 3-4, Toronto, ON

* **Dr. Keast: Wounds and Lymphedema: Prevalence and management**
* **Dr. Anna Towers: New ILA recommendations for diagnosis of lipedema**
* **Dr. Denise Campbell-Scherer: Why weight? What you need to know about the Canadian Adult Obesity Clinical Practice Guidelines.**
* **Céline Koryzma, PhD: Motivating patients to make meaningful and sustainable health behavior changes with relationship-centered care**
* **Surgical techniques: A panel discussion hosted by Dr. Siba Haykal. Panel members include: Dr. Claire Temple-Oberle; Dr. Andrew Simpson, and Dr. Benoît Cartier**
* **Dr. Anna Towers: How should we treat palliative cancer patients who have uncontrolled lymphedema?**

These are the notes that I took during the conference. I have also attached links to get to referenced research articles and educational materials.

*Please remember that these are notes- not full transcripts*. All of the presenters were fantastic professionals and I just know that you will find something interesting to inspire your practice.

I would love feedback on any aspect of these notes as I am planning to do this more in the future.

**Dr. Keast: Wounds and Lymphedema: Prevalence and management**

Interesting website: Wounds Canada: https://www.woundscanada.ca/

Journal of Wound Care article on the study of the prevalence of lymphedema in wound clinic:

https://www.magonlinelibrary.com/doi/abs/10.12968/jowc.2016.25.Sup4.S11

There are four stages of a wound

* Hemostasis
* Inflammation
* Proliferation
* Remodeling

A chronic wound is not progressing. This should be considered as a complication of a disease process such as:

* Venous stasis
* Peripheral Artery Disease
* Pressure injuries
* Chronic edema

If an amputation is performed due to diabetic foot ulcer there is a 50% risk of an amputation on the opposite side within 5 years as well as an increased risk of death.

Chronic edema defined

* Lasts more than 3 months
* Minimally responsive to elevation or diuretics
* One or more secondary skin changes.

Lymphatics and capillaries work together as a unit to care for the cellular matrix

Venous insufficiency is considered a dynamic or fluid overload lymphedema.

All chronic edema is lymphedema. There is a higher prevalence of wounds in LE lymphedema.

Most lymphedema is complex with one of his studies finding an average of 7.3 contributing comorbid complications in lymphedema patients.

Remember: The wound is on a patient. The patient is in an environment. Best practice is to perform a full assessment of history etc. BEFORE taking off the bandages to assess the wounds.

Check bloodwork for anemia and hyperglycemia. A1C above 12%=poor wound healing. Hemoglobin less than 100g/L is also risk. Get a really good description of pain.

Remember that meds such as calcium channel blockers, chemotherapy, and immune suppressants will impair wound healing.

In cases of arterial insufficiency, a vascular surgeon consult should be performed to address possible revascularization

Dermatitis happens because of loss of skin barrier function. Remember to use pH balanced soap and lotion. *(Another attendee at the conference told me about Glaxal Base Cream-this is not an endorsement of this product by myself or Dr. Keast).*

Matt’s Hypothesis has paper explaining barrier function of skin.

chrome-extension://bdfcnmeidppjeaggnmidamkiddifkdib/viewer.html?file=https://woundsinternational.com/wp-content/uploads/sites/8/2023/02/d58b8eca2912a2417f5bef62b4b5dfd1.pdf

**Components of Care**

* Manage underlying medical conditions
* Maximize nutritional status
* Promote exercise
* Meticulous skin care: pH balances soap; clean/dry between all toes and crevices; gentle emollients to restore skin barrier function; barrier film to protect peri wound skin from exudate
* Compression therapy: short stretch bandages or Velcro devices

Be sure to refer appropriately for biopsy. Sometimes a poorly healing wound is cancer. Pt’s with very fast growth may have lymphangiosarcoma.

All wounds that have been around for a period of time will have bacteria in it so swabbing too soon may lead to unnecessary antibiotic treatment.

**Stages of infection:**

* Contamination
* Colonization
* Local wound infection with overt and covert symptoms
* Spreading infection with bacteria in deeper tissues: erythema spreading more than 2cm from wound, lymphangitis, crepitus, wound breakdown; increased white cell count & c-reactive proteins
* Systemic infection

\*\*Remember that bilateral cellulitis **does not exist**

Cellulitis needs a point of entry. Check for cracks in feet, scratches, between toes D4 and D5.

Appropriate compression therapy if ABI is greater than 0.5 is critical to wound healing. Long stretch or Velcro/adjustable bandaging is preferred for calf muscle pump and interstitial pressure.

International Wound Infection Institute published best practices article in 2022: <https://www.magonlinelibrary.com/doi/full/10.12968/jowc.2022.31.Sup12.S10>

People recovering from foot ulcers need exercise. Consider “Ankle alphabets”-drawing each letter with your big toe. And TheraBand resistive exercises.

**Dr. Towers: New ILA recommendations for diagnosis of lipedema**

Diagnosis of lipedema must be standardized in order for accurate research and evidence-based practice.

A document was published Nov. 2020 by the International Lipoedema Association to clarify diagnosis and treatment of lipedema.

<https://www.magonlinelibrary.com/doi/full/10.12968/jowc.2020.29.Sup11b.1>

When the consensus statement was being created the Dutch guidelines for lipedema was used for definition and anything that could not be supported by research was ruled out.

The guidelines were created to describe a PURE lipedema. This is an important distinction as lipedema research is usually based on subjects who present with a complex presentation. (Lymphedema, Obesity…)

The following guidelines for diagnosis were created:

* Disproportionate increase in adipose tissue in the Lower Extremities (sometimes the upper extremities)
* Pain/sensitivity to touch/ allodynia. Pt rarely can tolerate testing for pitting.
* Normal hands and feet (if no lymphedema present)
	+ May have significantly thickened subcutaneous fat in the legs or arms with a sudden stop at the ankle or wrist.

Women tend to have varicosities. Hormonal changes may be associated with fat distribution.

Some research estimates lipedema prevalence to be 10-20%. Dr. Tower’s chart review finds ~3% pure lipedema.

40% of the United States is obese. 80% of lipedema patients are obese- weight loss does decrease symptomatic complaints.

Progression of lipedema is not related to disease progression it is related to obesity related progression.

There is no edema in lipedema so MLD for the purpose of lymphatic drainage is not indicated unless it is an obesity related lymphedema.

ICD 11 has a classification for lipedema: <https://www.findacode.com/icd-11/code-1172950828.html>

Something to seriously consider:

Body dysmorphic disorders. Persons who are unhappy with their bodies to an extent that their unhappiness interferes with life functions. Affects 1:50 people

Consider that fat distribution (cankles) at the ankle may just be “how the person is built”.

**UK recommendations for liposuction 2022**

* “Evidence for the safety of liposuction for lipedema is inadequate but raises concerns for major events such as… fat embolism and deep venous thrombosis”
* “Evidence on the efficacy of liposuction is also inadequate based on retrospective studies with methodological limitations”
* “Therefore, the procedure should only be used in the context of research” -with strict guidelines for participation

We know that obesity and physical inactivity are going to make lipedema worse but research on treatments are not reliable because inclusion criteria is too liberal.

Fibromyalgia is muscle pain/ Lipedema is tissue pain

Histology shows inflammatory condition/hypoxia and fat necrosis. MLD can be chosen for pain reduction.

**MYTHS**

* There is edema in lipedema
* Lipedema makes patients overweight
* Weight loss has no effect on lipedema
* Lipedema is a progressive disease
* Lipedema causes mental health issues
* Liposuction is effective for lipedema producing long-lasting results

Standards of treatment according to Dutch guidelines:

* Weight control
* Compression as tolerated
* Exercise

Questions asked:

About ketogenic diet which was challenged because this has to be a life-long practice in order for it to be effective.

About Duloxetine which is effective for pain relief- I am not sure where this comes into play for lipedema.

Durum’s disease is a more localized presentation than lipedema.

**Dr. Denise Campbell-Scherer: Why weight? What you need to know about the Canadian Adult Obesity Clinical Practice Guidelines.**

This is great even if you aren’t from Canada!

Dr. Campbell introduced the Edmonton Obesity Staging Scale which has been studied to be more accurate than BMI as a predictor of mortality.

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“Obesity is a prevalent, complex, and progressive condition …**that impairs health.”**

Obesity Guidelines Canada or 5AST in google will provide useful information for providers:

<https://obesitycanada.ca/5as-team/>

Prevention is key. Don’t do anything that you can’t do **forever.**

Most patients can loose 3-5% of their weight. This will consist of fat and fat-free mass (muscle). If you “yo-yo” diet the weight that you gain will not be fat-free mass- it will be fat. As a result, your ability to burn calories will be significantly reduced.

Physical Activity and Healthy food are one aspect and by far not the most effective aspect of weight loss.

When you wish to address weight with a patient it is best to ask “Is it OK if we talk about weight?”

Become familiar with obesogenic prescriptions: <https://obesitymedicine.org/medications-that-cause-weight-gain/>

4 M’s for assessment of obesity

* Mental
* Mechanic (physical impairments)
* Metabolic
* Milieu (socioeconomic class, education, occupation)

Persons taking pharmacologic weight loss with decreased appetite may need nutritional supplementation due to decreased appetite/intake of nutrients.

**Céline Koryzma, PhD: Motivating patients to make meaningful and sustainable health behavior changes with relationship-centered care**

Two book recommendations:

 *Healthy habits suck* by Baggley

 *Atomic Habits* by Clear

“Each of you is perfect just the way you are and all of you could use a little improvement”

-Shunryu Suzuki

There isn’t one thing that makes a person change suddenly- it’s a bunch of little things.

People tend to experience negative emotions when they don’t make healthy changes.

In order to change there needs to be a certain amount of privilege, and environmental safety.

Temporal discounting- the long-term consequences of unhealthy behavior seem to be something that will happen to someone else

Self-compassion can lead to caring for yourself now in order to feel better in the future. So, understanding instead of punishment is more helpful when we don’t meet our goals.

If you think about it healthy behavior is abnormal behavior. For example, choosing the pain/discomfort of exercising or taking extra time to cook a healthy meal.

Factors that motivate:

* Supportive healthcare provider relationship that encourages values
* Linking values to goals “What’s going to make it worth it?”
* Promote self-efficacy and habit change

Active listening and collaboration is relationship centered communication.

Research shows that there is a decrease in provider burnout and an increase in satisfaction when providers use relationship centered communication.

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| --- | --- |
| **Relationship** | **Clinician as expert** |
| Description  | Diagnose |
| Prediction | Determine |
| Choice | Evaluate outcome |

Ask “What are the good things about…” (smoking, having high blood sugar…)

“If there was an easy solution you would have found it already.”

MOTIVATIONAL INTERVIEWING

* Collaborative counselling designed to increased ambivalence (contradictory feelings)
* Only used with patients in contemplative phase of change
	+ Do you consider this to be a problem?
	+ Do you think it’s a good time to change some behaviors?
	+ Are you ready to start now?

Consider the answer to be like a traffic light.

If answer Is “no” then stop- red light! The goal is now to maintain the therapeutic relationship. “It’s okay, if you want to do this in the future, I am here.”

If the answer is a weird/awkward “yes” then it’s a yellow light- TIME FOR MOTIVATIONAL INTERVIEW

If it’s YES! Similar to the answer you would like to receive to a marriage proposal -then you continue with “typical” method of education, treatment plan, and reassessment.

1. Develop discrepancy: Think out loud about the pros and cons “on the one hand… on the other hand…” This leads to problem solving out of that “stuck” feeling
2. Find out why the behaviors are hard to do/” What is good about not having to put on your compression?”
3. Come up with list of reasons that why changing these behaviors would be worthwhile
4. Consider feelings associated with thinking about what it will feel like when doing the goal behavior.

“Yes, but..” is a sign of a polite argument.

“Rolling with resistance” Reflect back –“you are saying… what do you think would help?”

It’s okay to give advice but it needs to be specific to the barriers of the patient.

Values are about how you act, they are never fully achieved or completed, it may be hard but it’s worthwhile because you value it.

Feelings are like puppies-easily distractible, change quickly, and you can’t rely on them to get you where you want to go.

A life without health complications doesn’t equal a good or meaningful life.

What will reduced swelling allow you to do?

SMART Goals vs. Behavioral goals

1. Behavioral goals something the person has control over. NOT an outcome goal (i.e., weight loss vs. volume loss.)
2. Small goals-really small goals
3. Invite them to prove you wrong. Set a lower goal that can be hit 90% of the time then invite pt to prove you wrong.
4. Discuss what barriers may throw off their success.

Utilize habit stacking- add to what you already do.

Never miss twice.

Increase vs. decrease friction. For example, if you want to exercise set out the clothes etc. so the ability to do it is smooth.

Saturday self vs. Sunday self: Saturday self is energized/highly motivated. Use that energy to set up the circumstances so that the less motivated Sunday self is set up for success.

Some questions to ask if you have limited time to develop a therapeutic relationship.

* What do you already know?
* What do you want to know more about?
* What is bothering you?

Act first-don’t wait to feel better before you make a change.

**Surgical techniques:** A panel discussion hosted by Dr. Siba Haykal

Lymphedema Staging: 2013 Consensus document of the international Society of Lymphology: chrome-extension://bdfcnmeidppjeaggnmidamkiddifkdib/viewer.html?file=https://www.u.arizona.edu/~witte/2013consensus.pdf

Images of what lymphatics look like at different stages of lymphedema

<https://plos.figshare.com/articles/figure/_Staging_of_lymphedema_and_the_macroscopic_anatomical_findings_in_the_collecting_lymphatic_vessels_associated_with_the_stages_/274572>

**Dr. Temple Oberle= Preventative techniques**

Primary prevention: Avoid lymph node dissection

Secondary prevention: Immediate lymph reconstruction

Tertiary prevention: Treating lymphedema with surgical intervention

Procedures are difficult with many complications.

MSLTII: 2017 Complete Lymph Node Dissection Study (CLND):

<https://www.nejm.org/doi/full/10.1056/nejmoa1613210>

Found that the mortality rate was not significantly different in persons who had CLND vs those who were provided routine observation over a 10 year period.

24% lymph rate in patient who had CLND.

Nodal dissection is recommended over CLND- ultrasound observation and systemic therapy is used.

Quality of Life Questionnaire used:

ARM:

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LEG

chrome-extension://bdfcnmeidppjeaggnmidamkiddifkdib/viewer.html?file=https://www.honorhealth.com/sites/default/files/documents/medical-services/Leg-LYMQOL-form.pdf

Lymphovenous anastomosis (LVA) : immediate; takes 15 minutes to perform reconstruction

Sloane Kettering study found rate of 9.2% vs 32% in study of persons having LVA vs. those without.(I don’t have the notes on how to refer to this study)

Another study found that there is a higher rate of LE lymphedema vs. UE lymphedema when node dissection is performed

We have halved our lymphedema rate.

**Dr. Simpson= Physiologic surgery for lymphedema**

LVA vs. VLNT (Vascularized Lymphatic Tissue Transfer)

1935 Sir Harold Gilles described 1st case of flap dissection for lymphedema. Arm was sewn to the leg for weeks! No information beyond three month follow up.

Lymphatic vessels are very small (<1mm) minimally invasive.

THIS IS NOT A CURE FOR LYMPHEDEMA

Not for advanced lymphedema disease with thickened subcutaneous wall.

LVA= attach lymph node vessel directly to a vein. This is a day surgery. Low flow to low flow is a risk of closure of the anastomoses. MLD NEEDS TO BE PERFORMED DIFFERENTLY

 ***Massage towards incision to keep anastomosis open during first few months post op-this may be in the opposite direction of lymphatic flow. Discuss this in-depth with surgeon.***

It’s important to remember that distal lymphatics do have a large quantity of fluid so treatment of these areas can make an impact.

Appropriate for surgery if

* Early stage of lymphedema
* Identifiable healthy lymphatics on ICG
* Limited or no fibrotic tissue

VLNT= (flap) attaching a donor packet of nodes (from areas like: groin, axilla, supraclavicular nodes).

More significant risks than LVA due to risks of donor site infection or lymphedema.

There is no high-level evidence demonstrating efficacy.

Since this is a less frequently performed surgery a great amount of individual variation is out there. Each surgeon has a different “recipe”

Compression can’t be used immediately following surgery. The veins need to heal. The time frame is best determined by the surgeon. Beware of advice to wait extended amount of time like 3 years.

On-going conservative treatment is required.

**Dr. Benoît Cartier:** vascular surgeon performing “debulking” techniques on patients with advanced stages of lymphedema.

1918 Earliest description for surgical intervention for elephantiasis.

Once again, the discussion focused on the limited studies on lymphatic disease.

Studies on growth factors for angiogenic revascularization lend to more successful results with debulking surgery.

Many PowerPoint slides were presented to show the surgery as well as the results.

Patients remain in bed with feet elevated for one week following debulking surgery.

Liposuction vs. Debulking

* When legs have more fibrosis there is better result with debulking
* Liposuction is useful when fat is the greatest ration present
* The skin envelope needs to be reduced so that risks associated with having folded skin under compression are addressed.
* Maintenance for both MUST include compression/ CDT

During question-and-answer period

Transfer scars run perpendicular to the arm length so healing/thickening can create damming effect.

Blue tattooing around incision lasts a long time/sometimes forever.

ICG dye is radioactive with limited long-term risks. Accumulative effects must be considered with consultation with the MD.

When addressing primary lymphedema remember that there is altered lymphatic function. The best treatment is prevention.

Pt spoke to share that she had LVA performed then a VLNT. She was pleased with improvements with LVA but unhappy with 8 inch scar and digestive trouble following transplant from omentum.

**Dr. Anna Towers: How should we treat palliative cancer patients who have uncontrolled lymphedema?**

Discussion was performed in an open/roundtable method.

Malignant lymphedema: tumor is blocking flow to affected extremity. This can also be quite painful.

* There is a mix of lymphedema and venous edema
* Prominent veins
* Tense shiny skin
* Brachial plexopathy

Veins and nerves are compressed by the tumor. A referral to pain clinic may be appropriate.

Malignant lymphedema can be improved with chemo/rad therapy to keep tumor size under control.

Imaging is appropriate if any suspicion of arterial insufficiency exists. Bandaging contraindicated if there is arterial insufficiency.

Tumors can be bandaged over. If there are open areas bandaging is to tolerance and to support the needs of wound care.

If you see tumors/redness avoid MLD to this area- remember signs of lymphangiosarcoma

|  |  |
| --- | --- |
| **Benign** | **Malignant** |
| Slowly develops | Rapid onset (weeks) |
| Mostly painless | Increasing pain |
| Tissue consistency is soft/fibrotic/sclerotic | May have shiny skin |

As people get sicker the responsibility gets taken away from the patient and given to the family. Family in denial needs close interaction with palliative care team.

Daily cleansing, moisturizing, and use of Velcro devices.

DVT awareness:

* MLD- wait for guidance ~6 weeks- substitute exercise
* Velcro/comfortable compression
* Anticoagulated or thrombosed is okay for use of bandages (work with MD)

Increased risk of lymphedema:

* Hypoalbuminemia: below 28/25
* Venous hypertension, DVT, Inferior vena cava (IVC) compression
* Congestive heart failure (CHF)
* End stage renal
* Immobility
* Liver mets can cause edema
* Certain drugs

Effects of uncontrolled lymphedema

* Heavy limbs, trunk and genital edema
* Pain
* Impact on mobility
* Body image
* Impact on bladder and bowel management
* Cellulitis
* Lymphorreah-wet bedding/clothing, further skin breakdown(use ABD pads, multilayer bandaging and Velcro compression)
* Wounds
* Often accompanies by ascites

Contra-indications to compression

* Marked dynamic insufficiency
* Very short prognosis (< 3 weeks)
* Acute heart failure/pulmonary edema
* Arterial insufficiency in the involved limbs
* ABPI 0.5-0.8 use lower compression (20-30mmHg) ABPI less than 0.5 no compression

Assessment of edema at end of life

* What is contributing to edema?
* Assessment of prognosis- how quick is person progressing?
* MD support for lymphedema interventions
* THINK: mobility, function, comfort, appearance

Think of full leg bandaging in which one leg a day is use or alternate types of bandaging are used. Focus to prevent genital lymphedema.

Any movement helps to include PROM

May need higher dose of diuretics

Intermittent compression pumps are rarely used

SUBCUTANEOUS NEEDLE DRAINING:

BC Cancer agency defined protocol can be found on google but I can’t open it:

Symptom Management Guidelines: LYMPHEDEMA

BC Cancer

http://www.bccancer.bc.ca › 9. Lymphedema.pdf

Reference Manual (S-60 Subcutaneous Drainage for the Management of Lower. Extremity Edema). Pharmacologic. Management. •. Diuretics are not usually prescribed ...

Missing: needle ‎| Show results with: needle

Clein et al 2002 was referenced, however, I found this Clein et al 2004 article which appears to be most appropriate to this subject matter:

<https://journals.sagepub.com/doi/abs/10.1177/104990910402100314>

Incidence of cellulitis can be up to 25%

Medial thigh/foot is location for access to lymphatics

Control of lymphedema prevents need for subcu. needling

Never use a number for life expectancy. New treatments can surprise us.