



# The 2<sup>nd</sup> All Ireland Lymphoedema Conference



Wednesday 13<sup>th</sup> November  
2019

An Grianán, Termonfeckin,  
County Louth



# **The challenges of lymphoedema management in the morbidly obese patient A case report**



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# Background



Obesity has become a significant contributing factor in the development of lymphoedema and has a major impact on the success of treatment and its long-term management. The complexity of this patient group

is almost impossible to address in the absence of psychology intervention and without a bariatric service.

This case describes a patient whose health gradually deteriorated over a period of years and who is now on the road to rehabilitation with the addition of psychological input to his other therapies.

# History of present condition

- 53 year old male
- Referred to Belfast Trust lymphoedema service July 2013 with bilateral lower limb oedema secondary to obesity and cellulitis
- History of depression
- Hypertension
- Awaiting gastric band

# Social history

- Lives alone
- Unemployed
- Marriage breakdown
- Little contact with his 3 children

# Assessment and observations

- Bilateral lower limb oedema – present for 5 years
- Skin folds at ankles
- Skin intact
- Weight 205kg BMI 69.5
- Mobility limited by knee pain – walks with a stick
- Previous treatment for leg ulcer by practice nurse and intervention from TVN. Was fitted with stockings but stopped wearing these due to family issues.

# Intervention

- Modified Complex Decongestive Therapy (CDT) for 1 month
- Volume loss of 1 litre right leg and 800ml left leg
- Measured and fitted with custom-made compression stockings
- Education and advice regarding importance of skin care, exercise and weight-loss in overall management of condition.



# Progression

At 6 month review appointment Jan 2014

- Weight increased to 227.6kg (BMI 76.9)
- Significant increase in bilateral lower limb volumes
- Increased back and knee pain
- Reduced mobility
- Counselling regarding necessity of weight loss to gain control of leg swelling
- Referral to physical activity scheme
- Significant social problems impacting on ability to commit to weight loss and exercise programmes



# Further progression

Within the following year (Nov 2014)

- Further weight increase to 256.6kg (BMI 86.7)
- No longer wearing compression garments
- Had sustained several falls
- Pedometer – reported average step count of 150/day
- Advised that bandaging not effective in absence of commitment to diet and exercise
- Patient agreed to referrals to psychology/counselling and dietetics but GP advised she could not access psychology services nor bariatric surgery



# Ongoing deterioration

- Communication with patient's GP in following year – requests for further lymphoedema management
- Highlighted need for psychology/bariatric input – no availability
- Patient became housebound – home visit to reassess
- Seen by mental health hub, social worker and life coach
- Was still awaiting dietetic input.

# Domiciliary treatment

- September 2015 – December 2015
- Bandaging x 2 per week - lymphoedema therapist and assistant
- Activity coach concurrently x 2 per week for exercise programme
- Set realistic and achievable goals
- Patient able to be fitted with MTM garments again
- Carer input to don and doff.
- Christmas 2015 – patient able to walk down steps from apartment, transfer into car and go to spend Christmas Day with family.

# Backward steps

January – March 2016

- Weight increase to 277kg.
- Patient able to attend activity coach appointments as outpatient - ambulance service, bariatric stretcher with 4 crew.
- Attendance became sporadic and eventually discharged for repeated non-attendance
- GP informed of progressive weight gain and poor compliance with lymphoedema management.
- Patient referred to health psychology, social services
- Bariatric surgery request by GP via GI surgeon - unsuccessful

# Further deterioration



June 2017

- Case conference led by GP as patient's health and condition continued to decline
- Patient almost confined to bed
- Continual lymph leakage and skin breakdown both legs
- Repeated episodes of infection in skin
- Low mood

# MDT input

- District nursing – daily wound management
- Lymphoedema service – advice only
- Ergonomics advisors - seating, walking aids etc
- Care management
- Dietetics
- Occupational therapy
- N.I. Housing Executive

# Hospital admission

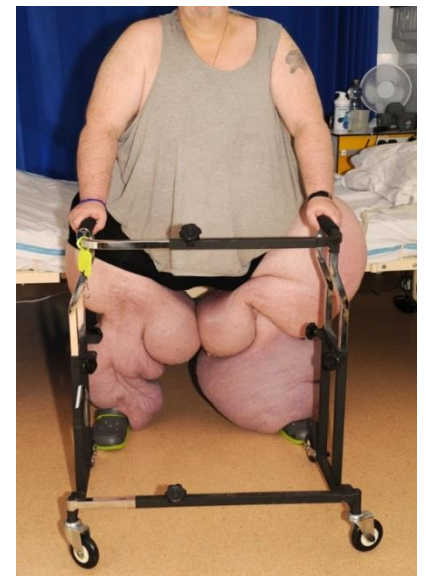
May 2018

- Cellulitis
- Patient admitted infectious diseases ward RVH, Belfast.
- Immobile – hoist for transfers
- Weight in excess of 320kg (BMI 101)
- Consultation with patient and family
- Liaison with nursing, TVN, physio, OT
- Supportive care



# Steps forward

- Remains an inpatient (18months)
- Psychology input
- Dietetic involvement – food diary
- Weight 252kg (reduction of 70kg)
- Rehabilitation
- Skin intact
- Modified compression
- Patient independent at ward level
- Plans for discharge
- Ongoing lymphoedema management





# Reflections

- Obesity is increasing in general population.
- Complex lymphoedema cases will become more common.
- Our resources are limited.
- Department of Health continue to lead on a plan to establish a regional obesity management service, including bariatric surgery.
- Importance of being a stakeholder.



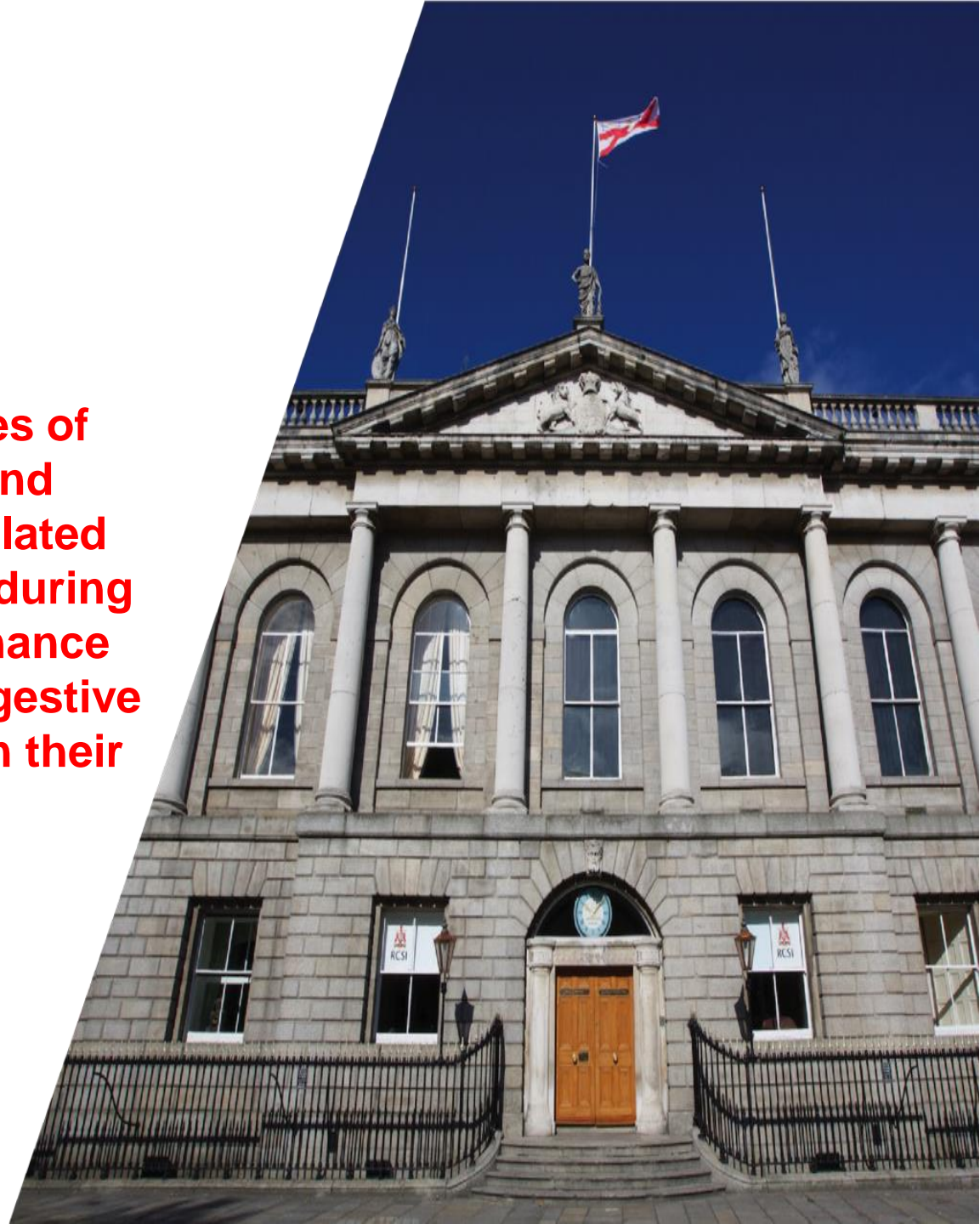


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**Exploring the experiences of  
patients with primary and  
secondary, non-cancer related  
lower limb lymphoedema, during  
the intensive and maintenance  
phases of Complex Decongestive  
Therapy and the impact on their  
lives**

Mary Costello, PhD



# Lymphoedema

- **The Lymphoedema Framework (2006) defines lymphoedema as:**  
  
**“An incurable, progressive condition which results in the swelling of a limb or limbs due to the accumulation of protein rich fluids in the interstitial spaces of the tissues ”.**
- **Lymphoedema can be either primary or secondary depending upon the aetiology.**



# Chronic Oedema

- **Chronic oedema is a term used to describe “a group of conditions characterised by the presence of swelling within tissues of the body, caused by the accumulation of excess fluid within the interstitial spaces of the affected area” (National Lymphoedema Partnership 2015)**
- **Chronic oedema is a complication of many co-morbidities, such as heart failure, reduced mobility, renal insufficiency, chronic venous insufficiency, obesity**
- **Secondary, non-cancer related lower limb lymphoedema results from unresolved chronic oedema**



# Background

- There is a lack of reliable prevalence rates of lower limb lymphoedema due to poor recognition of lymphoedema and resulting underdiagnosis
- The majority of prevalence studies focus on the population of cancer related lymphoedemas (Keast et al 2015, Poage et al 2008)
- Moffatt et al (2017) reported an increasing prevalence of chronic oedema (3.93/1000 population) in a comparable urban population when compared to the 2003 study (Moffatt et al 2003)



# Background

**Although lower limb lymphoedema is incurable and chronic, it can be managed successfully through the initiation of specific treatment modalities, known collectively as Complex Decongestive Therapy, which include;**

- Skin care**
- Compression**
- Exercise**
- Manual Lymphatic drainage**



# Research Questions

- 1. What is the impact of Complex Decongestive Therapy (CDT) as a treatment for primary and secondary lower limb lymphoedema during the intensive and maintenance phases of CDT, in relation to;**
  - ✓ Limb volume
  - ✓ Quality of life
  - ✓ Self-efficacy in managing self-care
- 2. What are the patients experiences of living with lymphoedema?**
- 3. What are the patients' experiences of the four elements of CDT?**





# Methods

A mixed methodology using both quantitative and qualitative data in a sequential manner was used among a purposive sample of 20 patients

- Inclusion criteria

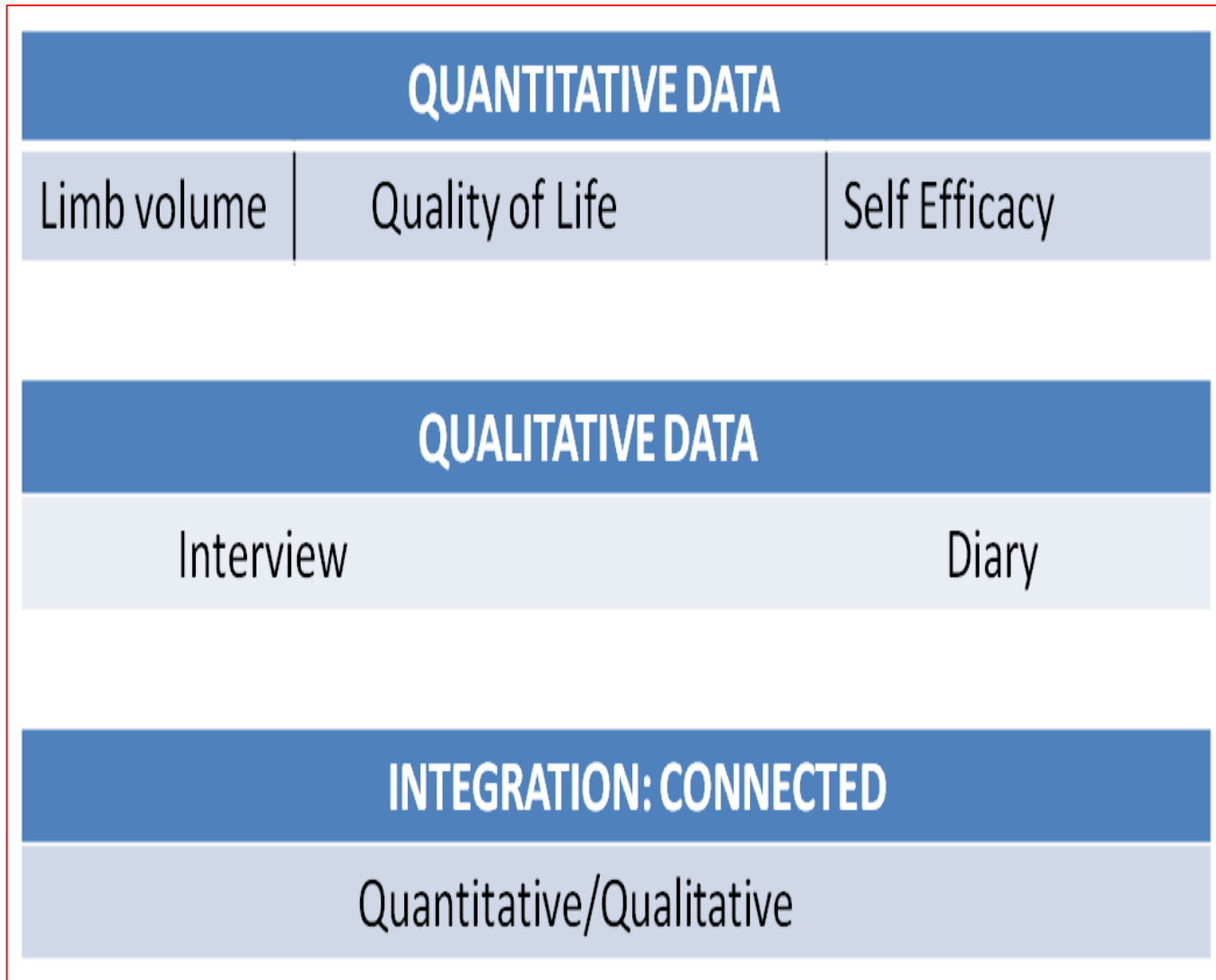
- Unilateral and bilateral primary and secondary , non-cancer related, lower limb lymphoedema,
- Stage 2-3,
- 18 years of age and over

- Exclusion criteria

- Secondary cancer – related lymphoedema



# MIXED METHODOLOGY



# Treatment Protocol

## Intensive Phase

- 60 min therapy session including:
  - manual lymphatic drainage
  - skin care
  - compression bandaging x three times weekly x 4 weeks
  - At week 4 the participant was measured for compression hosiery.

## Maintenance Phase

- 60 min. therapy session as above x twice weekly x 4 weeks.
  - Included verbal and written education on all aspects of self-care



# Data Collection

## Part 1:

A quantitative approach was used to measure;

1. Limb volume changes.
2. Quality of Life changes
3. Self-efficacy

## Part 2:

Semi structured interviews with participants.

## Part 3:

Participant diaries completed during maintenance self-care over 4-month period



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# Quantitative Data Collection Tools:

## Part 1

- **Quality of Life**
  - LYMQOL Leg – baseline, week 8 and week 24
- **Limb Volume**
  - 4cm interval circumferential measurements which were then converted to litres using the truncated cone formula at weeks 1-4, week 8,16 & 24
- **Self Efficacy**
  - PROMIS Self Efficacy for Managing Chronic Conditions – week 24



# Qualitative Data Collection Tool: Part 2

**Semi-structured, face to face interviews, using 10 open-ended questions which were divided into 3 parts;**

- **Experiences of living with lymphoedema**
- **Experiences of Complex Decongestive Therapy**
- **Challenges of Maintenance self care**



# Qualitative Data Collection Tool: Part 3

## Diary

Each participant was asked to complete a diary over a 4 month self care maintenance period and record reflections with regard to;

- Compression
- Exercise
- Skin care
- Simple lymphatic drainage
- Any other thoughts on self care



# Data Analysis

- **LYMQOL LEG & Quality of Life data were analysed using SPSS to provide descriptive statistics**
- **Limb volume and self efficacy data were analysed using Microsoft Excel to provide descriptive statistics and % change over time**
- **Interview data was analysed using inductive thematic analysis and the Braun & Clark 6 phase framework**
- **Diary data was analysed using a descriptive narrative approach**





# Demographics

CHARACTERISTICS		NO. (% POPULATION)	
GENDER	MALE	2 (10%)	
	FEMALE	18 (90%)	
AGE	18-40	2 (10%)	MEAN AGE 59 YEARS RANGE 19-80 YEARS
	40-60	8 (40%)	
	60-80	10 (50%)	
BODY MASS INDEX	18.5-25 HEALTHY	3 (15%)	MEAN BMI 36 kg/m <sup>2</sup> RANGE 22-60 kg/m <sup>2</sup>
	25-30 OVERWEIGHT	5 (25%)	
	30-50 MOD – MORBIDLY OBESE	9 (45%)	
	50-60 SUPER OBESE	3 (15%)	
AETIOLOGY	PRIMARY	10 (50%)	
	SECONDARY	10 (50%)	
STAGE	2	2 (10%)	
	3	18 (90%)	



# Findings: Quality of Life Scoring and % Change

QOL 0-10 SCORING	MEAN SCORE/RANGE /% CHANGE WK1-8	MEAN SCORE/RANGE /% CHANGE WK 8-24	MEAN SCORE/RANGE /% CHANGE WK 1-24
OVERALL	4.32/0-9/78%	8/3-10/-3%	8/5-10/48%
QOL 1-4 SCORING	MEAN % CHANGE/SD WK 1-8	MEAN % CHANGE/SD WK 8-24	MEAN % CHANGE/SD WK 1 -24
FUNCTION	-32% / 18%	-1%/ 25%	-36%/ 18%
APPEARANCE	-36%/ 17%	1% / 18%	-36% / 21%
SYMPTOMS	-37% / 18%	-1% / 22%	-37% / 18%
MOOD	-36% / 24%	7% / 38%	-33% / 18%



# Findings: Baseline Quality of Life scoring in all domains

Range of Scoring	Function No.of Participants (%)	Appearance No. of Participants (%)	Symptoms No. of Participants (%)	Mood No. of Participants (%)
1-2	6 (30%)	3 (15%)	8 (40%)	9 (45%)
2-3	7 (35%)	6 (30%)	10 (50%)	9 (45%)
3-4	7 (35%)	11 (55%)	2 (10%)	2 (10%)



# Findings: Limb Volume Measurements

Limb Volume	Week 1-8	Week 8-24	Week 1-24
MEAN % change	-14.97%	2.43%	-13.15%
Max Mean % change	-29.47%	24.71%	-29.93%
Min Mean % change	2.7%	-3.05%	2.7%
SD	8.76%	6.62%	9.72%



# Findings: Self Efficacy (week 24)

Domains	Mean	Min	Max	SD
Daily activities	16.5	4	20	4.9
Emotion	14.6	6	20	4.59
Social	18.9	12	20	2.33
Symptoms	16.5	9	20	3.43

The level of confidence with which a person feels that they can complete a task, score 1-5

- 1) I am not at all confident
- 2) I am a little confident
- 3) I am somewhat confident
- 4) I am quite confident
- 5) I am very confident

Scoring from 4-20



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# Findings: Semi Structured Interviews

Thematic analysis of 18 face to face semi-structured interviews identified three themes;

- 1. Health professionals lack of knowledge in the field of lymphoedema**
- 2. Physical, psychosocial and financial impact of lymphoedema**
- 3. Therapeutic benefits of Complex Decongestive Therapy**



Compression Hosiery	Exercise	Skin Care	SLD
<p>12-14 hrs daily (n=15)</p> <p>Challenges include application and removal, Heat/Summer</p>	<p>10min – 1 hour daily</p> <p>Walking</p> <p>Aqua aerobics</p>	<p>Full compliance with daily emollient.</p>	<p>10 min daily (n=6)</p> <p>Low importance (n=12)</p>



**Lower limb lymphoedema is a lifelong condition that responds positively to treatment. However, it does require the ongoing resolution and hard work of patient self care in order to maintain oedema reduction.**

**The maintenance of oedema reduction and quality of life for the patient with lymphoedema requires physical ability, knowledge and strong family and healthcare supports.**

**Living with lymphoedema in Ireland and internationally remains a struggle that requires input from health services in the areas of education, treatment, referral pathways and recognition of lymphoedema as a chronic condition that requires economic support.**



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