ILF-COM reporting from Parkwood Institute Research, Lawson Research Institute, London ON Canada

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Background:

Measurement of outcome in chronic oedema/lymphoedema management is subject to great international variation. This impacts on the following areas:

- Lack of reimbursement of Complex Decongestive Therapy (CDT) and compression therapy
- Lack of evidence to support the development of effective services
- Lack of data to benchmark outcomes of care within and between services
- Lack of standards for use in research
- Lack of standardized outcomes to compare with other diseases and compete for care health resources

The Aim of the Survey:

The survey had two inter-related aims:

- To provide greater understanding of the national and international challenges of chronic oedema/lymphoedema outcomes in different countries
- To provide greater clarity on the requirements for effective chronic oedema/lymphoedema outcome measures that can be developed and validated for international adoption

Methods:

Each national framework was invited to participate in the survey.

- Participants included patients, clinicians, academics, health agencies and medical device industry.
- The survey was disseminated through the use of Survey Monkey and the results were collated for each country as well as an international profile supported by the ILF secretariat.

Sampling framework for Canada:

The Canadian Lymphedema Framework requested the assistance of the Provincial Associations through sending a Letter of Information containing the link to survey to all their membership and by posting a link to the survey on their association's website. In addtion the survey link was disseminated to the database maintained by the Canadian Lympheddema Framework

Important Information Provided for Participamts:

1. The survey was entirely confidential. No personal information is collected other than country and whether the respondent is a patient or health care professional. For this reason Ethics approval was not required.
2. The surveys had 14 questions for patients and 17 for professionals. It was estimated to take 15 minutes.
3. The survey was open from January 15, 2019 to February 28, 2019.
4. The CLF team received the Canadian data and conducted an analysis.
5. The survey was also made available in French.

Results

Overall internationally there were 8014 responses to the survey. Fifteen were from specific countries and the remiander were listed as other. From specfic countries, 713 (8.9%) responses were from Canada. Of these 64.7% were completed by patients and 35.3% were from health professionals.

Acknowlegemnt:
The remarkable response results from the dedication and cooperation of the ProvincilaL Lymphedema Associations

The following questions were answered by health professionals only. The distribution of the occupations of the health professionals is shown in Figure 1. Health professionals are evenly distributed between private and public sectors with a few working in both areas. The main types of facilities are show in Table 1. Over 90% indicated that they treated persons with chronic oedema/lymphoedema. When asked whether they produced or solid medical devices for the treatment of chronic oedema/lymphoedema nearly half (48.74%) responded that this question was not applicable. Approximately one fifth (20.59%) responded yes.

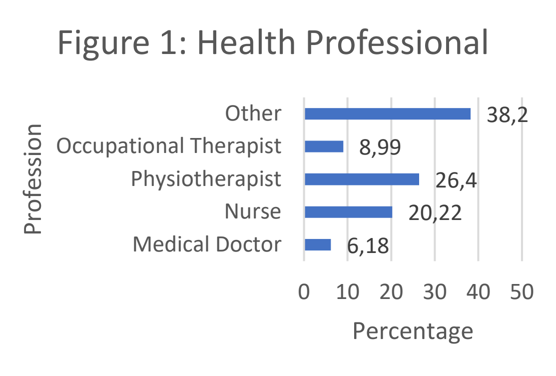
Figure 1: Health Professional

Table 1: Type of Facility (N = 153)

Facility	Number	Percentage
Community	35	17.86
Hospital	54	27.55
Lymphoedema Specialist Centre	23	11.73
Wound Specialist Centre	2	1.02
Academic Institution	9	4.59
Other	30	15.31

Commonly used outcome measures used by industry and health professionals are shown in decreasing order in Table 2. Anything used less than 20% of the time is not shown.

Table 2: Outcome Measures Most Commonly Used in Everyday Practice

Measure	Percentage
Circumference measurements	70.23
Mobility	66.51
Pain	64.19
Quality of Life	60.00
Patient Adherence	57.21
Photography	43.72
Episodes of Cellulitis	43.26
Weight/BM!	34.88
Circumference only without volume	33.95
Wound size	30.70
Complications of treatment	26.51
Wound type	24.19
Hospital admissions linked to chronic oedema	22.79

All remaining questions were answered by both patients and health professionals. 57.21% responded that outcomes were measured some or all of the time. Only 25.45% stated that they were not measured. The majority of respondents (62.58%) did not know if guidelines existed, while one third (33.48%) were aware of international, national or regional guidelines existed. For 69.12% some aspects of treatment were funded and only 17.08% reported that no aspects were funded.

In general participants reported that they paid for approximately half of their treatments for chronic oedema/lymphoedema. The only treatment consistently paid by 85.55% of respondents was massage therapy (manual lymphatic drainage) Respondents agreed that the top three outcomes which should be measured were Limb Volume (59.34%), Quality of Life (56.03%) and Mobility (33.22%). Patient Satisfaction (29.09%) and Cellulitis (26.28%) were close behind. Responded opinions on outcome measures indicating success are shown in Figure 2

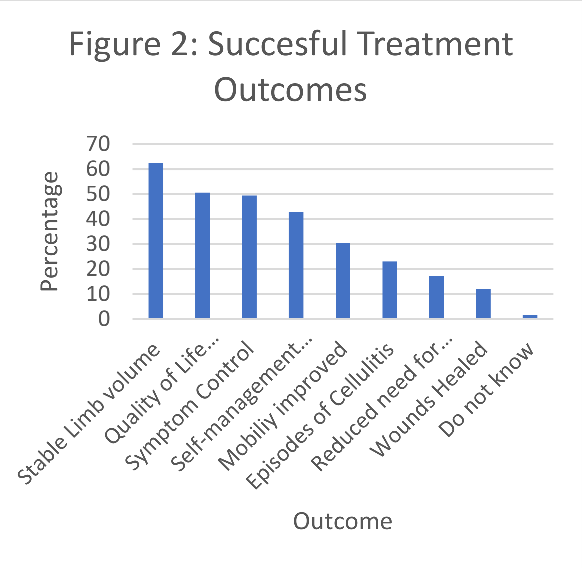
Figure 2: Succesful Treatment Outcomes

The two most commonly cited factors related to ineffective treatment were Limb Volume Increase (64.30%) and Uncontrolled Symptoms (58.18%). Factors for improvement are listed in Table 3.

Table 3: Factors for Improvement

Factor	Percentage Replied
Increased professional knowledge	78.93
Access to specialized chronic oedema/lymphedema services	75.75
Reimbursement of treatment	71.57
Increased patient knowledge	63.88
Access to compression therapy	60.37
Clinical and cost-effectiveness research	57.53
National guidelines and standards	57.19
Validated Outcome measures	46.49
Do not know	2.84

Discussion

It is important to recall that in Canada health care is a provincial responsibility. Thus, there are 14 different health systems when the territories and the federal government are included. Treatment standards are relatively consistent, but funding will vary from province to province. In some provinces much is covered and in others little is. What is consistently not covered is massage therapy.

Conclusions

The reply to the questionnaire was high and results focused consistently on key areas including limb volumes, quality of life, mobility and episodes of cellulitis as outcomes. Improvements in outcomes require increases in both patient and health professional knowledge and improved reimbursement.