



Health and quality of life in patients with leg lymphedema during maintenance phase

A naturalistic prospective cohort study

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Summary: *Background:* Complex decongestive therapy (CDT) is the standard conservative treatment for lymphedema. This study aims to provide insights into the maintenance phase of CDT, its impact on health and quality of life over six months, and identify factors influencing these outcomes in individuals with leg lymphedema. *Patients and methods:* This prospective cohort study assessed health and quality of life by Short-Form-36, Freiburg Quality of Life Assessment for lymphatic disorders (FLQA-lk), Knee Outcome Survey Activities of Daily Living Scale, Symptom Checklist-90 Revised, and Coping Strategies Questionnaire. Health status was expressed by means ($\pm SD$) and standardised response means (SRMs). Multivariate linear regression explored the score change of FLQA-lk. *Results:* Participants were on average aged 53.9 years, female (75.9%), and had two comorbidities ($n = 87$). On 22/26 dimensions, average improvements ranged from 8.7 to 0.7 (scores) respectively from -0.05 to 0.51 (SRMs). Most participants (89.7%) continued with manual lymphatic drainage and wore stockings regularly (95%) at baseline. Formal education, exercise and compression showed the highest, in trend statistically significant partial correlations. *Conclusions:* Health and quality of life in individuals with leg lymphedema can be stabilised and slightly improved during the maintenance phase of the CDT with regular use of compression stockings and manual lymphatic drainage.

Keywords: lymphedema, complex decongestive therapy, maintenance phase, health, quality of life, outpatient

Introduction

Lymphedema, a chronic and progressive condition if untreated, is characterised by swelling of the affected body part, functional limitations, discomfort, and reduced quality of life. A damage of the lymphatic drainage system (capillaries, collectors, nodes, or trunks) leads to a reduction of the transport capacity of the lymphatic system and to an accumulation of interstitial fluid in the interstitial spaces, and by that, to a lymphedema [1]. The cause of a primary lymphedema are genetic disorders or birth defects whereas in secondary lymphedema a damaged lymphatic system due to various diseases, injuries, and therapies are causative [1]. Although an estimated 120 million persons are affected worldwide by lymphedema, lymphedema and the impact on the affected individuals health and quality of life seems to be under-estimated, under-recognised and under-treated [2, 3].

In absence of causal treatments, the symptomatic approach of the complex decongestive treatment therapy (CDT) in two phases is widely accepted and considered the basic therapy of the conservative treatment [1, 3]. The first, intensive phase of the CDT includes manual lymphatic drainage (MLD) combined with multilayer compression bandaging, skin care, education and training for self-therapy/self-management, and exercise to promote

decongestion. This phase is under the supervision of one (outpatient treatment) or several (inpatient treatment) health care professionals and usually lasts between 2 and 4 weeks [4]. The aim of the intensive phase is to reduce the volume of the affected limb and to reduce or slow the progression of the disease. Several scientific publications have described the positive effects of the intensive phase on limb volume, functional limitations, discomfort, health, or quality of life in lymphedema [5, 6, 7, 8].

The second, maintenance phase of the CDT comprises wearing compression stockings, self-drainage if possible, skin care and exercise. Regular MLD is recommended in an individual frequency prescribed if necessary during this phase [9]. The aim of the maintenance phase is to maintain the improvements achieved during the intensive phase. This phase is highly dependent on the patient's self-management. Health care professionals are not or only minimally involved in this phase, no complications or exacerbations provided. No literature is available on the maintenance phase focusing on health and quality of life.

This paper aims 1) to provide insight to the maintenance phase of individuals with primary and secondary lymphedema of the lower extremities and its biopsychosocial impact on health and quality of life during 6 months and 2) to identify factors that influence the change of quality of life during the maintenance phase. The findings of this

study will inform healthcare providers and affected persons about the importance and the factors influencing the maintenance phase in order to improve quality of life of those affected.

Materials and methods

Patients

Between August 2015 and March 2024, patients consecutively referred to the rehabilitation clinic “Rehaklinik” in Bad Zurzach, Switzerland, by their family physician/general practitioner, internist or angiologist for an outpatient consultation at the department of angiology were screened for inclusion. Inclusion criteria were 1) age ≥ 18 years, 2) diagnosis of primary or secondary lymphedema of the leg stage II according to Földi / International Society of Lymphology (ISL; edema, pitting, limb elevation alone rarely reduces the tissue swelling) or stage III (hard edema, trophic skin and tissue alterations, with lobuli) [1, 3, 10].

Exclusion criteria were 1) patients older than 90 years with 2) an edema combined with a predominantly non-lymphatic component, especially edema caused by venous insufficiency ($>$ stage C2 according to the Clinical-Etiology-Anatomy-Pathophysiology (CEAP) classification), cardiac or renal failure, or liver insufficiency [6, 11, 12], and 3) mixed edema of unknown origin, and/or classification as predominant lymphedema was impossible, 4) lipedema, 5) indication for an intensive phase of a CDT, and 6) a body mass index (BMI) $>$ 50.0 reflecting morbid obesity. Further, 7) Persons with insufficient German language skills (reading and writing), 8) predominant severe somatic or mental illnesses, or insufficient psycho-intellectual abilities that prevented the completion of the questionnaire, and 9) the refusal to participate in the study were excluded from this study. The participants flow chart is presented in Figure 1.

All diagnoses, inclusions and exclusions were confirmed by the head of the angiology department (S.W.) through a physical examination, regardless of the initial admission diagnosis made by the family physician/general practitioner,

internist or angiologist. Written informed consent was obtained from all participants. The study protocol was approved by the Local Ethics Commission (Health Department of Aarau, Switzerland, EK AG 2008/026).

Intervention: medical outpatient consultation

The medical outpatient consultation was performed at the department of angiology by the head of the department (S.W.) or an experienced medical team member. The three pillars of basic diagnostics as recommended by the S2k Guideline “diagnostics and therapy of lymphedema” by the Association of the Scientific Medical societies in Germany (Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e.V., AWMF) were part of each medical consultation: history taking, inspection and palpation [13].

The medical consultation included a detailed (interim) medical history, clinical inspection and examination of the patient and the local lymphological findings. In addition, volumetry was performed using digital measurement with the perometer and manual measurement using the Kuhnke method. Both methods allow an assessment of the volume progression as an objective criterion of the clinical situation. Other findings such as tissue elasticity and degree of fibrosis cannot be standardised. Photographic documentation was also carried out, but this is also not scientifically standardised (exact same distance, camera settings, etc.). Results were compared with previous consultations, if data were available.

A specific focus of the medical outpatient consultation was on the self-management strategy and a stable situation to prevent from further progression of the lymphedema. If during the consultation, a clinically significant progression of the lymphedema, limited self-management capacity or complications were detected, an inpatient treatment was recommended, consisting of intensive CDT and comprehensive multidisciplinary rehabilitation. Details and effects regarding this inpatient treatment program have been published elsewhere [5].

Measures

Questionnaires were given to the patients participating in this study on the day of the medical consultation and returned to the study secretariat when completed. Six months after receiving the baseline questionnaire from the study secretariat, the follow-up questionnaire was sent to the participants by surface mail with a request for return. All participants gave written informed consent.

Sociodemographic and potentially confounding parameters, such as age, gender, BMI, occupation (working capacity), living conditions, sports habits, and formal education were recorded at admission to the clinic on a standardised form [6]. Details on lymphatic treatment and the regularity of wearing stockings were collected through

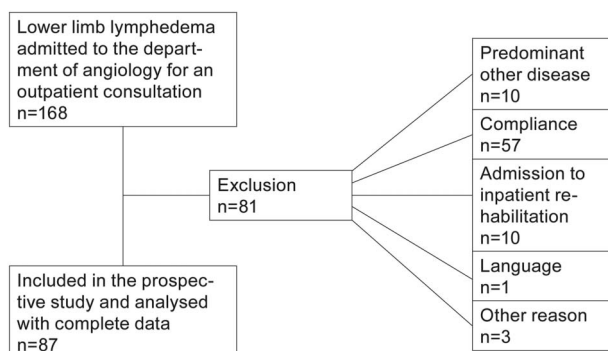


Figure 1. Flow chart of study participants. *n*: number of subjects.

specific questions. Comorbidities were retrieved from the patient's medical history.

To comprehensively assess health and quality of life including physical, emotional and social functioning, a set of five self-report measures was used: the Short Form 36 (SF-36) [14, 15, 16]; the Freiburg Quality of Life Assessment for lymphatic disorders, Short Version (FLQA-lk) [17, 18]; the Knee Outcome Survey Activities of Daily Living Scale (KOS-ADL) [19, 20, 21], and two scales from the Symptom Checklist-90-Standard (SCL-90-S) [22, 23]. This same set of instruments showed a high degree of comprehensiveness and specificity in the description of physical and mental health in a previous study with patients with lower limb lymphedema [5]. Readers are referred to those reports for more detailed information and the original literature on the questionnaires used [6, 11, 18].

The Coping Strategies Questionnaire (CSQ), a reliable tool for assessing pain coping strategies, was added to the previously utilised and tested set as the fifth scale [24]. Out of the eight scales, the three following scales were assessed: Catastrophizing (6 items), Control Pain and Decrease pain (1 item each).

Analysis

The questionnaire was handed to the patients on the day of the outpatient consultation at the department of angiology (baseline measurement) and sent to the home address by mail 6 months after reception of the baseline measurement at the study secretariat. All scores were converted into scales ranging from 0 to 100 indicating 0 = worst health, maximal symptoms, disability to 100 = best health, no symptoms, full function as originally described for the SF-36.

The instrument-specific "missing rules" had to be fulfilled in order to determine the scales and to be included in this analysis. At least 50% of the items had to be completed for each of the SF-36 scales, and 3/4 (76%) for the SCL-90-S [16, 22]. Since for the other instruments no "missing rules" had been reported in the initial publications, we applied a 2/3 missing rule (completion of 67% of the items required to determine the score) as previously reported [25]. All analyses were performed using the statistical software package IBM SPSS 30.0 for Windows® (SPSS Inc., Chicago, IL, USA).

Means with SDs were calculated for the socio-demographic and disease-related data. For all PROMs, standardised response means (SRMs) were reported in addition to means with SDs at baseline, follow-up, and the chance scores. The SRM is a standardised measure of score change that allows comparison of scores and measurements with different scaling and is dimensionless. It is calculated by dividing the mean score difference by the SD of the single score differences [26, 27].

Multivariate linear regression analysis was used to calculate the associations of different factors on the change in total FLQA-lk score (dependent variable) and modelled by FLQA-lk baseline score, sex, age, living situation, education,

number of comorbidities, and changes in sports activity score, in frequency of wearing stockings and in lymphatic drainage between baseline and follow-up. These are potential confounders for the FLQA-lk Total score.

Results

Patients

Socio-demographic variables and disease-related characteristics are presented in Table I. Data were available for $n = 87$ patients. The sample size was limited by the closure of the department of angiology for economic reasons. The

Table I. Socio-demographic and disease-relevant data at baseline ($n = 87$)

Characteristic	n	
Age	Mean \pm SD (years)	87 53.9 (14.7)
	Minimum–maximum	18.1–87.6
BMI	Mean \pm SD (kg/m ²)	87 27.0 (8.2)
	Minimum–maximum	15.6–61.7
Sex (%)	Female	66 75.9
Lymphedema diagnosis (%)	Stage II*	72 82.8
	Stage III*	15 17.2
Comorbidities (%)	None	9 10.3
	1	18 20.7
	2	23 26.4
	3	12 13.8
	4	14 16.1
Education (%)	≥ 5	11 12.6
	Basic school (8–9 years)	4 4.7
	Vocational training	31 36.0
	College/high school/university	51 59.3
Working capacity ^a (%)	Not working	20 23.0
	Part time	46 54.2
	Full time (42 h/week)	19 21.8
Working hours household ^b (%)	0–10	45 51.7
	11–20	23 26.4
	21–30	9 10.3
	≥ 31	7 8.0
Living situation (%)	Alone	26 31.3
	With partner	53 60.9
	Other	8 9.2
Sports (%)	None	4 4.6
	<1 hour/week	16 18.4
	1–2 hours/week	30 34.5
	>2 hours/week	37 42.5

Notes. SD = standard deviation; Missings: ^a $n = 2$, ^b $n = 3$; *lymphedema stages according to Földi/International Society of Lymphology.

on 18 of the 23 health scales, indicating better health [5]. For example, the outpatients' FLQA-Ik Health & quality of life score averaged by 64.8 ($SD = 18.6$) and the inpatients' 57.2 ($SD 19.1$, $n = 67$), which is significantly better ($t = 2.485$, $p = .010$). This suggests that the triage of patients for inpatient and outpatient management by the head of the department (S.W.) was appropriate, which is supported by the stable health status observed during the maintenance phase.

Strengths and Limitations

The main strength of the present study is the comprehensive information and analysis of the maintenance phase of the CDT in a prospective study. There is no other study in the literature on the maintenance phase focusing on the biopsychosocial health and quality of life in persons with lower limb lymphedema during the maintenance phase. The second strength is the extensive range of health scales included, with generic- as well as condition-specific PROMs addressing complementary aspects of health within the biopsychosocial health model in a prospective study. Additionally, the large number of participants with leg lymphedema that were assessed in a single specialised centre for lymphedema by clinical specialists is another strength. Many studies focus on breast-cancer related lymphedema and research on other forms of lymphedema is scarce.

Limitations include the naturalistic design, having enrolled individuals from a medical consultation at a specific and specialised rehabilitation clinic, but from a single centre. Further, detailed information on modalities of wearing compression stockings (during the day and/or overnight) and volume measurement at baseline and follow-up during the maintenance phase were not assessed.

Conclusions

This study showed that health and quality of life can be stabilised or even slightly improved in individuals with lower limb lymphedema during the maintenance phase of CDT. The primary objective of the maintenance phase – to maintain a stable situation – was achieved in terms of health and quality of life. Despite the lack of volume measurement as a quality indicator for the maintenance phase, it can be concluded that compliant individuals wearing compression stockings and receiving manual lymphatic drainage on a regular basis can sustain or even enhance their health and quality of life during the maintenance phase of CDT. Future studies should include longer follow-up periods to confirm the long-term stability of quality of life and health outcomes in this population.

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History

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Conflict of interest

The authors declare that there are no conflicts of interest.

Publication ethics

The study was approved by the ethics committee of Aarau, Canton Aargau, Switzerland (EK AG 2008/026) and written informed consent was obtained from all study participants. The study was conducted in accordance with the Declaration of Helsinki.

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The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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