

Quality of Care of Patients with Chronic Lymphoedema in Germany

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Key Words

Quality of care · Lymphoedema · Quality indicators · Health-related quality of life · Questionnaire

Abstract

Background: The management of lymphoedema is complex and should be based on guidelines. To date, no data assessing quality of care in lymphoedema in Germany are available. **Objective:** We aimed at evaluating the quality of care of lymphoedema in the metropolitan area of Hamburg using guideline-based indicators. **Methods:** Cross-sectional, community-based study including patients with lymphoedema. Assessment included a structured interview, clinical examination and patient-reported outcomes. Quality indicators derived from guidelines by a Delphi consensus were applied. **Results:** 348 patients (median age 60.5 years) with lymphoedema (66.4%), lipoedema (9.5%) or combined oedema (24.1%) were included. 86.4% performed compression therapy, 85.6% received lymphatic drainage. On average 55.0% of the quality of care criteria were met; 64.8% were satisfied with care. The distribution curve of the health care index was almost normal. Treatment by specialists led to a higher quality of care index. **Conclusion:** Although overall quality of care in lymphoedema is fair, many patients are not treated properly according to guidelines.

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Introduction

Chronic lymphoedema is associated with major impairments in patients' quality of life [1, 2] and an increased rate of complications [3–5]. Management of lymphoedema is complex and time-consuming and requires consequent and steady treatment [6, 7]. Clinical appearance is typically characterized by swelling and oedema of one or more limbs, sometimes involving the head, trunk or genitals. Chronic lymphoedema is caused by a defect in lymphatic tissue transport capacity leading to decreased drainage of lymphatic fluid. It results in the accumulation of lymph in interstitial spaces and in subcutaneous fatty tissues [8]. Primary lymphoedema caused by congenital dysplasia of lymphatic tissue must be differentiated from acquired secondary lymphoedema [9]. Reasons for development of secondary lymphoedema are manifold, most commonly evolving as a complication of cancer treatment but as well occurring due to chronic venous stasis, trauma, surgery, obesity, filariasis and other rare diseases such as intralymphatic histiocytosis [10–14]. Four stages of lymphoedema have been described [9, 15]. Stage 0 is characterized as latency stadium, presenting with impaired lymphatic fluence but no manifest oedema; this stage is of major importance in secondary prevention of lymphoedema. Stage I presents with a re-

versible oedema in contrast to stage II. In stage II, oedema becomes fibrotic, non-pitting and irreversible. Further disease progress results in elephantiasis with papillomatous outgrowths and hyperkeratosis (stage III).

The therapeutic regimen basically consists of compression, physical exercise, skin care and physical therapy. Physical therapy, known as complex decongestive therapy and also called combined physical therapy or complex decongestive physiotherapy, is a two-phase therapeutic strategy [15, 16]. In the first phase, manual lymphatic drainage and motion exercise is combined with multi-layered compression bandaging. The second phase aims at a conservation of the reached congestion by using a low-stretch elastic stocking or sleeve; continuing skin care, exercise and manual lymphatic drainage are needed.

Though lymphoedema is a common disease [17, 18] and therefore of major relevance in health care, only little is known about the quality of care in lymphoedema. The aim of this study was a structured evaluation of quality of care in lymphoedema in the metropolitan area of Hamburg, taking into account all sectors of care.

Methods

Study Design

This is a cross-sectional, community-based study in patients with lymphoedema or lipoedema in the metropolitan area of Hamburg, Germany.

Patients and Centres

Centres were recruited both by postal consignment and personal designation. Health care providers of all sectors of lymphoedema care were addressed including general practitioners, lymphologists, phlebologists, dermatologists, gynaecologists, medical supply stores, lymphoerapists, clinics, breast centres, homecare services, nursing homes as well as members of the 'Wundzentrum Hamburg e.V.' (wound centre Hamburg) and the 'Lymphnetz Hamburg e.V.' (lymph net Hamburg). Furthermore, patients and health care providers were addressed through flyers, posters, press releases and advertisements in regional newspapers as well as through information on distinct homepages. If patients were willing to participate, an individual appointment for interview and examination was arranged. Adult patients with primary or secondary lymphoedema or combined lipolymphoedema or lipoedema of any origin affecting the upper or lower limb were eligible for inclusion. Oedema had to already persist for at least 3 months.

Outcomes

Data acquisition was conducted by four medical students in advanced medical education, after training by specialized physicians (dermatologists, lymphologists) and lymphoerapists. Each data set consisted of a structured interview, physical examination including digital photo documentation, a health economic evaluation

on lymphoedema-related costs and assessment of patient-reported outcomes with a questionnaire. The interview included treatment history and clinical characteristics. A physical examination was performed consisting of standardized assessment and documentation of the affected parts of the body including Stemmer sign and circumference measurements. Clinical severity was analysed using the guideline-based stages from 0 to III [9]. The patient questionnaires included items on medical history of the disease, patient satisfaction with care and with treatment and patient-relevant benefit. The following outcomes parameters were measured: (a) socio-demographic data; (b) medical history; (c) lymphoedema therapy; (d) clinical status (case report form with photo documentation); (e) quality of life (disease-specific: FLQA-I (lymphoedema short version) [2], generic: EQ-5D including visual analogue scale); (f) health care pathways and quality of care (use of resources, attending physicians, access to specialists; self-treatment and effort; pathways of care; indicators of quality of care); (g) satisfaction with care (from the patient's perspective); (h) patient benefit (questionnaire assessing patient-defined benefit from lymphoedema treatment, Patient Benefit Index (PBI) [19]); (i) cost of illness (questionnaire on illness-related costs of lymphoedema [20]).

Quality of Care Indicators

The development of quality indicators based on recommendations of national and international treatment guidelines was conducted as follows: Indicators of quality of care were identified by a systematic literature research focused on national and international expert standards of diagnosis and therapy of lymphoedema. In a two-step Delphi consensus process consisting of 24 respectively 28 national experts, 12 quality indicators were developed. A single index of global quality of care was generated ranging from 0 (no quality achieved, none of the indicators fulfilled) to 1 (full quality achieved, all 12 indicators fulfilled) (for more details see Herberger et al. [19]). The indicators were assessed in this study by the investigators.

Ethics and Regulation

The study was conducted in compliance with the legal requirements for data protection and a vote from the local ethics committee was obtained.

Statistical Analysis

Data were analysed using the SPSS statistical package for Windows, version 18. They were analysed descriptively computing number and percentage in nominal scaled data, and minimum, maximum, median, mean, and standard deviation in interval scaled data. T tests for independent samples and χ^2 tests were applied to assess the subgroup differences.

Results

Centres and Patients

The 33 participating centres which actually recruited patients consisted of 15 physiotherapists, 7 general practitioners, 4 hospitals, 3 medical supply stores, 3 lymphologists and 1 dermatologist. 351 patient interviews were performed between June 2009 and June 2010. 49 of those patients (14.1%) had been recruited by advertisements in

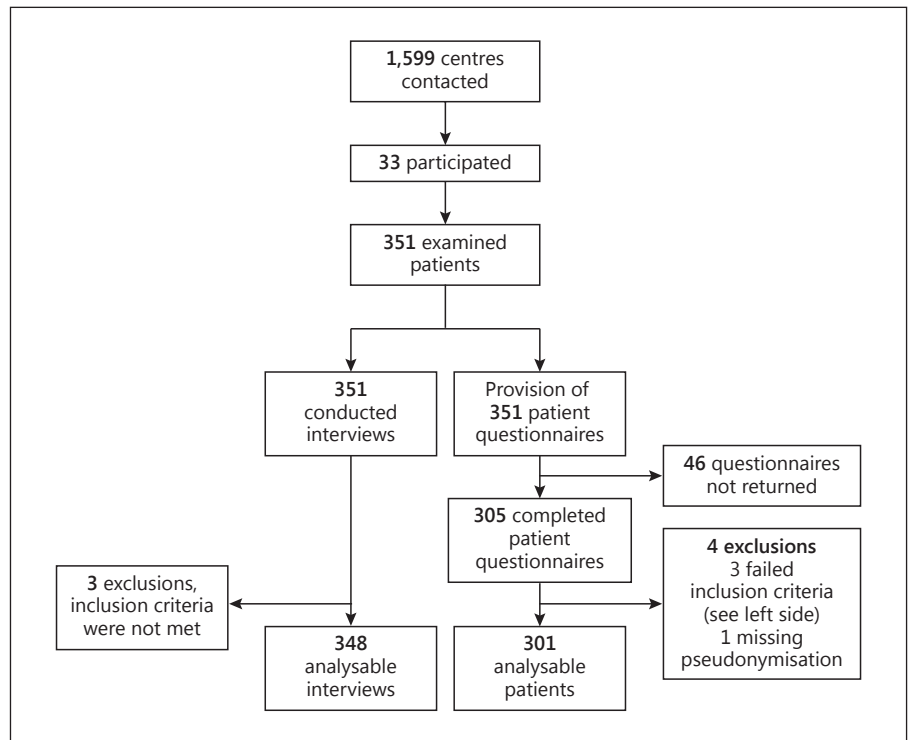


Fig. 1. Inclusion graph of the study patients (n = 348).

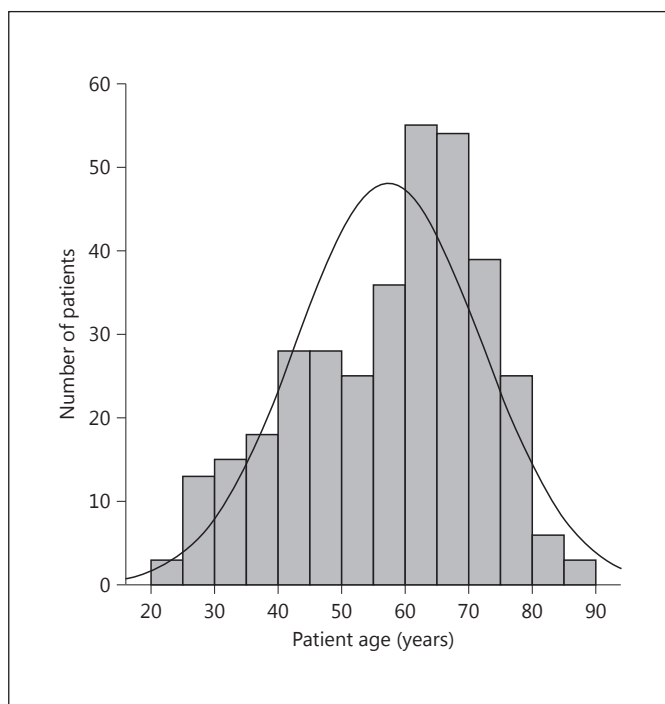


Fig. 2. Age distribution (n = 348).

newspapers. Three patients had to be excluded because of failed inclusion criteria. 305 patient questionnaires were returned; 3 of these belonged to the excluded patients, and 1 had to be dismissed because the pseudonymisation number had been removed by the patient. Thus, 301 patient questionnaires and 348 interviews could be analysed (fig. 1). Inclusion rates showed a nearly equal geographical allocation.

Sociodemographic Data

The majority of patients were female (90.8%) with a median age of 60.5 years (SD = 14.5, range 24–89; fig. 2). Only 2 patients were living in a nursing home. 60.8% of the patients were not employed, most of them (74.9%) due to retirement or early retirement, or due to incapacitation caused by the lymphoedema (5.5%). 79.7% were insured by statutory health insurances, 6.3% by private insurances and 12.3% by statutory health insurances with additional private insurance (table 1).

Clinical Data

Two thirds (66.6%) of the patients were suffering from lymphoedema, a quarter (24.1%) from combined lipo-lymphoedema and 9.5% from lipoedema alone (table 2). Lymphoedema was most frequently secondary (42.8%).

Table 1. Sociodemographic data of patients with chronic lymphoedema (n = 348)

Gender (n = 348)	
Women	90.8%
Men	9.2%
Marital status (n = 301)	
Unmarried	21.9%
Married	51.5%
Divorced	13.3%
Widowed	11.0%
Other/missing	2.4%
Education (n = 301)	
Grammar school	30.2%
Secondary school	33.2%
Advanced technical certificate	9.3%
General qualification for university entrance	23.6%
None/other/missing	4.0%
In paid work (n = 301)	
No	60.8%
Yes	38.5%
Missing	0.7%
Reason for unemployment (n = 191)	
Pensioner	74.9%
Incapacitated	5.5%
Unemployed	5.5%
Housewife/-man, student	6.6%
Other/missing	7.7%
Health insurance (n = 301)	
Statutory	79.7%
Statutory and private	12.3%
Private	6.3%
Missing	1.7%

The lower extremity was affected in 64.4%, the upper extremity in 18.1%, and in 17.5%, both arms and legs were affected. In more than half of the cases (56.3%) lymphoedema was located at two limbs, mostly both legs. 68 patients (19.5%) had had breast surgery prior to the oedema development.

Distribution of clinical stages was 11.8% of patients in stage 0, 35.6% in stage I, 44.8% in stage II and 6.9% in stage III (fig. 3). Mean body mass index was 31 (fig. 4). Mean disease duration was 14.7 years (median = 10.0, SD = 14.4). While half (45.1%) of the patients had had no pain within the last 7 days, a third (30.4%) was suffering from moderate to severe pain (arterial visual analogue scale of 5–10). The most common concomitant diseases were obesity (48.0%), hypertension (43.7%), venous insufficiency (30.5%), diabetes (13.8%) and chronic pain syndrome (13.2%). Frequent previous diseases were erysipelas (16.7%), breast cancer (15.5%), other malignant diseases (14.4%) and deep vein thrombosis (13.8%).

Table 2. Distribution of lymphoedema, lipoedema and lipolymphoedema and affected sites (n = 348)

Oedema type/affected site	n	%
Primary lymphoedema		
Leg	77	93.9
Arm	1	1.2
Both limbs (leg + arm)	4	4.9
Total	82	100.0
Secondary lymphoedema		
Leg	76	51.0
Arm	63	42.3
Both limbs (leg + arm)	7	4.7
Combination primary and secondary lymphoedema	3	2.0
Total	149	100.0
Lipoedema		
Leg	20	60.6
Both limbs (leg + arm)	13	39.4
Total	33	100.0
Lipolymphoedema		
Leg	52	61.2
Both limbs (leg + arm)	32	37.6
Total	85	100.0

Lymphoedema Care Provision

In median, patients had had 4.5 physician consultations because of the lymphoedema within the last 12 months (SD = 3.3, range 0–38). 52.5% of the patients had already consulted more than one physician for the oedema. 2.0% of all patients were supported by a nursing service. The majority of patients had been treated for oedema by a dermatologist (40.5%) at least once in the last 12 months, followed by general practitioners (21.3%), specialists for internal medicine (14.1%) or gynaecologists (12.4%). 71.2% (n = 247) of all patients were supplied by specialized health care providers affiliated with the 'Lymphnetz Hamburg e.V.' (LNHH). The LNHH is a regional association of specialized physicians, lymphotherapists and medical supply stores.

Diagnostic Work-Up

In the majority of patients Stemmer sign (54.6%) and circumference measurement (87.4%) had been performed in the past. Furthermore 56.9% had had a diagnostic work-up of veins and arteries. Only a small proportion had received a lymphography (4.6%), a lymphatic dye test (3.7%) or a functional lymphatic scintigraphy (2.6%).

36.2% of the patients reported that a control of correct fit of the compression stockings had been performed, in 20.6% of the cases stockings needed adjustment at least

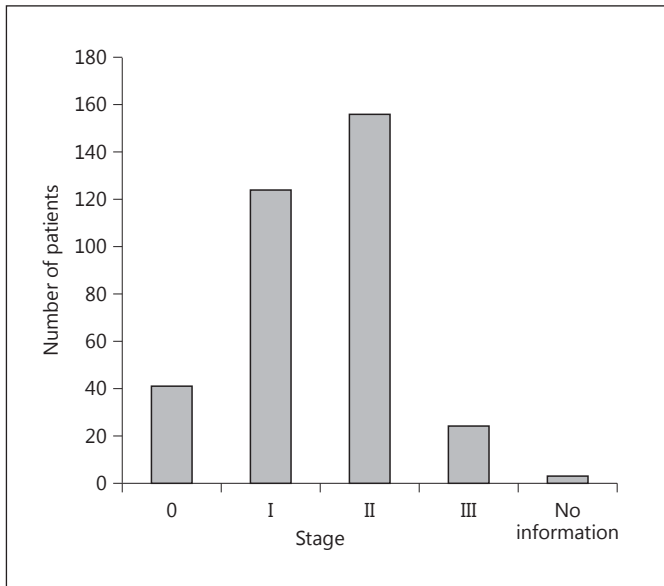


Fig. 3. Distribution of lymphoedema stages.

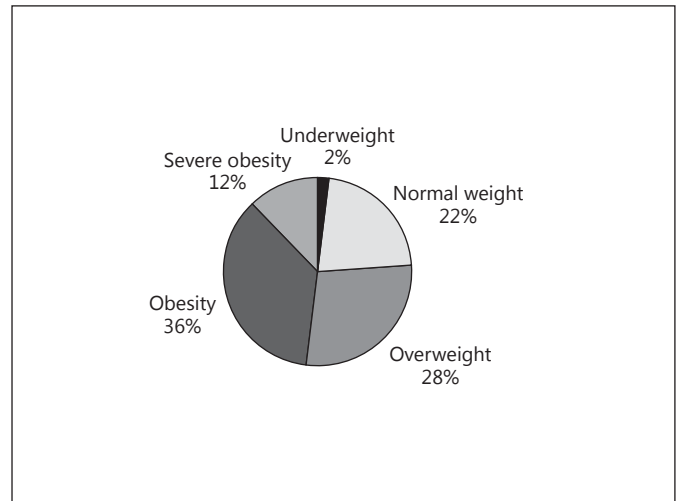


Fig. 4. Distribution of weight (n = 348). Underweight: BMI men <20, women <19. Normal weight: BMI men 20–25, women 19–24. Overweight: BMI men 26–30, women 25–30. Obesity: BMI 31–40. Severe obesity: BMI >40.

Table 3. Frequency of currently performed therapies per week (n = 348)

Frequency/ week	Lymphatic drainage		Compression bandages		Skin care at the affected limb		Physiotherapy with compression		Sports/exercise	
	n	%	n	%	n	%	n	%	n	%
0	50	14.4	317	91.1	146	42.0	317	91.1	131	37.6
1	72	20.7	5	1.4	7	2.0	9	2.6	35	10.1
2	188	54.0	9	2.6	17	4.9	8	2.3	37	10.6
3	28	8.0	10	2.9	20	5.7	5	1.4	39	11.2
4	4	1.1	3	0.9	8	2.3	–	–	16	4.6
5	5	1.4	1	0.3	6	1.7	1	0.3	5	1.4
6	–	–	–	–	1	0.3	–	–	4	1.1
7	1	0.3	3	0.9	133	38.2	8	2.3	79	22.7
9	–	–	–	–	–	–	–	–	2	0.6
14	–	–	–	–	10	2.9	–	–	–	–
Total	348	100	348	100	348	100	348	100	348	100

once. Correct fit of the compression stockings was rated by the interviewers in 82.1% of leg stockings and in 77.7% of arm stockings.

Therapy

85.6% of patients currently received lymphatic drainage, half of the patients (54.0%) twice a week. While nearly half of the patients (42.0%) performed no skin care, 38.2% used daily skin care. Physiotherapy with compression was only done by 8.9%. 37.6% did no sports, whereas 22.7% did sports daily (table 3).

Compression Therapy

Most patients (86.4%) were treated with compression, most of them (83.6%) with compression stockings and only 1.4% each with bandages or support stockings (table 4). 12.9% of all patients currently had no compression therapy. The majority of patients (70.4%) received flat-knitted compression stockings and 13.2% circular-knitted stockings. 71.9% were wearing compression stockings class II and 11.9% compression stockings class III, while in 13.4% of the cases compression class was unknown.

Table 4. Current compression therapy in the patients with chronic lymphoedema (n = 348)

	n	%
Compression therapy (n = 348)		
Yes	301	86.4
No	45	12.9
Unknown	2	0.6
Type of compression (n = 301)		
Stockings	291	83.6
Bandages	5	1.4
Support stockings	5	1.4
Type of stockings (n = 291)		
Circular-knitted	46	15.8
Flat-knitted	245	84.2
Compression class, patients with leg compression (n = 253)		
Class I	2	0.8
Class II	182	71.9
Class III	30	11.9
Class IV	5	2.0
Unknown	34	13.4
Compression class, patients with arm compression (n = 52)		
Class I	2	3.8
Class II	36	69.2
Class III	3	5.8
Class IV	1	1.9
Unknown	10	19.2
Stocking length, patients with leg compression (n = 253) ^a		
AD (half stocking)	74	29.2
AG (thigh stocking)	72	23.9
AT (tights)	78	25.9
Split compression	45	15.0
Age of oldest compression stocking (n = 301)		
0–6 months	92	27.9
7–12 months	99	30.0
13–24 months	79	23.7
>24 months	22	6.6
Unknown	9	3.0
Number of stockings in use (n = 301)		
0	3	0.9
1	71	23.6
2	120	39.9
≥3	102	33.9
Unknown	5	1.7

^a Multiple answers possible.

Concomitant Medication

The most frequently taken concomitant medications were antihypertensives (n = 146, 42.0%), analgetics (n = 69, 19.8%), diuretics (n = 56, 16.1%), anticoagulants (n = 52, 14.9%) and antilipidemic drugs (n = 53, 15.2%). No patient had venoactive drugs.

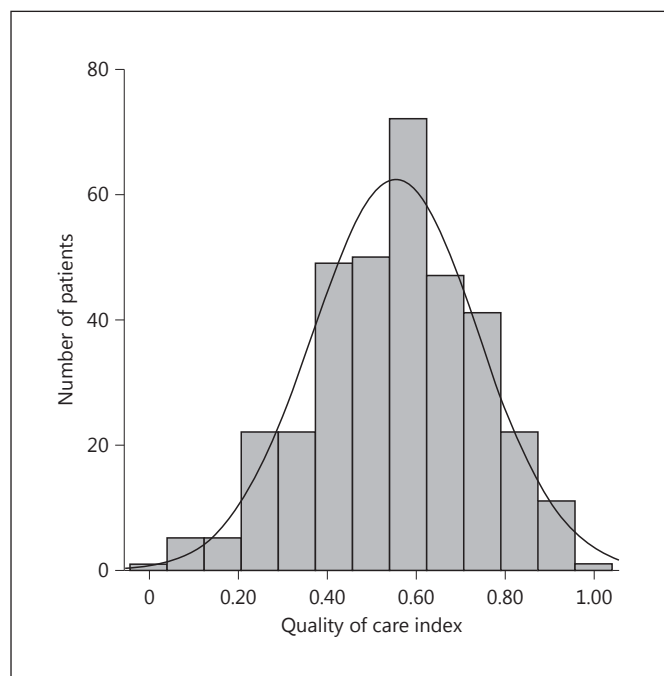


Fig. 5. Distribution of the health care index for chronic lymphoedema in the Hamburg area (n = 348).

Quality of Care and Quality of Care Index

The mean quality of care index was computed as 0.55 (SD = 0.19, range 0–1), which means that 55% of the quality indicators were achieved per patient on average (fig. 5). The criterion ‘information about skin care’ was the most rarely (7.5%) achieved item, followed by ‘history of erysipelas’ (30.7%), ‘total body examination’ (30.7%) and ‘control of correct fit of compression stockings’ (36.2%) (table 5).

Subgroup Analysis: Treatment by Specialized Health Care Providers

To check for differences in patients treated by specialized care providers, a subgroup analysis was performed. The proportion of patients currently treated by members of the LNHH was considerably higher (n = 247) than those who had never been treated in the LNHH (n = 97). Distribution of clinical characteristics was comparable in gender (LNHH female:male 93.1:6.9%; not LNHH 85.6:14.4%; table 6). Distribution of lymphoedema stages I, II and III was nearly equal in patients treated by other health care providers, nevertheless more patients not treated by the LNHH had stage 0 (8.1 vs. 19.6%). Type of oedema and localization was comparable in most items. The proportion of patients with arm oedema not treated by the

Table 5. Indicators of quality of care, proportion of patients who reached the indicators and subgroup analysis of patients treated/not treated by health care providers of the LNHH

Indicator	Proportion of patients achieving the indicator						
	all patients (n = 348)		patients treated in LNHH (n = 247)		patients not treated in LNHH (n = 97)		p ^b
	%	n	%	n	%	n	
<i>I. History</i>							
Recording of previous surgical interventions, malignant diseases	51.4	179	59.8	125	61.2	52	0.896
Documentation of history of erysipelas	30.7	107	37.2	81	28.7	25	0.184
<i>II. Diagnostics</i>							
Conduct of Stemmer sign (tissue and consistency during clinical examination)	89.1	310	94.2	227	86.0	80	0.023*
Total body examination during clinical examination	30.7	107	32.4	79	27.1	26	0.364
Measuring limb circumference or water plethysmography	87.4	304	93.4	228	76.0	73	<0.001**
<i>III. Therapy</i>							
Manual lymphatic drainage	85.6	298	90.7	224	72.2	70	<0.001**
Adequate compression therapy ^a	71.8	250	82.1	202	47.9	46	<0.001**
Control of correct fit of compression stockings	36.2	126	44.5	106	20.0	19	<0.001**
Recommendation of physical activity during compression treatment	61.2	213	69.4	170	46.5	40	<0.001**
<i>IV. Prevention</i>							
Recommendations concerning clothes ^c and trauma prevention	59.2	206	62.1	151	57.0	53	0.386
Instructions for regular skin care and hygiene or remediation of skin lesions	7.5	26	5.7	14	11.3	11	0.103
Involvement of patient and her partner in therapy	54.6	190	67.0	148	54.9	39	0.088

^a Use of multilayer compression bandages in phase I of complex physical decongestive therapy; use of flat-knitted compression stockings in phase II of complex physical decongestive therapy. ^b Group difference between patients currently treated by members of the LNHH and patients not treated by members of the LNHH. ^c No too tight apparel, no high-heeled shoes.

* Significant group difference (p < 0.05). ** Highly significant group difference (p < 0.01).

Table 6. Comparison of patients treated/not treated by specialised health care providers of the LNHH (n = 344)

Specification	Treated by LNHH, % (n = 247)	Not treated by LNHH, % (n = 97)
<i>Gender</i>		
Male	6.9	14.4
Female	93.1	85.6
<i>Clinical stage</i>		
Stage 0	8.1	19.6
Stage I	36.4	30.9
Stage II	47.4	42.3
Stage III	6.9	7.2
<i>Physician consultation last 12 months</i>		
Yes	95.5	68.0
<i>Type and localization of current oedema</i>		
Primary lymphoedema leg	25.5	18.6
Secondary lymphoedema leg	23.5	20.6
Lipoedema/combined lipolymphoedema leg	34.0	30.9
Primary lymphoedema arm	2.4	0.0
Secondary lymphoedema arm	17.0	32.0

LNHH was higher (17.0 vs. 29.9%), and type of leg oedema was nearly equal in both groups, except for lip-oedema. More patients with leg lipoedema were not treated by the LNHH (14.4 vs. 8.1%). Disease duration was considerably higher in the group treated by the LNHH (15.9 ± 15.1 vs. 12.1 ± 12.1) and more patients had had physician consultations during the last 12 months (95.5% compared to 68.0%, comparison of patients treated/not treated by health care providers of the LNHH).

The quality of care index in LNHH patients was 0.63 ± 0.16 compared to 0.53 ± 0.17 (p = 0.001; table 5). Significant differences were identified in items concerning diagnostics and therapy. The items 'circumferential measurement', 'Stemmer sign assessment', 'performance of manual lymphatic drainage', 'adequate compression therapy', 'control of correct fit of compression stockings' as well as 'information concerning physical activity' were significantly more frequently reached in the LNHH group.

Comparing patient groups younger or older than 60 years, no significantly different quality of care index was

found. Nevertheless significant differences could be observed in some items. Patients older than 60 years more frequently received manual lymph therapy (90.7 vs. 80.1%), but instructions for physical activity were scarce in this group (57.1 vs. 70.6%).

Satisfaction with Care

The majority of patients were satisfied with lymphoedema care provision (57.8% satisfied or very satisfied). 64.8% rated their oedema care to be good or very good. Drawbacks were therapists, physicians, lymph therapists as well as nurses not spending enough time (moderate to very small amount of time 60.8%) from the patient's point of view and missing cooperation between therapists. While 52.5% had consulted more than one therapist, only 14.6% of these patients felt confident with interdisciplinary cooperation. Lymphoedema treatment was time-consuming from the patients' perspective, two thirds (69.3%) needing time over and above treatment time by lymph therapists. While in 21.3% 10 min and in a further 20.9% less than 30 min additionally sufficed, 17.6% needed more than 30 min daily. While 56.5% felt quite well or well informed about their disease, the proportion of patients participating in patient education programs or self-help groups accounted to 23.9 and 2.0%. Nevertheless 55.5% of patients saw improvement potential in terms of care supply.

Quality of Life

Disease-specific quality of life (FLQA-1) was 2.4 in median (1 = minimal restriction, 5 = maximum restriction; $n = 295$, $SD = 0.8$). The global index of quality of life (EQ-5D, 0 = minimal quality of life, 100 = maximal quality of life) was 70.4 ± 23.7 on average ($n = 299$), the actual state of health as measured with the EQ-5D visual analogue scale was 63.3 ± 19.7 ($n = 297$).

Discussion

The aim of the present study was to assess the quality of care of patients suffering from lymphoedema or lip-oedema in a predefined geographical region. Previously developed guideline-based indicators of quality of care were applied for the first time, leading to an index allowing the appraisal of the overall care situation expressed in a single value.

So far, only little is known about quality of care in lymphoedema; open therapist questionnaire surveys indicate deficits in the diagnosis and management of lymphoedema [21, 22]. In a questionnaire-based survey mainly

addressing therapists and patients in the South West London community, which has a dedicated lymphoedema service, Moffatt et al. [17] found that 36% of patients were not receiving any treatment for their lymphoedema.

In the present study, patients with lymphoedema, lip-oedema and combined oedema were recruited from all sectors of health care provision in order to gain the broadest possible picture of the quality of care in the region. To ensure objectivity, all examinations and interviews were conducted by trained staff from CVderm and not by the attending therapists. Standardized questionnaires were used to obtain systematic data from the physician or health care provider and the patient.

Compared to Moffatt et al. [17] the proportion of patients receiving guideline-based care seems to be much higher in our survey [16]. Nevertheless only a small number of patients received broadly guideline-based treatment – the majority displayed shortcomings in diagnostic work-up, therapy and follow-up care.

Therapeutic deficits were identified in the type and frequency of performed compression therapy as well as physiotherapy. 12.9% of all patients had no compression therapy and the proportion of patients wearing class III stockings, as recommended by the guidelines, was relatively small (9.2% of patients with leg compression and 5.8% of patients with arm compression). Furthermore, compared to the long mean disease duration (15 years), the proportion of patients using compression stockings (83.6%), which would be adequately in the maintenance phase, is expandable.

A major field of improvement potential seems to be patient education. The small number of patients participating in patient education programs (23.9%) or self-help groups (2.0%) as well as the rarely achieved quality of care criterion 'information about skin care' indicates shortcomings in this field. However, the fact that lymphoedema is a disease which requires a high proportion of steady self-engagement by the patient supporting the therapy regime, e.g. performing skin care, compression therapy, sports or physiotherapy, prove the need for structured patient education.

Although patients' satisfaction with care was high, cooperation of therapists seems to be capable of development.

Quality of care was significantly higher in the group of patients treated by members of the LNHH. Subgroup analysis of specialized health care providers and independent therapists showed slight differences in distribution of clinical stages, e.g. a higher amount of stage 0 in patients not treated by the LNHH, but disease duration (15.9 vs. 12.1 years) was considerably higher in patients treated in

the LNHH. It could be assumed that a longer disease duration is associated with a higher proportion of severe disease stages. Maybe the equal contribution of disease stages points to a more effective treatment strategy in patients treated by specialized health care providers. Taken together, our data show that specialized and interdisciplinary treatment strategy in lymphoedema care results in higher quality of care, and these findings confirm pre-sumptions derived from earlier works [20, 23].

The high proportion of patients treated by the LNHH included in our trial as well as the fact that participation was voluntary could be suspected to be a weakness of our data. It could be considered that this patient group and the relatively high quality of care are not representative. Nevertheless a broad spectrum of different qualities of care was found. Moreover our data possibly show that lymphoedema care in the metropolitan area of Hamburg, an area with a high population density, is higher than average. Nevertheless our data for the first time allow insights into the strengths and weaknesses of the regional health care situation in lymphoedema. Structured health care assessments

in distinct diagnoses using a quality of care index may help to optimize the care situation. With respect to the subgroup of patients with lipoedema, a further limitation is the lower number of patients included. However it describes a reason for further studies focusing on this subject.

In further investigations, the health care situation could be compared with other geographical regions in Germany or international health care sectors. Moreover, application of the quality of care index may help control implementation of changes in the health care system.

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