Quality of life in patients with lymphoedema: Initial results of a Greek Lymphoedema Centre

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Abstract:

Aim: The aim of our study was to assess the role of an intensive multidisciplinary lymphoedema treatment program on health related quality of life (HRQoL), using the Freiburg Life Quality Assessment - lymphoedema (FLQA-l) as the study instrument.

Materials and Method: A prospective study included 35 patients with unilateral secondary limb lymphoedema who were followed for 3-4 weeks of intensive lymphoedema treatment program delivered by the multidisciplinary team and then by long-term home-based management guidelines. Patients were assessed in the beginning, in the end of the intensive program, at 6 and 12 month after treatment. Assessment included limb circumference measurements, skin condition, limb mobility, clinical assesement, and FLQA-l.

Results: 35 consecutive patients with unilateral secondary limb lymphoedema (International Society of Lymphology - ISL lymphoedema staging II, late II and III) were treated. 15 patients had lower limb while 20 patients had upper limb lymphoedema. Common causes of secondary lymphoedema were breast oncological surgery (57%) and gynaecological oncological surgery (14%). An overall improvement in terms of limb circumference measurements was recorded immediately after treatment ($p=0.000$) and was maintained at 6 ($p=0.01$) and 12 ($p=0.005$) months-follow up. An overall improvement of QoL was recorded for patients immediately after treatment ($p=0.005$) and at 6 ($p=0.047$)months after treatment, but not at 12 ($p=0.09$) months of follow up. Patients with lower limb lymphoedema had a greater improvement in QoL than patients with upper limb lymphoedema immediately after the treatment ($p=0.000$) but at six months time the QoL was improved more in upper limb patients ($p=0.003$). Patients with mobility and skin problems report an improvement in QoL after six months of treatment ($p=0.05$). A correlation was recorded between limb improvement and QoL measurements, but was statistically important only immediately after treatment ($p=0.018$) and not at 6 ($p=0.77$) and 12 ($p=0.29$) months. Thus, while the limb measurements improve the QoL improves. In terms of subgroup analysis, only patients with lower limb lymphoedema had improved their QoL according to limb measurements. Sex did not play any role on the outcome of the correlation between QoL and limb measurements improvement. For patients with mobility problems a correlation between QoL grade and limb improvement measurements was recorded (P: 0.035 after treatment, P: 0.000 at 6 months and P: 0.028 at 12 months). Skin problems also exhibited a correlation between QoL and limb measurement improvement (P: 0.000 after treatment, P: 0.200 at 6 months and P: 0.031 at 12 months).

Conclusion: A multidisciplinary intensive treatment program may improve the limb circumference and the QoL in patients with lymphoedema. The clinical improvement is not necessarily followed by the same degree of improvement in QoL. In particular patients with skin or mobility problems have the greatest imprtovement in QoL.

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INTRODUCTION

Lymphoedema is a pathological condition in which malformed or non-functioning lymphatics render transport capacity unable to remove normal lymphatic load. This condition leads to a fluid and protein load in the interstitium space and to the characteristic clinical signs of lymphoedema.[1] The incidence of lymphoedema reported in different studies varies widely as a result of the diversity in cancer treatment and measurement methods.[2] It is estimated that lymphoedema impacts upon more than 120 million world-wide.[3] Current epidemiology is thought to underestimate the number of patients suffering from lymphoedema by at least one third.[4] In many countries the provision of care for patients with lymphoedema is inadequate often as a result of under-recognition of this chronic, debilating condition[4-6] that can have deleterious effects on patients' physical and psychosocial health.[4]

Several facets such as pain and discomfort, sleep and rest, activities of daily living, dependence on medication and treatment, working capacity and social support are significantly affected by lymphoedema.[7] Pain in lymphoedema is directly correlated with activity limitation, participation restriction and sub-optimal health-related quality of life.[8] The World Health Organization has declared health to be "a state of complete physical, mental and social well-being and not merely the absence of disease".[9,10] Without proper treatment lymphoedema can lead to severe swelling, fibrosis, skin changes and infections. Early identification and management are crucial. There are numerous treatment options available for alleviating the consequences of lymphoedema. Means and techniques used in the diagnosis, assessment and treatment of lymphoedema vary. Management guidelines have been given and International consensus documents have been issued by the International Society of Lymphology and the International Lymphoedema Framework concerning the diagnosis and treatment of lymphoedema.[11] Given the fact that there is no cure, lymphoedema needs life-long treatment and requires a multidisciplinary approach in an individualized program that will address the special needs of each patient.[12]

Physical functioning is the domain most affected among lymphoedema patients,[13] but quantitative studies show that patients with lymphoedema experience greater levels of functional impairment, poorer psychological adjustment, anxiety and depression than the general population.[5] Healthy people have a better QoL in all domains of life, as well as in the overall general QoL, when compared to patients with lymphoedema.[7] HRQoL must be an important outcome in the management of patients with lymphoedema,[4] even though it is difficult to estimate the impact of lymphoedema in many aspects of everyday life.

The aim of our study was to assess the role of an intensive multidisciplinary lymphoedema treatment program on HRQoL, using the Freiburg Life Quality Assessment - lymphoedema (FLQA-l) as the study instrument.

MATERIALS AND METHODS

Participants: Thirty-seven consecutive patients with unilateral limb lymphoedema requiring high complexity case management (International Society of Lymphology - ISL lymphoedema staging II, late II and III) were assessed, by the multidisciplinary lymphoedema treatment team of the University General Hospital of Larisa. The two patients with primary lymphoedema were excluded from the study. (Table 1) Fifteen patients had lower limb unilateral lymphoedema while twenty patients had upper limb lymphoedema. Of those patients with upper limb lymphoedema 50% had also breast lymphoedema. Causes of secondary lymphoedema were oncological surgery for breast cancer, gynaecological cancer, non Hodgkin lymphoma, melanoma, injury (extended skin laceration) and venous insufficiency resulting in phlebo-lymphoedema. In some cases obesity was present as secondary aggravating factor. (Table 1) The individual characteristics, such as sex, age, BMI, upper/lower limb lymphoedema, years since onset of lymphoedema, lymphoedema (ISL) stage, cellulitis/erysipelas episodes and other comorbidities were recorded.

Patients with unilateral limb lymphoedema were chosen because in those patients it is possible to assess the reduction of the percentage excess volume of the swollen limb in comparison with the unaffected limb. Currently, it is not possible to establish an assessment way, in cases of bilateral limb oedema, that would represent a percentage of reduction to normal and those cases were excluded from the research. Only ISL stage II, late II and III were included in the study because ISL stage 0 or I did not require intensive management program. (Table 1)

Variable Lymphoedema Characteristics	N%
Cause of lymphoedema	
Breast cancer	20 (57)
Gynaecological cancer	5 (14,3)
Melanoma	2 (5,7)
Non-Hodgkins lymphoma	2 (5,7)
Injury	2 (5,7)
Venous insufficiency	4 (11,4)
Limb affected	
Upper limb lymphoedema	20 (57)
Lower Limb lymphoedema	15 (43)
Side of lymphoedema (for arm)	
Dominant side	9 (42,8)
Non Dominant side	12 (57,2)
Years since onset of lymphoedema	
Stage of lymphoedema	
ISL Stage II	16 (45,7)
ISL Stage Late II	11 (31,5)
ISL Stage III	8 (22,8)
Cellulitis / Erysipelas	
1-2 episode	10 (28,6)
Recurrent episodes	3 (8,6)
Comorbidities	
Skin problems	12 (34,3)
Mobility problems	7 (20)
Presence of pain	1 (2,9)

Table 1.

Multidisciplinary Lymphoedema Treatment Porgram: All 35 patients followed 3-4 weeks of intensive lymphoedema treatment program delivered by the team of vascular surgeons, dermatologists, physiotherapists, psychologist, dietician and social worker. The program, according to the management guidelines of the International Lymphoedema Framework (Lymphoedema Framework, 2006)[4,5] consisted of daily skin care, multi-layer compression bandaging, manual lymphatic drainage (MLD) according to necessity, intermitted pneumatic compression and individualized exercise program given by the team's physiotherapists. Dietary advice by the team's dietician was given to all patients and individualized diet program was given to those in need for BMI reduction. During the program all patients had a session with the team's psychologist and they were given advice on how to cope with the changes in life that a long-term condition that can't be cured, such as lymphoedema requires. Self-management guidelines (information, advice, education) were given throughout the treatment sessions and during a special atomic session by the team's physiotherapists. After the completion of the intensive program compression garments were prescribed, as needed, to all the patients, but the final choice of garment (circular/flat knitted, ready to order/custom made) depended largely on availability (not all garment choices are available in the city of Larisa) and on the patient's financial situation (In Greece only a small percentage for lymphoedema compression garments is reimbursed).

Assessment methods/tools:

The translation was made from German to Greek by two official translators and the Greek text was translated back to German by two other official translators, in order to assess the consistency of the translation. The Greek version of the FLQA-l was used for the research without testing for its psychometric properties and this must be taken into account when interpreting the results of the study.

Assessment was performed in the first day of the program, at its completion (3rd-4th week) and at 6 and 12 months after the completion of the program. The percentage of oedema reduction of the swollen limb was assessed by the same person, by tape measurements using a spring-loaded tape measure. Limb circumference measurements were compared to the unaffected limb. 10 circumferential measurements were taken of both limbs, and the four points of greater differences were taken into account. Satisfactory improvement for limb circumference was considered to be a >50% reduction of the difference with the unaffected limb.

The impact of the multidisciplinary intensive program on the patient's Quality of Life was assessed by a translation in Greek language of the Freiburg Life Quality Assessment Scale-lymphoedema module. The FLQA-l was developed by Augustine et al.[14,15] on the basis of previously validated FLQA vein questionnaire and records the health related quality of life of patients with lymphoedema. The questionnaire consists of 92 items that refer to the following scales "Physical Complaints", "Everyday life", "Social life", "Emotional well-being", "Treatment", "Satisfaction" and "Profession/Household". Each scale contains six items. Every item is evaluated on a five-point scale from "never" to "always" or "not at all" to "very". The questionnaire has also 3 Visual Analogue Scales ranging from "zero = very bad" to "ten = very good" that refer to satisfaction with general health, lymphoedema status and quality of life. The data were entered into spreadsheet as numbers from 1 to 5 (in the visual-analogue scales from 0 to 10). According to Augustine et al.[14,15] the FLQA-l is a valid and reliable QoL questionnaire specific for lymphoedema. It has been proven to be feasible for QoL evaluations in outpatient and inpatient settings. According to the questionnaire scoring system a decrease of >25% was considered satisfactory improvement, a decrease of 12-25% was considered as moderate improvement and a decrease of 12% was considered as non improvement. Furthermore, an increase of 12% was considered as non deterioration, an increase between 12% and 25% was considered as moderate deterioration and an increase of >25% was considered as major deterioration.

The presence of skin changes and mobility difficulties were recorded for all patients.

STATISTICS

A mixed models approach was adopted to examine the effect of several health indices on the Quality of Life measurements at the four different time points. All main effects were examined as well as all 2nd degree interactions for each time point. The statistical significance was in all cases set at 0,05. The analysis was carried out with the use of Stata v.13.0.

RESULTS

Table 2 shows the demographics of the patients. An overall improvement in limb circumference measurements was recorded for patients with lymphoedema which was statistically important immediately after treatment and was maintained at six and 12 months-follow up (Fig 1 and Table 3).

Variable	N%
Demographic	
Sex	
Male	4 (11.4)
Female	31 (88.6)
Age (y)	
<60 yrs	13 (37,1)
>60 yrs	22 (62,9)
BMI	
Underweight (<18.50)	0
Normal range (18.50-24.99)	5 (14,3)
Pre-obese (25.000-29.99)	6 (17,1)
Obese class I (30-34.99)	9 (25,7)
Obese class II (35-39.99)	10 (28,6)
Obese class III (>40)	5 (14,3)

Table 2. Show the demographics of the patients.

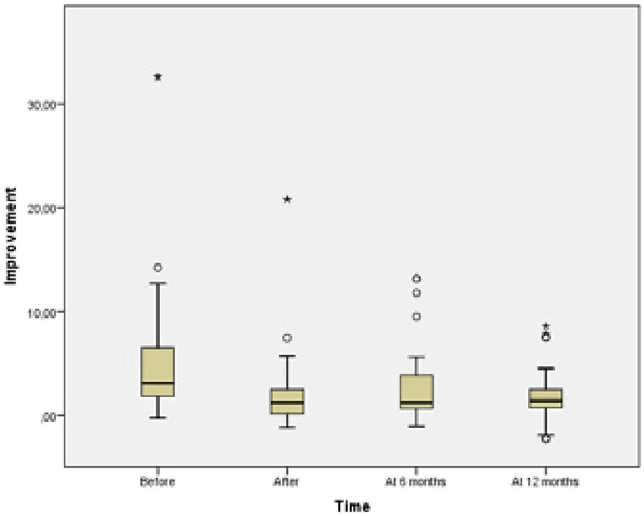

Figure 1. Improvement in limb size immediately after treatment and at 6 and 12 months after treatment. Improvement is calculated as the reduction in limb size differences between health and affected side. Statistically important improvement was recorded between before and after treatment and was maintained 12 months after treatment.

Pairwise Comparisons

Measure: MEASURE_1

(I) Improvement	(J) Improvement	Mean Difference (I-J)	Std. Error	Sig.b	95% Confidence Interval for Differenceb	
					Lower Bound	Upper Bound
1	2	3,047*	,500	,000	1,647	4,448
	3	2,811*	,820	,010	,515	5,108
	4	3,645*	,984	,005	,888	6,403

Based on estimated marginal means

*. The mean difference is significant at the ,05 level.

b. Adjustment for multiple comparisons: Bonferroni.

Table 3. Improvement in limb size immediately after treatment and at 6 and 12 months. Statistically important difference was recorded after treatment and at 6 and 12 months in comparison with before treatment.

An overall improvement of QoL was recorded for patients with lymphoedema undergoing the multidisciplinary intensive programme. Improvement in QoL was considered statistically important immediately after treatment and at 6 months after treatment, but not at 12 months (P: 0.005 after treatment, P: 0.047 at 6 months and P: 0.094 at 12 months) (Fig. 2 and Table 4). Patients with lower limb lymphoedema had a greater improvement in QoL than patients with upper limb lymphoedema immediately after the treatment but at six months time the QoL was improved more in upper limb patients. Patients with upper limb lymphoedema had statistically important improvement at six months assessment. At twelve months both upper and lower limb patients had lost part of the improvement in QoL (Fig. 3, Table 5.).

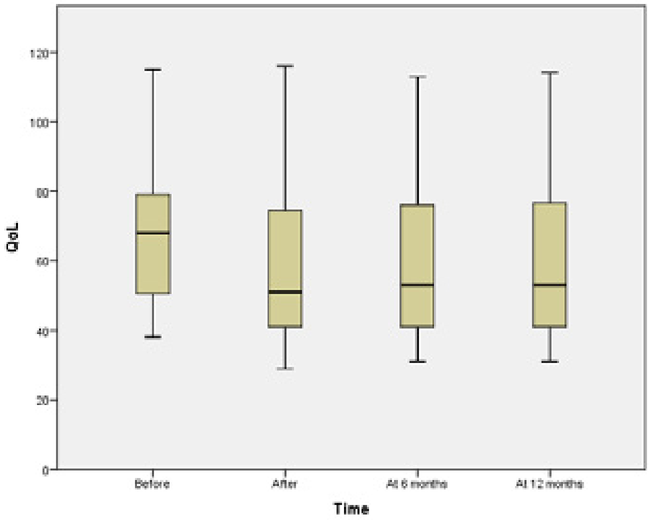

Figure 2. QoL of patients with lymphoedema before treatment, after treatment and at 6 and 12 months after treatment. Statistically important improvement was recorded between before and after treatment, was maintained at 6 months, but was lost at 12 months after treatment. A reduction in QoL scale score is considered as an improvement in QoL.

InQoL Time	Coef.	Std. Err.	z.	P>[z]	[95% Conf. Interval]	
After	-.3393669	.1215925	-2.79	0.005	-.5776839	-.1010499
At 6 months	-.228896	.1150945	-1.99	0.047	-.4544771	-.0033149
At 12 months	-.1975338	.1179216	-1.68	0.094	-.4286559	-.0335884

Table 4. Changes in QoL after treatment and at 6 and 12 months.

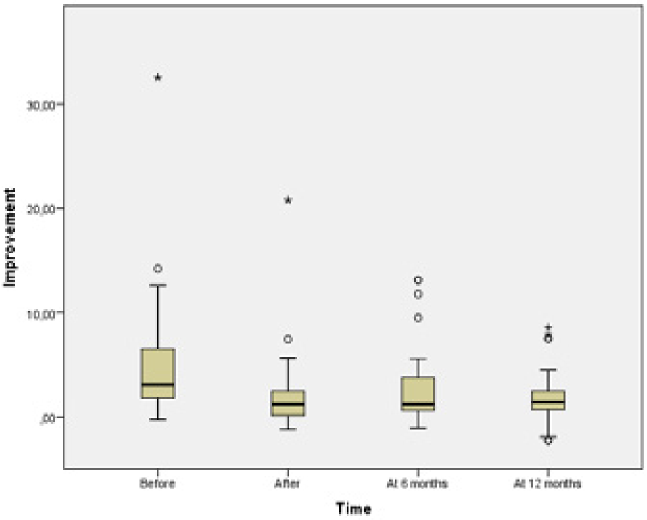

Figure 1. Improvement in limb size immediately after treatment and at 6 and 12 months after treatment. Improvement is calculated as the reduction in limb size differences between health and affected side. Statistically important improvement was recorded between before and after treatment and was maintained 12 months after treatment.

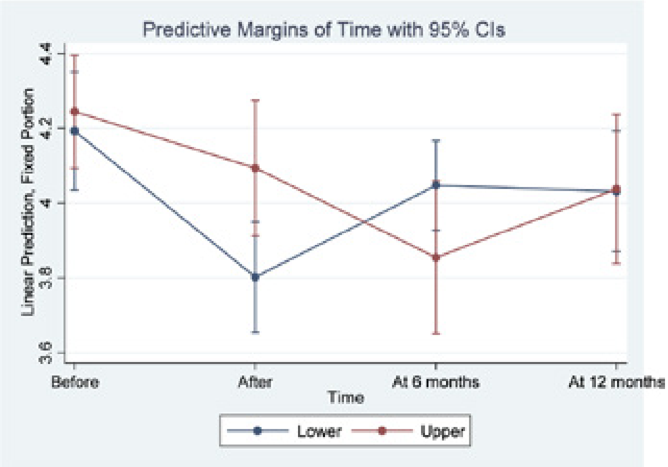

Figure 3. Changes in QoL immediately after treatment and at 6 and 12 months after treatment for patients with upper and lower limb lymphoedema.

	Delta-method		Unadjusted		Unadjusted	
	Contrast	Std. Err.	z	P>|z|	[95% Conf. Interval]	
Upper Limb Lymphoedema						
Time						
After vs Before	-.1510366	.1203051	-1.26	0.209	-.3868302	.084757
At 6 months vs Before	-.3901491	.1296337	-3.01	0.003	-.6442264	-.1360718
At 12 months vs Before	-.2072778	.1277608	-1.62	0.105	-.4576843	.0431288
At 6 months vs After	-.2391125	.1395182	-1.71	0.087	-.5125632	.0343382
At 12 months vs After	-.0562412	.1377798	-0.41	0.683	-.3262846	.2138023
At 12 months vs At 6 months	.1828713	.1459961	1.25	0.210	-.1032757	.4690183
Lower Limb Lymphoedema						
Time						
After vs Before	-.3904738	.1105214	-3.53	0.000	-.6070918	-.1738558
At 6 months vs Before	-.1454329	.1011291	-1.44	0.150	-.3436423	.0527766
At 12 months vs Before	-.1605508	.1150396	-1.40	0.163	-.3860243	.0649227
At 6 months vs After	.245041	.0969852	2.53	0.012	.0549534	.4351286
At 12 months vs After	.229923	.1114143	2.06	0.039	.011555	.4482911
At 12 months vs At 6 months	-.0151179	.1021042	-0.15	0.882	-.2152385	.1850026

Table 5. Changes in QoL immediately after treatment and at 6 and 12 months after treatment for patients with upper and lower limb lymphoedema.

Men and women had an improvement in QoL immediately after the treatment, but a part of the improvement was lost at six and twelve months. Overall men had greater improvement in QoL than women but the changes in QoL followed the same pattern (Fig. 4, Table 6.).

The presence of mobility and skin problems is a positive predictive factor for QoL improvement. Patients with mobility and skin problems report an improvement in QoL after six months of treatment (p=0.05). On the contrary, patients with no skin and mobility problems report an aggravation in QoL immediately after the treatment which is improved later on (intact skin) or at six months time which does not improve at 12 months (normal mobility) (Fig. 5 and Fig 6).

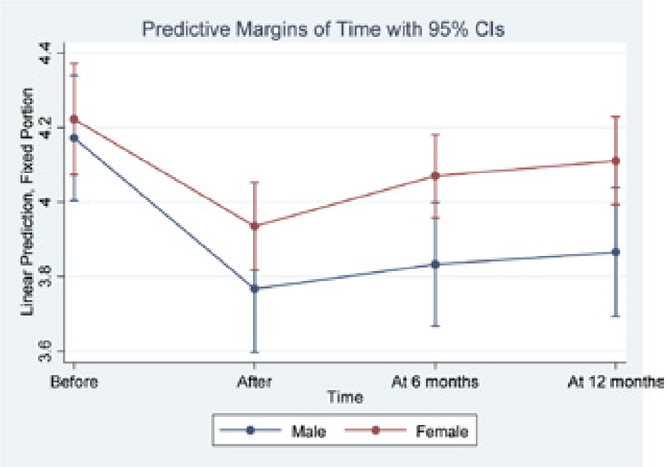

Figure 4. Changes in QoL immediately after treatment and at 6 and 12 months after treatment for men and women with limb lymphoedema.

	Delta-method		Unadjusted		Unadjusted	
	Contrast	Std. Err.	z	P>|z|	[95% Conf. Interval]	
Women with Lymphoedema						
Time						
After vs Before	-.2882223	.0970957	-2.97	0.003	-.4785263	-.0979183
At 6 months vs Before	-.1534115	.0950834	-1.61	0.107	-.3397715	.0329485
At 12 months vs Before	-.1117591	.0972161	-1.15	0.250	-.3022991	.0787808
At 6 months vs After	.1348108	.0826084	1.63	0.103	-.0270987	.2967203
At 12 months vs After	.1764632	.0850545	2.07	0.038	.0097595	.3431668
At 12 months vs At 6 months	.0416524	.0827499	0.50	0.615	-.1205344	.2038391
Men with Lymphoedema						
Time						
After vs Before	-.4057063	.1217578	-3.33	0.001	-.6443471	-.1670655
At 6 months vs Before	-.3391014	.120357	-2.82	0.005	-.5749968	-.1032061
At 12 months vs Before	-.3065959	.1230694	-2.49	0.013	-.5478075	-.0653843
At 6 months vs After	.0666049	.1208995	0.55	0.582	-.1703537	.3035635
At 12 months vs After	.0991104	.1236	0.80	0.423	-.1431411	.3413619
At 12 months vs At 6 months	.0325055	.1222203	0.27	0.790	-.2070419	.272052

Table 6. Changes in QoL immediately after treatment and at 6 and 12 months after treatment for men and women with limb lymphoedema.

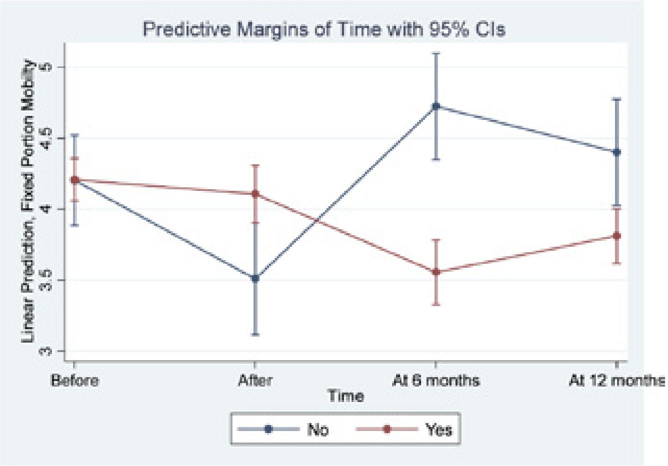

Figure 5. Changes in QoL immediately after treatment and at 6 and 12 months after treatment for patients with lymphoedema with or without mobility problems.

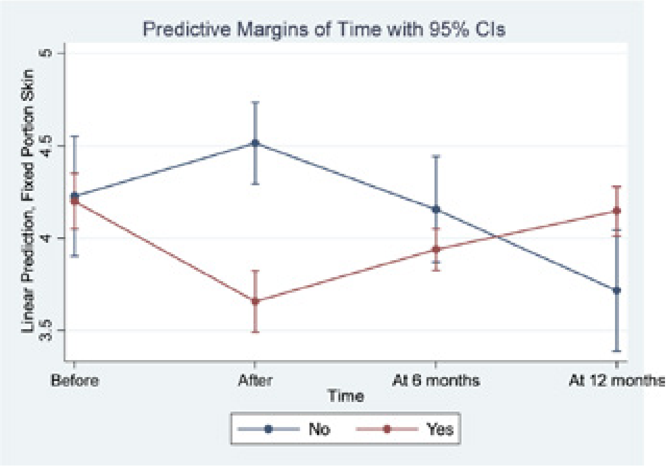

Figure 6. Changes in QoL immediately after treatment and at 6 and 12 months after treatment for patients with lymphoedema with or without skin problems.

Obesity and Stage of lymphoedema exhibited an oddly pattern as far as improvement in QoL is concerned. Normal weight patients did not exhibit any statistically important improvement in QoL. Pre-obese patients showed the biggest improvement in all obesity categories, only after six months time. Patients with obesity stage I, II and III exhibited statistical improvement immediately after treatment that was lost at six and twelve months. As far as lymphoedema stage is concerned, for Stage II and Late II QoL was improved after treatment and at six months interval but the improvement was not maintained at twelve months. Patients with Stage III lymphedema exhibited an odd deterioration in QoL at six months. Nevertheless, because of the vast range in frequency between obesity and lymphoedema stages, the number of patients in each stage group was relatively small and the results of the statistical analysis cannot be considered safe.

lnQoL	Coef.	Std. Err.	z	P>[z]	[95% Conf. Interval]	
Time#c.lnimpro						
Before	-.3020605	.1833072	-1.65	0.099	-.6613359	.0572149
After	-.6569541	.2784292	-2.36	0.018	-1.202665	-.1112429
At 6 months	-.0913182	.3181644	-0.29	0.774	-.7149089	.5322725
At 12 months	-.3061883	.2905757	-1.05	0.292	-.8757063	.2633297
Position#Time#c.lnimpro						
Upper#Before	.821623	.1031141	0.80	0.426	-.1199376	.2842622
Upper#After	.4580403	.2041322	2.24	0.025	.05794486	.858132
Upper#At 6 months	-.3020028	.2004035	-1.51	0.132	-.6947865	.0907808
Upper#At 12 months	.0088085	.2405023	0.04	0.971	-.4625674	.4801844
Sex#Time#c.lnimpro						
Women#Before	.0798347	.0959249	0.83	0.405	-.1081746	.267844
Women#After	.2642657	.1392286	1.90	0.058	-.0086173	.5371487
Women#At 6 months	.371338	.1517504	2.45	0.014	.0739127	.6687633
Women#At 12 months	.3856971	.146109	2.64	0.008	.0993287	.6720654
Mobility#Time#c.lnimpro						
Positive#Before	.007618	.2900087	0.03	0.979	-.5607886	.5760245
Positive#After	.9362823	.4429898	2.11	0.035	.0680382	1.804526
Positive#At 6 months	-1.833727	.4538416	-4.04	0.000	-2.72324	-.9442139
Positive#At 12 months	-.9247247	.4195186	-2.20	0.028	-1.746966	-.1024835
Skin#Time#c.lnimpro						
Positive#Before	-.0419826	.2763509	-0.15	0.879	-.5836205	.4996552
Positive#After	-1.345101	.2641116	-5.09	0.000	-1.86275	-.8274517
Positive#At 6 months	-.3418686	.266753	-1.28	0.200	-.864695	.1809577
Positive#At 12 months	.6742579	.3123213	2.16	0.031	.0621195	1.286396

Table 7. Correlation between improvement in limb measurements and QoL immediately after treatment for patients with upper and lower limb lymphoedema, for men and women and for patients with and without mobility and skin problems.

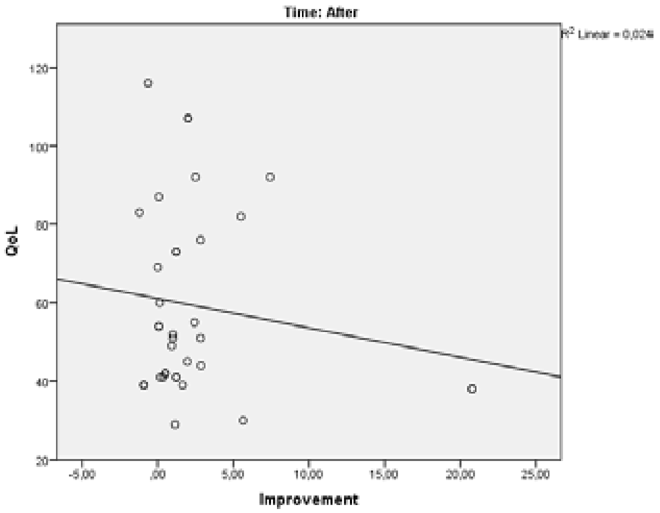

Figure 7. Correlation between improvement in limb measurements and QoL immediately after treatment

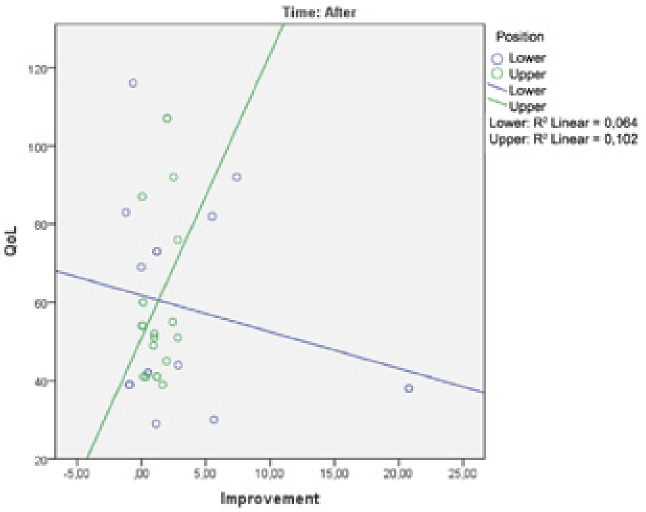

Figure 8. Correlation between improvement in limb measurements and QoL immediately after treatment for patients with upper and lower limb lymphoedema.

A correlation was recorded between limb improvement and QoL measurements, but was statistically important only immediately after treatment and not at 6 and 12 months (P: 0.018 after treatment, P: 0.774 at 6 months and P: 0.292 at 12 months) (Fig. 7 Table 7). Thus, while the limb measurements improve the QoL improves. An opposite correlation was found for the subgroup of patient with upper limb lymphoedema immediately after treatment (P: 0.025 after treatment, P: 0.132 at 6 months and P: 0.971 at 12 months) (Fig. 8, Table 7) meaning that improvement in limb circumference is not necessarily followed by improvement in QoL.

One the other hand a correlation between QoL and limb improvement for patients with lower lymphoedema was noted, but again only immediately after treatment (Fig. 8, Table 7). Women exhibited an opposite correlation between QoL grade and limb improvement measurements (P: 0.058 after treatment, P: 0.014 at 6 months and P: 0.008 at 12 months for women) (Fig. 9, Table 7) which actually matches the above mentioned results for the upper limb patients (upper limb patients were only women because of breast cancer treatment). Also for women it was recorded that even though big changes in limb improvement happened the changes in QoL that followed were small. For men because of the small number of participants the results cannot be taken into account.

The correlation between QoL and limb improvement for the different stages of obesity or different stages of lymphoedema also cannot be considered valid because of the small number of patients in each stage. For patients with mobility problems a correlation between QoL grade and limp improvement measurements was recorded (P: 0.035 after treatment, P: 0.000 at 6 months and P: 0.028 at 12 months) (Fig 10, Table 7). Skin problems also exhibited a correlation between QoL and limb measurement improvement (P: 0.000 after treatment, P: 0.2 at 6 months and P: 0.031 at 12 months) (Fig 11, Table 7).

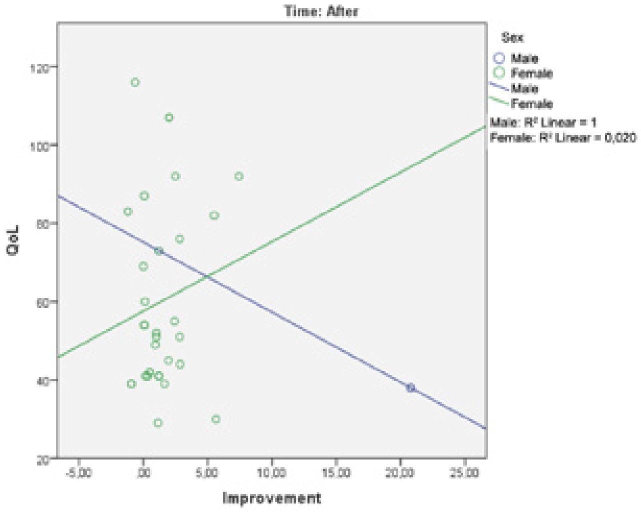

Figure 9. Correlation between improvement in limb measurements and QoL immediately after treatment for men and women with lymphoedema

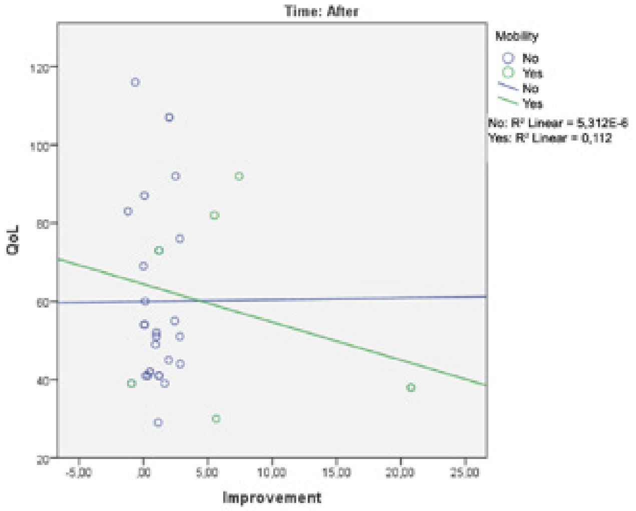

Figure 10. Correlation between improvement in limb measurements and QoL immediately after treatment for patients with lymphoedema with and without mobility problems

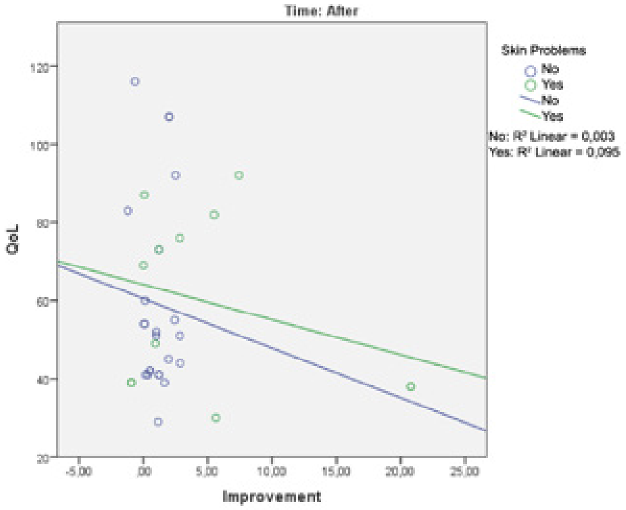

Figure 11. Correlation between improvement in limb measurements and QoL immediately after treatment for patients with lymphoedema with and without skin problems

DISCUSSION

Limb circumference or volume and joint mobility are common clinical outcomes for lymphoedema program.[16] Improvements in QoL (health perception, vitality and mental health) after rehabilitation have been reported for patients with arm lymphoedema.[17] It has been reported in the literature that Complex decongestive physiotherapy has a significant improvement on HRQoL specifically in gynaecological cancer patients with unilateral lymphoedema and that change in % excess volume is necessarily correlated with a change in physical functioning, social functioning, role-physical, bodily pain and general health and improvement in overall QoL.[18] On the other hand it was recently mentioned that the change in limb volume is not associated with a change in any of the HRQoL subscales they used.[19] In fact significant improvements are made in QoL following CDT, which are not necessarily correlated with limb volume reductio.[20] Increased limb volume is poorly related to the impact of lymphoedema on the patient[4,5] and in fact, circumference and mobility are only two of the factors affecting daily life and well-being in lymphoedema.[21] Total number of symptoms (pain, range of motion) may be more important than swelling while treating lymphoedema patients.[22,23] Also a number of factors that can affect HRQoL of lymphoedema patients have been identified. A significant correlation was found between an improvement in skin condition and an improvement in scores on the pain subscale of a QoL scale.[24] Other factors include, lack of lymphoedema awareness by health professionals, lack of information provided to patients, emotional responses such as shock, fear, annoyance, frustration and negative body image, high treatment cost in terms of time and disruption to lifestyle. Other factors leading to deficits in quality of life include the frequency of acute inflammatory episodes, the presence of pain, skin quality, lymphoedema in the dominant hand and reduced limb mobility.[4,5] The most distressing aspects of lymphoedema are local pain, embarrassment and limitations of physical activities.[25] It has been stated also that treatments should not be focusing only on decreasing arm volume without addressing other issues, such as pain because they may not result in improvements in activity, participation, or Health Related Quality of Life (HRQoL).[8]

In our study, improvement in limb circumference correlated with improvement in QoL in general, but when subgroups were taken into account it was noted that for women with upper limb lymphoedema the improvement in limb circumference was not necessarily followed by an improvement in QoL and in some cases the QoL exhibited deterioration. One explanation could be the fact that these patients are psychologically distressed and their QoL could have been affected by the breast cancer diagnosis treatment and prognosis, so the improvement in their limb appearance didn't have a great impact in their QoL. Another factor taken into account could be the necessity of wearing a long term maintenance material (glove and sleeve) that is still accompanied by the stigmatation of the disease at least in Greek society. On the other hand, it is stated that quality of life differs significantly for women with and without lymphoedema only when a subjective measurements is used, because subjective and objective tools investigate different aspects of lymphoedema.[26] It is possible that a subjective measure, such as the Lymphoedema and Breast Cancer Questionnaire (LBQO)[27] would have given different results.

Even though pain is considered a major correlation factor to QoL for lymphoedema patients, in our study only one of the patients reported pain related to lymphoedema and it could not be taken into account for the statistical analysis. The presence of mobility and skin problems was considered in our study important predictive factor that can influence the improvement of QoL after the treatment. On the contrary a number of patients who did not experience these problems and had intact skin and good mobility exhibited deterioration in their QoL and in our study it was translated that the treatment modules as well as the self-maintenance phase with the need of elastic garment and self bandaging for patients that have to cope only with limb volume could negatively affect their QoL. When assessing the effect of lymphoedema treatment, it is essential to determine whether the benefits to patient outweight the burden associated with treatment.[28] In our study, the number of patients whose QoL was affected negatively by the multidisciplinary program emphasizes the fact that for patients with no mobility and no skin problems, living with an unmanaged lymphoedema is easier than coping with daily lymphoedema self-management. Proper patient enrolment to an intensive program should address the patient's attitude towards self management. On the other hand, in this study BMI levels seemed to play a role in the QOL improvement in patients with lymphoedema. It has been previously described that increased BMI can affect negatively QOL.[29] Recently, it was shown that BMI was related to severe lemphoedema. The importance of an education care unit promoting personalized nutritional lifestyle and encouraging physical activity early in the management of cancer is of paramount importance.[30]

Considerations have to be taken into account concerning the assessment tool that was used in the study. HRQoL assessment of outcomes is made using patient-reported outcome (PRO) instruments or questionnaires, that quantify significant variables from the patient's perspective. The Nottingham Health Profile Part 1 (NHP-1) has been used for measurement of health-related quality of life of patients receiving conservative treatment for limb lymphoedema.[24] The SF-36 has been suggested to be appropriate for use with patients with lower limb lymphoedema.[31] The WHO 100-item QOL questionnaire (WHOQOL-100), which ascertains an individual's perception of QOL in the physical, psychological, level of independence, environmental and spiritual domains, as well as the general QOL has been administered in filarial lymphoedema patients.[7] A cancer specific questionnaire (EORTC-QLQ-C30) has been used for lymphoedema patient assessment.[32,33] The Dermatology Life Quality Index (DLQI)[34,35] and the modified version of Life Quality Index (LQI), focusing on the oedematous limb rather than the skin, have been administered to patients with Bancroftian filariasis.[25] Nevertheless, condition or disease specific measures might provide more sensitive assessment for specific populations, such as patients with lymphoedema.[36] The number of HRQoL specific for lymphoedema assessment instruments is limited. The Wesley Clinic Lymphoedema Scale (WCLS)[37] has no qualitative work and no formal psychometric analysis to confirm its' validity.[36] The Upper Limb Lymphoedema - 27 questionnarie (ULL-27)[38] has strong psychometric properties (Pusic et al, 2013) but its' use is limited for the upper limb. The Lymphoedema Quality of Life Inventory (LQOLI) is an instrument developed for patients with different types of lymphoedema. It is an instrument developed and tested in Australia but only published and translated and validated in Swedish.[39] At the beginning of our study, the FLQA-l was one of the few available instruments. It has showed good internal consistency (Cronabach's alpha was higher than 0.75 in all scales), has no floor and ceiling effects and satisfactory item selectivity. The test-retest reliability, sensitivity to change and convergent validity with other psychometric instruments has been reported as satisfactory.[24,25]

The main limitation of this study was the relatively small number of patients. The number of men patient in the study group was also small and it is difficult to draw conclusions. Additionally, weight loss or gain was not assessed. The different stages of obesity or different stages of lymphoedema also cannot be considered valid because of the small number of patients in each stage. Additionally, the majority of the patients did not strictly follow the dietary advice, while there was no official record of the diet scheme that each patient was presecribed.

CONCLUSION

A multidisciplinary intensive treatment program may improve the limb circumference and the QoL in patients with lymphoedema. The clinical improvement is not necessarily followed by the same degree of improvement in QoL. In particular patients with skin or mobility problems have the greatest imprtovement in QoL.

REFERENCES

1 Lymphedema Management and Complete Physical Decongesitive Therapy: A Manual for Treatment Paperback - 1 Apr 2010 by Hans Pritschow (Author, Editor), Christian Schuchhardt (Author, Editor), Angela Vollmer (Author), Oliver Gültig (Author), & 4 more

2 Petrek JA, Pressman PI, Smith RA. Lymphedema: current issues in research and management. CA Cancer J Clin. 2000;50(5):292-311. doi:10.3322/canjclin.50.5.292

3 Stout NL, Pfalzer LA, Springer B, et al. Breast cancer-related lymphedema: comparing direct costs of a prospective surveillance model and a traditional model of care. Phys Ther. 2012;92(1):152-163. doi:10.2522/ptj.20100167

4 Morgan P, Moffatt C. The National Lymphoedema Framework project. Br J Community Nurs. 2006;11(4):S19-S22. doi:10.12968/bjcn.2006.11.Sup2.20844

5 Morgan P, Doherty D, Moffatt C, et al. The National Lymphoedema Framework Project. Nurs Times. 2005;101(24):48.

6 Gary DE. Lymphedema diagnosis and management. J Am Acad Nurse Pract. 2007;19(2):72-78. doi:10.1111/j.1745-7599.2006.00198.x

7 Wijesinghe RS, Wickremasinghe AR. Quality of life in filarial lymphoedema patients in Colombo, Sri Lanka. Trans R Soc Trop Med Hyg. 2010;104(3):219-224. doi:10.1016/j.trstmh.2009.08.005

8 Dawes DJ, Meterissian S, Goldberg M, et al. Impact of lymphoedema on arm function and health-related quality of life in women following breast cancer surgery. J Rehabil Med. 2008;40(8):651-658. doi:10.2340/16501977-0232

9 Fayers, P.M. and Machin, D. (2000) Quality of life: Assessment, analysis and interpretation. John Wiley & Sons Ltd., Chichester.

10 Jäger G, Döller W, Roth R. Quality-of-life and body image impairments in patients with lymphedema. Lymphology. 2006;39(4):193-200.

11 Papadopoulou MC, Tsiouri I, Salta-Stankova R, et al. Multidisciplinary lymphedema treatment program. Int J Low Extrem Wounds. 2012;11(1):20-27. doi:10.1177/1534734612438436

12 Klernäs P, Kristjanson LJ, Johansson K. Assessment of quality of life in lymphedema patients: validity and reliability of the Swedish version of the Lymphedema Quality of Life Inventory (LQOLI). Lymphology. 2010;43(3):135-145.

13 Gethin G, Byrne D, Tierney S, et al. Prevalence of lymphoedema and quality of life among patients attending a hospital-based wound management and vascular clinic. Int Wound J. 2012;9(2):120-125. doi:10.1111/j.1742-481X.2011.00851.x

14 Augustine E, Corn M, Danoff J. Lymphedema management training for physical therapy students in the United States. Cancer. 1998;83(12 Suppl American):2869-2873.

15 Augustin M, Bross F, Földi E, et al. Development, validation and clinical use of the FLQA-I, a disease-specific quality of life questionnaire for patients with lymphedema. Vasa. 2005;34(1):31-35. doi:10.1024/0301-1526.34.1.31

16 Keeley V, Franks P, Quere I, et al. LIMPRINT in Specialist Lymphedema Services in United Kingdom, France, Italy, and Turkey. Lymphat Res Biol. 2019;17(2):141-146. doi:10.1089/lrb.2019.0021

17 Jäger G, Döller W, Roth R. Quality-of-life and body image impairments in patients with lymphedema. Lymphology. 2006;39(4):193-200.

18 Kim SJ, Park YD. Effects of complex decongestive physiotherapy on the oedema and the quality of life of lower unilateral lymphoedema following treatment for gynecological cancer. Eur J Cancer Care (Engl). 2008;17(5):463-468. doi:10.1111/j.1365-2354.2007.00877.x

19 [No authors listed] American Cancer Society Workshop on Breast Cancer Treatment-Related Lymphedema. New York, New York, USA. February 20-22, 1997. Cancer. 1998;83(12 Suppl American):2775-2890.

20 Weiss JM, Spray BJ. The effect of complete decongestive therapy on the quality of life of patients with peripheral lymphedema. Lymphology. 2002;35(2):46-58.

21 Voogd AC, Ververs JM, Vingerhoets AJ, et al. Lymphoedema and reduced shoulder function as indicators of quality of life after axillary lymph node dissection for invasive breast cancer. Br J Surg. 2003;90(1):76-81. doi:10.1002/bjs.4010

22 Hormes JM, Bryan C, Lytle LA, et al. Impact of lymphedema and arm symptoms on quality of life in breast cancer survivors. Lymphology. 2010;43(1):1-13.

23 Tsauo JY, Hung HC, Tsai HJ, et al. Can ICF model for patients with breast-cancer-related lymphedema predict quality of life?. Support Care Cancer. 2011;19(5):599-604. doi:10.1007/s00520-010-0857-2

24 Sitzia J, Sobrido L. Measurement of health-relat-

ed quality of life of patients receiving conservative treatment for limb lymphoedema using the Nottingham Health Profile. Qual Life Res. 1997;6(5):373-384. doi:10.1023/a:1018487411186

25 Chandrasena TG, Premaratna R, Muthugala MA, et al. Modified Dermatology Life Quality Index as a measure of quality of life in patients with filarial lymphoedema. Trans R Soc Trop Med Hyg. 2007;101(3):245-249. doi:10.1016/j.trstmh.2006.08.012

26 Bulley C, Gaal S, Coutts F, et al. Comparison of breast cancer-related lymphedema (upper limb swelling) prevalence estimated using objective and subjective criteria and relationship with quality of life. Biomed Res Int. 2013;2013:807569. doi:10.1155/2013/807569

27 Armer JM, Radina ME, Porock D, et al. Predicting breast cancer-related lymphedema using self-reported symptoms. Nurs Res. 2003;52(6):370-379. doi:10.1097/00006199-200311000-00004

28 Finnane A, Hayes SC, Obermair A, et al. Quality of life of women with lower-limb lymphedema following gynecological cancer. Expert Rev Pharmacoecon Outcomes Res. 2011;11(3):287-297. doi:10.1586/erp.11.30

29 Korhonen PE, Seppälä T, Järvenpää S, et al. Body mass index and health-related quality of life in apparently healthy individuals. Qual Life Res. 2014;23(1):67-74. doi:10.1007/s11136-013-0433-6

30 Leray H, Malloizel-Delaunay J, Lusque A, et al. Body Mass Index as a Major Risk Factor for Severe Breast Cancer-Related Lymphedema [published online ahead of print, 2020 Apr 13]. Lymphat Res Biol. 2020;10.1089/lrb.2019.0009. doi:10.1089/lrb.2019.0009

31 Franks PJ, Moffatt CJ, Doherty DC, et al. Assessment of health-related quality of life in patients with lymphedema of the lower limb. Wound Repair Regen. 2006;14(2):110-118. doi:10.1111/j.1743-6109.2006.00099.x

32 Park JE, Jang HJ, Seo KS. Quality of life, upper extremity function and the effect of lymphedema treatment in breast cancer related lymphedema patients. Ann Rehabil Med. 2012;36(2):240-247. doi:10.5535/arm.2012.36.2.240

33 Novackova M, Halaska MJ, Robova H, et al. A prospective study in detection of lower-limb lymphedema and evaluation of quality of life after vulvar cancer surgery. Int J Gynecol Cancer. 2012;22(6):1081-1088. doi:10.1097/IGC.0b013e31825866d0

34 McPherson T. Impact on the quality of life of lymphoedema patients following introduction of a hygiene and skin care regimen in a Guyanese community endemic for lymphatic filariasis: A preliminary clinical intervention study. Filaria J. 2003;2(1):1. Published 2003 Jan 24. doi:10.1186/1475-2883-2-1

35 Babu BV, Nayak AN, Rath K, et al. Use of the Dermatology Life Quality Index in filarial lymphoedema patients. Trans R Soc Trop Med Hyg. 2006;100(3):258-263. doi:10.1016/j.trstmh.2005.05.022

36 Pusic AL, Cemal Y, Albornoz C, et al. Quality of life among breast cancer patients with lymphedema: a systematic review of patient-reported outcome instruments and outcomes. J Cancer Surviv. 2013;7(1):83-92. doi:10.1007/s11764-012-0247-5

37 Mirolo BR, Bunce IH, Chapman M, et al. Psychosocial benefits of postmastectomy lymphedema therapy. Cancer Nurs. 1995;18(3):197-205.

38 Alliot F, Launois R. Lymphoedème et qualité de vie [Lymphedema and quality of life]. Rev Med Interne. 2002;23 Suppl 3:431s-435s. doi:10.1016/s0248-8663(02)80388-5

39 Klernäs P, Kristjanson LJ, Johansson K. Assessment of quality of life in lymphedema patients: validity and reliability of the Swedish version of the Lymphedema Quality of Life Inventory (LQOLI). Lymphology. 2010;43(3):135-145.