

CHANGES IN QUALITY OF LIFE OF PATIENTS WITH LYMPHEDEMA AFTER LYMPHATIC VESSEL TRANSPLANTATION

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ABSTRACT

There are multiple treatment options for patients with chronic lymphedema, and one successful approach is lymph vessel transplantation. As quality of life assessments are frequently not utilized in standard treatment regimes, we investigated the change in quality of life for patients with chronic lymphedema (total =212) who had undergone lymphatic vessel transplantation and conservative therapy for at least 6 months prior to operation. Quality of life was assessed by a modified standard questionnaire examining the physiological and psychological status of the patients. Results document a significant improvement in quality of life and underscore success of autologous lymphatic vessel transplantation as a therapy for lymphedema.

Keywords: lymphedema, lymphatic vessel transplantation, quality of life, lymphatic graft

In evidenced-based medicine, studies are generally based on objectivity, and treatment outcomes are assessed by their effects. Particularly for chronic and malignant diseases, which cannot be healed and impair patients' everyday life, it is necessary to apply additional and new criteria to judge the outcomes of different treatments. Outcomes of medical treatment

assessed traditionally by parameters like "death rate" or "survival time" are now evolving to not only "whether" and "for how long" there is a possibility of survival but "how is the life worth living" and "how harmful" is the situation (which may be the most important points of view particularly from the patient's perspective) (1). During the last few years, studies have demonstrated that patients with chronic lymphedema show a great impairment in these quality of life (QOL) measures. This finding goes along with limitations in many aspects of everyday living as well as a potentially negative body image and lowered self confidence compared to healthy individuals. The QOL of patients with lymphedema has been shown to be inferior with impaired general health, vitality, and sense of well-being (2). In our study we took interest in the changes in QOL of patients with lymphedema after lymphatic vessel transplantation and whether QOL was improved by operation.

MATERIAL AND METHODS

This retrospective study included patients with upper or lower limb lymphedema who have undergone microsurgical transplantation of lymphatic vessels and prior conservative treatment for lymphedema. Both conservative treatment and microsurgical transplantation of

lymphatic vessels are officially acknowledged methods for treating lymphedema in Germany. Inclusion criteria consisted of patients undergoing lymph vessel transplantation between January 1, 1983, and January 1, 2007, and having received standard conservative therapy for at least 6 months prior to the operation. Questionnaires were sent by mail and patients who had not answered after four weeks were contacted again by mail and telephone. All participation was completely voluntary. This project was part of the hospital's standard quality management procedure and, therefore, an additional IRB approval was not necessary. All data were de-identified before analysis. The final response rate was 73.0%. The total study population for analysis included 107 lower and 105 upper limb patients with lymphedema.

Assessment Instrument

To assess general health and whether lymph vessel transplantation was a successful treatment from the patients' point of view, we developed a specially designed questionnaire. We started with the standardized SF-12 quality of life instrument (shortened form of the SF-36), which has been used for many years as an instrument to evaluate QOL in different diseases (3). Then questions were then adapted to the main known complaint problems from patients with lymphedema. We added two more questions to evaluate the possible burden caused by the amount of time that was needed for conservative therapy and the impairment of wearing compression garments.

In order to guarantee an objective observation, we first tested the questionnaire for comprehensibility and suitability. Six patients (three male and three female), who were undergoing treatment and were not included in our study, were asked to fill out the questionnaires. The questionnaires were also tested by six members of the staff (two female nurses, a male nurse, one doctor, and

a medical student). Every participant rated the questionnaire as comprehensible and had no problems answering the questions.

We separated the questionnaire into two major sections with the first part assessing the period prior to the surgery and the second part after lymph vessel transplantation (12 questions in each). Each section addressed the three major themes described below and each question had five possible answers ranging from 1 (least harming with highest QOL) to 5 (most harming with lowest QOL). By utilizing a numerical scoring system, comparisons were accomplished by simply adding the number of points in the different parts of the survey for analysis. Scores were averaged for upper and lower limbs for each theme, standard error determined, and values used for before and after operation comparisons. All pre- and post-operative measurements and comparisons were evaluated with Mann-Whitney rank sum test, and significance was determined by $p \leq 0.001$ using SPSS.

Instrument Themes

Physiological Conditions

This section include four questions with three that assessed common problems for patients with lymphedema caused by the pressure of swollen tissue and skin: intensity of swelling, pain, and paresthesias. The additional physiological question inquired about occurrence of skin infections and erysipelas.

Psychological Conditions

This section contained four questions focusing on the social everyday- and family-life of the patients as well as their ability to work.

Burden of Conservative Therapy

This section consisted of two questions

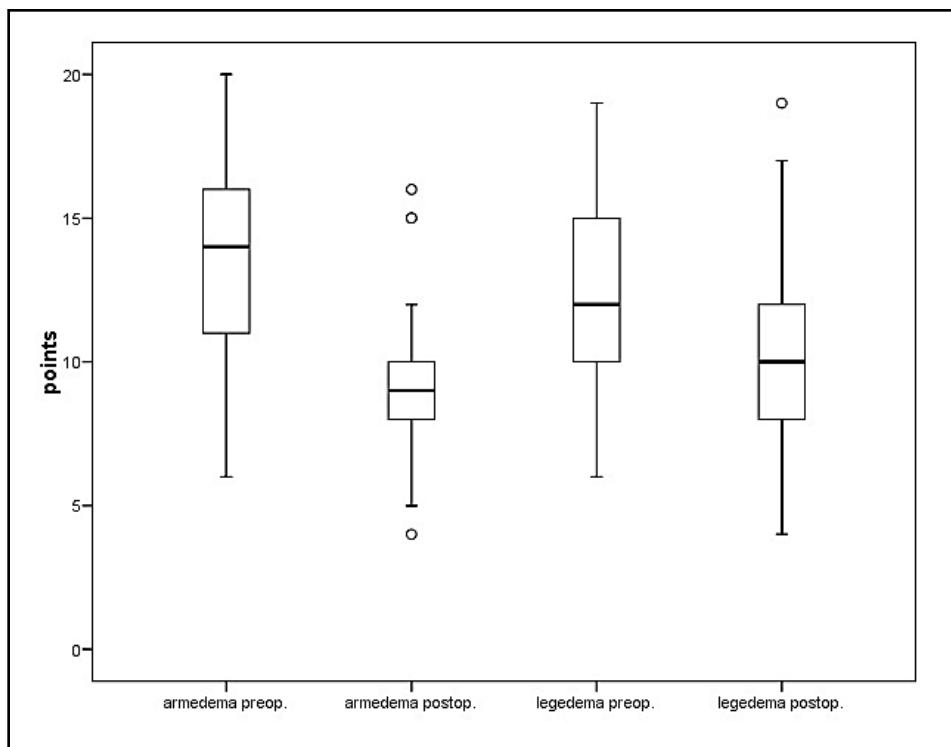


Fig. 1. Quality of life Physiological Condition values for patients with lymphedema of the arm (left side) and leg (right side) before and after lymph vessel transplantation. Data are presented as the 25th to 75th percentiles (boxes) with Mean (line in box), S.E. (bars), and outlying data points (circles).

focusing on the burdens of conservative therapy including frequency of received manual lymph drainage and the impairment caused by wearing special compressive stockings.

RESULTS

Physiological Conditions

For patients with arm lymphedema, the average score for physiological condition prior to operation was 13.8 ± 0.4 (mean \pm S.E.M) points. After operation, the average score fell to 9.1 ± 0.3 . This is a significant positive change in QOL of 4.7 ($p \leq 0.001$) (Fig. 1). For patients with leg lymphedema, the average score for physiological condition prior to operation was 12.3 ± 0.4 (mean \pm S.E.M) points. After operation, the average

score fell to 10.1 ± 0.4 points which is a significant positive change in QOL of 2.2 points ($p \leq 0.001$) (Fig. 1).

Psychological Conditions

For patients with arm lymphedema, the average score for psychological condition prior to operation was 15.6 ± 0.5 (mean \pm S.E.M) points. After operation, the average score fell to 11 ± 0.5 . This is a significant positive change in QOL of 4.6 points ($p \leq 0.001$) (Fig. 2). For patients with leg lymphedema, the average score for psychological condition prior to operation was 13 ± 0.5 (mean \pm S.E.M) points. After operation, the average score fell to 11.4 ± 0.6 which is a significant positive change in QOL of 1.6 points ($p \leq 0.001$) (Fig. 2).

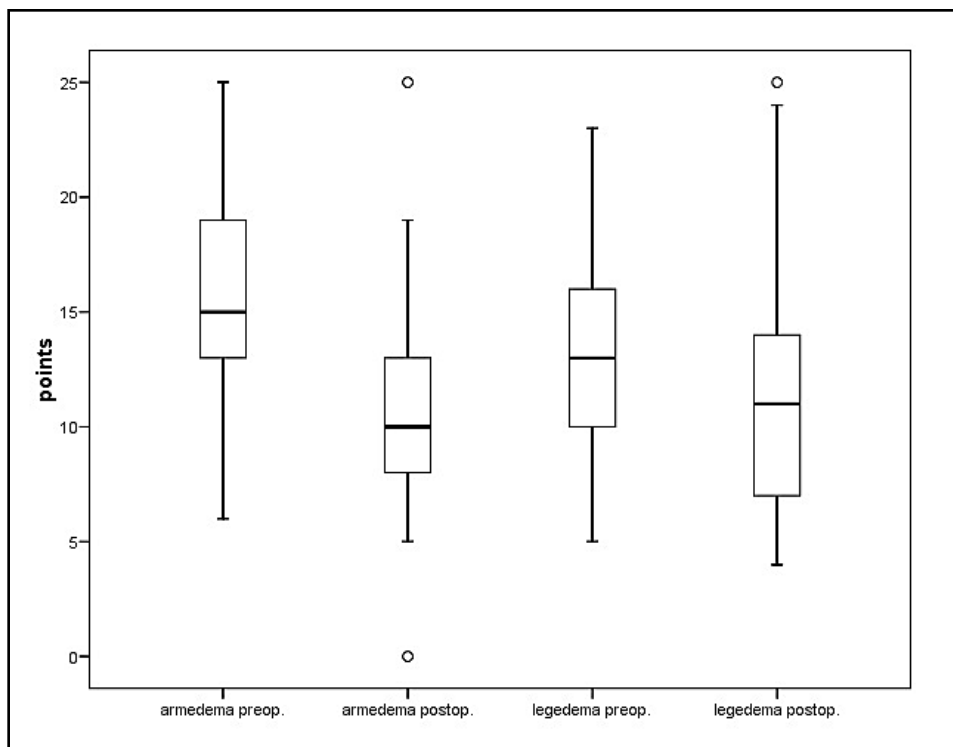


Fig. 2. Quality of life Psychological Condition values for patients with lymphedema of the arm (left side) and leg (right side) before and after lymph vessel transplantation. Data are presented as the 25th to 75th percentiles (boxes) with Mean (line in box), S.E. (bars), and outlying data points (circles).

Burden of Conservative Therapy

For patients with arm lymphedema, the average score for burden of conservative therapy prior to operation was 9 ± 0.2 (mean \pm S.E.M) points. After operation, the average score fell to 6.4 ± 0.3 points. This is a significant positive change in QOL of 2.6 points ($p \leq 0.001$) (Fig. 3). For patients with leg lymphedema, the average score for burden of conservative therapy prior to operation was 8.1 ± 0.3 (mean \pm S.E.M) points. After operation, the average score fell to 7.9 ± 0.3 points. This positive change in QOL percentage points was not significant ($p = 0.411$) (Fig. 3).

DISCUSSION

The difficulty of measuring Quality of

Life is that it is hard to find a comparable base for evaluation of subjective burdens or conditions. Therefore, quantification and representation of the subjective well-being of the patient is often not assessed despite its value. Validated instruments to gain an assessment of the current condition of the patients are needed (4), and these will be also of value in measuring improvement or degradation of conditions following therapy. Our questionnaire adhered to evaluation of two large ranges in quality of life including physical health (physical functionality, fitness, pain) and mental health (psychological health and well-being) (5). Additionally, we asked about the burden of conservative, non-surgical therapy prior to and after the operation. Therefore, the baseline data represents the situation after having undergone complex physical

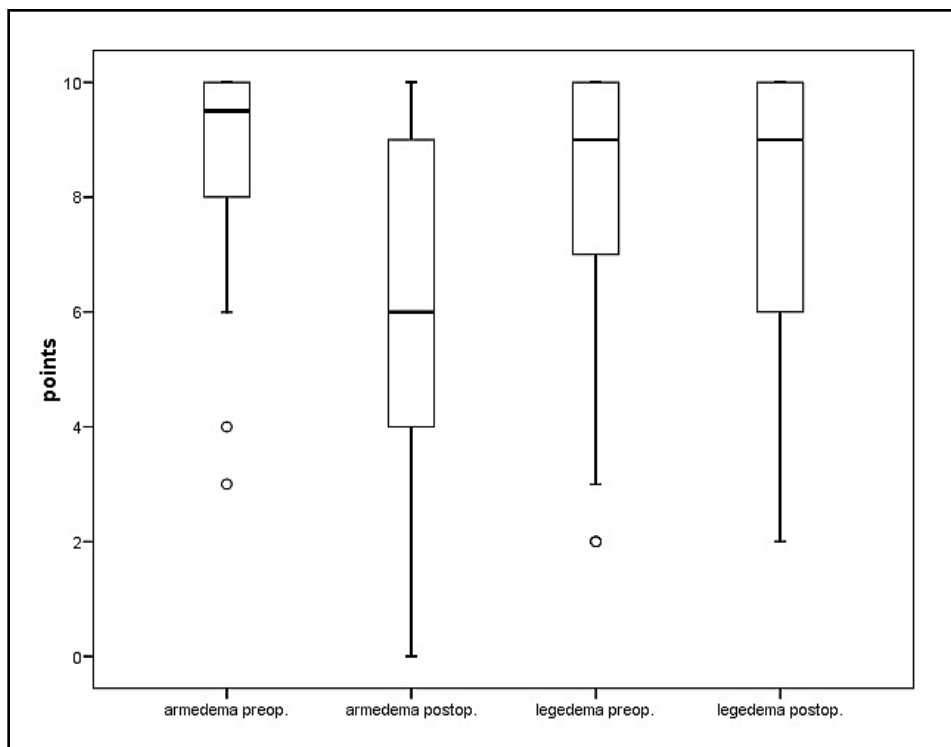


Fig. 3. Quality of life Burden of Conservative Therapy values for patients with lymphedema of the arm (left side) and leg (right side) before and after lymph vessel transplantation. Data are presented as the 25th to 75th percentiles (boxes) with Mean (line in box), S.E. (bars), and outlying data points (circles).

treatment for at least 6 months. The mean duration of edema prior to surgery was 7 years. During this time period the patients underwent conservative therapy according to their compliance. The minimum time period of intensified complex decongestive therapy was 6 months.

In all three assessment categories, an improvement of quality of life was seen after operation. In the Physiological Condition, patients demonstrated higher QOL values after operation, and this result was independent of whether the patients had upper or lower limb lymphedema. This finding may be explained by reduction of edema volume following the operation as has been shown in prior research (6). A lower lymphedema volume should increase mobility of the patients and reduce symptoms such as heaviness and paresthesia in the swollen

tissue as well as the pain caused by tension of the skin.

The improvements in the Psychological Condition are also likely due to the volume reduction, which increases mobility and improves performance of everyday life activities (7). These improvements were seen both in patients with arm and leg lymphedema. In addition, patients generally indicated an improvement in their psychological situation and their social relations, referring to their partners, families, and general social environment. After the operation, they felt life was more worth living, and the problem of finding clothes that fit (which often is a great impairment for patients with lymphedema) was notably eased.

Questions focusing on the Burden of Conservative Therapy which not only causes visible restrictions by wearing compressive

garments but also represents a substantial organizational burden to follow a regular schedule of therapy, demonstrated that patients with arm lymphedema felt their situation was more tolerable after the operation. They also describe reductions in the amount of time spent for conservative therapy and in wearing compressive garments. This matter seems of utmost importance for patients with upper limb lymphedema because wearing elastic garments on their arms is obvious in public. In contrast, patients with lymphedema of the lower limbs, despite also a tendency for amelioration, showed no significant QOL improvement or reduced burden in this range of conservative therapy. One reason might be that patients can hide the elastic stockings on the leg much better than on the arm, and therefore wearing elastic stockings is less disturbing for the patient.

For arm lymphedema, parallels can be seen with the observations from our earlier study in 1990 in which 34 patients with upper limb lymphedema needed a lower frequency of conservative treatment 6 months after lymph vessel transplantation and only 10 needed manual lymph drainage regularly after the operation (8). In addition, only 11 of these 34 needed to wear compressive stockings on a regular basis. Despite these positive results in the arm, it is still unproven whether this result applies to patients with lower limb lymphedema. This difference may relate to the greater difficulty in reducing lymphedema of the lower limb due to the higher hydrostatic pressure in the leg necessitating continued conservative treatment.

Another important effect on our study is the length of time that has passed since the first patient who underwent an operation to completion of this research. The first patient we included in our study had an operation in 1982, which was 25 years prior to the end of our survey. Although this seems a very long time to evaluate a situation prior to an operation, the results seem reliable and were very similar compared to the evaluations of

QOL of patients who underwent the operation only a short time ago.

In prior studies (9), volume reduction achieved after lymph vessel transplantation in arm and leg edemas were analyzed. Average long term volume reductions of 47.5% in patients with upper limb lymphedema and 39.7% in those with lower limb lymphedema correlated with the outcome of this QOL study. These significant decreases in volume would be expected to have a positive effect in everyday life for the patient. Therefore, results of this QOL study can be correlated with prior studies concerning volume reduction of lymphedema after lymph vessel transplantation.

Another interesting finding is the significant reduction in number of required complex decongestive therapy (CDT) sessions after operation in both groups. The number of patients who received CDT more often than eight times per month, in the group with arm edema was reduced from 49 to 19 patients. In the group with patients who had leg edema, the number was reduced from 36 to 25 patients.

Similar results were seen in the necessity of using compression garments. 35 patients with upper limb lymphedema needed continuous use of compression garments prior to the operation with reduction to 16 patients after operation. In the group with leg lymphedema, 48 patients wore compression garments prior to operation and 42 patients after operation.

In summary, lymph vessel transplantation can result in a significant improvement of QOL even for those patients who have undergone conservative treatment for lymphedema for at least 6 months. This improvement allows these patients to realize an improvement in everyday living. Therefore, lymph vessel transplant in carefully selected patients should be considered a viable tool to reduce the constant inconvenience of this disorder.

Note: Copies of the survey instrument

developed by Springer et al in German or English can be obtained from the senior author RGH Baumeister at baumeister@lymphtransplant.com

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