

## QUALITY-OF-LIFE AND BODY IMAGE IMPAIRMENTS IN PATIENTS WITH LYMPHEDEMA

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### ABSTRACT

*The psychological and social consequences of chronic lymphedema are still often overlooked, as is the frequency with which they occur. Secondary lymphedema after mastectomy or breast-conservation procedures following the diagnosis of breast cancer is especially common and represents a substantial problem for those affected. The aim of this study was to investigate differences in body image and quality of life (QOL) between female lymphedema patients and trauma patients and to further monitor the changes in female lymphedema patients during three weeks of rehabilitation. This survey was conducted on 80 female patients at the State Hospital of Wolfsberg/Carinthia, Austria, 40 were trauma patients and the other 40 patients had some type of lymphedema, 20 of these patients were located in the general lymphedema ward and 20 in rehabilitation. The Frankfurt Body Image Questionnaire was used to determine body image, and the German version of the Short Form-36 Health Survey was used to determine QOL. The results indicate that female lymphedema patients are greatly affected in various areas of body image and QOL. Lymphedema patients show significantly lower body image scores in seven of nine areas compared to trauma patients. Female lymphedema patients also describe their QOL as being lower in the areas of general health perception, vitality and*

*mental well-being. After rehabilitation, there were improvements in the evaluation of physical functioning and an increased acceptance of the body. Patients also showed a significant increase in health perception, vitality and mental health.*

**Keywords:** lymphedema, body image, quality of life, breast cancer, cancer survivorship

The psychological and social consequences of chronic lymphedema are still often underrated, as is the frequency with which they occur (1) with only a few empirical studies addressing the issue. Secondary lymphedema after mastectomy, breast-retaining operations and adenocarcinoma is especially common and represents a considerable problem for those affected (2-6). This study aimed to investigate impairments in body image and QOL in female lymphedema patients (7,8) in comparison to a control group. Both groups experience physical changes due to their condition and a reduction in QOL due to temporary or chronic impairments. The effectiveness of rehabilitation measures on the lymphedema ward was also tested. A person's emotional and cognitive perception of her body and the comparison with the prevailing ideal of beauty among women has a strong bearing on feelings of self-esteem and QOL. In modern times, women see slimness as being an ideal (9,10) – a blatant comparison to the

shapelessness and lack of physical aesthetics of lymphedema patients.

Rehabilitation measures also refer to improvements in the symptoms of edema and thus improvements in body image are also expected. Changes in psychological variables and improvements in volume of edematous limbs and BMI (body mass index) are therefore seen as indicators for successful therapy.

## METHODS

The study was conducted at the Department of Lymphology and the Trauma Department at the State Hospital of Wolfsberg/Carinthia, Austria. Inpatients at the lymphology and Trauma Department were requested to answer the Frankfurt Body Image Questionnaire (FKKS) (11) and QOL (12). Data were collected on both socio-demographic and disease-specific aspects. Lymphedema patients were asked questions on primary vs. secondary edema, duration of illness, etiology, stage of edema and limb volume, and trauma patients were questioned about the type of injury suffered. Both groups were asked at the beginning to record the number of limbs affected, their body weight, and height (if necessary the weight was measured – the BMI calculated)

The subjects (n=80) came from two large groups (40 female patients from the Trauma Department and 40 female patients from the Department of Lymphology). The patients with lymphedema were divided with 20 from the lymphedema ward and the remaining 20 from the general rehabilitation ward. The 20 patients in the Department of Lymphology were questioned again at the beginning and at the end of their three week stay in the rehab department.

Women have a 3.5:1 ratio of prevalence of lymphedema compared to men and correspondingly, we carried out the study with female lymphedema patients due to the low number of men in the department. The Frankfurt Body Image Questionnaire (11) was used to determine body image. These

scales were originally developed to determine the physically-oriented dimensions of a person's self-concept, but then further developed into an independent measuring tool for recording a person's body concept. The questionnaire contains nine scales developed through factor analysis (reliability:  $r=.87$  to  $r=.96$ ) :

- 1) Scale on Health and Physical Well-being (German abbr.: SGBK)  $rtt=.77$   
Measured with 6 items; physical well-being
- 2) Scale on Personal Hygiene and Outward Appearance, Consideration of Physical Efficiency (German abbr.: SPKF)  $rtt=.86$   
Measured with 6 items; personal hygiene; outward appearance and consideration of physical efficiency
- 3) Scale on Physical Efficiency (German abbr.: SKEF)  $rtt=.87$   
Measured with 10 items; sensed physical efficiency and mobility
- 4) Scale on Physical Contact (German abbr.: SKKO)  $rtt=.85$   
Measured with 6 items; physical contact pleasantly/unpleasantly
- 5) Scale on Sexuality (German abbr.: SSEX)  $rtt=.59$   
Measured with 6 items; sexuality, attractiveness facing the other sex
- 6) Scale on Physical Self-acceptance (German abbr.: SSAK)  $rtt=.75$   
Measured with 6 items; aesthetic aspects and biological body-functions
- 7) Scale on Physical Acceptance by Others (German abbr.: SAKA)  $rtt=.49$   
Measured with 4 items; thoughts about physical acceptance by others
- 8) Scale on Aspects of Physical Appearance (German abbr.: SASE)  $rtt=.63$   
Measured with 14 Items; distinguishing marks – hair, voice, face, hands
- 9) Scale on Dissimulatory Physical Processes (German abbr.: SDIS)  $rtt=.33$   
Measured with 4 items; body odor, halitosis

The German version of the Short Form-

36 Health Survey was used to determine QOL (SF-36; 12). The survey comprises both physical and mental components of health-oriented QOL, i.e., the subjective perception of health by those affected, and thus especially reflects the definition of health by the World Health Organization (WHO), which explicitly includes mental and social aspects.

The SF-36 health survey comprises eight dimensions of subjective health perception:

- 1) Physical Functioning (PFI)  $\alpha=.94$   
Measured with 10 items; limitations in physical activities because of health problems
- 2) Role Physical (ROLPH)  $\alpha=.89$   
Measured with 4 items; limitations in usual role activities because of physical health problems
- 3) Pain (PAIN)  $\alpha=.88$   
Measured with 2 items; bodily pain
- 4) General Health (GHP)  $\alpha=.76$   
Measured with 5 items; general mental health (psychological distress and well-being)
- 5) Vitality (VITAL)  $\alpha=.80$   
Measured with 4 items; vitality (energy and fatigue)
- 6) Social Functioning (SOCIAL)  $\alpha=.74$   
Measured with 2 items; limitations in social activities because of physical or emotional problems
- 7) Emotional Role Function (ROLEM)  $\alpha=.85$   
Measured with 3 items; limitations in usual role activities because of emotional problems
- 8) Mental Health (MHI)  $\alpha=.80$   
Measured with 5 items; general mental health perceptions

A comparison between lymphedema patients and trauma patients was undertaken to test the varying impact of chronic or temporary impairments. Both measurements were also presented to the 20 lymphedema rehabilitation patients at the beginning and at the end of their stay in the rehabilitation department in order to assess the effect of rehabilitation.

The statistical analyses in the empirical section of this publication were completed using SPSS 10.0. Chi-square, univariate and multivariate covariance analyses were calculated according to the data supplied.

## RESULTS

The average age of the patients was  $52.18 \pm 15.44$  (mean  $\pm$  S.D.; range 18 and 83 years). The sample was median split (Md=55) into two age groups for further calculations. The subjects had a body mass index of between 17.5 and 64.2. The average BMI of all subjects was  $29.97 \pm 8.48$ . Lymphedema patients had a higher average BMI ( $33.82 \pm 9.40$ ) than the patients in the Trauma Department ( $26.13 \pm 5.22$ ) ( $p=0.000$ ). The majority of patients already belong to the category of being "overweight" (BMI >25) or having "adiposity" (BMI >30) (13). The 20 rehab patients were able to attain a significant reduction in BMI after their three week stay in comparison to the first measurement at the beginning of their stay ( $34.94 \pm 9.59$  to  $33.58 \pm 9.07$ ) ( $p=0.000$ ).

The trauma patients had various reasons for their stay in hospital – mainly fractures, torn ligaments, but also knee and hip operations. 15% ( $n=6$ ) of the 40 lymphedema patients suffered from primary lymphedema, and 85% ( $n=34$ ) suffered from secondary lymphedema.

Reasons for the onset of lymphedema (from case history review) showed that the edema had developed postoperatively in 25% ( $n=10$ ) of the subjects, 22.5% ( $n=9$ ) reported onset of lymphedema after carcinoma, 22.5% ( $n=9$ ) did not know the reason for the onset, 15% ( $n=6$ ) indicated that the edema was caused by adiposity, 7.5% ( $n=3$ ) stated that lymphedema had occurred after inflammation, and the remaining 7.5% ( $n=3$ ) equally attributed its onset to heart disease, varicose veins or an injury.

In regard to the progress of lymphedema, 32.5% ( $n=13$ ) of patients were in stage 1, 60% ( $n=24$ ) were in stage 2 and 7.5% ( $n=3$ ) in

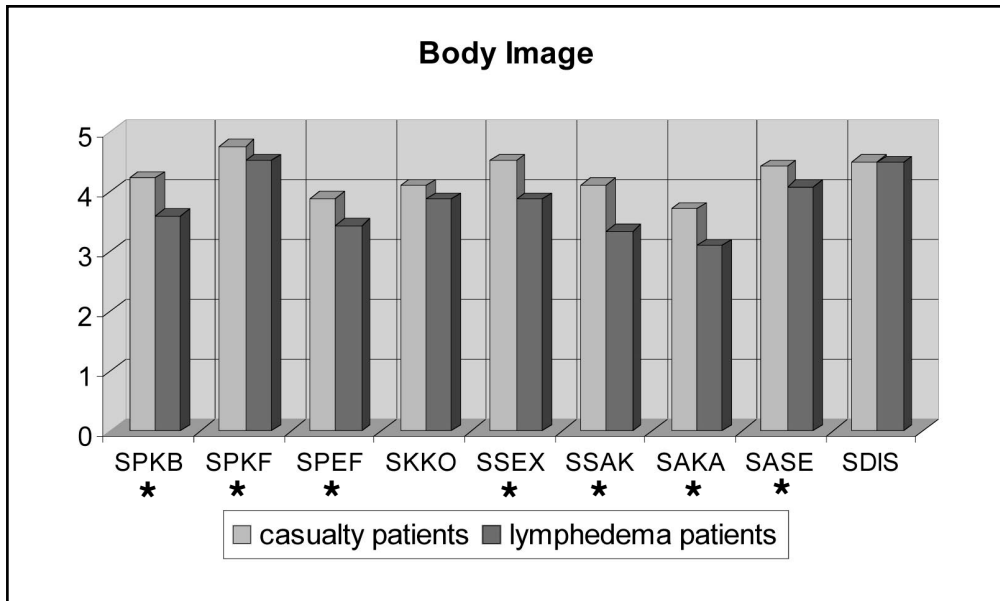


Fig. 1: Body Image from female trauma and lymphedema patients. SGBK: Scale on Health and Physical Well-being Skala, SPKF: Scale on Personal Hygiene and Outward Appearance, Consideration of Physical Efficiency SKEF: Scale on Physical Efficiency SKKO: Scale on Physical Contact, SSEX: Scale on Sexuality, SSAK: Scale on Physical Self-acceptance, SAKA: Scale on Physical Acceptance by Others, SASE: Scale on Aspects of Physical Appearance, SDIS: Scale on Dissimulatory Physical Processes (\*= significantly worse evaluations for lymphedema patients).

stage 3. The average duration of the disease was 11.2 years. Patients in the general lymphedema ward had suffered from lymphedema for an average of 10.85 years and rehabilitation patients for an average of 11.55 years.

The volume of edematous limbs among the 40 patients was recorded by means of computer-assisted volumetry. The 40 lymphedema patients showed an average volume of  $12.36 \pm 5.63$  liters at the beginning of their stay. The 20 rehab patients were able to reduce their average volume of  $13.10 \pm 6.94$  liters at the beginning of the treatment to  $11.89 \pm 6.05$  liters at the end of the treatment, indicating an overall significant average loss in volume of limbs of 1.22 liters.

Various therapeutic measures were carried out during the patients' stay on the lymphedema ward. Complex decongestive physiotherapy was made available to patients, as were many other different therapies including aerobic exercise, physiotherapy,

electrotherapy, ultrasonic therapy, relaxation exercises, biofeedback, adiposity exercise, respiratory therapy, laser therapy and ergo therapy (physical exercise to raise the self-sufficiency, productivity, and recreation e.g., after cerebral insult). Psychologists, social counselors and nutrition experts carried out group training sessions on disease-specific topics. There were also group training sessions on the topic of lymphedema, which aimed to provide insight into the illness for lymphedema sufferers.

The lymphedema patients received an average of  $9.1 \pm 3.00$  different therapeutic treatments during their three week stay, whereby the number of treatments varied between 3 and 16 predominated by complex decongestive therapy.

Differences in physical perception (Fig. 1) were identified when comparing the body image of lymphedema patients and trauma patients.

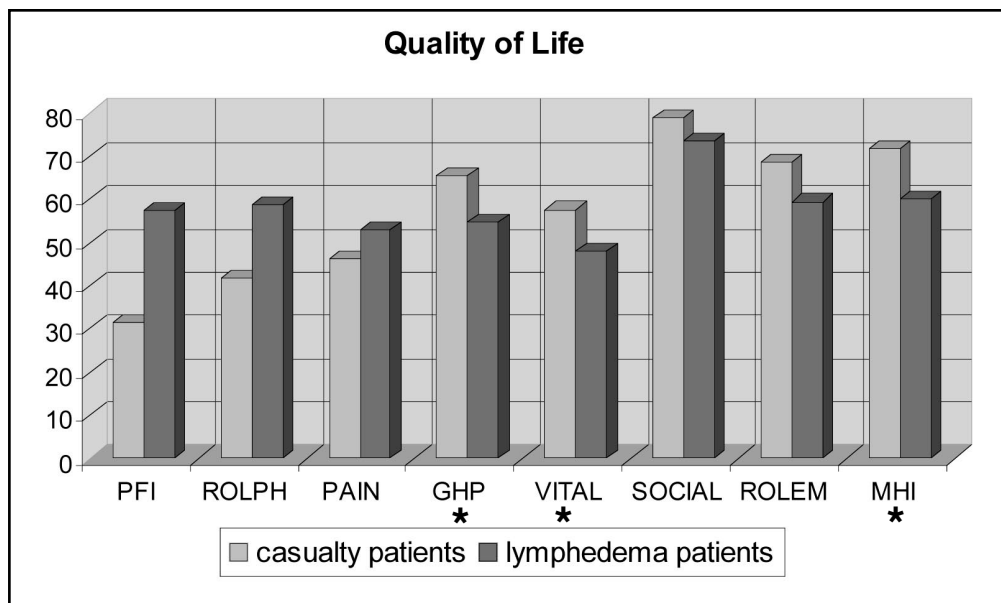


Fig. 2: QOL from female trauma and lymphedema patients. PFI: Physical Functioning, ROLPH: Physical Role Function, PAIN: Pain, GHP: General Health, VITAL: Vitality, SOCIAL: Social Functioning, ROLEM: Emotional Role Function, MHI: Mental Health (\*= significantly worse evaluations for lymphedema patients).

Lymphedema patients showed significantly lower evaluations of their body image than trauma patients in seven of the nine areas represented in the following scales: Health and Physical Well-being (SGBK;  $p=0.004$ ); Personal Hygiene and Outward Appearance, Consideration of Physical Efficiency (SPKF;  $p=0.065$ ); Sexuality (SSEX;  $p=0.000$ ) and in the area of Physical Self-acceptance (SSAK;  $p=0.000$ ); Physical Acceptance by Others (SAKA,  $p=0.006$ ), and Aspects of Physical Appearance (SASE;  $p=0.020$ ). There were no differences between the patient groups in the areas Physical Contact (SKKO;  $p=0.298$ ) and Dissimulatory Physical Processes (SDIS;  $p=0.975$ ).

The results in the area of QOL also showed that the group of lymphedema patients differed greatly from the group of trauma patients (Fig. 2). Lymphedema patients showed significantly lower values on the following QOL Scales: General Health (GHP;  $p=0.012$ ); Vitality (VITAL;  $p=0.071$ )

and Mental Health (MHI;  $p=0.021$ ). No significant differences were noted in other scales.

Twenty patients were tested to evaluate the effect of a three-week stay in the Rehab Department on the Lymphedema Ward. No significant effects were seen in the multivariate analysis (Fig. 3) in the area of Body Image. Trends for improvement in the values of Physical Self-acceptance (SSAK;  $p=0.193$ ), and decreases in the scores for Personal Hygiene and Outward Appearance, Consideration of Physical Efficiency (SPKF;  $p=0.131$ ) and Dissimulatory Physical Processes (SDIS;  $p=0.130$ ) did not reach significance. These trends could reflect a relief in the extensive preoccupation of patients with their own personal hygiene and their specific focus of attention towards their own body.

In the area of QOL, measured with SF-36, significantly higher values were reported in the areas of Vitality (VITAL;  $p=0.010$ ) and Mental Health (MHI;  $p=0.003$ ) at the end of

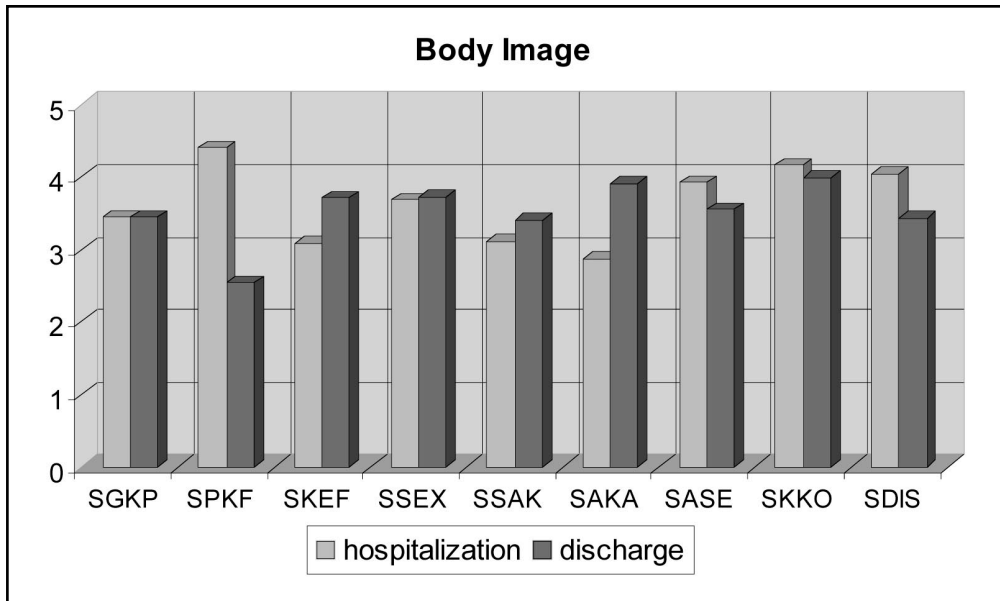


Fig. 3: Body Image from female lymphedema patients during their three week stay. SGBK: Scale on Health and Physical Well-being Skala, SPKF: Scale on Personal Hygiene and Outward Appearance, Consideration of Physical Efficiency SKEF: Scale on Physical Efficiency SKKO: Scale on Physical Contact, SSEX: Scale on Sexuality, SSAK: Scale on Physical Self-acceptance, SAKA: Scale on Physical Acceptance by Others, SASE: Scale on Aspects of Physical Appearance SDIS: Scale on Dissimulatory Physical Processes.

a three week stay in rehabilitation than at the beginning. No significant differences were found in other scales (Fig. 4).

#### DISCUSSION

Several studies (1-10,14,15) have determined reduced QOL in the area of physical health among lymphedema patients. Extensive unsatisfactory QOL among lymphedema patients, little energy and vitality, pain and limited physical functioning have also been reported. Our results confirmed that female lymphedema patients are greatly affected in the various areas of body image and QOL in comparison to trauma patients.

Changes in QOL of lymphedema patients through conservative therapy have been described by Augustin et al (2) with the conclusion that improvements in QOL were especially effective in the areas of physical symptoms. In regard to body image, the

group of trauma patients greatly differed from the group of lymphedema patients in all body image areas. Both groups were not different in the areas of body image and dissimulatory body processes, e.g., body odor, halitosis. Many lymphedema patients exhibited adiposity according to their BMI, but patients with adiposity and without lymphedema report negative self-evaluations in the areas of dissimulatory body processes and impairment in the area of body contact in comparison to people who are not overweight (16).

Lymphedema patients had an extremely negative view of themselves in the area of Physical Functioning, a scale which relates the degree of perceived strength and tenacity as well as the degree of mobility and the flexibility of motor behavior. Carter (17) stated that professions involving heavy lifting and holding and fine motor activities such as writing, typing and all kinds of paperwork

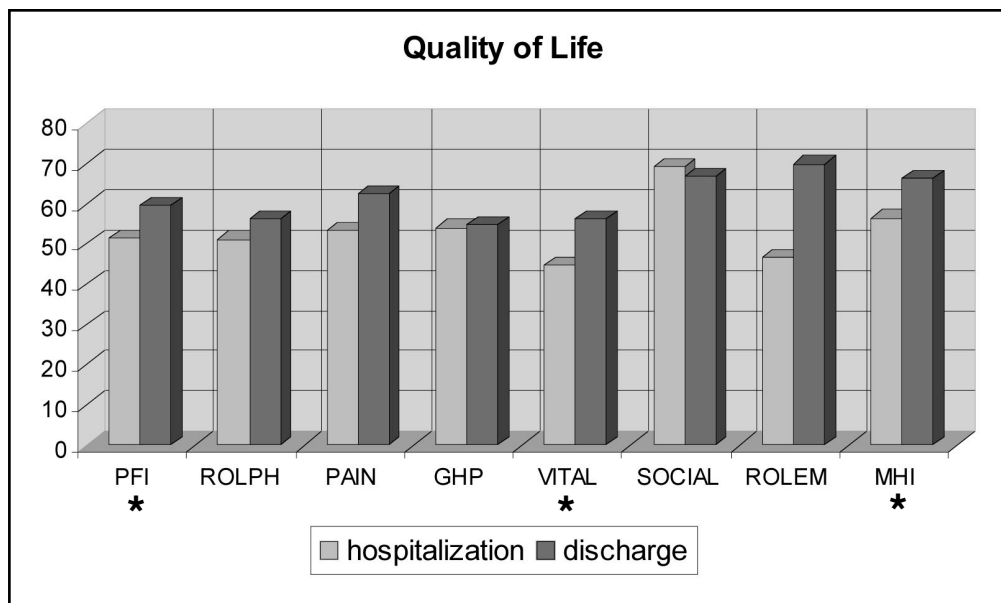


Fig. 4: QOL from female lymphedema patients during their three week stay. PFI: Physical Functioning, ROLPH: Physical Role Function, PAIN: Pain, GHP: General Health, VITAL: Vitality, SOCIAL: Social Functioning, ROLEM: Emotional Role Function, MHI: Mental Health (thick= significantly better evaluations for lymphedema patients after a three week stay).

are very difficult for those suffering from lymphedema and that they may even have to change jobs because they are no longer able to carry out such activities.

Lymphedema patients also showed a negative body image in the area of sexuality. Apart from the obvious problems, which can be determined immediately, such as the deformity of body parts, Carter (17) carried out structured interviews and determined that women suffering from lymphedema often tend to take off their elastic bandages or do not use their lymphatic pump in bed in order to appear more attractive for their partners. It would be of great interest to carry out further investigations on the topic of sexuality among lymphedema sufferers, especially in order to improve counseling and support of people afflicted with the condition. Various recommendations regarding information, which could make life easier for patients with lymphedema, and suggestions for therapy, have been published (18-20).

After rehabilitation, there was an increase

in physical self-acceptance and a decrease in attention to personal hygiene, physical evaluation, and outward appearance and dissimulatory body processes which could be a sign of relief from the extensive preoccupation with body shape and body image. It might be more difficult to alter people's body image than their QOL, but success of the therapy is reflected in both areas.

Attention to mental and social burdens in the treatment of lymphedema patients still proves to be a challenge. There are great discrepancies in the treatment of these patients in different hospitals despite an increased awareness of the problem of integrating physical, mental and social parameters into treatments. Clinical-psychological and psychotherapeutic interventions should thus be increasingly incorporated into the rehabilitation process in order to meet the individual problems described by rehabilitation patients within the framework of a bio-psycho-social treatment model while at the same time addressing the legal task of rehabilitation.

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