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THE EFFECT OF COMPLETE DECONGESTIVE THERAPY ON THE QUALITY OF LIFE OF PATIENTS WITH PERIPHERAL LYMPHEDEMA

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ABSTRACT

Lymphedema is a chronic disorder which can adversely affect quality of life (QOL). The purpose of this study was 1) to evaluate whether QOL was improved in patients with lymphedema following Complete Decongestive Therapy (CDT), and 2) whether limb volume change as a result of treatment correlated with change in QOL. Thirty-six patients with peripheral lymphedema from varying causes were enrolled in the study. The QOL of each participant, with regard to physical, functional, and psychosocial concerns, was measured by pre- and post-treatment questionnaires. Percent edema volume reduction was calculated for each patient with only one affected limb. QOL pre- and post-treatment scores were assessed by multivariate repeated measures analysis. QOL scores differed significantly ($p<0.05$) between pre- and post-treatment in all areas of inquiry. Patients with lower extremity lymphedema had significantly greater mean improvement in QOL scores compared with patients with upper extremity lymphedema ($p=0.02$). There was no correlation between percent edema volume reduction and post-treatment QOL improvement. This study suggests that significant improvements are made in the QOL of patients exhibiting peripheral lymphedema following CDT, which is not necessarily correlated with limb volume reduction.

Lymphedema is the accumulation of fluid in the interstitium from insufficiency in the transport capacity of the lymphatic system (1,2). This condition manifests as swelling of one or more limbs and often the corresponding quadrant of the trunk (1). It is regarded as either primary or secondary depending on the etiology. Primary lymphedema is the result of abnormal development of the lymphvascular system (2-4), whereas secondary lymphedema stems from damage to lymphatics or lymph nodes from trauma, disease, surgery, or irradiation (3,5). Iatragenic causes of secondary lymphedema include diagnostic or therapeutic lymph nodal excision, injuries to adjacent lymphatics, vein stripping, arterial reconstruction, and radiation therapy (2). With multiple etiologies, the true incidence of lymphedema is not known but probably more common than usually appreciated. Primary lymphedema occurs in approximately 1 in 10,000 people by the age of 20 years, with women affected more often than men (4). Each year there are approximately 180,000 new cases of breast cancer in women in the USA and an estimated 75% of these individuals undergo breast surgery with axillary dissection for staging or therapy (5). Some sources report approximately a 30% incidence of arm lymphedema in women who have undergone modified radical mastectomy (2,5-8). Lower extremity lymphedema after operative treatment of prostate, pelvic, or skin cancers

popular dogma of avoiding physical activity especially of the affected arm after breast cancer therapy is clearly misguided. In brief, continued activity at the pre-cancer treatment level is not only more satisfying for the patient but it is not associated with exacerbation of arm swelling. Of course, one presumes that these women with lymphedema faithfully wear a compression garment during exercise. Although most of the increase in blood flow with exercise goes to the muscle compartment (which is not swollen in lymphedema), a small increase in circulation concomitantly occurs in the skin and subcutaneous tissue. Without sufficient external compression, one would anticipate that with a greater microvascular surface area for fluid exchange and capillary filtration, tissue fluid/lymph formation would be enhanced and without the countervailing force of elevated interstitial pressure generated by a low stretch elastic sleeve, edema accumulation would worsen.

In the final analysis, however, QOL issues, while relevant and important to clinical outcome, only indirectly relate to the physical disability associated with secondary arm lymphedema. Not unexpectedly, the benefit of edema reduction has its greatest effect on physical well-being and less so on emotional and psychological symptomatology. Whereas important to address as part of the full clinical picture, QOL is really irrelevant to the success or failure of edema reduction except insofar as motivating compliance. Simplistically, when you correct the physical problem [as Weiss and Spray document (1) and as de Godoy suggests (2) in the case of lower extremity lymphedema], the mental outlook on life typically improves. On the other hand, it is equally clear in the clinical setting of cancer or other life-threatening ailment, edema reduction alone cannot solve myriad other anxiety-provoking concerns. Perhaps, we make too much of an ado about QOL when we address peripheral edema or other physical ailments because correction of the presenting physical abnormality is at least a legitimate beginning to improve patient outlook and performance, and failure to do so is almost certain to aggravate an already compromised attitude toward life. As clinician/researchers, we should still direct most of our efforts and energy to resolving the central physical disability to alleviate suffering, while recognizing that each individual carries a host of co-morbidities and complex ideations that demand understanding and compassion.

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can develop with regional lymph node removal, similar to arm lymphedema after treatment of breast cancer. Genital, unilateral or bilateral lower extremity lymphedema occurs in up to 70% of patients having undergone radical lymph node dissection for prostate cancer (2). One article reported the occurrence of lymphedema in the lower extremity and trunk to be approximately 20% among patients undergoing groin dissection for primary skin tumors (9). Edema or lymphedema associated with lower extremity venous insufficiency may occur from venous decompensation creating an additional workload of excess capillary filtrate on the lymphatic vasculature (2). Sometimes the etiology of the edema is uncertain and there is no clear clinical distinction between lymphedema and other edema. Edema resulting from cardiac failure or surgical procedures, for example, may evolve into a mixture of both edema and lymphedema as the lymph vascular safety factor is exceeded or the lymph transport capacity is compromised.

Numerous emotional and health related problems can result from lymphedema (2,5,10,11). Of great concern is the high risk of infection and skin changes associated with chronic lymphedema. Adverse skin changes develop as tissue texture becomes increasingly fibrotic, which leads to a firm, uncomfortable limb. Lymphangiosarcoma, a rare but usually fatal form of cancer, can develop in an area of longstanding severe lymphedema (2). Patients also experience embarrassment and inconvenience of increased limb size, discomfort, and diminished movement and function of the affected limb, each of which compromise quality of life (10,12,13). Moreover, lymphedema following cancer treatment serves as a constant reminder of the original disease and its treatment, which adds to one's already emotional burden.

No cure exists for lymphedema and treatment is typically aimed at reduction of limb size. Few treatment options existed for lymphedema patients in the USA prior to the mid-1980's. Those available consisted of limb elevation, use of pneumatic compression pumps, and/or compression garments. Treatment involving combined therapies was developed in Europe in the 1930s and was introduced to the USA in the 1980's. One such treatment, complete decongestive therapy (CDT) is now recognized as an effective non-operative technique for management of peripheral lymphedema (5,12,14), and is recommended by the International Society of Lymphology (3). CDT significantly reduces lymphedema volume, which can be maintained with patient compliance and therapist recommendations (5,12,14).

Literature pertaining to lymphedema is becoming more prevalent as this condition is recognized as a disabling disorder and as more effective treatments become available. Most studies evaluating peripheral lymphedema treatment use volumetric measurements of the limb as the primary tool for assessing treatment effectiveness (15). Whereas these measurements are of value, other factors including subjective impressions, psychosocial implications, and other quality of life issues perceived by the patient, need to be considered in the overall assessment of treatment effectiveness (11,15-17). The Oncology section of the American Physical Therapy Association confirms these factors in their recommendation for research into these issues (18). Still other sources site the need for more information on measurable outcomes regarding the impact of lymphedema and treatment on individuals with this condition (10,15,19).

This study was undertaken to examine 1) whether QOL was improved in persons with lymphedema from multiple causes following CDT, and 2) whether limb volume change, as a result of CDT treatment, was associated with change in QOL.

MATERIALS AND METHODS

Subjects

Criteria for inclusion in the study were patients who were physician-referred for lymphedema therapy to a single hospital-based outpatient physical therapy clinic between April 1, 1999 and April 1, 2000. Patients were included in the study if they were able to attend treatment 3-5 times per week, and consented to comply with the entire CDT treatment. Thirty-six adult patients, representing individuals from southwestern Missouri, agreed to participate. Informed consent was obtained from each patient upon entering the study. Demographics on patient characteristics are shown in *Table 1*. The patient population consisted of 10 men and 26 women, accounting for 27.8% and 72.2% of the population, respectively. Patients ages encompassed eight categories in the range of 20-90 years, with most of the patients (61.1%) falling into the age range of 60 to 79 years. The mean and standard deviation for body mass index (BMI) was 30.3 ± 6.7. Patients, in general, tended to be obese regardless of the degree of lymphedema. Approximately 36% of patients reported living alone. The causes related to lymphedema may be found in *Table 1*. Most patients had swelling only in the left arm (30.6%) or both legs (30.6%). Approximately 69% of patients with upper extremity lymphedema had swelling in the non-dominant arm and 31% in the dominant limb. Time from onset of swelling to treatment was extremely variable and likely related to the patient's ability to recall this information. Whereas the mean time from onset of swelling to treatment was approximately 44 months, the range was 1 month to 16.7 years. Nearly one-half of all patients (41.7%) reported having had previous treatment for lymphedema.

Data Collection Tool

In order to assess the quality of life (QOL) among patients, a data collection tool in the form of a questionnaire was created (see Appendix). The questionnaire was drafted in original form (by author JMW) based on frequent concerns patients with lymphedema expressed about their condition, and comments on improvement following treatment. Preliminary observations on many patients with lymphedema revealed that most were concerned with issues far more extensive than limb size alone. The impact the condition had on comfort, ability to function, perceived appearance, and relationship with others was of utmost importance to their QOL. For these reasons, items on the questionnaire were divided into physical, functional, and psychosocial concerns. Questions addressing physical complaints included those of pain and other discomforts, size, texture, strength and motion of the affected limb, and whether they had experienced episodes of infection in their swollen limb. Areas of functional inquiry included to what extent lymphedema interfered with home, work, or recreational activities, and clothing fit. Psychosocial measures inquired about body image, the extent to which lymphedema made them frustrated or depressed, and effects of lymphedema on socializing and relationships with others. The questionnaire consisted of analog scales ranging from 1 (no complaints) —7 (severe complaints). Patients indicated on each scale the degree to which a particular physical, functional, or psychosocial measure affected them. A draft of the questionnaire was reviewed by ten patients with lymphedema, two therapists trained in lymphedema management, ten physical therapists, physical therapy faculty, and a biostatistician. All suggestions for improvement were considered and a final questionnaire evolved. To validate the items which construct the scales for the three attributes (physical, function, and psychosocial), the questionnaire was evaluated by an after-the-fact statistical analysis. This method of validation computes the correlation between each item and the proposed scale as a whole. Questions that were not significantly correlated with the rest of the scale were removed.

TABLE 1
Demographics and Patient Characteristics

Characteristic	N	Percent
Gender		
Male	10	27.8
Female	26	72.2
Living Alone		
Yes	13	36.1
No	23	63.9
Diagnosis related to edema/lymphedema		
Mastectomy	9	25.0
Lumpectomy	4	11.1
Hysterectomy	4	11.1
Other cancers	3	8.3
Venous Insufficiency	1	2.8
S/P DVT	3	8.3
Orthopedic injury/surgery	3	8.3
Vein stripping	3	8.3
S/P cellulitis	1	2.8
S/P necrotizing fasciitis	1	2.8
Congestive heart failure	1	2.8
Primary lymphedema	3	8.3
Location of swelling		
Right UE	5	13.9
Left UE	11	30.6
Right LE	3	8.3
Left LE	6	16.7
Both LE	11	30.6
Dominant arm affected		
Yes	5	31.3
No	11	68.8
Those with previous treatment	15	41.7

	Mean±SD	Range
Time from onset of swelling (months)	43.9±69.3	1- 200
Treatment duration (days)	34.67±19.51	3 - 73
Number of treatments	16.72±9.66	4 - 49
BMI	30.7±6.7	20.7 - 51.6

BMI=Body Mass Index; S/P=status post; DVT=Deep vein thrombosis; UE=upper extremity; LE=lower extremity

Measurements and Procedures

Circumferential measurement was used to determine limb volume due to ease and efficiency in a clinical setting. It also provides adequate information on the distribution of edema within the limb when multiple sites are measured, has yielded reliable volumes in the lower extremities (15,20), and is the manner of measurement commonly reported in scientific literature (21). Measurements were taken with a standard metric tape measure at 5 to 6 sites per limb in patients exhibiting upper or partial lower extremity lymphedema. Measurements were taken at eight sites when patients presented with full lower extremity lymphedema. An attempt was made to obtain same-site repeated measures. This was accomplished on the lower extremity by placing a measuring board under the patient's leg and measuring at identified intervals. Upper extremity measurements were taken at identified intervals using a tape measure along the lateral aspect of the arm. Measurements were taken by one of four therapists experienced in lymphedema management. Edema volume was calculated using the formula for estimating the volume of a truncated cone: Volume $=H (Ct^2 + Ct \times Cb + Cb^2) /12$, where H = height, Ct= circumference of the top of the cone, and Cb = circumference at the base of the cone (5,12,14). Volumes for each segment were summed to arrive at total limb volume. Percent edema volume reduction was calculated by comparing the affected to the unaffected limb volumes in patients with unilateral limb swelling. Documentation of percent edema volume reduction is the most commonly cited means of reporting change in size of a lymphedematous limb (5,12,14,16).

Subjects completed a questionnaire at the initial visit. Circumferential measurements were recorded during the initial evaluation, periodically throughout treatment, and at the final visit. Each patient underwent a course of CDT 3-5x per week. Duration of treatment in weeks depended on the severity of the patient's condition and individual response to treatment. CDT consisted of manual lymph drainage (MLD), compression bandaging, exercise, and skin care. Patients were issued compression garments as a final component of the treatment. A complete description of the methodology of CDT treatment is given by Ko et al (14). MLD is a light massage technique, performed in a particular sequence. In theory, it stimulates lymph vessels to contract more frequently and move tissue fluid to functioning non-obstructed lymphatic regions (14). Manual lymph drainage was performed for 45 minutes when a single limb was affected, and for 30 minutes per extremity on those with bilateral lymphedema. Treatments were performed by a physical therapist or a massage therapist certified in the Vodder technique of MLD. The limb was washed and a low pH skin lotion (Eucerin, Beiersdorf, Inc, Norwalk, CT) was applied prior to bandaging. Compression bandaging was applied to the limb using padding (Artiflex, Beiersdorf Inc, Norwalk, CT) and low stretch bandages (Rosidal K, Lohmann Gbgh, Neuwied, Germany) utilizing gradient compression decreasing from distal to proximal on the limb. Patients were instructed to perform muscle and joint pumping exercises twice daily, while wearing bandages, to assist with lymphatic drainage *(Tables 2,3)*. Muscle contraction against the rigid support of low stretch bandages results in increased superficial lymphatic vessel activity and improves lymph transport (22). Compression garments (either Jobst, Beiersdorf-Jobst, Toledo, OH or Juzo, Julius Zorn, Cuyahoga Falls, OH) were issued at the completion of intensive therapy and the patient was instructed in proper donning and wear. Instructions were also given for edema-control activities to be continued at home. Two weeks following discharge, each patient returned to the clinic for limb measurements and QOL was reassessed via the questionnaire. No patient was lost to follow-up.

TABLE 2
Exercises Performed by Patients with Upper Limb Lymphedema*

1. Take 10 deep breaths.
2. Slowly roll head side to side. 10x
3. Shoulder shrugs, inhaling while raising the shoulders and exhaling when lowering. 10x
4. Tighten your abdominal muscles and press your low back against the chair. Exhale while tightening the muscles for 5 seconds. 10x.
5. Press your hands together at shoulder level in front of you and hold 5 seconds while exhaling. 10x
6. Pretend you are pulling on the ends of a 2 foot stick held in front of your chest for 5 seconds. Exhale while pulling. 10x
7. Alternately reach your arms overhead in front of you and pull your hand toward your chest, as if climbing a ladder. 20x.
8. Stretch both arms out to your sides, then cross them across your chest and hug your shoulders with your hands. 10x
9. Reach your hand in the air and turn your wrist as if unscrewing a light bulb. 10x.
10. Rotate wrists in circles. 25x.
11. Open and close your fingers. 25x.

*Sitting in chair with good back support

Data Analysis

Scores for QOL were obtained from the questionnaire by summing the answers for those questions that contributed to each attribute separately (physical, functional, psychosocial). In other words, the numeric value, which each patient indicated for each question, was summed across questions that specifically addressed the issues of that attribute, being either physical, functional, or psychosocial. A lower score indicated better QOL. Comparisons of QOL scores, obtained pre- and post- treatment, were evaluated by multivariate repeated measures analysis of covariance using procedures in SAS (Statistical Analysis System) (23). The advantage of such an analysis is that it requires fewer experimental units because each patient serves as his/her own control, thereby eliminating subject variability from experimental error. Patient demographics and characteristics *(Table 1)* were initially entered into the analysis as covariates to adjust for potential differences in QOL scores which may have arisen from factors other than treatment. In addition, a treatment function value (treatment time/number of treatments) was calculated for each patient in order to assess differences in treatment regimen that might affect QOL scores.

All data are presented as mean ± SD (standard deviation). Spearman's rank-order correlation (24) was computed to determine if edema volume reduction was related to change in QOL post-treatment among patients with unilateral lymphedema. The variable reflecting the change in QOL was

TABLE 3
Exercises Performed by Patients with Lower Limb Lymphedema*

1. Take 10 deep breaths.
2. Slowly roll head side to side. 10x
3. Shoulder shrugs, inhaling while raising the shoulders and exhaling when lowering. 10x
4. Perform partial sit-ups bringing the head and shoulders up, causing the abdominal muscles to tighten. 10x
5. Gently pinch the buttocks together as you lift your bottom up slightly. 10x
6. Bend your hips and knees bringing the knees toward your chest. 10x
7. Place your hands on the outside of your thighs, and gently press your hands toward each other as you push your thighs apart. 10x
8. Place a pillow between the knees and squeeze the pillow. 10x
9. Gently tighten muscles on top of your thighs, causing the knees to straighten and hold for 5 seconds. Exhale while tightening the muscles. 10x
10. Place the knees in a slightly bent position and then lift one foot up until the knee straightens. Alternate with the other leg. 10x
11. With the knees slightly bent, press the heels into the surface trying to bend them a little further. Exhale as you hold this exercise 5 seconds. 10x
12. Rotate your ankles in circles and pump them up and down. 25x

*Lying on bed with leg elevated on several pillows

calculated by subtracting the post-treatment score from the pre-treatment score. This method generally yielded a positive value.

RESULTS

The mean pre-treatment lymphedema volume for all patients combined was 4703 ± 2897 cm^3. Mean post-treatment volume was 2750 ± 2329 cm^3. The mean arm volume for pre-and post-treatment was 3086 ± 763cm^3 and 2038 ± 1285 cm^3, respectively. Mean leg volume for pre- and post-treatment was 7936 ± 2898 cm^3 and 4175 ± 3287 cm^3, respectively. There was a total reduction in lymphedema volume of 66.4% for all patients. Mean arm and leg volume reduction was $56 \pm 37\%$ and $87 \pm 68\%$, respectively.

Mean pre- and post-treatment QOL scores for each of the three attributes are shown in *Fig. 1*. The mean pre- and post-treatment scores for physical aspects were 27.2 ± 8.2 and 14.8 ± 6.7, respectively. Mean pre- and post-treatment scores for functional attributes were 21.0 ± 8.5 and 11.8 ± 8.1, respectively. Mean QOL scores for psychosocial measures also differed from pre- to post-treatment (11.5 ± 6.5 and 7.5 ± 5.6, respectively). Scores for each of the attributes (physical, functional, and psychosocial) differed significantly ($p<.03$) from pre- to

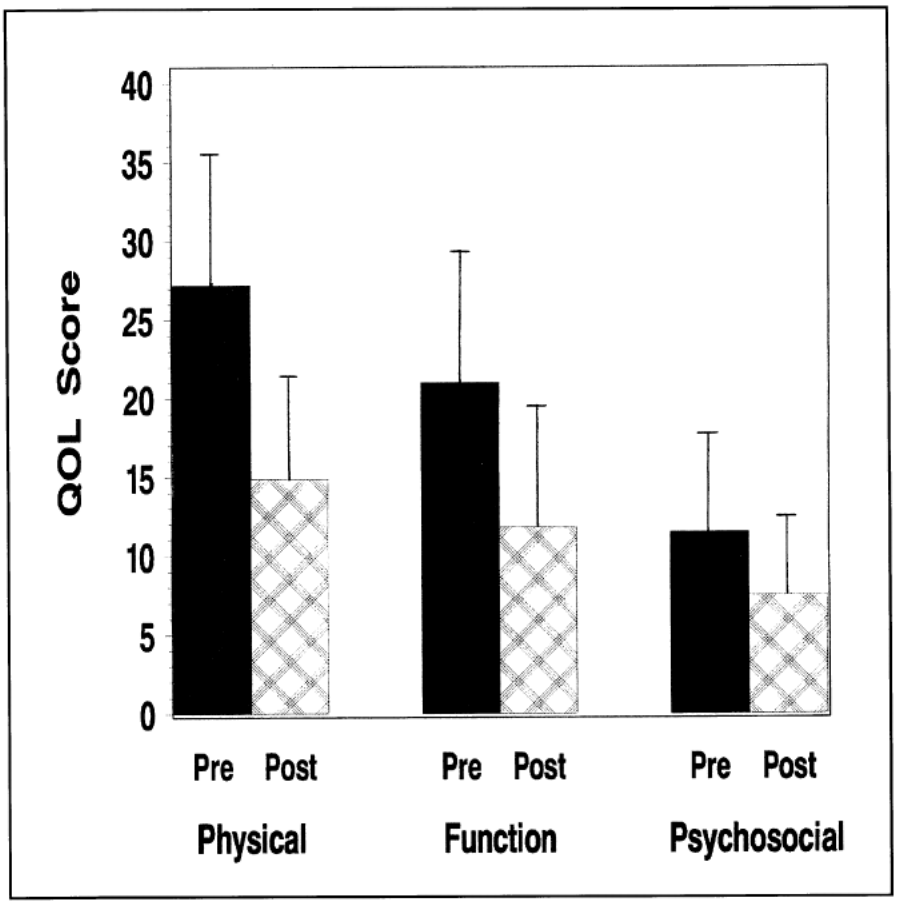

Fig. 1. Pre- and post-treatment quality of life (QOL) scores (mean ± standard deviation) assessing physical, functional, and psychosocial attributes of patients with upper or lower extremity lymphedema. Note that the lower scores indicate better QOL (see Questionnaire in the Appendix).

post-treatment, indicating an improvement in QOL owing to improved physical, functional, and psychosocial measures after CDT treatment. Patient characteristics, with the exception of location of swelling, did not have a significant effect ($p>.05$) on any of the QOL attributes from pre- to post-treatment. There was some evidence from the repeated measures analysis of covariance that treatment function was associated with change in QOL of psychosocial attributes. This phenomenon was not easily explainable and most likely due to chance attributed to the small sample size.

Post-treatment change in QOL for physical attributes differed significantly ($p=0.02$) among patients with upper versus lower limb edema, as shown in *Fig. 2*. There was a greater decrease in QOL scores post-treatment for patients with lymphedema in one or both lower extremities (15.5) when compared to those patients with swelling in either upper extremity (8.4). This decrease suggests that CDT treatment improved QOL more dramatically in those with leg lymphedema than in those patients with arm lymphedema by means of physical improvement.

The correlations between edema volume reduction and change in QOL after treatment were -0.19, -0.26, and -0.29, respectively, for physical, psychosocial, and functional

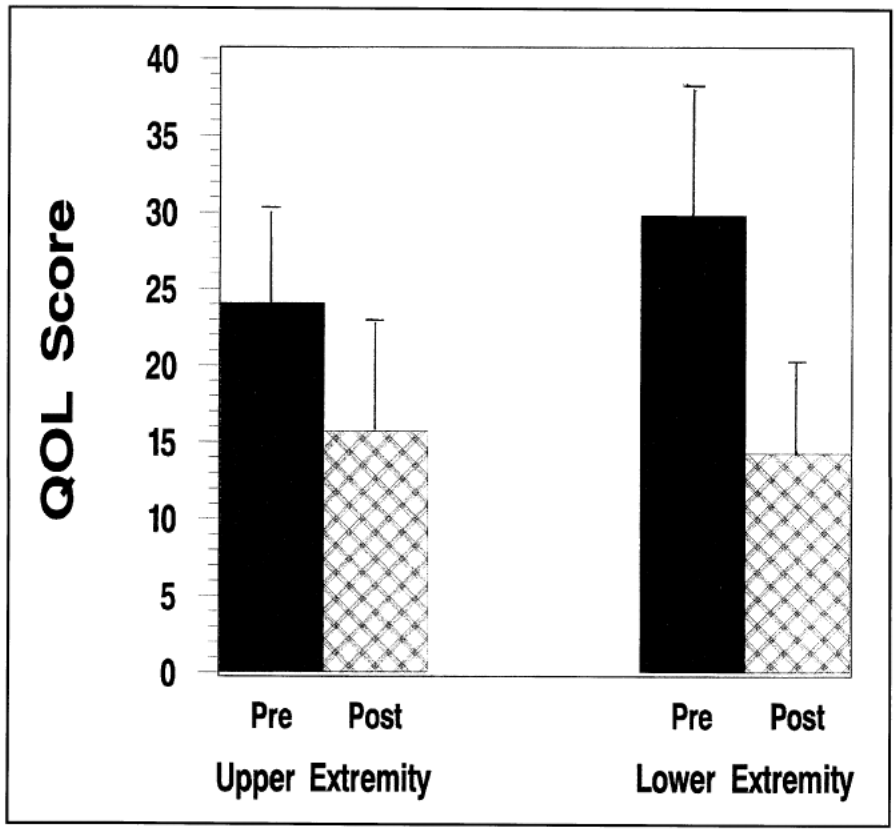

Fig. 2. Pre- and post-treatment quality of life (QOL) scores (mean ± standard deviation) for physical attributes of patients with upper and lower extremity lymphedema. Note that the lower scores indicate better QOL (see Questionnaire in the Appendix).

attributes. Although there was a trend toward an association between decreased edema volume with an increased change in QOL scores (as noted by the negative correlations), this trend was not statistically significant ($p>0.1$). This may be due in part to the small sample of patients available for data collection. Percent edema volume reduction was calculated in only 24 of the 36 patients because 12 had swelling in both limbs; it was not possible to evaluate percent volume reduction for those bilaterally affected.

DISCUSSION

Lymphedema from multiple causes adversely affects QOL. Among patients with breast cancer, arm lymphedema negatively influenced lifestyle due to pain, limited clothing options, and functional impairment at work, home, and during recreation (6,17). Additional studies have revealed poorer QOL measures among patients with breast cancer related arm lymphedema when compared with those without arm lymphedema (13). In a recent article of breast cancer survivors, Passik and McDonald found women with arm lymphedema experienced higher levels of psychological, social and functional morbidity when compared with women without arm lymphedema (11). In this study, participants indicated via a pretreatment questionnaire that lymphedema had an adverse impact on their physical, functional, and/or psychosocial capabilities.

The present study suggests that CDT in

lymphedema patients significantly improves QOL. Overall, patients reported post-treatment improvements in physical, functional, and psychosocial aspects, as determined by the questionnaire. CDT had the greatest impact on physical measures. Sitzia and Sobrido (16) reported similar improvements in QOL of patients with lymphedema following MLD or simple massage and compression bandaging. Using the Nottingham Health Profile Part 1 (NHP-1), they reported that patients had the greatest improvement in physical mobility. They also concluded that the NHP-1 was useful in assessing physical aspects of QOL, but less helpful with regard to psychological and emotional attributes. The data collection tool used here was able to detect significant changes in physical, functional and psychosocial post-treatment measures.

Additionally, this study revealed better improvement in physical QOL measures, post-treatment, among patients with lower limb lymphedema than those with upper limb lymphedema. Perhaps this finding relates to those presenting with lower extremity swelling having more diverse etiologies of their condition. Those with lower extremity swelling may have had more of a mix of edema and lymphedema which responded more rapidly and effectively to CDT treatment. It is of interest that patients with lower limb lymphedema presented with poorer physical attribute scores, pre-treatment, when compared with those with upper extremity swelling. This occurrence is likely attributable to a relatively large percentage of individuals having bilateral lower extremity lymphedema and greater areas of involvement, when contrasted to patients with only upper unilateral limb involvement. As of 1997, Sitzia and Sobrido (16) were unable to find reports comparing QOL of patients with upper limb edema to those with lower limb edema.

Limb volume reduction is assumed to be an important measure of treatment success as gauged by the large number of studies using it as an outcome for analysis. Dennis (25) noted that patient satisfaction after treatment appeared to be associated with amount of limb volume reduction, although few have quantified the reduction necessary for a successful outcome (15). Despite significant edema volume reductions with CDT, the results from this study did not support an association between limb volume reduction and QOL among the three attributes tested, a finding supported by others (16,26). The lack of association suggests that edema volume reduction is only part of what influences improvement in QOL.

Several instruments are described for assessing the impact of lymphedema on QOL. Velanovich and Szymanski used the SF 36 to measure QOL in breast cancer patients with arm lymphedema (13). The Nottingham Health Profile is regularly used in British studies of this nature and has undergone evaluation of validity and reliability (16). Mirolo et al developed a lymphedema subscale, the Wesley Clinic Lymphedema Scale (WCLS) from the Functional Living Index – Cancer (FLIC), and applied this measuring tool to the QOL of lymphedema patients (26). Sitzia in a review of outcome indicators, noted an absence of measures important to patients, citing in particular the areas of limb movement and pain (15). The questionnaire developed for this study was designed to measure outcomes on those concerns most important to patients with lymphedema. Many authors have conveyed the need for research that explores the impact of lymphedema on QOL, functional ability, psychosocial functioning, body image, and self-esteem (10,15,19), and the QOL questionnaire was designed to explore those specific areas. It also met 5 of 6 criteria recommended by Strawbridge as important to measuring QOL (27). Mortimer et al (7) found straightforward inquiry both useful and reliable in ascertaining the presence of arm swelling in patients treated for breast cancer, and it seems reasonable that similar inquiry would also be helpful for measuring QOL.

CONCLUSION

This is the first known report that examined the effects of CDT on QOL of patients with lymphedema from a wide variety of etiologies. It further demonstrates that significant improvement may be made in the QOL of these patients after CDT with regard to physical, functional, and psychosocial aspects. The study also reports the differing effects of treatment on QOL among patients with upper compared with lower limb lymphedema, and suggests that QOL is greatly diminished among those with bilateral leg lymphedema. Post-treatment QOL scores for physical measures were significantly greater among this latter group of patients when compared with patients with unilateral upper limb lymphedema. Results of this study also support previous studies that found limb volume reduction unrelated to improved QOL in patients with peripheral lymphedema. This finding emphasizes the need for evaluating concerns of importance to the patient, and not merely objective measures of limb volume reduction. Further research, supported by larger patient populations, may be required to determine which treatment method best improves QOL of patients with varying characteristics and sites of lymphedema.

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Appendix. Lymphedema Questionnaire

Listed below are symptoms or problems many individuals with lymphedema report. Please indicate to what extent these problems associated with your lymphedema have affected you in the past 2 weeks. Circle one number; #1 indicates no complaint and #7 the most severe complaint.

1. The amount of pain associated with my lymphedema is:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
no pain severe pain

2. The amount of other uncomfortable sensory complaints (heaviness, tightness, burning, tingling, numbness, etc.) List your complaints and number their severity.

_____ _____ _____ _____ _____
1-7 1-7 1-7 1-7 1-7

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
no complaints severe complaints

3. In comparison to my unaffected limb, the size of my swollen limb seems:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
same size extremely large

4. The skin texture of my swollen limb feels:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
normal extremely firm

5. Lymphedema restricts movement of my swollen limb:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
full movement no movement

6. The strength in my swollen limb compared with the normal limb:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
equal strength extremely weak

7. How often have you become ill with an infection in your swollen limb requiring oral antibiotics or hospitalization **in the past 2 YEARS.**

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
never <1x/yr 1-3x/yr 4-6x/yr 7-9x/yr 10-12x/yr >12x/yr

8. Lymphedema affects my body image (ie. "how I think I look"):

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all severely

9. Lymphedema interferes with socializing with others:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all completely

10. Lymphedema interferes with intimate relations:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all always

11. Lymphedema "gets me down" (i.e., feelings of depression, frustration, or anger due to the lymphedema):

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
never continuously

12. Lymphedema interferes with duties at home:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all completely

13. Lymphedema interferes with duties at work: Answer this only if it applies.

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all completely

14. Lymphedema interferes with my preferred recreational activities:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all completely

15. Lymphedema interferes with the proper fit of clothing:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all greatly

16. Lymphedema interferes with my sleep:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all greatly

17. I must rely on others for help due to my lymphedema:

1 ----------2 ----------3 ----------4 ----------5 ----------6 ----------7
not at all completely