DOI: https://doi.org/10.4038/gmj.v30i3.8237



# Evaluation of psychosocial support for lymphatic filariasis-related lymphoedema using the PSB-CL15 questionnaire

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*Submitted on 27.08.2024 and accepted for publication on 30.04.2025*

## ABSTRACT

**Introduction:** Lymphoedema (LE) due to lymphatic filariasis (LF) is considered a neglected, lifelong disease. This study aims to deliver and evaluate psychological support provided to a sample of patients using a newly developed, culturally appropriate questionnaire.

**Methods:** Two groups of patients with lymphoedema due to lymphatic filariasis in Southern Sri Lanka were enrolled in a case-control study to assess the effect of psychosocial support on their Psychosocial Burden (PSB) using a disease-specific questionnaire (PSB-CL15).

**Results:** The scale scores indicated a significant improvement in the total score as well as in all four dimensions (social, physical, fear, and humiliation) following the psychosocial support intervention. However, the humiliation dimension appeared more resistant to improvement according to the individual item analysis.

**Conclusions:** The psychosocial burden of LF patients with LE can be successfully alleviated through psychological support, and the dimensions of PSB can be effectively identified using the PSB-CL15 questionnaire.

**Keywords:** *Chronic lymphoedema, Lymphatic filariasis, Psychosocial support, PSB-CL15 questionnaire.*

## Introduction

Lymphatic filariasis (LF) is a chronic, debilitating disease that occurs due to living or dead parasites blocking the lymphatic vessels of dependent parts of the body (1). This blockage leads to chronic swelling called lymphoedema (LE), which persists throughout the patient's life. Patients with LE due to LF suffer from enormous physical and psychosocial burden (PSB) (2).

Sri Lanka was acknowledged to have eliminated LF as a public health problem in 2016 (2), considering the low transmission rate of the disease (3). However, LE and its related disease burden have not been eliminated and have persisted for decades. The physical management of LE *i.e.* Community Home-Based Care (CHBC) has been incorporated into the national programme through the Anti-Filariasis Clinics (4). However, adequate psychosocial support appears to be lacking.

When designing a method to provide psychosocial support for LE patients, the ability to assess the outcomes of the method is essential. The assessment of psychosocial support should be both reliable

and effective. Since the PSB of LF is considered culturally specific (4), and LE-related PSB encompasses multiple facets of stressors, a pre-planned, single method of psychosocial support will not be suitable for everyone. Different dimensions of PSB must therefore be assessed using an effective method-both before and after psychosocial support-to determine its effectiveness. The Psychosocial Burden in Chronic Lymphoedma Questionnaire - 15 items (PSB-CL 15) have been developed and validated to address this issue (5).

When providing psychosocial support to LE, in-depth interviews with patients could be the most effective approach for assessing individual cases. However, a disease-specific questionnaire with the ability to screen multiple dimensions is the most appropriate method for achieving concurrent validity. PSB-CL15 validated Sinhala translation is the most appropriate currently available tool designed for local Sri Lankan setting (5).

The aim of the study was to assess the PSB of patients with LE and to evaluate the psychosocial support provided by a specially designed intervention programme. The study assessed adaptive and progressive psychosocial support provided by the designed programme to a group of LE patients with LF in comparison to a control group of LE patients that receives routine care.

## Methods

Patients were enrolled in the study from the Anti-Filariasis Campaign, National Hospital Galle, and the Filarial Research and Training Unit, University of Ruhuna after obtaining written informed consent. A total of 60 patients who had moderate to severe psychosocial burden according to the PSB-CL15 assessment (cut-off = 11) were randomly assigned to each arm of the case–control study (30 patients per arm).

The intervention programme comprised multiple components: one-hour psychosocial support session and a 30-minute health education session. The health education programme included information on LF and its treatment, presented with illustrations using a specially prepared booklet.

The PSB-CL15 scale was administered to identify psychosocially dominant areas that required intervention. If a patient scored high in a particular dimension, special attention was given to the corresponding issues. Patients were advised to maintain a diary noting on how their PSB originated, their thoughts at the time, and how they responded and recovered from each situation.

The test group received four sessions of psychosocial support, including the baseline session, over a period of six weeks. The subsequent three sessions were conducted at specific intervals of one, two, and six weeks after enrolment. At each meeting, the test group received a new session on Community Home-Based Care (CHBC). Patient diaries were reviewed at each clinic visit, and participants were instructed to continue maintaining the diary until the six-month follow-up meeting with the investigation team.

The control group received only routine CHBC training as a part of Morbidity Management and Disability Prevention (MMDP) programme during monthly and three-monthly clinics following the baseline session. Routine CHBC did not include psychosocial care and focused solely on the physical management of the affected limb.

### Blinding process:

The overall coordinator randomized the selected sample and was blinded to the PSB-CL15 scores. The intervention programme was blinded to the patients; however, it was not blinded to the clinical psychologist. Baseline results and patient group allocations were blinded to the assessors. Data unblinding was performed only after completion of the study for statistical analysis.

### Analysis

The final analysis was conducted as pre-planned, using data from 30 patients in each arm. The PSB-CL15 scores at baseline (pre-intervention) and after six months (post-intervention) were compared using independent sample t-tests (Figure 1).

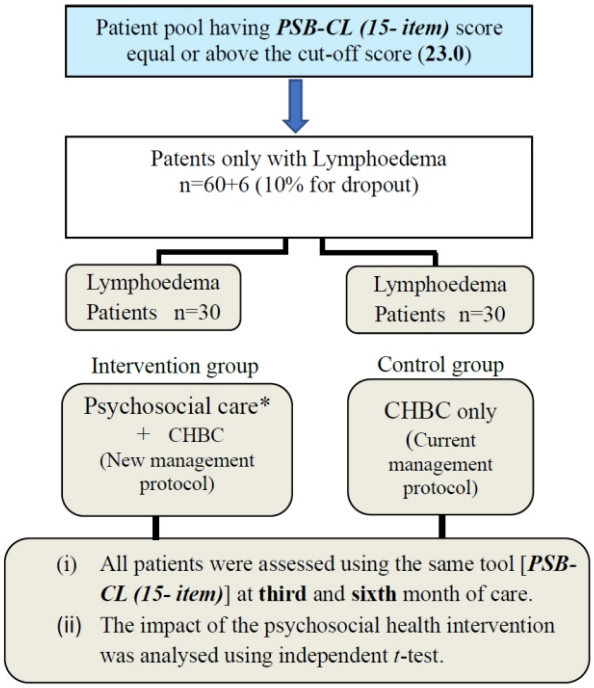


**Figure 1:** Flowchart showing the method of intervention

## Results

### Comparison of demographic data between intervention and control groups at baseline

Table 1 indicates that the proportion of females (58.3%) in the intervention group was slightly higher, but the gender ratio was nearly the same in both the intervention and control groups. The mean age was slightly higher in the control group (52.4 years), but the difference was not statistically significant. The age group distribution also remained comparable between the two groups at baseline.

Both groups had equal numbers of married and unmarried patients. The educational level of the overall sample was satisfactory (over 71.7%). However, a few patients in the intervention group (10%) had completed only primary education, whereas the proportion of patients with only primary education was significantly higher in the control group (36.7%, $p<0.01$). In contrast, a significantly higher proportion of patients in the intervention group (50.0%, $p<0.01$) had studied up to or beyond the GCE Advanced Level (A/L).

Nearly twice as many patients were unemployed in the control group (53.3%) compared to the intervention group (30.0%), although this difference was not statistically significant ($p=0.06$). Approximately 90% of patients in both groups belonged to the middle- and low-income categories, and income distribution was comparable between the intervention and control groups at baseline.

A considerable proportion of patients (around 40%) were not employed in either group, but the employment status distribution remained comparable between the intervention and control groups. The affected limb (right or left) was not considered in the analysis, as PSB scores did not show any association with the affected side. No patients with upper limb swelling were included in the study.

Lymphoedema grading was conducted according to Dreyer's classification (6) and both the intervention and control groups had comparable numbers of patients with mild and severe grades of lymphoedema at baseline (Table 1).

Mean PSB-CL15 scores were not significantly different between test and control groups except for the mean score of social dimensions ($p=0.02$); thus, the two groups were comparable at baseline. In post intervention, there is a statistically significant difference between mean scores of test group and control group in all four dimensions tested ($p < 0.001$ in all) (Table 2).

### Assessment of the success of the intervention programme using PSB-CL15 scale mean scores

There was a slight increase in the total mean score in the control group (27.6 vs. 28.4), whereas the corresponding score in the intervention group was significantly reduced after the intervention programme (25.4 vs. 11.6; $p<0.001$).

Analysis of the dimension mean scores showed that, in the intervention group, post-intervention mean scores of all four dimensions were significantly improved compared with those of the control group. In contrast, the control group demonstrated only a marginal improvement in the physical dimension.

A total mean score reduction of 13.8 points was observed in the intervention group following the intervention programme. However, the corresponding score in the control group remained almost unchanged or showed a slight increase. The mean score reduction in the intervention group was most notable in the physical (4.5) dimension, followed by fear (4.3), social (4.0), and humiliation (1.1) dimensions, in descending order (Table 3). The only dimension that showed a slight improvement in the control group was the physical dimension (0.3) (Table 2).

**Table 1:** Comparison of the baseline data of the intervention (n= 30) and control (n=30) groups

| Characteristic | Intervention Group n (%) | Control Group n (%) | Total n (%) | *p-v*alue |
|---|---|---|---|---|
| **Gender** | | | | 0.793 |
| Male | 13 (43.3) | 12 (40.0) | 25 (41.7) | |
| Female | 17 (56.7) | 18 (60.0) | 35 (58.3) | |
| **Age group (years)** | | | | 0.502 |
| 14 - 40 | 8 (26.7) | 7 (23.3) | 15 (25.0) | |
| 41 - 60 | 16 (53.3) | 13 (43.3) | 29 (48.3) | |
| >60 | 6 (20.0) | 10 (33.4) | 16 (26.7) | |
| Mean age (SD) years | 47.5 (13.9) | 52.4 (15.5) | 49.9 (14.7) | 0.199 |
| **Marital status** | | | | 0.626 |
| Married | 14 (46.7) | 20 (66.7) | 34 (56.7) | |
| Unmarried | 15 (50.0) | 5 (16.7) | 20 (33.3) | |
| Living together after divorce | 0 (0.0) | 1 (3.3) | 1 (1.7) | |
| Widowed | 1 (3.3) | 4 (13.3) | 5 (8.3) | |
| **Educational status** | | | | 0.004 |
| No schooling | 1 (3.3) | 2 (6.6) | 3 (5.0) | |
| Primary education | 3 (10.0) | 11 (36.7) | 14 (23.3) | |
| Up to GCE O/L | 11 (36.7) | 14 (46.7) | 25 (41.7) | |
| GCE A/L or above | 15 (50.0) | 3 (10.0) | 18 (30.0) | |
| **Current employment status** | | | | 0.060 |
| Currently working | 21 (70.0) | 14 (46.7) | 35 (58.3) | |
| Unemployed | 9 (30.0) | 16 (53.3) | 25 (41.7) | |
| Household monthly income (Rs.) | | | | 0.400 |
| <20,000 | 11 (36.7) | 10 (33.3) | 21 (35.0) | |
| 20,000 - 40,000 | 14 (46.7) | 18 (60.0) | 32 (53.3) | |
| >40,000 | 5 (16.6) | 2 (6.7) | 7 (11.7) | |
| **Employment category** | | | | 0.754 |
| Professional/ semi-professional | 2 (6.7) | 1 (3.3) | 3 (5.0) | |
| Skilled worker | 3 (10.0) | 5 (16.7) | 8 (13.3) | |
| Semi-skilled worker | 9 (30.0) | 11 (36.7) | 20 (33.4) | |
| Self-employed | 2 (6.7) | 3 (10.0) | 5 (8.3) | |
| Unemployed/ housewife | 14 (46.6) | 10 (33.3) | 24 (40.0) | |
| **Lymphoedema status** | | | | 0.927 |
| Lower grades (I & II) | 31 (86.1) | 33 (86.8) | 64 (86.5) | |
| Higher grades (≥III) | 5 (13.9) | 5 (13.2) | 10 (13.5) | |

**Table 2:** Mean scores in different dimensions and total scores obtained by PSB-CL15 scale in both interventions (test) and control groups at baseline and post-intervention time points.

| Dimension | Baseline | | Post-intervention | |
|---|---|---|---|---|
| | Control Group | Test Group | Control Group | Test Group |
| **Social** | 10.3±1.9 | 8.8±2.7 | 11.2±1.4 | 4.8±2.1 |
| | $t$=-2.4; $p$=0.02 | | $t$=-14.1; $p$<0.001 | |
| **Fear** | 6.1±1.6 | 6.0±2.7 | 6.2±1.4 | 1.6±1.4 |
| | $t$=-0.2; $p$=0.86 | | $t$=-12.4; $p$<0.001 | |
| **Humiliation** | 3.6±1.8 | 2.9±2.4 | 3.7±1.6 | 1.8±1.5 |
| | $t$=-1.3; $p$=0.2 | | $t$=-4.7; $p$<0.001 | |
| **Physical** | 7.6±1.0 | 7.7±1.7 | 7.4±1.0 | 3.3±0.7 |
| | $t$=0.3; $p$=0.8 | | $t$=-17.6; $p$<0.001 | |
| **Total** | 27.6±3.9 | 25.4±5.6 | 28.4±3.1 | 11.6±2.8 |
| | $t$=-1.7; $p$=0.09 | | $t$=-22.2; $p$<0.001 | |

Independent sample $t$-test was employed with 2 tailed significance $p$=0.05

**Table 3:** PSB-CL15 mean score change in each dimension

| Domain | Group | Mean change | *t*-test | *p*-value |
|---|---|---|---|---|
| Social | Control | 0.90 ± 0.40 | | |
| | Test | -3.97 ± 0.40 | -8.9 | <0.001 |
| Fear | Control | 0.13 ± 0.22 | | |
| | Test | -4.33 ± 0.41 | -9.6 | <0.001 |
| Humiliation | Control | 0.10 ± 0.30 | | |
| | Test | -1.07 ± 0.26 | -2.9 | 0.005 |
| Physical | Control | -0.27 ± 0.19 | | |
| | Test | -4.47 ± 0.32 | -11.3 | <0.001 |
| Total | Control | 0.87 ± 0.67 | | |
| | Test | -13.83 ± 0.77 | -14.4 | <0.001 |

Mean change expressed in mean ±SEM; Independent sample $t$-test was employed with 2 tailed significance $p$=0.05

Item-by-item mean score change analysis of both the intervention and control groups showed that the **physical** and **fear** dimensions recorded the highest reductions in mean scores (Table 4). The greatest mean score reduction was observed in item 14 (physical dimension) of the PSB-CL15 scale: *"Do you suffer from intermittent fever as a result of this disease condition?"*. The second highest reduction was also recorded under the physical dimension: *"Do you have difficulty in sitting or standing due to this disease condition?"*. The third highest reduction was recorded under the fear dimension: *"Do you have any fear that this disease will worsen further?"*

Only three items showed slight improvement in the control group, mainly within the physical dimension-specifically, *"Do you suffer from intermittent fever as a result of this disease condition?"* and *"Do you have difficulty in sitting or standing due to this disease condition?."*

**Table 4:** The mean item score changes in PBS-CL15 scale

| Questions in PSB-CL 15 | Mean change ± SEM | | *t*-Test | *p*-value |
|---|---|---|---|---|
| | Test group | Control group | | |
| 1. Has your diseased condition affected your day-to-day activities adversely? | -0.40±0.14 | 0.13±0.09 | -3.2 | 0.002 |
| 2. Do you experience any discomfort during travelling as a result of this disease condition? | -0.20±0.09 | 0.27±0.13 | -3.0 | 0.004 |
| 3. Do you get the assistance of the others in attending to your work as a result of this disease condition? | -0.33±0.10 | 0.07±0.11 | -2.7 | 0.008 |
| 4. Are you disgusted or frustrated with your life as a result of this disease condition? | -1.83±0.23 | -0.07±0.11 | -6.9 | <0.001 |
| 5. Do you feel sorry for yourself when you see a person "hale and hearty"? | -0.53±0.15 | 0.10±0.17 | -2.8 | 0.007 |
| 6. Do you have any fear that this disease will worsen further? | -1.97±0.19 | 0.10±0.07 | -10.2 | <0.001 |
| 7. Do you have any fear that you would become disabled for a long? | -0.87±0.16 | 0.17±0.08 | -5.6 | <0.001 |
| 8. How much this disease is troublesome to you when considering your health and other issues? | -0.87±0.16 | 0.17±0.11 | -5.3 | <0.001 |
| 9. Do you have worries that other members of your family will get infected with this illness through you? | -1.30±0.18 | 0.10±0.27 | -4.3 | <0.001 |
| 10. Do you try to keep this diseased condition a secret from the others? | -0.43±0.12 | 0.20±0.09 | -4.2 | <0.001 |
| 11. Do you feel ashamed whenever your neighbours see your diseased condition? | -0.53±0.16 | 0.17±0.24 | -2.4 | 0.02 |
| 12. Do you think your family members will feel ashamed as a result of your disease condition? | -0.10±0.13 | -0.27±0.14 | 0.9 | 0.38 |
| 13. Do you have difficulties in sitting or standing due to this disease condition? | -2.07±0.20 | -0.10±0.11 | -8.7 | <0.001 |
| 14. Do you suffer from intermittent fever as a result of this disease condition? | -2.60±0.14 | -0.27±0.14 | -11.6 | <0.001 |
| 15. Do you suffer from pain as a result of this disease condition? | 0.20±0.17 | 0.10±0.06 | 0.6 | 0.58 |

Mean change expressed in mean ± SEM; Independent sample t-test employed with 2 tailed significance $p$=0.05

## Discussion

The primary aim of this study was to evaluate the effectiveness of the psychological support given to patients with LE due to LF. The scale effectively assessed the intervention by producing meaningful and interpretable results. Psychosocial support, primarily designed to reduce disease-related fear and build confidence through the Community Home-Based Care (CHBC) programme, led to significant improvements in number of domains (Table 4, items 4 and 6).

A modest improvement in physical parameters was also observed in the control group, which received only CHBC as part of MMDP programme, consistent with previous findings (7). The PSB-CL15 scale was sensitive enough to detect this minor improvement, confirming its potential as a reliable monitoring tool. When CHBC was combined with psychosocial support, a synergistic effect was evident, particularly in the physical dimension (Table 4, items 13 and 14). These findings confirm that the PSB-CL15 scale can effectively assess and monitor PSB among LE patients.

The study also demonstrated that psychosocial support can significantly reduce PSB scores within six months. However, wider implementation of such programmes depends on the human and financial capacity of national MMDP systems (8). As Sri Lanka's current MMDP framework lacks structured psychosocial and socioeconomic rehabilitation components, the present study provides evidence to support integrating these elements. To facilitate this, a booklet titled *Guidelines for the Psychosocial Management of Patients with Lymphoedema due to Lymphatic Filariasis* has been prepared for use by medical officers (9).

## Limitations

Although the intervention showed positive outcomes, several limitations were noted. Improvements varied across dimensions, with humiliation showing minimal change, indicating the need for broader socioeconomic interventions. The short duration (six months) is limited to long-term assessment. Comorbidities, demographic imbalance (notably more females and educational differences), and varying literacy levels may have influenced results, though investigator assistance reduced bias. The effect of family income on psychosocial burden remained unclear, as economic stress appeared linked more to social expectations than income itself.

## Conclusions and recommendations

The PSB-CL15 scale proved to be a valid tool for monitoring psychosocial burden and the effectiveness of interventions among LE patients. The combined approach of CHBC and psychosocial support yielded significant improvements in physical and psychological well-being. To sustain and enhance these outcomes, Sri Lanka's MMDP programme should incorporate psychosocial and socioeconomic rehabilitation components, including social inclusion, income-generating activities, and welfare linkages, as recommended by WHO (2).

Psychosocial care must be individualised, as a uniform intervention may not suit every patient. Future studies should focus on evaluating diverse psychosocial models to better address patient-specific needs and reduce the stigma associated with lymphoedema.

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