

Original Research Article

## **Impact of Lymphatic Filariasis on Quality of Life of Affected Individuals: A Community Based Cross Sectional Survey**

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### **ABSTRACT**

**Background:** Lymphatic filariasis is an important public health problem worldwide. Global Programme to Eliminate Lymphatic Filariasis (GPELF) is based on two strategies (i) interrupt transmission and (ii) morbidity management to reduce the disability. This study evaluated the effect of lymphatic filariasis on the affected patients.

**Methodology:** Community based cross sectional study was conducted for 2 months between June-July 2015 among 66 lymphatic filariasis patients. Structured questionnaire was used for the interview and the results were analysed using SPSS version 20.

**Results:** Out of 66 patients 39 (59%) were males and 27 (41%) were females. Mean duration of disease was 17.2 years. Majority (98.5%) of the patients had lymphedema of lower limb. Mean overall quality of life score was 69.81. There was no significant difference in the overall quality of life score between males and females. The overall quality of life score increased with increase in severity of the disease. Least domain specific score was observed in the domain of mobility and 2/3<sup>rd</sup> of patients had psychological problems and problems in social participation.

**Conclusion:** Morbidity management programmes should also focus on the psychological and social aspects of the disease along with physical rehabilitation of the patients.

**Key words:** Impact, Lymphatic Filariasis, patients, quality of life.

### **INTRODUCTION**

Lymphatic filariasis (LF) is an important public health problem worldwide. Globally it is ranked as second leading cause of chronic disability amongst other causes. An estimated 120 million people are infected and 1.3 billion are at risk of infection worldwide. Estimated 40 million people suffer disabling clinical manifestations. [1] Nearly one third of the affected people are living in India. Changes in the lymphatic system due to the infection leads to varying clinical manifestations like lymphedema, hydrocele, chyluria, elephantiasis and others. [2,3] The clinical

manifestations of the disease usually appear many years after the initial infection and the disease does not cause immediate mortality. [4] In many circumstances the disability remains uncorrected even after medical treatment. The resulting chronic disability due to the disease lasts for decades and it affects even the day to day activities of the affected individual. The major problem of the disease is managing the chronic disability and the indirect effects associated with it. The individual faces difficulties in fulfilling the day to day activities due to the chronic disability associated with LF and this makes the individual dependent on the

family members. Either the affected person is not able to go for work or their working capacity is affected leading to economic and other associated psychosocial problems in the family. They also face emotional problems and social stigmatization [4-9] due to their disease status. The disease also has indirect effect on the family members in the form of economic and social problems. All the above mentioned factors like effect on daily routines, occupation status, and emotional, economic and social problems affect the quality of life of the LF patients. Occurrence of acute painful attacks in the form of acute filarial lymphangitis (AFL) or acute dermato lymphangio adenitis (ADLA) is common among LF patients which creates additional burden. The strategies of Global Programme to Eliminate Lymphatic Filariasis (GPELF) focus on interruption of LF parasite transmission and morbidity management to reduce the disability. [1,3,10] Since morbidity management is one of the components of GPELF, it is important to assess the extent of the effect of morbidity on the physical, psycho-social problems faced by the affected individuals for the success of the programme. This study focused on assessing the quality of life of lymphatic filariasis patients.

#### **Objectives:**

To study the quality of life (QOL) of lymphatic filariasis patients

#### **METHODOLOGY**

A community based cross sectional descriptive study was conducted among 66 lymphatic filariasis patients residing in an urban area of Tiruchirappalli. All the patients were confirmed cases of lymphatic filariasis who were taking treatment in Filariasis Morbidity Control Clinic at Woraiyur, Tiruchirappalli. The clinic provides services for management of morbidities associated with filariasis, health education, community surveys and other programme related activities. A total of 125 patients were availing the services in the clinic. For the purpose of feasibility, 66 patients who were residing in Woraiyur

were selected for the study. The study was carried out between June-July 2015. Ethical clearance was obtained from the Institute Ethical Committee. Details of the patients were obtained from the morbidity control clinic. After obtaining informed consent, each individual patient was interviewed in their home using Lymphatic Filariasis Specific Quality of life Questionnaire (LFSQQ). LFSQQ is a validated questionnaire [11] developed by Institute of Applied dermatology, Kerala, India to assess the quality of life (QoL) of lymphatic filariasis patients. The questionnaire includes various domains of problems related to lymphatic filariasis. It assesses the patient's health status in the past 30 days through 7 domains: Mobility, self care, usual activities, disease burden, pain/discomfort, psychological health and social participation. Each domain has various numbers of questions/items which address the problems due to the disease status. Each item is scored under five categories - no problem, mild, moderate, severe and most severe. Since some questions may not be applicable for all patients, the overall quality of life is calculated based on the number of questions answered and raw score. Total score ranges from 0 to 100 where Zero indicates worst QoL and 100 indicates better QoL i.e., Higher the score better is the quality of life. Information on the socio-demographic details of the participants was also collected. Dreyer's staging was used to assess the clinical stage of lymphedema among the participants. The data was entered in MS excel and analyzed using SPSS version 20.0. Student t test and spearman correlation was used to assess the relation between the variables. The proportion of participants who had the results was presented in the form of mean and percentage.

#### **RESULTS**

Of the 66 patients interviewed 39 (59%) were males and 27 (41%) were females. Mean age was 56.38 and 53.33 among males and females respectively.

**Table 1: Age, occupation and socio-economic status of the patients**

S. No	Age group	Number (%)
1	31-39 years	6 (9)
2	40-49 years	25 (37.9)
3	50-59 years	17 (25.8)
4	≥60 years	18 (27.3)
Occupation status		Number (%)
1	Employed	24 (36.4)
2	Unemployed	42 (63.6)
Socio-economic status <sup>[12]</sup>		Number (%)
Class I Upper		1 (1.5)
Class II Upper Middle		9 (13.6)
Class III Lower Middle		18 (27.3)
Class IV Upper Lower		21 (31.8)
Class V Lower		17 (25.8)
		66 (100)

Majority (37.9%) of the study population belong to 40-49 years of age. Table 1 shows the age distribution of the patients. The mean duration of disease was 17.2 years in the study group. Only 36% of the study population were employed and rest (63.6%) were unemployed. More than 50% of the study population belonged to upper lower and lower socio-economic status based on modified Kuppuswamy classification for 2015.

**Table 2: Clinical profile of the patients**

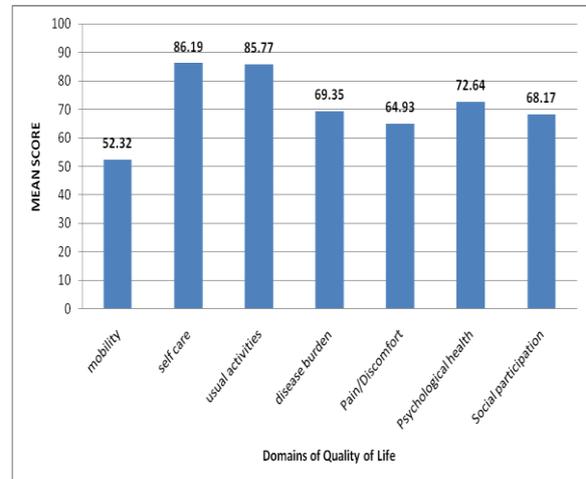
Clinical manifestation	Number (%)
Lymphedema of lower limb	59 (89.4)
Lymphedema of upper limb	1 (1.5)
Hydrocele and lymphedema of lower limb	6 (9.1)
Stages of lymphedema <sup>a</sup>	
1 Swelling reversible overnight	4 (6)
2 Swelling not reversible overnight	29 (44)
3 Shallow skin folds	17 (25.8)
4 Skin knobs	7 (10.6)
5 Deep skin folds	5 (7.6)
6 Presence of "mossy lesions"	4 (6)
7 Unable to care for self	0

a- Dreyer's staging <sup>[13]</sup>

Majority (89.4%) of the study population had lymphedema of lower limb and only 1 person presented with lymphedema of upper limb. The lymphedema was reversible in only 6% of the study population and rest of the participants has some problem related to lymphedema. Table 2 shows the clinical profile of the patients.

Mean overall quality of life score was 69.81. There was no significant difference in the overall quality of life score between males (69.8) and females (69.7) with t value of 0.09 and p value of 0.993. The overall quality of life score increased

with increase in severity of the disease with r value of 0.74 and p value of 0.00. Spearman correlation was used to analyze the relation between severity of disease and QoL score.



**Figure 1: Bar chart showing mean quality of life scores for each domain**

Least domain specific mean score of 52.32 was noticed in the domain of mobility, which means the quality of life of lymphatic filariasis patients of this study was poor in this domain. Highest domain specific score of 86.19 was observed in the domain of self care which denoted that the patients were able to take care of their own activities. Figure 1 shows the mean quality of life scores for each domain.

In the present study we observed that a small proportion of lymphatic filariasis patients had very severe problem in all the domains of Indian lifestyle of LFSQQ. Majority of the patients had either mild or moderate problem. In the domain of mobility patients had severe problems when they had to walk for a long distance, stand for a long time and climb steps. Most of the patients did not have severe problem in taking care of themselves. Within the domain of usual activities, patients did not have problems in their own household activities but they had problems in gardening, agrarian work and continuing their job. Almost 40% of the patients did not face associated problems of the disease like fever, wound, itching except for limb weight where 50% of the patients had problems due

to the weight and size of their limb. For each question under psychological health and social participation only a small proportion (30%) of the patients were in the category of no problem due to the disease and the rest (70%) had at least some

problem due their disease status ranging from mild to very severe problem because of their disease status. Table 3 and 4 shows the quality of life scores for each domain under LFSQQ.

**Table 3: Proportion of study population who had impact of lymphatic filariasis on physical health parameters**

Domains	No problem	Mild	Moderate	Severe	Very severe
<b>Mobility</b>					
Sitting & getting out of chair	24.2	33.3	16.8	15.1	10.6
Sitting & standing from floor	7.6	12.1	45.4	27.3	7.6
Standing a long time	9.1	13.7	16.7	42.3	18.2
Lying down over cot	60.6	15.1	15.1	4.6	4.6
Climbing steps	13.6	21.2	21.2	22.7	21.2
Putting foot wear	25.5	21.2	25.5	9	18.8
Walking long distance		9.1	22.7	43.9	24.3
Traveling by public transport	18.2	39.4	13.6	21.2	7.6
<b>Self care</b>					
Dressing	81.8	6.1	12.1	-	-
Bathing	63.6	27.3	9.1	-	-
Washing clothes	39.4	22.7	25.8	9.1	3
Using Indian toilet	50	13.7	6.1	21.2	9
Using European toilet	Not answered since none of the participants had European toilet in their house				
<b>Usual activities</b>					
cooking	68.2	22.7	6.1	3	
cleaning the floors	59.1	27.2	4.5	7.6	1.5
Gardening	42.4	48.5	6.1	1.5	1.5
Agrarian work	19.7	33.3	21.2	12.1	13.6
Leisure activities	42.4	37.9	7.6	1.5	10.6
Continuing Job	25.8	24.2	25.8	9.1	15.1
Education	Not applicable for the study participants				
<b>Disease burden</b>					
Filarial fever	39.3	30.3	22.7	-	7.7
Foul smell	54.5	21.2	15.1	4.5	4.5
Itching	34.8	25.8	22.7	13.6	3
Wound	45.4	27.2	25.7	1.5	-
Weight of the limb	7.5	48.5	18.2	15.1	10.6
<b>Pain/Discomfort</b>					
At night	42.4	28.8	13.6	4.5	10.6
During day	27.2	30.3	24.2	15.1	3
Walking	-	45.4	22.7	19.7	12.1
Sitting	25.7	15.1	39.3	19.7	-
Joint pain	22.7	25.8	34.8	-	16.7
In unaffected limb	56	34.8	4.5	4.5	-
Painful ulcer	65.1	18.2	16.7	-	-

**Table 4: Proportion of study population who had impact on psychological and social health**

Domains	No problem	Mild	Moderate	Severe	Very severe
<b>Psychological health</b>					
Sense of failure	30.3	21.2	18.2	18.2	12.1
Fear something bad might happen	62.1	13.6	6	18.2	-
Discouraged/tensed about future	37.9	30.3	19.7	12.1	-
Feeling neglected by friends, family	37.9	30.3	18.2	13.6	-
Feeling lonely	43.9	37.9	12.1	-	6
Feeling tensed about your disease	45.5	9.1	15.1	12.1	18.1
Difficulty in concentration, memory	43.9	18.1	9.1	16.7	12.1
<b>Social participation</b>					
Change in life style	22.7	33.3	24.2	13.6	6
problem in moving around freely without feeling self-conscious	43.9	21.2	25.6	-	9.1
problem in approaching people	34.8	31.8	9.1	12.1	12.1
problem joining in social activities	37.8	10.6	30.3	9.1	12.1
problem faced because of ill health	27.2	24.2	25.7	22.7	-

## DISCUSSION

The domain of mobility had lowest domain specific mean score of 52.32 compared to other domains. Difficulty in mobility might affect occupation of the patients which was reflected in difficulty in continuing the job among 75% of the patients and 63.6% of the patients were unemployed. Majority (73%) of the study population belonged to economically productive age group but they had difficulty in job related activities either they had to quit the job or reduce their working hours. Thus the disease had an indirect effect on the economic status of the family. More than 50% of them were in upper lower and lower socio-economic category. Significant impact of lymphatic filariasis on socio-economic status was shown by other studies where the cost of treatment of acute attacks and loss of work time contributed for the low economic status among the participants. [14,15] All the participants in the present study had lymphedema which was similar to another report in India. [16] In the present study 65 (98.5%) participants presented with lymphedema of lower limb, except for one female patient who had lymphedema of upper limb. This is similar to another study which reported that majority of the patients with lymphedema had involvement of lower limb. [17] Among the participants of the present study, edema of the lower limb was severe enough to cause problems in mobility like standing for long time, walking long distance, climbing steps and sitting down. The same was reflected in the mean total quality of life score as a low mean score in the domain of mobility. The mean score was also low in the domain of disease burden due to the occurrence of acute painful attacks which affects the quality of life of the affected individuals. Effect of lymphatic filariasis on mobility and problems of acute attacks have been described in few other studies. [14,15,18] The responders of the present study had high mean total score in the domain of self care which means that the affected individual were able to take care of the daily activities on their own.

Psychological health was affected in almost 70% of the study participants. A literature review on health related quality of life among lymphedema patients reported that lymphedema patients experience higher level of psychological problems that general population. [19] On an average 70% of the participants in the present study had problems in social participation which reflected the other study reports where social isolation among the participants was noticed. [20,21] There were reports of treatment neglect due to social isolation.

## CONCLUSION

Quality of life of lymphatic filariasis patients was affected mainly due the problems in mobility followed by disease burden because of the acute painful attacks of lymphadenitis and lymphangitis. Improvement in the quality of life scores can be used as a method to assess the effect of morbidity management for the patients. Almost two third of the affected individuals had problems in psychological health and social participation. Morbidity control programmes should also focus on improving the psychological health of the patients and social acceptance of the disease.

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