

Research Article

# Assessing the Quality of the Life of Lymphatic Filariasis Patients with Elephantoid Legs in a Post Mass Drug Administration (MDA) Phase Residing in Cherthala Taluk, Alappuzha

Shilpa M<sup>1</sup>, KN Panicker<sup>2</sup>, Teena Mary Joy<sup>3</sup>

<sup>1</sup>MPH Scholar, <sup>3</sup>Associate Professor, Department of Community Medicine and Public Health, Amrita Institute of Medical Sciences, Kochi, Kerala, India.

<sup>2</sup>Professor, Emeritus, Amrita Institute of Medical Sciences, Kochi, Kerala, India.

DOI: <https://doi.org/10.24321/0019.5138.202286>

## I N F O

### Corresponding Author:

Teena Mary Joy, Department of Community Medicine and Public Health, Amrita Institute of Medical Sciences, Kochi, Kerala, India.

### E-mail Id:

teenatixon@gmail.com

### Orcid Id:

<https://orcid.org/0000-0002-2127-7709>

### How to cite this article:

Shilpa M, Panicker KN, Joy TM. Assessing the Quality of the Life of Lymphatic Filariasis Patients with Elephantoid Legs in a Post Mass Drug Administration (MDA) Phase Residing in Cherthala Taluk, Alappuzha. J Commun Dis. 2022;54(3):27-31.

Date of Submission: 2022-08-22

Date of Acceptance: 2022-09-25

## A B S T R A C T

**Introduction:** Elephantoid legs due to past LF infection are common in Cherthala, Alappuzha, Kerala. The physical disability refers to impairment of bodily functions and difficulties in performing daily chores. The study aims to assess the quality of life of filarial patients in the post MDA phase.

**Objectives:** To assess the quality of life of lymphatic filariasis patients in the post MDA phase.

**Methodology:** A cross sectional study was conducted at Thaickal and Chethy Panchayats of Cherthala through health camps with the help of the Accredited social health activists (ASHAs). People with lymphoedema living in these areas were considered eligible for the study after taking their consent. 114 chronic filarial patients were recruited for the study employing a validated questionnaire; Lymphatic Filariasis Specific Quality of Life Questionnaire (LFSQQ). The domain scores were expressed as mean with standard deviation. An independent t-test was used to compare the mean scores among various groups based on demographic characters.

**Results:** Among the 7 domains, the least score was for the mobility domain indicating that mobility was the major concern affecting in their quality of life. The highest domain score was observed in the Psychological Health domain indicating that they have mentally adjusted to this condition.

**Conclusion:** In the present study to assess the quality of life of LF patients, the least domain score was for mobility and the highest domain score was for Psychological Health.

**Keywords:** Lymphatic Filariasis, Lymphoedema, Quality of life

## Introduction

Lymphatic Filariasis (LF) remains a major Public Health problem in central Kerala, India in the coastal areas despite the interruption of transmission employing the Mass Drug Administration. Elephantoid legs due to past infection are very common in these parts, causing serious morbidity and disability. It is well known that it has many serious social repercussions due to the strong stigma attached to the disease, because of the deformity/disability caused by the disease. The stigma results in social isolation, emotional distress, and delay in diagnosis and treatment.<sup>1</sup> The morbidity and disability impair the normal daily activities of the patients who suffer from the disease. The disability associated with Lymphatic Filariasis shows varied patterns ranging from tolerable to severe. Functional performance is assessed based on the components of activities of daily living. The first component is Self-care which includes using the toilet, bathing, grooming and dressing. The second component is that of mobility which includes movement; climbing, walking and standing. The next component of domestic activities includes clean up, washing clothes, preparing food and purchasing articles.<sup>2</sup>

We are assessing the quality of life of lymphatic filariasis patients based on these domains. To prevent lymphoedema from getting worse, patients should be referred to a lymphoedema therapist so that they can be educated about some basic principles of care such as hygiene, elevation, exercises, skin and wound care, and wearing appropriate footwear.<sup>3</sup> The Global Programme to Eliminate Lymphatic Filariasis (GPELF) has two main pillars, one being Mass Drug Administration to interrupt transmission and the second is the management of morbidity, the which is by prevention of adenolymphangitis attacks of lymphatic vessels which occurs repeatedly. Repeated episodes of adenolymphangitis cause the aggravation of pain, oedema and physical disability. Daily practice of foot care reduces the risk of secondary bacterial infections and exercising the limbs helps to increase the lymph flow. Measures to reduce lymphoedema in initial stages reduces the risk of infection and reduces lymphoedema.<sup>3</sup> The primary aim of the present study was to assess the quality of life of the lymphatic filariasis patients.

## Material Methods

### Ethics

Institutional ethical clearance was obtained (ECASM-AIMS-2021-399) and informed consent was taken from each participant before the interview.

### Study Design

A cross sectional study was done to assess the quality of life.

## Study Setting

Cherthala Taluk, Alappuzha district, Kerala, India, which is the lone endemic pocket of Brugian filariasis in the country.

## Study Population

Study was conducted at Thaickal and Chethy Panchayat at Cherthala Taluk, Alappuzha district, Kerala. The Accredited Social Health Activists (ASHAs) in the panchayaths had the lists of people suffering from LF in the area. With the assistance of these ASHAs, patients were contacted. Camps were organized for lymphatic filariasis patients having elephantoid legs at Chethy and Thaickal panchayaths of Cherthala. The camps were held at local school halls or local church halls which were close to the homes of the LF patients. Any person with lymphoedema living in an LF-endemic area was considered eligible for the study after signing the consent form.

## Inclusion Criteria

Any patient suffering from LF-related lymphoedema of the lower limbs with any degree of severity.

## Exclusion Criteria

Bedridden patients.

## Study Tool

The validated questionnaire used in the present study was developed by:

Institute of Applied Dermatology, Kasaragod, Kerala, India.

This questionnaire is an adaptation of the Lymphatic Filariasis Standard Quality of life Questionnaire (LFSQQ).

The LFSQQ has 7 domains and rates the overall health of the patient in the past 30 days. The questionnaire consists of 44 questions. The domains of the study are the following:

- Mobility: 8 Questions
- Self Care: 5 Questions
- Usual Activities: 7 Questions
- Disease Burden: 5 Questions
- Pain/ Discomfort: 7 Questions
- Psychological Health: 5 Questions
- Social Participation: 7 Questions

The scoring of each question is as follows:

- No Problem: 4
- Mild: 3
- Moderate: 2
- Severe: 1
- Most Severe: 0
- Question unanswered, not relevant: 0

A higher score indicates better quality of life. The percentage

analysis was done based on the questions answered in each domain.

The overall QOL is calculated by the formula:

- Overall QOL=Total score/ (4\*number of questions answered)\*100
- The domain score is calculated by the formula:
- Domain score = Total score on domain/ (4\*number of questions answered in the domain)\*100

### Data Collection and Analysis

Validated questionnaires were administered for assessing the quality of the life of patients. Data collected in the questionnaire included patient contact details, age, gender, duration of disease, occupation etc. Camps were organized for lymphatic filariasis patients who had morbidities such as elephantoid legs. They were invited to the camp through ASHA workers and a study was conducted on 114 patients to assess their quality of life in the past 30 days using the validated questionnaire.

### Data Analysis

In statistical analyses, Quality of life is expressed in the Mean with standard deviation. The data was entered into MS Excel and analyzed using SPSS Version 20. The domain scores were expressed as mean with standard deviation. T-test and ANOVA were applied to independent variables followed by the determination of mean differences (MD), with a 95% confidence interval (CI).

### Results

In Table 1, a majority of the population belongs to the age group of above 50 which is 96.5% and only 3.5% of the population belongs to less than 50. 46.5% of the population were males and 53.5% were females. Considering education, 36.8% of the population had primary school education, 32.5% attended middle school, 27.2% attended high school and only 3.5% population were illiterate. More than two thirds (71.1%) were employed and 28.9% of the population were unemployed. 94.7% population were married and only 5.3% were unmarried.

**Table 1. Distribution of the study population based on socio demographic characteristics (n = 114)**

S. No.	Socio Demographic Characteristics	Frequency (n=114)	Percentage (100)
1.	Age	<50	4
		>=50	110
2.	Gender	Male	53
		Female	61
3.	Marital Status	Married	108
		Unmarried	6
4.	Education	Illiterate	4
		Primary School	42
		Middle School	37
		High School	31
5.	Occupation	Unemployed	33
		Employed	81

**Table 2. Lymphatic Filariasis specific quality of life and its domains**

Quality of life domains	Mean	Standard Deviation
Mobility	37.25	12.48
Self-care	47.89	12.68
Usual activities	38.40	12.58
Disease Burden	54.21	16.16
Pain / Discomfort	42.98	12.07
Psychological Health	66.82	16.94
Social Participation	59.51	13.82
Overall QoL	48.71	8.84

**Table 3. Comparison of overall quality of life score with various socio-demographic factors**

Variable		Overall quality of life (Mean ± Standard Deviation)	P-value
Age	<50	63.21 ± 8.90	0.041
	≥50	48.19 ± 8.41	
Gender	Male	51.03 ± 8.89	0.008
	Female	46.70 ± 8.34	
Occupation	Employed	52.22 ± 7.67	0.006
	Unemployed	47.29 ± 8.92	
Education *	Illiterate	47.30 ± 5.87	0.281
	Primary School	46.69 ± 9.17	
	Middle School	49.93 ± 9.09	
	High School	50.18 ± 8.17	
Marital Status	Married	48.77 ± 9.02	0.759
	Unmarried	47.63 ± 4.71	

\*One-way ANOVA was used,  $p < 0.05$  statistically significant.

In Table 2, the overall specific quality of life among lymphatic filariasis patients was found to be  $48.71 \pm 8.84$ . Among the 7 domains, the least domain score was found to be in the domain of mobility ( $37.25 \pm 12.48$ ), which means that the quality of life of lymphatic filariasis patients was poor in this domain. The highest domain-specific score was observed in the domain of Psychological Health ( $66.82 \pm 16.94$ ).

From the table, it was observed that there is a significant difference in the overall quality of life with age, which indicates a better quality of life among lymphatic filariasis patients in the age group of <50 ( $63.21 \pm 8.90$ ) ( $p = 0.041$ ). Based on gender, a significant difference is observed in the overall quality of life between males ( $51.03 \pm 8.89$ ) and females ( $46.70 \pm 8.34$ ) ( $p = 0.008$ ). Occupation also played a significant difference in the overall quality of life in lymphatic filariasis patients. Employed patients had a mean overall quality of life of  $52.22 \pm 7.67$  and unemployed had  $47.29 \pm 8.92$  ( $p = 0.006$ ). Education and marital status did not show a significant difference in the overall quality of life in lymphatic filariasis patients.

## Discussion

In the present study, a majority of the patients were more than 50 years of age, (96.5%) similar to a study conducted in Kerala and Sri Lanka,<sup>2,4</sup> and a majority of the participants were women (53.5%).<sup>5</sup> Most of the participants had primary school level of education (36.8%) as compared to another study of Yogyakarta.<sup>6</sup> The domain of mobility had the lowest domain-specific mean score ( $37.25 \pm 12.48$ ) compared to other domains. 28.9% of the patients were unemployed since the associated morbidities made it difficult for them to continue with their jobs. The disease affects the economic status of the diseased people and their family indirectly

as they had to quit their job or reduce the working time comparing to other studies where the least domain specific mean score was found to be mobility.<sup>7,8,9,10</sup> In contrast to the study conducted in Tiruchirappalli,<sup>7</sup> the highest domain specific score was found in psychological health in the present study. Hence it can be concluded that the patients were well-adjusted with their disease emotionally. This finding is contradictory to the study which assessed the burden of the mental health of lymphatic filariasis patients. The study noted that the burden of depressive illness in filarial patients was 5.09 million disability-adjusted life years (DALYs) and 229,537 DALYs attributable to their caregivers.<sup>11</sup> Also, the patients who suffer from other NTDs for example Human African Trypanosomiasis (HAT) had poor mean QoL as observed in a study from Congo.<sup>12</sup> Usual activities domain and mobility domain had only a slight difference in their scores of 37.25 and 38.40 respectively, which shows that the participants were having difficulty in continuing their job, cooking and cleaning. The social participation domain mean score was 59.51, which implied that most of the participants did not have a problem interacting with people or having the disease did not affect their relationships with their family members or neighbours as seen elsewhere.<sup>13</sup>

In the present study, oedema of the lower limb causes problems in mobility like sitting and getting out of a chair, standing for a long time, climbing steps and putting on foot wear. Thus it was reflected in the mean total quality of life score as a low mean score in the domain of mobility.<sup>7</sup>

## Conclusion

Patients with Lymphatic Filariasis reported a lower quality of life primarily because of mobility issues. Scores of the mobility domain can increase only when the patients

are able to commute to the place where the morbidity management and disability prevention (MMDP) activities are conducted. This clearly indicates that the morbidity management and disability intervention centres should be placed in close proximity where the patients are concentrated. A highly decentralised system of morbidity control must hence be initiated. MMDP clinics as per WHO guidelines need to be established at the earliest.<sup>14</sup>

Change in quality-of-life ratings with respect to time can be used to assess the impact of morbidity control operations.

Even though the psychological domain scores are relatively higher than other domain scores, psychological well-being should still be considered with top priority by the MMDP programmes.

### Acknowledgement

We thank WHO/TDR for funding this project to the senior author. A special thanks to Community health workers of Cherthala especially Ms.Jiji for mobilizing the patients.

**Source of Support:** WHO/TDR

**Conflict of Interest:** None

### References

1. Perera M, Whitehead M, Molyneux D, Weerasooriya M, Gunatilleke G. Neglected patients with a neglected disease? A qualitative study of lymphatic filariasis. *PLoS Negl Trop Dis.* 2007 Nov;1(2):e128. [PubMed] [Google Scholar]
2. Muttappallymyalil J, Marickar Y, Elizabeth K, Sreedharan J. Disability related to self - care management among patients with chronic lymphatic filariasis in Kerala, India. *Nepal J Epidemiology.* 2015 Mar 31;5. [Google Scholar]
3. Prevention CC for DC and. CDC - Lymphatic Filariasis - Epidemiology & Risk Factors [Internet]. 2021 [cited 2022 Jun 29]. Available from: <https://www.cdc.gov/parasites/lymphaticfilariasis/epi.html>.
4. Chandrasena TN, Premaratna R, de Silva NR. Lymphoedema management knowledge and practices among patients attending filariasis morbidity control clinics in Gampaha District, Sri Lanka. *Filaria J.* 2004 Aug;3(1):6. [PubMed] [Google Scholar]
5. Smith EL, Mkwanda SZ, Martindale S, Kelly-Hope LA, Stanton MC. Lymphatic filariasis morbidity mapping: a comprehensive examination of lymphoedema burden in Chikwawa district, Malawi. *Trans R Soc Trop Med Hyg.* 2014 Dec;108(12):751-8.[PubMed] [Google Scholar]
6. Watu E, Supargiyono, Haryani. The effect of lymphoedema exercises and foot elevation on the quality of life of patients with elephantiasis. *J Trop Med.* 2020 May;2020:6309630. [PubMed] [Google Scholar]
7. Hemalatha K, Prabhakar R. Impact of lymphatic filariasis on quality of life of affected individuals: a community based cross sectional survey. Undefined [Internet]. 2016 [cited 2022 Aug 3].
8. Disability and quality of life in patients with lymphatic filariasis in rural Southern India. Available from: <https://clinicaltrials.gov/ct2/show/NCT01629771> [Internet]. Cited 2022 Jul 30.
9. Aggithaya MG, Narahari SR, Ryan TJ. Yoga for correction of lymphedema's impairment of gait as an adjunct to lymphatic drainage: A pilot observational study. *Int J Yoga.* 2015 Jan;8(1):54-61.[PubMed] [Google Scholar]
10. Thomas C, Narahari SR, Bose KS, Vivekananda K, Nwe S, West DP, Kwasny M, Kundu RV. Comparison of three quality of life instruments in lymphatic filariasis: DLQI, WHODAS 2.0, and LFSQQ. Specht S, editor. *PLoS Negl Trop Dis.* 2014 Feb;8(2):e2716. [PubMed] [Google Scholar]
11. Ton TGN, Mackenzie C, Molyneux DH. The burden of mental health in lymphatic filariasis. *Infect Dis Poverty.* 2015;4:34. [PubMed] [Google Scholar]
12. Mudji J, Ackam N, Amoako YA, Madinga B, Mumbere P, Agbanyo A, Blum J, Phillips RO, Molyneux DH. Mental distress and health-related quality of life in gambiense human African trypanosomiasis: a case-control study in the Democratic Republic of Congo. *Trans R Soc Trop Med Hyg.* 2022 Apr 26:trac035.[PubMed] [Google Scholar]
13. Asiedu SO, Kwarteng A, Amewu EKA, Kini P, Aglomasa BC, Forkuor JB. Financial burden impact quality of life among lymphatic Filariasis patients. *BMC Public Health.* 2021 Jan;21(1):174. [PubMed] [Google Scholar]
14. Morbidity management and disability prevention (MMDP) [Internet]. Cited 2022 Sep 30. Available from: <https://www.who.int/activities/building-capacity-of-national-programmes-to-implement-who-recommended-strategies/morbidity-management-and-disability-prevention>.