International Journal of Health Sciences and Research
www.ijhsr.org ISSN: 2249-9571

Original Research Article

Health Related Quality of Life (HRQoL) Among Patients with Lymphatic Filariasis

K.T.Harichandrakumar[1], M.Kumaran[2]

[1]Department of Medical Biometrics & Informatics, Jawaharlal Institute of Post Graduate Medical Education & Research (JIPMER), Dhanwantiri Nagar Pondicherry - 605 006, India.
[2]Department of Statistical Sciences, Kannur University, Mangattuparamba Campus, Kannur, Kerala

Corresponding Author: K.T.Harichandrakumar

Received: 30/01/2017 *Revised: 17/02/2017* *Accepted: 21/02/2017*

ABSTRACT

Health Related Quality of Life (HRQoL) measures assesses a person's perception about their physical, mental and social well being in their daily life. Lymphatic Filariasis is a major public health problem and the two major chronic manifestations are lymphoedema and hydrocele. The objective of the present study was to assess the HRQoL among filarial lymphoedema patients and to compare with age, gender and occupation matched normal individuals. A total of 239 filarial lymphoedema patients and 204 normal subjects were participated in the study. The HRQoL was assessed by using Short Form-36 (SF-36) questionnaire. The mean age was marginally higher among the patients with higher grades of lymphoedema ($P>0.05$), and the average duration of disease was significantly higher ($P<0.05$) among higher grades of lymphoedema. The HRQoL scores were found to be significantly lower ($P<0.05$) among the lymphoedema patients than the normals. The mean HRQoL scores in lymphoedema patients were half or less than the half of the mean score in normal subjects. The HRQoL was found to be significantly lower ($P<0.05$) among the patients with Adenolymphangitis (ADL) and the HRQoL scores was found to be significantly decreased ($P<0.05$) with the progression of the diseases. The existing morbidity management programme should broaden its domain by incorporating programmes to improve the quality of life in all the aspects such as physical, mental and social well being of the patients. An effective mechanism should also be evolved to reach the programme to all the patients to improve its coverage and consumption.

Key Words: Lymphatic Filariasis, Lymphoedema, Health Related Quality of Life (HRQoL).

INTRODUCTION

The health of a community has been measured traditionally by the presence of disease (morbidity) and the causes of death (mortality) within a community. Even though morbidity and mortality measures remain the essential markers of a community's health, other supplemental measures have been identified to provide a more multidimensional profile of the health of a community [1] by following the definition of Health by WHO as "Health is a state of complete physical, mental and social well-being not merely the absence of disease, or infirmity". [2,3] The idea of expanded measures of the health of a community is the concept of Health-Related Quality of Life (HRQOL). In public health and in medicine, the concept of health-related quality of life refers to a persons' or group's perceived physical and mental health over time and it has become an important component of health surveillance and is generally considered as valid indicators of service needs and intervention outcomes. [4] Physicians have often used

health-related quality of life (HRQOL) to measure the effects of chronic illness in their patients to better understand how an illness interferes with a person's day-to-day life. The HRQoL measurements help the physicians in better understanding the results of their treatment not only in the well being in physical dimension of but also in spirit of treatment or quality of life. [5] The public health professionals use HRQoL to assess the the effects of numerous disorders, disabilities, and diseases in different populations. [5] Assessment of HRQoL in different populations can identify subgroups with poor physical or mental health and can help guide policies or interventions to improve their health. [4] HRQOL assesses a person's perception of their physical, mental and social well being over time and is closely related to the perceived burden of that person's self-reported chronic and behavioral risk factors. From a broader perspective, HRQOL can help monitor the national public health goal of "increasing the quality and years of healthy life". [4]

The health outcomes of a population can be measured in terms of etiology and pathogenesis. The health outcome measurement systems have expanded the measurement of health beyond the classical endpoints of mortality and morbidity in clinical practice. [6,7] Health-related quality of life has emerged as an outcome measure in modern medicine and it is viewed from bio-psycho-social perspectives. HRQoL has been extensively used as an important attribute in patient care and clinical studies as well as health economic evaluations. [8]

Lymphatic filariasis (LF) caused by filarial parasites remains an important public health problem and is one of the most debilitating neglected tropical diseases. After 13 Years programme of the Global Programme to Eliminate Lymphatic Filariasis, the estimates on current burden showed that about 68 million people were affected that includes 36.45 million microfilaria carriers, 19.43 million hydrocele cases and 16.68 million lymphoedema cases. [9] This infection leads to permanent lymphatic dysfunction in virtually all infected individuals and clinical disease in a subset of these infected individuals. [10] The different health states of lymphatic filariasis causes long-term sufferings, high social and economic burden [11-15] and is ranked as the second leading cause of disability. [16, 17] The major clinical manifestations of lymphatic filariasis are lymphoedema of the limbs – whereby lymphatic dysfunction can lead to swelling of the limbs which becomes permanent and, with repeated painful episodes of bacterial lymphangitis, known as acute attacks causes considerable acute morbidity and progression of lymphoedema to elephantiasis [18] and hydrocele.

Following the World Health Assembly Resolution 50.29 in 1997, [19] the Global Programme for the Elimination of Lymphatic Filariasis (GPELF) was established in early 2000. GPELF consists of 2 components as (a) to interrupt the transmission of infection through Mass Drug Administration (MDA) with Diethylcarbamizine (DEC) or co-administration with Albandazole and (b) to reduce LF-related disability in those, already affected by chronic manifestations of the disease through Morbidity Management and Disability Prevention Activities (MMDPA). MMDPA includes basic limb hygiene, which can prevent secondary infections causing the acute episodes (Adenolymphangitis) among lymphoedema patients, and surgical corrections for hydrocele cases. [20] One goal of the Global Programme to Eliminate Lymphatic Filariasis (GPELF) is to provide basic care for persons who suffer from the major forms of filariasis-related morbidity, both acute (inflammatory episodes) and chronic (lymphoedema and hydrocele) and it aims at reducing the morbidity and improving the quality of life of chronic patients, which is irreversible. [21]

The knowledge on the impact of chronic illness on functioning and well being in patients in their physical, mental and social dimensions of life have become

essential and therefore efforts to incorporate quality of life in medical care outcome studies are increasing. [22] The assessment of HRQL is an attempt to determine how variables within the dimension of health (e.g., a disease or its treatment) relate to particular dimensions of life that have been determined to be important to people in general (generic HRQL) or to people who have a specific disease (condition-specific HRQL). HRQL concepts emphasize the effects of disease on different aspects such as physical, social/role, psychological/emotional, and cognitive functioning. The concept domains of HRQoL also include symptoms, health perceptions, and overall quality of life. [23]

Monitoring the impact of intervention is an inbuilt component of the programme and is essential to assess the progress and endpoints. HRQoL can be used as a tool to assess the impact of Morbidity management programme. [21] The proper understandings about the domains of health which are adversely affected by the disease when compared to matched normal subjects are very essential for the planning of intervention strategies and also its implementation. The objective of the present study is to assess the HRQoL of patients with filarial lymphoedema when compared to the age, gender and occupation matched normal individuals and also to assess how the HRQoL varies between different grades of lymphoedema

MATERIALS & METHODS

Study participants

The study was carried out in Puducherry and in two LF endemic villages in Villupuram District of Tamil Nadu state in south India. A total of 239 filarial lymphoedema patients identified through the line listing of cases as part of morbidity management programme, which is the second pillar in the Global Programme to Eliminate Lymphatic Filariasis, were included in the study. The patients were classified into different health states (grades of lymphoedema) following WHO classification criteria. [24] A total of 204 normal subjects (apparently healthy subjects) were also selected from the same locality for comparison. The normal subjects were selected from the same locality for socio-economic and cultural matching. A recall period of 30 days was considered as ideal so that the patient could recollect the sufferings experienced due to their chronic problem due to LF.

Health states

The two major clinical manifestations of Lymphatic Filariasis are Lymphoedema and Hydrocele. The present study had included only the patients with filarial lymphoedema. Lymphoedema patients participated in the study were further classified as lymphoedema grade 1 (L1 – pitting oedema of the limb that is reversible on elevating the limb), lymphoedema grade 2 (L2 – pitting/non-pitting oedema that is not reversible on elevation of the limb and the skin is normal), lymphoedema grade 3 (L3 – Non-pitting oedema of the limb, not reversible on elevation and the skin is thickened), lymphoedema grade 4 (L4 – Non-pitting oedema with fibrotic and verrucous skin changes). These sub-groups were made based on the criteria recommended by the World Health Organization (WHO, 1992). Acute attack of adenolymphangitis (ADL), which is the recurrent attacks of fever associated with inflammations of the lymph nodes and/or lymph vessels associated with chronic manifestation were considered as co-morbidity.

Instrument

The HRQoL was assessed by using the Short Form-36 (SF-36) questionnaire. SF-36 was derived from the General Health Survey of the Medical Outcomes Study. [22] The scoring system for the SF-36 is relatively complex in which lower scores are indicative of greater impairments and lower quality of life. SF-36 consists of 36 items and it generates subscale scores for P*hysical Functioning, Role Limitations due to Physical problems, Bodily Pain, General Health perceptions, Vitality, Social*

Functioning, Role-limitations due to Emotional Problems, and Emotional Well-Being (Mental Function). Two summary scores can also be derived from the SF-36: the *Physical Component Summary (Physical Health)* and the *Mental Component Summary (Mental Health)* which leads to an Overall Quality Score (*HRQoL score*). A score ranging from 0 (indicating the worse health status) to 100 (indicating the best health status) is assigned for each sub-domain, domain and overall HRQoL.

The data was collected through personal interview with the study participants and the interview was conducted in patients' domestic settings after briefing them the purpose of the interview. Informed consent was obtained from each respondent before the interview. Confidentiality of the data was maintained as per ethical guidelines (ICMR, 2000).

Data analysis

The distribution of categorical data related to socio-demographic characteristics such as gender, educations status, occupation status, marital status, type of houses and clinical characteristics such as ADL status and grade of lymphoedema were expressed as frequencies and percentages. The continuous data such as age of the patients, income, duration of diseases, SF-36 sub-domain scores, domain scores and overall scores were expressed as mean with standard deviation. The comparison of the distribution of categorical data mentioned above between the groups was carried out by using Chi-squares test. The comparison of age, income, sub-domains score, domains score and the overall score between the groups was compared by using Independent Students t-test or Mann Whitney U test whichever is appropriate. Among the patients with lymphoedema, the comparison of the sub-domain score, domain scores and the overall scores between different socio-demographic characteristics and also in relation to the ADL status were also carried out by using Independent Students t-test or Mann Whitney U test whichever is appropriate. One way Analysis of variance or Kruskal Wallis test was used to compare the SF-36 scores between different grades of lymphoedema. All statistical analysis was carried out at 5% level of significance using IBM-PASW Statistics 19.0 (SPSS version 19.0) software.

RESULTS

A total of 239 patients with different grades of lymphoedema and 204 normal subjects were participated in the study. The gender distribution of the study subjects showed that among Lymphoedema patients, 152 (63.6%) patients were females and in normal subjects, 112 (55 %) subjects were females and it shows that gender distribution is comparable between the groups (P>0.05). The mean age among the lymphoedema patients participated in study was 48.6 and among the normal subjects it was 47 years. The average income among lymphoedema patients was 5030 rupees and among normal subjects it was 5375 rupees. The difference in the mean age and income between lymphoedema patients and normal subjects were not significantly different (P>0.05). The comparison of the education status shows that among the lymphoedema patients 26% had no formal education, 28% had primary level education, 38% had secondary level and 8% had college level education. Among normal subject 30% had no formal education, 33% had primary level education, 34% had secondary level education and the remaining 3% had college level education. This shows that the distribution of the education status is almost equally distributed in both the study groups and therefore the groups are comparable in relation to the education status (P>0.05). In a sizeable proportion of the study subjects, majority of them (89.7%) are living with spouse and 10.3% are singles in normal subjects and among lymphoedema patients, 91.6% are living with spouse and 8.4% were singles and the study groups are comparable (P>0.05) with regards to the marital status of study participants. Regarding the

distribution of the type of houses, 85.3% of the normal subjects are living in *Pucca* and the remaining 14.7% are in *Hut/Kutcha* houses and among lynphoedema patients it was 83.4% and 16.7% respectively, which shows that the type of houses are almost equally distributed in both normal subjects and lymphoedema patients (P>0.05).

Among the 239 Lymphoedema patients, 5% had grade-I lymphoedema, 40% had grade-II, 35% had grade-III and 20% had grade-IV lymphoedema. The mean age and duration of the disease varies according the grades of lymphoedema. The average age of patients among the patients with grade-I lymphoedema was 46 years and among grade II,III and IV were respectively 47 years, 49 years and 51 years. This shows that the mean age is higher among the patients with higher grades of Lymphoedema, but the difference was not found to be statistically significant. (P>0.05). The average duration of disease among the patients with grade I,II,III and IV were respectively 10.4, 16.5, 21.9 and 26.2 years. This shows that the duration of disease is significantly higher among higher grades of lymphoedema (P<0.05).

The average scores in each sub-domains of SF-36 were estimated and compared between lymphoedema patients and normal subjects and the details of the comparison of the average scores in 8 sub-domains between the lymphoedema patients and normal subjects are given in Table-1. The comparison of the SF-36 sub-domains between the normal subjects and Lymphoedema patients shows that the HRQoL scores in all the sub-domains were found to be significantly lower (P<0.001) among lymphoedema patients than normal subjects. The mean score of almost all the sub-domains among lymphoedema patients were half or less than the half of the mean score in normal subjects. This clearly indicates the impact of disease in different domains of health among lymphoedema patients.

Table-1 : Comparison of SF-36 sub-domains between Lymphoedema patients and Normal subjects

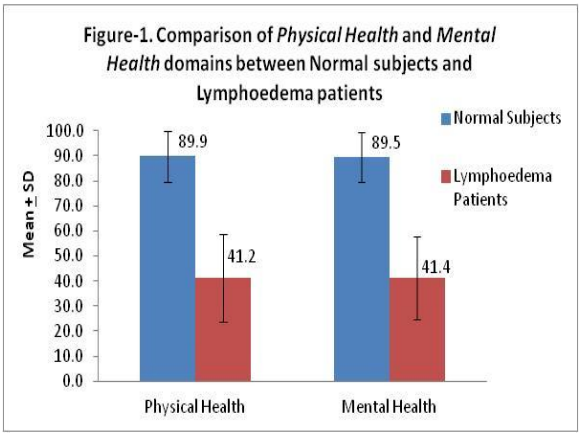
SF-36 Domains	Group	Samples	Mean	Standard Deviation	Statistical Significance
Physical Function	Normal Subjects	204	90.4	11.9	
	Lymphoedema patients	239	50.0	30.2	P<0.001
Role Physical	Normal Subjects	204	100.0	0.0	P<0.001#
	Lymphoedema patients	239	34.5	46.0	
Body Pain	Normal Subjects	204	83.3	19.5	P<0.001
	Lymphoedema patients	239	41.5	13.6	
General Health	Normal Subjects	204	89.3	10.9	P<0.001
	Lymphoedema patients	239	36.2	12.9	
Vitality	Normal Subjects	204	86.6	12.6	P<0.001
	Lymphoedema patients	239	43.8	12.8	
Social Functioning	Normal Subjects	204	85.8	17.0	P<0.001
	Lymphoedema patients	239	43.3	15.3	
Role Emotional	Normal Subjects	204	100.0	0.0	P<0.001#
	Lymphoedema patients	239	39.1	47.6	
Emotional Well-Being (Mental Function)	Normal Subjects	204	85.8	13.2	P<0.001
	Lymphoedema patients	239	44.7	14.2	

Non parametric test

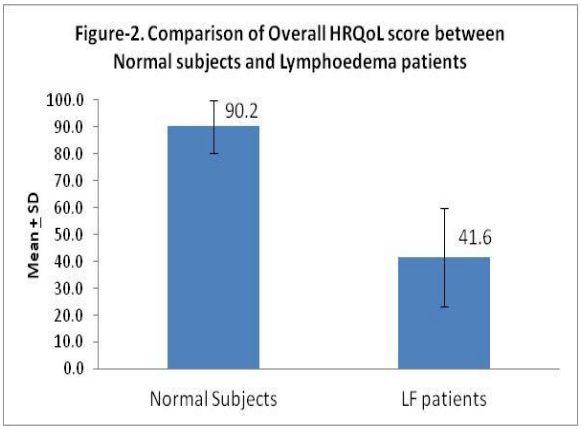
The details of the comparison of the SF-36 domains (*Physical Health* and *Mental Health*) scores between the lymphoedema patients and normal subjects are given in Figure-1. The mean score in the *Physical Health* domain among the Lymphoedema patients was 41.2(± 17.4) against 89.9 (± 10.2) in normal subjects, and the difference in the means score of *Physical Health* between the normal subjects and Lymphoedema patients was statistically significant (P<0.001). This shows that the *Physical Health* was severely impaired among Lymphoedema patients when compared to normal subjects. The normal subjects' *Physical Health* was found to be 2.18 times higher than lymphoedema patients on average. This clearly indicates the level of physical burden due to disease among the lymphoedema patients.

The Mental Health was also severely impaired among Lymphoedema patients

when compared to the normal subjects. The mean score of *Mental Health* domain among the LF patient was 41.4 (±16.5) and it was found to be significantly lower (P<0.001) than the normal subjects (89.5± 10.2). This shows that the *Mental Health* of the Lymphoedema patients is also less than the half of the *Mental Health* of the normal subjects and the details are given in Figure-1.



The *overall HRQoL* score was calculated and compared between lymphoedema and normal subjects. The mean HRQoL score among the patients with LF was 41.6 (±18.1) and among the normal subjects it was 90.2 (±9.8). The HRQoL among lymphoedema patients was found to be significantly lower (P<0.001) than the normal subjects. The *overall HRQoL* among normal subjects was more than the double (2.2 times higher) when compared to lymphoedema patients and the details are given in figure-2.



The analysis was carried out to identify the socio-demographic and clinical factors associated with HRQoL among Lympodema patients. The socio-demographic factors such as gender, education status, occupation status and type of houses were not found to be significantly associated (P>0.05) with the level of HRQoL among lymphoedema patients. However, The Adenolymphangitis (ADL) is playing an important role in the prognosis of the disease and also with the level of HRQoL.

The comparison of HRQoL in relation to the ADL status is given in Table-2. The quality score was found to be significantly lower (P<0.01) among the patients with ADL when compared to the patients without ADL in all the sub-domains except *Physical Function, Body Pain and Emotional well-being* (P>0.05). The means scores in *Physical Function, Body Pain and Emotional well-being* were also found to be lower among the patients with ADL than the patients without ADL, but the difference was not found to be statistically significant (P>0.05). The mean score in the *Physical Health* domain among the patients with ADL was 39.11 (± 16.36) and among the patients without ADL was 56.94 (± 17.27). This shows that the mean score in the physical health among the patients with ADL was significantly lower (P<0.01) than the patients without ADL. The mean scores in *Mental Health* domains among the patients with ADL was 39.42 (±15.93) and it was also found to be significantly lower (P<0.01) than the patients without ADL (56.32± 12.50). The mean *overall HRQoL* score between the patients with and without ADL were 39.31±17.19 and 59.05±15.44 respectively. The *overall HRQoL* was significantly lower (P<0.05) among the patients with ADL when compared to the patients without ADL. This shows that the patients with ADL had very poor HRQoL as the ADL episodes further worsen the quality of life in all the domains of health.

Table: 2. Comparison of HRQoL in relation to ADL status					
SF-36 Sub-Domains	ADL Status	Samples	Mean	SD	Statistical Significance
Physical Function	No ADL	28	60.71	35.43	P>0.05
	with ADL	211	48.53	29.22	
Role Physical	No ADL	28	83.93	35.50	P<0.01#
	with ADL	211	27.96	43.23	
Body Pain	No ADL	28	46.14	12.57	P>0.05
	with ADL	211	40.89	13.60	
General Health	No ADL	28	43.71	11.06	
	with ADL	211	35.18	12.85	P<0.01
Vitality	No ADL	28	50.18	12.66	
	with ADL	211	42.99	12.66	P<0.01
Social Functioning	No ADL	28	50.00	12.27	P<0.01
	with ADL	211	42.36	15.48	
Role Emotional	No ADL	28	89.29	31.50	P<0.01#
	with ADL	211	32.39	45.42	
Emotional Well-Being (Mental function)	No ADL	28	48.43	12.48	
	with ADL	211	44.17	14.38	P>0.05
SF-36 Domains					
Physical Component Score (Physical Health)	No ADL	28	56.94	17.27	
	with ADL	211	39.11	16.36	P<0.01
Mental Component Score (Mental Health)	No ADL	28	56.32	12.50	
	with ADL	211	39.42	15.93	P<0.01
Overall HRQoL					
Overall HRQoL	No ADL	28	59.05	15.44	
	with ADL	211	39.31	17.19	P<0.01

Non parametric test

Table: 3. Comparison of SF-36 sub-domains between the grades of lymphoedema					
SF-36 Sub-domains	Lymphoedema grades	Samples	Mean	SD	Statistical significance
Physical Function	Lymphoedema Grade-I	12	82.50	18.28	P<0.001
	Lymphoedema Grade-II	95	75.79	25.12	
	Lymphoedema Grade-III	83	31.45	9.83	
	Lymphoedema Grade-IV	49	23.27	11.66	
Role Physical	Lymphoedema Grade-I	12	75.00	45.23	P<0.001#
	Lymphoedema Grade-II	95	43.16	49.79	
	Lymphoedema Grade-III	83	24.70	37.95	
	Lymphoedema Grade-IV	49	24.49	43.45	
Body Pain	Lymphoedema Grade-I	12	59.83	8.16	P<0.001
	Lymphoedema Grade-II	95	52.00	0.00	
	Lymphoedema Grade-III	83	38.24	9.70	
	Lymphoedema Grade-IV	49	22.20	5.98	
General Health	Lymphoedema Grade-I	12	64.50	3.37	
	Lymphoedema Grade-II	95	44.58	4.51	P<0.001
	Lymphoedema Grade-III	83	31.92	7.89	
	Lymphoedema Grade-IV	49	20.20	6.92	
Vitality	Lymphoedema Grade-I	12	70.42	5.42	P<0.001
	Lymphoedema Grade-II	95	48.74	5.00	
	Lymphoedema Grade-III	83	45.54	8.23	
	Lymphoedema Grade-IV	49	24.90	7.18	
Social Functioning	Lymphoedema Grade-I	12	77.08	11.72	
	Lymphoedema Grade-II	95	50.00	0.00	P<0.001
	Lymphoedema Grade-III	83	42.17	9.90	
	Lymphoedema Grade-IV	49	23.72	14.03	
Role Emotional	Lymphoedema Grade-I	12	72.22	44.57	P<0.01#
	Lymphoedema Grade-II	95	47.37	49.72	
	Lymphoedema Grade-III	83	33.33	44.48	
	Lymphoedema Grade-IV	49	24.49	43.45	
Emotional Well-Being (Mental Function)	Lymphoedema Grade-I	12	73.67	7.33	P<0.001
	Lymphoedema Grade-II	95	51.07	6.48	
	Lymphoedema Grade-III	83	45.73	8.48	
	Lymphoedema Grade-IV	49	23.35	5.12	

Non parametric test

The lymphoedema patients participated in the study were classified according to their grades of lymphoedema. Among the 239 patients, 12 (5%) patients had grade-I lymphoedema, 95 (40%) patients had grade-II lymphoedema, 83 (35%) had grade-III lymphoedema grade-III and the remaining 40 (20%) had grade-IV

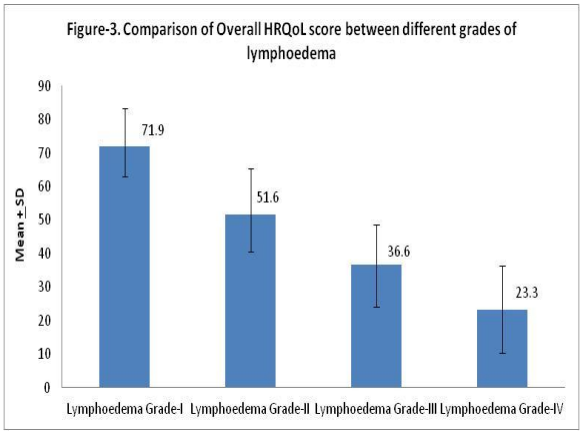
lymphoedema. The HRQoL was calculated for all the grades of lymphoedema and compared. The details regarding the SF-36 sub-domain scores between different grades of lymphoedema are given in Table-3. The lymphoedema had severely affected the patients in their daily life in all the aspects of life and the level of HRQoL varies according their grades of lymphoedema. The mean scores in all the eight sub-domains of SF-36 were significantly decreased (P<0.001) with the progression in the grades of lymphoedema and it indicates that the advanced grades of lymphoedema had very poor quality of life than the early grades in all the sub-domains, *Physical function, Role Physical function, Body Pain, General Health, Vitality, Social Functioning, Role Emotional function and Emotional Well-Being*

The comparison of the *Physical Health* and *Mental Health* domains between different grades of lymphoedema is given in Table-4. The mean score of *Physical Health* among the patients with grade-I lymphoedema was 70.5 (±9.6), grade-II Lymphoedema 52.9 (±12.3), grade III Lymphoedema 34.4 (± 10.5) and grade IV lymphoedema was 23.01 (±9.7). The mean scores was found to be significantly decreasing (P<0.001) while progressing the grades of lymphoedema. Similarly the mean score of *Mental Health* among the patients with grade-I lymphoedema was 71.6 (±8.95), grade-II was 48.4 (±10.9), grade III was 39.7 (± 12.4) and grade IV was 23.3 (±13.1). This shows that mean scores in mental health also found to be significantly decreasing (P<0.001) with the progression in the grades of lymphoedema. This suggests that the progression in the grades of lymphoedema had severely affected the patients in their *Physical* and *Mental Health* domains.

Table-4. Comparison of SF-36 domains between the grades of lymphoedema

SF-36 Domains	Lymphoedema grades	Samples	Mean	SD	Statistical significance
Physical Component Scores (Physical Health)	Lymphoedema Grade-I	12	70.45	9.65	P<0.001
	Lymphoedema Grade-II	95	52.85	12.33	
	Lymphoedema Grade-III	83	34.37	10.47	
	Lymphoedema Grade-IV	49	23.01	9.72	
	Total	239	41.20	17.40	
Mental Components Scores (Mental Health)	Lymphoedema Grade-I	12	71.58	8.95	
	Lymphoedema Grade-II	95	48.35	10.86	P<0.001
	Lymphoedema Grade-III	83	39.74	12.44	
	Lymphoedema Grade-IV	49	23.33	13.05	
	Total	239	41.40	16.47	

The comparison of overall HRQoL between different grades of lymphoedema is given in Figure-3. The mean scores of the overall HRQoL among the patients with grade-I lymphoedema was 71.9 (± 11.4), grade-II Lymphoedema 51.6 (±13.8), grade III Lymphoedema 36.6 (± 12) and grade IV lymphoedema was 23.3 (±12.9). This shows that the overall quality of life worsens while progressing the grades of Lymphoedema and the difference in the means scores between the grades of lymphoedema was found to be statistically significant (P<0.05).



DISCUSSION & CONCLUSION

Following the definition of Health by WHO as "Health is a state of complete physical, mental and social well-being not merely the absence of disease, or infirmity";

the health assessment has gone beyond the gathering of data on the presence or the absence of disease and the quantification of individuals' "amount of life". [25] The Overall concept of health is enriched and a need arises to focus on areas such as the individual's ability to operate in society, disability, access to health services or the individuals' subjective perception of general well-being. The new bio-psycho-social models which integrates both biomedical and psycho-social models [25-27] and it combines the biological, individuals and societal perspective of health in a coherent fashion. [25] Traditionally outcomes in medicine and health care have largely been determined by objective medical evaluation and it has become clear that the perspective of the patient is also a critical variable. There is an increasing recognition that what matters most to patients is how well they are able to function in their day-to-day life [28] and the self-reported health status is receiving increasing attention in epidemiological and outcomes research. [29] The concept HRQoL assesses a person's perception of their physical, mental and social well being over time and is closely related to the perceived burden of that person's self-reported chronic and behavioral risk factors.

The present study assessed the level of HRQoL among the patients with different grades of filarial lymphoedema and compared with the normal subjects. This study comprised of 239 lymphodema patients and 204 normal subjects. The study groups were comparable (P>0.05) in relation to the socio-demographic characteristics considered for the study such as gender, education status, occupation status, marital status and type of house. Among lymphoedema patients, the average age of the patients marginally increases (P>0.05) with the progression in the grades of lymphedema and average duration of disease was found to be significantly higher (P<0.001) among the patients with higher grades of lymphoedema when compared to lower grades of the lymphoedema. Episodes of acute attacks of ADL within last one year at the time of our data collection was reported in 211 (88.3%) patients and about 91.8% of the grade IV lymphoedema patients and 90.4% of the grade-III lymphoedema patients had the ADL episodes within an year at the time of our data collection. The number of episodes of acute attacks of ADL within a year at the time of our data collection was comparable (P>0.05) between the genders.

The average scores in all the sub-domains were significantly lower (P<0.001) among lymphoedema patients than normal subjects. When compared to the normal subjects, the Quality score in *Role Physical function and Role Emotional function* among lymphoedema patients were only 34.5% and 39.1%. The quality scores among lymphoedema patients in other sub-domains such as *Physical function, Body Pain, General Health, Vitality, Social Functioning, and Emotional Well-Being* was 55.3%, 49.8%, 40.5%, 50.6%, 50.4%, and 52.0% respectively when compared to the normal subjects. The *Physical Health* was severely impaired among LF patients when compared to normal subjects. The *Physical Health* score among the lymphoedema patients was only 45.8% of the scores in normal subjects. Similarly the *Mental Health* was also very severely affected as the average score of *Mental Health* among the lymphoedema patients was only 46% which is less than the half of the average score among normal subjects. This shows the normal subjects average scores in both Physical Health and Mental Health was about 2.2 times higher than the lymphoedema patients. The study also shows that the HRQoL score do not vary between different socio-demographic characteristics in lymphoedema patients, necessitating equal attention to all the patients in the preventive measures and management of diseases irrespective of their socio-demographic characteristics.

Acute episodes of adenolymphangitis (ADL), an acute health state is of short duration and transient in

nature, but recurring among the chronic cases of LF. ADL is playing an important role in the prognosis of the disease and it is considered as co-morbidity. ADL among lymphoedema patients can cripple the affected individual up to 5 days [15] and physically incapacitated due to pain, lymphadenitis, lymphangitis, and inflammation of the part of the limb/scrotum involved. [30] Fever associated with chills and systemic manifestations such as nausea, vomiting, and loss of appetite confine the patient in this health state to bed for 3–5 days. [31] The ADL among the patients further worsen the health status [32] and it leads to more physical and psychosocial burden among the patients. [33] The present study assessed the perceived quality in all the domains of health and estimated the quality score in different domains in SF-36 among the patients in relation to their ADL status. The scores in most of the sub-domains, *Physical and Mental Health* domains and also the overall HRQoL was significantly lower (P<0.01) among ADL patients, indicating the impact of ADL on physical, mental and social well being among lymphoedema patients. This suggested preventive measures to protect the patients from the ADL attacks to arrest the further progression and to improve their HRQoL. Acute episodes of local inflammation associated with lymphoedema are mostly the results of bacterial infection of the skin with entry lesions. Careful cleaning can be extremely helpful in healing the infected surface area and to reduce the bacterial infection of the skin with entry lesions. Management of morbidity associated with LF is an important feature of global programme to eliminate LF [27] and it related to managing, treating, or alleviating filarial disease includes basic hygiene and skin care to prevent ADL attacks and reduce the risk of lymphoedema progression. The lymphoedema had severely affected the patients in their daily life and when compared to the normal subjects, the patients with advanced grade of lymphoedema had only 25% of the quality of life in different sub-domains of health. Among the lymphodema patients, the quality varies with the grades of lymphoedema and the patients with advanced grades of lymphoedema had very poor quality in all the domains of health. The patients were reported with poor quality in all the sub-domains of SF-36 Viz. *Physical Health, Role Physical, Body Pain, General Health, Vitality, Social Functioning, Role Emotional and Emotional Well-Being.*

The mean scores in *Physical Health* domain was found to be significantly decreasing (P<0.001) while increasing the grades of lymphoedema. This suggests that the progression in the grades of lymphoedema had adversely affected in physical health. The normal subjects had about 4 times more *Physical Health* than grade-IV lynphoedema, 2.6 times more than grade III lymphoedema and 1.7 times more than grade II lymphoedema and 1.3 times more than grade-I lymphoedema. Similarly mean scores in *Mental Health* also found to be significantly decreasing (P<0.001) with the increase in the grades of lymphoedema. Regarding the comparison of quality score in *Mental Health*, the normal subjects had about 4 times more mental health than grade-IV lymphoedema, 2.3 times more than grade III lymphoedema, 1.9 times more when compared to grade II lymphoedema and 1.4 times more than grade-I lymphoedema. This indicates that the levels of sufferings of the lymphoedema patients in their physical, mental and social well-being are immense and it varies with the progression of the disease. Earlier study was also reported that patients with filarial lymphoedema was severely affected in the physical and psychosocial domains, [33,34] undergoing high level of stigmata and discrimination [35-37] limitations in physical activities, pain and embarrassment due to lymphoedema, [38] Severe impairments in mobility, self-care and daily activities [39] and poor quality of life in all the domains of health and overall quality among lymphoedema patients. [40] A study on

health status among the patients with lymphatic filariasis from the same geographical region also reported that the health status among the patients with lymphatic filariasis was impaired and the level of impairments varies with the grades of lymphoedema as the health status score decreases with the increase in the grades of lymphoedema. [32]

HRQoL describes or characterize what the patient has experienced due to the disease and also the result of medical care, HRQoL measures are useful and important supplements to traditional physiological or biological measures of health status. [26] The present study demonstrates the impact of lymphoedema on patient's physical, mental and social well-being of life and daily life and how much it adversely affected the patient's livelihood when compared to the normal subjects. This study also highlighted the level of HRQoL among the patients with different grades of Lymphoedema. The HRQoL among the patients with filarial lymphoedema patients was very poor and it very badly affected in all the domains of health. The existing Morbidity Managements and Disability Prevention Activities under the Global Prgramme to Eliminate Lymphatic Filariasis programme should broaden its domain by incorporating programmes to improve all the aspects such as physical, mental and social well being of the patients' daily life. An effective mechanism should also be evolved to reach the programme to all the patients to improve its coverage and consumption.

ACKNOWLEDGEMENT

The authors are grateful to the Director, Dean (Research) and Dean (Academics) of Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER), Pondicherry for their constant support and encouragement. We express our sincere thanks to the patients and the normal subjects who participated in this study.

REFERENCES

1. Lobo A. Physical Activity and health in elderly. Betham Books, ISBN:978-1-60805-100-7
2. World Health Organization: The constitution of the World Health Organization. *WHO Chronicle* 1947, 1:6-24.
3. Bowling, A. (2001) Health-Related Quality of Life: Conceptual Meaning, Use and Measurement. In: Bowling, A., Ed., Measuring Disease: A Review of Disease-Specific Quality of Life Measurement Scales, 2nd Edition, Open University Press, Buckingham. - References - Scientific Research Publish.
4. Centers for Disease Control and Prevention. Measuring healthy days: Population assessment of health-related quality of life. Centers for Disease Control and Prevention**,** Atlanta, Georgia 2000.
5. Hafez AA, Tavassoli E, Hasanzadeh A, Reisi M, Javadzade SH, Imanzad M. Quality of life in peptic ulcer patients referring to Al-Zahra hospital of Isfahan, Iran. Gastroenterol Hepatol Bed Bench. 2013;6(Suppl 1):S87–92.
6. Ellwood PM. Shattuck lecture--outcomes management. A technology of patient experience. N Engl J Med. 1988 Jun 9;318(23):1549–56.
7. Bullinger m. German translation and psychometric testing of the sf-36 health survey: preliminary results from the iqola project. Social Science & Medicine. 41(10):1359–66.
8. Cutler, D. M., McClellan, M., & Newhouse, J.P, (1998). What has increased medical-care spending bought? American Economic Review 1998, 88: 132-136.
9. Ramaiah KD, Ottesen EA. Progress and Impact of 13 Years of the Global Programme to Eliminate Lymphatic Filariasis on Reducing the Burden of Filarial Disease. PLOS Neglected Tropical Diseases. 2014 Nov 20;8(11): e3319.
10. Dreyer G, Norões J, Figueredo-Silva J, Piessens WF. Pathogenesis of lymphatic disease in bancroftian filariasis: a clinical perspective. Parasitol Today (Regul Ed). 2000 Dec;16(12):544–8.
11. Gyapong JO, Gyapong M, Evans DB, Aikins MK, Adjei S. The economic burden of lymphatic filariasis in

northern Ghana. Ann Trop Med Parasitol. 1996 Feb;90(1):39–48.
12. Gyapong M, Gyapong J, Weiss M, Tanner M. The burden of hydrocele on men in Northern Ghana. Acta Trop. 2000 Dec 1;77(3):287–94.
13. Dreyer G, Norões J, Addiss D. The silent burden of sexual disability associated with lymphatic filariasis. Acta Trop. 1997 Jan;63(1):57–60.
14. Ramaiah KD, Kumar KNV, Ramu K, Pani SP, Das PK. Functional impairment caused by lymphatic filariasis in rural areas of South India. Tropical Medicine & International Health. 1997 Sep 1;2(9):832–8.
15. Gyapong JO, Gyapong M, Evans DB, Aikins MK, Adjei S. The economic burden of lymphatic filariasis in northern Ghana. Ann Trop Med Parasitol. 1996 Feb;90(1):39–48.
16. World Health Organization, 1995. World Health Report, Geneva.
17. Durrheim DN, Wynd S, Liese B, Gyapong JO. Editorial: Lymphatic filariasis endemicity--an indicator of poverty? Trop Med Int Health. 2004 Aug;9(8):843–5.
18. Pani SP, Yuvaraj J, Vanamail P, Dhanda V, Michael E, Grenfell BT, et al. Episodic adenolymphangitis and lymphoedema in patients with bancroftian filariasis. Trans R Soc Trop Med Hyg. 1995 Feb;89(1):72–4.
19. World Health Assembly: Elimination of Lymphatic Filariasis as a public health problem. World Health Assembly, Geneva A50.29; 1997.
20. Gyapong JO, Kumaraswami V, Biswas G, Ottesen EA. Treatment strategies underpinning the global programme to eliminate lymphatic filariasis. Expert Opin Pharmacother. 2005 Feb;6(2): 179–200.
21. Kumari AK, Krishnamoorthy K, Harichandrakumar KT, Das LK. Health Related Quality of Life, an appropriate indicator to assess the impact of morbidity management and disability prevention activities towards elimination of lymphatic filariasis. Filaria Journal. 2007;6:8.
22. Stewart AL, Greenfield S, Hays RD, Wells K, Rogers WH, Berry SD, et al. Functional status and well-being of patients with chronic conditions. Results from the Medical Outcomes Study. JAMA. 1989 Aug 18;262(7):907–13.
23. Ware JE. The status of health assessment 1994. Annu Rev Public Health. 1995;16:327–54.
24. World Health Organization, 1992. Informal Consultation on Evaluation of Morbidity in Lymphatic Filariasis. WHO/TDR/FIL/MAD/Geneva, 92.3, pp. 1–8.
25. Prieto L, Sacristán JA. Problems and solutions in calculating quality-adjusted life years (QALYs). Health Qual Life Outcomes. 2003 Dec 19;1:80.
26. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA. 1995 Jan 4;273(1):59–65.
27. World Health Organization, 2001. Lymphatic filariasis. Wkly. Epidemiol.Rec. 76 (20), 149–154.
28. Hays RD, Kallich JD, Mapes DL, Coons SJ, Carter WB. Development of the Kidney Disease Quality of Life (KDQOLTM) Instrument. Qual Life Res. 1994 Oct 1;3(5):329–38.
29. Andresen EM, Gravitt GW, Aydelotte ME, Podgorski CA. Limitations of the SF-36 in a sample of nursing home residents. Age Ageing. 1999 Oct;28(6):562–6.
30. Krishnamoorthy K. Estimated costs of acute adenolymphangitis to patients with chronic manifestations of bancroftian filariasis in India. Indian J Public Health. 1999 Jun;43(2):58–63.
31. World Health Organization, 1984. Fourth Report of the WHO Expert Committee on Filariasis. Lymphatic Filariasis. WHO Technical Report Series 102.
32. Harichandrakumar KT, Krishnamoorthy K, Kumari AK, Das LK. Health status of lymphatic filariasis assessed from patients using seven domains five levels (7D5L) instrument. Acta Trop. 2006 Oct;99(2–3):137–43.
33. Kumari AK, Harichandrakumar KT, Das LK, Krishnamoorthy K. Physical and psychosocial burden due to lymphatic filariasis as perceived by patients and medical experts. Trop Med Int Health. 2005 Jun;10(6):567–73.

34. Wijesinghe RS, Wickremasinghe AR. Physical, psychological, and social aspects of quality of life in filarial lymphedema patients in Colombo, Sri Lanka. Asia Pac J Public Health. 2015 Mar;27(2):NP2690-2701.
35. Kumari AK, Harichandrakumar KT, Krishnamoorthy K, Das LK. The stigmata and discrimination experienced, in southern India, by cases of lymphatic filariasis. Annals of Tropical Medicine & Parasitology. 2010 Jul 1;104(5):421–6.
36. Person B, Bartholomew LK, Gyapong M, Addiss DG, van den Borne B. Health-related stigma among women with lymphatic filariasis from the Dominican Republic and Ghana. Soc Sci Med. 2009 Jan;68(1):30–8.
37. Chandrasena TG a. N, Premaratna R, Muthugala M a. RV, Pathmeswaran A, de Silva NR. Modified Dermatology Life Quality Index as a measure of quality of life in patients with filarial lymphoedema. Trans R Soc Trop Med Hyg. 2007 Mar;101(3):245–9.
38. Gyapong M, Addiss DG, van den Borne B. Health-related stigma among women with lymphatic filariasis from the Dominican Republic and Ghana. Soc Sci Med. 2009 Jan;68(1):30-8.
39. Wang L, Hu Y, Tang A, Fang H, Gan W. Investigation on life quality of patients with chronic lymphatic filariasis in Yuhang district of Hangzhou. Zhongguo Ji Sheng Chong Xue Yu Ji Sheng Chong Bing Za Zhi. 2011 Apr 30;29(2):159–61.
40. Wijesinghe RS, Wickremasinghe AR. Quality of life in filarial lymphoedema patients in Colombo, Sri Lanka. Trans R Soc Trop Med Hyg. 2010 Mar;104(3):219–24.

How to cite this article: Harichandrakumar KT, Kumaran M. Health related quality of life (HRQoL) among patients with lymphatic filariasis. Int J Health Sci Res. 2017; 7(3):256-268.

****