

## Measurement of Quality of Life in patients of Leprosy attending Outdoor Patient Department at Tertiary Care Center of Ahmedabad: A Cross Sectional Study

AD Solanki<sup>1</sup>, JP Barot<sup>2</sup>, JH Patel<sup>3</sup>, NM Patel<sup>4</sup>, D Patel<sup>5</sup>, N Nagrani<sup>6</sup>, A Arora<sup>7</sup>

Received : 06.12.2019

Accepted : 17.04.2019

Leprosy is a chronic infectious disease caused by the *Mycobacterium leprae*, which primarily affects the peripheral nervous system and secondarily the skin and having great impact on patients' quality of life. A cross sectional study was carried out to assess and evaluate the Quality of Life (QOL) of Leprosy patients at tertiary care center of Ahmedabad over a period of 8 months using Dermatology Life Quality Index (DLQI) designed by Finlay and Khan. In our study we included 87 Leprosy patients who were >16 years and also released from treatment (RFT) patients with Male: Female ratio was 3:1, majority of patients (42.52%) were in the middle age group (31-45 yr). Mean duration of disease was 3.2 year. The mean DLQI score was 10.58±2.57%. According to DLQI score categorization 47 patients (54.02%) were having very large effect on their quality of life. There was no significant difference observed between gender, age & education in all subdomain of quality of life. Statistically significant difference (p<0.001) was noted with duration of disease and presence of deformity. Conclusion of our study was that deformities and social stigma associated with leprosy has great impact on quality of life of leprosy affected persons even after the disease gets bacteriologically cured.

**Keywords :** Dermatology Life Quality Index, Deformity, Stigma, Leprosy

### Introduction

Leprosy word comes from the Greek word "Lepra" means "scale" and also known as "Hansen's disease" after the name of Norwegian physician Gerhard Armauer Hansen. Leprosy is a chronic infectious disease caused by the *Mycobacterium*

*leprae* (Hansen 1875), which primarily affects the peripheral nervous system and secondarily the skin. In ancient India, the disease has been called "Vat rakta" denoting the cases of neural component and "Arunkushta" represented the cutaneous form of leprosy.

<sup>1</sup> Dr Avanita D. Solanki, MBBS, MD (Dermatology), Associate Professor

<sup>2</sup> Dr Jigna Barot, MBBS, MD (Dermatology), Assistant Professor

<sup>3</sup> Dr Jahnavi H. Patel, MBBS, MD Second Year Resident

<sup>4</sup> Dr Neela M. Patel, MBBS, MD (Dermatology), Professor & Head

<sup>5</sup> Dr Dhara Patel, MBBS, MD Second Year Resident

<sup>6</sup> Dr Neha Nagrani, MBBS, MD Final Year Resident

<sup>7</sup> Dr Anisha Arora, MBBS, MD Final Year Resident

Department of Dermatology, AMC MET Medical College & Sheth L.G. Hospital, Ahmedabad, Gujarat, India

**Correspondence :** Dr Jigna Barot, **Email:** jignabarot1@yahoo.in

Leprosy has affected humanity for thousands of years. Every year more than 2,00,000 new leprosy cases are registered globally and India accounts for 60% of new cases reported globally. According to NLEP Annual Report (2017-2018), the incidence (new case detection) rate of leprosy in India was 9.27/1,00,000 population whereas in Gujarat it was 10.10/1,00,000 population.

Leprosy can lead to physical disabilities and deformities which are sometimes irreversible. These disabilities lead to patients' isolation from society and consequently leading to decrease in their quality of life. Visible deformity in leprosy patients is still the biggest culprit for social stigma and taboos. Although leprosy can be medically cured completely, still it is difficult to bring immediate removal of stigma attached to disease particularly in a holistic society like India. Social stigma impacts negatively on early diagnosis and treatment leading to increase in transmission of disease and prevalence of disability/ deformity (Bottene et al 2012).

The concept of "Quality of life" broadly encompasses how an individual measures the 'goodness' of multiple aspects of their life. The term quality of life incorporates the multi-dimensional nature and perception of overall quality of life, but often is quoted as the impact of an illness or injury on quality of life (CDC 2000). These evaluations include one's emotional reactions to life occurrences, sense of life fulfillment and satisfaction, disposition and satisfaction with work and personal relationships. The measurement of psychosocial issue in addition to biomedical measures has important role in ensuring positive patient outcome from both clinician's and patient's perspective, and is an important outcome measure when evaluating treatment.

In this study, a standardized questionnaire was used to evaluate the impact of leprosy on the daily

life of leprosy patients and analyzing their quality of life.

### Patients and Methods

The study was conducted in the Dermatology Out Patient Department of AMC MET Medical College and L.G. Hospital, Ahmedabad, Gujarat from November 2018 to August 2019. Leprosy patients who are > 16 years of age and willing to take part in study were included. Patients who were on treatment and also who released from treatment but on follow up were included in study after detailed history taking and clinical examination.

Dermatology Life Quality Index (DLQI) designed by Finlay and Khan (1994) was used to assess the quality of life of leprosy patients. Written informed consent was obtained from all patients after informing that participation is voluntary. The questionnaire was applied to each patient individually by the same dermatologist and questionnaire of patient's native language was used which was readily available.

DLQI includes 10 questions, which are subdivided into following subdomains: symptoms and feelings, daily activities, leisure, work and school, personal relationship and treatment. The score for each question being interpreted as: 0 - not at all or not relevant; 1- a little; 2- a lot; 3- very much. The final overall score of the questionnaire is interpreted as follows: 0- 1: no effect at all on patient's life; 2-5: small effect on patient's life; 6-10: moderate effect on patient's life; 11-20: very large effect on patient's life; 21-30: extremely large effect on patient's life. DLQI is calculated by summing the scores of all questions. The score ranges between 0-30.

### Results

Eighty-seven patients affected with leprosy were included in the study during the period of 8 months. Majority of patients (75.7%, n=66) were male with male female ratio being 3:1. The details of demographic profile, disease duration,

**Table 1 : Demographic details**

<b>Gender</b>	
Male	66(75.86%)
Female	21(24.14%)
<b>Age</b>	
0-30	21(24.14%)
31-45	37(42.52%)
46-60	19(21.83%)
>60	10(11.49%)
<b>Education</b>	
Literate	60(68.96%)
Illiterate	27(31.03%)
<b>Occupation</b>	
Labourer	46(52.87%)
Homemaker	16(48.39%)
Others	16(48.39%)
Unemployed	9(10.34%)
<b>Family Income</b>	
<6000	52(59.77%)
>6000	35(40.22%)
<b>Disease Duration</b>	
1-3 yr	62(71.26%)
3-5	22(25.28%)
>5	3(3.44%)
<b>Deformity</b>	
0	44(50.57%)
1	29(33.33%)
2	11(12.64%)
3	3(3.44%)

disability status of the study participants is described in Table 1. The patient's age ranged between 18 to 70 years with maximum number of patients (42.52%, n=37) were aged between 31 and 45 years of age. The mean age was 36.5 years. The mean duration of disease in our patients was 3.2 year. Majority of patients (68.96%, n=60) were literate in our study, 9 patients (10.34%) had finished their tertiary education.

In our study majority of male patients (52.8%, n=46) were working as labourers, 16 patients (18.3%) were doing job and 9 (10.34%) were unemployed. Out of 21 female 16 female (18.3%) were homemaker & 5 females (5.74%) were working in farms. Most of the patients were living in medium sized family having family income below Rs. 6000 per month. Out of 87 total 39 patients (44.82%) were having tuberculoid leprosy while 46 patients (52.87%) were having lepromatous leprosy, one patient had pure neural & one had histoid leprosy. A total of 72 (82.75%) patients were on leprosy treatment during the study, 15 (17.24%) patients were released from treatment. Out of total 87 patients, 18 patients were having lepra reactions. 11 of these 18 cases were on MDT and 7 developed reaction post MDT. Out of 87 patients 29 (33.34%) were having Grade 1 deformity in form of loss of sensations and redness of eyes, 11 patients (12.64%) were having Grade 2 deformity in form of clawing of hand and

**Table 2 : DLQI score in leprosy patients included in this study**

	<b>DLQI (No=87)</b>	<b>No. of patients</b>
DLQI score categorization	Small effect (2-5)	5(5.74%)
	Moderate effect (6-10)	34(39.08%)
	Very large effect (11-20)	47(54.02%)
	Extremely large effect (21-30)	1(1.14%)
Overall DLQI score	Mean±SD	10.58 ±2.57

**Table 3 : DLQI subdomain score and total score**

Subdomain of DLQI	Mean Score
Symptoms and feelings	3.03±1.04
Daily activities	2.05±0.96
Social and Leisure	1.10±0.81
Work and school	4.02±1.47
Prolonged relationship	0.22±0.41
Treatment	0.15±0.36
Total	10.58±2.70

**Table 4 : Difference between factors and subdomains of quality of life**

GENDER	No of pt	SYMPTOMS & Feelings	Daily Activities	Work & school	Social & leisure	Relation	Treatment
MALE	66	3.06±1.04	2.04±0.95	4.2±1.23	1.07±0.83	0.24±0.43	0.15±0.36
FEMALE	21	3±1.04	2±0.89	3.52±1.99	1.14±0.72	0.14±0.35	0.14±0.36
P VALUE		0.81	0.86	0.063	0.72	0.33	0.91
<b>AGE</b>							
0-30	58	2.87±1.07	2.01±1.04	3.82±1.55	1.12±0.72	0.21±0.41	0.12±0.33
30-60	19	2.90±0.95	2.02±1.02	3.97±1.44	1.02±0.75	0.19±0.39	0.11±0.31
>60	10	3.03±1.03	2.06±0.97	4.03±1.42	1.13±0.81	0.23±0.42	0.15±0.36
P VALUE		0.90	0.99	0.88	0.87	0.97	0.95
<b>DISEASE DURATION</b>							
1-3yr	62	3.01±1.02	2.04±0.95	3.06±0.95	1.08±0.78	0.20±0.40	0.13±0.34
3-5	22	2.98±1.03	2.06±0.97	3.97±1.49	1.07±0.79	0.20±0.40	0.14±0.35
>5yr	3	4.05±1.01	3.15±0.98	4.06±1.43	2.15±0.81	1.21±0.41	1.15±0.35
P VALUE		<0.001	<0.001	<0.001	<0.001	<0.001	<0.001
<b>EDUCATION</b>							
LITERATE	60	2.90±1.02	2.01±0.99	3.98±1.51	0.98±0.75	0.22±0.41	0.13±0.34
ILLITERATE	27	3.03±1.03	2.06±0.97	4.03±1.42	1.13±0.81	0.23±0.42	0.15±0.36
P VALUE		0.58	0.82	0.88	0.40	0.91	0.80
<b>INCOME</b>							
<5000	53	3.03±1.03	2.06±0.97	4.03±1.42	1.13±0.81	0.23±0.42	0.15±0.36
>5000	34	2.94±0.93	2.02±0.89	3.78±1.59	1.04±0.66	0.2±0.40	0.14±0.35
P VALUE		0.68	0.84	0.44	0.58	0.74	0.89
<b>OCCUPATION</b>							
Labour	46	3.05±1.02	2.11±0.97	4.11±1.30	1.14±0.83	0.22±0.42	0.15±0.36
Homemaker	16	2.93±1.12	1.81±0.83	3.62±2.06	0.93±0.68	0.18±0.40	0.12±0.34

Others	25	2.92±0.86	2.2±0.76	3.88±1.23	0.96±0.67	0.28±0.45	0.16±0.37
P VALUE		0.94	0.97	0.88	0.89	0.95	0.95
<b>DEFORMITY</b>							
1	29	1.98±1.02	1.04±0.96	3.02±1.47	1.05±0.78	0.20±0.40	0.13±0.33
2	11	3±1.03	2.06±0.96	3.98±1.48	1.08±0.79	0.98±0.41	0.56±0.35
3	3	3.05±1.01	2.46±0.98	4.06±1.43	2.15±0.81	1.21±0.41	1.15±0.35
P VALUE		<0.001	<0.001	<0.001	<0.001	<0.001	<0.001

feet, lagophthalmos and ulcers, 3 patients (3.44%) were having Grade 3 deformity in the form of severe resorption of digits and loss of vision. All patients except those having severe deformities continued in their line of employment.

Table 2 shows number of patients having effect on their quality of life due to leprosy. Mean DLQI in 87 patients was  $10.58 \pm 2.70$ . Majority of the patients had significant effect on their quality of life due to leprosy according to DLQI score. According to DLQI score categorization 47 patients (54.02%) were having very large effect on their quality of life; Out of them majority of patients were having lepromatous leprosy and lepra reaction. The patient with extremely large effect on quality of life was suffering from recurrent lepra reaction and was having loss of vision due to leprosy making him dependent on his family members.

Table 3 shows mean score of each subdomain in leprosy patients with total mean score of  $10.58 \pm 2.70$ . Majority of patients have significant effect on their social life, routine activities & interpersonal relationship affecting general well-being of patients.

Table 4 shows difference between factors & subdomain of quality of life. There was no significant difference observed between gender, age & education in all subdomain of life. Highly significant differences were observed among

disease duration and disability level in all the subdomain of quality of life.

### Discussion

Despite existence of leprosy since thousands of years, even now a days there is stigma present to the disease because of the visible deformities and disabilities caused by it. In most cases it affects people from lower socio-economic status, which also compromises the quality of life.

According to this study most of the patients had DLQI score between 11 to 20 showing very large effect on quality of life & majority of patients were having disease duration more than 1 year. In our study we noticed that DLQI scores increased with increasing clinical severity of disease as higher score was noted in lepromatous pole and patients with lepra reactions due to more constitutional symptoms and deformities causing significant impairment of each subdomain of life. In pure neural leprosy score was high because of the diagnosis was delayed due to ignorance on the part of patient due to which patient had already developed deformity in the form of motor and sensory weakness. Patients with small effect on their quality of life were early detected and treated before any disability or deformity developed. However, there was no significant difference in DLQI scores between those who still have leprosy and who were released from treatment. This suggested that the burden of disease on quality of life of leprosy patients

continues to be a problem even after treatment completed because of occurrence of recurrent lepra reaction and social stigma attached to the disease. This finding is also seen in study conducted in Vietnam on DLQI (Hunt et al 2018).

We also recorded the each subdomains of DLQI questionnaire which showing that most of the patients has affected symptoms and feelings subdomain. Symptoms and feelings include embarrassment due to skin lesions. We noticed that this domain was affected more in reactions patients due to development of new lesions, nerve pain and constitutional symptoms associated with reactions. Very few patients of our study felt embarrassed due to brown red pigmentation induced by Clofazimine. Apart from skin lesions, the stigma attached to the disease has significant effect on patient's emotional well-being. Work and school subdomain was affected due to deformities and development of neuritis in lepra reaction patients that restrict the patient's working and schooling. On the same topic of the DLQI, we also faced similar problem as reported in another study in China, since the DLQI's question nine is about sexual life (An et al 2010). This is culturally sensitive question and because the participants were being interviewed, they may not have answered it reliably.

On calculating the difference between various variable and its relation with quality of life we found that there was no significant difference observed with variable like sex, gender & education which is supported by the study done on DLQI in Vietnam (Hunt et al 2018). Statistically significant difference was noted with duration of disease and presence of deformity as prolong duration affects general well-being of the patients and deformity largely affect the daily activities and employment status making them dependent on other family members. According to our study, out of 87 patients, 29(33.34%) patients were

having Grade 1 deformity and 11(12.64%) having Grade 2 deformity, these are also supported by NLEP (2016-2017) showing higher incidence of grade 1 deformity (4.11%) compared to grade 2 (3.87%).

This study shows that even after five decades of the introduction of MDT in the National programme and major success in reducing the number of leprosy patients, we are still unable to abolish social stigma and taboo associated with leprosy which causes greater impact on psychosocial aspects of life impairing quality of life of patients even after the disease get cured.

Therefore, early diagnosis, treatment along with proper counseling & training in self care along with vocational rehabilitation should play important role in improving the quality of life of patients with leprosy. It is a well designed hospital based cross-sectional longitudinal study on DLQI. Authors should emphasize that NLEP should also incorporate DLQI as one of the indicators for programme performance in order to see improvement in DLQI over the years which would attract more persons affected with Leprosy for early diagnosis and management and would face less social stigma due to various complications and disabilities.

In this study we measured Quality of Life using DLQI. The DLQI has been used in Brazil (Proto et al 2010). This has also been used in PB type leprosy patients as well as in patients with lepromatous leprosy in China (An et al 2010). We evaluated the QOL in patients of leprosy who are on treatment as well as who are cured of leprosy. We didn't take the control group for the comparison which might be the drawback that we can't compare the subdomains affected in normal population. Further these findings cannot be directly extrapolated to leprosy patients being handled by the programme in their own settings. Nevertheless our data highlights the aspects that deserve focus for assessment and remediation.

## Conclusion

In spite of living in an era where leprosy has been declared eliminated as public health problem, we are still unable to abolish social stigma and taboo associated with leprosy which cause greater impact on psychosocial aspects of life impairing quality of life of patients even after the disease get cured. Early diagnosis, treatment along with proper counseling & training in self care along with vocational rehabilitation plays important role in improving the quality of life of patients with leprosy.

## References

1. An JG, Ma JH, Xiao SX et al (2010). Quality of life in patients with lepromatous leprosy in China. *J Eur Acad Dermatol Venereol.* **24** : 827-832.
2. Bottene, Iza Maria Corrêa, & Reis, Vitor Manoel Silva dos (2012). Quality of life of patients with paucibacillary leprosy. *Anais Brasileiros de Dermatol.* **87(3)**: 408-411. <https://dx.doi.org/10.1590/S0365-05962012000300009>
3. Centers for Disease Control and Prevention (2000). Measuring healthy days: Population Assessment of health. Related quality of life. Atlanta, Georgia.
4. Finlay AY and Khan GK (1994). Dermatology life quality index - a simple practical measure for routine clinical use. *Clin Exper Dermatol.* **19(3)** : 210-216.
5. Hansen GA (1875). On the etiology of leprosy. *Brit & Foreign Med-Chir Rev.* **55**: 459-489.
6. Hunt WT, Hung NT, Troung NN et al (2018). A case control study comparing the Dermatology life quality index rating of patients undergoing leprosy treatments, people cured of leprosy and control in Vietnam. *Lepr Rev.* **89** : 46-55.
7. National Leprosy Eradication Programme (NLEP) Annual Report (2017-2018). New Delhi: Central Leprosy Division Directorate, General of Health Services, Ministry of Health and family Welfare Government of India.
8. Proto RS, Machado Filho CD, Rehder JR et al (2010). Quality of life in leprosy: a comparative analysis between patients in the amazon region and patients in Santo Andre in the ABC region of Sao Paulo, Brazil. *An Bras Dermatol.* **85**: 939-941.

**How to cite this article** : Solanki AD, Barot JP, Patel JH et al (2020). Measurement of Quality of Life in patients of Leprosy attending Outdoor Patient Department at Tertiary Care Center of Ahmedabad: A Cross Sectional Study. *Indian J Lepr.* **92**: 139-145.