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Original Article

A study on the quality of life of patients with leprosy: A cross-sectional study

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ABSTRACT

Background: Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. If not detected early and treated adequately, it leads to disabilities and deformities, in turn leading to social stigma and discrimination. Hence, leprosy has an impact on the Quality of Life (QoL) of the affected. **Materials and Methods:** This study was conducted at the Dermatology Department and Leprosorium Hospital. A total of 164 leprosy patients were assessed for QoL with the Dermatology Life Quality Index (DLQI) questionnaire. **Results:** Among the total of 164 patients, leprosy had no effect on the QoL of 14 (8.54%) patients, a small effect on the QoL of 34 (20.73%) patients, a moderate effect on the QoL of 47 (28.66%) patients, a large effect on the QoL of 64 (39.02%) patients, and an extremely large effect on the QoL of 5 (3.05%) patients. Among the demographic variables, age, occupation, and socioeconomic status had an impact on the QoL of patients with leprosy. **Conclusion:** Leprosy is an ancient disease and continues to be the most feared due to deformities and the social stigma associated with it. The clinical spectrum, reactions, deformities, and disability have a profound impact on the QoL of patients with leprosy.

Keywords: Leprosy; DLQI questionnaire; Quality of life

INTRODUCTION

Leprosy is a common chronic infectious disease known worldwide and mentioned as early as 600 BC in the Indian literature in the Sushruta Samhita [1]. Leprosy is a chronic disease caused by *Mycobacterium leprae*, infectious in some cases, affecting the peripheral nervous system, the skin, and other tissues, such as the reticuloendothelial system, bones, joints, mucous membranes, eyes, testes, muscles, tendons, kidneys, adrenal glands.

The WHO launched the Global Leprosy Strategy 2016–2020 "Accelerating towards a leprosy-free world" in 2016. Its goal is to strengthen efforts to combat leprosy and prevent disability, especially in children impacted by the disease living in endemic countries [2]. There were 127,558 new cases of leprosy detected worldwide in 2020 according to official figures from 139 countries in six WHO regions. Among the new leprosy cases, 7,198 new cases were detected with grade 2 disabilities (G2D), and the new G2D rate was recorded at 0.9 per million in the population. At the end of the year 2020, the prevalence was 129,389 cases on treatment, and the prevalence rate corresponded to 16.7 per million of the population [3].

Leprosy is the most ostracized disease due to its resultant physical deformity and social stigmatization associated with it. The disabilities and physical deformities are due to reactions, delayed treatment, and the insidious progression of the disease. These disabilities may lead to social stigmatization, resulting in the isolation of the patient from society, adversely affecting their interpersonal relationship, marriage, employment, and social activity, leading to a decrease in QoL [4].

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According to the WHO, quality of life is the individual's view of their position in the perspective of the culture and value systems in which they live and in relation to their goals, standards, expectations, and concerns [5]. Leprosy-related QoL may be impacted by a number of variables, including the onset and progression of the disease, duration of the disease, social factors, and clinical variables, such type of leprosy, reactions, nerve involvement, disability grade, deformity, and systemic involvement. There are several studies on the assessment of QoL of patients with leprosy, in eastern India [6], Brazil [7], and China [8]. However, similar studies of QoL have not been done in south India. Therefore, this study was conducted to evaluate the QoL of patients with leprosy in our population.

MATERIALS AND METHODS

The study was conducted at the Dermatology Department and Leprosorium Hospital after taking approval from the institutional ethics committee. The cases were documented over twelve months from April 2020 to March 2021. A total of 164 patients with leprosy were included in our study. After receiving consent, all patients exhibiting the cardinal signs of leprosy who were eighteen years of age or older, of either sex, and willing to engage in the study were included in our study. In each case, detailed history taking and thorough general, physical, local, and systemic examinations were done with regard to the clinical features of leprosy. In all cases, necessary investigations were performed if required. Patients who did not give consent to the study, pregnant women, and lactating mothers were excluded from the study. The Dermatology Life Quality Index (DLQI) questionnaire developed by Finlay et al. [9] was employed to assess the QoL of the patients with leprosy. It was a simple, validated, ten-question questionnaire, each question with three marks. The DLQI was determined by summing the results of each question, which yielded a minimum score of 0 and a maximum score of 30. A score of 0–1 indicated no effect on the patient's life. A score of 2–5 indicated a small effect on the patient's life. A score of 6–10 indicated a moderate effect on the patient's life. A score of 11–20 indicated a large effect on the patient's life. A score of 21–30 indicated an extremely large effect on the patient's life. The greater the score was, the more the QoL is impaired [9].

Statistical Analysis

This was a cross-sectional study and the collected data was entered in Microsoft Excel and analyzed with descriptive statistics expressed in terms of frequencies in the form of tables and charts. For statistical significance, the chi-squared test was employed.

RESULTS

Among the total of 164 patients, leprosy had no effect on the QoL of 14 (8.54%) patients. There was a small effect in 34 (20.73%) patients, followed by a moderate effect in 47 (28.66%) patients, a large effect in 64 (39.02%) patients, and an extremely large effect in (3.05%) patients.

In total, there were 126 (76.82%) male patients and 38 (23.17%) female patients. Leprosy had no effect on the QoL of 13 (10.3%) male patients. There was a small effect in 25 (19.8%), a moderate effect in 33 (26.2%), a large effect in 51 (40.5%), and an extremely large effect in 4 (3.2%) male patients. Leprosy had no effect on the QoL of 1 (2.6%) female patient, a small effect in 9 (23.7%) female patient, a moderate effect in 14 (36.8%), a large effect in 13 (34.2%), and an extremely large effect in 1 (2.6%) female patient (Table 1).

Among the 164 patients included in the study, the youngest patient was nineteen years old and the oldest one was 92 years old. Most of the patients (61; 37.2%) were in the age group of 21– 40 years, followed by 55 (33.5%) patients in the group of 41–60 years, 38 (23.2%) in the group of 61–80 years, 6 (3.7%) in the group of 18–20 years, and 4 (2.4%) above 80 years of age (Table 1).

The study included 164 patients. The mean ± SD of the age of the patients was 47.33 ± 17.47 and the mean ± SD of the DLQI score was 9.24 ± 4.72. The median age and DLQI score were 46.50 and 10.00, respectively (Table 2).

Among the 164 patients, 72 (43.9%) were laborers, followed by 31 housewives (18.9%), 21 farmers (12.8%), 10 students (6.1%), 8 vendors (4.9%), 8 office workers (4.9%), and 14 others (8.5%).

Among the 164 patients, a majority belonged to the upper lower (78; 47.56%) socioeconomic class, followed by the lower middle (48; 29.26%), upper middle (17; 10.36%), lower (12; 7.32%), and upper (9; 5.49%) (Table 1 and Fig. 1).

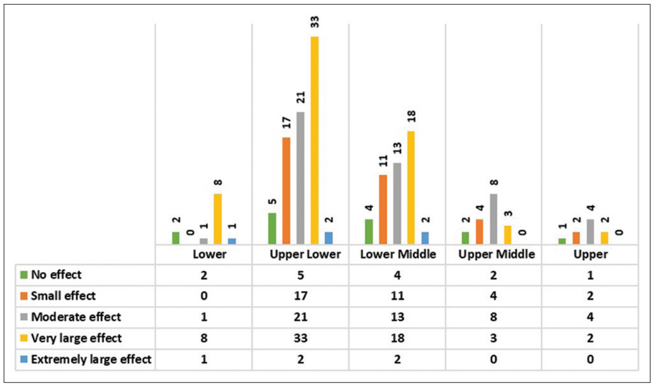
Among the 164 patients, the number of patients belonging to tuberculoid leprosy (TT), borderline tuberculoid leprosy (BT), borderline leprosy (BB),

Table 1: Association of sociodemographic variables with the DLQI.

Sociodemographic variable	No effect	Small effect	Moderate effect	Large effect	Extremely large effect	Total	*p* value
Sex							
Male	13 (10.3%)	25 (19.8%)	33 (26.2%)	51 (40.5%)	4 (3.2%)	126 (100%)	0.447
Female	1 (2.6%)	9 (23.7%)	14 (36.8%)	13 (34.2%)	1 (2.6%)	38 (100%)	
Age							
18–20 yrs.	0 (0%)	0 (0%)	6 (100%)	0 (0%)	0 (0%)	6 (100%)	0.000
21–40 yrs.	7 (11.5%)	15 (24.5%)	22 (36.15%)	17 (27.9%)	0 (0%)	61 (100%)	
41–60 yrs.	5 (9.09%)	13 (23.6%)	13 (23.6%)	21 (38.2%)	3 (5.4%)	55 (100%)	
61–80 yrs.	2 (5.3%)	4 (10.5%)	5 (13.2%)	26 (68.4%)	1 (2.6%)	38 (100%)	
> 80 yrs.	0 (0%)	2 (50%)	0 (0%)	1 (25%)	1 (25%)	4 (100%)	
Occupation							
Laborer	5 (6.9%)	15 (20.8%)	20 (27.8%)	30 (41.7%)	2 (2.8%)	72 (100%)	0.006
Housewife	1 (3.2%)	7 (22.6%)	12 (38.7%)	11 (35.5%)	0 (0%)	31 (100%)	
Farmer	1 (4.8%)	4 (19%)	4 (19%)	11 (52.4%)	1 (4.8%)	21 (100%)	
Student	2 (20%)	5 (50%)	3 (30%)	0 (0%)	0 (0%)	10 (100%)	
Vendor	3 (37.5%)	0 (0%)	3 (37.5%)	2 (25%)	0 (0%)	8 (100%)	
Office worker	0 (0%)	3 (37.5%)	4 (50%)	1 (12.5%)	0 (0%)	8 (100%)	
Others	2 (14.3%)	0 (0%)	1 (7.1%)	9 (64.3%)	2 (14.3%)	14 (100%)	
Socioeconomic status							
Lower	2 (16.7%)	0 (0%)	1 (8.3%)	8 (66.7%)	1 (8.3%)	12 (100%)	0.426
Upper lower	5 (6.4%)	17 (21.8%)	21 (26.9%)	33 (42.3%)	2 (2.6%)	78 (100%)	
Lower middle	4 (8.3%)	11 (22.9%)	13 (27.1%)	18 (37.5%)	2 (4.2%)	48 (100%)	
Upper middle	2 (11.8%)	4 (23.5%)	8 (47.1%)	3 (17.6%)	0 (0%)	17 (100%)	
Upper	1 (11.1%)	2 (22.2%)	4 (44.4%)	2 (22.2%)	0 (0%)	9 (100%)	

Table 2: Mean, median, and SD of age.

Variable	Mean ± SD	Median	Range
Age (yrs.)	47.33 ± 17.47	46.50	73
DLQI score	9.24 ± 4.72	10.00	23



	Lower	Upper Lower	Lower Middle	Upper Middle	Upper
🟩 No effect	2	5	4	2	1
🟧 Small effect	0	17	11	4	2
⬜ Moderate effect	1	21	13	8	4
🟨 Very large effect	8	33	18	3	2
🟦 Extremely large effect	1	2	2	0	0

Figure 1: Socioeconomic status of patients with leprosy and the DLQI score.

borderline lepromatous leprosy (BL) and lepromatous leprosy (LL) was 12 (7.32%), 49 (29.87%), 2 (1.22%), 28 (17.07%), and 73 (44.51%), respectively. The majority of the cases with the LL type of leprosy (58; 79.5%) were found to have a large effect in the DLQI and were also statistically significant ($p = 0.000$) (Table 3 and Fig. 2).

A reaction (type 1 or type 2) was present in 63 (38.41%) patients, was associated with a moderate effect in the DLQI, and was found to be statistically significant ($p = 0.000$) (Table 3).

Deformities were present in 78 (47.55%) patients and absent in 86 (52.44%) patients. Among the 78 patients, a grade 1 deformity was present in 9 (5.48%) and a grade 2 deformity was present in 69 (42.07%). A majority of the patients with grade 2 deformities were found to be associated with a large effect (57; 82.6%) in the DLQI and were found to be statistically significant. Deformities had a positive correlation with the DLQI score. The presence of deformities led to a higher impact on the quality of life (Table 3 and Fig. 3).

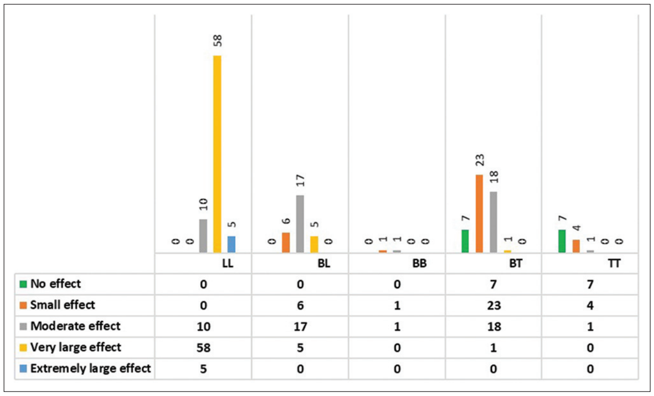
Among the demographic variables, age (correlation coefficient: 0.434) and occupation (correlation coefficient: 0.015) had a positive correlation with the DLQI. Age was found to have a statistically significant impact in the DLQI ($p < 0.05$). Socioeconomic status (correlation coefficient: -0.234) was found to have a negative correlation.

DISCUSSION

The patient with leprosy, if not treated early and adequately, progresses with deformities and disabilities leading to the stigmatization of the disease and the impairment of their quality of life. However, few studies have attempted to identify and evaluate the actual impact of the illness on the patient's quality of life.

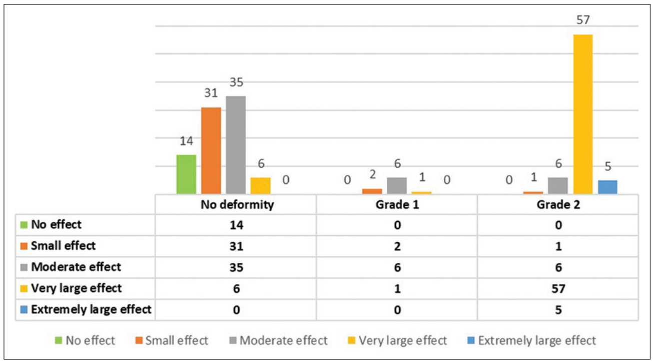
Table 3: Association of the spectrum of leprosy, reactions, and deformities with respect to the DLQI.

	No effect	Small effect	Moderate effect	Large effect	Extremely large effect	Total	*p* value
Leprosy type							
LL	0 (0%)	0 (0%)	10 (13.7%)	58 (79.5%)	5 (6.8%)	73 (100%)	0.000
BL	0 (0%)	6 (21.4%)	17 (60.7%)	5 (17.9%)	0 (0%)	28 (100%)	
BB	0 (0%)	1 (50%)	1 (50%)	0 (0%)	0 (0%)	2 (100%)	
BT	7 (14.3%)	23 (46.9%)	18 (36.7%)	1 (2%)	0 (0%)	49 (100%)	
TT	7 (58.3%)	4 (33.3%)	1 (8.3%)	0 (0%)	0 (0%)	12 (100%)	
Leprosy reaction							
Type 1	0 (0%)	12 (31.6%)	23 (60.5%)	3 (7.9%)	0 (0%)	38 (100%)	0.000
Type 2	0 (0%)	0 (0%)	12 (48.0%)	12 (48.0%)	1 (4.0%)	25 (100%)	
No reaction	14 (13.9%)	22 (21.8%)	12 (11.9%)	49 (48.5%)	4 (4.0%)	101 (100%)	
WHO disability grading (1998)							
Grade 0	14 (16.3%)	31 (36.0%)	35 (40.7%)	6 (7.0%)	0 (0%)	86 (100%)	0.000
Grade 1	0 (0%)	2 (22.2%)	6 (66.7%)	1 (11.1%)	0 (0%)	9 (100%)	
Grade 2	0 (0%)	1 (1.4%)	6 (8.7%)	57 (82.6%)	5 (7.2%)	69 (100%)	



	LL	BL	BB	BT	TT
■ No effect	0	0	0	7	7
■ Small effect	0	6	1	23	4
■ Moderate effect	10	17	1	18	1
■ Very large effect	58	5	0	1	0
■ Extremely large effect	5	0	0	0	0

Figure 2: Clinical spectrum of leprosy and the DLQI score.



	No deformity	Grade 1	Grade 2
■ No effect	14	0	0
■ Small effect	31	2	1
■ Moderate effect	35	6	6
■ Very large effect	6	1	57
■ Extremely large effect	0	0	5

Figure 3: WHO disability grading of leprosy and the DLQI score.

The majority of the cases in our study had some adverse impact on their quality of life due to leprosy. The disease had a large effect on the QoL of 64 (39.02%) patients, followed by a moderate effect in 47 (28.66%) patients. In a study conducted by Nirmalya et al. [6], the disease had a very significant impact on 39 (34.21%) patients' QoL. Numerous other studies have demonstrated that leprosy has an adverse impact on the patient's QoL [10,11].

In the present study, the mean ± SD of the age of the patients was 47.33 ± 17.47 and the mean ± SD of the DLQI score was 9.24 ± 4.72. In studies done by Budel et al. [12] and Nirmalya et al. [6], the mean DLQI scores were 10.23 ± 7.79 and 8.48 ± 5.48, respectively.

In our study, leprosy was more frequent in male patients (76.82%) than female (23.17%). Our study was in concordance with other studies. In a study done by Kalita et al. [13], males constituted 71.43% and females constituted 28.57%. In a study by Raghavendra et al. [14], 78% were males and 22% were females. Leprosy affects both sexes, yet, in most parts of the world, males are more likely to contract leprosy than females [14]. This increased incidence among males may be explained by the fact that it is the males who tend to go more often for outdoor work for earning than females. Hence, males have higher chance of exposure to infection and contracting the disease.

A majority of the patients (67; 40.85%), were in the age group of 18–40 years, followed by 55 (33.53%) in the group of 41–60 years. The mean ± SD of the age of the patients was 47.33 ± 17.47. In a study by Nirmalya et al. [6], a majority of the patients (32; 28.07%) were in the age group of 41–50 years, and the mean age was 38.11 ± 12.16 years. In our study, age had a positive correlation and statistically significant impact in the DLQI ($p < 0.05$). Meanwhile, in a study by Nirmalya et al. [6], there was no strong correlation and no significant effect on the QoL.

In our study, a majority of the patients belonged to the upper lower (78 (47.56%)) socioeconomic class, followed by the lower middle (48; 29.26%). Socioeconomic status was found to have a negative correlation with the DLQI score. Similar observations were seen in a study by Anil Kumar et al. [15] and Singh et al. [16]. Thus, by most of the studies, leprosy is more common in the low-income group, as the lower class is associated with overcrowding, malnutrition, illiteracy, poor personal hygiene, heavy work, and ignorance of injuries, which are the important factors in the acquisition of disease in the case of leprosy [17,18].

Among the total 164 patients in our study, 73 (44.51%) patients had lepromatous (LL) leprosy, followed by 49 (29.87%) patients with borderline tuberculoid (BT) leprosy. A majority of LL-type leprosy (58, 79.5%) were found to experience a large effect on the DLQI and were also statistically significant ($p = 0.000$). Similar observations were seen in studies by Vara and Marfatiya [19] (LL in 52%, BT in 36%) and Jindal et al. [20] (LL in 33%, BT in 28%). However, in a study by Nirmalya et al. [6], LL was in 16.67% and BT was in 35.07% [6]. Thus, the clinical spectrum of leprosy observed has varied from study to study and place to place.

In our study, a leprosy reaction (type 1 and type 2) was present in 63 (38.41%) patients, was associated with a moderate effect in the DLQI, and was found to be statistically significant ($p < 0.05$) (Table 1). A similar observation was seen in a study by Nirmalya et al. [6], in which a leprosy reaction (type 1 and type 2) was present in 51 (44.74%) patients and had a positive correlation with the DLQI score.

In our study, deformities were present in 78 (47.55%) patients and absent in 86 (52.44%). Among the 78 patients, grade 1 deformities were present in 9 (5.48%) patients and grade 2 deformities were present in 69 (42.07%). A majority of the patients with grade 2 deformities were found to be associated with a large effect (57; 82.6%) in the DLQI and were also found to be statistically significant ($p < 0.05$) (Table 2).

Deformities had a positive correlation with the DLQI score. A higher DLQI score resulted from the existence of deformities. Similar findings were made in a study by Nirmalya et al. [6], who found that deformities were present in 44 (38.60%) patients and absent in 70 (61.40%).

CONCLUSION

Leprosy is an ancient disease and continues to be the most feared due to deformities and the social stigma associated with it. Our study attempted to reveal the impact of leprosy on quality of life. Among the demographic variables, age, occupation, and socioeconomic status were found to have an impact on QoL. Clinical aspects such as the spectrum of leprosy, reaction, deformities, and disability have a profound impact on the QoL of the patients. Therefore, the early detection of leprosy and adequate treatment along with grade 1 disability assessment and management will prevent patients with leprosy from going into grade 2 disability and also improves their quality of life.

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