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Original Article

Transforming Lives: Understanding the Quality of Life of Leprosy Patients in Northern India

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Leprosy also known as Hansen's disease, is a long-lasting infectious condition that considerably affects the quality of life of those affected. The purpose of this study is to assess the impact on quality of life of leprosy patients in a tertiary care center located in North India. 172 patients suffering from leprosy and aged 16 or over were recruited for the study, and their quality of life was measured using the Dermatology Life Quality Index (DLQI). From the data, it was found that a large section of the sample population (90.7%) noted that their quality of life has reduced with a mean DLQI score of 9.31±6.21. Patients suffering from lepromatous leprosy and pure neuritic types had worse quality of life estimates compared to borderline and tuberculoid leprosy patients who reported having relatively better estimates. Also, the presence of complications and the duration of illness significantly lowered the quality-of-life scores. The demographic characteristics which included age, sex, marital status and socio-economic status did not relate significantly to the DLQI scores. The study demonstrates the heterogenous burden of leprosy from physical, psychological, and social perspectives and highlights the importance of developing comprehensive care plans alongside medical attention to enhance patient outcomes.

Keywords: Leprosy, Quality of Life, Northern India, Stigma, Tertiary Care Center, DLQI

Introduction

Leprosy or Hansen's disease is perhaps one of the world's oldest and most dreaded diseases that has tormented humans throughout history, leaving lasting impressions on religion, literature and art. Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* and *Mycobacterium lepromatosis*. These microorganisms infect the nerves and the skin (Bhat & Prakash 2012). Globally, nearly 200,000 new cases of leprosy are detected each year with India contributing to almost 60% of total global burden of leprosy as per WHO report 2020 (Murthy 2004). According to WHO leprosy update data 2019, Leprosy is a major global problem and serious public health disease in developing countries accounting for 202155 new cases globally and 114451 new cases in India (WHO 2020). Leprosy has most serious effects on body tissues consequent to infection of the skin, nerves and eyes and as a result of immune response (Bhat & Prakash 2012, Waters et al 1971). It is also one of the most important causes of peripheral neuropathy. If left untreated, leprosy can cause nerve

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damage, leading to muscle weakness, atrophy and permanent disabilities (Shetty 2023). Apart from the physical burden of disease, leprosy patients are also subjected to social stigma and discrimination (Marahata et al 2018, Adhikari et al 2014, Asampong et al 2018). The multiple burden of cosmetic deterioration, physical disabilities, financial impact of disease treatment and lost opportunities coupled with social stigma and discrimination has a huge impact on the quality of life of leprosy patients. In different studies conducted in different environments, leprosy has been seen to affect the quality of life of affected patients with moderate-to-severe magnitude (Das et al 2020, Tare et al 2021, Pai et al 2022). In our study, we calculated the quality of life and then analyzed its association with factors like type of leprosy, complications, and socio-economic factors. We compared the results to determine which factors were affecting it. Although most factors did not show a significant effect, we emphasized quality of life by taking measures to prevent future deformities and disabilities in patients, aiming to improve their quality of life.

Materials and Methods

A cross- sectional study for a duration of 20 months from Jan 2022 till Aug 2023 was carried out in the Department of Dermatology of Era's Lucknow Medical College and Hospital, Lucknow, a tertiary care centre in northern India. This study was approved by the ethics committee, informed and written consent taken from all the patients.

A total of 172 patients of either sex aged 16 or above with diagnosis of leprosy confirmed by either slit skin smear or skin biopsy or based on clinical symptoms or with combination of these modalities were enrolled in this study, the patients were started treatment after assessing the quality of life and few patients had taken treatment previously. Patients were classified by Ridley -Jopling (1966) and IAL classification (Ganapati & Revankar 1985). Definitions described by Brandsma & van Brakel (2003) were used for disability grading. All the patients were clinically examined and demographic details were noted. Our primary objective was to study the quality of life and see associations between quality of life and type of leprosy, complications and socioeconomic factors.

The quality of life was assessed using Dermatology Life Quality Index (DLQI) questionnaire designed by Finlay & Khan (1994). DLQI score was calculated according to the standard method.

All the details were recorded on case sheets for individual patient which was used for computing data and application of statistical tools using SPSS (Statistical Package for Social Sciences) Version 21.0 statistical Analysis Software. The values were represented in Number (%) and Mean ±SD. Chi-square test was used to test the significance of categorical data while to test the significance of two mean values student 't' test was used, to test the significance of more than two mean values ANOVA test was used. Level of significance was $p<0.05$.

Patients with co-morbidities like arthritis, cardiac disease, COPD, tuberculosis, stroke, psoriasis, primary psychiatric disorder or any other medical condition which could impact quality of life were excluded from this study.

Results

Important results of the study are shown in Tables 1 to 6 and Figs. 1 &2.

Demographic Profile

Age of the patients ranged from 16 to 83 years. Mean age of patients was 36.57±14.14 years. 66.3 % were males and 69.3 % of the enrolled patients were married. Most were unemployed (32 %) followed by homemakers (19.2 %) and farmers (15.1 %). 53.5 % patients were from urban areas as compared to 46.5 % patients from rural areas. Upper lower and lower class according to Modified Kuppuswamy scale

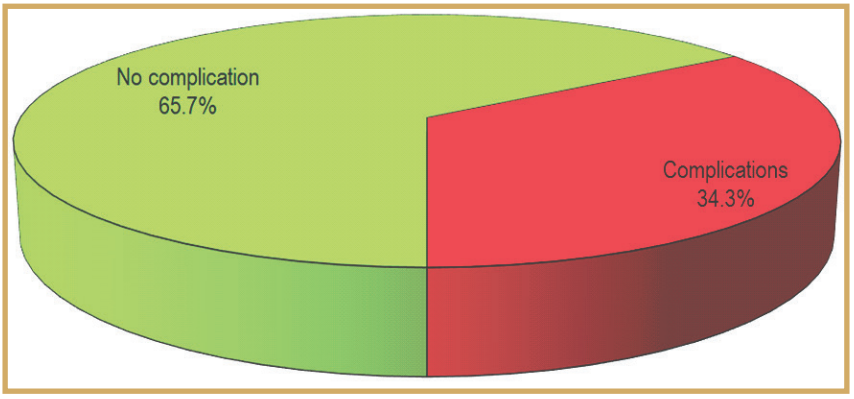

Fig. 1 : Complications rate in the studied patients of leprosy.

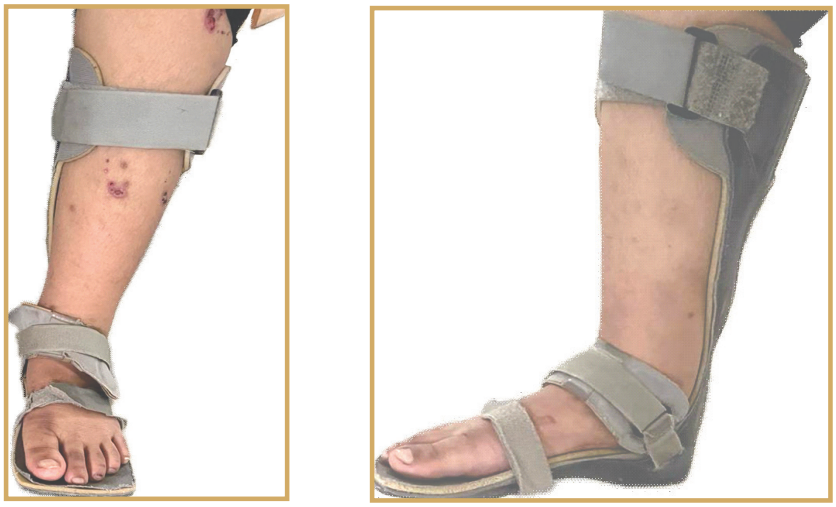

Fig. 2 : Splints used by leprosy affected persons for deformity management.

(Saleem & Jan 2021). comprised majority of the study (58.7 %). No significant association of mean DLQI scores was seen with age, sex, marital status, occupation, place of residence, education and socio-economic status (Table 1).

Leprosy Profile- Clinical Types and Complications

A total of 44 patients (25.6 %) were diagnosed with borderline tuberculoid leprosy which was the most common clinical type followed by lepromatous leprosy (23.9 %). Only 7% were of pure neuritic type. 34.3 % of the patients presented with leprosy related complications. Type 2 reaction was the most common complication (13.4 %) followed by type 1 reaction and claw hand deformity (7 % each) (Fig. 1, Table 3)

Impact on Quality of Life

Impact on quality of life was seen in 90.7 % of the cases. Mean DLQI±SD (Range) was 9.31±6.21 (0-24). Maximum patients (33.1 %) experienced large impact in their quality of life followed by 28.5 % who suffered moderate impact. This was

Table 1 : Association of QoL with Demographic Profile of patients (n=172).

SN	Characteristic	n	Mean DLQI±SD	Significance ('p'-value)
	Age			
	<40 Years	104	8.86±5.85	F=1.035; p=0.358
	40-59 Years	59	9.78±6.33	
	>60 Years	9	11.56±9.22	
	Sex			
	Male	114	9.20±6.22	t=0.331; p=0.741
	Female	58	9.53±6.25	
	Marital status			
	Married	102	10.01±6.11	F=2.053; p=0.132
	Unmarried	63	8.06±5.68	
	Widow/Widower	7	10.43±10.57	
	Occupation			
	Farmer	26	9.00±5.31	F=1.025; p=0.416
	Labourer	8	12.00±7.71	
	Skilled labourer	10	8.00±6.50	
	Shopkeeper/Pvt. Business	19	10.26±6.55	
	Teacher	5	9.40±5.59	
	Student	16	6.06±4.31	
	Homemaker	33	9.73±6.65	
	Unemployed	55	9.67±6.43	
	Resident			
	Rural	80	9.04±6.19	t=0.543; p=0.588
	Urban	92	9.55±6.26	
	Education			
	Illiterate	44	10.30±7.23	F=0.945; p=0.454
	Primary School	46	9.85±5.98	
	Middle School	12	6.33±6.91	
	High School	29	9.03±5.21	
	Intermediate	17	9.12±6.92	
	Graduate	24	8.46±4.72	
	Socioeconomic status			
	Lower	30	9.67±6.13	F=0.475; p=0.754
	Upper Lower	71	8.66±6.64	
	Lower Middle	19	8.90±5.20	
	Upper Middle	47	10.13±5.99	
	Upper	5	10.40±7.27	

further followed by small impact in 22.7 % and extremely large impact in 6.4 % of the patients respectively. 16 patients had no impact on their quality of life (Table 2).

Table 2 : Distribution of cases according to quality of life profile (n=172).

SN	Category	No.	%
1.	No impact (0-1)	16	9.3
2.	Small impact (2-5)	39	22.7
3.	Moderate impact (6-10)	49	28.5
4.	Large impact (11-20)	57	33.1
5.	Extremely large impact (21-30)	11	6.4
	Mean DLQI±SD (Range)	9.31±6.21 (0-24)	

Table 3 : Association of quality of life (DLQI) with clinical type.

SN	Clinical Type	n	Mean DLQI±SD	
1.	BB	24	5.96	4.89
2.	BL	29	9.45	4.28
3.	BT	44	6.95	5.79
4.	LL	41	14.27	5.32
5.	TT	22	5.95	5.12
6.	Pure Neuritic	12	13.58	6.20
	F=14.32; p<0.001			

Abbreviations: BB=borderline borderline; BL=borderline lepromatious; BT= borderline tuberculoid; LL= lepromatous; TT= tuberculoid

Table 4 : Association of quality of life (DLQI) with complications.

SN	Complications	N	Mean DLQI±SD	
1.	No	113	7.37	5.63
2.	Yes	59	13.03	5.59
	t=4.447; p<0.001			
	Complication type			
1.	Type 1 reaction	12	14.17	6.99
2.	Type 2 reaction	23	14.26	4.97
3.	Claw Hand deformity	12	11.17	6.16
4.	Ulcer	4	12.00	1.41
5.	Foot drop	2	14.50	0.71
6.	Grade 2 neuritis	2	8.50	4.95
7.	Grade 3 deformity/Wrist drop	2	13.00	4.24
8.	Partial claw deformity	2	8.50	9.19
	F=0.816; p=0.578			

Table 5 : Comparison of mean DLQI scores among patients with different duration of illness.

SN	Duration	No. of cases	Mean DLQI	SD
1.	<6 months	52	3.62	3.71
2.	7-12 months	31	7.71	3.62
3.	13-24 months	43	10.49	4.48
4.	25-48 months	43	15.28	4.34
5.	>48 months	3	22.33	1.53
	F=59.024; p<0.001			

Mean DLQI scores were significantly higher for LL and Pure neuritic types (14.27±5.32 & 13.58±6.20) followed by BL and BT types (9.45±4.28 & 6.95±5.79). BB and TT types (5.96±4.89 & 5.95±5.12) had lowest DLQI scores. Statistically, there was a significant association between clinical type and DLQI scores (p<0.001) (Table 3).

Patients having leprosy complications had significantly higher DLQI scores as compared to those not having complications (p<0.001). There was no statistically significant difference in DLQI scores among different complications (p=0.578) (Tables 4 & 5).

Duration of illness ranged from 1 to 72 months mean duration was 19.03±15.57 months. Mean DLQI score of patients with duration of illness ≤6 months (3.62±3.71) was minimum followed by those with duration 7-12 months (7.71±3.62) while maximum DLQI score was observed for patients with duration of illness ≥48 months (22.33±1.53) followed by those with 25-48 months duration (15.28±4.34). With increasing duration of disease there was a significant increase in DLQI scores (Table 5).

Discussion

Quality of life is an area of concern in patients of leprosy and requires an in-depth study regarding its magnitude and relationship with different clinico-demographic variables. Hence, the present study was carried out to study the quality of life of leprosy patients and to trace its link with demographic factors, clinical classification of leprosy and complications associated with leprosy. The present cross- sectional study was carried out in which a total of 172 leprosy patients aged between 16 and 83 years (mean age of 36.57±14.14 years; 66.3% males; 59.3% married; 32% unemployed; 52.3% illiterate or educated up to primary school, 58.7% from lower/upper lower socioeconomic class; mean duration 19.03±15.57 months) were enrolled and evaluated for quality of life using Dermatology Life Quality Index (DLQI).

In the present study, the age profile of the patients was quite diversified with age range spanning from 16 to 83 years. Mean age of patients was 36.57±14.14 years. Majority of patients were around 20-40 years age range. There was a predominance of males (66.7%). The age and sex profile of the patients in the present study is similar to that reported by Gan and Voo (Gan & Voo 2021) who reported the mean age of patients as 37.96 years and found 70.4% of them to be males. Compared to the present study, Liyanage et al (2021) reported the mean age of patients to be slightly older (45.7 years) and proportion of males slightly lesser (61.9%). In another study, Umniyati et al (2022) not only reported the mean age of patients to be much higher (47 years) but also reported a dominance of females (56.4%). The higher prevalence of

males in different studies as well as in the present study could be owing to the higher prevalence of leprosy in males as compared to that in females throughout the world with almost two males as compared to one female being affected by it (Kumar et al 2004). The younger population found in our study may be due to increasing awareness of leprosy over a time in our area. Most patients now recognize symptoms, like numbness, and seek medical attention for them. This is why we observed a higher number of patients and a diverse population from various awareness groups.

Major chunk of patients was married (59.3%), were homemakers or unemployed (51.2%), had urban residence (53.5%), and were either illiterate or educated up to primary level (52.3%) with dominance of those from lower/upper lower socioeconomic class (58.7%). It may be noted that leprosy affects and limits the occupational opportunities of a patient which eventually could have been responsible for decline in quality of life of patients. As far as the dominance of urban residents in the present study, it may be attributed in part to the location of our facility and reflects cumulative representation of suburban patients too. Lower socioeconomic status, lack of education, and poor living conditions increase the risk of leprosy. At the same time, having leprosy limits patients' social and job socio economic opportunities, which can lead to a drop in their economic status, causing stress and psychological burden that affects their quality of life.

In our study, BT (25.6%), LL (23.8%) and BL (16.9%) types together comprised the majority of cases. Type 1 and 2 disabilities and deformities were present in 34.3% of the cases. Similar to the present study, Das et al (2020*)* too found BT (35.1%) as the most common clinical type but it was followed by TT (32.5%). However, in the present study, TT comprised only 12.5% of the study population. On the other hand, Gan &Voo (2021) found borderline lepromatous (42.6%) and lepromatous (LL) (37%) as the most dominant clinical types. It is worth mentioning that patients who are towards the lepromatous pole of leprosy and those with deformities and with paresthesia and anaesthesia tend to have a poor quality of life as compared to other patients.

In this study, we used DLQI scale to assess the quality of life and found that the impact of leprosy on quality of life was seen in most of the cases (90.7%). Large to extremely large impact was seen in nearly two-fifth (39.5%) patients. Tare et al (2021*)* too found very large to extremely large effect on quality of life of 33.3% of their patients. In the present study, mean DLQI was 9.31±6.21. Compared to this Gan & Voo (2021) who also had a demographically similar study population reported the mean DLQI as 8.31±6.15. In another study, Das et al (2020) reported mean DLQI as 8.48±5.48. A slightly higher mean DLQI score was reported by Sasithra & Raja (2023) who reported it to be 10.5±5.1 and found very large to extremely large effect in 45.9% cases. Relatively higher mean DLQI and a higher proportion of those having very large to extremely large effect in their study as compared to the present study could be attributed to the difference in type of study population. In the present study, most of the patients were visitors of a dermatology clinic as compared to their study in which all the patients were receiving treatments at a rehabilitation center.

In the present study we did not find a significant association of demographic factors with quality of life (DLQI) scores. Similar to the present study Das et al (2020*)* too failed to find a significant association of DLQI scores with age, residence, socioeconomic status and marital status. Most of the other studies did not find sex or other sociodemographic factors to be significantly associated with quality of life scores (Tare et al 2021). The association of quality of life scores

with demographic factors has generally remained inconsistent with some studies showing association of some demographic factors with QoL scores.

Different clinical types of leprosy were found to have a significant association with the quality of life. LL and pure neuritic types had worst quality of life while BB and BT types had the best scores. Patients with complications/ disability also had significantly poor quality of life as compared to those not having complications. Furthermore, longer duration of disease was also seen to be significantly associated with a poor quality of life. Most of our patients had visible deformities and they tend to hide them, implying that visibility of deformity and social stigma associated with it are the driving factors behind declining quality of life of leprosy patients. The effect of complications on DLQI could be understood as presence of complications impairs the ability to perform activities of daily life.

It is possible that some of the patients lack adequate awareness about leprosy and its complications. This gap in knowledge may be preventing them from visiting the outpatient department (OPD) or adhering to regular follow-ups. Consequently, the duration of leprosy increases, negatively impacting the quality of life and leading to additional complications.

To address this issue, we initiated a reporting system at our tertiary center to facilitate access to government aid and improve patient compliance with treatment. We also collaborated with the physiotherapy department to begin physical rehabilitation for patients (Fig. 2). This approach aimed to treat deformities and enhance the quality of life for those affected.

In our effort to raise awareness, we organized social campaigns and conducted activities within our department. These initiatives helped patients recognize the symptoms of leprosy and understand the importance of consistent treatment adherence.

Despite these efforts, leprosy cases continue to rise possibly due to persistent social stigma and limited awareness. It is essential to implement comprehensive measures to curb its spread and improve the quality of life for affected individuals.

Limitations of the Study

One of the limitations of the present study was limited data related with extent of disability. Moreover, most of the patients had only a short duration of illness owing to which long term impact of leprosy on quality of life could not be studied at great length. Study of association between social stigma experience and quality of life could have highlighted social aspect of the problem.

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