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ORIGINAL ARTICLE

A study of quality of life of leprosy patients in a tertiary care centre in Kerala

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Abstract

Background: Leprosy is an infectious disease associated with a many stigmas and superstitions, and can affect the Quality of Life (QoL). *Objective:* The objective of this study was to assess the effect of leprosy on the QoL of the patients and to find out whether there is any association with specific demographic and clinical factors. *Material and Methods:* The QoL was evaluated for 60 leprosy patients who visited the Dermatology outpatient department of a tertiary care facility in Kerala, South India, using the Dermatology Life Quality Index (DLQI) questionnaire. It was a cross-sectional descriptive research. Results: Of the 60 patients, 23 (38.33%) had no adverse effects on their quality of life due to leprosy, while the remaining patients experienced varied degrees of compromise. The mean DLQI score was 4.03 ± 4.83, which is lower than the previous studies and can be attributed to the people's higher health standards and education level. Significant association was found with clinical factors like site of lesion, nerve palsy, trophic ulcer, and disability. *Conclusion:* The QoL of individuals afflicted by leprosy is negatively impacted. A lower DLQI score in the study shows that the effect can be reduced with a better health care system and education.

Keywords: Leprosy, Quality of life, DLQI questionnaire

Introduction

Leprosy is a long-standing illness that is linked to many stigmas and myths. It has a lengthy incubation time and is caused by Mycobacterium leprae [1]. With the discovery of the causative organism, many changes have occurred in the treatment, prognosis, and attitude towards the disease. Still the stigma associated with the disease persists. Dermatology Life Quality Index (DLQI) questionnaire is a tool used internationally to assess the Quality Of Life (QoL) in various dermatological conditions. Though India has got the most significant burden of leprosy, not many studies are published in the literature which is done among the Indian population to assess the QoL of leprosy patients. In this context, this study is intended to determine the QoL of leprosy treated patients and those undergoing treatment using the DLQI questionnaire.

In recent decades, there has been growing interest in understanding the psychological effects and the broader effect on QoL in patients suffering from various skin diseases [2]. Skin conditions often extend beyond physical symptoms, profoundly affecting individuals' sense of contentment, morale, perception of attractiveness, job opportunities, and interpersonal relationships [2]. Leprosy is a disease affecting skin as well as nerves [3]. This unique characteristic of the disease is a major factor in the severe physical and psychological consequences it inflicts on patients. In addition, leprosy leads to social stigmatization and isolation of the patients due to the deformities caused by it. It also leads to an extensive loss of workforce and thus financial loss to the society[4].

To understand the full impact of the leprosy on the daily lives of the diseased individuals, assessment of the QoL is critical. Though there is a lack of leprosy-specific QoL index, the DLQI has been used effectively in many of the previous studies [5-6] to ascertain the effect of leprosy on lives of diseased patients. The DLQI comprises of 10 questions that address various aspects of living with skin conditions, which are categorized into following sub-domains: everyday activities, leisure, prolonged relationships, work and school, symptoms and feelings, and treatment [7-8]. The greater the score, the greater is the impairment of QoL [7]. Thus DLQI provides an assessment of impact of leprosy on patients' lives. This information helps to develop targeted interventions to improve the welfare of people living with leprosy.

Material and Methods

In 2020-2021, this cross-sectional study was carried out for a year in the Dermatology outpatient department of the Integrated Institute of Medical Sciences (Government Medical College, Palakkad, Kerala, India) approved by Institutional Ethics Committee (IEC/GMCPKD22/19 dated 22/7/2019). The sample size was statistically calculated as per the formula: $n= [Z_{1-\alpha/2}]^2 \sigma^2/\mu^2$ and was found to be 60 [9-10]. Convenient sampling method was used to include the participants for the study. The clinically proven cases of leprosy in individuals aged more than 18 years who had completed three months of treatment and those who were within 5 years of release from treatment were included in the research following the acquisition of informed consent. Those patients with coexisting disorders that could impair the QoL were excluded from the study. The DLQI, designed by Finlay and Khan [8], was employed in this study to evaluate leprosy patients' QoL. The questionnaire was applied to each Dermatology patient in their local language (Malayalam, Hindi, and Tamil), which was readily available and validated. Additionally, the patient's clinical and demographic characteristics were evaluated. The DLQI comprises of ten multiple-choice questions organized into six domains. Four possible answers for each question translate into scores ranging from 0 to 3 and 30 is the highest possible score. The following criteria were used to evaluate the scores: no compromise (0-1), mild compromise (2–5), moderate (6–10), severe (11–20) and very severe compromise of QoL (21–30). The analysis was done using the Statistical Package for the Social Sciences. Means and percentages were calculated. Kruskal-Wallis and Mann-Whitney tests were used.

Results

Sixty patients with leprosy who came to the OPD for 1 year and satisfied the inclusion criteria were enrolled in the study. The male-to-female ratio was 1.8, with 39 (65%) males and 21 (35%) females. Patients' ages ranged from 18 to 75, and the majority belonged to the age group of 31-45 (n=25, 41.7%). The mean age was 40.7 yrs. The demographic and clinical details are given in Table 1.

The mean DLQI score was 4.03 ± 4.83. The maximum score obtained was 18. According to the DLQI, 37 patients (61.67%) experienced an impact on their QoL due to leprosy. Mild compromise was observed in 35% (n=21) of patients, while 13.3% (n=8) had moderate compromise and another 13.3% (n=8) had severe compromise. No patients had very severe compromise (Figure 1).

Table 1: Clinical and demographic profile of study participants

Variables (n=60)		n (%)
Gender	Female	21 (35.00%)
Age	<= 30	14 (23.33%)
	31-45	25 (41.67%)
	46-60	15 (25.00%)
	>60	6 (10.00%)
Education	Illiterate	2 (3.33%)
	School education	52 (86.67%)
	College education	6 (10.00%)
Occupation	Unemployed	5 (8.33%)
	Housewives	16 (26.67%)
	Manual labourers	14 (23.33%)
	Others	25 (41.67%)
Socioeconomic status	Below poverty line	46 (76.67%)
	Above poverty line	14 (23.33%)

Variables (n=60)		n (%)
Spectrum	Neuritic	3 (5.00%)
	Indeterminate	2 (3.33%)
	Tuberculoid	0 (0%)
	Borderline tuberculoid	42 (70.00%)
	Mid borderline	1 (1.67%)
	Borderline Lepromatous	6 (10.00%)
	Lepromatous Leprosy	6 (10.00%)
Presence of reaction	No reaction	45 (75.00%)
	Type 1	14 (23.33%)
	Type 2	1 (1.66%)
Grade of deformity	Grade 0	43 (71.67%)
	Grade 1	5 (8.33%)
	Grade 2	12 (20.00%)

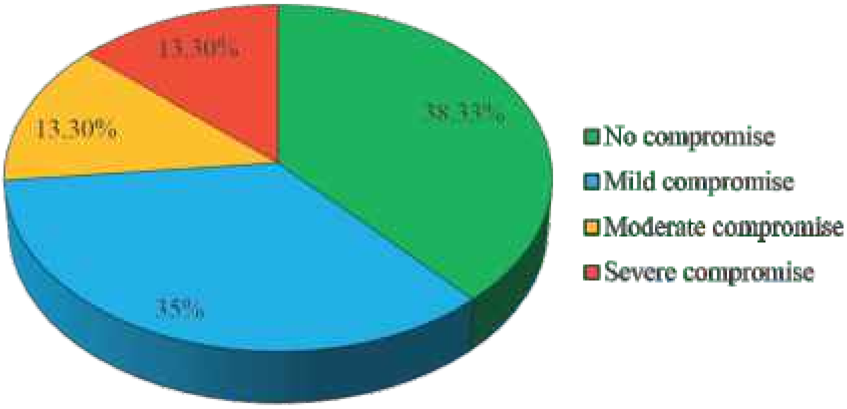

Figure 1: Distribution of leprosy patients as per DLQI compromise

The frequency of impairment and mean score in each domain among the patients enrolled is shown in Table 2, respectively. Most of the patients (60%, n=36) showed impairment in symptoms and feelings, and 40% (n=24) showed impairment in daily activities. Many had problems in their personal relationships to the extent that a patient's spouse filed for divorce due to the disease.

Table 3 displays the relationship between the DLQI score and the clinical and demographic profiles. There was a strong correlation between the patients' QoL and the lesion site. Patient with lesions over the exposed area were found to have significant impairment in the QoL than patients with lesions on non- exposed area. There was also significant association with presence of nerve palsy, trophic ulcer, and disability with QoL of the patient. As the treatment duration crossed 1 year, the QoL was significantly impaired. No statistically significant association was noted with demographic factors like age, gender, educational qualifications, occupation and socioeconomic status and other clinical parameters like spectrum or reaction.

Table 2: Effect of leprosy on different subdomains of DLQI

Subdomains and their maximum score	Mean score
Symptoms and feelings (6)	1.4 ± 1.56
Daily activities (6)	0.95 ± 1.63
Leisure (6)	0.62 ± 1.2
Work and school (2)	0.38 ± 0.72
Personal relationships (6)	0.37 ± 0.72
Treatment (3)	0.35 ± 0.68

Table 3: Correlation of DLQI score with respect to demographic and clinical profile

Demographic and clinical data		Number of patients	DLQI score (mean ± SD)	*p*
Gender	**Male**	39	4.03 ± 5.22	0.47
	Female	21	4.05 ± 4.11	
Age	**<30 years**	14	4.29 ± 5.25	0.98
	30-45 years	25	4.4 ± 5.38	
	45-60 years	15	3.33 ± 3.6	
	>60 years	6	3.67 ± 5.08	

Continued...

Demographic and clinical data		**Number of patients**	**DLQI score (mean ± SD)**	***p***
Site of the lesion	**Exposed site**	37	4.57 ± 5.12	**0.034***
	Not exposed site	9	0.78 ± 1.2	
	Both	13	4.0 ± 4.22	
Nerve palsy	**Not present**	53	3.28 ± 4.09	**0.007***
	Present	7	9.71 ± 6.8	
Trophic ulcers	**Present**	5	7.4 ± 3.78	**0.029***
	Absent	55	3.73 ± 4.83	
Disability	**Grade 0**	43	2.74 ± 3.79	**0.003***
	Grade 1	5	7.2 ± 7.29	
	Grade 2	12	7.33 ± 5.28	
Duration of treatment	**6months**	16	3.06 ± 4.61	0.050
	1 year	38	3.68 ± 4.23	
	>1 year	6	8.83 ± 6.88	

**p value < 0.05 is considered as significant*

Discussion

This study has shown the impact of leprosy in several facets of life's quality. Regarding age, most patients were of 31-45 years, the socially and economically active age group. This was consistent with the Belgaumkar *et al*. [11]. In our study, males were more than females, which was consistent with the previous studies [12-13]. The observed differences in the impact of leprosy on the QoL between males and females may be attributed to social and behavioral factors. Typically, males tend to be more socially active and are often engaged in work outside the home, which increases their interaction with a broader range of people. This increased social exposure can lead to various consequences that affect their quality of life differently than females.

In the present study, most patients (61.67%) exhibited some impairment in their QoL, while 38.33% reported no impairment. The mean DLQI score was 4.03 ± 4.83, notably lower than most previous studies. This difference might be attributed to the better educational status and healthcare system available to the patients in this study. In our study, only 3.33% of patients (n=2) were illiterate. Kerala also has the highest literacy rate [14] and health index [15] among all states in India. So the higher levels of education might contribute to better health literacy, allowing patients to manage their condition more effectively and access resources that improve their quality of life. Education can reduce the stigma associated with leprosy [16]. Health education on leprosy to patients, their caregivers and the community is very important. This helps them to be empowered in their treatment and to have the confidence and understanding to combat opposition they may face from others. This also helps in tolerance and acceptance of their condition [16]. Access to high-quality healthcare services, including early diagnosis, effective treatment, and comprehensive support, can mitigate the impact of leprosy on patients' lives. This can prevent the progression of the disease and reduce the risk of complications, thereby maintaining a higher QoL.

The study reveals that nerve palsy and disability significantly impair the QoL of patients. This finding aligns with the results by Das *et al*. [12]. Additionally, the presence of trophic ulcers also negatively impacts the QoL. An interesting finding from the current study is a statistically significant association between QoL and patients with lesions in exposed areas. Lesions in visible areas like the face, hands, and arms can cause considerable embarrassment and anxiety, impacting social interactions and mental health [7]. The visibility of these lesions can lead to heightened self-consciousness, social stigma, and reduced self-esteem, which are major contributors to a lower quality of life.

Conclusion

Leprosy is a disease known to impair the QoL. However, the significantly lower DLQI scores observed in our study can be attributed to several interrelated factors that enhance the QoL of leprosy patients. Better literacy levels empower patients with knowledge and skills for effective disease management. Early detection and proper treatment prevent severe complications, while a good healthcare system ensures comprehensive and continuous care. Public awareness programs reduce stigma and promote social support, improving outcomes. Collectively, these elements highlight the importance of a multi-faceted approach in managing leprosy and enhancing the QoL for those affected by the disease.

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References

1. Gujarati RV, Naik PNM, Kunti S, Sudheer N, Dungarwal Y. Leprosy, still a burden! A retrospective study in a tertiary health care centre over recent 5 years. *J Krishna Inst Med Sci Univ* 2023; 12(1):68-77.
2. El-Refaei AMA, Daifalla AEM, Kasem SM, Bayomy HE. Health related quality of life in Egyptian leprosy patients using DLQ and WHOQOL-BREF questionnaires. *J Clin Exp Dermatol Res* 2018; 9: 475.
3. Lockwood DN, Saunderson PR. Nerve damage in leprosy: a continuing challenge to scientists, clinicians and service providers. *Int Health* 2012; 4(2): 77-85.
4. Raghavendra BN, Aneesh S, Yarramachu S, Gopal ADS, Muneer M. Clinical pattern of deformities and disabilities in leprosy patients in rural Bangalore-A two year study at tertiary level hospital. *Indian J Clinic Exp Dermatol* 2017; 3(3): 101-109.
5. Nayak KK, Manjunath NC. A study on the quality of life of patients with leprosy: A cross-sectional study. *Our Dermatol Online* 2023; 14(2):121-126.
6. Samanta S, Bandyopadhyay A, Bhattacherjee S, Mukherjee A. Dermatological quality of life among leprosy patients residing at a rehabilitation center in north-eastern India: A cross-sectional study. *Clin Dermatol Rev* 2023; 7(2):148-152.
7. Padmakar S, Ramudu RV, Kumari S, Pal B. Assessment of quality of life and depression in generalized and localized vitiligo patients. *J Krishna Inst Med Sci Univ* 2023; 12(1):24-31.

8. Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)–a simple practical measure for routine clinical use. *Clin Exp Dermatol* 1994; 19(3): 210–216.
9. Joseph GA, Rao PS. Impact of leprosy on the quality of life. *Bull World Health Organ* 1999;77(6):515–7.
10. Bello AI, Dengzee SA, Iyor FT. Health related quality of life amongst people affected by leprosy in South Ghana: A needs assessment. *Lepr Rev* 2013;84:76–84.
11. Belgaumkar VA, Sodhi B, Patil PP, Bhatt N. Impact of leprosy on the quality of life in India: A decade post-elimination. *J Skin Stem Cell* 2021; 8(3): e120879.
12. Das NK, De A, Naskar B, Sil A, Das S, Sarda A, *et al*. A quality of life study of patients with leprosy attending the dermatology OPD of a tertiary care center of Eastern India. *Indian J Dermatol* 2020; 65(1):42-46.
13. Tare DA, Viswanath V, Pai KS, Samel DR. A quality of life study in patients with leprosy using DLQI and WHOQOL-BREF questionnaires. *Indian J Dermatol* 2021; 66(5):574.
14. Literacy Rate in India Statewise (RGI&NSSO). Ministry of Statistics and Program Implementation. Government of India. mospi.gov.in. Available from: https://mospi.gov.in/literacy-rate-india-state-wise-rgi-nsso
15. Healthy states progressive India. Report on the ranks of state and union territories. Niti Aayog. Ministry of Health and Family Welfare 2021: 1-198.
16. Rafferty J. Curing the stigma of leprosy. *Leprosy Review* 2005; 76(2):119-126.

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