

QUALITY OF LIFE AMONG LEPROSY PATIENTS ATTENDING A TERTIARY CARE CENTER IN EASTERN INDIA – A CROSS-SECTIONAL STUDY

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Received : 18/05/2023
Received in revised form : 12/06/2023
Accepted : 28/06/2023

Keywords:

Leprosy, quality of life, *Mycobacterium leprae*, Dermatology Life Quality Index, WHO-QOL-Bref.

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DOI: 10.47009/jamp.2023.5.4.213

Source of Support: Nil,
Conflict of Interest: None declared

Int J Acad Med Pharm
2023; 5 (4); 1063-1067



Abstract

Background: Leprosy, or Hansen's disease (HD), is an ancient bacterial disease caused by *Mycobacterium leprae* bacillus, which produces a chronic infection in humans that affects mainly peripheral nerves and skin and produces a spectrum of clinical phenotypes. Although the disease is curable and significant efforts have been undertaken for its elimination, the visible manifestations of the disease, complications and the deformities combined with the social stigma and lack of accurate knowledge about the disease continue to pose a significant challenge to the Quality of life of leprosy patients. This study aims to assess the impact of leprosy on the quality of life of leprosy patients using two questionnaires and to find out if there is any association between the quality of life and various socio-demographic as well as disease variables. **Materials and Methods:** All patients above the age of fifteen years presenting with the cardinal symptoms of leprosy were included in the study after taking written informed consent. Patients with any other co-existing debilitating disease or disability, psychiatric problems, systemic or personal conditions which might have an impact on the Quality of life (QoL) were excluded from the study. Socio-demographic data and detailed history regarding the symptoms, duration of disease and treatment history was recorded. Thorough general physical, systemic, cutaneous and nerve examination was done. Patients were requested to answer the questions of the DLQI questionnaire and WHOQOL-Bref questionnaire after clearly explaining the meaning of the questions to them in their preferred language. The answers were noted by the same dermatologist in every case. The DLQI and WHOQOL-Bref score was then calculated. The scores were evaluated and compared at the end of the study. **Result:** A total of 112 patients were included in the study in the age group of 15-72 years and the mean age was 39.1 ± 5.8 years. There were 70 males and 42 females included in the study and the male-female ratio was 1.6:1. According to the DLQI scores, moderate effect was seen in 41(36.6%) patients, followed by very large effect in 27(24.1%) patients, small effect in 23(20.5%) patients, extremely large effect in 12(10.7%) patients and no effect in 9(8%) patients. The mean DLQI score was 9.1 ± 4.7 . There were 63(56.2%) new patients, 15(13.3%) RFT (released from treatment), 11(9.8%) relapse patients and 23(20.5%) defaulters. According to the WHOQOL-Bref score, the mean value and standard deviation is 52.1 and 21.2 in the physical domain, 58.4 and 19.1 in the psychological domain, 42.8 and 23.3 in the social relationships and 55.2 and 17.9 in the environmental domain. **Conclusion:** Assessment of the quality of life of leprosy patients helps us to understand the burden of the disease on the physical, emotional, professional and social aspects of the patient's life as well as the associated factors so that we can provide necessary interventions to significantly improve their quality lives.

INTRODUCTION

Leprosy, or Hansen's disease (HD), is an ancient bacterial disease caused by *Mycobacterium leprae*

bacillus, which produces a chronic infection in humans that affects mainly peripheral nerves and skin and produces a spectrum of clinical phenotypes.^[1] India accounts for approximately 60% of the global leprosy burden despite declaring elimination in

2005.^[2] Although multi-drug therapy has been proven to be very effective and significant efforts have been undertaken by the National Leprosy Eradication Program for leprosy elimination, the visible manifestations of the disease, its complications, the deformities of the face, hand and feet, disabilities combined with the social stigma and lack of accurate knowledge about the disease continue to pose a significant challenge to the Quality of life(QoL) of leprosy patients, both new and treated. World Health Organization has defined QoL as the “individual's perception of their position in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”.^[3] Several studies conducted in various parts of the world have demonstrated the adverse impact that leprosy has on lives of patients as well as their families due to social factors like social isolation, unemployment, decline of interpersonal relationships, low self-esteem as well as disease factors like multi-bacillary disease, lepromatous leprosy, systemic involvement, reaction states, nerve involvement, deformities and disabilities.^[4-6]

MATERIALS AND METHODS

Study type and period: This is a cross-sectional study that was carried on for one year from January 2022 to December 2023 after ethical approval. We included 112 patients in our study.

Study Design: All patients above the age of fifteen years presenting with the cardinal symptoms of leprosy and giving their written informed consent to participate in the study were enrolled. Patients with any other co-existing debilitating disease or disability, psychiatric problems, systemic or personal conditions which might have an impact on the Quality of life (QoL) were excluded from the study. Details of the patients like their age, gender, education, occupation, employment status, family income and marital status was recorded. Relevant and detailed history taking regarding the symptoms, duration of disease and treatment history was taken. Thorough general physical, systemic, cutaneous and nerve examination was done.

Dermatological Life Quality Index(DLQI): It is a simple 10 questions validated questionnaire that has been used in many different dermatological disorders and was developed by Professor A Y Finlay and colleagues, is one of the most used instruments for assessing dermatology specific QoL. It is available in many different languages. Each question has 3 marks. The DLQI is calculated by summing the score of each question resulting in a maximum of 30 and a minimum of 0. Higher score represents more impairment of QoL.^[7]

WHOQOL-Bref questionnaire: The WHO-QOL-Bref contains four domain scores and has two individually scored items about an individual's overall perception of the quality of life and health. It consists of 26 items scored from 1 to 5 on a Likert

scale. Four domain scores are scaled in positive direction, with higher scores indicating a higher quality of life. For this study, we used the sum of the raw scores of each constituent item of the four domains, including physical health (7 items), psychological health (6 items), social relations (3 items), and environmental (8 items). The final scores of overall qualities of life and each domain were calculated, resulting in final scores in a scale from 0 - 100. The overall score and that of each domain is considered good if it is more than 50% of the maximum attainable score both in a domain and in total.^[8]

Patients were requested to answer the questions of the DLQI questionnaire and WHOQOL: Bref questionnaire after clearly explaining the meaning of the questions to them in their preferred language. The answers were noted by the same dermatologist in every case. The DLQI and WHOQOL-Bref score was then calculated. The scores were evaluated and compared at the end of the study.

Statistical Analysis: The data was recorded and analyzed by using SPSS software and Microsoft Excel. Tabulation, mean, standard deviation and percentages were calculated. T-test and ANOVA tests were used to compare the domain scores as well as the contributing factors. A p value of less than 0.05 was considered statistically significant.

RESULTS

A total of 112 patients were included in the study in the age group of 15-72 years and the mean age was 39.1 ± 5.8 years. There were 70 males and 42 females included in the study and the male-female ratio was 1.6:1. Majority of patients (38.3%) belonged to the upper-lower socio-economic status followed by 32(28.5%) in the lower-middle socio-economic status according to the modified Kuppuswamy scale. Eighty-two (73.2%) patients enrolled in the study were married. The level of education was most commonly higher-secondary in patients 45(40.1%) followed by secondary in 42(37.5%) patients. Out of the total 112, 61 (54.4%) patients were unemployed and 34(30.3%) patients were self-employed [Table 1].

There were 63(56.2%) new patients, 15(13.3%) RFT (released from treatment), 11(9.8%) relapse patients and 23(20.5%) defaulters. The commonest sub-type of leprosy was Borderline-Tuberculoid (BT) in 57(50.8%) patients, followed by Borderline-Lepromatous (BL) in 27(24.1%) patients, Lepromatous-Lepromatous (LL) in 12(10.7%), Pure Neuritic in patients in 9(8%) patients and Borderline-Borderline (BB) in 7(6.2%) patients. The duration of symptoms was greater than one year in 66(58.9%) patients. The mean duration of disease was 1.8 (0.5) years. A total of 8 (7.1%) and 19(16.9%) patients were in Type 1 and Type 2 reaction states respectively. Grades of disability was

type 1 and type 2 in 12(10.7%) and 16(14.2%) patients respectively [Table 2].

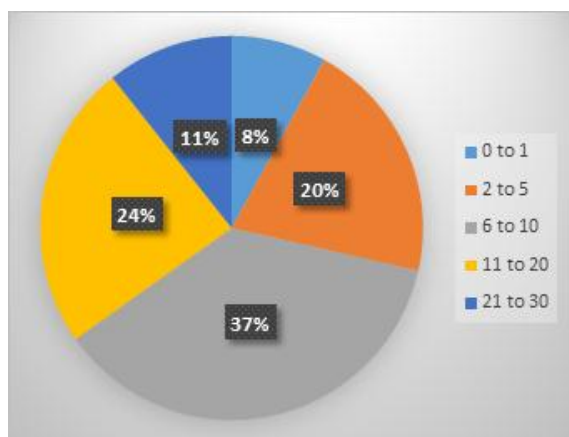


Figure 1: Distribution of patients according to Dermatological Life Quality Index scores (0 to 1- no effect, 2 to 5- small effect, 6 to 10- moderate effect, 11 to 20- very large effect, 21 to 30-extremely large effect.

According to the DLQI scores, moderate effect was seen in 41(36.6%) patients, followed by very large effect in 27(24.1%) patients, small effect in 23(20.5%) patients, extremely large effect in 12(10.7%) patients and no effect in 9(8%) patients [Figure 1]. The mean DLQI score was 9.1 ± 4.7 . It was seen that demographic variables like males ($p < 0.005$), upper-lower ($p < 0.005$) and lower economic status ($p < 0.003$), primary education ($p < 0.004$), unemployed status ($p < 0.001$), unmarried status ($p < 0.005$) were associated with

higher scores and higher impairment of QoL. Disease factors like LL sub-type ($p < 0.001$), longer duration of disease ($p < 0.005$), type 2 reaction states ($p < 0.003$) and Grade 2 deformity ($p < 0.002$) were also significantly associated with higher DLQI scores. Other factors were not statistically significant. According to the WHOQOL-Bref score, the mean value and standard deviation is 52.1 and 21.2 in the physical domain, 58.4 and 19.1 in the psychological domain, 42.8 and 23.3 in the social relationships and 55.2 and 17.9 in the environmental domain [Table 3 and Figure 2]. These scores were significantly associated with unemployment ($p < 0.005$), LL sub-type of leprosy ($p < 0.0003$), treatment-defaulters ($p < 0.005$), type 2 reaction states ($p < 0.0001$) and Grade 2 deformity ($p < 0.002$).

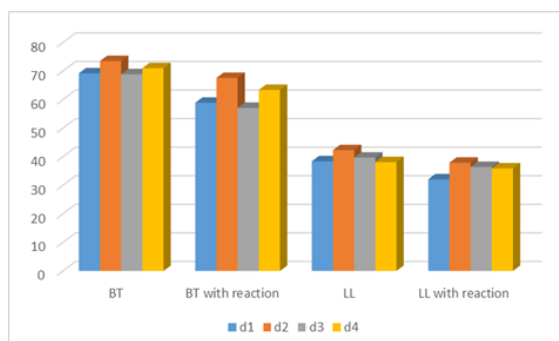


Figure 2: Domain score difference between BT and LL and Type 1 and Type 2 reactions [d1-physical health, d2- psychological health, d3- social relationship, d4- environment

Table 1: Socio-demographic data

Age (in years)	Number of patients and Percentage (%)
15-29	17(15.1%)
30-44	40(35.7%)
45-59	36(32.1%)
>60	19(16.96%)
Gender	
Male	70(62.5%)
Female	42(37.5%)
Socio-economic status	
Upper	0(0)
Upper-middle	9(8%)
Lower-middle	32(28.5%)
Upper-lower	43(38.3%)
Lower	28(25%)
Education	
Primary	13(11.6%)
Secondary	42(37.5%)
Higher secondary	45(40.1%)
Graduate	12(10.7%)
Occupation	
Unemployed	61(54.4%)
Self-employed	34(30.3%)
Paid employment	17(15.1%)
Marital status	
Unmarried	24(21.2%)
Married	82(73.2%)
Widowed	6(5.3%)
Divorced	0(0)

Table 2: Disease-specific data

Type of leprosy	Number of patients and Percentage(%)
BT	57(50.8%)
BB	7(6.2%)
BL	27(24.1%)
LL	12(10.7%)
Pure neuritic	9(8%)
Duration of symptoms	
<1 year	66(58.9%)
>1 year	46(41%)
Reaction state	
NIL	85(75.8%)
Type 1	8(7.1%)
Type 2	19(16.9%)
WHO disability grade	
0	84(75%)
1	12(10.7%)
2	16(14.2%)
Current status	
New	63(56.2%)
RFT	15(13.3%)
Relapse	11(9.8%)
Defaulter	23(20.5%)

Table 3: Mean and standard deviation of the level of Quality life across various domains

Domains	Score Mean (SD) range 0-100
Physical	52.1(21.2)
Psychological	58.4 (19.1)
Social relationships	42.8 (23.3)
Environment	55.2 (17.9)

DISCUSSION

This study shows negative impact of leprosy on the QoL of patients and highlights the socio-demographic and disease factors which are more strongly associated with a poorer QoL. Our study comprised of 112 patients, 70 males and 42 females. The male preponderance could be due to more chances of infection as well as more health-seeking behavior of males and this finding was similar to previous other studies.^[5,9-11] The mean age in our study 39.1 years, which is an age group with great social and economic significance. Majority of the patients belonged to the lower socio-economic age group similar to previous other studies.^[5,12,13] Majority of the patients in our study were of borderline type (81.1%) with 24% patients presenting with reactionary states. Deformities were present in 24.9% patients which is much lower compared to the pre-elimination era.^[13] The mean duration of disease was 1.8 years in our study. Maximum patients enrolled in our study were new patients (56.2%). The mean DLQI in our study was 9.1 ± 4.7 . Previous similar studies have shown a DLQI score of 8.48 ± 5.48 and 10.23 .^[5,14] Moderate effect was seen in 41(36.6%) patients, followed by very large effect in 27(24.1%) patients, small effect in 23(20.5%) patients, extremely large effect in 12(10.7%) patients and no effect in 9(8%) patients [Figure 1]. Male patients were found to have lower QoL in our study, similar to previous study by Belgaumkar et al,^[4] and contrary to study by Joseph et al.^[13] Patients belonging to lower socio-economic status, lower grade of education and the unemployed had lesser

QoL compared to their counterparts. This implies that literacy and employment have a positive co-relation with the QoL similar to previous studies.^[12,13] Disease factors like lepromatous leprosy, Type 2 reactionary states, disabilities and those with longer duration of disease were significantly associated with higher DLQI. This could be due to severe systemic and functional impairment in the multi-bacillary cases. Recurrent manifestations like erythema nodosum leprosum, neuritis, iridocyclitis, orchitis, and glomerulonephritis due to immune-complex deposition in various organs is usually seen in these cases which leads to a detrimental effect on the QoL.^[15,16] Various other ocular manifestations like brow and eyelash madarosis, Various other ocular manifestations like brow and eyelash madarosis, Lagophthalmos, corneal opacity, retinal lesions and phthisis bulbi also occur in leprosy.^[17] Thus, early diagnosis and initiation of multi-drug therapy and timely management of the reaction states and complications is beneficial in improving the overall QoL.

According to the WHOQOL-Bref score, the mean value and standard deviation is 52.1 and 21.2 in the physical domain, 58.4 and 19.1 in the psychological domain, 42.8 and 23.3 in the social relationships and 55.2 and 17.9 in the environmental domain [Table 3 and Figure 2]. Thus, greater negative impact was seen over the physical and social domains. We did not observe any significant gender-wise differences across the various domains. Similar to the DLQI scores, WHOQOL-Bref score was also negatively associated with unemployment, LL sub-type of leprosy, type 2 reaction states and Grade 2 deformity which can be attributed to the same reasons. The

score was also significantly associated with treatment defaulters.

The strength of our study is that we have evaluated QoL using two different standard questionnaires, and co-relation of QoL with several socio-demographic and disease-related variables has been assessed.

CONCLUSION

This study shows that even after official elimination of leprosy from India, leprosy patients continue to face significant challenges in maintaining their quality of life. In our study, male sex, lower socio-economic status, lower education status, unmarried and unemployment were social factors which adversely affected the quality of life. The LL subtype, longer duration of disease, type-2 reaction states, deformities and treatment defaulters were more commonly associated with a poor quality of life. There was a good overall concordance between the DLQI and WHOLQOL-Bref questionnaires in our study. Thus, there remains a need for patient and society education and awareness regarding leprosy. Early diagnosis and treatment as well as proper counselling of the patients and family members regarding the nature and the course of disease is beneficial. Social and occupational rehabilitation along with physiotherapy play a good role in preventing deformities and disabilities. All these measures would help us to significantly improve the quality of life of leprosy patients.

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