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**Original Research Article**

# Assessment of quality of life of patients with leprosy treated at a tertiary care centre in western Maharashtra

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## ABSTRACT

**Background:** Leprosy still remains an important public health problem in India. Though effective treatment is available, but delay in diagnosis and seeking treatment often results in patients presenting with deformity and disability affecting their quality of life. This study aimed to evaluate the quality of life of leprosy patients with grade-1 or above disability and to identify certain factors affecting QOL.
**Methods:** A cross-sectional study was conducted at the Government Leprosy Hospital in western Maharashtra using the WHO quality of life assessment questionnaire, WHO-QOL (BREF).
**Results:** In the assessment of QoL, the lowest rating was observed in the social domain, and the highest was observed in the environmental domain. Males had better QOL scores in all domains as compared to their female counterparts. The internal consistency of WHOQOL-BREF was acceptable to the facets and domains.
**Conclusions:** Leprosy not only causes physical suffering but also impacts bodily image, leading to low confidence, ostracization from family and society, as well as economic deprivation, leading to poor quality of life.

**Keywords:** Leprosy, Quality of life, WHO

## INTRODUCTION

Amongst the communicable diseases, leprosy is still prevalent in different parts of the world, particularly affecting the developing and underdeveloped countries. Though India had achieved elimination status (prevalence rate <1/10000) more than a decade ago, the prevalent cases keep occurring despite having adequate therapy for the disease. As per reports received, only 2 states are yet to achieve elimination status (Chhattisgarh and the Union territory of Dadra and Nagar Haveli) in India.[1] Leprosy is a chronic, granulomatous, infectious, and contagious disease caused by the bacterium *Mycobacterium leprae,* primarily affecting the skin and peripheral nerves.[2] The highest morbidity is associated with reactional states and neural involvement due to the disease, which can cause physical incapacities and deformities, resulting in disability, moreover leading to rejection behaviours and discrimination against the patient, with eventual ostracization from society due to the stigma attached to it. Besides the physical aspects, disabilities may also predispose people to developing psychological, economic and social problems in the form of marital disharmony, unemployment, and lack of family and interpersonal relationships. The quality of life of people affected by leprosy may therefore be compromised due to impairments that restrict their daily functioning in productive activities, as well as participation restrictions arising from a disabling environment.[3-6] This study, thus, attempted to assess the quality of life of the people with leprosy-related residual impairment and disability, as well as socio-demographic factors affecting the quality of life.

Assessments of the quality of life at periodic intervals are therefore desirable to guide future programmes and policies intended to achieve the well-being of patients.

## METHODS

It was a cross-sectional study. The present study was undertaken with the objectives of determining the quality of life and the factors affecting the quality among people affected by leprosy (PAL) with grade 1 and above disability seeking treatment at a government Leprosy Hospital and Rehabilitation tertiary care centre in western Maharashtra.

### *Sample size calculation and sampling technique*

The mean score of quality of life was obtained from a review of the literature.[5,6] Sample size was calculated to estimate 95% confidence interval for mean for various domains of quality of life (QOL) using WHOQOL-BREF scale with absolute error of margin of 0.5 and finite correction (n=150), the minimum required sample size came out to be 101. All registered new/old patients (both men and women), 18 years of age and above, with grade 1 or above deformity seeking treatment and among them who gave consent were studied. A total of 150 patients were registered during the period of study.

### *Data collection*

After obtaining clearance from the institutional ethical committee, the dataset was collected by personally visiting the hospital during both OPD hours as well as visiting the wards at the hospital regularly during the period of study (January-June 2025). Data was collected using an interview technique using a pre-tested structured questionnaire for collecting the socio-demographic details of all the participants (both women and men) who agreed to participate in the study and gave consent. Data was also collected on information on leprosy, like the type of leprosy at the time of diagnosis, family history of leprosy, surgeries experienced due to leprosy and disability due to leprosy. The inclusion criteria included those who were above 18 years of age with grade 1 and above disability and without any mental disturbances, and gave consent. Thus, the dataset was collected from 101 patients. Quality of life (QOL) information was collected using the instrument WHOQOL-BREF. This questionnaire consists of 26 questions, two general questions, and the remaining 24 encompass four domains: physical, psychological, social relations and environment. Each item uses a 5-point response scale, with higher scores indicating a better QOL.

### *Data analysis*

Data was analysed using SPSS24. Descriptive statistics, including proportions, measures of central tendency and measures of dispersion, were used to describe the data. To compare total WHOQOL-BREF scores between two groups, analysis of variance (ANOVA) was utilized.

## RESULTS

### *Socio-demographic profile*

The present study was carried out among 101 leprosy-affected persons seeking treatment at leprosy shows, showing the mean age of the study participants to be 60.96±12.89 years, with the majority, 60 (59.4%), belonging to the age group of 60-79. The majority of them were males, 70 (69.3%). The illiteracy level in the study subjects was about 56(55.4%), with all participants being unemployed currently.

**Table 1: Socio-demographic details of study participants.**

| Socio-demographic variables | | Number | % |
|---|---|---|---|
| **Sex** | Male | 70 | 69.3 |
| | Female | 31 | 31 |
| **Marital status** | Unmarried | 21 | 20.8 |
| | Married | 41 | 40.6 |
| | Divorced | 12 | 11.9 |
| | Separated | 10 | 9.9 |
| | Widowed | 17 | 16.8 |
| **Education** | Illiterate | 56 | 55.4 |
| | Primary | 32 | 31.7 |
| | Middle school | 08 | 7.9 |
| | High school and above | 05 | 4.95 |
| **Type of leprosy at diagnosis** | Paucibacillary | 80 | 79.2 |
| | Multibacillary | 21 | 20.8 |
| **Duration since disease diagnosis** | <15 years | 29 | 28.7 |
| | 16-30 years | 45 | 44.6 |
| | 31-45 years | 27 | 26.7 |
| **Site of deformity** | One or both hands | 08 | 7.9 |
| | One or both feet | 22 | 21.8 |
| | Hands and feet both | 60 | 59.4 |
| | Eyes, hands and feet | 11 | 10.89 |
| **Surgery undergone due to leprosy** | Yes | 66 | 65.3 |
| | No | 35 | 34.7 |

Information on leprosy revealed that 80 (79.2%) were of multibacillary type (>5 patches) at the time of diagnosis. The mean duration since the diagnosis of the disease of the study participants was 23.58 years, and about 3/4$^{th}$ of the study participants had no family history of leprosy. The majority of participants had grade-2 disability (99%), with the majority (59.4%) having deformity of both hands and feet (Table 1).

### *WHO-QOL (BREF) score*

QOL scores were assessed using the WHOQOL BREF (Table 2). The mean domain scores of the various domains were computed, and it was as follows: physical domain 20.37±3.80, psychological domain 17.66±3.88, social relationship domain 7.366±2.31 and environment domain 22.71±4.91. The overall QOL score was calculated using the sum of the responses, and the mean overall quality of life was found to be 16.86±3.30. Association between various socio-demographic variables and QOL domain scores is depicted in Table 3.

**Table 2: Mean score of different QOL domains among study participants.**

| QOL domains | Mean±SD |
|---|---|
| **Physical domain** | 20.37±3.80 |
| **Psychological domain** | 17.66±3.88 |
| **Social domain** | 7.36±2.31 |
| **Environmental domain** | 22.71±4.97 |
| **Overall QOL** | 16.86±3.30 |

**Table 3: Comparison of sociodemographic variables with the various domains of quality of life.**

| Socio-demographic variables | | Quality of life domains | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Physical | | | Psychological | | | Social | | | Environmental | | | Overall QOL | | |
| | | Mean | SD | P value | Mean | SD | P value | Mean | SD | P value | Mean | SD | P value | Mean | SD | P value |
| **Age (years)** | 20-39 | 20.67 | 3.64 | 0.396 | 17.67 | 3.60 | 0.986 | 8 | 2.44 | 0.610 | 22.22 | 5.56 | 0.904 | 17.13 | 3.04 | 0.929 |
| | 40-59 | 20.92 | 4.93 | | 17.43 | 4.95 | | 7.63 | 2.53 | | 23.25 | 5.88 | | 17.12 | 3.81 | |
| | 60-79 | 20.20 | 3.57 | | 17.77 | 3.64 | | 7.11 | 2.29 | | 22.67 | 4.64 | | 16.78 | 3.32 | |
| | 80-99 | 18.14 | 3.02 | | 17.43 | 2.82 | | 7.71 | 1.49 | | 21.86 | 4.45 | | 16.28 | 1.66 | |
| **Sex** | M | 20.53 | 4.o3 | 0.323 | 17.94 | 4.35 | 0.295 | 7.57 | 2.45 | 0.184 | 22.91 | 5.51 | 0.555 | 17.03 | 3.71 | 0.448 |
| | F | 19.72 | 3.24 | | 17.06 | 2.59 | | 6.91 | 1.92 | | 22.28 | 3.56 | | 16.49 | 2.19 | |
| **Marital status** | U | 19.35 | 3.58 | 0.407 | 16.95 | 3.39 | 0.817 | 6.60 | 2.08 | 0.040 | 20.35 | 4.23 | | 15.81 | 2.42 | 0.386 |
| | M | 20.85 | 4.01 | | 18.10 | 4.31 | | 7.60 | 2.43 | | 22.90 | 5.84 | | 17.13 | 4.08 | |
| | S | 20.25 | 3.85 | | 17.93 | 5.00 | | 8.19 | 2.53 | | 24.63 | 4.28 | | 17.46 | 3.09 | |
| | W | 18.43 | 1.51 | | 16.86 | 1.57 | | 5.43 | .976 | | 21.86 | 2.85 | | 15.64 | .643 | |
| | D | 20.75 | 4.05 | | 17.50 | 2.87 | | 7.69 | 1.92 | | 23.63 | 3.81 | | 17.39 | 2.63 | |
| **Education** | ill | 19.29 | 3.46 | 0.002 | 17.02 | 3.22 | 0.036 | 6.88 | 2.02 | 0.049 | 21.91 | 4.08 | 0.102 | 16.11 | 2.86 | 0.008 |
| | P | 21.10 | 3.27 | | 17.90 | 4.45 | | 7.65 | 2.45 | | 22.87 | 5.62 | | 17.23 | 3.33 | |
| | M | 20.00 | 16.59 | | 17.88 | 4.61 | | 8.00 | 2.92 | | 24.13 | 5.11 | | 17.50 | 3.77 | |
| | H | 25.60 | 4.56 | | 22.80 | 3.03 | | 10.67 | 1.52 | | 29.00 | 6.40 | | 20.95 | 3.42 | |
| **Type of leprosy** | PB | 20.52 | 4.20 | 0.733 | 19.05 | 4.23 | 0.072 | 8.33 | 2.51 | 0.029 | 24.05 | 5.52 | 0.168 | 17.76 | 3.73 | 0.162 |
| | MB | 20.20 | 3.71 | | 17.30 | 3.73 | | 7.10 | 2.20 | | 22.36 | 4.79 | | 16.62 | 3.16 | |
| **Disease duration (years)** | <15 | 20.62 | 3.97 | 0.547 | 17.04 | 3.79 | 0.285 | 7.97 | 2.50 | 0.172 | 23.03 | 5.08 | 0.132 | 17.01 | 3.22 | 0.197 |
| | 16-30 | 19.80 | 3.56 | | 17.45 | 3.46 | | 6.93 | 2.06 | | 21.69 | 4.25 | | 16.26 | 3.22 | |
| | 31-45 | 20.67 | 4.04 | | 18.63 | 4.54 | | 7.41 | 2.43 | | 24.07 | 5.72 | | 17.69 | 3.43 | |
| **Site of deformity** | One/both hands | 22.78 | 4.54 | 0.027 | 19.11 | 3.85 | 0.251 | 8.11 | 2.42 | 0.046 | 25.52 | 5.76 | 0.006 | 18.80 | 3.83 | 0.018 |
| | One/both feet | 20.55 | 3.82 | | 17.68 | 3.59 | | 7.09 | 2.32 | | 23.09 | 5.39 | | 17.10 | 3.07 | |
| | Hands and feet | 20.24 | 3.65 | | 17.78 | 4.13 | | 7.63 | 2.34 | | 23.00 | 4.59 | | 16.92 | 3.34 | |
| | Eyes, feet and hands | 17.60 | 2.45 | | 15.60 | 2.41 | | 5.60 | .966 | | 17.90 | 2.42 | | 14.17 | 1.00 | |
| **History surgery** | Yes | 20.33 | 3.79 | 0.818 | 17.68 | 3.97 | 0.928 | 7.42 | 2.16 | 0.710 | 22.88 | 4.86 | 0.637 | 16.93 | 3.30 | 0.750 |
| | No | 20.15 | 3.87 | | 17.61 | 3.75 | | 7.24 | 2.61 | | 22.38 | 5.23 | | 16.71 | 3.35 | |

Sex-M-male, F-female, Marital status-U-unmarried, M-married, S-separated, W-widowed, D-divorced, Education-ill-Illiterate, P-primary school, M-middle school, H-high school and above. Type of Leprosy: PB-Paucibacillary, MB-Multibacillary.

Higher scores were observed among males under all domains compared to those in females; however, the differences were marginal. Social domain scores were lower in both males and males, however, no significant association was observed between gender and QOl under any domains. No statistically significant association was found between different age groups under any of the domains; however lowest score was observed among aged participants. Overall QOL scores were found to be lowest among illiterates and highest among high school graduates and above. A statistically significant association among different education groups was found under the physical domain, psychological domain, social domain and overall QOl ($p<0.05$). Among the leprosy-affected persons, the presence of a disability had an adverse effect on the overall quality of life. Those who had deformity of eyes, hands and feet combined together had the lowest QOL scores, and a statistically significant association among different sites of deformity group was found under the physical domain, social domain, environmental domain and overall QOL ($p<0.05$).

## DISCUSSION

Our study showed social domain scores were lowest among all the scores. The social domain reflects how people are with their personal relationships, sex life and social support from family and friends.[7] It may be due to the fact that families which are poor may be forced to spend most of their income on providing support to people with disability if they don't have their own income, and in doing so, valuable income-generating time is spent to help this person in performing daily life activities. In spite of the presence of deformities, the physical domain score in our study was found to be high and is similar to a study conducted by Mankar et al, whereas a study in Brazil reported the lowest score in the physical domain.[6,8] This might have been because the majority of the participants in our study were diagnosed a long time ago. Living with the disease over the years, people might have learnt to overcome their obstacles in the physical component and could have adapted to the existing environment. Studies conducted by Centre et al and Brouwers et al had findings similar to our study, with the highest score in the environmental domain and the lowest score in the social domain.[5,9] In the current study, no association was found between different age groups in relation to physical, psychological, social and environmental domains. Studies conducted by Costa et al and Bello et al had similar findings to our study.[8,10] However, study conducted by Geetha et al showed a significant association between age groups and quality of life scores, which is contrary to our results.[11] The current study showed a statistically significant association among different levels of education within all the domains. The participants who had studied high school and above had a better overall QOl mean score, while participants who were illiterate had the lowest QOl mean score. Similar study findings were reported by Kumar et al and Leite et al in their study.[9,12] In the current study overall QOL score was found to be highest among those who had deformity of one or both hands and lowest among participants with deformity of hands, feet and eyes and the association was found to be statistically significant under different domains.

## CONCLUSION

The present study discussed about the quality of patients of leprosy with disability. The various socio-demographic variables, such as age, education, and marital status, had an overall influence on the quality of life. With regard to the quality of life, the highest level of dissatisfaction was observed under the social domain. Early diagnosis and treatment will consequently help in reducing the burden of patients presenting late with disability. Socio-economic rehabilitation in the form of providing employment opportunities as well as helping them to get back to their family life will consequently boost their morale, confidence and help them to improve their quality of life. Moreover, IEC activities are of equal importance in creating awareness pertaining to the disease in both patients and the community.

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