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**Original Research Article**

# Quality of life among leprosy patients in the western province, Sri Lanka

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## ABSTRACT

**Background:** Leprosy can affect the quality of life (QOL) of a person in many ways. Deformities and disabilities in leprosy leads to physical impairment. The stigma associated with leprosy leads to social isolation, which affects patient psychologically. By assessing the QOL would give an in-depth understanding of the effects on leprosy in different dimensions of health.
**Methods:** A descriptive cross-sectional study was conducted to assess the QOL of 572 adult leprosy patients attending clinics in the western province using a locally validated Sinhala version of the WHOQOL-BREF questionnaire. Consecutive sampling method was used and data were collected using an interviewer-administered questionnaire (IAQ). The scores ranged from 1 to 5 for overall QOL and overall general health questions.
**Results:** The overall QOL had a mean score of 3.4 (SD=0.8) and overall general health had a mean of 3.6 (SD=2.2). The mean scores of domains of WHOQOL-BREF included physical 69.8 (SD=17.1), psychological 68.2 (SD=16.6), social 55.1 (SD=25.0), environment 64 (SD=18.3) in the sample. With regards to socio-demographic factors, a higher QOL was observed in patients <60 years, male sex, passed O/L or above and currently employed with an income of rupees forty thousand (200$) or more and living in a permanent house. Higher QOL was also observed in patients without disability and who perform daily activities alone.
**Conclusions:** QOL of leprosy patients was higher in physical, psychological, environment domains and was lower in the social domain. Continuous awareness programmes should be conducted for health workers and community to early identification, which reduces disabilities and improve QOL.

**Keywords:** Leprosy, Quality of life, WHOQOL-BREF, Sri Lanka

## INTRODUCTION

Leprosy, also known as Hansen's disease, is a chronic progressive bacterial infection caused by *Mycobacterium leprae*. In Sri Lanka, nearly 2000 leprosy cases were reported annually during the last two decades. Sri Lanka achieved the leprosy elimination target of WHO in 1995 (less than 1 case per 10,000 population). Over the past ten years, the new case detection rate in Sri Lanka was around 10 per 100,000 population.[1] The prevalence and incidence of leprosy in 2012 in Sri Lanka were 0.77 per 10,000 population and 10.38 per 100,000 population respectively.[2] The proportion of patients having deformities was elevated to 10% in 2015 from 7.1% in 2014, suggesting an increase in the identification of complications following country-wide surveillance activities.[3,4] In 2015, the western province had the highest percentage (38%) of leprosy cases in Sri Lanka.[3]

World health organization quality of life group (WHOQOL) in 1994 defined the QOL as individuals perceptions of their position in life in the context of the culture and value systems in which they live and in

relation to their goals, expectations, standards and concerns.[5] Thus, QOL is a subjective phenomenon which can be influenced by individual's experience, beliefs and expectations.[6]

Leprosy causes reduction of QOL of a person in various ways. Physically by impairment of vision, muscle weakness, thickening of the nerves, hypopigmented anaesthetic patches with deformities. Also, there is significant social and self-stigma associated with leprosy that can lead to the social isolation of patients, which affects them psychologically.

To date, no research had been carried out to assess the QOL of leprosy patients in Sri Lanka. Assessing the QOL of leprosy patients is essential to get an in-depth understanding of the effects of the illness on different dimensions of health. Our research would enable the health care professionals and the system to devise relevant interventions to improve the quality of the policies, including planning and implementation of preventive strategies.

## METHODS

### *Study design*

We used a descriptive cross-sectional study design to assess the QOL of adult leprosy patients. Ethical approval was granted by the ethics review committee of the medical research institute (reference no: 55/2017).

### *Research setting and participants*

The study sample consisted of 586 leprosy patients aged 15 years and above (WHO multi-drug therapy regime for adults is given to this age group) who have been residing in the area during last one year and attending government leprosy or dermatology clinics in the western province.[7] The western province consists of three districts namely Colombo, Gampaha and Kalutara.

The clinic leprosy register was used as the sampling frame. Consecutive sampling method was adopted to recruit patients. Since leprosy patients are less in number, all patients who fulfilled the eligibility criteria were recruited for the study during the data collection period.

### *Research instruments*

IAQ containing 23 questions to gather basic information on disease and treatment, socio-demographic data, housing and living conditions and the WHO QOL assessing questionnaire (WHOQOL-BREF) which has been previously translated to Sinhala language and validated to the Sri Lankan general population was used as the study instruments.[8]

The QOL questionnaire (WHOQOL-BREF) has four domains consisting of a total of 26 items. Out of 26 items, four domains were derived from 24 questions and two questions on overall QOL. Each question uses a 5 point response scale (1-not at all, 2-not much, 3- moderately, 4- a great deal and 5- completely). Marks were allocated as one to five numerical values where the response not at all is scored one mark and response completely is scored five marks. The mean scores of items within each domain were used to calculate the domain score. Mean scores with standard deviations were calculated for each domain. There is no cut off value to differentiate between good QOL with poor QOL. Better QOL can be assumed with higher scores.[5] WHOQOL-BREF (26 item version) was derived from WHO QOL 100 (100 item version). Mean scores ranged from 0-100 are comparable with WHOQOL-BREF. The level of significant difference was $p<0{\cdot}05$.

Each item assessed the QOL of patients in the preceding two weeks.[5] We used the interviewer-administered method since the respondents were of different educational levels and abilities to read. Data collection was carried out by three trained data collectors.

## RESULTS

There were 586 patients of which 14 patients did not consent to participate. Therefore, the study was carried out among 572 patients, with a response rate of 97.6%.

### *Demographic characteristics*

Highest proportions of patients were in the age group of 30-44 years (n=184, 32.2%), and most patients were married (n=418, 73.1%). Mean age of the study population was 45.7 years, ranging from 15 to 94 years. The sample consisted of 61.9% (n=354) males, 88.1% (n=504) Sinhala and 72.6% (n=415) Buddhists (Table 1).

### *Socioeconomic characteristics*

A majority (n=238, 41.6%) had an education level of up to ordinary level and only 4.7% (n=27) had no formal education. Most were paid employees (n=261, 45.6%). Most of the patients (n=265, 46.3%) had a monthly family income of ₹Rs. 20,001-40,000. Of the 572 patients, a large majority (n=503, 88%) lived in a permanent house (Table 2).

### *Assessment of QOL*

The QOL was assessed using the validated WHOQOL-BREF, based on a four-domain structure and one facet on overall QOL and general health.

**Table 1: Distribution by demographic characteristics.**

| Demographic characteristics | Frequency (n=572) | Percentage (%) |
|---|---|---|
| **Age (in years)** | | |
| **15-29** | 100 | 17.5 |
| **30-44** | 184 | 32.2 |
| **45-59** | 155 | 27.1 |
| **60 and above** | 133 | 23.2 |
| **Mean=45.7, SD=16.5, median=45, range=15-94** | | |
| **Sex** | | |
| **Male** | 354 | 61.9 |
| **Female** | 218 | 38.1 |
| **Ethnicity** | | |
| **Sinhala** | 504 | 88.1 |
| **Tamil** | 37 | 6.5 |
| **Moor** | 31 | 5.4 |
| **Religion** | | |
| **Buddhist** | 415 | 72.6 |
| **Christian** | 95 | 16.6 |
| **Hindu** | 31 | 5.4 |
| **Islam** | 31 | 5.4 |
| **Marital status** | | |
| **Married** | 418 | 73.1 |
| **Unmarried** | 128 | 22.4 |
| **Widowed** | 20 | 3.5 |
| **Divorced** | 06 | 1.0 |

**Table 2: Distribution by socioeconomic characteristics.**

| Socioeconomic characteristics | Frequency (n=572) | Percentage (%) |
|---|---|---|
| **Level of education** | | |
| **No formal schooling** | 27 | 4.7 |
| **Up to grade 5** | 91 | 15.9 |
| **Up to grade 8** | 87 | 15.2 |
| **Up to ordinary level** | 238 | 41.6 |
| **Up to advanced level** | 117 | 20.5 |
| **Tertiary education** | 12 | 2.1 |
| **Employment status** | | |
| **Unemployed** | 241 | 42.2 |
| **Self-employed** | 70 | 12.2 |
| **Paid employment** | 261 | 45.6 |
| **Monthly family income** | | |
| **Less than ₹Rs. 20,000** | 207 | 36.2 |
| **₹Rs. 20,001-40,000** | 265 | 46.3 |
| **₹Rs. 40,001-60,000** | 60 | 10.5 |
| **More than ₹Rs. 60,000** | 40 | 7.0 |
| **Nature of the living premises** | | |
| **Permanent** | 503 | 88.0 |
| **Semi-permanent** | 59 | 10.3 |
| **Improvised** | 10 | 1.7 |

**Table 3: Distribution by physical health, psychological health, social relationships and environment aspects of QOL.**

| Domains | Score Mean (SD) range 0-100 |
|---|---|
| **Physical** | 69.8 (17.1) |
| **Psychological** | 68.2 (16.6) |
| **Social relationships** | 55.1 (25.0) |
| **Environment** | 64.0 (18.3) |

**Table 4: Mean domain scores of WHOQOL-BREF by type of disease.**

| Domains | Paucibacillary (n=128) | | Multibacillary (n=444) | | Significance |
|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | |
| **Physical** | 75.3 | 17.2 | 68.2 | 16.8 | t=4.19, p<0.001 |
| **Psychological** | 72.7 | 15.0 | 66.9 | 16.9 | t=3.51, p<0.001 |
| **Social relationships** | 58.0 | 24.7 | 54.3 | 25.0 | t=1.45, p>0.05 |
| **Environment** | 68.2 | 21.9 | 62.8 | 17.0 | t=2.96, p<0.05 |

**Table 5: Distribution by socio-demographic characteristics and mean domain scores.**

| Socio-demographic factors | N (%) | Physical mean (SD) | t sig. | Psychological mean (SD) | t sig. | Social mean (SD) | t sig. | Environmental mean (SD) | t sig. |
|---|---|---|---|---|---|---|---|---|---|
| **Age (in years)** | | | | | | | | | |
| **<60** | 439 (76.7) | 71.6 (15.7) | t=4.83 | 69.7 (16.3) | t=4.12 | 59.1 (23.7) | t=7.13 | 64.6 (17) | t=1.48 |
| **60 or more** | 133 (23.3) | 63.6 (20.1) | P<0.001* | 63 (16.8) | P<0.001* | 42.2 (24.6) | P<0.001* | 61.9 (22.1) | P<0.05* |
| **Sex** | | | | | | | | | |
| **Male** | 354 (61.9) | 71.9 (17.8) | t=3.73 | 69.3 (17.2) | t=2.10 | 57.1 (25.7) | t=2.40 | 64.9 (18.4) | t=1.46 |
| **Female** | 218 (38.1) | 66.4 (15.4) | P<0.001* | 66.3 (15.6) | P<0.05* | 52.0 (23.4) | P<0.05* | 62.6 (18.1) | P<0.05* |
| **Marital status** | | | | | | | | | |
| **Currently married** | 418 (73.1) | 68.7 (16.6) | t=-2.48 | 68.5 (15.7) | t=0.77 | 57.7 (24) | t=4.15 | 64.3 (17.6) | t=0.54 |
| **Currently unmarried**** | 154 (26.9) | 72.7 (18.3) | P<0.05* | 67.3 (18.9) | P>0.05 | 48.1 (26.2) | P<0.001* | 63.3 (20.3) | P>0.05 |
| **Level of education** | | | | | | | | | |
| **Grade 11 or below** | 443 (77.4) | 68.2 (17.3) | t=-4.21 | 66.2 (16.8) | t=-5.53 | 51.9 (24.8) | t=-5.95 | 61.2 (17.5) | t=-7.20 |
| **Passed O/L and higher** | 129 (22.6) | 75.3 15.4) | P<0.001* | 75.1 (14.1) | P<0.001* | 66.3 (22.4) | P<0.001* | 73.8 (17.8) | P<0.001* |
| **Employment status** | | | | | | | | | |
| **Currently employed***** | 332 (58) | 72.3 (16.1) | t=4.13 | 70.1 (16) | t=3.22 | 59.2 (24.3) | t=4.65 | 64.8 (15.8) | t=1.24 |
| **Currently unemployed** | 240 (42) | 66.3 (17.9) | P<0.001* | 65.6 (17.1) | P<0.001* | 49.5 (24.8) | P<0.001* | 62.9 (21.3) | P<0.05* |
| **Monthly family income** | | | | | | | | | |
| **Less than ₹Rs. 40,000** | 472 (82.5) | 68.8 (17.4) | t=-2.76 | 66.8 (16.6) | t=-4.32 | 52.6 (24.9) | t=-5.46 | 62.5 (18.6) | t=-4.39 |
| **₹Rs. 40,000 or more** | 100 (17.5) | 74.1 (15) | P<0.05* | 74.6 (15.4) | P<0.001* | 67.2 (21.7) | P<0.001* | 71.2 (14.9) | P<0.001* |
| **Living premises** | | | | | | | | | |
| **Permanent** | 503 (87.9) | 70.5 (17.1) | t=2.56 | 68.9 (16.1) | t=3.07 | 56.3 (24.7) | t=3.11 | 65.5 (17.9) | t=5.29 |
| **Semi-permanent****** | 69 (12.1) | 64.8 (16.7) | P<0.05* | 62.4 (19.1) | P<0.05* | 46.4 (25.0) | P<0.05* | 53.3 (18.1) | P<0.001* |

*Sig.-significant; **currently unmarried: widowed, divorced and separated groups were amalgamated; ***currently employed: self and paid employed groups were amalgamated; ****semi-permanent group: semi-permanent and improvised groups were amalgamated.

**Table 6: Distribution by disease-related factors and mean domain scores.**

| Disease-related factors | N (%) | Physical mean (SD) | t sig. | Psychological mean (SD) | t sig. | Social mean (SD) | t sig. | Environmental mean (SD) | t sig. |
|---|---|---|---|---|---|---|---|---|---|
| **Status of treatment** | | | | | | | | | |
| **Treatment completed** | 287 (50.1) | 69.5 (17.8) | t=0.38 | 69.1 (16.8) | t=1.38 | 57.4 (24.7) | t=0.57 | 66.2 (17.8) | t=2.87 |
| **Treatment not completed** | 285 (49.8) | 70.1 (16.4) | P>0.05 | 67.2 (16.4) | P<0.05* | 52.9 (25.1) | P<0.05* | 61.8 (18.6) | P<0.05* |
| **Disability status** | | | | | | | | | |
| **Without disability** | 239 (41.8) | 73.7 (15) | t=5.31 | 71.6 (16) | t=4.66 | 58.8 (24.8) | t=3.35 | 66.5 (17.3) | t=3.07 |
| **With disability**** | 333 (58.2) | 66.3 (18.1) | P<0.001* | 65.2 (16.6) | P<0.001* | 51.9 (24.7) | P<0.001* | 61.8 (19) | P<0.05* |
| **Comorbidity status** | | | | | | | | | |
| **Present***** | 166 (29.1) | 65.6 (15.1) | t=-3.82 | 64.8 (17.1) | t=-3.10 | 50.3 (24.6) | t=-2.98 | 63.1 (20.3) | t=0.81 |
| **Absent** | 406 (70.9) | 71.5 (17.5) | P<0.001* | 69.6 (16.3) | P<0.05* | 57.1 (24.9) | P<0.05* | 64.4 (17.4) | P>0.05* |
| **Performance of daily activities** | | | | | | | | | |
| **Perform alone** | 557 (97.3) | 70.3 (16.6) | t=4.95 | 68.7 (16.2) | t=4.36 | 55.6 (24.8) | t=2.48 | 64.3 (18.2) | t=2.48 |
| **Dependent on others** | 15 (2.7) | 48.6 (22) | P<0.001* | 50 (22.3) | P<0.001* | 39.4 (27.9) | P<0.05* | 52.5 (18.3) | P<0.05* |

*Sig.-significant with disability **-patient having physical impairments related or not related to leprosy; comorbidity present*** -this includes patients with other disorders (e.g., diabetes, hypertension) in addition to leprosy.

***Overall QOL and general health facet***

An individual's overall perception of QOL and overall perception of health was assessed. Mean overall QOL and overall general health scores were 3.4 and 3.6, respectively.

***Physical health, psychological health, social relationships and environment aspects of QOL***

The lowest mean QOL score was in the social domain 55.1 (SD=25) and the highest QOL score was in physical domain 69.8 (SD=17.1) (Table 3).

***QOL by type of disease***

In all domains, the mean scores were higher in paucibacillary patients. Except for the social relationship domain. These differences were statistically significant, except for the social relationship domain (Table 4).

***Factors associated with QOL***

The mean scores of the four domains obtained under selected socio-demographic and disease-related factors were compared to see whether there are any association between selected characteristics and the domains.

***Socio-demographic factors associated with QOL***

Table 5 illustrates the mean physical QOL domain scores, psychological QOL domain scores, social QOL domain.

***Disease-related factors associated with QOL***

Table 6 illustrates the disease-related factors with quality of life. Except for two factors, all the other factors were statistically significant.

## DISCUSSION

In the present study, leprosy was commonly found among the males in the economically productive age group (age 30-44). Although the majority of them were employed, they were in the low-income category. However, a large proportion of the sample had a permanent house which reflects a better infrastructure development in Sri Lanka, which evolved over the past few decades. However, still many leprosy patients stay in urban slums, that is overcrowded which facilitate disease transmission. Therefore, until all these socioeconomic determinants are addressed, the reduction of the leprosy incidence will be a difficult task.[9]

The highest QOL scores were reported in the physical domain, and the lowest scores were reported in the social relationships' domain. Social relationships domain reported lower scores due to poor sexual satisfaction, poor social support (support got from friends) and impaired personal relationships of the study sample. The WHOQOL-BREF tool was not used to assess QOL of leprosy patients in Sri Lanka previously. However, in comparison to studies conducted by Thenuwara, in 2013 and Kasturiarachchi in 2009 among patients with chronic diseases (diabetes and tuberculosis) using WHOQOL-BREF to assess the QOL, leprosy patients in the present study had higher QOL in all four domains.[10,11] A study by Mankar et al 2011 in India using the same tool had reported lower scores compared to Sri Lankan patients in all four domains of WHOQOL-BREF.[12] The population and the cultural difference may have been the possible explanation of these differences. A better interpretation could have been provided if the present study compared the QOL of leprosy patients with the general population. However, in the present study, it was not possible to select a control group from the general population since it was costly, needs a sizeable human resource for data collection and time-consuming.

When comparing PB and MB groups, the MB group had a lower score for all domains compared to the PB group except in the social domain. Social factors were equally distributed among the two groups. Multibacillary cases were associated with a high percentage of grade II disability which affects the QOL that may be one of the reasons for this difference.[9]

A statistically, significant low mean QOL in all four domains were seen among patients of age ≥60 years and females indicating old age and having other comorbidities, reduces the QOL. Females were not having adequate time for leisure activities as males, due to their social roles such as being caregivers for their families, preparing food and carrying out other household chores that are prescribed and influenced by culture.[13] In Sri Lankan culture, females are more vulnerable to discrimination. Among the employed, females usually get a lower daily wage than males. The unemployed females have to get money from their spouses, parents or children. Therefore, female unemployment can result in poor QOL compared with males. As leprosy is a stigmatizing condition, patients are reluctant to reveal the disease to society, which may result in getting poor social or financial support and can, in turn, affect the QOL.[12]

### *Limitations*

This study assessed the QOL in a cross-section of leprosy patients who were in different stages of treatment without a control group. Having a control group was not practically feasible due to the cost, human resources and the time constraints. Furthermore, children under 15 years were excluded from the study since they are not mature enough to give proper answers to the QOL and the other questionnaires. Therefore, the findings apply only to adult patients which limits the generalizability.

## CONCLUSION

Assessment of QOL of leprosy patients using the WHOQOL-BREF showed that QOL was good in physical, psychological, environment domains and poor in social relationships domain. PB patients had higher QOL when compared to MB patients in all four domains. Higher QOL was observed in sociodemographic factors like age <60 years, male sex, passed O/L or higher, currently employed, income ₹Rs. 40,000 (200$) or more and living in a permanent house. Patients without disability and those who can perform their daily activities alone had higher QOL.

### *Recommendations*

Regular awareness and training on early identification of leprosy should be given to hospital and field health workers which will lead to early detection and reduce complications and improve the QOL of patients. Further studies comparing QOL among leprosy patients and the general population would provide a better comparison of the QOL and further studies are needed to assess the change in the QOL of leprosy patients following treatment.

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