A Quality of Life Study of Patients with Leprosy Attending the Dermatology OPD of a Tertiary Care Center of Eastern India

Nirmalya K Das, Abhishek De¹, Biswanath Naskar, Amrita Sil², Sudip Das¹, Aarti Sarda¹, Gobinda Chatterjee

Abstract

Background: Leprosy is a chronic infectious disease caused by Mycobacterium leprae affecting the skin, peripheral nervous system, and other tissues. The disease is associated with social stigma, and the patients sometimes suffer social discrimination because it often leads to visible physical deformities. Hence, leprosy may have severe impact on the quality of life (QoL) of patients. Aims and Objectives: The aim of this study was to assess the effect of leprosy on the QoL of the affected patients and to find out whether there is some association with certain demographic and clinical factors. Materials and Methods: The Dermatology Life Quality Index (DLQI) questionnaire was used to assess the QoL of 114 patients with leprosy who attended dermatology outpatient department of a tertiary care center of eastern India. This was a cross-sectional study. Results: Among a total of 114 patients, leprosy had no impact on the QoL of 15 (13.16%) patients. There was a mild impact in 23 (20.18%) of the patients. There was moderate impact in 37 (32.46%) of the patients. The disease had severe impact in the QoL of 39 (34.21%) patients. None of the patients had a very severe impact. Several of the clinical aspects such as nerve involvement, systemic features, deformity, disability grade, and type of leprosy have significant impact on QoL. Among the demographic factors, gender had some effects on QoL. Conclusion: Leprosy adversely affects the QoL of those affected. Although it is considered a social disease, at least in our part of the country, demographics have minimal effect on the QoL. Rather, important clinical aspects such as systemic features, nerve involvement, reaction, deformity, and disability have profound impact on the QoL of the patients.

Key Words: DLQI questionnaire, leprosy, quality of life

Introduction

Leprosy, the age-old disease described as early as 600 BC¹ in Susruth Samhita, still remains one of the most ostracized diseases due to its resultant physical deformity and social stigmatization associated with it. India has always been a country with the highest number of patients with leprosy in the world. The physical deformities due to no treatment or delayed treatment cause psychological and social disabilities. These disabilities can lead to social stigmatization, resulting in isolation of the patient from the society and a decrease in the quality of life (QoL).² Multidrug therapy has been very effective in the past few decades and the patients have benefitted greatly. However, often the effects of the disease linger on indefinitely due to the residual permanent impairments.³ Considerable efforts have been made to reduce the development of disability in patients with leprosy. Still there are a large number of cured patients with residual deformities.⁴ These deformities can have a negative impact on the QoL of patients with leprosy and even on those who have been cured of the infection.⁵

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.”⁶ The concept of QoL includes physical activity, psychological condition, degree of independence, and social relationship.⁷ The QoL in leprosy can be affected by various factors including the onset and duration of disease, social factors, clinical factors such as nerve involvement, systemic features,
defirmity, disability grade, and type of leprosy. Stigma toward persons affected by leprosy and their families can also adversely affect their QoL due to its impact on their mobility, interpersonal relationship, marriage, employment, leisure, and social activity.[14]

A lot of people of our country are adversely affected by poverty, illiteracy, and unhygienic living conditions. The additional burden of the disease is likely to reduce their QoL further. Contrarily, people living under such adverse conditions may not perceive the disease to cause much change in their QoL.

There are several studies of QoL assessment of patients with leprosy from Africa, South America, and parts of Asia.[9-13] However, similar studies of good quality have not been done from eastern India. Hence, the study was conducted to assess the QoL of patients with leprosy in our population. Moreover, the assessment of QoL of patients with leprosy is also very important for successful implementation of any rehabilitation program.

The primary objective of this study was to assess the QoL of patients with leprosy in this region using Dermatology Life Quality Index (DLQI)[14] as a tool.

The secondary objectives were to assess how demographic profile of these patients affects QoL, whether clinical classification of leprosy has any bearing on QoL, and to assess whether clinical aspects of the disease such as presence of patches, systemic features, nerve involvement, deformity, and disability grade have an impact on it.

Materials and Methods

The study was conducted in the Department of Dermatology, Institute of Post Graduate Medical Education and Research, Kolkata, India. Cases were recorded over a period of 2 years from 2016 to 2017. We included 114 patients in our study.

All patients presenting with cardinal signs of leprosy and willing to participate in the study through a written informed consent were included in the study. Patients with leprosy with any other debilitating disease, psychiatric problem, and other medical conditions which may have an impact on QoL were excluded from the study.

We have used DLQI[14] which had been validated in Hindi, English, and Bengali as the tool for assessing the QoL in patients with leprosy. The questionnaire was applied to each patient individually by the same investigator. DLQI,[14] developed by Professor A Y Finlay and colleagues, is one of the most used instruments for assessing dermatology specific QoL. It is a simple 10 questions validated questionnaire that has been used in over 40 different skin conditions in over 80 countries and is available in over 90 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. The higher the score is, the more the QoL is impaired. The DLQI can also be expressed as a percentage of maximum score [Figure 1].

Patients attending dermatology outpatients department were screened for leprosy. Written informed consent was taken from the patients. History and clinical examination findings were recorded in a case record form. Then patients were requested to answer the questions of the DLQI questionnaire after clearly explaining them the questions in their preferred language. DLQI scores were calculated. DLQI scores were compared and evaluated at the end of the study.

This is a questionnaire-based descriptive study. All clinical data were recorded at first visit.

Data were analyzed by appropriate statistical tests using statistical software, Statistica version 26.0 (IBM Corporation, Armonk, NY, USA).

Results

Among a total of 114 patients, leprosy had no impact on the QoL of 15 (13.16%) patients. There was a mild impact in 23 (20.18%) of the patients. There was moderate impact in 37 (32.46%) of the patients. The disease had severe impact in the QoL of 39 (34.21%) patients. None of the patients had very severe impact.

In total, there were 88 male patients and 26 female patients. Leprosy had no effect in the QoL of 13 (14.77%) of the male patients. There was a mild impact in 23 (26.14%), moderate impact in 24 (27.27%), and severe impact in the QoL of 28 (34.56%) of the male patients. Leprosy had no impact in the QoL of two (7.69%) of the female patients. There was moderate effect in 13 (50%) of the female patients. The disease had severe impact in the QoL of 11 (42.30%) of the female patients [Table 1].

The mean DLQI score among the 114 patients was 8.48 ± 5.48. The range of the DLQI score was 0–20. The median score was 8 (3–12). The affection of different aspects of DLQI is depicted in Table 2.

Among the 114 patients included in the study, the youngest patient was 11 year old and the oldest one was 75 year old. Most of the patients [32 (28.07%)] were in the age group of 41–50 years. Fifty (43.86%) patients were from rural areas. About 36 (31.58%) patients were from suburban areas and 28 (24.6%) were from urban areas. A total of 62 (57.82%) patients belonged to low socioeconomic status and 51 (44.74%) belonged to middle socioeconomic status. Only one (0.88%) patient was of high socioeconomic status.

Among the demographic features, gender had an important impact on QoL (P < 0.05). Other
Das, et al.: Leprosy quality of life study

A majority of our patients had some form of nerve involvement (81, 71.05%). A substantial number of patients (52, 45.61%) had systemic features. Reaction (Type 1 or Type 2) was present in 51 (44.74%) patients. Patches were present in 102 (89.47%) patients. The presence of patches did not have any statistically significant correlation with DLQI score. Nerve involvement had a positive correlation with DLQI score. Systemic features had a strong positive correlation with DLQI score. Reactions also had a positive correlation with DLQI score. Therefore, the more the presence of nerve involvement, systemic features, and reactions, the more the DLQI score and the more the adverse impact on QoL. The presence of patches did not have much impact on QoL.

Among a total of 114 patients in our study, 37 (32.46%) of the patients had tuberculoid (TT) leprosy, 40 (35.07%) had borderline tuberculoid (BT) leprosy, 6 (5.26%) had borderline (BB) leprosy, 11 (9.65%) had borderline lepromatous (BL) leprosy, 19 (16.67%) had lepromatous (LL) leprosy, and 1 (0.88%) had pure neural (PN) type of leprosy.

The spectrum of leprosy had a statistically significant positive correlation with DLQI score. The DLQI score increased from TT pole towards LL pole. That showed that there was more impairment in the QoL of patients of the LL pole than in patients of the TT pole [95% Confidence Interval (CI) = 0.103 to 0.443; \( P = 0.002 \)].

Deformity was present in 44 (38.60%) patients and was absent in 70 (61.40%) patients. Deformity had a positive correlation with DLQI score. Presence of deformities led to higher DLQI score [95% CI = 0.367 to 0.639; \( P < 0.0001 \)] and so has more negative impact on the QoL.

Of the patients with disability, 62 (54.39%) had Grade 1 disability and 44 (38.60%) had Grade 2 disability. Grade of disability had a positive correlation with DLQI score [95% CI = 0.429 to 0.681; \( P < 0.0001 \)]. Therefore, the more the presence of deformity and higher the disability grade, the greater is the DLQI score and the more is the adverse impact on QoL.

**Discussion**

It is believed by all that leprosy has some effects QoL. However, very few studies have tried to detect and assess the actual impact of the disease on the QoL of the patients. It is also unusual that there is hardly any study which has tried to find out factors (demographic or disease-related) which are responsible for the adverse impact on the QoL. A large number of people in India are still affected by leprosy. Keeping this background in mind, we wanted to find out the extent of damage this disease causes in the QoL of a patient. We also wanted to identify some of the demographic and clinical factors which are associated with this adverse effect on QoL.

### Figure 1: Dermatology Life Quality Index questionnaire

| DERMATOLOGY LIFE QUALITY INDEX |  |
|-------------------------------|--|
| Hospital No: | Date: | Score: |

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick only one box for each question.

1. **Over the last week, how much has your skin caused you pain?**
   - Very much
   - A lot
   - A little
   - Not at all

2. **Over the last week, how much has your skin caused you to be self-conscious?**
   - Very much
   - A lot
   - A little
   - Not at all

3. **Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?**
   - Very much
   - A lot
   - A little
   - Not at all

4. **Over the last week, how much has your skin influenced the clothes you wear?**
   - Very much
   - A lot
   - A little
   - Not at all

5. **Over the last week, how much has your skin affected any social or leisure activities?**
   - Very much
   - A lot
   - A little
   - Not at all

6. **Over the last week, how much has your skin made it difficult for you to do any sport?**
   - Very much
   - A lot
   - A little
   - Not at all

7. **Over the last week, has your skin been very itchy?**
   - Yes
   - No
   - Not relevant

8. **Over the last week, how much has your skin caused you to be embarrassed or painful?**
   - Very much
   - A lot
   - A little
   - Not at all

9. **Over the last week, how much has your skin prevented you from working or studying?**
   - Yes
   - No
   - Not relevant

10. **Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?**
    - Very much
    - A lot
    - A little
    - Not at all

Please check you have answered EVERY question. Thank you.

*AY Finlay, GK Khan, April 1992 www.dermatology.org.uk, this must not be copied without the permission of the authors.*

**Meaning of DLQI Scores**

- 0-1 = no effect at all on patient’s life
- 2-5 = small effect on patient’s life
- 6-10 = moderate effect on patient’s life
- 11-20 = very large effect on patient’s life
- 21-30 = extremely large effect on patient’s life

Demographic factors such as age, habitat, and socioeconomic status had no statistically significant impact on DLQI score [Table 3].
Das, et al.: Leprosy quality of life study

The disease had a very large effect on the QoL of the patients. Although there was paucity of data regarding the actual impact of leprosy on QoL, our study reveals that there is a huge adverse impact of leprosy on QoL. Other studies have shown that leprosy has a strong correlation and it can be said that age of patients with leprosy does not have significant effect on their QoL. Similar results regarding the relationship of age to QoL was shown in a study conducted by Bello et al. [21]

In our study, 62 (57.82%) of the patients belonged to low socioeconomic class. In a study conducted by Kumar et al. too, most of the patients belonged to low socioeconomic status. The possible reason for this increased incidence of the disease in low socioeconomic group may be due to overcrowding, poor hygiene, and increased exposure. However, there was no significant impact of socioeconomic status on QoL.

To the best of our knowledge, no other study before us has tried to find out the clinical factors of leprosy which have effect on QoL. In our study, we found that clinical factors such as systemic features, nerve impairment, reaction, type of leprosy, deformity, and disability grades had significant impact on the QoL of patients with leprosy. Demographic factors such as age, socioeconomic status, and habitat did not have much impact on the QoL. Another interesting point noted in our study is that the presence of patch, which is long considered as a social stigma, has no significant effect on the QoL.

Table 1: Gender distribution of the impact on QoL

| Effect on QoL         | No. (%) of patients (n = 114 patients) | No. (%) of males (n = 88) | No. (%) of females (n = 26) | P (between groups) |
|-----------------------|----------------------------------------|---------------------------|----------------------------|--------------------|
| No effect             | 15 (13.16%)                            | 13 (14.77%)               | 2 (7.69%)                  | 0.615              |
| Small effect          | 23 (20.18%)                            | 23 (26.14%)               | 0 (0%)                     | 0.024              |
| Moderate effect       | 37 (32.46%)                            | 24 (27.27%)               | 13 (50%)                   | 0.203              |
| Very large effect     | 39 (34.21%)                            | 28 (24.56%)               | 11 (42.30%)                | 0.643              |
| Extremely large effect| 0 (0%)                                 | 0 (0%)                    | 0 (0%)                     | 0                  |

QoL=Quality of life, P-value obtained by Chi-square test between male and female patients

Table 2: Affection of different aspects of DLQI

| Parameter                  | Total DLQI score (max 30) | Symptoms and feelings score (max 6) | Daily activities score (max 6) | Leisure score (max 6) | Work and school score (max 3) | Personal relationships score (max 6) | Treatment score (max 3) |
|----------------------------|---------------------------|-----------------------------------|--------------------------------|-----------------------|-----------------------------|-----------------------------------|------------------------|
| Mean±SD                    | 8.48±5.48                 | 2.10±1.53                         | 2.21±1.49                      | 1.01±1.22             | 1.62±1.24                   | 0.80±1.11                         | 0.80±0.76               |
| Range                      | 0-20                      | 0-6                               | 0-5                            | 0-5                   | 0-3                         | 0-4                               | 0-3                    |
| Median (IQR)               | 8                         | 2 (1, 3)                          | 2 (1, 3)                       | 1 (0, 2)              | 2 (0, 3)                    | 0 (0, 1)                          | 1 (0, 1)                |

QoL=Quality of life; DLQI=Dermatology Life Quality Index; SD=Standard deviation; IQR=Interquartile range

Table 3: Association of demographic features with DLQI score

| Parameter                  | Correlation coefficient | 95% Confidence Interval | P     |
|----------------------------|-------------------------|-------------------------|-------|
| Age                        | 0.072                   | −0.114 to 0.252         | 0.448 |
| Gender                     | −0.187                  | −0.359 to 0.004         | 0.046 |
| Residence                  | −0.128                  | −0.305 to 0.057         | 0.173 |
| Socioeconomic status       | −0.100                  | −0.278 to 0.087         | 0.295 |
| Marital status             | −0.062                  | −0.243 to 0.124         | 0.515 |

To the best of our knowledge, no other study before us has tried to find out the clinical factors of leprosy which have effect on QoL. In our study, we found that clinical factors such as systemic features, nerve impairment, reaction, type of leprosy, deformity, and disability grades had significant impact on the QoL of patients with leprosy. Demographic factors such as age, socioeconomic status, and habitat did not have much impact on the QoL. Another interesting point noted in our study is that the presence of patch, which is long considered as a social stigma, has no significant effect on the QoL.

Conclusion

Leprosy was long regarded as a social disease. However, there was paucity of data regarding the actual impact of leprosy on QoL. Our study reveals that there is a huge impact of leprosy on the QoL of the patients. Although it is considered a social disease, at least in our part of the study, it is considered a social disease, at least in our part of the study.
the country, demographics has minimal effect on the QoL. Rather, important clinical aspects such as systemic features, nerve involvement, reaction, deformity, and disability have profound impact on the QoL of the patients.

Multidrug therapy has been greatly successful to reduce the burden of leprosy in our country. Even then it is largely believed that stigma and social discrimination persist. Our study has clearly revealed that most of the factors which are adversely affecting the QoL in patients with leprosy are preventable. Therefore, it can be concluded that the impact of leprosy on QoL can be reduced greatly if the disease is diagnosed early and treated effectively. Efforts and research must continue for finding out better methods of early detection and effective management of leprosy.

**Financial support and sponsorship**
Nil.

**Conflicts of interest**
There are no conflicts of interest.

**References**
1. Lowe J. Comments on the history of leprosy. Lepr Rev 1947;18:54-64.
2. Wang CH. Quality of life and health for persons living with leprosy. Nurs Sci Q 1997;10:144-5.
3. Calcraft JH. The effects of stigma of leprosy on the income generation of the leprosy affected people in the Terai Area of south-east Nepal. As Pacif Dis Rehabil J 2006;17:73-89.
4. Vaz M, Diffey B. Should nutritional status evaluation be included in the initial needs assessment of leprosy patients with disability prior to Socio-Economic Rehabilitation. Lepr Rev 2001;72:206-11.
5. Tsutsumi A, Izutsu T, Islam AM, Maksuda AN, Kato H, Wakai S. The quality of life and mental health and perceived stigma of leprosy patients in Bangladesh. Soc Sci Med 2007;64:2443-53.
6. WHOQoL Group. Development of the World Health Organization WHOQol-BREF quality of life assessment. Psychol Med 1998;28:551-8.
7. Halioua B, Bemmont MG, Lunel F. Quality of life in dermatology. Int J Dermatol 2000;39:801-6.
8. Wong ML. Designing programmes to address stigma in leprosy: Issues and challenges. Asia Pac Disabil Rehabil J 2004;15:3-12.
9. Costa MD, Terra Fde S, Costa RD, Lyon S, Costa AM, Antunes CM. Assessment of quality of life of patients with leprosy reactional states treated in a dermatology reference center. An Bras Dermatol 2012;87:26-35.
10. Geetha K, Dhanalakshmi A, Judie A. A study to assess the impact of leprosy on quality of life among leprosy patients in government rehabilitation home at Paranur. Int J Pharm Clin Res 2015;7:466-8.
11. An JG, Ma JH, Xiao SX, Xiao SB, Yang F. Quality of life in patients with lepromatous leprosy in China. J Eur Acad Dermatol Venereol 2010;24:827-32.
12. Santos VS, Oliveira LS, Castro FDN, Gois-Santos VT, Lemos LMD, Ribeiro Mdo CO, et al. Functional activity limitation and quality of life of leprosy cases in an endemic area in northeastern Brazil. PLoS Negl Trop Dis 2015;9:e0003900.
13. Tsutsumi A, Izutsu T, Akramul Islam MD, Amed JU, Nakahara S, Takagi F, et al. Depressive status of leprosy patients in Bangladesh: Association with self-perception of stigma. Lepr Rev 2004;75:57-66. Erratum in: Lepr Rev. 2004;75:205.
14. Finlay AY, Khan GK. Dermatology life quality index (DLQI): A simple practical measure for routine clinical use. Clin Exp Dermatol 1994;19:210-6.
15. Barkataki P, Kumar S, Rao PS. Knowledge of and attitudes to leprosy among patients and community members: A comparative study in Uttar Pradesh, India. Lepr Rev 2006;77:62-8.
16. Geetha AJ, Sundar Rao PS. Impact of leprosy on the quality of life. Bull World Health Organ 1999;77:515-7.
17. Proto RS, Machado CDS, Rehder JR, Paixao MP, Angelucci RL. Quality of life in leprosy: A comparative analysis between patients in the Amazon region and patients in Santo Andre in the ABC region of Sao Paulo, Brazil. An Bras Dermatol 2010;85:939-41.
18. Budel AR, Raymundo AR, Costa CF, Gerhardt C, Pedri LE. Profile of patients affected by Hansen’s disease seen at the outpatient clinic of dermatology at Hospital Evangélico de Curitiba. An Bras Dermatol 2011;86:942-6.
19. Costa MD, Terra Fde S, Costa RD, Lyon S, Costa AM, Antunes CM. Assessment of quality of life of patients with leprosy reactional states treated in a dermatology reference center. An Bras Dermatol 2012;87:26-35.
20. Ramos JM, Romero D, Belinchón I. Epidemiology of Leprosy in Spain: The Role of the International Migration. PLoS Negl Trop Dis 2016;10:e0004321.
21. 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.
22. Anil Kumar, Anita G, Yadav VS. Some epidemiological observations on leprosy in India. Int J Lep 2001;69:234-40.