Quality of Life of Persons Affected by Leprosy in an Endemic District, West Bengal, India

Pitchaimani Govindharaj, Sampathkumar Srinivasan, Joydeepa Darlong

Abstract

Introduction: Leprosy still remains a public health problem in India. Stigma and associated psychosocial problems are common in leprosy and may affect the quality of life (QoL). This study aimed to assess the QoL of the person affected by leprosy living in Purulia district, West Bengal. Methods: A cross-sectional study was conducted among 358 persons affected by leprosy above the age of 18 years and who were reporting at tertiary leprosy referral hospital, Purulia, West Bengal, from April to July 2017. The World Health Organization QoL (WHOQOL-BREF) scale was used to measure the QoL and the scale had four domain; physical health, psychological health, social relationship, and environmental health. Results: Of the 358 respondents, 41% were female, 60% were aged between 18 and 45 years, and 58% were literate. Half of the participants (55%) were farmer and labor, and 75% of the participants’ family income was below Rs. 5000 per month. One hundred and forty-four (40%) participants had physical disability. There was a highly significant difference seen among the person affected by leprosy between those with visible deformity and no deformity in four domains. The participants with visible deformity had lower QoL than the person without deformity. Conclusion: The study observed that the person affected by leprosy with visible deformity had lower QoL. Early detection and management would prevent the deformity and might improve the QoL of persons affected by leprosy.

Key words: Disability, leprosy, quality of life, stigma, world health organization quality of life-BREF

Introduction

Quality of life (QoL) is the general well-being of an individual or society experiencing the standard of health, comfort, and happiness and it is a highly subjective measure. The World Health Organization (WHO) defines QoL as an individual’s perception 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; this definition considers the person’s physical and psychological health, social relationships, personal beliefs, environment, and their relationship to salient features of their environment.[1] The term QoL incorporates the multidimensional nature and perception of overall QoL but often is quoted as the impact of an illness or injury on the QoL.[2]

The Center for Disease Control and Prevention, USA, in the year 2000, defined the health-related QoL (HRQoL) as “An individual’s or group’s perceived physical and mental health over time” which covers broad domains including physical, psychological, economic, spiritual, and social well-being.[2] Measuring the HRQoL can bridge boundaries between disciplines and among social, mental, and medical services.

Leprosy is still a public health problem with <200,000 new cases of leprosy being registered worldwide annually, with 62% of cases in India.[3] In India, a total of 127,334 new cases were detected during the year 2016–2017, and 4.6% of them had Grade 2 disability at the time of diagnosis.[6] Physical disabilities caused by the disease may result in enormous psychological consequences and more possibility of worsening QoL.[6-7] Leprosy and leprosy-related disabilities may predispose people to develop psychological, economic, and social problems.
which have an adverse effect on QoL.[6] This study aimed to assess the QoL and the factors associated with the QoL of persons affected by leprosy reporting at leprosy referral center, Purulia, West Bengal, India.

Materials and Methods
A hospital-based, cross-sectional study was conducted with 358 individuals affected with leprosy who attended the hospital outpatient department between April and June 2017.

Study settings
The study took place in the tertiary leprosy referral hospital, which was located in the district of Purulia in the state of West Bengal in eastern India. Purulia district was endemic for leprosy.[9]

Participant eligibility
All persons affected with leprosy who were 18 year of age and above, diagnosed as leprosy at least 1 year prior to the time of interview, who were willing to participate, and gave informed consent were included. Persons who were living in the leprosy colony were excluded.

Semi-structured questionnaire
A semi-structured questionnaire was prepared to collect the demographic profile and disease profile of persons affected with leprosy. The demographic profiles included gender, age, education, occupation, family income, and family size. The disease profiles included disease duration and disability grade.

World Health Organization quality of life-BREF
The QoL of the respondents was assessed with the WHOQoL-BREF which consisted of a total of 26 items on a 5-point Likert scale developed by WHOQoL Group.[10] The validated Bengali version of WHOQOL-BREF was administered to assess the QoL.[11,12]

The questionnaire assessed the perception of the last 4 weeks. Of the 26 questions, two assessed the perception of QoL and health of the patient, and the others 24 questions measured the following broad domains: physical health (7 items), psychological health (6 items), social relationships (3 items), and environment (8 items) with a higher score indicating a better QoL. Raw scale scores for each domain was calculated by adding values of single items and it was then transformed to a score ranging from 0 to 100, where higher scores indicated higher levels of QoL.

Reliability
In this study, the Bengali version of WHOQoL-BREF was tested and determined the internal consistency and reliability. The Cronbach’s alpha score was 0.957. Corrected item-total correlation ranged from 0.281 to 0.868, with 24/26 items falling at or above 0.40. Cronbach’s alpha scores for the scale with each individual item deleted ranged from 0.954 to 0.960. The translated version of WHOQOL-BREF had been shown to have very good internal consistency and reliability.

Procedure
One author was assigned to recruit participants, described the study to the respondents, obtained informed consent, and performed the interview with the assistance of trained field investigators. The interview consisted of gathering information about present demographic and disease status followed by administration of the WHOQOL-BREF scale. All interviews were conducted in vernacular language “Bengali.” The interview was conducted in strict privacy after building rapport with the respondents and precaution was taken to avoid emotional distress of participants. In case of any emotional distress, the interview was terminated.

Ethical considerations
The study was approved by Doctoral Research Committee, Department of Sociology, Bharathidasan University and the Research Committee, The Leprosy Mission Trust, India. The participation of the respondents of the study was voluntary and information was collected anonymously after obtaining written consent from each of them by assuring confidentiality throughout the data collection period.

Data analysis
The data were entered into Microsoft Excel database and analyzed using SPSS. The descriptive statistics, independent t-test, and ANOVA were done to compare the groups. *P*<0.05 was regarded as statistically significant.

Results
The details of demographic profile, disability status, and disease duration of the study participants were described in Table 1. Of the 358 respondents, 41% were female, 60% were aged between 18 and 45 years, 58% were literate, and 55% of them were doing occupation as labor and farmer. Nearly half of the respondents were living in a medium size family and majority had their monthly family income below Rs. 5000 in Indian currency. More than half of the respondents had physical impairment (Grade 1; 18% and Grade 2; 40%) and 60% had their disease duration >3 years.

Figure 1 shows the respondents’ QoL of different domains. The respondents mean score in physical health domain was 60.92±18.91, 61.37±19.88 in psychological domain, 68.78±20.07 in social relationship domain, and 66.40±15.18 in environmental domain.

Relationship between quality of life domains
Table 2 shows the relationship between domains of QoL. A strong positive correlation was observed between
Table 1: Demographic profile, disability status, and disease duration of the respondents (n=358)

| Status                  | Frequency (%) |
|-------------------------|---------------|
| Gender                  |               |
| Male                    | 212 (59.2)    |
| Female                  | 146 (40.8)    |
| Age (in years)          |               |
| 18-30                   | 69 (19.3)     |
| 31-45                   | 145 (40.5)    |
| 46-60                   | 111 (31.0)    |
| Above 60                | 33 (9.2)      |
| Education               |               |
| Illiterate              | 207 (57.8)    |
| Literate                | 151 (42.2)    |
| Occupation              |               |
| Labor                   | 99 (27.7)     |
| Farmer                  | 96 (26.8)     |
| Homemaker               | 135 (37.7)    |
| Others                  | 28 (7.8)      |
| Family size             |               |
| Small family            | 128 (35.8)    |
| Medium family           | 167 (46.6)    |
| Large family            | 63 (17.6)     |
| Family income           |               |
| Below Rs. 5000          | 270 (75.4)    |
| Above Rs. 5000          | 88 (24.6)     |
| Disability grade        |               |
| Grade 0                 | 150 (41.9)    |
| Grade 1                 | 64 (17.9)     |
| Grade 2                 | 144 (40.2)    |
| Disease duration (years)|               |
| 1-3                     | 144 (40.2)    |
| 3-5                     | 112 (31.3)    |
| Above 5                 | 102 (28.5)    |

Figure 1: Mean score of the quality of life domain (n=358)

each QoL domains; physical health, psychological, social relationship, and environment.

Table 3 shows the difference between factors and domains of QoL. There was no significant difference between gender and education in all the domains of QoL. In occupation, there was a significant difference in psychological domain and environment. Highly significant differences were observed among age, family income, disease duration, and disability level in all the four domains of QoL; physical, psychological, social relationship, and environment.

**Discussion**

In the context of health and disease, QoL is commonly referred to as HRQoL and includes domains that are related to physical, mental, emotional, social functioning, and the social context in which people live. HRQoL is now recognized as an important measurement in public health. Multidrug therapy has been a successful treatment in leprosy rehabilitation program. However, individuals still experience disability secondary to nerve function impairment and continuing experience of stigma and discrimination due to disability. The present study measured the QoL of persons affected with leprosy.

Overall, the results showed that more or less similar QoL was observed for both the males and females in all the four domains; physical health, psychological health, social relationship, and environmental health. A study conducted by Dinesh et al. in India measured QoL with the WHOQOL-BREF, observed similar results that both the males and females had similar QoL in all the domains. In contrary, a study from India conducted by Joseph and Rao found that QoL decreased progressively in person with leprosy and women had a better QoL score than men in all the four domains.

This study found that younger persons recorded better QoL compared to elderly persons in all the four domains. A similar study conducted in Tamil Nadu, India, by Dinesh et al., found similar findings only in the domains of physical health and social relationship. In education, more or less similar QoL observed for both the literate and illiterate persons in all the four domains.

Mostly stigma and discrimination faced by people affected by leprosy due to physical disabilities led to impairment of the QoL. Similarly, in this study, those with Grade 2 disability at the time of diagnosis had impaired QoL in all the domains than those with either Grade 1 or no disability (P<0.01).

Leprosy predominantly affects the poor and marginalized people. Studies also observed that family income level influences the QoL of the persons affected by leprosy.
In this study, the family income level had significant association with the QoL of the persons affected by leprosy. The higher the family income better was the QoL in all the domains than those with the lesser family income. A study from India by Nagargoje et al. found that those who were on treatment and diagnosed within 1-year duration had more impaired QoL than longer duration and treatment completed persons. In this study, the QoL was impaired as the duration of disease increased above 3 years.

Early diagnosis of the disease and appropriate and timely treatment will reduce the complications, further minimize the activity limitation and participation restriction, consequently prevent the deterioration in the QoL. Furthermore, continued counseling with improved health education to persons affected by leprosy can improve their QoL. In 2016, the WHO launched a new global

| Status          | n   | Physical health | Psychological health | Social relationship | Environment health |
|-----------------|-----|-----------------|----------------------|---------------------|--------------------|
| Gender          |     |                 |                      |                     |                    |
| Male            | 212 | 60.10±18.51     | 60.66±20.20          | 68.67±20.15         | 66.35±15.07        |
| Female          | 146 | 62.12±19.48     | 62.41±19.42          | 68.96±20.01         | 66.47±15.38        |
| Age (years)     |     |                 |                      |                     |                    |
| 18-30           | 69  | 66.58±20.03     | 68.25±20.64          | 75.64±20.21         | 72.25±15.51        |
| 31-45           | 145 | 60.44±19.23     | 59.86±19.74          | 67.29±20.61         | 64.96±15.32        |
| 46-60           | 111 | 60.39±17.48     | 61.04±18.60          | 68.96±18.43         | 66.63±13.16        |
| >60             | 33  | 53.03±16.94     | 54.79±20.02          | 60.42±19.01         | 59.76±16.67        |
| P               |     |                 |                      |                     |                    |
| Education       |     |                 |                      |                     |                    |
| Illiterate      | 207 | 61.20±19.27     | 61.62±20.01          | 68.29±20.89         | 65.74±14.80        |
| Literate        | 151 | 60.54±18.46     | 61.66±19.75          | 69.46±18.93         | 67.31±15.68        |
| P               | 0.74| 0.82            | 0.59                 | 0.33                |                    |
| Occupation      |     |                 |                      |                     |                    |
| Labor           | 99  | 61.37±17.94     | 61.66±19.20          | 70.52±19.07         | 66.83±13.47        |
| Farmer          | 96  | 58.21±18.35     | 57.72±19.73          | 66.02±19.67         | 64.45±14.37        |
| Homemaker       | 135 | 61.16±19.54     | 61.98±19.59          | 68.24±20.37         | 65.85±15.67        |
| Others          | 28  | 67.54±20.21     | 69.96±22.01          | 74.79±22.53         | 74.25±19.02        |
| P               | 0.14| 0.03*           | 0.16                 | 0.02               |                    |
| Family income   |     |                 |                      |                     |                    |
| Below 5000      | 270 | 59.22±19.21     | 59.47±20.17          | 66.49±20.87         | 64.45±15.26        |
| Above 5000      | 88  | 66.15±17.04     | 67.19±17.83          | 75.84±15.47         | 72.40±13.30        |
| P               | 0.00**| 0.00**         | 0.00**               | 0.00**              |                    |
| Disease duration (years) | |                 |                      |                     |                    |
| 1-3             | 144 | 65.83±17.98     | 65.97±19.19          | 73.83±17.81         | 69.76±13.81        |
| 3-5             | 112 | 57.10±18.25     | 57.82±19.26          | 64.39±21.33         | 64.94±15.34        |
| >5              | 102 | 58.20±19.55     | 58.77±20.40          | 66.48±20.27         | 63.76±16.07        |
| P               | 0.00**| 0.00**         | 0.00**               | 0.00**              |                    |
| Disability grade|     |                 |                      |                     |                    |
| Grade 0         | 150 | 68.55±17.18     | 68.96±18.33          | 75.80±16.75         | 72.13±13.71        |
| Grade 1         | 64  | 63.86±15.03     | 63.52±16.65          | 71.88±15.91         | 67.06±12.23        |
| Grade 2         | 144 | 51.67±18.30     | 52.51±19.30          | 60.10±21.68         | 60.15±15.47        |
| P               | 0.00**| 0.00**         | 0.00**               | 0.00**              |                    |

*p<0.05, **p<0.01. SD: Standard deviation.
strategy for leprosy calling for stronger commitments and accelerated efforts to stop disease transmission and end associated discrimination and stigma, to achieve a world free of leprosy. The National Leprosy Eradication Programme, India, made a strategy to reduce stigma in leprosy mainly through information, education, and communication activities and spreading the awareness.

The study was conducted with a large sample size and measured the QoL with validated tools. Due to resource and time limitations, the study was conducted as a cross-sectional study in a tertiary leprosy referral center which was treating and rehabilitating the persons affected by leprosy for more than 100 years. Cultural and environmental aspects might play important role in QoL but they were not taken into account in the present study. Since this study was taken up at a remote area, the findings might not be generalizable.

Conclusion

The study observed that the physical disability, disease duration, and family income were influencing more on QoL. Continued monitoring, counseling, and socioeconomic rehabilitation might improve the QoL of persons affected with leprosy.

Acknowledgment

The authors express sincere thanks to Professor and Head Dr. M. Thavamani, Department of Sociology, Bharathidasan University, Tamil Nadu; Dr. Famkima Darlong, Superintendent, The Leprosy Mission Hospital, Purulia; and The Research domain, The Leprosy Mission Trust India, New Delhi, for their guidance and encouragement. We thank Ms. Sneha Mahato, Mr. Subir Ketiar, and Mr. Deepraj Mardy for their sincere involvement in data collection. We thank all the persons who participated in this study. We extend our sincere thanks to the staff of the Physiotherapy department, Purulia Leprosy Mission Hospital, for their support.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. The World Health Organization quality of life assessment (WHOQoL): Position paper from the World Health Organization. Soc Sci Med 1995;41:1403-9.
2. Centers for Disease Control and Prevention. Measuring Healthy Days: Population Assessment of Health-Related Quality of life. Atlanta, Georgia: Centers for Disease Control and Prevention; 2000.
3. World Health Organization. Global leprosy update, 2016: Accelerating reduction of disease burden. Wkly Epidemiol Rec 2017;92:501-20.
4. National Leprosy Eradication Programme (NLEP). Annual Report 2015 – 2016. New Delhi: Central Leprosy Division Directorate, General of Health Services, Ministry of Health and Family Welfare Government of India. Available from: http://www.nlep.nic.in/pdf/revised%20Annual%20report%2031st%20March%202015-16.pdf. [Last accessed on 2017 Nov 27].
5. Leekassa R, Bizuneh E, Alem A. Prevalence of mental distress in the outpatient clinic of a specialized leprosy hospital. Addis Ababa, Ethiopia, 2002. Lepr Rev 2004;75:367-75.
6. Kisivuli AJ, Othieno CJ, Mburu JM, Kathuku DM, Obondo A, Nsokho PW, et al. Psychiatric morbidity among leprosy patients in Teso and Busia districts of western Kenya. East Afr Med J 2005;82:452-6.
7. Singh GP. Psychosocial aspects of Hansen’s disease (leprosy). Indian Dermatol Online J 2012;3:166-70.
8. Proto RS, Machado Filho CD, Rehder JR, Paixão MP, Angelucci RI. Quality of life in leprosy: A comparative analysis between patients in the Amazon region and patients in Santo André in the ABC region of São Paulo, Brazil. An Bras Dermatol 2010;85:939-41.
9. National Leprosy Eradication Programme (NLEP). District Wise Annual New Case Detection and Prevalence as on March 2015, New Delhi: Central leprosy. Directorate General of Health Services, Government of India. Available from: http://www.nlep.nic.in/pdf/Distwise%20NCDR-Mar. 15%.pdf. [Last accessed on 2017 Nov 27].
10. Development of the World Health Organization WHOQoL-BREF quality of life assessment. The WHOQoL group. Psychol Med 1998;28:551-8.
11. Izutsu T, Tsutsumi A, Islam A, Matsuo Y, Yamada HS, Kurita H, et al. Validity and reliability of the Bangla version of WHOQoL-BREF on an adolescent population in Bangladesh. Qual Life Res 2005;14:1783-9.
12. Tsutsumi A, Izutsu T, Kato S, Islam MA, Yamada HS, Kato H, et al. Reliability and validity of the Bangla version of WHOQoL-BREF in an adult population in Dhaka, Bangladesh. Psychiatry Clin Neurosci 2006;60:493-8.
13. Ferrans CE. Definitions and conceptual models of quality of life. In: Lipscomb J, Gotay CC, Snyder C, editors. Outcomes Assessment in Cancer. Cambridge, England: Cambridge University; 2005. p. 14-30.
14. Institute of Medicine (US) Committee on Assuring the Health of the Public in the 21st Century. The Future of the Public’s Health in the 21st Century. Washington (DC): National Academies Press (US); 2002. Available from: https://www.ncbi.nlm.nih.gov/books/NBK221239/. [Last accessed on 2017 Nov 27].
15. Gold M. Summary Measures of Population Health and Beyond: A look at U.S. Federal Activities in Measuring the Health of Populations. WHO Conference. Working Paper No. 11. Ottawa, Canada: Statistical Commission and Economic Commission for Europe; 2000. p. 23-5.
16. Hagerty MR, Cummins RA, Ferriss AL, Land K, Michalos AC, Peterson M, et al. Quality of life indexes for national policy: Review and agenda for research. Soc Indic Res 2001;55:1-96.
17. Dinesh G, John KR, Logaraj M. An assessment of quality of life among leprosy affected persons residing in leprosy settlements of Chengalpet Taluk, Kancheepuram, Tamil Nadu. Natl J Res Community Med 2016;5:149-54.
18. Joseph GA, Rao PS. Impact of leprosy on the quality of life. Bull World Health Organ 1999;77:515-7.
19. van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R, et al. Disability in people
affected by leprosy: The role of impairment, activity, social participation, stigma and discrimination. Glob Health Action 2012;5:1. DOI: 10.3402/gha.v5i0.18394.

20. Tsutsumi A, Izutsu T, Islam AM, Maksuda AN, Kato H, Wakai S, et al. The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh. Soc Sci Med 2007;64:2443-53.

21. World Health Organization, South-East Asia. Leprosy: The Disease. Available from: http://www.searo.who.int/entity/leprosy/topics/the_disease/en/. [Last accessed on 2017 Nov 27].

22. Chatterjee T, Haldar A, Misra R, Saha B. Study of certain social correlates in leprosy cases. Indian J Community Med 2001;26:189-91.

23. Singh S, Sinha AK, Banerjee BG, Jaswal N. Participation level of the leprosy patients in society. Indian J Lepr 2009;81:181-7.

24. Seshadri D, Khaitan BK, Khanna N, Sagar R. Dehabilitation in the era of elimination and rehabilitation: A study of 100 leprosy patients from a tertiary care hospital in India. Lepr Rev 2015;86:62-74.

25. Nagargoje A, Mundhada GR, Deshmukh SB, Saboo AV. Psychiatric co-morbidity in persons with Hansen’s disease. J Evid Based Med Healthc 2015;2:2872-81.

26. World Health Organization. Global Leprosy Strategy 2016-2020: Accelerating Towards a Leprosy-Free World. New Delhi: World Health Organization, Regional Office for South-East Asia; 2016.

27. National Leprosy Eradication Programme (NLEP). Strategic Framework for Reduction of Stigma and Discrimination. Available from: http://www.nlep.nic.in/pdf/Stigma.pdf. [Last accessed on 2017 Nov 25].