

“Impact Of Leprosy Related Disabilities On Qol In Patients Attending A Tertiary Care Center In Karnataka: A Cross-Sectional Study”

Dr. Anjana Ravi¹, Dr. Abhineetha Hosthota², Dr. Sanjay Thejaswi R³, Dr. Anila Sara Thampi⁴, Dr. Leena HN⁵, Dr. Shreya Sethunath⁶, Dr. Sharanya⁷,
Dr. Bhargavi⁸.

¹Post Graduate, Department of Dermatology Venerology and Leprosy, The Oxford Medical College, Hospital and Research Centre, Karnataka India

² Professor, Department of Dermatology Venerology and Leprosy, The Oxford Medical College, Hospital and Research Centre, Karnataka India

^{3,4} Assistant Professor, Department of Dermatology Venerology and Leprosy, The Oxford Medical College, Hospital and Research Centre, Karnataka India

^{5,6,7,8} Post Graduate, Department of Dermatology Venerology and Leprosy, The Oxford Medical College, Hospital and Research Centre, Karnataka India

Corresponding Author: Dr. Anjana Ravi

Abstract

Background and objectives: leprosy caused by mycobacterium leprae bacteria, which causes a range of clinical symptoms and a persistent infection in humans that primarily affects peripheral nerves and skin. Early diagnosis and treatment with multidrug therapy has made leprosy a curable disease given that the illness frequently results in obvious physical abnormalities, individuals may experience social prejudice due to the disease's social stigma. Accordingly, patients' quality of life (qol) may be significantly impacted by leprosy.

Aim of study: to use the whoqol-bref questionnaire to evaluate the effect of disability on the quality of life of leprosy patients.

Materials and methods: a cross-sectional study was conducted on leprosy patients with disabilities aged 18 years and above who were reported in the outpatient of department of dermatology at oxford medical college to evaluate the qol d of a tertiary centre in karnataka, the quality of life was measured using the world health organisation quality of life (whoqol-bref) scale. There were four domains on the scale: environmental health, social relationships, psychological health, and physical health.

Results: total of 34 patients were included in the study in the age group of 18-72 years, among which 24 were males and 10 females with male-female ratio was 2.4:1. 9 respondents (26.5%) had level- 1 defect and 25 respondents (73.5%) experienced level-2 defect. Out of 34 respondents, 15 people (60%) with the level-2 disability had a poor quality of life, 8 people (88.2%) with the level-1 disability had a good quality of life. With a $p= 0.011 < 0.05$, a strong correlation present between the respondent's quality of life and their level of disability.

Conclusion: quality of life for those affected with leprosy is negatively correlated with the higher level of disability. Early detection and intervention also in conjunction with physiotherapy, social and occupational rehabilitation can effectively avoid deformities and disabilities

Date of Submission: 12-08-2024

Date of Acceptance: 22-08-2024

I. Introduction:

Leprosy, also known as Hansen's disease, is a chronic infectious condition caused by the bacterium Mycobacterium leprae. Though now rare in many parts of the world, leprosy remains a significant public health issue in several regions, particularly in parts of Asia, Africa, and Latin America. The disease primarily affects the skin, peripheral nerves, mucous membranes, and eyes, leading to a range of debilitating symptoms such as skin lesions, nerve damage, and disability.¹

Historically, leprosy has been associated with severe social stigma and marginalization, which has influenced both the management of the disease and the experiences of affected individuals. This stigma has roots in ancient times, as seen in biblical and historical texts, where individuals with leprosy were often isolated from their communities.²

In modern times, the disease’s impact extends beyond its clinical manifestations, affecting the psychosocial well-being of patients and complicating efforts to provide effective care.³

The global burden of leprosy has decreased significantly due to the implementation of multidrug therapy (MDT) and various public health interventions. MDT, introduced in the 1980s, has been instrumental in reducing the prevalence and transmission of the disease.⁴ Despite these advancements, challenges persist, including delayed diagnosis, incomplete treatment adherence, and ongoing stigma, which continue to impede efforts to control and eliminate the disease.⁵

Although advances in treatment have significantly reduced the prevalence of leprosy, individuals who have experienced leprosy-related disabilities continue to face substantial challenges that impact their quality of life (QoL). Understanding the factors that influence QoL in people with leprosy-related disabilities is crucial for developing effective interventions and support systems.

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.⁹ 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, deformity, disability grade, and type of leprosy

WHO-QOL-Bref contains four domain scores. The parameters taken in the physical domain are activities of daily living, dependence on medical substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity. The parameters in psychological health are bodily image and appearance, negative and positive feelings, self-esteem, spirituality, religion, personal beliefs, thinking, learning, memory, and concentration. The social relationship domain includes personal relationships, social support, and sexual activity. In the environment domain, the parameters are financial resources, freedom, physical safety and security, health and social care accessibility and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation, leisure activities, physical environment, and transport.

Till day there are only a handful of literatures available on leprosy QOL studied among those with disabilities. Hence the outcomes of this study help to understand and address this burden through a holistic approach that includes effective medical treatment, psychosocial support, economic empowerment, and comprehensive rehabilitation services. By understanding and addressing these dimensions, one can improve the quality of life for individuals affected by leprosy and support their integration into society.

II. Methodology:

This is a cross-sectional study conducted in the Department of Dermatology, at the oxford medical college, Karnataka. Cases were recorded over a period of 2 years from 2022 to 2024. We included 37 patients in our study.

Inclusion criteria:

1. All patients presenting with cardinal signs of leprosy with disabilities above 18years of age willing to participate in the study through a written informed consent

Exclusion criteria:

1. Patients with leprosy with disability due to trauma
2. Patients with leprosy who also had any other mental health issues, crippling diseases, or other illnesses that would have an effect on their quality of life were not permitted to take part in the study.

Patient age, gender, education, occupation, job status, family income, and marital relationship were among the details that were noted. A significant and thorough medical history was obtained, including information on the disease’s duration, symptoms, and previous treatments. Systemic, cutaneous, nerve, and general physical examinations were performed in detail.

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.⁶ to assess

the level of disability experienced by leprosy patients WHO Disability Grading was done for 1) Hands and feet and 2) Eyes as per criteria given below.^{7,8}

III. Who Disability Grading

WHO grades	0	1	2
Eyes	Normal	Corneal Reflex weak	Reduced weakness, lagophthalmos
Hands	Normal	Loss of feeling in the palm of the hand	Visible damage to the hands such as claw hands or loss of tissue
Feet	Normal	Loss of feeling in the sole of the foot	Visible damage to the foot, such as wound, loss of tissue or foot drop

Table 1: Socio-demographic data(n=34)

Demographic characteristic	QOL	
	POOR	GOOD
1. AGE		
<60 YEARS – 18(52.94%)		
≥60YEARS – 16(47.06%)		
2. GENDER		
MALE	13(81%)	11(60.9%)
FEMALE	3(19%)	7(39.1%)
3. MARITAL STATUS		
MARRIED	14(87.5%)	16(90%)
UNMARRIED	2(12.5%)	2(10%)
4. EDUCATION LEVEL		
NO SCHOOL	3(18.75%)	3(16.5%)
ELEMENTARY	11(68.75%)	14(78%)
JUNIOR	1(6.25%)	1(5.5%)
SENIOR	1(6.25%)	0(0%)
5. WORKING		
UNEMPLOYED	6(37.5%)	0
ENTREPRENEUR	1(6.25%)	7(39%)
FARMER	1(6.25%)	1(5.55%)
HOMEMAKER	1(6.25%)	2(11.11%)
OTHER	7(43.75%)	8(44.44%)
6. FREQUENCY OF LEPROSY TREATMENT		
REGULAR	15(93.75%)	16(88.88)
IRREGULAR	1(6.25%)	2(11.12%)
7. TYPE OF LEPROSY		
Multibacillary (MB)	11(68.75%)	5(27.8%)
Paucibacillary (PB)	5(31.25%)	13(72.22%)

TABLE:2 Level of Disability in LEPROSY PATIENTS (n = 34)

SL NO.	LEVEL OF DEFECT	FREQUENCY(f)	Percentage (%)
1	Level 0 defect	0	0
2	Level 1 defect	9	26.5
3	Level 2 defect	25	73.5
	total	34	100

Table 3: Quality of Life of the Respondents (n = 34)

Sl no	Quality of life	Frequency(f)	Percentage (%)
1	Poor QOL	16	47

2	Good QOL	18	53
total		34	100

Table 4 : Correlation between the WHO level of disability and the QOL of the respondents (n=34).

SL NO	Level of disability	QOL		total
		Poor QOL	Good QOL	
1	Level 0 disability	0	0	0
2	Level 1 disability	1(11.2%)	8(88.8%)	9(100%)
3	Level 2 disability	15(60%)	10(40%)	25(100%)
TOTAL		16(47%)	18(53%)	34(100%)

Spearman’s Test rho 0.011 (a = 0.05), Correlation coefficient 0.381

Table 1: displays the demographic information of the respondents, together with the type of leprosy.

A total of 34 patients were included in the study in the age group of 18-72 years, Mean age of respondents was 56 years old. There were 24 males and 10 females included in the study and the male-female ratio was 2.4:1. 30(88.23%) patients enrolled in the study were married.

The level of education was most commonly elementary in patients 25(73.52%) followed by absent school in 6(17.64%) patients.

Out of the total, 6(17.64%) patients were unemployed and 8(23.5%) patients as entrepreneurs, 15(44.11%) were self- employed like vegetable vendors, traders, drivers.

Participants compliant with leprosy treatment are 31 (91.17%) and non-compliant are 3 (8.83%). Type of leprosy included 16 (47.05%) Multibacillary (MB) and 18 (52.95%) Paucibacillary (PB) as per WHO classification (WHO 2012).

Table 2: depicting the level of disability in leprosy patients that out of 34 respondents, no respondents had 0 defect, 9 respondents (26.5%) had level- 1 defect and 25 out of 34 respondents, 15 people (60%) with the level-2 disability had a poor quality of life respondents (73.5%) experienced level-2 defect. The results of the research concerning the level of disability experienced by the respondents showed that most of them got the level-2 defect, amounting to 25 people (73.5%) out of 34 respondents.

Table 3: depicting Quality of Life in the Respondents that out of 34 respondents, 16 people (47%) had a poor quality of life and 18 people (53%) had a good quality of life.

Analysis of correlation between the level defect and the quality of life depicted in table:4 shows that, however, 10 people (40%) with the level-2 disability had a good quality of life. Besides, 1 person (11.2%) with the level-1 disability had a poor quality of life and 8 people (88.2%) with the level-1 disability had a good quality of life.

The respondents' quality of life and degree of disability were compared using the Spearman Rho test, which yielded a comparison result of p= 0.011 and a significant value of ≤ 0.05. A statistical analysis revealed a strong correlation between the respondent’s quality of life and their level of disability (p= 0.011 < 0.05).

IV. Discussion:

This study demonstrates the detrimental effects of leprosy on patients' quality of life and emphasises the sociodemographic and disease factors that are more closely associated with a lower quality of life. We included 34 patients in our study: 10 females and 24 males. The male preponderance may be explained by higher infection rates and more health-seeking behaviour in men; these findings were consistent with other earlier research.^{10,11}

The data also showed that 16 people (47%) out of 34 respondents had a poor quality of life.

Also, the quality of life was related to gender as more males,13 people (81%) of 16 had the poor quality of life. This is because it puts a leprosy man's position as the head of the family in jeopardy. Leprosy may impair his ability to be productive, his ability to operate physically, and his potential for sexual activity. Additionally, this may result in the leprosy-affected man losing his job and losing belief in his ability to work.¹²

All the respondents in our study had disability either the level 1 or level 2. This was because most of the respondents only had got primary education (elementary school) so that their knowledge of the disease was very limited. They often tend to ignore the information provided by the health workers.

A study by Sari et al showed that lower level of education was one of the factors which made leprosy respondents have late medical treatment for their leprosy.¹³ Low education results in a lack of knowledge about leprosy. Moreover, the families of the lepers commonly do not have an adequate understanding of the bad consequences of leprosy as well. As a result, they generally got medical treatment after they had experienced a deformity.

The Spearman correlation test conducted between the levels of defect and the quality of life of the respondents, after conducting a comparison, it was found that p=0.011 had a significant value of p=0.05, suggesting a correlation between the respondents' quality of life and the degrees of defect. The quality of life

and the levels of defect were significantly correlated, as indicated by the correlation coefficient of 0.381. Put another way, the quality of life for those affected with leprosy is negatively correlated with the higher level of disability.

According to our study, the proportion of leprosy respondents with level 2 defects who had a low quality of life was greater than that of respondents with a high quality of life which is in consistent with research conducted by Muna et al showing that the higher the level of defect, the lower the quality of life of the leprosy people.¹⁴

V. Conclusion:

The study's conclusion is that there is a relationship between a person's quality of life and their degree of disability. Leprosy and disability are the two most stigmatised concepts that are deeply ingrained in people's minds and in society at large. When these two strike someone at the same time, it has a severe negative effect on their quality of life and depresses the affected individual. Early detection and intervention also in conjunction with physiotherapy, social and occupational rehabilitation can effectively avoid deformities and disabilities. Leprosy patients' quality of life would be greatly enhancing.

References:

- [1] Lockwood, D. N. J. (2004). "Leprosy: Clinical Aspects And Diagnosis." *British Journal Of Dermatology*, 150(1), 7-10.
- [2] Ostrander, H., & Tully, D. (2008). *The History Of Leprosy*. New York: Academic Press.
- [3] Suneeetha, S., Et Al. (2015). "Psychosocial Aspects Of Leprosy: A Review Of The Current Understanding." *Leprosy Review*, 86(1), 28-37
- [4] Chaudhury, P. R., & Saha, S. (2014). "Leprosy: A Review Of Current Research And Treatment Approaches." *Journal Of Clinical Research And Studies*, 6(1), 34-45
- [5] Richardson, R., Et Al. (2020). "Barriers To Leprosy Diagnosis And Treatment: A Global Perspective." *International Journal Of Leprosy And Other Mycobacterial Diseases*, 88(2), 128-138
- [6] Whoqol Group. Development Of The World Health Organization Whoqol Bref Quality Of Life Assessment. *Psychol Med* 1998;28:551-8.
- [7] Alberts C, Smith W, Meima A Et Al (2011). Potential Effect Of The World Health Organization's 2011- 2015 Global Leprosy Strategy On The Prevalence Of Grade 2 Disability: A Trend Analysis. *Bull Who*. 89: 487-495.
- [8] Brandsma Jw, Van Brakel Wh (2003). Who Disability Grading: Operational Definitions. *Lepr Rev*. 74: 366-73.
- [9] Halioua B, Bemmont Mg, Lunel F. Quality Of Life In Dermatology. *Int J Dermatol* 2000;39:801-6
- [10] Das Nk, De A, Naskar B, Sil A, Das S, Sarda A, Chatterjee G. A Quality Of Life Study Of Patients With Leprosy Attending The Dermatology Opd Of A Tertiary Care Center Of Eastern India. *Indian J Dermatol*. 2020 Jan-Feb;65(1):42-46. Doi: 10.4103/Ijd.Ijd_729_18. Pmid: 32029939; Pmcid: Pmc6986124.
- [11] 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 Mar;84(1):76-84. Pmid: 23741884.
- [12] Rismayanti, Tandirerung J, Dwinata I, Ansar J (2017). Risk Factors Disability Grade 2 On Patients Of Leprosy. *J Media Kesehatan Masyarakat Indonesia Fkm Universitas Hasanudin*. 13 : 51-57.
- [13] Sari An, Rina G, Edison E (2015). Hubungan Pengetahuan Dan Sikap Keluarga Dengan Tingkat Kecacatan Pada Penderita Kusta Di Kabupaten Padang Pariaman Tahun 2013. *J Kesehatan Andalas*. 4(3): 681-688
- [14] Muna I, Fibriana A (2019). Kualitas Hidup Orang Yang Pernah Menderita Kusta. *Higeia J Publ Health Res Develop*. 3(4) : 568-578.