Quality of Life among Patients in a Selected Leprosy Colony of Kathmandu: A Cross-sectional Study

Angelina Adhikari, BSc. Nursing; Nisha Maharjan, Master's in Adult Nursing
B & B Medical Institute, Lalitpur, Nepal.

Address of Correspondence:
Angelina Adhikari, BSc. Nursing
B & B Medical Institute, Lalitpur, Nepal
Email: angelina.adhikari004@gmail.com, Phone: +977-9813883891

Leprosy is a chronic infectious disease with a gradual and permanent impairment risk. If left untreated, it can have a variety of effects on a person's quality of life (QOL), including developing physical, psychological, and social problems. Hence, this study assessed the quality of life among patients in a selected leprosy colony of Kathmandu. A cross-sectional research design was conducted among 110 patients, using a simple random sampling technique in *Khokana* leprosy colony in September 2023. Quality of life was assessed using the WHOQOL-BREF questionnaire. Ethical approval was obtained from the Institutional Review Committee of B&B Hospital. Data was analyzed using descriptive and inferential statistics (Chi-square test). Most of the respondents were of aged between 56 to 80 years (54.5%), female (54.5%), married (68.2%), Janajati (47.3%), illiterate (67.3%), family size of 3-4 (34.5%) and disease duration 51-70 years (34.5%). The mean QOL score was highest in the social domain (61.0±15.1) and lowest in the physical domain (49.2±12.1). The majority had good QOL (75.5%), followed by poor (24.5%). The QOL was significantly associated with marital status, family size, and disease duration.

Keywords: leprosy, Nepal, patient, quality of life.

Leprosy is a chronic infectious disease caused by Mycobacterium leprae, affecting skin, peripheral nerves, mucosa of the upper respiratory tract, and eyes. Despite the nationwide elimination of leprosy as a public health problem in 2009, more than 3000 new cases of leprosy were recorded annually thereafter.[1]

Quality of life (QoL) describes how satisfied a population or individual is at a particular time in their lives, taking into account the positive and negative aspects of their lives.[2] People affected by leprosy typically have a lower quality of life (QoL) than the general population. Leprosy impairs people's ability to operate physically and socially, having an impact on their psychological condition. Evidence showed the poor QOL of people with leprosy in Nepal, however, data remains scarce.[3] Therefore, this study aimed to assess the quality of life among leprosy patients residing in a *Khokana* Leprosy Colony in Nepal.

Materials & Methods

A descriptive analytical study was conducted among 110 patients with Leprosy residing in the *Khokana* Leprosy Colony, supported by the Nepal Leprosy Relief Association (NELRA). NELRA is actively implementing medical, hostel, scholarship, and rehabilitation programs to support leprosy-affected individuals and their families. Ethical approval was obtained from the B&B ethical review committee, while administrative approval was obtained from NELRA. Informed consent was taken from all the respondents. Those who were not willing to participate in the study were excluded. Privacy and confidentiality of the information were maintained throughout the study. The standard tool, World Health Organization Quality of Life–BREF (WHOQOL-BREF), consists of two parts and was used for the data collection. Part 1 includes questions related to socio-demographic data and disease-related variables.[3,4] Part 2 had the 26 questions used to measure QOL, 24 questions on four domains, including the physical domain (7 items), psychological domain (6 items), social relations domain (3 items), and environment domain (8 items). Question number 1 measures individuals' overall perception of QOL, and question 2 asks about their overall perception of their health. Questions 3,4, and 26 are the negative phrased items which were reversed and recoded. The mean score of the items within each domain was used to calculate the raw score. Raw scores were then transformed to a 0–100 scale using a transformation formula. A higher score reflects a better QOL.[4] The standard validated Nepali version of the tool was administered with face-to-face interviews.

All the data was reviewed, checked, and verified for its completeness, consistency, and accuracy. Data was coded and entered into a statistical package for the social sciences (SPSS) version 20.0 for statistical analysis. Descriptive statistics like mean, frequency, percentage, and standard deviation were used to describe the socio-demographic variables and disease-related variables. Inferential statistics, i.e., Pearson chi-square test and continuity correction used to find out the association between quality of life and socio-demographic variables and disease-related variables.

Results

More than half of the respondents were aged between 56-80 years (54.5%) and were female (54.5%). The higher proportion of respondents were married (68.2%), Janajati (47.3%), illiterate (67.3%), with a family size of 3-4 members (34.5%), and a disease duration of 51-70 years (34.5%), as shown in **Table 1**.

Sociodemographic and disease-related characteristics

Variables	**Number (n)**	**Percent (%)**
Age (in years)		
≤30	6	5.5
31-55	32	29.1
56-80	60	54.5
>81	12	10.9
Gender		
Male	50	45.5
Female	60	54.5
Marital Status		
Married	75	68.2
Unmarried	9	8.2
Widow	26	23.6
Ethnicity		
Brahmin/Chhetri	33	30.0
Janajati	52	47.3
Dalit	17	15.5
Madhesi	8	7.3
Educational Status		
Illiterate	74	67.3
Can read and write only	20	18.2
Primary level	8	7.3
Secondary level	8	7.3
Family Number		
Alone	31	28.2
2	29	26.4
3-4	38	34.5
5-6	9	8.2
>6	3	2.7
Disease Duration (years)		
≤10	8	7.3
11-30	23	20.9
31-50	34	30.9
51-70	38	34.5
>71	7	6.4

Table 1: Socio-Demographic and Disease-Related Variables of Respondents (n=110)

Domain	x̄±SD	Min-Max	x̄±SD Transformed Score (0-100)
Physical	11.9±1.9	21.4–75.0	49.2±12.1
Psychological	12.4±2.1	4.2-83.3	52.4±13.4
Social	13.8±2.4	25.0–100.0	61.0±15.1
Environmental	13.5±1.5	31.3-87.5	59.7±9.5

Table 2: Respondents' Quality of Life in Different Domains

Table 2 shows the mean score for QOL. QOL mean score was highest in the social domain (61.0±15.1) and lowest in the physical domain (49.2 ± 12.07).

Among 110 respondents, the majority (75.5%) had a good quality of life, whereas 24.5% had a poor quality of life, as demonstrated in **Figure 1**.

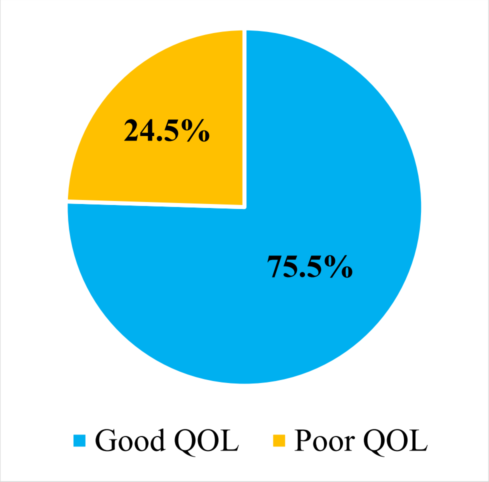

Figure 1: Levels of QOL among respondents with leprosy (n=110)

Table 3 shows the results of chi-square test between QOL and socio-demographic and disease-related variables. The quality of life was significantly associated with marital status (<0.05), family size (<0.05), and duration of disease (p=0.04).

Discussion

The study reveals that the social domain had the highest QOL score, with a mean score of 61.0. The score for the physical domain was comparatively lower (49.2) than the environmental domain (59.7) and psychological domain (52.4). The finding in the present study is consistent with the study conducted in Indonesia among 30 leprosy patients, where the highest score was in the Social domain (66.0), followed by the environmental domain (63.1), and lowest in the physical health domain (51).[5] Also, the findings are consistent with the study conducted in Indonesia among 110 people with leprosy, which revealed higher QOL score in the physical health domain (62.5) and lower in the psychological domain (50.2).[6] In contrast, the study conducted in Sri Lanka among 527 leprosy patients reported lowest mean in the social domain (55.1) and highest in the physical domain (69.8).[7]

Variables	QOL Level		$\chi 2$ Value	p-value
	Good, n (%)	Poor, n (%)		
Age (in years)				
≤60	39 (84.8)	7 (15.2)	3.7	0.05
>60	44 (68.8)	20 (31.2)		
Gender				
Male	41 (82.0)	9 (18.0)	2.1	0.2
Female	42 (70.0)	18 (30.0)		
Marital Status				
Married	63 (84.0)	12 (16.0)	9.3	<0.05*
Others#	20 (57.2)	15 (42.8)		
Ethnicity				
Janajati	40 (77.0)	12 (23.0)	0.1	0.7
Others##	43 (74.2)	15 (25.8)		
Educational Status				
Illiterate	53 (71.6)	21 (28.4)	1.8	0.2
Literate	30 (83.3)	6 (16.7)		
Family Members				
≤2	36 (61.0)	23 (39.0)	12.7	<0.001**
>2	47 (92.2)	4(7.8)		
Disease Duration (in years)				
≤45	44 (84.6)	8(15.4)	4.5	0.04*
>45	39 (67.2)	19(32.7)		

**Pearson's Chi-Square Test, Significant at p-value <0.05; **Using Continuity correction test at 5% level of significance; #Others: Unmarried, Widow; ##Others: Brahmin/ Chettri, Dalit, Madhesi*

Table 3: Association of Quality of Life with Socio-Demographic and Disease-Related Variables (n=110)

This study showed that most respondents (75.5%) had a good level of QOL, and 24.5% of respondents had a poor level of quality of life. This finding is consistent with the findings of the study conducted in Indonesia among 30 respondents, where 93.3% had a good quality of life and 6.7% had a poor quality of life.[5] Similarly, this study is consistent with the study conducted in Tamil Nadu, India, among 151 leprosy patients in a government rehabilitation home, (17.8%) patients had poor quality of life, (73.5%) of patient had moderate quality of life and (8.6%) patient had good quality of life.[8] On the other hand, the finding is contradictory to the study conducted in Chennai, India, which found that 45% of leprosy patients had poor quality of life, 36% had moderate, and 19% had satisfactory QOL. The difference could be due to differences in the study setting.[9]

This study disclosed that there was no association between quality of life with age, gender, ethnicity, and educational status. On the other hand, there was an association between quality of life with marital status *($p<0.05$),* family size *($p =<0.001$),* and duration of disease *($p = 0.04$).* The findings are also consistent with the study conducted in Ahmedabad, India, among 87 leprosy patients, where there was no significant difference observed between gender, age & education, but a statistically significant difference ($p<0.001$) was noted with duration of disease and presence of deformity.[10] In contrast, in the study conducted in Indonesia among 110 patients, there were significant associations between quality of life and the following socio-demographic factors: age ($p=0.02$), but there was no association with marital status and duration of disease.[6]

Conclusion

In conclusion, the majority of the respondents had high QOL, while almost a quarter of them had a low QOL. Marital status, family number, and disease duration were significantly associated with the QOL. Patients with leprosy should be provided with holistic care to enhance their physical, mental, and psychological well-being.

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