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Original Research Article

Quality of life assessment among leprosy patients residing at leprosy home in a district of Eastern Odisha: a cross-sectional study

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ABSTRACT

Background: Leprosy remains a significant public health concern in India, contributing substantially to disability, stigma, and impaired quality of life (QoL), despite its elimination as a public health problem. Persons affected by leprosy often experience long-term physical, psychological, and social consequences, particularly those with visible disabilities. This study aimed to assess the quality of life and patterns of disability among leprosy-affected persons residing in a leprosy care and rehabilitation centre in a district of Eastern Odisha.

Methods: A cross-sectional study was conducted in December 2024 among 80 adult leprosy patients residing at the Leprosy Care and Rehabilitation Centre, Cuttack, using universal sampling. Sociodemographic details and disability grades were recorded. QoL was assessed using the WHOQOL-BREF questionnaire. Domain-wise transformed scores were calculated, and data were analyzed using SPSS version 17. Statistical significance was set at $p<0.05$.

Results: Of the 80 participants, 64% were male and the mean age was 56.6±18.2 years. A majority (87%) had Grade 2 disability. The lowest QoL scores were observed in the social and psychological domains. Overall, 62% of participants rated their quality of life as poor or very poor. Male gender, younger age, higher education, better socioeconomic status, unmarried status, and contact with family were significantly associated with better QoL in one or more domains.

Conclusions: Leprosy continues to severely compromise quality of life, particularly in the social and psychological domains, among affected individuals in Eastern Odisha. Comprehensive rehabilitation, stigma reduction, psychosocial support, and family-centered interventions are essential alongside medical management to improve overall well-being.

Keywords: Leprosy, Quality of life, WHOQOL-BREF, Disability, Stigma

INTRODUCTION

Leprosy, also recognized as Hansen's disease, is a chronic granulomatous infectious disease caused by Mycobacterium Leprae. It is an ancient disease in India with its early description in 'Sushruta Samhita' written in 600 BC.[1] Mycobacterium leprae is an acid-fast, gram positive bacilli having special affinity for Schwann cell of nerve. One of the main obstacles to leprosy control efforts is still social stigma brought on by ignorance, fear, and superstitious beliefs. It results in progressive damage to peripheral nerves in untreated or inadequately treated patients, leading to nerve impairments and visible disabilities resulting in limitation of physical activities, social exclusion and a lower quality of life in some patients.[2] The Quality of life (QoL) is a highly subjective multidimensional concept which includes physical health, psychological health, level of independence, social relationships, personal beliefs and the relationship with one's environment.[3] 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.[4] The fear of leprosy causes stigma and discrimination because people don't know enough about it, which leads to more misconceptions about how the disease is spread and how to treat it. The fact that most of those with untreated leprosy end up with severe deformities and disfigurements has contributed to the stigma.[5] This disease is an important cause of crippling deformities. Individuals with Hansen's disease are very likely to suffer from psychiatric issues.

The affected people have high psychological problems such as divorce, unemployment and displacement from their native place of residence.[6] NLEP work towards spreading awareness and reducing stigma attached with the disease.[7] The implementation of ASHA-based surveillance for Leprosy suspects (ABSULS), in which workers at the grassroots level continuously examined and reported suspected, further strengthened surveillance. Special emphasis under the Focused Leprosy Campaign (FLC) was given to areas that were difficult to access or had child cases and cases with disabilities.[7] As part of the Global Leprosy Strategies for 2030, 120 countries are expected to report zero new autochthonous cases, reduce the number of new cases identified annually by 70%, reduce the rate of new cases with grade 2 disabilities by 90% (per million), and reduce the rate of leprosy cases in children by 90% (per million).[7]

Despite being proclaimed eradicated from India in 2005 as a public health issue, it still accounts for 58% (the highest) of all cases worldwide.[7] In year 2019 -20, 114451 new cases were detected while 65164 new cases during 2020-21.[8] Recently, Odisha Govt has declared Leprosy as a ‘Notifiable Disease’ in the state and accordingly all persons dealing with diagnosis, treatment and follow up in Govt. or Pvt. hospitals must report all diagnosed cases to the respective CDM and PHO/ADPHO. In 2020–21, Odisha ranked in third and fourth place, respectively, in terms of new Leprosy cases and Grade 2 disabilities.[8] Given these facts, the research studies conducted in Odisha are very limited. Therefore, the rationale behind conducting this study is to gain knowledge about the problems faced by the people affected by leprosy and to assess their QoL.

METHODS

A cross-sectional study was conducted in December 2024 among leprosy patients staying in the Leprosy Care and Rehabilitation centre, Cuttack. Using Universal sampling, a total of 80 study participants were selected which included all the diagnosed Leprosy cases above 18 years of age with some grades of disability. Those who did not give consent and were not present during the time of data collection were excluded from the study. A predesigned, pretested, structured questionnaire was used to obtain relevant information regarding demographic details and extent of disabilities. WHO QOL- BREF, a self-reported questionnaire, was used to assess the quality of life of the study participants. It comprises of 24 items distributed among 4 domains (Physical, Psychological, Social, Environmental) and 2 other items used to measure overall QOL and general health. The transformed mean score of each domain was used to calculate the domain wise QOL.[9,10] The data was entered in Microsoft excel worksheet and analysed using SPSS version 17. The normality of data was tested. Frequency, percentage, mean, standard deviation, median, inter quartile range, Inferential statistics were used and a p-value of <0.05 was taken as statistically significant. Clearance from the Institutional Ethical Committee and a written permission from the In-charge of Leprosy Care and Rehabilitation centre, Cuttack was obtained prior to the beginning of the study.

RESULTS

The sociodemographic details of the research participants are displayed in Table 1. Out of the total 80 participants, 64% were male and 36% were female, with the mean age of 56.6±18.2 years. Maximum (88%) participants belonged to rural area and only 12% belonged to urban area. The majority of participants were Hindu 77 (98%) and the rest 3 (2%) were Muslim. The number of married participants was 46 (58%) followed by unmarried 20 (25%), widowed 11 (14%) & deserted 3 (3%). Majority of the participants belonged to lower class 44 (54%) followed by lower middle 17 (21%), middle class 13 (16%) and upper middle 6 (9%). 50 participants were literate (63%) and 30 had no formal education (37%). Figure 1 shows the distribution of grade of disabilities among the study participants of which 11 (13%) were having Grade 1 disability and 69 (87%) were having Grade 2 disability.

Table 2 shows the WHO BREF QOL Domain wise scores. The mean score for physical domain was 46±16 and 37±15 for psychological domain. The median score for social domain was 34 (IQR=33) and 44(IQR=17) for the environment domains. Thus, the social and psychological domains have the lowest QOL. Table 3 shows the distribution of overall quality of life among study participants. Majority of the participants (40%) rated their overall quality of life as ‘poor’, followed by ‘Neither poor nor good’ (24%), ‘very poor’ (22%) and ‘good’ (14%) but none of them reported ‘very good’ QOL.

The association between different socio-demographic variables with the four domains of QOL is represented in Table 3. Gender-wise comparison revealed that males had significantly higher mean scores than females in the physical, environmental, and social domains, indicating better perceived well-being in these areas. However, the difference in the psychological domain was not statistically significant. A statistically significant association of age was established with physical and environmental domain scores but not with psychological and social domains.

Table 1: Sociodemographic details of the study participants (n=80).

Variables	Frequency (N)	Percentage (%)
Age (years)		
20-39	14	18
40-59	28	35
60-79	29	36
≥80	9	11
Sex		
Male	51	64
Female	29	36
Religion		
Hindu	77	96
Muslim	3	4
Residency		
Urban	9	11
Rural	71	89
Education		
Literate	50	63
Illiterate	30	37
Occupation		
Employed	13	16
Un employed	67	84
Socio economic status		
Lower	44	55
Lower middle	17	21
Middle	13	16
Upper middle	6	8
Marital status		
Unmarried	20	25
Married	46	57
Widowed	11	14
Deserted	3	4
Family status		
In contact with family	48	60
Not in contact with family	32	40

Table 2: WHO BREF QOL domain wise scores.

Domains	Score
Physical (mean ± SD)	46±16
Psychological (mean ± SD)	37±15
Social (median)	34 (33)
Environmental (median)	44 (17)

Education and marital status were significantly associated with all four quality-of-life domains. Literate participants reported better physical health, psychological well-being, social relationships, and environmental conditions compared to illiterate participants, highlighting the positive role of education in overall quality of life.

Table 3: Distribution of overall quality of life among study participants (n=80).

Quality of life	Frequency (%)
Very poor	18 (22)
Poor	32 (40)
Neither poor nor good	19 (24)
Good	11 (14)
Very good	0 (0)

Table 4: Association between different socio demographic variables with the four domains of QOL.

Variables		Physical (mean±SD)	Psychological (mean±SD)	Social Median (IQR)	Environmental Median (IQR)
Age (years)	20-39	52±19	39±15	50 (18)	46 (21)
	40-59	47±16	36±17	33 (33)	45 (15)
	60-79	39±14	33±13	33 (28)	40 (14)
	≥80	50±14	40±14	16 (37)	46 (43)
	P value	0.032	0.48	0.14	0.03
Gender	Male	49±16	38±15	41 (25)	46 (18)
	Female	39±15	32±13	25 (29)	40 (29)
	P value	0.015	0.075	0.014	0.041
Education	Literate	48±17	39±15	41 (27)	46 (18)
	Illiterate	40±15	32±14	29 (19)	40 (19)
	P value	0.035	0.037	0.003	0.026
Marital status	Unmarried	51±22	43±18	41 (25)	46 (21)
	Married	46±12	37±17	33 (16)	43 (18)
	Widowed	35±18	25±14	16 (00)	34 (25)
	Deserted	28±00	8±00	8 (00)	25 (00)
	P value	0.036	0.001	0.001	0.008
SES	Lower	47±18	34±16	25 (33)	40 (15)
	Lower middle	40±7	35±12	33 (7)	43 (12)
	Middle	43±17	38±11	50 (16)	56 (13)
	Upper middle	43±17	46±15	50 (16)	65 (19)
	P value	0.145	0.285	0.012	0.001
Family status	In contact with family	47±15	40±14	33 (16)	47 (17)
	Not in contact with family	44±18	31±15	17 (39)	39 (21)
	P value	0.379	0.009	0.001	0.000

The QOL was better in unmarried individuals than married, widowed and deserted participants. The association between socioeconomic status and QOL scores was statistically significant in the environmental and social domains, where participants belonging to middle and upper-middle classes demonstrated higher scores, but not in the physical and psychological domains.

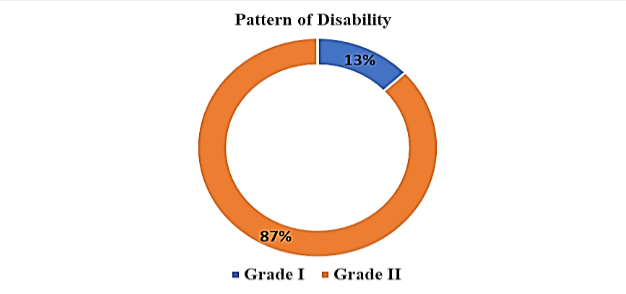

Figure 1: Distribution of grade of disabilities among study participants (n=80).

Family status played an important role in quality of life. Participants who were in contact with their family had significantly better psychological, social, and environmental domain scores compared to those not in contact, while no significant difference was observed in the physical domain.

DISCUSSION

In this study of 80 leprosy patients residing at the Leprosy Care and Rehabilitation Centre in Cuttack, the overall quality of life was found to be quite poor, especially in the social and psychological domains. The majority of patients (87%) had a Grade 2 disability, and 40% had a poor overall quality of life, indicating multifaceted disadvantages that persisted even after the treatment ended. Most of the participants (89%) belonged to rural area which is in concordance with the study conducted by Ujjwal et al, Pai et al conducted a cross-sectional study using WHOQOL-BREF among 50 leprosy patients in India and observed that psychological and physical domains were more adversely affected, with female patients and those of older age showing lower QoL scores across domains, similar to trends seen in our participants.[11,12] This suggests that psychological sequelae and social marginalization remain prominent determinants of quality of life among persons affected by leprosy. A tertiary dermatology centre study of 114 patients in Eastern India ^{by} Das et al using DLQI found that leprosy caused moderate to severe QoL impairment, with nerve involvement and deformities linked to poorer scores.[13] This aligns with our findings of lower physical and social domain scores in our study participants. Studies from different Indian regions reinforce the link between higher disability grades and poorer QoL. In West Bengal, Govindharaj et al reported reduced WHOQOL-BREF scores, especially in psychological and social domains due to stigma.[14] Similarly, Belgaumkar et al also in his study found that over half of patients had overall scores ≤50, with psychological wellbeing more affected than social relationships.[15]

Gender differences in QoL have also been reported in the Indian context. Both Pai et al and Belgaumkar et al observed that female leprosy patients tended to have lower QoL scores than males, particularly in psychological and social domains — a trend that resonates with our finding that females scored lower in several QoL domains although the psychological difference did not reach statistical significance.[12,15] Educational and marital status, which were significantly associated with QoL in our study, have been similarly implicated elsewhere. Solanki et al found that lower education and socioeconomic status were linked to poorer QoL in leprosy patients due to reduced access to information, rehabilitation opportunities, and social support, factors that likely compound the adverse effects of disability and stigma.[16]

Although specific studies focusing solely on Odisha are limited, a pilot intervention study conducted by Noordende et al in Odisha showed that WHOQOL-BREF scores improved following a family-based resilience program, reinforcing the notion that social support and community interventions can substantially influence the quality of life among affected persons.[17]

CONCLUSION

The present cross-sectional study highlights that leprosy continues to exert a profound negative impact on the quality of life of affected individuals residing in a leprosy care and rehabilitation centre in Eastern Odisha. A very high proportion of participants were living with Grade 2 disability, reflecting delayed diagnosis and long-standing disease. Overall quality of life was predominantly poor, with the social and psychological domains being the most severely affected, underscoring the persistent stigma, social isolation, and emotional distress experienced by leprosy-affected persons even after completion of medical treatment. Despite national elimination of leprosy as a public health problem, the findings reveal that leprosy-related disability, stigma, and social exclusion remain major challenges in Odisha. These factors substantially compromise quality of life and indicate that elimination of disease transmission alone is insufficient without comprehensive rehabilitation and psychosocial support. Therefore, quality-of-life assessment should be considered an essential component of leprosy control and rehabilitation programmes.

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