Indian J Lepr 2025, 97 : 221-229

http://www.ijl.org.in

Original Article

Change in Social Participation among Leprosy Cases Post Reconstructive Surgery in Chhattisgarh state, India- A Prospective Study

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Received: 30.09.2024 Revised: 16.03.2025 Accepted: 20.04.2025

Leprosy or Hansen's disease, caused by *Mycobacterium leprae*, primarily affects skin and peripheral nerves. This causes hypopigmented skin patches and nerve inflammation leading to visible deformities and disabilities. Limitations of physical activities and social exclusion are major problems affecting the leprosy afflicted persons (LAPs). Correction of deformities can help in reducing this participation restriction. Using the participation scale, a prospective study was conducted on 53 cases at leprosy referral hospitals in Chhattisgarh to assess the change in the participation restriction among participants operated for grade 2 limb disability. The participation restriction among the study participants was assessed thrice, that is before reconstructive surgery and at three and six months post-reconstructive surgery. Improvement in social participation was evident, reflected by a statistically significant progressive decrease in participation restriction.

Keywords: Leprosy, Participation Restriction, Reconstructive Surgery, P-Scale

Introduction

Leprosy or "Hansen's disease" is one of the oldest diseases known to mankind. *Mycobacterium leprae*, a bacterium, is the causative agent. Skin and peripheral nerves are most commonly involved (Sasaki et al 2001). The chronic inflammation of the peripheral nerves causes disabilities that lead to decreased social involvement and participation restriction among leprosy patients affected with disabilities (Abdela et al 2020).

Participation in the community involves fulfilling one's role in society or engaging in group activities. Leprosy-related stigma is arguably the oldest form of disease-related stigma in human history. People with leprosy are often stigmatized

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due to the belief that they have committed a sin or violated a taboo, either in this life or in the past. Throughout time, people affected with leprosy have faced restrictions in various areas of life due to disease, disability, deformity, caste, creed, race, gender, or other stigmatizing conditions. Addressing these participation restrictions is a primary goal of many rehabilitation interventions. Consequently, measuring participation is crucial to assess needs, monitor progress, and evaluate the impact of rehabilitation efforts. The Participation Scale, used in the study (van Brakel et al 2006), is a standardized pre-tested tool of 18 items graded 1 to 5, to assess the restrictions caused by disabilities resulting from leprosy. The total is grouped into 5 categories. The scale is designed to be culturally neutral, utilizing comparisons between the individuals and their healthy peers. Many studies were done in India and abroad using the Participation or P-scale, and a few were done prospectively. As the disabilities and participation restriction are dynamic phenomenon, the need to keep on generating data relevant to the programme management remains important. The present study was planned to assess the role of reconstructive surgery in addressing participation restrictions among grade 2 limb disabilities due to leprosy in the current scenario.

Methodology

The Institutional Scientific and Ethical Committee of Pt JNM Medical College, Raipur, approved this prospective study. Necessary permissions were obtained from the Director of RLTRI & ROHFW Raipur and the Medical Superintendent of TLM Hospital Chandkhuri, Baitalpur. Data collection occurred from October 2022 to December 2023.

Participants were enrolled and assessed before and after reconstructive surgery. The initial assessment took place immediately before surgery, then subsequent assessments were conducted at three- and six-months post-surgery during follow-up visits (van Brakel et al 2006).

Written consent was obtained from patients admitted for reconstructive surgery in the inpatient departments of leprosy referral institutes. Those who consented were clinically examined, and patients meeting the inclusion criteria were enrolled in the study. Enrolled participants were interviewed using semi-structured and structured questionnaires. Socio-demographic details were also collected using self-designed information sheet. Since all participants were fluent in Hindi, a validated Hindi version of the structured questionnaire was used. Similarly, during follow-up visits, assessments were conducted at three- and six-months post-surgery. Few participants who did not report to the leprosy referral institutes for follow-up were contacted by telephone. These patients were requested to visit the nearest government health centres from their residences, and then follow-up dates were decided based on the availability of the participants.

The data was entered into a Microsoft Excel 2010 spreadsheet and checked for completeness and accuracy. Categorical variables were presented as frequencies and percentages, while quantitative variables were presented as Mean ± SD. Paired t-test was employed to examine changes in participation scale scores. Statistical analysis was performed using Epi Info and Jamovi software, with a p-value of < 0.05 considered statistically significant.

Results

Of the 53 participants enrolled in the study, 41 (77.4%) were from RLTRI, Raipur, and 12 (22.6%) were enrolled at TLM Hospital Baitalpur. Age and gender distribution of participants are summarised in Tables 1 and 2.

As presented in Table 2, majority that is 75.5%

Table 1: Age groups of enrolled participants in years (n= 53).

SN	Age of the patient (in years)	Frequency	Percentage
(a)	*(b)*	*(c)*	*(d)*
1	≤ 20	09	16.9
2	20 - 30	15	28.3
3	30 - 40	16	30.2
4	40 - 50	07	13.2
5	50 - 60	05	9.4
6	>60	1	2
7	**Total**	**53**	**100**

Mean age = 31.94 years, S.D = 11.94. 75% of the study participants belong to the age group of less than 40 years. Only 2% of the study participants were of more than 60 years of age.

Table 2: Gender-wise distribution of enrolled participants (n=53).

SN	Gender of the participant	Frequency	Percentage
(a)	***(b)***	***(c)***	***(d)***
1	Male	40	75.5
2	Female	13	24.5
3	**Total**	**53**	**100**

Table 3: Status of participation restriction using Participation scale among study participants at three assessment stages (n = 53).

SN	Grades of Participation restriction	During Enrolment (Before Surgery)		At First, follow up		At Second, follow up	
		Frequency	%	Frequency	%	Frequency	%
1	No Significant restriction (0-12)	00	00	04	7.4	05	9.5
2	Mild restriction (13-22)	05	9.4	07	13.1	11	20.9
3	Moderate restriction (23-32)	08	15.1	09	17.1	15	28.5
4	Severe restriction (33-52)	18	33.9	31	58.7	20	38
5	Extreme restriction (53-90)	22	41.6	02	3.7	02	3.8
	Mean ± S.D of Participation scale scores	45.3 ± 15.9		36.3 ± 14.1		29.3 ± 12.4	

Table 4: Analysis of improvement in participation restriction post-reconstructive surgery among grade 2 limb disability cases of leprosy using repeated measures ANOVA (n = 53).

Source	Unadjusted DF	Unadjusted mean square	F value	Unadjusted p-value	Adjusted p-value by G-G	Adjusted p-value by H-F
Assessment Stage	1	229140.226	384.947	0.00	0.00	0.00

Abbreviations: ANOVA; Analysis of variance, DF; Degrees of freedom, G-G; Greenhouse Geisser Epsilon, H-F; Hyunh-Feldt Epsilon.

(40) study participants were males and 24.5% (13) were females.

The mean age of study participants was 31.9 ± 11.5 years, and the maximum 75% (40 Participants) were 40 years or younger (Table 1). 62.3% (33 participants) were married, and 37.7% (20 participants) were never married. 79% (42 Participants) belonged to Class IV & V (Lower middle & Lower) socioeconomic status according to the modified BG Prasad socioeconomic scale 2023. About 53% were educated up to primary or middle school. About 98.1% (52 Participants) had MB leprosy, and 2% (1 Participant) had PB leprosy, all meeting the study's inclusion criteria for grade 2 limb disability. Family history data indicated that 19% had a family history of leprosy, and 62% (33 Participants) had a history of neuritis.

Findings of P-Scale: The participation scale scores showed the status of participation restriction at three assessment stages (Table 3). Participation scale scores decreased progressively in the consecutive stages of the assessment, indicating a progressive improvement in participation restriction.

Statistical analysis of the change in the participation scale scores recorded over the three stages of assessment was done using the repeated measures ANOVA with Bonferroni's correction. The unadjusted p-value and adjusted p-values by Greenhouse Geisser Epsilon & Hyunh-Feldt Epsilon show a statistically significant decrease in the participation scale scores over the three assessment stages. Improvement in participation restriction was greater in participants having a history of neuritis than in participants having no history of neuritis (t = 2.095, p = 0.041).

Study participants not doing physiotherapy scored greater (Mean= 34.04 ± 12.799) than the participants doing physiotherapy (Mean= 18.67 ± 11.793), (t= 2.978, p= .022). Hence, there was a greater improvement in participation restriction after reconstructive surgery with physiotherapy.

Change in the participation scale score (Change in social participation) after reconstructive surgery was greater in: Males (14.70±14.10, n=40, p=0.92)) than in females (14.38±8.75, n=13, p=0.92), underweights (17.75±16.78, n=24, p=0.14) than in normal weights (12.03±7.95, n=29, p=0.14), lower socioeconomic status class IV & V (14.71±14.29, N=41, P=0.90) than in upper & middle-class I, II, III (14.33±6.78, n=12, p=0.90), participants with no history of lepra reaction (15.07±13.52, n=45, p=0.45) than in participants having a history of lepra reaction (12.13±8.99, n=08, p=0.45), participants having BCG scar (18.79±21.19, n=14, p = 0.346)) than in participants without BCG scar (13.13±8.12, n=39, p=0.346), participants with no alcohol abuse (15.89± 14.38, n= 35, p= 0.26) than with alcohol abuse (12.17± 9.31, n= 18, p = 0.26)

Discussion

Leprosy is unique among infectious diseases due to its feature of causing disabilities in the affected humans. Ancient Vedic texts indicate that leprosy rendered a person's body unacceptable for divine rituals, leading to the practice of live burial (Sinha et al 2010). Throughout history, leprosy has resulted in the severe ostracization of affected individuals, as well as those who tended to them, effectively exiling them from their communities (Alam et al 1997). The identification of *Mycobacterium leprae* by Hansen in 1873 marked a turning point, transforming leprosy from a perceived divine punishment to a scientifically understood illness, thereby fostering a slow but significant shift towards greater acceptance (Hansen's Discovery 2008).

Disabilities have a huge impact on the physical, mental, and social domains of health. In the past, individuals affected by leprosy experienced social exclusion, discrimination, loss of function, and limited social mobility (Ahmad & Katoch 2021). While many individuals affected by leprosy are now included in social and cultural events, a significant number still face limited social participation and difficulty forming strong community relationships (Thilakavathi et al 2012). Recent developments in health programs worldwide highlight the concern about preventing disabilities and the damages due to disabilities in the lives of people affected by leprosy. The integration of leprosy services into public healthcare, coupled with improved case finding and treatment, has positively shifted societal attitudes and increased acceptance of people affected by leprosy. However, self-stigma persists, and significant socio-cultural challenges, particularly for cured but disabled individuals, remain largely unaddressed (Katoch et al 2017).

Even with advancements in treatment and understanding, leprosy stigma remains a significant issue. Many affected individuals continue to face social ostracization, with some residing in segregated colonies (Rao 2015). Disability and ulcers, common complications of leprosy, contribute to this stigma. However, community-based interventions have proven effective in mitigating these negative perceptions (Raju et al 2008). The issues of delayed diagnosis, treatment non-compliance, resulting deformities, and subsequent social dehabilitation are closely linked (Guthi & Sreedevi 2018). These factors contribute to many leprosy patients, particularly those with visible deformities, experiencing dehabilitation and living in segregated colonies, where the availability of free resources plays a role in their continued residence (Raju & Rao 2018).

The age of the people affected with leprosy disabilities signifies the most impacted demographic section. The present study revealed that the participants' mean age was 31.9 ± 11.5 years. This age group is highly productive for the development of the country. The burden of disabilities on the young age group is a setback for the nation. A similar study was conducted by Steinau et al (2011) on a technique for posterior tibial tendon transfer (Stirrup plasty) in foot drop deformity and improvement in the quality of life of 53 subjects, the mean age of participants in the study was 37 years.

According to the NLEP annual report 2020-21, 39% of the new leprosy cases were females (NLEP 2020-21). The proportion of female participants was analysed in the present study, 24.5 % were females, and 75.5 % were males. In a study conducted by Tiendrebeogo et al (1996), the prevalence of disabilities among males was 32.1%, whereas among females, it was 14.2%. Relative to females, the relative risk for males was 2.26.

Multibacillary (MB) leprosy patients as per the

WHO classification, have more nerves affected than the paucibacillary (PB) leprosy patients. There are greater chances of the development of visible deformities in the MB leprosy patients than in the PB leprosy patients. In the present study, 98.1% (52) of the participants were MB leprosy cases, and 1.9% (1) were PB leprosy cases, all with grade 2 limb disability as per the study inclusion criteria.

Disability profiling of the study participants in the present study was done. Examination of the participants revealed that 70% had a disability of upper limb. In the study conducted by Palo et al (2019), 76% of participants had upper limb deformities; also in the study done by Asia et al (2015), 60% of the participants having grade 2 disability suffered from the disability of upper limbs.

Based on marital status, 62.3% (33) of the participants in this study were married, and 37.7% (20) were never married. In a study done by Brouwers et al (2011) also 65% were married, and married participants registered a better quality of life than participants who were never married. Based on socioeconomic status, 79% (42) of the participants in the study belonged to Class IV & V (Lower middle & lower) class as per the modified BG Prasad socioeconomic scale, and 53% were educated up to primary & middle school. In a study conducted by Guthi et al (2016), at Kurnool (A.P) 76% of the participants belonged to the lower middle and lower classes and it was statistically significant, 65% were educated up to the primary school level.

In the past, many studies were done to assess the participation restriction among the people affected with leprosy-related disabilities. Cunha et al (2016) found in their study that 58% of participants did not have any restriction to participation, while 14% showed mild restriction, 8% moderate restriction, and 20% severe restriction, and in the study conducted by Bense et al (2013) on 250 randomly selected study subjects, 56·8% of participants had no participation restrictions, 15·6% had mild social restrictions, 8 % had moderate, 11·2% had severe, and 8·4% had extreme participation restrictions.

In a systematic review and meta-analysis by de Paula et al (2019), a total of 2,447 reports were identified. 177 full-text articles were assessed for eligibility, and 32 studies were included in the systematic review. Of these, 24 studies reported sex information, encompassing 39,571 patients, 24,218 (61.2%) of whom were male. Male patients with leprosy had a higher likelihood of physical disability compared to female patients (pooled OR: 1.66; 95% CI: 1.43–1.93; I^2: 81.3%; P < .001). Individuals with multibacillary leprosy were four times more likely to develop physical disability than those with paucibacillary leprosy (pooled OR: 4.32; 95% CI: 3.37–5.53; I^2: 88.9%; P < .001). Patients experiencing leprosy reactions had a greater likelihood of disability (pooled OR: 2.43; 95% CI: 1.35–4.36; I^2: 92.1%; P < .001). Additionally, patients with lepromatous leprosy faced 5- to 12-fold higher odds of developing disability.

In the past, many studies were done to assess the change in social participation after reconstructive surgery in people affected with leprosy. A prospective study on reconstructive surgery in leprosy was conducted by van Veen et al (2011) in Bangladesh, 15 out of 222 interviewed participants opted for the surgery. Social participation assessed by the p-scale improved over time in both groups, but significant findings were found only in the non-operated group.

In the present study, at the time of enrolment (before reconstructive surgery) - 41.6% suffered from extreme restriction, 33.9% from severe restriction, 15.1% from moderate restriction & 9.4 % from mild restriction. None of the

participants were found to have any significant restrictions before reconstructive surgery.

Cohen et al (2022) assessed participation restriction after surgical intervention. Participation scale scores were assessed after surgery among 22 leprosy patients who had undergone posterior tibial tendon transfer. The mean participation scale score was 22.5, signifying moderate participation restriction. In this study, the mean participation scale score was 45.3 ± 15.9, which comes under severe to extreme restriction.

Roy et al (2023) used a p-scale to assess participation restriction in 80 post-tendon transfer surgery grade 2 disability cases of leprosy. The p-scale showed a significant decrease in score, indicating improvement in social participation after surgery. However, in the study conducted by Singh et al (2009), 245 respondents (195 who were seeking treatment from the leprosy clinics and 50 respondents staying in the Kushtha Ashram), 54.28% reported no participation restriction. 20.40% reported mild participation restriction. 11.24% reported moderate participation restriction. 10.23% reported severe participation restriction. 3.67% reported extreme participation restriction before surgery. Similar observations were reported by Ramasamy et al (2019); their research noted that 15% of participants experienced mild to moderate limitation, while 10% faced severe to extreme restriction. These limitations tend to emerge as the disease advances.

In this study, there was a greater improvement in participation restriction among the participants practicing physiotherapy. Similarly, in the study conducted by Hassan & Zafar (2023), physiotherapy practice alleviated pain, increased muscle power and joint mobility, and improved psychosocial rehabilitation among people affected with leprosy-associated deformities.

Conclusions and a way forward

The present study found that participation restriction among the study participants was reduced after reconstructive surgery. Augmentation of efforts for mobilization of people affected with leprosy disabilities for reconstructive surgery is the need of the hour. An increase in efforts can be applied as follows:

Community mobilization: Organizing discussions on reconstructive surgery on social platforms such as village fairs, community meetings, public debates, dances and concerts, social media, print media, and electronic media.

Involvement of formal non-formal and religious leaders for acceptance of reconstructive surgery- they can educate their congregations about the surgical realities of leprosy. They can help to promote awareness campaigns, influence public opinion, and foster an inclusive environment for the people affected with leprosy disabilities.

Involvement of Anganwadi centers and Village Health Nutrition and Sanitation Day (VHNDs) can be used as a social platform for organising community sensitization and awareness campaigns.

The present study is done in a limited resource setting with a relatively smaller sample size. A large-scale study is needed to better understand the outcome among leprosy-affected cases. A community-based screening campaign can be planned to find hidden, unreported grade 2 disability cases of leprosy. Individuals with confirmed grade 2 disability cases of leprosy can be sensitized and counselled for reconstructive surgery.

Acknowledgments

We thank The Leprosy Mission Trust, in-charge officers, and all the participants and colleagues working in The Leprosy Mission Hospital Chandkhuri, Baitalpur, The Leprosy

Mission Hospital, Champa, and Regional Leprosy Training and Research Institute, Raipur (C.G.) for the permission and support during all the stages of this research. We also acknowledge the Participation scale development team, Dr. Wim van Brakel, KIT Leprosy Unit Wibautstraat 137J 1097 DN, Amsterdam, Netherlands for the Participation scale used in the study.

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How to cite this article : Sharif SA, Verma N, Jaiswal P et al (2025). Change in Social Participation among Leprosy Cases Post Reconstructive Surgery in Chhattisgarh state, India - A Prospective Study. *Indian J Lepr.* **97**: 221-229.