

Original Research Article

Occupational outcomes of reconstructive surgery among individuals with leprosy-related deformities in Telangana

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ABSTRACT

Background: Leprosy related deformities can severely impact an individual's ability to work, leading to social and economic challenges. Reconstructive surgery (RCS) helps restore mobility and functionality, improving quality of life. However, its overall impact on daily functioning and livelihood remains less explored. This study assesses how RCS influences work and living conditions for individuals with leprosy-related deformities.

Methods: A descriptive cross-sectional study was conducted at a non-governmental organization in Hyderabad, from January to April 2024. A total of 120 adults who underwent RCS for leprosy related deformities in the past 10 years were included. Data were collected through direct interviews using a structured questionnaire. Occupational impact was assessed using a Likert scale adapted from the Swedish self-reported satisfaction questionnaire.

Results: RCS positively impacted daily activities for 77% of participants, while 16% were neutral and 7% reported a negative effect. For occupation, 53% saw improvement, 31% remained neutral, and 16% experienced a negative impact. However, 41% remained unemployed post-surgery, with many still facing challenges in securing or retaining jobs. A comparison of occupations before and after surgery showed a shift from agriculture, daily wage work, and self-employment to higher unemployment rates.

Conclusions: RCS improves functional abilities and independence in leprosy patients, enhancing their ability to perform daily activities. However, high post-surgery unemployment highlights the need for vocational rehabilitation and social support. Comprehensive rehabilitation programs are essential to facilitate occupational reintegration and long-term well-being.

Keywords: Disability, Leprosy, Occupational impact, Reconstructive surgery, Rehabilitation

INTRODUCTION

Leprosy is also known as Hansen's disease, is a chronic infectious disease caused by *Mycobacterium leprae*, an acid-fast bacillus. Leprosy primarily affects the skin, peripheral nerves, mucous membranes of the upper respiratory tract, and eyes. If untreated, it can lead to disabilities in a small percentage of patients. Visible deformities are a major contributor to stigma, significantly impacting health-seeking behaviour and social inclusion. Early detection and timely treatment with multidrug therapy (MDT) play a crucial role in

reducing the burden of leprosy.¹ Disability refers to any impairment, activity limitation, or restriction in participation. In leprosy, physical disability is classified by the WHO into three grades: Grade 0 indicates no disability, Grade 1 reflects sensory loss without visible deformities, and Grade 2 involves visible deformities or damage to the eyes, hands, or feet.²

According to WHO Weekly epidemiological record 2023 data, 184 countries, territories, and areas reported 182,815 new leprosy cases, with females accounting for 72,845 (39.8%) and children for 10,322 (5.6%). Globally, 9,729 new cases presented with grade-2 disabilities (G2D),

including 266 cases (2.7%) among children. The majority of countries with high new case detection rates are located in the WHO African and South-East Asia regions.³ In India, as of 2023, the registered prevalence rate of leprosy was 59.691 per million population, with the highest global number of new cases at 107,851, with an ANCDR of 7.55 per 100,000, including 2,335 cases of G2D and 43 G2D cases among children under 15 years of age. The number of districts with a prevalence rate below 1 per 10,000 population increased from 542 (2014-15) to 634 (2023-24). The Prevalence Rate declined from 0.69 to 0.60.^{1,4,5}

Leprosy-related disabilities are stigmatized, affecting social and psychological well-being. They limit activities and social participation, while also impacting occupations and economic status, leading to debilitation, which further reduces quality of life, attitudes, and actions.⁶ Reconstructive surgery (RCS) restores functionality and appearance, helping individuals overcome stigma and regain dignity. Pre- and post-operative physiotherapy are essential for ensuring optimal recovery and long-term success. Early correction of deformities supports leprosy control strategies by demonstrating that disabilities can be treated.⁷⁻⁹

Leprosy-related disabilities continue to affect individuals even after treatment, limiting their social participation and employment opportunities.^{2,10,11} RCS can help restore functionality and improve the quality of life by addressing these physical impairments.¹²

Assessing the occupational impact of RCS on disabled leprosy patients is essential for understanding how such interventions influence their capacity to work and sustain livelihoods. Employment is a key factor in determining an individual's self-esteem, financial independence, and social acceptance. For disabled leprosy patients, returning to or improving their employment status post-surgery can represent a significant step toward reducing the stigma associated with the disease, achieving economic stability, and improving their overall quality of life.

This study aims to explore how RCS impacts the occupational reintegration of leprosy patients with disabilities in Hyderabad, Telangana, an area that has long struggled with the burden of leprosy. By understanding these effects, we can identify areas where further support may be needed and inform strategies for improving the socio-economic rehabilitation of leprosy patients.

METHODS

This study assessed the impact of RCS on the lives of individuals with leprosy-related disabilities, with a specific focus on occupational outcomes. A descriptive cross-sectional study was conducted at the Shivananda Rehabilitation Home (SRH), a non-governmental organization based in Hyderabad, Telangana, from

September 2023 to March 2024.¹³ The study included 120 individuals aged 18 years and above, affected by leprosy and having undergone RCS within the past 10 years. Participants were selected based on having completed the post-operative period, leading normal lives at home at least one month at home and attending check-ups and physiotherapy at SRH. Individuals who were bedridden, without any disabilities, or diagnosed with mental disorders or hearing loss were excluded from the study.

Data were collected through direct interviews conducted by the investigator using a structured questionnaire. The questionnaire included sociodemographic details, type of surgery, duration since surgery, occupation before and after surgery, and the occupational impact of RCS. The occupational impact section was adapted from the Swedish self-reported satisfaction questionnaire used in a study evaluating satisfaction with upper limb RCS in individuals with tetraplegia.¹² The activities and occupation components were selected from the questionnaire to assess the surgery's impact. The questionnaire employed a Likert scale, ranging from 'strongly agree' to 'strongly disagree' to evaluate activities and occupational functionality.

Ethical clearance was obtained from the Institutional Ethical Committee (IEC) of the University of Hyderabad (IEC number UH/IEC/2023/580), and permission to conduct the study was granted by SRH. The study purpose was explained to participants in their native language, and written informed consent was obtained. Interviews were conducted at SRH. residences based on their availability. Data were collected through a structured questionnaire administered to all participants. The questionnaire included information related to demographic and clinical characteristics, as well as the occupational impact of RCS. Data were entered and analyzed using Microsoft Excel. Descriptive statistics were presented using graphical representations, including bar charts and pie charts. All data were stored securely with access limited to the research team. No statistical tests were performed in this study. All findings were visually depicted to highlight trends and relationships in the collected data.

RESULTS

The study included 120 participants, with 75% (90) male and 25% (30) female, predominantly aged between 21-30 years (46.67%, 56), followed by those aged 31-40 years (26.67%, 32) and above 40 years (18.33%, 22), with a mean age of 31.38±8.52 years. Regarding residence, 53.33% (64) lived in urban areas, while 46.67% (56) were from rural backgrounds. Education levels varied, with 14.17% (17) of participants being illiterate, 27.50% (33) having completed secondary school, and 22.50% (27) being graduates. Employment-wise, 28.33% (34) worked full-time, 5.83% (7) part-time, 25.00% (30) were self-employed, and 40.83% (49) were unemployed. Most participants (82.50%, 99) came from nuclear families,

with the rest (17.50%, 21) belonging to joint families. In terms of marital status, 58.33% (70) were married, 39.17% (47) single, and the remainder were either divorced (2) or widowed (1). Income distribution showed that 45.00% (54) earned less than 5,000 INR per month, with smaller percentages in higher income brackets. As for the type of surgery received, 50.8% (61) underwent right hand surgery, and other common procedures included left hand (27.5%, 33) and right foot surgeries

(8.3%, 10). Post-surgery, six surgeries addressed both left and right hands, while foot surgeries included 10 on the right foot and 6 on the left. Only one case had both hand and foot surgery. Lagophthalmos surgeries were with just 2 procedures. Post-surgery, 84 (69.9%) had undergone the procedure more than one year ago, and 9.1% (11) had surgery within the last six months. The demographic characteristics are provided to contextualize the present study findings in Table 1.

Table 1: Socio-demographic characteristics of participants.

Variable	Number (%)
Sex	
Male	90 (75)
Female	30 (25)
Age group (in years)	
18-20	10 (8.33)
21-30	56 (46.67)
31-40	32 (26.67)
Above 40	22 (18.33)
Mean±SD	31.38±8.52
Type of residence	
Rural	56 (46.67)
Urban	64 (53.33)
Education level	
Illiterate	17 (14.17)
Pre-school education	1 (0.83)
Primary school (1-5)	13 (10.83)
Secondary school (6-10)	33 (27.50)
Intermediate	26 (21.67)
Graduate	27 (22.50)
Above graduate	3 (2.50)
Employment	
Full-time work	54 (45.00)
Part-time work	7 (5.83)
Self-employed	30 (25.00)
Unemployed	29 (24.17)
Type of family	
Joint family	21 (17.50)
Nuclear family	99 (82.50)
Marital status	
Single	47 (39.17)
Married	70 (58.33)
Divorced	2 (1.67)
Widowed	1 (0.83)
Income per month	
Below 5,000	54 (45.00)
6,000-10,000	25 (20.83)
11,000-15,000	16 (13.33)
16,000-20,000	11 (9.17)
Above 20,000	14 (11.67)
No. of children	
0	10 (8.33)
1	17 (14.17)
2	35 (29.17)
>2	11 (9.17)

Continued.

Variable	Number (%)
Not applicable	47 (39.17)
Type of surgery	
Right hand surgery	31 (50.8)
Left hand surgery	33 (5)
Right- and left-hand surgery	5 (6.5)
Right foot surgery	10 (8.3)
Left foot surgery	6 (5)
Right and left foot surgery	1 (0.8)
Hand and foot surgery	1 (0.8)
Laparolithotomy	2 (1.6)
Post RCS duration	
<6 months	11 (9.1)
>6 months-1 year	25 (20.8)
>1 year-4 years	64 (53.3)
>4 years	20 (16.6)

Impact on activities and occupational outcomes

The effect of RCS on participants activities and occupational outcomes is depicted in Figure 1. Regarding the ability to perform more activities after surgery, 83 participants were agreed that they can perform more activities, while 12 disagreed. Similarly, 83 participants were agreed that activities were easier to perform, 25 were neutral and 5 were disagreed. Regarding performance in faster activities 78 participants were agreed that they can perform activities faster, 30 were neutral and 7 disagreed. In terms of function independence, 41 participants were strongly agreed, 55 agreed, 18 were neutral, 3 disagreed, and 3 strongly disagreed that they were able to function more independently. As for requiring less assistance from others, 35 strongly were agreed, 68 agreed, 11 were neutral, 4 disagreed, and 2 strongly disagreed.

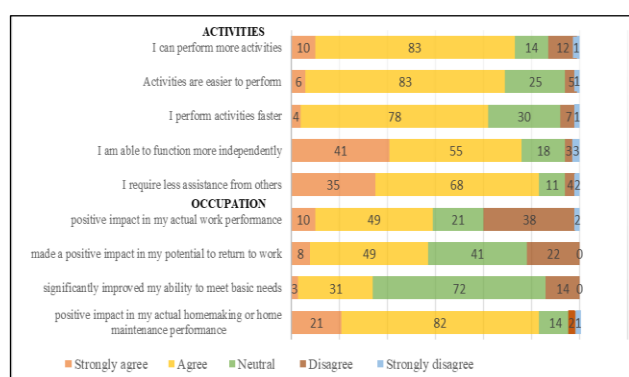


Figure 1: Impact of RCS on activities and occupation.

Regarding the positive impact on actual work performance, 49 participants were agreed, 21 were neutral and 38 were disagreed. On the potential to return to work, 8 strongly agreed, 49 agreed, 41 were neutral and 22 were disagreed. When asked about the improvement in meeting basic needs, 3 participants strongly agreed, 31 agreed, 72

were neutral and 14 were disagreed. Regarding the positive impact on homemaking or home maintenance performance, 21 participants were strongly agreed, 82 were agreed, 14 were neutral and 2 were disagreed.

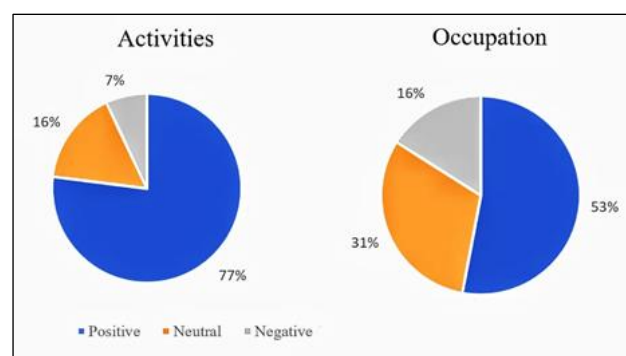


Figure 2: Overall impact of RCS on activities and occupation.

The results from Figure 2 demonstrate overall impact of RCS, that the majority of participants were experienced a positive effect of RCS on their activities and occupation, although a notable proportion remained neutral or perceived a negative impact in some areas. With respect to activities, 77% of participants felt that RCS had a positive impact on their ability to perform activities, 16% were neutral, and 7% felt that the impact was negative. Similarly, for occupation, 53% of participants were reported a positive impact of RCS on their occupational performance, 31% were neutral, and 16% felt that the impact was negative.

After RCS, 19.1% (23) of participants were changed their occupation, while 42.5% (51) continued in their previous occupation. Additionally, after RCS, 32.5% (39) of participants were unemployed while 5.8% (7) were employed for the first time (Figure 3). These findings

highlight that a portion of individuals were experienced a change in their occupation post-surgery, while many remained in their prior roles, with a significant proportion still facing unemployment.

A comparison of participants' occupations before and after RCS revealed some shifts in employment patterns. Before RCS, 14% (17) of participants were engaged in agriculture, 3% (4) in business, 6% (7) in construction work, 10% (12) as daily wage workers, 22% (26) held jobs, 21% (25) were self-employed, and 24% (29) were unemployed.

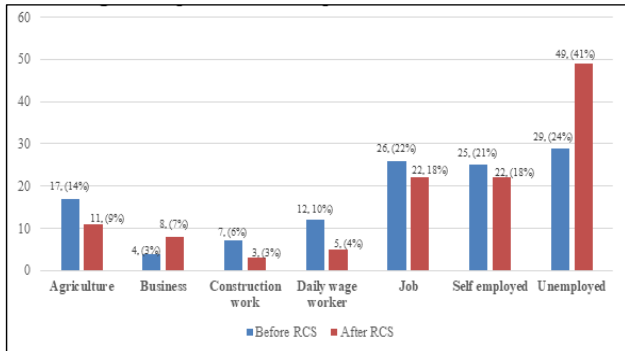


Figure 3: Comparison of occupation before and after RCS.

After RCS, there was a decrease in the percentage of individuals working in agriculture (9%, 11), construction work (3%, 3), daily wage work (4%, 5), and self-employment (18%, 22). The percentage of individuals engaged in business increased to 7% (8), and the proportion of participants employed in jobs decreased slightly to 18% (22). Notably, the percentage of unemployed participants rose to 41% (49) after RCS.

These findings suggest that while some individuals transitioned into different occupations, a significant proportion experienced a shift towards unemployment after undergoing RCS, indicating potential challenges in reintegration into the workforce.

The reasons for changes in occupation among the participants were diverse, with the most common being pain, which was reported by 73% of the individuals as a primary factor for altering their work activities. Personal issues followed as a significant reason, cited by 13% of the participants. Appearance was a contributing factor for 4%, likely due to the physical deformities associated with leprosy-related disabilities. Fear of ulcers was reported by 6% of participants as a concern influencing their decision to change occupations, while 4% of the participants indicated that the change in occupation was due to the doctor's suggestion as part of their rehabilitation and recovery plan. These findings highlight the complex interplay of physical, psychological, and medical factors in shaping the occupational lives of individuals following RCS for leprosy.

DISCUSSION

The responses to the questions related to activities and occupation, post-reconstructive surgery show notable improvements in functionality and occupational outcomes among the participants. These results indicate that RCS has had a positive influence on the participants' ability to perform daily activities and significantly impacted their occupational performance. However, the responses related to the potential for returning to work and meeting basic needs varied, suggesting a more complex impact in these areas.

The findings of this study on the impact of RCS among leprosy patients are comparable to the results of several studies that have explored similar findings, although there are some variations in the outcomes. A study by Bhatt et al found that hand deformities were the most common in leprosy, with 30.7% claw hand cases and 6.9% ulnar nerve abscesses, indicating the impact on the ulnar nerve. This aligns with our study, where most surgeries addressed hand deformities, highlighting the need for early intervention and RCS.¹⁴

A study conducted by Lenka et al, reported that only 33.3% of patients changed their profession to avoid further risk after surgery.¹⁵ This finding highlight that RCS patients opted for a career change following post-surgery, possibly due to the recognition of limitations imposed by their disability or a desire to prevent further health risks. In our study, we found that 19.1% of participants had changed their occupation after surgery. This could suggest that individuals continued in their previous professions, perhaps due to fewer perceived risks or better post-surgical adaptation.

A study by Roy et al highlighted that tendon transfer surgery significantly reduced levels of activity and participation restrictions among leprosy patients.¹⁰ This study aligns with our findings that RCS led to improvements in the ability to perform daily activities, with 77% of participants reporting positive impacts on their ability to perform activities. However, it is important to note that while tendon transfer surgery focuses on specific functional improvements, our study looked at a broader range of reconstructive procedures, which may account for the differences in the nature of the improvements observed.

A study by Shrivastava et al found that RCS had a transformative impact on leprosy patients, restoring lost functionality and mobility while improving psychological well-being.⁸ This aligns with our study, where a significant number of participants reported improvements in their independence and reduced need for assistance after surgery. However, in contrast to Shrivastava's findings, our study observed a substantial increase in unemployment post-surgery, with 41% of participants being unemployed after RCS. This suggests that while physical improvements were achieved, the ability to

reintegrate into the workforce may still be challenging for some patients, potentially due to factors such as stigma, lack of skills, or limited opportunities in the job market. Similar to the findings of Lenka et al where 90% of patients were satisfied with physical improvement, our study also observed a shift in occupational patterns post-RCS, indicating that surgery can contribute to improved performance in activities.

The overall outcome of the surgical correction of claw hand in leprosy patients, as reported by Ebenezer et al, was 76.6% good to excellent with 80.8% of patients reporting satisfaction which aligns with our study results 77% of participants felt that RCS had a positive impact on their ability to perform activities.¹⁶ The functional improvement, as reported by Nardi et al, leads to a shift in occupation from high-risk activities to low-risk occupations.¹⁷ Our study reflects this as well, with a decrease in occupations like agriculture, construction, and daily wage work post-surgery, suggesting that RCS may encourage patients to seek less physically demanding and less risk working environments. However, while functional and occupational improvements post-surgery are evident, the persistence of a high unemployment rate (41%) post-RCS in our study reflects the ongoing challenge leprosy patients face in reintegration into the workforce. This suggests that while RCS addresses physical disabilities, additional measures are needed to support social and occupational reintegration.

While our study found a positive impact on daily activities and occupation, it also revealed that a considerable portion of participants continued to face challenges in finding or maintaining employment after RCS. These challenges could be related to factors like grade of disability, type of surgery, socio-economic factors, limited access to resources, lack of vocational training, or societal stigma. The post-surgical period might also require better rehabilitation and reintegration strategies to enhance the ability of leprosy patients to engage fully in the workforce and society. A key limitation of this study is the lack of pre-surgery data, which could have provided a more comprehensive understanding of the changes in occupational status and functionality before and after RCS. As study mainly relied on descriptive analysis without any statistical test limit the assessment of statistical significance. Additionally, the study relies on self-reported data, which may be subjected to recall bias.

CONCLUSION

In conclusion, the study highlights the positive impact of RCS on the ability of leprosy patients to perform daily activities and enhances their independence. However, challenges remain in terms of occupational reintegration and employment, with a significant proportion of participants facing unemployment after surgery. The findings of this study align with previous research, suggesting that while RCS restores functionality and

improves psychological well-being, there is a need for additional support in vocational rehabilitation and societal reintegration.

Recommendations

Vocational training and rehabilitation programs should be provided to help leprosy patients regain employment and support their socio-economic reintegration. Psychological counselling and support systems are essential to help patients cope with emotional and social challenges after surgery. Public awareness campaigns can reduce stigma and workplace discrimination, improving their chances of successful reintegration. Additionally, future studies should include pre-surgery data and long-term follow-up to assess the sustained impact of RCS on daily activities and employment.

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