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Original Article

Quality of Life Among Persons Affected by Deformities Due to Leprosy Who Underwent Reconstructive Surgery in Hyderabad, Telangana, India

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Leprosy is a chronic neglected tropical disease (NTD) that in a proportion of cases leads to physical disabilities and social stigma, significantly impacting the quality of life (QoL) of those affected. Reconstructive surgery (RCS) is an effective intervention aimed at correcting these disabilities, improving physical functioning, and enhancing social reintegration. This study assesses the quality of life among persons affected by deformities due to leprosy who underwent RCS, focusing on their overall well-being post-surgery. This descriptive cross-sectional study was conducted among 120 individuals who underwent RCS at Shivananda Rehabilitation Home, Hyderabad, Telangana, using a convenience sampling method. The World Health Organization's WHOBREF questionnaire was utilized to assess quality of life across four domains: physical, psychological, social, and environmental. Of the 120 participants, 90 were males and 30 females. The physical domain recorded the highest mean score of 69.68±11.02, while the psychological domain had the lowest mean score of 56.90±11.06. The social and environmental domains had mean scores of 64.72±12.30 and 64.29±7.33, respectively. Significant associations were found between the QOL domains and factors such as age, education, residence, employment, number of children, personal income, and time since RCS. The study reveals that reconstructive surgery has a positive impact on the quality of life of among persons affected by deformities due to leprosy, particularly in physical, social, and environmental domains. Continuous efforts to raise awareness about the benefits of RCS can further help individuals affected by leprosy-related disabilities lead more fulfilling lives, reducing stigma and enhancing their societal participation.

Keywords: Leprosy, Hansen's Disease, Quality of Life, Disability and Reconstructive Surgery, Telangana, India

Introduction

Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by *Mycobacterium leprae* (WHO Data, n.d.). The WHO reports that in 2015, there were 2,11,973 new cases of leprosy from 106 different countries. India, Brazil, and Indonesia have a higher incidence of leprosy (Eyanoer 2018). Although curable, the disease can lead to long-term physical disability if not treated early, as it primarily affects the skin, peripheral nerves, and mucosal surfaces. Globally, 9,554 new cases with grade-2 disability (G2D) were identified of which 278 (3%) were in children. Most countries with high rates of new cases are in the WHO regions of Africa and southeast Asia. According to WHO data from 2022, India has the highest number of new leprosy cases in the world, at 1,03,819 and

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number of new G2D leprosy cases with 2,363 reported in 2022 (WHO Disability Data, n.d.). For many patients, the resulting deformities and disabilities can severely impact their quality of life (QoL), especially in social, psychological, and functional aspects.

Over the past few decades, efforts to control leprosy have led to a significant decline in its incidence globally. However, the stigma associated with leprosy remains a challenge, particularly in developing countries where individuals often face discrimination and social isolation. This not only affects their self-esteem but also limits their participation in daily activities, leading to a lower QoL.

In response to the debilitating effects of leprosy-related deformities, reconstructive surgery (RCS) has been introduced as a key intervention. The aim of RCS is to restore function and improve the appearance of physical deformities, particularly those affecting the hands, feet, and eyes (NLEP, n.d.). This surgical approach not only has physical benefits but also plays a vital role in improving patients' psychosocial well-being and reintegration into society. Quality of life assessments have become an essential part of evaluating the success of reconstructive surgeries in leprosy patients (John et al 2005). QoL is a multidimensional concept that includes physical health, psychological state, social relationships, and the environment in which people live (WHO QOL, n.d.). Research on QoL post-RCS for leprosy patients can provide valuable insights into how surgery impacts various aspects of their lives beyond physical recovery.

The objective of this study is to assess the quality of life among persons affected by deformities due to leprosy who underwent RCS, focusing on their overall well-being post-surgery. By assessing the QoL post-surgery, this study aims to understand the broader effects of surgical interventions and highlight the importance of continued support for patients in their post-operative rehabilitation and social reintegration.

Materials and Methods

This descriptive cross-sectional study was conducted among persons affected by deformities due to leprosy aged above 18 years who had underwent RCS from September 2023 to March 2024 at Shivananda Rehabilitation Home, Hyderabad. The sample size calculated was 120 by taking the prevalence as 50% using a formula, $n= 4pq/l^2$. The study included person affected by deformities due to leprosy aged above 18 years who had underwent RCS, post RCS duration below 10 years and persons who are willing to participate in the study. People who are bedridden, without disabilities and suffering from mental disorders, hearing loss were excluded from the study. Ethical Clearance was obtained from Institutional Ethics Committee (IEC) from University of Hyderabad under IEC number (UH/IEC/2023/580). Permission to conduct the study was obtained from Shivananda Rehabilitation Home, a Non-Governmental Organisation located in Hyderabad, Telangana. It operates nation-wide. Written Informed consent was obtained from each participant after explaining the study's purpose.

Quantitative method with convenience sampling technique was used for data collection. A semi structured questionnaire was used to collect the socio demographic data and WHO BREF Questionnaire was used to assess the quality of life (WHO QoL). It comprises of 26 questions on the individual's views on health and well-being which includes physical, psychological, social and environmental domains. The responses were assigned scores ranging from 1 to 5 points.

Data Analysis

Microsoft Excel was used for the analysis. Anova was used to determine the association between

socio demographic variables and quality of life domains. A p value of *P*< 0.05 was considered statistically significant at 95% confidence interval.

Results

Data collected from 120 participants is presented in Tables 1-3.

Table 1 summarises the data about socio-demographic characteristics. The study sample consisted of 120 participants, with 90 (75%) being male and 30 (25%) females. This result stated that leprosy was more frequent in males than females and similar to other study findings. The majority of participants were aged between 21-30 years (46.67%), with a mean age of 31.38 ± 8.52 years. Regarding their residence, 64 (53.33%) were from urban areas, while 56 (46.67%) were from rural areas. In terms of education, 33 (27.50%) had completed secondary school, while 30 (25%) were graduates and above, and 17 (14.17%) were illiterate. Employment status showed that 49 (40.83%) were unemployed, and 34 (28.33%) were engaged in full-time work. Most participants belonged to nuclear families (82.50%), and 70 (58.33%) were married. Regarding personal

Table 1: Socio demographic characteristics of participants.

Variable	n (%)
Gender	Male = 90 (75%)
	Female = 30 (25%)
Age	18-20 = 10 (8.3%)
	21-30 = 56 (46.6%)
	31-40 = 32 (26.6%)
	Above 40 = 22 (18.3%)
	Mean = 31.38 ± 8.52
Residence	Rural = 56(46.6%)
	Urban = 64 (53.3%)
Level of education	Illiterate = 17 (14.1%)
	Pre-school education (early education /Anganwadi) = 1 (0.8%)
	Primary school (1-5) = 13 (10.8%)
	Secondary school (6-10) = 33 (27.5%)
	Intermediate (10+2) = 26 (21.6%)
	Graduate and Above (undergraduate and PG, PhD) = 30 (25%)
Employment status	Full-time work = 34 (28.3%)
	Part-time work = 7 (5.8%)
	Self-employed = 30 (25%)
	Unemployed = 49 (40.8%)
Type of family	Joint family = 21 (17.5%)
	Nuclear family = 99 (82.5%)
Marital status	Single = 47 (39.1%)

	Married = 70 (58.3%)
	Divorced = 2 (1.6%)
	Widowed = 1 (0.8%)
Personal Income	Below 5,000/ month = 54 (45%)
	6,000 – 10,000/ month = 25 (20.8%)
	11,000 – 15,000/ month = 16 (13.3%)
	16,000 – 20,000/ month = 11 (9.1%)
	Above 20,000/month = 14 (11.6%)
No. of children	0 = 10 (8.3%)
	1 = 17 (14.1%)
	2 = 35 (29.1%)
	>2 = 11 (9.1%)
	Not applicable = 47 (39.1%)
Type of surgery	Right hand surgery = 61 (50.8%)
	Left hand surgery = 33 (27.5%)
	Right- and left-hand surgery = 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%)
	Lagophthalmos = 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%)

Table 2: Quality of Life among study participants according to WHO BREF quality of life domains.

Variables	**Quality of life among persons affected by deformities due to leprosy who underwent RCS**
Quality of life domains	**Domain wise mean ± SD**
Physical Domain	69.68±11.02
Psychological Domain	56.90±11.06
Social Domain	64.72±12.30
Environmental Domain	64.29±7.33

Table 3: Association between socio demographic variables and quality of life domains.

Variable	Mean ± SD			
Category	**Physical**	**Psychological**	**Social**	**Environmental**
Age				
18-20 years	75±6.7	55±8.9	68.3±9.4	65.3±6.9
21-30 years	69.5±11.1	55.7±10.9	63.6±12.7	64.5±7.5
31-40 years	69.4±10.3	58.9±10.9	66.6±13.2	63.5±7.7
Above 40 years	67.2±12.3	57.7±12.6	62.8±10.8	64.3±6.7
P value	**0.001***	0.06	**0.02***	**0.02***
Gender				
Male	69.4±11.2	56.5±11.2	64.2±12.2	64.3±7.1
Female	69.7±9.9	58±10.4	66.1±12.5	64.2±8.1
P value	0.14	0.28	0.26	0.26
Education				
Illiterate	63.2±12.9	52.6±12.4	59.3±12.1	59.7±7.5
Pre-school	60.7	58.3	66.6	56.2
Primary	63.4±13.6	56.0±12.4	59.6±12.1	60.3±7.1
Secondary	69.0±10.6	56.0±11.3	62.3±11.6	64.3±5.5
Intermediate	73.9±6.9	60.2±8.9	65.7±12.0	65.5±6.4
Graduate& above	72.7±9.1	56.9±11.0	64.7±12.3	64.2±7.3
P value	**0.002***	**0.01***	**0.003***	**0.009***
Residence				
Rural	68.3±11.5	54.6±11.3	63.5±12.8	63.1±7.4
Urban	70.5±10.3	58.9±10.4	65.7±11.7	65.3±7.1
P value	**0.002***	**0.01***	**<0.001***	**0.004***
Employment				
Full time	71.2±9.9	59.0±10.5	66.6±13.9	66.1±6.9
Part time	67.3±8.8	54.1±6.3	55.9±10.4	61.1±5.9
Self employed	69.8±11.6	58.6±12.1	65.2±11.8	63.7±6.6
Unemployed	68.4±11.5	54.7±11.0	64.2±11.4	63.7±8.0
P value	**0.002***	0.05	**0.01***	**0.02***
Type of family				
Nuclear	70.0±10.9	56.9±11.3	63.9±11.7	64.0±6.9
Joint	67.1±10.6	56.5±9.9	68.2±14.5	65.3±9.1
P value	0.29	0.46	0.41	0.40
Marital status				
Single	72.4±8.7	55.8±8.3	64.7±14.4	65.4±6.6
Married	68.1±11.7	58.2±12.3	65.5±9.9	63.8±7.4
Divorced	57.1±10.1	41.6±5.8	50±11.7	60.9±11.0
Widowed	57.1	41.6	33.3	46.8
P value	0.15	0.31	0.33	0.24

No: of children				
0	66.7±13.9	52.9±13.1	63.3±12.5	61.8±7.6
1	70.5±9.6	58.8±11.3	68.6±10.4	64.7±8.6
2	66.8±13.1	58.3±12.9	64.5±8.8	63.0±7.4
>2	66.5±8.6	57.5±13.0	60.6±14.4	64.7±7.4
NA	72.4±8.7	55.8±8.3	64.7±14.4	65.4±6.6
P value	**0.003***	0.07	**0.01***	**0.02***
Personal income				
Below 5,000	66.8±10.1	54.5±11.3	62.9±11.2	63.0±7.9
6,000-10,000	69.1±10.1	53.3±10.4	64±12.6	62.2±6.0
11,000-15,000	68.9±12.8	58.5±6.8	60.4±13.7	66.2±4.8
16,000-20,000	73.7±13.1	63.2±9.8	71.2±7.7	64.4±6.7
Above 20,000	77.8±6.2	65.4±9.9	72.6±12.8	70.3±6.6
P value	**0.01***	0.05	**0.01***	**0.02***
Change in Occupation				
Yes	73.9±9.4	60.3±10.1	65.1±11.3	66.5±7.7
No	71.0±8.0	59.1±9.5	68.4±12.8	65.6±6.9
Employed	69.8±18.6	52.3±13.7	58.3±4.8	60.2±6.6
Unemployed	63.7±11.7	51.9±11.5	60.2±11.6	61.3±7.7
P value	**0.03***	0.05	**0.03***	**0.04***
Post RCS Duration				
<6 months	66.8±14.2	48.1±9.9	60.6±13.4	63.9±11.1
6 months-1 year	70.7±9.3	55.5±10.2	66.3±15.1	66.2±8.2
>1 year-4 years	70.0±10.5	58.3±11.9	63.9±11.6	64.1±6.7
>4 years	67.6±12.3	58.9±7.1	67.5±9.7	62.6±5.3
P value	**0.03***	0.09	0.07	0.09
Type of surgery				
Right hand	70.7±12.0	56.7±12.0	66.1±13.7	65.5±7.4
Left hand	67.9±10.9	56.0±9.0	64.3±11.2	63.1±7.3
Both hands	75±8.7	66.6±7.4	68.0±9.7	63.0±2.3
Right foot	66.7±5.0	55.8±8.8	58.3±8.7	64.3±7.6
Left foot	72.0±3.5	61.8±13.2	63.8±8.6	65.1±6.6
Both foot	60.7	45.8	50	59.3
Hand and foot	57.1	41.6	50	50
lagophthalmos	58.9±2.5	50±11.7	66.6	54.6±2.2
P value	**0.04***	0.18	0.12	0.20

*Statistical significance at $P < 0.05$

income, 54 (45%) earned below 5,000 INR per month, and 25 (20.83%) earned between 6,000 and 10,000 INR monthly.

The number of children varied, with 35 (29.17%) having two children, while 47 (39.17%) were not applicable. Participants underwent different types of reconstructive surgeries, with right-hand surgery being the most common (50.8%), followed by left-hand surgery (27.5%). The post-surgery duration showed that 64 (53.3%) had undergone surgery more than one year but less than four years prior, and 25 (20.8%) had surgery between six months and one year earlier.

Table 2 shows that physical domain has the highest mean score i.e. 69.68±11.02 and the psychological domain has the lowest mean score i.e. 56.90±11.06. social domain score is 64.72±12.30 and environmental domain score is 64.29±7.33.

Table 3 shows the association between the socio-demographic profile and quality of life domains. The comparison of the four quality of life domains physical, psychological, social, and environmental across various age groups showed significant variation in the physical, social, and environmental domains, with the physical domain showing the highest significance (P=0.001), indicating that age has a strong effect on physical health outcomes post-reconstructive surgery. The mean QoL scores of the physical and psychological domains were lower in females compared to males, but this difference was not statistically significant. The mean QoL scores of social and environmental domains were also less among females, but it was not statistically significant across these domains (P>0.05).

Education level had a significant impact on all domains, particularly the physical (P=0.002) and social (P=0.003) domains. Residence also played a significant role, with urban participants scoring higher across all domains, especially in the psychological (P=0.01) and social (P<0.001) domains. Employment status significantly affected the physical (P=0.002) and social (P=0.01) domains, with full-time workers reporting better outcomes than those unemployed. Family type did not show a statistically significant difference in any domain (P>0.05).

Marital status was also not significant (P>0.05) in any domain. The number of children had a significant impact on physical (P=0.003) and social (P=0.01) domains, with those having more children reporting better social support. Personal income had a significant influence across domains, particularly the physical (P=0.01) and social (P=0.01) domains, indicating higher income groups had better outcomes. Change in occupation after surgery significantly affected physical (P=0.03) and environmental (P=0.04) domains. The duration since surgery had a significant effect on the physical domain (P=0.03), with those in the 6 months to 1-year category reporting the best outcomes. Finally, the type of surgery showed significant differences only in the physical domain (P=0.04), with participants undergoing both hand surgeries reporting better physical health.

Discussion

Regarding age, the physical domain showed significant variation, with younger individuals (18-20 years) reporting better physical QOL compared to older age groups. These findings are consistent with a study by Dinesh et al which found that younger leprosy patients had better physical health outcomes post-RCS due to quicker recovery and less comorbidity (Dinesh et al 2016). A study conducted by Bhat et al (2024) reported that as age increases, quality of life decreases, a finding that closely aligns with the results of the present study.

Males had lower mean scores compared to females across all domains, though the

differences were not statistically significant in any domain; these findings are supported by a study conducted by Sinha et al., which demonstrated that the quality of life of males is greatly affected (Sinha et al 2023).

The quality-of-life scores were nearly the same for both illiterate and literate individuals, a finding supported by a study conducted by Govindharaj et al (2018). This is possibly due to similar living conditions and social support systems in old age homes, regardless of educational status (Govindharaj et al 2018). Employment status showed a significant impact across all the domains, with full-time workers reporting better outcomes. This is consistent with the study by Mathew et al which highlighted that stable employment effects the quality of life and psychological well-being (Mathew et al 2023).

The type of surgery performed significantly affected physical QOL, with patients undergoing hand surgeries reporting better physical outcomes. Similar results were observed by Palo et al who found that hand and foot surgeries are more commonly associated with better physical rehabilitation (Palo et al 2019).

Finally, the duration since surgery showed that patients between 6 months and 1-year post-RCS had the best physical outcomes, which is supported by Lenka et al. They emphasized that patients who had underwent RCS reported an improved quality of life compared to their experiences prior to the procedure (Lenka et al 2019).

A study which was conducted by (Pai et al 2022) revealed that psychological domain was having lowest mean score i.e. 61.28. Another study which was conducted by Tare et al revealed that psychological domain was having severe impact when compared to remaining domains similar to this study findings (Tare et al 2021).

In conclusion, the findings of our study broadly align with existing literature, emphasizing the multifactorial nature of QOL among leprosy patients post-RCS. Factors such as age, gender, education, and employment play critical roles in shaping recovery outcomes, with timely intervention and rehabilitation crucial for improving patients' physical and social reintegration. Future research should focus on long-term follow-up and addressing psychological disparities, especially among women, to further enhance the quality of life for leprosy patients.

Limitations:

As quality-of-life assessment may change over time of post-surgery this could influence the results, and longer-term follow up could provide a more comprehensive understanding. As this is not a comparative study, comparing the quality of life among persons affected by deformities due to leprosy who have undergone RCS with those who have not may provide valuable insights into the effectiveness and impact of surgery on patient's well-being. Also comparing quality of life before and after the surgery provides a direct assessment of the impact of Surgery on patient's well-being and functioning and psychological health.

Additionally, the absence of baseline Quality of Life (QoL) data before surgery limits the ability to conclusively determine the degree of improvement post-surgery. Future research should incorporate longitudinal designs to track QoL changes over time.

Conclusion

The quality-of-life people affected by leprosy was significantly impaired due to deformities. The findings of this study reveal that after undergoing RCS the quality of life among persons affected by deformities due to leprosy was good for majority of the participants under all domains. Half of

the participants were continuing in the same occupation after RCS. Ultimately, RCS not only improves physical functioning but also plays an important role in improving overall quality of life of persons affected by leprosy.

Recommendations

Considering the findings of this study which are also supported by several other reports discussed in this article, it is emphasized that advancement of RCS techniques and their access to needy persons is vital for enhancing occupational outcomes and quality of life of people affected by leprosy. Providing access to assistive devices and technologies can facilitate independence and participation in daily activities. Efforts should continue for establishment/ strengthening of specialized RCS centres within the Government Hospitals/ other health care facilities dedicated to leprosy care and rehabilitation.

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