

Navigating Limitations in Leprosy Care: The Interplay of Functional Impairment, Safety Awareness and Self-Esteem

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Abstract—Background And Need: Leprosy, a chronic infectious disease affecting the peripheral nerves, often leads to visible deformities like claw hands, foot ulcers, and finger loss causing not just functional disability but also social stigma and loss of self-esteem. These challenges severely restrict daily activities, participation, and overall quality of life. Unlike earlier studies limited to specific lesion and region, this study takes a holistic approach, assessing whole body deformities through questionnaires.

Objective:

1. To assess activity limitation by SALSA scale (screening activity limitation and safety awareness)
2. To assess participation by participation scale.
3. To assess overall self-esteem by Rosenberg self-esteem scale.

Methodology

This study assesses activity limitation, social participation, and self-esteem in leprosy patients using three scales: SALSA, screening activity limitation and safety awareness (vision, mobility, self-care, work, dexterity), participation scale (social roles, restrictions graded from 0-90), and Rosenberg self-esteem scale (personal satisfaction). Each question in all these scales consists of scores for analysis purpose which will help reflect the overall quality of life in patients with leprosy before and after the intervention.

Result: The analysis revealed a higher prevalence of functional limitation among leprosy patients. The SALSA scale had mean quantitative score of 41.08, participation score of 23.17, and Rosenberg self-esteem score of 13.26.

Conclusion: leprosy impacts patients physically and psychosocially, causing disability and stigma. These challenges reduce functional ability, self-esteem. By assessing these areas will help us understand their quality of life so that effective rehabilitation will address functional limitations and improve overall well-being of these individuals.

Index Terms—leprosy, deformities, functional limitation, self-esteem, social stigma, physiotherapy intervention

I. INTRODUCTION

Leprosy is a chronic infectious, granulomatous, slowly evolving disease with incubation period of 9-20 years caused by mycobacterium leprae that affects the peripheral nervous system, resulting neurological and dermatological abnormalities as well as sensory and motor impairments in eyes, hands and feet. Mycobacterium leprae the causative agent of leprosy, was discovered by G.H. Armauer Hansen in Norway in 1873¹. In 1981, there were 57.2 cases of leprosy per 10,000 people in India; by 2025, that number had dropped to just 0.57. This shows a 99% decrease in the prevalence rate and a 98% decrease in cases receiving treatment during a 44-year period. Since March 2006, when the yearly report revealed a prevalence rate of less than 1 per 10,000 (0.84), the number of new cases detected has decreased by 37. Drug therapy is effective in curing mycobacterial infections, but ineffective for treating nerve damage and disabilities which require rehabilitation. These disabilities cause functional capacity loss, which has an impact on self-esteem, social interactions and discrimination. These disabilities are caused when there is interaction of mycobacterium leprae with schwann cells that causes irreversible loss of peripheral nerve tissue followed disabilities^[2]. Conditions like partial claw hand, which is due to involvement of ulnar nerve, and when median nerve is involved along with ulnar nerve, the clawing becomes complete in all fingers i.e total claw hand. Also, wrist drop due to involvement of radial nerve, ape's thumb deformity due to , ape's thumb

deformity due to involvement of median nerve, foot drop due to involvement of peroneal nerve, hammer toe due to involvement of posterior tibial nerve, facial palsy due to facial nerve, trophic ulcers due to pressure bearing parts of foot that causes deformity. Leprosy hampers the freedoms and capabilities of individuals and affected communities and often excludes individuals from social life due to associated stigma ³.

Physical disabilities in leprosy is defined by WHO in 3 categories-

Grade 0-absence of disability and no visible damage or deformities on eyes, hands and feet

Grade 1- loss of protective sensibility in eyes, hands or feet, but no visible damage or deformities.

Grade 2- presence of deformities or visible damage to eyes (lagophthalmos), visible damage to hands and feet (ulceration claw etc) ⁴.

Mode of transmission: The route of transmission are still not entirely known although there is increased risk of infection due to close and prolonged contact with aerosols generated during coughing and sneezing from the affected person, also there is possibility of direct and indirect exposure from environment ^{3,5}.

Risk factors: leprosy infection is correlated with socio-economic conditions and poverty. Crowded settings, poor hygiene, increasing age, poor sanitation, low levels of education may cause increased chances of transmission ^{4,6,7,8}.

Signs and symptoms:

- Numbness in limbs (hands and feet)
- Loss of sensation in affected patch of skin
- Loss of eyebrows and eyelashes

Deformity in leprosy has been classified according to its pathogenesis as primary and secondary.

The disease process started by *Mycobacterium leprae* is directly responsible for primary deformity. The result of primary nerve injury is secondary deformity. A few of the abnormalities have many causes. Cosmetic deformities, such as elevated or hypopigmented patches, nodular infiltration mostly of the face and ears, and occasionally osteitis of the tiny bones of the hands and feet, are examples of primary deformities that arise during the active phase of the disease ⁹. Physical impairments in leprosy make day to day tasks challenging and impact their

social participation in society. Affected individuals may be devalued by their families and communities as a result of the illness, which can lead to psychological issues, stigma, discrimination, and social exclusion. This in turn affects the quality of life of these individuals.

II. MATERIALS AND METHODS

An observational study was conducted in a leprosy care center with 100 participants chosen by convenient sampling, including individuals with developed deformities, ulcers, and those who had undergone multidrug therapy treatment. Individuals with active infection and unwilling to participate in the study were excluded. Standardized measures were employed, including the SALSA scale (which has five domains linked to activity limitation), the participation scale (participation restriction), and the Rosenberg self-esteem scale (self-confidence in society). Each participant received previous knowledge about the research protocol and possible outcomes, and anonymity will be protected. Informed consent was obtained from each subject, and data was collected using questionnaires to assess functional limitations, participation restrictions, and diminished self-esteem.

Participants were about the purpose of the study and asked to provide written informed permission. These scales, which include a questionnaire that shows a person's impaired capacity to carry out everyday household or work-related tasks, will serve as the basis for data collection. This will have an impact on the person's social participation and lower self-esteem among leprosy patients. and Each scale includes questions about the self-perception, work-related participation, and the ability to complete tasks on one's own.

SALSA (screening activity limitation, safety awareness scale):it consist of five domains as

- a. vision -Has the patient any difficulty in vision
- b. Mobility-Does the patient face difficulty walking barefoot, walking longer distances, walking on uneven surfaces
- c. Self-care- Does the patient have any difficulty holding hot utensils, or is he aware about the hot and cold temperatures.
- d. Work-How patients deal with tools, opening and closing of bottle caps, overhead activities.

- e. Dexterity-Fine motor tasks like, manipulation of objects, needling, opening and closing of shirt buttons, and picking up things from floor

Participation scale: comprises questions about the patient's involvement in various aspects of society, such as jobs, household participation, and functions. The answers are scored as yes, no, sometimes, or irrelevant, and the results are based on grades of restriction: No significant restriction (0–12), mild restriction (13–22), moderate restriction (23–32), severe restriction (33–52), and extreme restriction (53–90).

Rosenberg self-esteem scale: This scale includes questions on the self, such as how satisfied the person is with themselves and whether they have a positive or negative attitude toward their surroundings. Strongly agree, agree, disagree, and strongly disagree will be used to score responses.

For analytical purposes, each of these scales' questions has a score. This was examined in leprosy patients who have suffered malformations after receiving multi-drug therapy. When these three scores are combined, it will be easier to see how they are generally constrained in their ability to participate in society and daily activities, as well as how these limitations impact their self-esteem and lower their quality of life.

This study examines the effects of reduced quality of life (dependent variable) and impaired functional activity and engagement (independent variable) on the self-esteem of leprosy patients in leprosy care centers. Functional limitation and participation were selected as independent variables because previous research has shown that deformities have an impact on an individual's participation in society due to impaired activity in society, which in turn affects the individuals' self-esteem and lowers their quality of life. Standardized evaluation instruments comprising patient-reported questions will be used to evaluate independent variables. The dependent variable will be evaluated using a scale that includes self-esteem-related questions, and every percentage will be impacted.

The constant variables in the study included the Patients who have undergone multidrug therapy treatment and individuals who are no longer active. The study was conducted in a single resource setting, the Leprosy Care Center. Control variables were taken into consideration to ensure that they do not

affect the dependent variables included in the study. All patients were asked to complete the same task to prevent bias. Age was one of the control variables because it provides precise data and can be compared with other groups. Additionally, it can help understand the relationship between age and level of physical activity.

Inferential statistics were used to examine the associations between the variables, whereas descriptive statistics, which include mean, standard deviation, and frequency distribution, were used to examine the variables. The association between the Rosenberg self-esteem scale, participation scale, and salsa scale was examined using Pearson's correlation coefficient. The analysis was conducted using SPSS 27.0, with a significance threshold of $p=0.05$.

III. RESULT

One hundred individuals between the ages of eighteen and eighty were selected from the Leprosy Care Center in Miraj. The age distribution showed that 2% of patients were between the ages of 18 and 20, 29% were between the ages of 21 and 40, 52% were between the ages of 41 and 60, and 17% were between the ages of 61 and 80.[table1,graph1]In that context, 81% of the participants were men and 19% were women [table 2,graph2].The SALSA scale indicated that 6% had no limitations, 30% had mild limitations, 50% had moderate limitations, and 14% had severe limitations. 41.08 ± 8.56 (18.58) is the mean $\pm$ SD [table3,graph3]. Participation scale distribution: 17% of people had no substantial constraints, 31% had mild restrictions, 38% had moderate restrictions, 13% had severe restrictions, and 1% had extreme restrictions Mean $\pm$ SD 23.17 ± 9.44 (2-56)[table4,graph4].Rosenberg self-esteem distribution revealed that 53% of people had poor self-esteem (0–15).46% of patients had normal values (15–25), and 1% had strong self-esteem (26–30) mean $\pm$ SD 13.26 ± 4.64 (2–26)[table5,graph5].Pearson's correlation coefficient indicates that the SALSA scale and participation scale have a strong positive connection (0.516, $p=0.0001$)[table6, graph6.1], whereas the participation scale and Rosenberg self-esteem scale have a significant negative correlation (-0.409, $p=0.0001$)[table6, graph 6.3].

IV. FIGURES AND TABLES

I. Distribution of patients according to age

2% of the patients were in the age group of less than 20 years, 29% in 21-40 years, 52% in 41-60 years and 17% of the patients were in the age group of 61-80 years. (Insert table 1 and graph 1 here)

Age Group(yrs)	No of patients	Percentage
≤20 yrs	2	2
21-40 yrs	29	29
41-60 yrs	52	52
61-80 yrs	17	17
Total	100	100
Mean±SD	48.60±13.90(18-80 yrs)	

II. Distribution Of Patients According To Gender

81% of patients were males and 19% of them were females. (Insert table 2 and graph 2 here)

Gender	No of patients	Percentage
Male	81	81
Female	19	19
Total	100	100

III. Distribution Of Patients According To Scale

30% of the patients had mild limitations, 50% had moderate and 14% of the patients had severe limitations of salsa scale.(Insert table 3 and graph 3 here)

Salsa Scale	No of patients	Percentage
No Limitation(0-24)	6	6
Mild Limitation(25-39)	30	30
Moderate Limitation(40-49)	50	50
Severe Limitation(50-59)	14	14
Total	100	100
Mean±SD	41.08±8.56(18-58)	

IV. Distribution Of Patients According To Pscale Scoring

31% of the patients had mild restrictions, 38% had moderate and 13% of the patients had severe

restrictions about p-scale.(Insert table 4 and graph 4 here)

p Scale	No of patients	Percentage
No significant restrictions(0-12)	17	17
Mild Restriction(13-22)	31	31
Moderate Restriction(23-32)	38	38
Severe Restriction(33-52)	13	13
Extreme Restriction(53-90)	1	1
Total	100	100
Mean±SD	23.17±9.44(2-56)	

V. Distribution Of Patients According To RSE Scale

53% of the patients had low self-esteem score, 46% had normal and only 1% of patients had high self-esteem score. (Insert table 5 and graph 5 here)

RSE Scale	No of patients	Percentage
Low Self Esteem(0-15)	53	53
Normal(Average, 15-25)	46	46
High Self Esteem(26-30)	1	1
Total	100	100
Mean±SD	13.26±4.64(2-26)	

VI. Correlation Between Salsa Scale,Pscale And RSE Scale Scoring

Pearson's Correlation Coefficient

By using Pearson's correlation coefficient significant positive correlation was found between Salsa scale and p-scale ($r=0.516$, $p=0.0001$), and significant negative correlation was found between Salsa scale and RSE Scale ($r=0.431$, $p=0.0001$) and between p-scale and RSE scale ($r=0.409$, $p=0.0001$). (Insert table 6 here)

Scale	Mean	Std. Deviation	N	Correlation		
				Salsa Vs p-scale	Salsa Vs RSE Scale	p-scale Vs RSE Scale
Salsa Scale	41.08	8.56	100	0.516 P=0.0001, S	-0.431 P=0.0001, S	-0.409 P=0.0001, S
p-Scale	23.17	9.44	100			
RSE Scale	13.26	4.64	100			

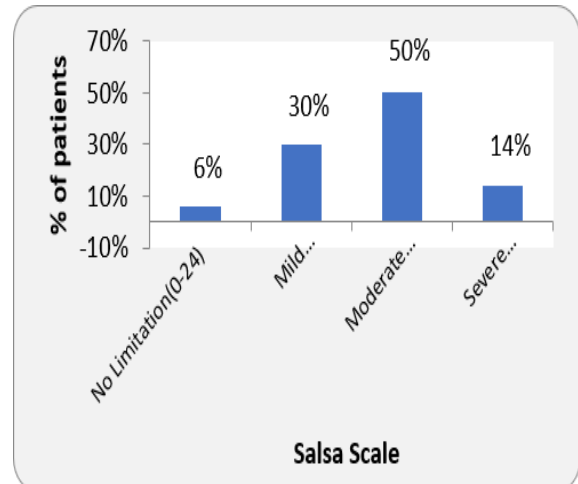


Figure 3- Distribution According To Salsa Scale

Graph

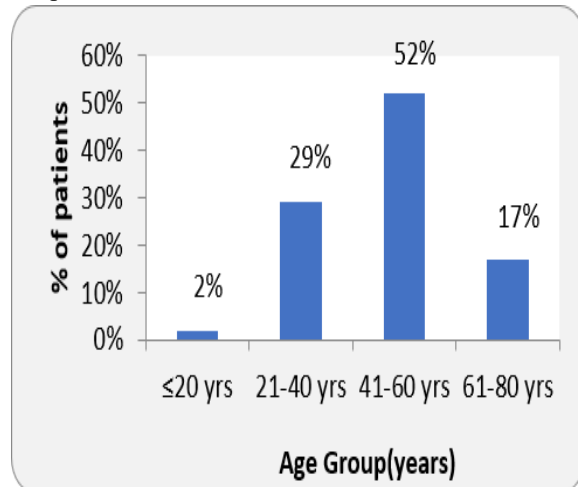


Figure 1- Distribution according to age

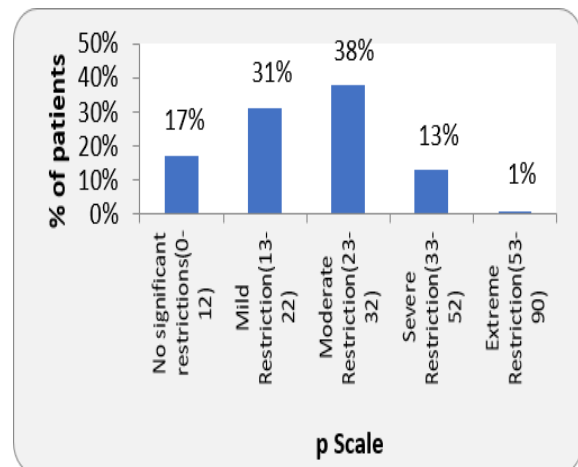


Figure 4- Distribution According To P-Scale

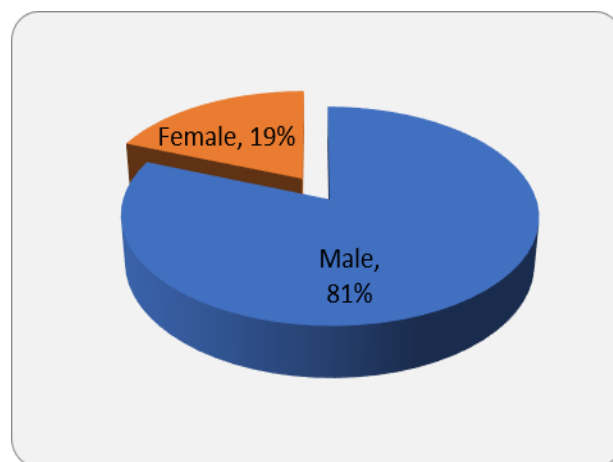


Figure 2- Distribution According To Gender

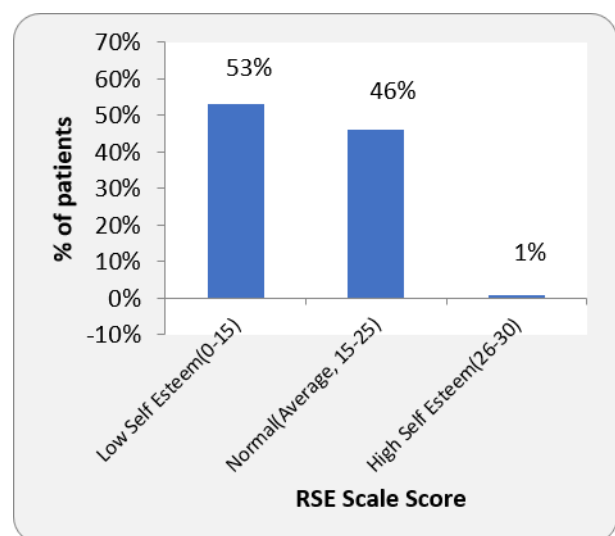


Figure 5- Distribution According To RSE Scale

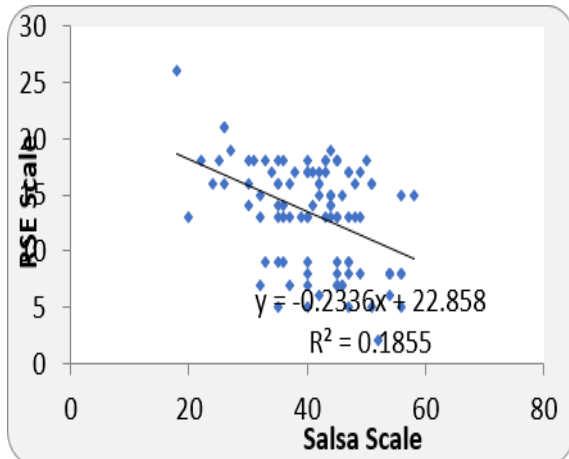


Figure 6- Correlation Between Salsa Scale And P-Scale

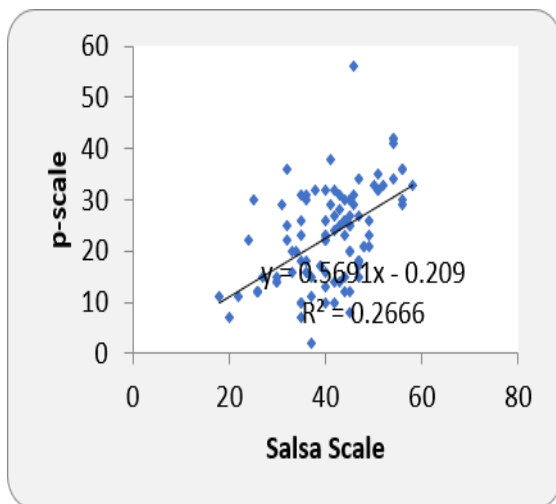


Figure 7- Correlation Between RSE Scale And Salsa Scale

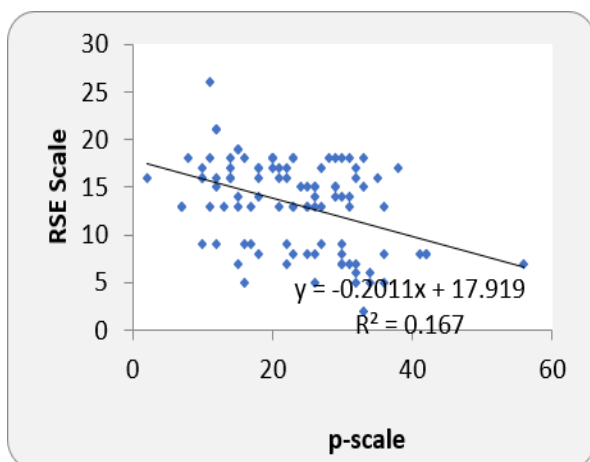


Figure 8- Correlation Between RSE Scale And P-Scale

V. CONCLUSION

Beyond its medical classification as an infectious disease, leprosy poses a significant social and psychological burden, significantly lowering the quality of life for people who are affected. People with severe disease symptoms face several challenges in their day-to-day lives, including physical limitations due to stiff joints, weak muscles, and impaired senses. The defects they develop lead to social stigma, which in turn causes discrimination and social isolation, which ultimately lowers their self-esteem. Due to misconceptions about the illness, these people frequently have little employment options. Fear and social labeling result from ignorance. This study shows how these malformations impact these people's social engagement and quality of life in terms of stigmatization and social isolation.

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