Activity Limitation of People Affected by Leprosy in an Endemic District in West Bengal, India

Pitchaimani Govindharaj[1*], Sampathkumar Srinivasan[2], Joydeepa Darlong[3]

1. Department of Allied Health Sciences, Sri Ramachandra Institute of Higher Education & Research (DU), Chennai, India
2. Department of Sociology and Population Studies, Bharathiar University, Coimbatore, Tamil Nadu, India
3. The Leprosy Mission Trust India, New Delhi, India

ABSTRACT

Purpose: *This study aimed to assess the level of activity limitation, and the factors associated with it, among people affected by leprosy who were reporting at a leprosy referral centre of Purulia, in West Bengal state, India.*

Method: *A cross-sectional study was conducted among 358 individuals affected by leprosy. Persons recruited for this study were above 18 years of age, married, and had been diagnosed with leprosy for at least 1 year at the time of the interview. A semi-structured questionnaire was used to gather information about the respondents' socio-economic and disease status. The Screening of Activity Limitation and Safety Awareness (SALSA) Scale was used to measure activity limitation.*

Results: *Of the 358 respondents, 59% were male, 60% were between 18 and 45 years of age, and 42% were illiterate. About 144 or 40% of the respondents had Grade 2 disability and 60% had disease duration of more than 3 years. There were 229 individuals (64%) who had no limitation in activities, 103 (29%) had mild limitation and 26 (7%) had moderate to severe limitation in activities. There is a significant association between gender, age, occupation, physical disability and disease duration with activity limitation.*

Conclusion: *It appears that limitations in activities among persons affected by leprosy are associated with being a woman, a housewife, an aged person, and with longer disease duration. The physical disability was intrinsically associated with limitation in activities.*

Key words: *leprosy, activity limitation, disability, India*

* **Corresponding Author:** Pitchaimani Govindharaj, Lecturer in Sociology, Department of Allied Health Sciences, Sri Ramachandra Institute of Higher Education & Research (DU), Chennai, India. Email: pitchu_mani83@yahoo.com

INTRODUCTION

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* and it affects the skin and peripheral nervous system (World Health Organisation, 2010). Disabilities in leprosy are mainly due to damage to peripheral nerves (Britton and Lockwood, 2004; Vijayan and Wilder-Smith, 2016; Rathod et al, 2020). Nerve damage can occur as part of lepra reaction with signs of acute inflammation. Damage to the nerves results in impairment of sensory, motor and autonomic functions, leading to anaesthesia, paralysis of muscles in eyes and extremities, loss of sweating and fissures or cracks or ulcers over extremities. These impairments can worsen over time if they are not recognised and the necessary interventions taken (Darlong et al, 2017). Early detection and treatment of nerve function impairment would prevent the occurrence of disability (Nicholls et al, 2003; Van Veen et al, 2006; Van Brakel and Officer, 2008; Ramasamy et al, 2019).

Several dimensions of disability are recognised in the International Classification of Functioning, Disability and Health (ICF), namely, body structure (impairment), activity (activity limitations) and participation (participation restrictions). Impairment is a problem in body function or structure (WHO, 2001). An activity limitation is a difficulty, encountered by an individual in executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations. The classification also recognises the role of physical and social environmental factors in affecting disability outcome (Van Brakel et al, 2012). Moreover, disabilities due to leprosy affect limitation in activities of an affected individual (De Souza et al, 2016).

Aim

Hence, this study aimed to assess the level of activity limitation and to study the factors associated with activity limitation of people affected by leprosy who were reporting at a leprosy referral centre of Purulia, in West Bengal state, India.

METHOD

Study Design

A cross-sectional descriptive study was conducted with 358 individuals affected by leprosy.

Study Setting

The participants were recruited from among those who attended the leprosy referral outpatient department of a tertiary hospital in Purulia district, of West Bengal state in Eastern India, from April to June 2017.

Sample Size

Records of adult clients (18 years of age and above) who had visited the hospital over the last 5 years were extracted from the registration database of the study institute. On an average, 3430 clients had visited every year for treatment, and this number was rounded off to 3500 to determine the sample size. The actual sample size for the study was determined by using open source epidemiologic statistics for public health (Dean et al, 2013), by assuming 5% marginal error, 95% confidence interval (alpha=0.05), and the proportion of 50%. Results showed that the required sample size for the study was 347 respondents.

Participants

The inclusion criteria:

- People diagnosed with leprosy for at least 1 year at the time of interview;
- Above 18 years of age and married;
- Willing to participate and give informed consent.

The exclusion criteria:

- People not capable of independent communication.

Data Collection

Semi-structured Questionnaire - A semi-structured questionnaire was prepared to collect the demographic profile and disease profile of people affected by leprosy. The demographic profile included information on gender, age, education, occupation, family income, and family size. The disease profile included disease duration and disability grade. The level of disability was measured by the World Health Organisation (WHO) disability grade system which grades clients with leprosy according to disabilities of the eyes, hands and feet (Brandsma and Van Brakel, 2003).

Screening of Activity Limitation and Safety Awareness Scale (SALSA Scale)

The SALSA is a questionnaire that measures activity limitation and risk awareness in peripheral neuropathy mainly due to leprosy and diabetes. The SALSA Scale was developed and tested in six languages - Chinese (Mandarin), English, Hausa, Hebrew, Portuguese (Brazilian), Tamil - by the SALSA Collaborative Study Group (2007). It is a cross-cultural tool, comprising 20 items related to three domains - mobility, self-care and work. It is a subjective tool, placing the interviewees at the centre and presenting how the clients perceive their functional level. Each item of the SALSA Scale ranges from '0' to '4' (0 - 'I do not do this activity', 1 - 'The activity is easy to carry out', 2 - 'The activity is a little difficult to carry out', 3 - 'The activity is very difficult to carry out', and 4 - 'I physically cannot do the activity' or 'I avoid the activity because of risk').

The scores range from '0' (minimum) to '80' (maximum) points. People with scores ranging from 10 to 24 are considered to experience no limitation in activities; those with scores from 25 to 39 are with mild limitation; 40 to 49 with moderate limitation; 50 to 59 with severe limitation; and 60 to 80 with extreme limitation.

In this study, the Bengali translation of the SALSA Scale was used to measure the level of activity limitation (SALSA Scale Bengali). The Bengali version of the SALSA Scale was translated and validated (face and content validity) by the SALSA Scale development group. However, the study group has not tested the reliability.

Construct Validity - The Bengali version Participation Scale (P Scale) (Van Brakel et al, 2006) and the World Health Organisation Quality of Life (WHOQOL-BREF) Scale (WHOQOL Group, 1998; Tsutsumi et al, 2006) were used to establish the construct validity of the Bengali version of the SALSA Scale. The P Scale and WHOQOL-Bref were used to measure the social participation restriction and quality of life of people affected by leprosy, respectively. The researcher hypothesised that activity limitation of the people affected by leprosy would be positively correlated with the P Scale and inversely correlated with WHOQOL-Bref.

Reliability - In this study, the internal consistency was used to test the reliability of the Bengali version of the SALSA Scale. Internal consistency is considered good if alpha ranges between 0.70 and 0.90 (Cardol et al, 2001).

Procedure

The first author was assigned to recruit participants, describe the study to them and obtain informed written consent. The first author performed the interview with the assistance of three trained field investigators.

The interview consisted of gathering information about present demographic and disease status followed by administration of the SALSA Scale, P Scale and WHOQOL-BREF Scale. All interviews were conducted in the local language – Bengali - and in strict privacy after building rapport with the respondents. Interviews lasted from 30 to 45 minutes. At any sign of emotional distress, the interview could be terminated; however there was no occasion to do so.

Data Analysis

The data was entered in the Microsoft Excel database and analysed using SPSS. The descriptive statistics and Chi-square test were done to compare the groups. Independent 't' test was done for the items to observe the difference between males and females. Reliability analysis was performed for 20 items of the SALSA Scales. Pearson correlation analysis was performed for construct validity. P-values less than 0.05 were regarded as statistically significant.

Ethical Considerations

The study was approved by the Doctoral Research Committee members of the Department of Sociology, Bharathidasan University, and the Research Ethics Committee of The Leprosy Mission Trust India. The participation of respondents in the study was voluntary and information was collected anonymously after obtaining written consent from each of them. Confidentiality was maintained throughout the data collection period.

RESULTS

Details of the respondents' demographic profiles, disability status and disease duration are described in Table 1. Of the 358 respondents, 59% were male and 41% were female. Most of them (214 or 60%) were between 18-45 years of age, 42% were illiterate and 55% had occupations such as labourer and farmer. About 47% of the respondents were living in medium-sized families (5 to 8 members) and 75% of their monthly family income was below Rs.5000 (Indian currency). Visible impairments (WHO Grade 2) were present among 144 (40%) of the respondents and 60 % of them were diagnosed more than 3 years ago.

Table 1: Demographic Profile, Disability Status and Disease Duration of the Respondents (n=358)

Status	Frequency	Percent
Gender		
Male	212	59.2
Female	146	40.8
Age		
18-30 years	69	19.3%
31-45 years	145	40.5%
46-60 years	111	31.0%
Above 60 years	33	9.2%
Education		
Illiterate	207	57.8
Literate	151	42.2
Occupation		
Labourer	99	27.7
Farmer	96	26.8
Housewife	135	37.7
Others (Professional & Business)	28	7.8
Family Size		
Small Family (4 members)	128	35.8
Medium Family (8 members)	167	46.6
Large Family (>8 members)	63	17.6
Family Income		
Below Rs.5,000	270	75.4
Above Rs.5,000	88	24.6
WHO Disability Grade		
Grade 0	150	41.9
Grade 1	64	17.9
Grade 2	144	40.2
Disease Duration		
1 to 3 years	144	40.2
3 to 5 years	112	31.3
Above 5 years	102	28.5

Internal Consistency

The results showed that the reliability coefficient (Cronbach's alpha) was 0.891. Corrected item-total correlation ranged from 0.880 to 0.897, with all the 20 items falling at or above 0.880 (shown in Table 2). The Bengali version of the SALSA Scale has been shown to have very good internal consistency and reliability.

Table 2: Descriptive Statistics of the Items of the SALSA (range per item 0-4) and Corrected Item-Total Correlation (n=358)

	Items	Mean	Std. Deviation	Corrected Item- Total Correlation	Cronbach's Alpha if Item Deleted
1	Can you see (enough to carry out your daily activities)?	1.3352	.53916	.048	.897
2	Do you sit or squat on the ground?	1.4078	.70305	.396	.890
3	Do you walk barefoot? (e.g. most of the time)	1.5475	.87718	.347	.893
4	Do you walk on uneven ground?	1.6844	.87820	.446	.889
5	Do you walk longer distances? (i.e. longer than 30 minutes)	1.6816	.85945	.440	.889
6	Do you wash your whole body? (using soap, sponge, jug; standing or sitting)	1.1369	.43092	.538	.887
7	Do you cut your finger or toenails? (e.g. using scissors or clippers)	1.1704	.53611	.570	.885
8	Do you hold a cup or basin with hot contents? (e.g. drinks, food)	1.2318	.63457	.620	.883
9	Do you work with tools? (i.e. tools which you hold in your hands to help you work)	.9749	.78995	.290	.894

10	Do you carry heavy objects or bags? (e.g. shopping, food, water, wood)	1.3631	.75740	.645	.882
11	Do you lift objects above your head? (e.g. to place on a shelf, on your head, to hang clothes to dry)	1.1676	.89183	.585	.884
12	Do you cook? (i.e. prepare food both hot and cold)	.7709	.75448	.273	.894
13	Do you pour hot liquids?	1.0391	.73613	.452	.888
14	Do you open/close screw capped bottles? (e.g. oil, water)	1.2179	.67572	.743	.880
15	Do you open jars with screw-on lids? (e.g. jam)	1.2402	.68054	.725	.880
16	Do you handle or manipulate small objects? (e.g. coins, nails, small screws, grains and seeds)	1.2179	.61495	.757	.880
17	Do you use buttons? (e.g. buttons on clothing, bags)	1.1788	.60935	.749	.880
18	Do you thread needles? (i.e. pass thread through the eye of a needle)	1.0978	.79490	.501	.887
19	Do you pick up pieces of paper, handle paper or put it in order?	1.1760	.58915	.727	.881
20	Do you pick up things from the floor?	1.1872	.59045	.685	.882

Construct Validity

The total score of the SALSA Scale had a moderate positive correlation with the P Scale (r = 0.402, p=0.000) and a moderate negative correlation with WHOQOL total score (r = -0.507, p=0.000).

Activity Limitation

Among the 358 respondents, 229 (64%) had no limitation in activities, 103 (29%) had mild limitation and 26 (7%) had moderate to severe limitation in activities (shown in Table 3).

Table 3: Level of Activity Limitation Measured by SALSA Scale (n=358)

Activity Limitation	Frequency (n)	Percent (%)
No limitation (0-24)	229	64.0%
Mild limitation (25-39)	103	28.8%
Moderate limitation (40-49)	17	4.7%
Severe limitation (60-80)	9	2.5%

Association between Variables and Activity Limitation

To understand the association between activity limitation and other variables, data was dichotomised based on the SALSA Scale score - scores of 24 or less were described as 'no activity limitation' and above 24 as 'activity limitation' (shown in Table 4). The results showed that there is no association between education and family income with activity limitation. However, gender, occupation, disability grade and disease duration of the respondents showed a highly significant association with activity limitation.

Table 4:Association between Variables and Activity Limitation (n=358)

	Activity Limitation					
Status	**No Activity Limitation n = 229**		**Activity Limitation n = 129**		**Total n = 358**	**p-value**
Gender						
Male	150	71%	62	29%	212	<0.01
Female	79	54%	67	46%	146	

Age						
18-30 years	55	80%	14	20%	69	<0.05
31-45 years	89	61%	56	39%	145	
46-60 years	65	59%	46	41%	111	
Above 60 years	20	61%	13	39%	33	
Education						
Illiterate	125	60%	82	40%	207	.099
Literate	104	69%	47	31%	151	
Occupation						
Labourer	73	74%	26	26%	99	<0.01
Farmer	67	70%	29	30%	96	
Housewife	70	52%	65	48%	135	
Others	19	68%	9	32%	28	
Family Income						
Below Rs. 5000	168	62%	102	38%	270	.229
Above Rs. 5000	61	69%	27	31%	88	
Disability Grade						
Grade 0	126	84%	24	16%	150	<0.01
Grade 1	45	70%	19	30%	64	
Grade 2	58	40%	86	60%	144	
Disease Duration						
1 to 3 years	107	74%	37	26%	144	<0.01
3 to 5 years	67	60%	45	40%	112	
Above 5 years	55	54%	47	46%	102	

The multivariate Chi-square distribution was done to observe the activity limitation by gender (shown in Table 5), age (shown in Table 6), occupation (shown in Table 7) and disease duration (shown in Table 8), with disability grade. The results showed that there is an association observed among the disability grade '0' and grade '1' group between gender and activity limitation (shown in Table 5). Among the disability grade '1' group, there is an association observed between occupation and activity limitation (shown in Table 7).

Table 5: Activity Limitation by Gender and Disability Grade of the Respondents (n=358)

Disability Grade	Gender	Activity Limitation				Total	p-value
		No		Yes			
Grade 0	Male	76	89%	9	11%	85	<0.05
	Female	50	77%	15	23%	65	
	Total	126	84%	24	16%	150	
Grade 1	Male	34	92%	3	8%	37	<0.01
	Female	11	41%	16	59%	27	
	Total	45	70%	19	30%	64	
Grade 2	Male	40	44%	50	56%	90	0.188
	Female	18	33%	36	67%	54	
	Total	58	40%	86	60%	144	

Table 6: Activity Limitation by Age and Disability Grade of the Respondents (n=358)

Disability Grade	Age	Activity Limitation				Total	P-value
		No		Yes			
Grade 0	18-30 years	43	91%	4	9%	47	0.124
	31-45 years	49	77%	15	23%	64	
	46-60 years	28	85%	5	15%	33	
	Above 60 years	6	100%	0	0%	6	
	Total	126	84%	24	16%	150	
Grade 1	18-30 years	5	71%	2	29%	7	0.945
	31-45 years	19	70%	8	30%	27	
	46-60 years	14	67%	7	33%	21	
	Above 60 years	7	78%	2	22%	9	
	Total	45	70%	19	30%	64	
Grade 2	18-30 years	7	47%	8	53%	15	0.958
	31-45 years	21	39%	33	61%	54	
	46-60 years	23	40%	34	60%	57	
	Above 60 years	7	39%	11	61%	18	
	Total	58	40%	86	60%	144	

Table 7: Activity Limitation by Occupation and Disability Grade of the Respondents (n=358)

Disability Grade	Occupation	Activity Limitation				Total	p-value
		No		Yes			
Grade 0	Labourer	42	89%	5	11%	47	0.076
	Farmer	28	93%	2	7%	30	
	Housewife	44	75%	15	25%	59	
	Others	12	86%	2	14%	14	
	Total	126	84%	24	16%	150	
Grade 1	Labourer	15	83%	3	17%	18	<0.01
	Farmer	17	100%	0	0%	17	
	Housewife	9	36%	16	64%	25	
	Others	4	100%	0	0%	4	
	Total	45	70%	19	30%	64	
Grade 2	Labourer	16	47%	18	53%	34	0.467
	Farmer	22	45%	27	55%	49	
	Housewife	17	33%	34	67%	51	
	Others	3	30%	7	70%	10	
	Total	58	40%	86	60%	144	

Significance Test between Gender and Activity Limitation

The significance test was done for the individual item between gender and activity limitation and significant difference observed in item-4 (walk on uneven ground), item-5 (walk longer distance), item-9 (work with tools), item-11 (lift objects above head), item-12 (cook), item-13 (pour hot liquids) and item-18 (thread needle).

The results showed that the female respondents had slightly higher limitation than male respondents in activities such as walking on uneven ground, walking longer distance, lifting objects above head, cooking, pouring hot liquids and threading a needle. The male respondents in turn had slightly higher limitation in working with tools than the female respondents.

Table 8: Activity Limitation by Disease Duration and Disability Grade of the Respondents (n=358)

Disability Grade	Disease Duration	Activity Limitation				Total	p-value
		No		Yes			
Grade 0	1 to 3 years	66	84%	13	16%	79	0.984
	3 to 5 years	39	85%	7	15%	46	
	Above 5 years	21	84%	4	16%	25	
	Total	126	84%	24	16%	150	
Grade 1	1 to 3 years	26	74%	9	26%	35	0.157
	3 to 5 years	7	50%	7	50%	14	
	Above 5 years	12	80%	3	20%	15	
	Total	45	70%	19	30%	64	
Grade 2	1 to 3 years	15	50%	15	50%	30	0.412
	3 to 5 years	21	40%	31	60%	52	
	Above 5 years	22	35%	40	65%	62	
	Total	58	40%	86	60%	144	

DISCUSSION

Leprosy-related disability is a challenge to public health. Disability is more than a mere physical dysfunction as it includes activity limitations, stigma, discrimination, and social participation restrictions. Globally, the new cases with grade 2 disability numbered more than 10000 in 2014-2018 and 11323 cases were registered in the year 2018 (WHO, 2019). In India, 3666 new cases with grade 2 disability were reported in the year 2018 (WHO, 2019). The current study revealed the level of activity limitation and the factors associated with activity limitation of people affected by leprosy.

In the present study, about two-thirds of the participants (64%) had reported no activity limitation whereas one-third of them (36%) experienced some limitation in activity. Among those with activity limitation, 7% had moderate to severe limitation in activities. The proportion of people with limitation in activities was lower in this study than the 58% found in the study by Nardi et al (2012) and the 67% in the study by De Souza et al (2016) in Brazil, and the 60% found in the study in Indonesia by Van Brakel et al (2012).

In the current study, more females (46%) than males (29%) experienced activity limitation and the reason may be that females are mainly engaged in household work. Findings of this study are consistent with the findings of the study conducted in Brazil (Nardi et al, 2012) and Indonesia (Van Brakel et al, 2012). On the contrary, another similar study from Brazil (Santos et al, 2015) found that there was no difference in activity limitation among the males and females.

Older persons affected by leprosy suffered more limitation in activities when compared to younger persons; this was consistent with the findings of the study conducted in Brazil (Nardi et al, 2012). The activity limitation among literate and illiterate respondents was not influenced by the educational status. However, the Brazilian study found that limitation of activities was experienced by those who had less than 6 years of schooling, compared to those who attended school for longer periods (Nardi et al, 2012).

The study by Nardi et al (2012) in Brazil, found that people affected by leprosy and with low-risk occupations (activities or occupations that do not require intense or constant effort or repetitive movements for most of the day) had reported higher limitation in activities, and people with low incomes had reported higher limitation in activities when compared to those with higher incomes. The present study found that homemakers experienced higher limitation in activities. It is interesting to observe that respondents from the low family-income group as well as from the high-income group experienced the same level of activity limitation.

Studies from India suggest that physical disabilities do affect the quality of life (Govindharaj et al, 2018) and social participation (Ramasamy et al, 2018; Govindharaj et al, 2019; Ramasamy et al, 2019) of people affected by leprosy. The present study demonstrated that people who had visible impairments (grade 2 disability - 60%), experienced more activity limitation compared to those respondents who had only loss of sensation (grade 1 - 30%). Studies from Philippines (Boku et al, 2010), Indonesia (Van Brakel et al, 2012), Brazil (Nardi et al, 2012; Santos et al, 2015) and India (Kamble et al,2012) also reported similar findings.

Furthermore, the study observed that the activity limitation was greater among persons who had a longer history of disease duration. This study shows that the females with disability (grade 0 and grade 1) had more limitation in activities than the males.

The internal consistency of the SALSA Scale was good and the Cronbach alpha was 0·96. The construct validity of the SALSA was supported by the moderately positive correlation with the P-Scale and moderately negative correlation with the WHOQOL-BREF. The SALSA Scale is reliable and valid to measure activity limitation in people affected by leprosy.

Limitations

The study assessed the activity limitation among people affected by leprosy with a large-sized sample. However, there are some limitations. Due to resource and time constraints, this was conducted as a cross-sectional study in a tertiary leprosy referral centre and the study has not been retested. Future studies will need to investigate the SALSA Scale test-retest reliability and to validate the Scale. Further comparative and intervention studies need to be undertaken on activity limitation among people affected by leprosy.

CONCLUSION

This study shows that the SALSA Scale is an easy tool to measure the activity limitations among people affected by leprosy. Activity limitations of people affected by leprosy are associated with being a woman, a housewife, an aged person and with longer disease duration. The physical disability was intrinsically associated with activity limitations. Multidisciplinary rehabilitation approaches may help to improve the activities of daily living among people affected by leprosy and also improve their quality of life.

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