

## **STUDY ON CLINICO - EPIDEMIOLOGICAL PROFILE, ACTIVITY LIMITATION AND SOCIAL STIGMA AMONG LEPROSY PATIENTS IN KANCHEEPURAM DISTRICT, TAMIL NADU**

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### **ABSTRACT**

To study the Clinico – Epidemiological profile of the Leprosy patients. This study was carried out among Leprosy patients in Kancheepuram District to study the Clinico - Epidemiological Profile, Activity Limitation and Social Stigma prevailing among them. Leprosy patients visit the out- patient department associated with this Institute and also stay in the Blocks or in the Wards inside the Institute. Almost 92% had completed treatment among them 78. 5% were on regular treatment. About 20. 5% had history of lepra reactions and 67. 5% had under-went corrective surgeries due to complications.

### **Keywords**

leprosy, tuberculoid, Mycobacterium leprae and Multi-drug therapy.

### **Introduction**

Leprosy is a chronic granulomatous disease caused by Mycobacterium leprae. [ 1] Leprosy is a highly infectious disease with low pathogenicity; many individuals acquire the infection, while only a few develop the disease. It affects people of all ages, and both sexes, however its incidence is higher in men than in women. Leprosy is transmitted through direct and prolonged contact with a multi-bacillary contagious patient and untreated skin or mucous membranes of the upper airways. The transmission of leprosy is linked to socio-economic factors such as nutritional status, hygiene and living conditions. Genetic factors are also linked with individual's predisposition to acquire leprosy. [ 2]

According to WHO classification, leprosy can be classified into paucibacillary (up to five skin lesions) and multibacillary (more than five skin lesions). Among the paucibacillary forms are indeterminate leprosy and tuberculoid leprosy, and among the multibacillary forms are borderline leprosy and lepromatous leprosy. [ 2]

Infiltration of Mycobacterium leprae into Schwann cells results in inflammation of the nerves, which can lead to a progressive loss of nerve fibre function mostly in the eyes, hands, and feet. It also leads to loss of sensory, motor, and autonomic nerve function resulting in loss of thermal, nociceptive, and pressure senses; muscle paresis; and dryness of the skin. [ 4,5] Multi-drug therapy ( MDT) can cure leprosy, and, if instituted early, can prevent the disability caused by infiltration of M. Leprae. However, leprosy is often diagnosed too late, when permanent impairment has already occurred. The multidrug leprosy treatment has no effect on the nerve fibres already damaged. [ 2] Even after completion of treatment, a significant proportion of patients sustain disability from nerve damage, requiring continued care to limit further complications.[ 6]

Leprosy is an important cause of preventable disability. [ 7 ] Disability is a broad term covering any impairment, activity limitation or participation restriction. [ 8] Impairments may give rise to disabilities, such as limitations of activities involving the use of hands, feet and eyes, and restrictions in social participation due to perceived stigma.[ 9-12]. The high level of incapacity prevailing among leprosy patients has been the main problem associated with the disease,

because it interferes directly with the daily activities, causing economic losses, as well as psychological trauma because of stigma and discrimination.[ 2] Prevention of disabilities is one of the priorities of the leprosy control programme, and it is present in all stages of treatment, including follow -up post- discharge.[ 2]

Health centres for the care of leprosy patients realize the importance of prevention of disabilities, in order to provide them an improved physical, socio- economic and emotional state. There has been very little research so far in India regarding leprosy in a view to explore the problems faced by them. Thus, the objective is to describe the clinical and epidemiological profile of patients with leprosy and to assess the extent of disability and its determinants and to explore the prevailing stigma among the leprosy patients. Therefore, exploring the disabilities, activity limitation and stigma in leprosy affected persons can help to understand the problems associated with leprosy better and therefore can direct on programmes for early detection and management of leprosy, on the disability and stigma reduction strategies and intervention programs.

## MATERIALS AND METHODS

### Study Design

This study is a community based descriptive cross – sectional study conducted in Kancheepuram district, Tamil Nadu.

### Study Area

This study was carried out in and around a village, Nemmeli with a population of 3099, consisting of 1560 males and 1539 females in Tirukalukundram Taluk under Chengalpattu administrative division of Kancheepuram District. (Population Census 2011 ). Central Leprosy Training and Research Institute, which works for the leprosy patients is located in this area. Most of the leprosy patients reside in and around the Institute. Leprosy patients visit the out- patient department associated with this Institute and also stay in the Blocks or in the Wards inside the Institute. Outside the Institute, they reside in leprosy colonies and rehabilitation homes. Since most of the leprosy patients reside in this village, hence this village was chosen as the study area.

### Study Population

Adults more than 18 years of age, with known hi story of Leprosy were the study population.

### Inclusion Criteria

Adults more than 18 years of age, with known history of Leprosy were included in the study. Patients who were willing to participate in the study were included.

### Exclusion Criteria

- Leprosy patients who were not available during data collection were excluded.
- Those who were not willing to participate in the study were excluded.

### Ethical Approval

The study proposal was presented and approval from Institutional Ethics Committee was obtained prior to the pretesting. The approval letter is enclosed.

### DATA ANALYSIS

The data analysis was done using descriptive and analytical statistics. The descriptive statistics analysed were presented as frequency distribution and percentage. The analytical statistics used were Chi – square, Odds Ratio and Confidence Interval to determine the association of Socio-demographic characters with WHO disability grading, activity limitation, social stigma. P value

< 0. 05 was considered as statistically significant value. Data was analysed using the software SPSS, version 16 software.

## RESULTS

Socio-demographic features of the study population are shown in Table 1. Among the study participants, 38% belonged to 61 -75 years of age, 36. 5 % belonged to 45 - 60 years of age and 17% belonged to less than 45 years of age. About 71. 5% of the study subjects were males and 28.5 % were females. Almost, 37. 5% had no formal education and 31% had middle/ high school education. Regarding the previous occupational status, 62% of the respondents were previously unemployed and 42.5% were engaged in skilled employment. Currently, 85% of the study participants were unemployed, 8 .5 % worked part time and 6. 5% worked full time. Nearly, 79 % of them belonged to lower socioeconomic status and 17% belonged to upper lower socioeconomic status, according to BG Prasad Scale. Among the study population, 41% were married, 26% were unmarried, and 17% lived separately from their spouse. Almost 44.5 % of the respondents were living with their families, 41% lived alone and 14. 5% were living with their relatives. About, 19% had family history of and 81% did not have family history of leprosy.

**Table 1: Socio-demographic features of the study population.**

S.No	Socio- Demographic Characteristics	Frequency (N=200)	Percentage (%)
1.	<b>Age</b>		
	Less than 45	34	17.0
	45- 60	73	36.5
	61- 75	76	38.0
	More than 75	17	8.5
2.	<b>Gender</b>		
	Male	143	71.5
	Female	57	28.5
3.	<b>Religion</b>		
	Hindu	164	82.0
	Christian	311	17.0
	Muslim	2	1.0
4.	<b>Educational Status</b>		
	No formal education	75	37.5
	Primary	21	10.5
	Middle/ High School	62	31.0
	Diploma/ Graduate	8	4.0
5.	<b>Previous Occupation</b>		

	Unemployed	52	62.0
	Unskilled	28	14.0
	Semi-skilled	33	16.5
	Skilled	85	42.5
	Clerical/Shop owner	1	0.5
	Professional	1	0.5
<b>6.</b>	<b>Socio Economic Status (BG Prasad)</b>		
	Upper	1	0.5
	Upper Middle	1	0.5
	Lower Middle	6	3.0
	Upper Lower	34	17.0
	Lower	158	79.0
<b>7.</b>	<b>Current Employment Status</b>		
	Unemployed	170	85.0
	Part Time	17	8.5
	Full time	13	6.5
<b>8.</b>	<b>Marital Status</b>		
	Unmarried	52	26.0
	Married	82	41.0
	Widower	32	16.0
	Separate	34	17.0
<b>9.</b>	<b>Living Status</b>		
	With Relatives	29	14.5
	With Family	89	44.5
	Alone	82	41.0
<b>10.</b>	<b>Family History of Leprosy</b>		
	Present	38	19.0
	Absent	162	81.0

### **Clinico-epidemiological profile of the study population**

Clinico- epidemiological profile of the study population is represented in Table 2 . Based on Ridley – Jopling Classification, it was found that majority of the study participants, 44% were suffering from tuberculoid type of leprosy, whereas, 24% were suffering from borderline lepromatous leprosy, followed by borderline ( 18 %), lepromatous (12%) and borderline

tuberculoid leprosy ( 2 %). Based on WHO classification for leprosy, 61. 5% belonged to paucibacillary type leprosy and 38.5% belonged to multibacillary type leprosy. Almost 82% of the diagnosed patients sought treatment from government hospitals, 4% sought treatment from private clinics and 4% from sought treatment from other types of alternative medicine. Nearly, 81% of the treated patients had a history of relapse. Almost, 92% had completed their treatment for leprosy and 8 % are currently on treatment. Among the study participants, only 78 .5% were on regular treatment and 21.5% were on irregular treatment. Almost, 20. 5% of them experienced lepra reaction in the due course of their disease. Among the study population, 67 .5 % had history of surgery due to complications of leprosy in the past. Nearly, 80. 5% suffered from Diabetes Mellitus and 6. 5% suffered from Hypertension.

**Table 2: Use of protective measures among the study population**

S.No	Use of Protective Measures	Frequency*	Percentage
1.	Special footwear	145	72.5
2.	Crutches	39	19.5
3.	Splint for hands	20	10.0
4.	Walking stick	13	6.5
5.	Eye Glass	12	6.0
6.	Wheel Chair	11	5.5
7.	Elastic Compression Stocking	7	3.5

\*Multiple responses of each variable.

**Clinico-Epidemiological Profile of the Study Participants**

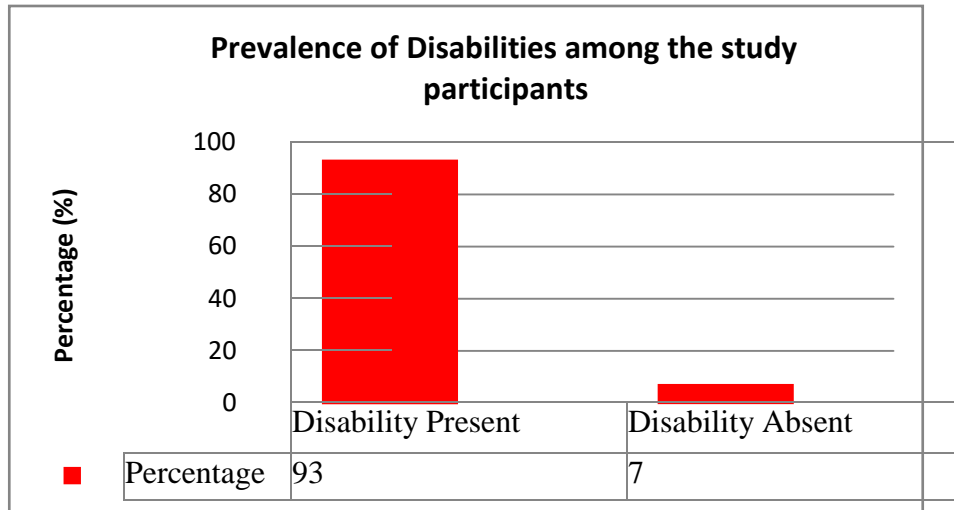
The mean age at diagnosis, years since diagnosis and duration of treatment are represented in Table 3. The mean age at diagnosis of leprosy was 30.25 years, mean years since diagnosis was 29.61 and mean duration of treatment is 3.6 years.

**Table 3: Various scales used in this study**

S.No	Grading	Min	Max	Mean	Standard Deviation
1.	WHO Disability Grading	0	12	6.60	2.834
2.	Social Stigma	0	45	26.66	14.116
3.	SALSA – Activity Limitation	0	80	41.63	14.428

Prevalence of Disabilities among the study participants is represented in Figure 1. It is seen that 93% of the study participants suffered from disabilities and 7 % did not have any disabilities.

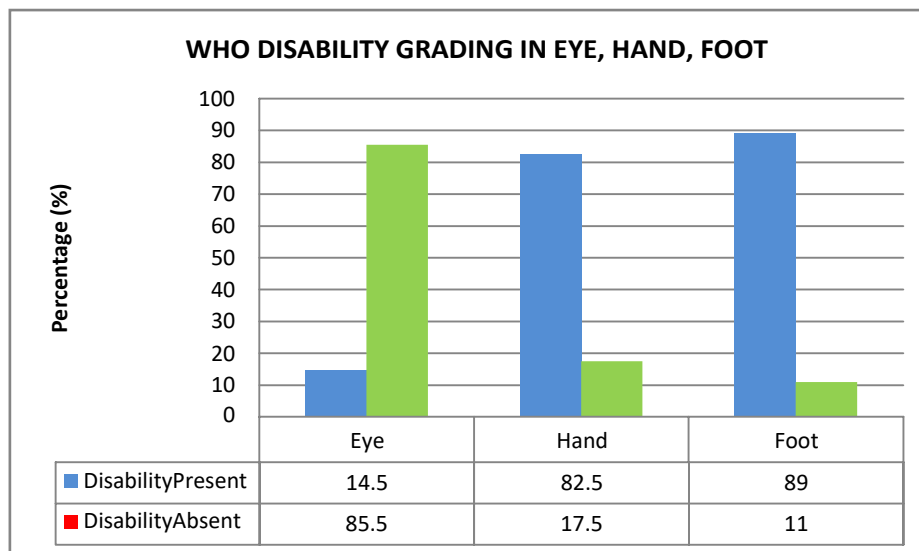
**Fig 1: Prevalence of Disabilities among the study participants**



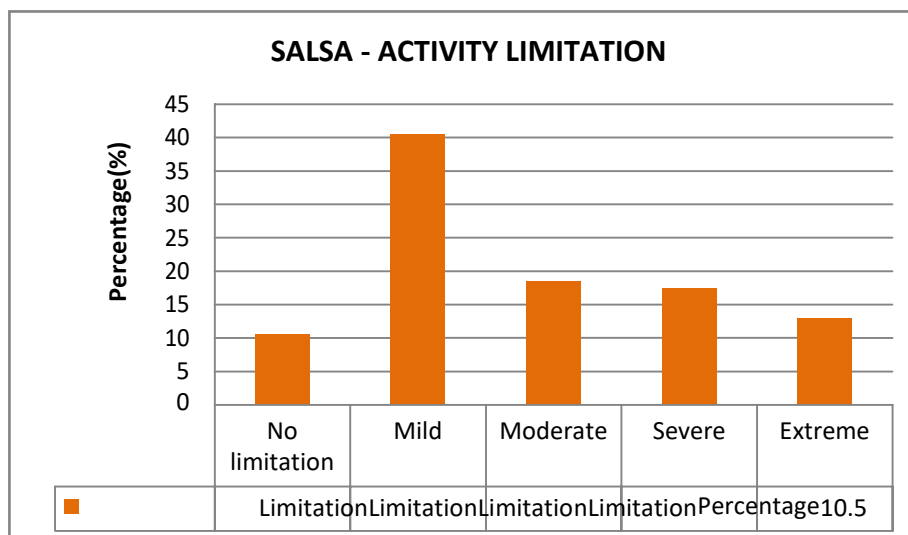
**WHO disability grading among the study participants**

The WHO disability grading among the study population is shown in Figure 2. Among the study participants, who suffer from disability, 14.5% had disabilities pertaining to the eye. Almost, 82.5 % had disabilities involving the hands and 89% of the study participants had disability involving the foot.

**Fig 2: WHO disability grading among the study participants**



Prevalence of activity limitation among the study participants is represented in Figure 3. About, 89.5% of the participants had activity limitation and 10.5% did not have any activity limitation.



**Fig 3: Grading of Scale for activity limitation and safety awareness**

Prevalence of presence of social stigma among the study participants is represented in Figure 5. Nearly, 67.5% had social stigma while 32.5% did not have social stigma according to Explanatory Model Interview Catalogue EMIC scale.

**Table 4 : Association between socio demographic factors and the presence of activity limitation among the study participants**

S. No	Characteristics	N= 200	Activity Limitation Present (n= 179)	Percentage (%)	Odds Ratio	95 % Confidence interval	Chi Square Value	P value
1.	<b>AGE</b>							
	More than 60	93	88	94.6	3.0945	1.09 - 8.81	4.856	0.028 *
	Less than or equal to 60	107	91	85.0				
2.	<b>GENDER</b>							
	Female	57	55	96.4	4.2137	0.95 - 18.72	4.146	0.042 *
	Male	143	124	86.7				
3.	<b>RELIGION</b>							
	Hindu	164	145	88.4	0.4489	0.10 - 2.02	1.142	0.285
	Others	36	34	94.4				
4.	<b>EDUCATION</b>							
	No formal education	75	72	96.0	4.0374	1.15 - 14.21	5.395	0.02 *
	Literate	125	107	85.6				
5.	<b>SOCIO ECONOMIC STATUS ( BG PRASAD SCALE)</b>							

	Class 4 & 5	192	171	89 . 0	1 . 1633	0 . 14 - 9 . 93	0 . 0192	0 . 889
	Class 1 , 2 & 3	8	7	87 . 5				
6.	<b>CURRENT EMPLOYMENT STATUS</b>							
	Unemployed	167	154	92 . 2	3 . 7908	1 . 43 - 10 . 07	. 7 . 942	0 . 005 *
	Employed	33	25	75 . 7				
7.	<b>MARITAL STATUS</b>							
	Unmarried	52	43	82 . 6	0 . 4216	0 . 17 - 1 . 07	3 . 465	0 . 063
	Married	148	136	91 . 8				
8.	<b>LIVING STATUS</b>							
	Alone	87	83	95 . 4	3 . 6745	1 . 19 - 11 . 35	. 5 . 708	0 . 017 *
	With Others	113	96	84 . 9				
9.	<b>FAMILY HISTORY OF LEPROSY</b>							
	Present	38	33	86 . 8	0 . 7233	0 . 25 - 2 . 11	0 . 353	0 . 553
	Absent	162	146	90 . 1				

\*p value <0.05 – statistically significant at 95% CI

Association between clinic epidemiological profile and the presence of activity limitation among the study participants is shown in Table 14. A strong statistically significant association was found to be present between treatment status and activity limitation (  $p=0.005$ ,  $X^2 = 4.77$ ) with an odds ratio of 4. 8( 95% CI - 1.5-15 . 5 ). Activity limitation and years since diagnosis were found to have a strong statistically significant association ( $p=0. 002$ ,  $X^2 = 9.88$  ) with an odds ratio of 7.8 ( 95% CI – 1.8-34.7). There was no association between other clinic-epidemiological profile characteristics and activity limitation.

## DISCUSSIONS

In this study, majority of the study participants, almost 38% belonged to 61 -75 years of age, 36.5% belonged to 45 -60 years of age and 17 % belonged to less than 45 years of age. In a study by Nardi SMT et al, 52.3 % of the study participants were above 55 years of age, followed by 34. 7%, who belonged to 35 -54 years of age.[ 9] In Samona J et al study, 30.3% belonged to 61 - 70 years of age followed by 24 . 2 % belonging to 51 - 60 years of age. [ 13] In this study, about 71.5% of the study subjects were males and 28.5 % were females. In a study by Boku N et al, in the group consisting of people affected by leprosy with visible impairments, 71% were males, which was similar to this study Regarding the educational status of the participants in this study, almost, 37 . 5 % had no formal education and 31% had middle/high school education. Educational status of the study participants was similar to the study conducted by Samona J et al, where 38.9 % of them were illiterates and 40.3% had education upto 5 years. [ 14] In a study conducted by Van Brakel WH et al, 31.9% had no formal education and 43. 9% had education up to primary school level.[ 15]

Currently in this study, 85% of the study participants were unemployed, 8 . 5 % worked part time and 6. 5% worked full time. Unemployment status was drastically higher in this study compared



to other studies. In a study by Slim FJ, 55% were unemployed. [ 16] In a study conducted by Boku N et al, in the group consisting of people affected by leprosy with visible impairments, 54% were unemployed. [ 17] In a study conducted by Samona J et al, 52.2% were unemployed, 13% had part time work and 34. 8% had full time work.[ 18] There was a strong statistically significant association present between WHO disability grading and socioeconomic status, living condition of the participants, current employment status and history of corrective surgery in the past. In a study by Castro LE et al, WHO Disability grading was associated with age, education and patients on multi drug therapy.[ 14] However, age and education was not found to be associated with WHO disability grading in this study. In a study by Santos VS et al, functional limitation was associated with physical, psychological, social and environmental domains according to WHO Qo L domains. [ 19] In a study by Adhikari B et al, EMIC Stigma scale was found to be statistically associated with disability/ deformity, presence of ulcer and odour of the ulcer. [ 9] In a study by Castro LE et al, social restriction was associated with presence of disability and multibacillary type of leprosy. [ 20] There was a strong statistically significant association present between activity l imitation and age, sex, education, current employment status, living condition, treatment status & years since diagnosis. In a study by De Souza VT et al, SALSA score was statistically associated with degree of impairment. [ 21] In a study by Masuchi MH et al, SALSA score was associated with age and visual impairment. [ 2] In a study by Monteiro LD et al, there was a strong statistically significant association found between activity limitation and older age, paucibacillary type of leprosy, social participation. [ 22] In a study by Nardi SM et al, a strong statistical association was found between activity limitation and gender, age, income, education, occupational risk, type of leprosy, presence of co-morbidities. [ 23]

## CONCLUSION

This study assessed the clinic- epidemiological profile, activity limitation and social stigma among the leprosy patients in Kancheepuram District, Tamil Nadu. The study reveals that, 85% of the leprosy patients were unemployed. As far as the marital status was concerned, 43 % of the patients were unmarried or divorced and 41% were living alone. Among the study subjects, 44% had Tuberculoid Leprosy according to Ridley-Jopling Classification. According to WHO Classification of leprosy, 61.5% suffered from paucibacillary type of leprosy. Almost 92% had completed treatment among them 78. 5% were on regular treatment. About 20. 5% had history of lepra reactions and 67. 5% had under-went corrective surgeries due to complications.

WHO Disability Grading had a strong statistical association with socio economic status, current employment status, living condition and history of corrective surgery. Social stigma was found to be associated with age and current employment status. SALSA – Activity Limitation was associated with age, gender, education, employment, living condition, treatment status and years since diagnosis.

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**Ethical approval:** The study was approved by the Institutional Ethics Committee

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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