

## Original Research Article

# Disability due to leprosy: a socio-demographic study in Leprosy Hospital, Chamba, Himachal Pradesh

Pragya Dixit, Arvind Kumar Dhiman\*

Department of Community Medicine, Pt Jawahar Lal Nehru Medical College, Chamba, Himachal Pradesh, India

**Received:** 04 October 2018

**Revised:** 09 January 2019

**Accepted:** 10 January 2019

**\*Correspondence:**

Dr. Arvind Kumar Dhiman,

E-mail: [dr.arvinddhiman77@gmail.com](mailto:dr.arvinddhiman77@gmail.com)

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### ABSTRACT

**Background:** Leprosy is a chronic granulomatous disease caused by *M. leprae* bacilli and one of the important cause of preventable disability.

**Methods:** This study was a cross sectional one, conducted at Leprosy Hospital, Sarol, Chamba, Himachal Pradesh over a period of two months, May and June 2018. The study used convenient sampling and all 20 disabled patients who were receiving treatment at Leprosy Hospital were included in the study. Socio demographic data which included age, marital status, occupation, type and duration of disability was collected and analyzed. To screen for activity limitation and safety awareness SALSA scale was used. A score of 25 or more points is indicative of activity limitation and disability.

**Results:** In total 20 patients were evaluated, out of which 12 were male and 8 female and the mean age of patients was 51 years. Around 90% of female patients were illiterate and financially dependent while on the contrary 90% male patients were literate and financially independent. All the patients presented with some or severe disability according to Salsa scale. There was significant association of age, education, marital status and employment status with disability.

**Conclusions:** In spite of elimination of leprosy in India, cases of disability and deformity have not declined as expected. Awareness about warning signs among patients and timely diagnosis by health professionals can curb cases of disability among leprosy patients.

**Keywords:** Leprosy, Disability, SALSA scale

### INTRODUCTION

Leprosy is a chronic granulomatous disease caused by *M. leprae* bacilli, which affects mainly the superficial tissues like skin and peripheral subcutaneous nerves, mucosa of upper respiratory tract and the eyes. The microorganism possesses a high infectivity but low pathogenicity, that is, it infects many people but few fall ill. The main route of transmission is by droplet mode. The other usual mode of transmission is by direct skin to skin contact with the ulcerative lesion of leprosy patient.<sup>1</sup>

In 1991 the World Health Assembly passed a resolution to “eliminate” leprosy as a public health problem by the year 2000. Elimination of leprosy is defined as a registered prevalence rate of less than 1 case per 10,000 persons. The target was achieved on time at global level. India achieved this target in 2005. The prevalence rate of the disease has dropped by 99%: from 21.1 cases per 10,000 people in 1983 to 0.2 cases per 10,000 people in 2015. There were 2,16,108 new leprosy cases registered globally in 2016, according to the official figures from 145 countries from the six WHO Regions. India, Brazil

and Indonesia has highest burden of disease. With 1,27,326 new cases, India accounted for 60% of the global new cases. Brazil, reported 26,395 new cases representing 13% of the global new cases; and Indonesia reported 17202 new cases, 8% of the global case load.<sup>2</sup>

Leprosy has five clinical forms: undetermined, tuberculoid, pure neural, borderline and lepromatous. Pure neuritic leprosy clinically present as peripheral neuropathy with functional impairment of single or multiple nerves but without other cardinal signs of leprosy, i.e. typical skin lesions. In peripheral far flung health institutes, for diagnosing leprosy in the absence of slit skin smear or biopsy more emphasis was laid on the skin lesions (hypopigmented anesthetic skin patch). Thus it is quite likely that these pure neuritic leprosy patients are often missed. Also, when these pure neuritic leprosy patients are finally diagnosed, it is too late and they land up after receiving various treatments other than MDT. The main reason for delayed detection is lack of clinical expertise of primary health care workers. The patient is also unaware of early symptoms like loss of sensations or a hypo pigmented patch leading to delay in seeking medical help. Some patients are reluctant to seek help due to social stigma attached to the disease. Consequently such patients present with disabilities and deformities.

Disability not only refers to physical impairments, but covers any impairment, activity limitation or participation restriction affecting a person, according to the International Classification of Functioning, Disability and Health (ICF).<sup>3</sup> Thus it is important to determine the dimension and nature of these disabilities through specific periodic assessment and its relation to education, gender, age, occupation and marital status. Some questionnaires are used for assessment of activity limitation and safety awareness; the SALSA scale. The SALSA scale measures activity limitation in people with a peripheral neuropathy, such as diabetes and leprosy.<sup>4</sup>

The present study was conducted at Leprosy Hospital, Sarol, Chamba, India. It was Asia's first leprosy hospital indicating the long history of prevalence of this disease in this area. Although many studies are conducted to analyze the disability limitation in leprosy patients, no such study was done in this far flung area having historical leprosy treatment activities, catering patients of Northern Himachal and bordering areas of Jammu and Kashmir.

The present study has been undertaken to study the relation of disability among leprosy patients with education, gender, age, occupation and marital status.

## METHODS

This study was a cross sectional one, which was conducted at Leprosy Hospital Sarol, Chamba, Himachal Pradesh, India over a period of two months, May and June 2018. The study used convenient sampling and all

20 disabled patients who were receiving treatment at Leprosy Hospital were included in the study. Personal interviews were conducted by the researcher himself/herself Socio demographic data which included age, marital status, occupation, type and duration of disability was collected.

To screen for activity limitation and safety awareness SALSA scale was used. It consists of 20 items covering mobility, self care and ability to do different activities. If the patient is able to carry out an activity he/she should rate the ease with which the activity is undertaken. If no reason for not undertaking the activity is noted. The SALSA score has a hypothetical range from 0 to 80 and a score of 20 would indicate that patient has no activity limitation. Higher scores would mean increased activity limitation. A score of 25 or more points is indicative of activity limitation.<sup>4</sup> The collected data was coded appropriately and analyzed using SPSS 20.0.

## RESULTS

In total 20 patients were evaluated, out of which 12 were male and 8 female and the mean age of patients was 51 years. Maximum males were married and living with spouse and maximum females were either widow, divorced or separated. Regarding education, around 90% of female patients were illiterate, while on the contrary 90% of male patients were at least able to read and write. Also majority of females were unemployed and economically dependent on family for sustenance, while maximum males were self employed (Table 1).

**Table 1: Demographic distribution of people affected by leprosy.**

Variables	Male (n=12)	Female (n=8)	Total (n=20)
Age (yrs)	51 (34-68)	51 (42-60)	
Mean age (yrs)	51		
Marital status	N (%)	N (%)	N (%)
Married	7 (58.3)	3 (37.5)	10 (50)
Single	3 (25)	0 (0)	3 (15)
Separated/ Divorced/ Widow	2 (16.5)	5 (62.5)	7 (35)
Education			
Illiterate	2 (16.5)	7 (87.5)	9 (45)
Primary	7 (58.3)	1 (12.5)	8 (40)
Higher/ advanced	3 (25)	0 (0)	3 (15)
Employment			
Self employed	10 (83.5)	2 (25)	12 (60)
Job	0 (0)	0 (0)	0 (0)
Unemployed	2 (16.5)	6 (75)	8 (40)

Taking into account the SALSA scale, maximum patients presented with some limitation (around 60%) and remaining with severe limitation. There was significant

association of gender with disability ( $p=0.009$ ) Males were more affected than females. More people of older age group (50-70 years) were affected by severe disability than of younger (30-50 years) age group. Also majority of patients with severe disability were single/separated/ divorced/ widow, while majority of patients

with some disability were married. There was strong association of education with disability ( $p=0.0045$ ). Almost all the patients with severe disability were illiterate. Disability also had a significant association with employment status ( $p=0.009$ ). Majority of severely disabled patients were jobless (Table 2).

**Table 2: Demographic distribution of patients with leprosy in relation to severity of disability, according to SALSA scale.**

Variable		Some disability	Severe disability	P value
<b>Gender</b>	Male	2	10	0.009
	Female	2	6	
<b>Age (in years)</b>	30-50	9	3	0.1675
	50-70	3	5	
<b>Marital status</b>	Single/separated/divorced/widow	3	7	0.0198
	Married	9	1	
<b>Education</b>	Illiterate	2	7	0.0045
	Literate	10	1	
<b>Employment</b>	Self employed/job	10	2	0.009
	Unemployed	2	6	

## DISCUSSION

In the present study males were more commonly affected by some or severe form of disability in comparison to females. The disability was significantly associated with gender ( $p=0.009$ ). Similar finding was observed by Asia and others in a study conducted at Maharashtra.<sup>5</sup> Singhi from a study undertaken in Jodhpur, Rajasthan found similar association. Males because of their outdoor occupation and heavy physical work are more prone to injuries and disabilities.<sup>6</sup>

Significant proportions of female patients in our study were single, separated, divorced or widow. In contrast maximum of male patients were married and living with spouse. Similar finding was observed by Van et al in a study conducted at Indonesia.<sup>7</sup> The proportion of persons who were separated, divorced or widowed was higher among women (22.5%) than among men (8.3%;  $p<0.001$ ). Women in Asian society are generally dependent on family and have limited say in family matters. With disability they are generally looked down upon by partner, leading to abandonment or divorce.<sup>7</sup> Nardi et al in a study conducted at Delhi Cantt area reported that there was no difference in percentages of disability in leprosy patients, those who were with partner (31.5%) and without partner (33%).<sup>8</sup> This difference might be due to different study setting and difference in urban rural socio cultural practices and status of women.

Education has a significant influence ( $p=0.0045$ ) on severity of disability. In the present study illiterate patients were more severely disabled. Similar finding was reported by Umi et al in leprosy patients of Java. In them, educational status and years lost to disability (YLD) were inversely related.<sup>9</sup> Likewise Kaur et al in their study done at Varanasi found out that low level of awareness led to

delayed time of diagnosis and increased chances of deformity and disability.<sup>10</sup> Therefore Illiteracy and low priority to self care remain a major deterrent to self reporting causing delayed treatment and subsequent disability.

Disability has a direct bearing on employability as evident in the present study ( $p=0.009$ ). Majority of the severely disabled patients were unemployed and patients with some disability were either self employed or in some form of job. Similarly Nardi et al found out that as grade of disability increased employability decreased.<sup>8</sup> Most of the people affected by leprosy were engaged in low risk professions or were unemployed. This is explained by the fact that activity limitation due to disability encourages people to change from jobs that need greater physical effort to jobs that require low physical efforts or to stop working altogether.

## CONCLUSION

In spite of introduction of multi drug treatment since last 30 years supplemented by contact surveys, increased efforts to detect cases early in the community and use of information technology cases of leprosy and deformity/disability have not declined as expected. Timely diagnosis of Grade I disability is of great importance for disability elimination. Disability prevention can be achieved by active collaboration between health care professionals, patients and their family. Only then the goal of prevention of disability in leprosy patients can be realized.

*Funding: No funding sources*

*Conflict of interest: None declared*

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

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**Cite this article as:** Dixit P, Dhiman AK. Disability due to leprosy: a socio-demographic study in Leprosy Hospital, Chamba, Himachal Pradesh. *Int J Community Med Public Health* 2019;6:590-3.