

## Disability in New Leprosy Cases - Magnitude, Pattern and Associated Factors: A Cross Sectional Study in a Subdivision of Darjeeling District, West Bengal

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Leprosy is an infectious disease, which may lead to disability before, during or after treatment. Leprosy is associated with social stigma and discrimination because of disability and disfigurement and recognized as a disease of major public health significance. As factors associated with occurrence and management of disabilities may vary from area to area, it is important to generate this information in affected populations. This study has been carried out to determine the extent and pattern of disabilities among newly diagnosed leprosy cases, factors associated with disability, provision and utilization of disability preventive services. This cross-sectional study was conducted in Siliguri subdivision of Darjeeling district, West Bengal. All newly diagnosed and registered leprosy cases in a reference year (April 2013 - March 2014) were included. Detailed medical examination and interviews were carried out to assess the disability and to study the relevant aspects. The entire collected data was analysed using SPSS software and chi-square, binary logistic regression were applied to test association between disability and other epidemiological correlates. It was observed that all the disabilities were in multibacillary (MB) cases only. Child leprosy rates of 5.5% appears to be promising statistics. Among 110 new leprosy cases studied, overall proportion of disability was 15.5%; grade 1 and grade 2 disabilities were 9.1% and 6.4% respectively. Hand was the commonest site of involvement, whereas grade 2 disability was highest in feet (2.7%). Disability status was found to be significantly associated with number of nerve involvement and history of treatment interruption. Utilization of disability preventive services was found very poor. Significantly the proportion of disability was highest among leprosy cases aged 60 years or more (37.5%). As no disability was noted in patients below 15 years, march towards achieving one of the targets of Global Leprosy Strategy 2016-20 appears to be closing to goal. Though the situation may be better comparably to some other parts of country, yet the overall proportion of disabilities as well as grade 1 and grade 2 disabilities among newly diagnosed leprosy cases is unacceptably high in the studied area. Community based studies and appropriate interventions can help in achieving the targets pertaining to leprosy situation in general and access to quality services in particular.

**Key words :** Darjeeling, Disabilities, Grades of Disability, Leprosy Cases, Preventive Services

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## Introduction

Leprosy still strikes fear in the minds of people as a mutilating, contagious and incurable disease. This is mostly because of disfigurement and disability caused by the disease (Govt. of India, Guidelines on reduction of stigma and discrimination 2011). Among communicable diseases, leprosy is a leading cause of permanent physical disability (WHO 2005). Leprosy causes various degrees of disabilities and it mainly occurs in hands, feet and eyes. World Health Organization (WHO) classified disability in leprosy into two grades - grade 1 and grade 2 (Brandsma and Van Brakel 2003). These disabilities if not identified and managed timely and appropriately may result in permanent handicap also. It is also known that deformities/disabilities associated with leprosy are mainly responsible for social stigma and discrimination against patients and their families in many societies. Hence, the need for early identification and management of disabilities in leprosy is emphasized.

Leprosy is a highly focused disease throughout the globe. The global elimination was achieved by the year 2001, except some endemic countries. India had a long history of effort against leprosy. The country achieved the goal of elimination at the national level in December 2005 (Govt. of India, Leprosy Situation as on August 2007, 2007a). Besides early detection and management of all new leprosy cases present focus is on prevention of disabilities and provision of rehabilitative services for leprosy patients. Thus a new initiative has been implemented namely 'Disability Prevention and Medical Rehabilitation' (DPMR) with primary objectives to prevent disabilities and worsening of existing deformities in all needy leprosy affected persons. The services are recommended to be provided through the already existing primary, secondary and tertiary level health care infrastructures in

the country (Govt. of India, Disability prevention and medical rehabilitation 2007b).

Few studies at various places and setting in different states also reported varied proportions of disabilities and associated factors (Jain et al 2011, Sarkar et al 2012, Chavan and Patel 2011, Jindal et al 2009, Kumar et al 2008, Thakkar et al and Patel 2014). However, community based evaluated information in West Bengal, particularly in Darjeeling district is lacking. The status of disability preventive services provision and utilisation (selfcare advice, selfcare kits, microcellular rubber footwear, protective sunglasses, reconstructive surgery etc) is another important issue of present day concern, which has not yet been widely studied or documented. Assessment of these aspects of the disease and the related programme will help the health planners and authorities to develop appropriate strategies and activities at various levels for effective provision of services in this area. Global Leprosy Strategy 2016-20 has already set the target of zero disability in child cases and overall disability rates of less than one per million population (Global leprosy Strategy 2016-20). With this perspective, the present study was done with the aim of generating information regarding extent of disabilities, factors associated with disabilities and utilisation of relevant services among new leprosy cases (Govt. of India, Guidelines for "Other-cases" under NLEP 2007c) in a subdivision of Darjeeling district, West Bengal.

## Materials & Methods

This descriptive cross-sectional study was carried out on newly diagnosed (Govt. of India, Guidelines for "Other-cases" under NLEP 2007c) and registered leprosy patients in the programme during a reference period of one year (April 2013-March 2014) in Siliguri Subdivision of Darjeeling district, West Bengal. Darjeeling district has four

sub divisions (Darjeeling, Kurseong, Kalimpong and Siliguri), more than 90% leprosy cases of this district were reported from the Siliguri sub division. We intended to include all such cases in the study area with at least one month duration after diagnosis and initiation of multi drug therapy (MDT). These cases were diagnosed, classified into paucibacillary (PB) and multibacillary (MB) types and treated as per WHO guidelines followed by NLEP (NLEP 2013). Out of total 125 cases in the reference year, 15 were excluded (1 person died before assessment and 14 others could not be traced even after repeated attempts) and thus a total of 110 cases were studied.

Ethical approval was obtained from the Institutional Ethics Committee of North Bengal Medical College. Permission and co-operation of the district health authorities were sought prior to data collection. The subjects were contacted at their respective residential places, those fulfil the eligibility criteria were briefed about the purpose and nature of the study and a informed consent was obtained for interview and clinical examination.

Disability assessment was done following the recommended guidelines (Govt of India, Training Manual for Medical Officers 2013) in daylight maintaining privacy and dignity of the subjects. Physical examination, examination of eyes, sensory test (ST), nerve examination, voluntary muscle tests (VMT), and tests to detect early muscle weakness were done as per the prescribed procedures. Female patients were examined in presence of another female preferably her own family member. Presence of disability in hands, feet and eyes was categorized according to WHO disability grades (Brandsma and Van Brakel 2003). The highest grade given in any of the part was used as the disability grade for that patient. EHF (Eye, Hand, Feet) score i.e. sum of all the individual disability grades for two

eyes, two hands and two feet was recorded. Thus for every subject EHF score ranged from 0–12. Higher number of EHF score indicates more severe form of disability according to the assessment guidelines (Govt of India, Training Manual for Medical Officers 2013).

Data regarding socio-demographic characteristics, other associated factors related to the registered leprosy cases as well as provision and utilisation of disability prevention and medical rehabilitation services was obtained by interview of the study subjects and review of available records.

Collected data were checked for consistency, entered in Microsoft Excel data sheet and analysed by IBM Statistical Package for Social Sciences (SPSS) version 20. Data were organized and presented using the principles of descriptive statistics. Chi-square test and binary logistic regression were applied to test association between disabilities and other epidemiological co-relates. For the dependant variable presence of disability, the predictor variables included in the analysis were: gender, religion, caste, socioeconomic status, literacy status, delay in diagnosis, interruption in taking medicines, reaction during treatment and number of skin patches and nerve involvement.

## **Results**

Out of 125 newly registered cases in the reference year, only 110 cases were studied; the response rate being 88%. Findings are presented in Fig. 1 and Tables 1-4. Most of the cases (63.6%, 70/110) belonged to 15-44 years age group (Fig. 1) with mean age of the cases being 33.52 years (SD  $\pm$ 14.583); indicating mostly economically productive age group being affected by the disease. Proportion of childhood cases (< 15 years) was 5.5%. Cases were noticed in higher proportion among males (62%, 68/110) than females (Table 3) with male to female ratio

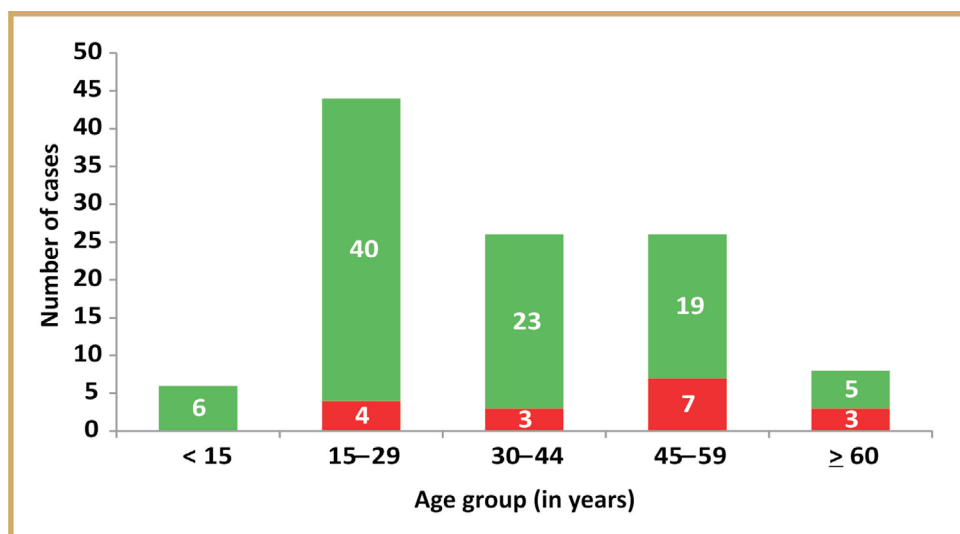


Fig 1 : Disability status in different age groups (Grade 1 and 2 combined, red colour are the numbers of patients having disabilities)

Table 1: Disability in new leprosy cases according to types of cases (n=110)

Factors	Disability		Total	Statistical tests
	Present (%)	Absent (%)		
<b>Types of cases</b>				
Pauci-bacillary	0 (0)	40 (100)	40	$\chi^2 = 11.490$ , df=1, p = 0.001
Multi-bacillary	17 (24.3)	53 (75.7)	70	
Total	17 (15.5)	93 (84.5)	110	

Table 2 : Sites of involvement and grades of disability (n=110)

Site of involvement	Grades of disability			Total N (%)
	Grade 0 N (%)	Grade 1 N (%)	Grade 2 N (%)	
Eye	108 (98.2)		2 (1.8)	110 (100)
Hands	102 (92.7)	6 (5.5)	2 (1.8)	110 (100)
Feet	103 (93.7)	4 (3.6)	3 (2.7)	110 (100)

of 1.6:1. Cases were mostly seen among Hindus (79.1%) and majority belonged to SC category.

Almost 3/4th of the cases were from rural areas, half of them were illiterate. Cases were found

**Table 3 : Association of disability with socio-demographic variables (n=110)**

Variables	Disability		Total	Statistical tests AOR (95% CI)
	Present (%)	Absent (%)		
<b>Gender</b>				
Male	11 (16.2)	57 (83.8)	68	1 (Referent)
Female	6 (14.3)	36 (85.7)	42	0.526 (0.107–3.135)
<b>Religion</b>				
Hindu	13 (14.9)	74 (85.1)	87	1 (Referent)
Muslim & Christian	4 (17.4)	19 (82.6)	23	0.281 (0.034–2.658)
<b>Caste</b>				
General	2 (5.1)	37 (94.9)	39	1 (Referent)
Schedule caste	7 (14.9)	40 (85.1)	47	0.061 (0.912–69.195)
Schedule Tribe	4 (30.8)	9 (69.2)	13	0.152 (0.533-57.312)
Other backward class	4 (36.4)	7 (63.6)	11	0.404 (0.237-35.893)
<b>Literacy status</b>				
Illiterate	13 (23.6)	42 (76.4)	55	1 (Referent)
Literate	4 (7.3)	51 (92.7)	55	0.162 (0.085–1.512)
<b>Occupation</b>				
Housewives	3 (12.5)	21 (87.5)	24	1 (Referent)
Unskilled workers	10 (31.2)	22 (68.8)	32	0.938 (0.107–11.293)
Skilled workers*	2 (6.3)	30 (93.7)	32	0.520 (0.076-3.684)
Others#	2 (9.1)	20 (90.9)	22	0.0482 (0.237-21.041)
Total	17 (15.5)	93 (84.5)	110	110 (100)

\* Also includes – business/service, # Students, unemployed and at home persons.

more in joint families (57.3%) and substantial proportion of them had either family history (32.7%) or any contact history with leprosy cases (43.6%). Majority of the cases (63.6%) were found to be of multi-bacillary types and disabilities were seen in these MB cases only (Table 1).

#### **Disability - extent, pattern and co-relates :**

Among these 110 new leprosy cases studied, 17 (15.5%) had deformities/ disabilities (Table 1, Fig 1); of them 10 (9.1%) had grade 1 and 7 (6.4%) had grade 2 disabilities. Combination of both

types of disabilities was also observed among few subjects. It was noted that, majority of grade 2 disabilities were in feet (2.7 %), followed by in eyes (1.8%) and hands (1.8%). Grade 1 disability was found maximum in hands (5.5%), followed by 3.6% in feet (Table 2). Further analysis showed that, among 7 leprosy cases having grade 2 disabilities 5 persons had single site involvement (4.5%) and only 2 subjects had multiple site involvement. Visible deformity was noted among 7 (6.4%) subjects. Most common form of

**Table 4 : Association of disability with clinico-therapeutic profiles of new leprosy cases (n=110)**

Variables	Disability		Total	Statistical tests AOR (95% CI)
	Present (%)	Absent (%)		
Gap in diagnosis (months)				
< 2	2 (6.9)	27 (93.1)	29	1 (Referent)
2 – 5	4 (8.9)	41 (91.1)	45	0.451 (0.235-25.884)
≥ 6	11 (30.0)	25 (70.0)	36	0.576 (0.291-9.197)
Number of skin patches				
Single	1 (1.9)	53 (98.1)	54	1 (Referent)
≥ 2	16 (20.0)	40 (80.0)	56	0.156 (0.50–76.298)
Number of nerve involvement				
Nil	1 (2.1)	47 (97.9)	48	1 (Referent)
Single	1 (4.0)	24 (96.0)	25	0.090 (0.721-93.672)
≥ 2	15 (40.5)	22 (59.5)	37	0.012* (2.033-342.83)
Interruption in taking drugs				
Yes	13 (39.4)	20 (60.6)	33	1 (Referent)
No	4 (5.2)	73 (94.8)	77	0.001* (0.015–0.367)
Reaction during treatment				
Yes	2 (28.6)	5 (71.4)	7	1 (Referent)
No	15 (14.6)	88 (85.4)	103	0.786 (0.046–10.188)
Total	17 (15.5)	93 (84.5)	110	110 (100)

deformity was ulcer of sole (3.6%), followed by ulcer of palm (1.8%). Clawing of fingers and lid gap was found in 1 study subject (0.9%).

EHF score signifies severity of disability. 17 persons (15.4%) had EHF score in between 1-9. Among them majority had score 1 (6.4%), 3.6% had score 3 and 2.7% had score 2. One person each (2.7%) had score 6, 7 and 9.

None of the paucibacillary case (PB) was found to have any form of disability; whereas among the 70 multi-bacillary cases (MB) (63.6% of total cases), 17 (24.3%) had disability (Table 1), the distribution being statistically significant

( $p=0.001$ ). Proportion of disability was highest among leprosy cases aged 60 years or more (37.5%). Significantly no disability was noted below 15 years (Fig. 1). The proportion of subjects having disabilities increased significantly with increase in age ( $p=0.006$ ). The proportion of disabilities was also found to be higher among males, illiterates, unskilled workers and persons belonging to scheduled tribe & OBC categories than their counterparts. However, binary logistic regression revealed no significant association with these socio-demographic variables (Table 3).

Binary logistic regression analysis suggests that the odds of suffering from disabilities were significantly higher among leprosy cases having 2 or more nerve involvement and those who had history of treatment interruption ( $\geq 7$  days). Though, multiple skin patches, time gap in diagnosis (ranges from 1 week to 12 months with mean duration of 3.8 months), history of reaction during treatment (with MDT) were not found to be significantly associated with disabilities (Table 4). However, the regression model could explain 58.7% variation (Nagelkerke R square = 0.587).

#### **Disability preventive and rehabilitative services:**

Assessment of the relevant service provision revealed, among the 17 study subjects having disabilities, only 6 (35.3%) had been given self care advice by the health care providers and only 3 (17.6%) of them were provided self care kits. Moreover, among 2 patients with eye disabilities, none were provided protective sunglasses. Two leprosy cases with clawing of fingers, though eligible but none of them were provided corrective splint. However, among 3 leprosy cases with grade 2 disabilities of feet being eligible for MCR footwear; two of them were provided with MCR footwear.

#### **Discussion**

Overall extent of disability among new leprosy cases as well as its proportion in terms of different grades may vary from place to place and also over time. The comparative discussion of the findings of the present study with that of other evidences clearly supports this. Various studies in India (Jain et al 2011, Sarkar et al 2012, Chavan and Patel 2011, Jindal et al 2009, Kumar et al 2008, Thakkar and Patel 2014) and across the world (Withington 2005, Rad and Ghaderi 2007, Pimentel et al 2004, Noor et al 2010, Soomro et al 2008, Entezarmahdi et al 2014) have also reported varying proportion of disabilities among

new leprosy cases. In India, some previous studies have reported various proportions of disabilities ranging from 20.1% to 62.6% (Chavan and Patel 2011, Jain et al 2011, Sarkar et al 2012).

Extent of disability among new leprosy cases in the area of Darjeeling was found to be substantially high in the year (April 2013-March 2014). Among 110 new leprosy cases studied in year, overall 15.5% had any disability, with 9.1% and 6.4% grade 1 and grade 2 disabilities respectively. In the same year, the reported proportion of overall disability among new leprosy cases in West Bengal (Govt. of India, NLEP, PIP 2012) as a whole was much lower (5.56%) than the study area (15.5%). The proportion of grade 2 disability in the studied area (6.4%) was also found higher than the state level (2.57%) and the overall country level (4.14%).

A study in Nagpur city reported 12.38% grade 2 disabilities among new leprosy cases (Chavan and Patel 2011). A study from Gwalior District showed 62.6% overall disability with 41.75% grade 2 disabilities (Jain et al 2011). Another study in Bankura district of West Bengal reported overall proportion of disability as 20.1% with 8.6% grade 2 disabilities (Sarkar et al 2012).

Present study also revealed that hand was the commonest site for disabilities (mainly in the form of anaesthesia), whereas most common sites for visible deformity were in feet (as ulcer). Hands as the most common site for disabilities were also reported by Jain et al (2011), Chavan and Patel (2011), Soomro et al (2008) and Noor et al (2010) in their studies in various places of India and abroad. On the contrary, in a study at Bankura district of this state by Sarkar et al (2012) noted feet as the most common site for disabilities. Assessment of these patterns of disabilities is essentially required at local/regional level for appropriate planning and provision of relevant services. Proportion of disabilities was

more in leprosy patients who had 2 or more nerve involvement and subjects with history of treatment interruption. Similar association was also reported by Jain et al (2011).

Though overall proportion of disabilities among new leprosy cases has decreased, but still the proportion of grade 2 disabilities (6.4%) in the studied area was alarmingly high, indicating probably delayed diagnosis of the cases. This part of the programme implementation needs to be carefully addressed to have the impact of the interventions, as we are far away from the national target of 1.98% to be reached at end of 12th five year plan (Govt. of India, NLEP, PIP 2012). Current Global Leprosy Strategy 2016-20 has target of zero disability in children which seems to have been achieved in this area, this however, needs to be validated at field level. However, the target of less than 1 per million populations seems to far off yet achievable. Thus to further reduce the proportion of grade 2 disabilities and to reach the desired target emphasis should be strengthened for early detection of the cases. It is not clear as how much these disabilities are contributing to social stigma and vice versa. It will be important to carefully look into these aspects which have already been the focus of NLEP ( Govt of India 2011).

The present study revealed certain important issues related to 'DPMR' component of the national leprosy elimination programme. Among all the cases with disabilities, only 1/3rd of them had been given self care advice and majority of them (76.5%) were not practicing self care because of unawareness. Very few of the eligible disabled cases were provided with self care kits and MCR footwear. Thus it can be inferred from the above findings that provision and utilization of relevant disability preventive services in the studied area, though available but not up to the desired level.

Role of some other factors like delay in diagnosis, interruption in drug consumption, reactions during treatment etc might be considered as causative reasons for disability. Though these assumptions are not supported by definite empirical evidences and case based analysis. From the interpretation of the data it was also clear that there was lack of adequate interpersonal communication between the health care providers and the leprosy affected persons, particularly in terms of utilization of provided services.

Despite adequate safeguards the following limitations in the present study could not be avoided. Some of the registered new leprosy cases could not be contacted in spite of repeated visits. Clinical profile of the cases was solely based on the recorded information in the relevant records/registers maintained at different health facilities rather than actually assessed by the researcher; this might have led to information bias. Appropriate assessment of provision and use of DPMR services ideally requires multiple visits; which could not be done in the present study. Recall bias during interview for some variables could not be avoided.

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