Original Article

Disability among new leprosy patients, an issue of concern: An institution based study in an endemic district for leprosy in the state of West Bengal, India

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ABSTRACT

Background: Both magnitude and severity of disability in new leprosy patients measure indirectly the disease transmission in the community and rapidity of case detection. Various factors might be associated with the presence of impairment at registration. **Aims:** To find out the prevalence of both grade 1 and grade 2 disability among new leprosy patients along with association of some clinical and sociodemographic factors. **Methods:** A cross-sectional study was carried out in the Skin out patient department (OPD) of a Tertiary care hospital in West Bengal, which is situated in a highly endemic district of leprosy (prevalence was 6.5/10000, year 2007). About 244 new leprosy patients were interviewed and clinically examined during Aug'06-Jun'07. Data was analysed in percentages, χ^2 test, Anova. **Results:** Proportion of disability was quite high among the studied new leprosy patients, 11.5% had grade-1 and 8.6% had grade-2. Disability was more among the patients with pure neuritic type of leprosy (<0.001), multibacillary leprosy (*P*=0.000), patients with delayed registration (*P*=0.000) and who were engaged as manual laborers (*P*=0.001). Feet were commonly involved site and nerve function impairment, both sensory and motor were the commonest nature of disability found in this study. **Conclusion:** To reduce new leprosy cases with grade-2 disability, early diagnosis of the leprosy patients and searching for grade-1 disability should be routine procedure in our health system, for which thorough neurological examination along with appropriate preventive measures is the need of the hour.

Key words: New leprosy patient, pure neuritic type, registration delay, WHO disability grade (1998)

INTRODUCTION

Widespread implementation of MDT has clearly been extremely successful in curing and reducing the prevalence of leprosy throughout the world including India. As on 1st April' 09 the prevalence rate of leprosy in India was 0.72/10000. In recent years under leprosy control programme more attention has been given to prevention of disability.[1,2] Among communicable diseases, leprosy remains a leading cause of peripheral neuropathy and disability in the world, despite extensive efforts to reduce the disease burden. In 2009, WHO launched the Enhanced Global strategy for further reducing the disease burden due to leprosy for 2011-2015, under which the target was to reduce number of new cases of leprosy with grade-2 disability (G2D) per 100000 population by at least 35% between the end of 2010 and the end of 2015 instead of leprosy prevalence. In 1995-2010 G2D has decreased every 5 year by 12.7% in Brazil, 7.7% in China, 53.7% in India, and 35.9% in Thailand (endemic countries in the world at present).[3]

Pure neuritic leprosy clinically present as peripheral neuropathy with functional impairment of single

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or multiple nerves but without other cardinal signs of leprosy, i.e. typical skin lesions and sometimes even presence of Acid Fast Bacillus (AFB). In regions endemic for leprosy, there is a tendency to attribute peripheral neuropathy to leprosy without any specific investigation. In such cases the diagnosis depends on finding definite nerve thickening with Nerve Function Impairment (NFI) i.e. sensory NFI or motor NFI or both.[4] Since for diagnosing leprosy more emphasis was laid on the skin lesions (hypopigmented anesthetic skin patch), it is quite likely that these pure neuritic leprosy patients are often missed. On the other hand when these pure neuritic leprosy patients are finally diagnosed as having leprosy, it is too late (after receiving various treatments other than MDT) and they consequently present with disability. However, those who suffer from neuritic symptoms and signs along with skin lesion/s are quickly diagnosed since awareness regarding the hypopigmented anesthetic patch in the skin is more among people living in leprosy endemic area. As a result, their health-seeking behavior is good and health personnel are also more skillful in diagnosing these cases with skin lesion/s than those with only nerve pathology.

Disability assessment is a very relevant measure of leprosy control. However, routinely in our Healthcare System only G2D record (WHO) is maintained, whereas grade-1 assessment, though is more important in terms of prevention of disability, is a neglected issue. Therefore timely diagnosis of grade-1 disability, is urgently required for disability limitation and mitigation. Searching for associated factors will definitely help to lessen the suffering of many leprosy patients.

In this perspective, this cross-sectional study was carried out in a tertiary care hospital situated in a highly endemic district in West Bengal during 2006-2007 to find out the proportion of disability (both grades) among new leprosy patients along with some socio-demographic and clinical factors associated with it.

METHODS

The present study was a cross-sectional analysis of 244 new leprosy patients who were diagnosed as suffering from leprosy for the first time and had not taken any antileprotic drug in the past. We assessed some socio-demographic, clinical factors and disability grade of these study population in the Skin OPD of a tertiary care hospital, which is situated in a highly endemic district of leprosy in West Bengal, India.

The study was in accordance with Helsinki Declaration of 1975, as revised in 2000. Before data collection, IEC clearance and written permission from administrative authority of this tertiary care hospital was undertaken.

Study site

The data was collected from the patients attending the Skin OPD of B.S. Medical College and Hospital, Bankura. The district Bankura is situated in western part of West Bengal. Bankura is well known for its high endemicity due to leprosy since long, with block-wise Prevalence Rate varying from $2/10^4$ to $18/10^4$ in 2006-2007.[5] There was a separate designated area in the Skin OPD to examine leprosy patients.

Study subjects

All the new leprosy patients who had attended this hospital during the study period were eligible for the study and included in the study after taking informed consent from them. Data was collected from registered new leprosy patients (already been diagnosed by the on duty medical officer in charge of leprosy) after their registration but before collecting antileprotic drugs. Total 244 new leprosy patients were interviewed in respect to socio-demographic factors and clinically examined for which the 'National Leprosy Eradication Programme (NLEP) Training Manual for Medical Officers' was followed.[6]

Measurements

Data was collected from new leprosy patients by interview, clinical examination and record review of OPD ticket. All the information was collected in the pretested semistructured questionnaire. Data regarding sociodemographic variables like age, sex, education, occupation, marital status, registration delay were recorded in the first part of the schedule. Registration delay was considered as the time gap between noticing of first symptom/s by the patient (guardian in case of children) and coming to the health facility for registration and starting of antileprotic drug.[7,8] It was recorded as stated by the patient and based on the patient recall although this time gap was validated by cross-checking against significant family, local or national events or religious festivals.

Clinical evaluation

Second part of the examination schedule consisted of the clinical evaluation. For type of leprosy, WHO

clinical classification which is simply based on number of skin lesions and number of thickened nerves was followed. Only when there was diagnostic confusion, patients were referred to slit skin smear. Nerve Function Impairment (NFI) was defined as clinically detectable impairment of motor, sensory or autonomic nerve function.[9] In case of pure neuritic type, single nerve thickening along with sensory and/or motor NFI was classified as PB and more than one nerve thickening along with sensory and/or motor NFI was classified as MB. For disability classification WHO 3-point scale in 1998 was followed for hands, feet and eyes. For overall disability grade of a patient the maximum grading at any of these sites was considered.[10] For sensory testing of hands and feet, light touch (just enough to indent the skin very slightly) of the tip of ball point pen was used, as repeatability of ball pen testing was moderate to good in the hands of trained staff other than universal availability of the testing instruments.[11] Six sites in each palm and four sites in each sole were tested.[11] If the patient could not identify the touch within 2 cm. of the tested site (eyes closed), it was recorded as one insensitive point.[12] The ballpen test was considered positive if 2 or more test sites in either hand or foot did not feel the stimulus (i.e., sensory NFI was present).[11] Motor nerve function impairment (NFI) was assessed by voluntary muscle testing (VMT) of the commonly examined peripheral nerves (in leprosy) and graded as S (strong), W (weak), P (paralysed).[6] Both W (weak) and P (paralysed) were recorded as motor NFI present. For assessing motor NFI in hands, abduction of thumb, little finger and index fingers, opposition of thumb and extension of wrist against resistance were tested separately for both sides. Similarly for feet, tested movements were dorsiflexion of feet, eversion of feet, extension of hallux. Any visible impairments like cracks/wounds, absorption of fingers/toes, clawing of fingers/toes, contractures, wrist/foot drop or any other impairments were recorded as grade-2 disability of hands and feet. For testing loss of corneal sensation (grade-1 disability of eye) light touch of the cotton wisp from the lateral side was approached. It was also noted whether blinking of the eyes was normal or not. To asses motor NFI in eyes, the patients ability to in close the eyes both lightly and tightly against resistance was tested. For grade-2 disability of eye, visible impairments like lagophthalmos, corneal opacities and iridocyclitis, loss of eye brows were recorded. Visual acuity was tested in a semidark area by Snellen's chart for each eye separately at 6 metres distance (as visual acuity 6/60 is the demarcation line between grade-1 vs. grade-2 other than visible deformity).[10] In case there was any diagnostic problem, eye specialist was contacted. The variables studied were WHO disability grade, leprosy clinical type, number of skin lesions, nature of disability in eyes, hands and feet.

Data analysis

Data was collected, compiled and analysed using Epi-Info, Version 3.5.3. Data was described in proportions, mean values, χ^2, Anova as applicable.

WHO disability grading 1998[10]

Hands and feet

Grade '0' No anesthesia, no visible deformity or damage.

Grade '1' Anesthesia present, but no visible deformity or damage.

Grade '2 Visible deformity or damage present.

Eyes

Grade '0' No eye problem due to leprosy, no evidence of visual loss.

Grade '1' Eye problem due to leprosy present, but vision not severely affected as a result of this (vision 6/60 or better; can count fingers at 6 metres distance, corneal sensation testing-optional).

Grade '2' Severe visual impairment (vision: worse than 6/60: Inability to count fingers at 6 metres distance), also includes lagophthalmos, iridocyclitis and corneal opacities.

RESULTS

Data from 244 interviewed new leprosy patients showed that 20.1% had disability, among which 11.5% had grade-1 (loss of sensation) and 8.6% had grade-2 (visible deformity) disability. Out of the studied new leprosy patients, 23 patients (9.4%) had no skin lesions, i.e. they were pure neuritic type. These patients were diagnosed on the basis of thickened peripheral nerves with sensory NFI or motor NFI or both. Both grade-1 (39.1%) and grade-2 (21.8%) disability were more among these pure neuritic leprosy patients. Patients with more than five skin lesions also had more disability than patients with ≤5 lesions (grade 1-10.5 vs 7.8%, grade 2-8.9 vs 6.5%). These findings were also statistically significant ($P<0.001$). Proportions of patients availing Multidrug Therapy

for leprosy from this health facility with registration delay more than 6 months were more both for pure neuritic type (91.3%) and with >5 skin lesions (88.1%) compared to those having ≤5 skin lesions (37.9%). This association was also statistically significant ($P<0.001$). We have described these findings in Table 1.

Findings from Table 2 showed that MB patients had significantly more disability than PB patients (31.6% vs 10%, $P=0.001$). This table also showed that patients who had registered early i.e. within 6 months, suffered less from any grade of disability (3.8%). Proportion of disability increased as delay in registration increased viz. 34.5% had grade-1 and 44.8% had grade-2 disability when patients came within 13-23 months but this proportion increased to 55.6% for grade-2 and 33.3% for grade-1, when registration delay was ≥24 months. This association of degree of disability with registration delay was statistically significant ($P=0.000$). Table 2 also showed that mean registration delay increased with increase in grade of disability. When this mean registration was analyzed by Anova, it was statistically significant (F-89.86; $P<0.01$). Manual laborers like rickshaw-puller, agricultural laborer, carpenter, barber, etc. had significantly ($P<0.001$) more disabilities than those who were engaged in other occupations like businessmen, clerks, students, etc. Other associated factors for increased proportion of disability among new leprosy patients found in this study were (not shown in Table 2) increase in age ($P=0.143$), male sex ($P=0.05$), illiteracy ($P=0.117$), divorced/separated patients ($P=0.40$).

Feet were commonly involved site of disability among studied new leprosy patients followed by hands. Sensory nerve function impairment was commonly

Table 1: Association of new leprosy patients (pure neuritic type and with skin lesion/s) with disability grade and registration delay

Variables	Number of Skin lesion/s						
	Neuritic (none)	>5	1-5	Total	x^2	df	*P*
WHO disability grade	(*n*=23,9.4%)	(*n*=67)	(*n*=154)	(*n*=244)			
0	9 (39.1)	54 (80.6)	132 (85.7)	195 (79.9)			
1	9 (39.1)	7 (10.5)	12 (7.8)	28 (11.5)	27.09	2†	<.001*
2	5 (21.8)	6 (8.9)	10 (6.5)	21 (8.6)			
Registration delay in ms.‡	(*n*=23)	(*n*=67)	(*n*=153)	(*n*=243)§			
≤6	2 (8.7)	8 (11.9)	95 (62.1)	105 (43.2)			
7-12	7 (30.4)	47 (70.1)	46 (30.1)	100 (41.2)	43.05	2‖	<.001*
13-23	11(47.8)	8 (11.9)	10 (6.5)	29 (11.9)			
≥ 24	3 (13.1)	4 (6.1)	2 (1.3)	9 (3.7)			

(Figures in parentheses indicate columnwise percentages.) *significant. †(Chi-sq. has been done between grade 0 vs grade 1 and 2 with or without skin lesion/s) ‡Registration delay: Time gap between noticing first symptoms and registration along with starting of antileprosy treatment.[12] §one patient was uncertain(having 1-5 skin lesion) so excluded. ‖(Chi-sq. has been done between ≤12ms. vs >12ms)

Table 2: Distribution of disability (WHO grade) with respect to type of leprosy, registration delay and occupation of the study population

Variables	WHO disability grade					
	0 no.(%)	1 no.(%)	2 no.(%)	x^2	df	*P*
Type of leprosy						
PB (*n*=130)	117 (90.0)	10 (7.7)	3 (2.3)			
MB (*n*=114)	78 (68.4)	18 (15.8)	18 (15.8)	17.6	1*	0.000†
Registration delay in months						
≤6 (*n*=105)	101 (96.2)	2 (1.9)	2 (1.9)			
7-12 (*n*=100)	86 (86.0)	13 (13.0)	1 (1.0)			
13-23 (*n*=29)	6 (20.7)	10 (34.5)	13 (44.8)	105.53	1‡	0.00†
≥24 (*n*=9)	1 (11.1)	3 (33.3)	5 (55.6)			
Mean delay in mth	6.9 ± 3.9	14.2 ± 6.9	19.6 ± 7.5		§F_{obs}-89.86,F_{tab}4.6	0.01†
Occupation						
Manual‖ (*n*=70)	47 (67.2)	13 (18.5)	10 (14.3)			
Others** (*n*=174)	148 (85)	15 (8.6)	11 (6.4)	9.97	1	0.001†

*χ^2 has been calculated between grade 0 vs grade 1 and 2 combined and leprosy type. †significant ‡χ^2 has been calculated between grade 0 vs grade 1 and 2 combined and registration delay. ≤12 ms. vs 12 ms. **rest of the study population. §Anova has been calculated between mean registration delay and different grades of disability. ‖People working as farmers, day-laborers, rickshaw-pullers, carpenters, barb/ers, etc[1]

found disability both in hands (10.3%) and feet (13.9%) followed by motor NFI (hands-9.4%, feet-11.1%). Both in hands and feet males suffered more than the females in both sensory NFI (hands-11.8 vs 8%, feet-15.3 vs 12%) and motor NFI (hands-11.8 vs 6%, feet-13.2 vs 8%). Cracks/wounds (grade-2) were found more in feet than hands (7 vs 2.9%). In eyes 2.9% had loss of corneal sensation (grade 1), 1.2% each had lagophthalmos and severe visual impairment (acuity of vision <6/60 i.e. grade-2). These eye disabilities were almost equal for both sexes.

We have described these sites and natures of disabilities found among studied new leprosy patients in Table 3.

DISCUSSION

At the beginning of this new millennium we have been able to reach the last mile in the race to eliminate leprosy in most part of the world including India. The nature of leprosy problem is thus shifting from simply providing antileprosy treatment to the affected persons to dealing with the consequences of leprosy especially prevention of disability due to leprosy. Occurrence of disability in leprosy indicates some lacunae in the leprosy control. The findings in the current study showed that proportion of new leprosy patients with disability was quite high, 11.5% had grade-1 and 8.6% had grade-2. One of the reasons may be - the study area was situated in the skin OPD of a tertiary care hospital of leprosy-high endemic district. At National level to assess programme effectiveness only grade-2 disability record is maintained but for prevention of disability, grade-1 assessment is more important. Because, before visible deformity (grade-2) occurs, nerve function impairment definitely occurs (sensory, motor or both) i.e. those patients with G2D must have passed through the stage of grade-1. Therefore while examining any leprosy case, after examination of skin lesions, thorough neurological examination of peripheral nerves is essential. For this, assessment of sensory NFI, motor NFI are needed along with nerve palpation for thickening, tenderness, reaction for detection of grade-1 disability. This will enhance the focus on reaching the target of World Health Organisation's 2011-2015 Global leprosy strategy to reduce the prevalence of G2D.[3] A study in Thailand clinic by Schreuder among new leprosy patients showed prevalence of grade-1 and 2 disability almost similar to this study.[13]

Table 3: Nature of disability found in different sites of studied leprosy patients and sex (*n*=49)*

Nature of disability in different sites	Female (*n*=100)	Male (*n*=144)	Total (*n*=244)
Disability in eyes			
Loss of corneal sensation	3 (3.0)	4 (2.8)	7 (2.9)
Unable to tight eye closure	1 (1.0)	1 (0.7)	2 (0.8)
Unable to light eye closure (lagophthalmos)	1 (1.0)	2 (1.4)	3 (1.2)
Severe visual impairment (<6/60)	1 (1.0)	2 (1.4)	3 (1.2)
Loss of eye brow/eye lashes	_	2 (1.4)	2 (0.8)
Disability in hands			
Sensory NFI†	8 (8.0)	17 (11.8)	25 (10.3)
Motor NFI†	6 (6.0)	17 (11.8)	23 (9.4)
Cracks/wounds	2 (2.0)	5 (3.5)	7 (2.9)
Mobile claw fingers	1 (1.0)	3 (2.1)	4 (1.6)
Contractures	_	1 (3.1)	1 (2.0)
Disability in feet			
Sensory NFI†	12 (12.0)	22 (15.3)	34 (13.9)
Motor NFI†	8 (8.0)	19 (13.2)	27 (11.1)
Cracks/wounds	6 (6.0)	11 (7.6)	17 (7.0)
Mobile claw toes	_	2 (1.4)	2 (.01)
Foot drop	1 (1.0)	3 (2.1)	4 (1.6)

*Multiple response (Figures in the parentheses indicates columnwise percentages). NFI†: Nerve function impairment

Another cause of increased proportion of disability among new leprosy patients in the present study may be that 9.4% patients were pure neuritic type, 39.1% of them had grade-1 and 21.8% had grade-2 disability. Nearly two-thirds of them (60.9%) had registered late i.e. ≥12 months. These findings were also statistically significant ($P<0.001$). As for diagnosing leprosy more emphasis is given on skin lesions and as a result of repeated Modified Leprosy Elimination Campaign in this high endemic district, awareness among common people regarding leprosy with hypopigmented anaesthetic skin patch was more. Therefore health seeking behavior of these patients with skin lesions was more with early, appropriate and regular management in contrast to leprosy patients with no skin lesion (pure neuritic type). Health care providers, unless remember leprosy as one of the causes of peripheral neuropathy, specially in highly endemic areas it is quite likely that these pure neuritic leprosy patients are often missed. Finally when they are diagnosed as having leprosy, it is too late (after receiving various treatments from quacks, ojhas and other traditional healer or no treatment at all). This delay in diagnosis pushes them to bear the brunt of disability due to leprosy. A study in South India by Mahajan and others had found lower proportion of neuritic leprosy (4.6%) compared to this study[14] but the study in Nepal by van Brakel showed nearly similar proportion (8.7%) of

neuritic leprosy patients.[15] Kumar *et al*.,[16] also found (2004) paralytic deformity was highest (26%) among neuritic leprosy patients.

In our study we found that MB patients had significantly more ($P<.0003$) disability compared to PB patients, similar to the findings as shown by Schreuder (PB-11%, MB-33%),[13] De Oliviera and others (PB-12%, MB-37%),[17] Richardus (PB-9.8%, MB-37.6%).[18] If the pathogenesis of leprosy is considered it is quite likely that multibacillary patients with more nerve involvement along with sensor and motor nerve function impairment will have more disability. The most important factor to prevent disability in leprosy patients is early detection and adequate treatment of neural impairment. Registration delay is a recognized risk factor for disability in leprosy, but is the result of complex interactions between physical, social, economic and psychological factors. It was seen from Table 3, that proportion of disability significantly increased ($P<0.000$) with increase in registration delay. Mean registration delay was also significantly more (F-89.86; $P<0.01$) along with increase in grade of disability. The study by Schreuder[13] revealed a highly significant linear trend with registration delay and G2D. Richardus and others[18] concluded that early diagnosis and subsequent activities for prevention of disability could prevent impairments in more than 30% of all patients in Bangladesh, which was more than any intervention at later stage that could be achieved.

Among the studied new leprosy patients, disability was significantly ($P<0.001$) more among those who were manual laborer than patients engaged in other occupations like service personnel, businesspersons, shopkeeper, housewives etc. This finding was in conformity with the findings of other studies-Withington and others[1] (manual work 18.2% vs others 11.9%), Krishnan and others.[19] Leprosy patients, as a result of nerve involvement (which is inevitable in this disease) suffer from loss of sensation in hands and/or feet and often with motor weakness. This increased their vulnerability towards injuries, burns, thorn prick, etc specially who were engaged in manual occupation or had to walk for long distances. Other factors in association with disability found in this study were increased proportion of disability with increase in age ($P=0.143$), male sex ($P=0.05$), illiteracy ($P=0.117$), divorced/separated patients ($P=0.40$).

In leprosy, eyes, hands and feet are the commonly affected areas of impairment even in advanced stages. For mobility and other vital activities of daily living, a person has to depend on eyes, hands and feet. For this reason, WHO has chosen these three sites for disability assessment. In this study for the new leprosy patients, feet were involved more compared to hands and eyes. Sensory NFI was the commonest nature of disability found in both hands and feet followed by motor NFI. In eyes, loss of corneal sensation was the commonly found nature of disability. These findings emphasize the importance of routine assessment of NFI of all new leprosy patients to search for grade-1 disability. After diagnosis if we can properly educate these patients for self care like not to walk bare foot, daily inspection of hands/feet for any blisters, red spots, oliohydrotherapy, physiotherapy, eye care, change in occupation, etc. any visible deformity will not occur. Visible deformity (grade-2) were more in feet. Males suffered more than their female counterparts, which may be due to their more exposure to outdoor activities making them more vulnerable to different injuries. The findings of the study by Croft and others in Bangladesh among new leprosy patients also showed similar findings.[9]

One of the limitation of the study was sample size, being only 244 new leprosy patients. Data collection was done alone by the first author and total time needed to complete the interview and clinical examination of each patient was 20 minutes (average) in outdoor settings. Another limitation was in the year 2006, when the data collection was undertaken, more than 60% horizontal integration of the leprosy control program to the general healthcare system in this district had occurred. Therefore, although the study area was situated in a tertiary care hospital, total number of new leprosy patients examined were small. Other limitations were age verification was not possible, validation of diagnosis by leprosy expert was done only in 10% sample of patients (though κ statistic was.84). Registration delay though verified with due importance (local event calendar), variations due to recall bias (however small) could not be avoided.

In spite of the above limitations, this is an important study which provides information on grade-1 disability and pure neuritic type of leprosy among new leprosy patients along with association of some clinical and sociodemographic factors. As leprosy prevalence came down, searching for these groups

should be of intensive focus if we want to identify disability at the earliest opportunity. For this reason, thorough neurological examination of commonly examined peripheral nerves should be mandatory so that pure neuritic leprosy and grade-1 disability are not missed. Information Education and Communication at all levels i.e., individual, community, patients and health personnel for early and timely diagnosis of leprosy, starting MDT and adopting proper preventive measures is the need of the hour. This will facilitate to reach the 'WHO's enhanced global strategy target (year 2011-2015) to reduce the number of new leprosy cases with grade-2 disability.'

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