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A study of untreated leprosy affected children reporting with Grade 2 disability at a referral centre in West Bengal, India

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Summary
Setting: An observational study of children diagnosed with leprosy and Grade 2 disability at a referral centre in West Bengal, India.
Methods: A descriptive study was conducted of 21 children, diagnosed as new cases of leprosy with Grade 2 disability (G2D), and registered for treatment at The Leprosy Mission Hospital, Purulia, West Bengal, India. The socio-demographic and medical details were obtained from the patients' charts. In-depth interviews were carried out with both the children and their parents to inquire about the factors responsible for the delay in diagnosis.
Results: During a 3-year study period (2013–15), 1938 people were diagnosed as new active cases of leprosy at our referral centre; among the registered patients, 319 (16·5%) were children aged between 4 and 15 years, of whom 159 (50%) were diagnosed with multibacillary disease and 21 (6·6%) were reported with G2D. The disability proportion was lower in children compared with adults and higher in MB children compared with PB children. Paralysis of the intrinsic muscles of the hand was seen in 15 children and of these, 10 children had right hand ulnar paralysis and three had bilateral ulnar-median paralysis. Several children had noticed a patch as the first symptom and 15 had a leprosy-affected parent.
Conclusion: This study shows that there is still a problem of children developing G2D before the diagnosis of leprosy is made, and points to some of the social factors responsible for delayed reporting and prompt starting of MDT. Better communication and innovative methods of persuading the families to report early need to be tested and urgently implemented.

Keywords: Disability, Grade 2 deformities, Leprosy, Children, Reporting delay

Work was undertaken at The Leprosy Mission Hospital, Purulia, West Bengal, India.
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Introduction

Leprosy is a chronic mycobacterial infectious disease that affects human populations, including children, progressing gradually to disability unless checked by treatment with multi-drug therapy (MDT).[1] It is generally assumed that the proportion of new cases presenting with disability at diagnosis is related to the average delay between the onset of symptoms (e.g. a skin patch) and establishing the correct diagnosis. Disabilities among children are particularly tragic and preventable.[2] Several studies have reported visible disabilities among children and suggested various methods to prevent them.[3] However, it seems that the task of persuading families to present their children early for MDT has not been easy and disabilities among newly reported cases are found to occur frequently.[4,5]

The recent operational guidelines of the World Health Organization (WHO) emphasise the need for reducing Grade 2 disabilities (G2D) among children to zero.[6] The children who report with G2D have delayed seeking medical attention due to several reasons[7,8] which are mostly social or medical.[9] Social factors may include lack of awareness of leprosy and of leprosy services, family background including occupation, education and financial difficulties and distance from the nearest leprosy centre. Medical factors may include the fact that nerve damage can sometimes be the first manifestation of leprosy. It is a tragedy when children are brought for treatment only after visible deformities have occurred,[4] and also when children with leprosy are not correctly diagnosed at first presentation to a health worker.

Therefore, an observational study of children with leprosy and Grade 2 disability was carried out in a referral centre in West Bengal, India and critically analysed.

Methods

This is a descriptive study of all newly diagnosed leprosy-affected children reporting with G2D who registered for treatment between January 2013 and December 2015, at The Leprosy Mission Hospital, Purulia, West Bengal, India. This institution was first established as a home for leprosy patients in 1888 and now provides general medical services as well as comprehensive leprosy care to patients of Purulia and the surrounding districts and states of Jharkand, Bihar and Odisha.

The participants were identified after routine examination according to the hospital protocol for confirmation of cases of leprosy, which includes a full body examination for skin lesions, sensory testing (ST), voluntary muscle testing (VMT) and slit skin smear for bacterial index (BI). Each patient underwent detailed body charting, sensory testing using the 2 g Semmes-Weinstein monofilament (SWM) for the palm and the 10 g monofilament for the sole, and voluntary muscle testing for 12 peripheral nerves.[10] The socio-demographic and medical details were obtained from the patients' charts. An in-depth qualitative study was done by interviewing the children with G2D, and their parents, to probe the individual, familial and health system factors responsible for the delay in diagnosis.

Permission was obtained from the Superintendent of The Leprosy Mission Hospital, Purulia for conducting the study. Informed, oral consent was obtained from all the parents or guardians of the participants. All relevant data from the charts were extracted from charts and entered into Excel sheets and analysed using SPSS.

Table 1. New cases of leprosy registered for treatment and disease type from 2013–2015

	Adult			Child			
New cases of leprosy	M $n = 986$	F $n = 633$	Total $n = 1619$	M $n = 176$	F $n = 143$	Total $n = 319$	Total $n = 1938$
Year							
2013	387	263	650 (82%)	82	65	147 (18%)	797
2014	316	221	537 (85%)	51	46	97 (15%)	634
2015	283	149	432 (85%)	43	32	75 (15%)	507
Disease type							
MB	809 (82%)	474 (75%)	1283 (89%)	87 (49%)	72 (50%)	159 (11%)	1442
PB	177 (18%)	159 (25%)	336 (68%)	89 (51%)	71 (50%)	160 (32%)	496
Total	986	633	1619 (84%)	176	143	319 (16%)	1938

Results

In the study period, 1938 people were diagnosed as new cases of leprosy at the hospital. Of these, 319 (16·5%) were children, with ages ranging from 4 to 15 years; the mean age of new child cases was 11 years. Table 1 presents the proportion of males and females.

One thousand four hundred and forty-two (74%) patients were classified as multibacillary cases, of whom 159 (11%) were children (shown in Table 1).

Among the children, 31 (10%) were under 7 years of age, 159 (50%) had multibacillary leprosy (compared with 89% of adults), and 28 (9%) had a positive bacterial index, of whom 23 (7%) had BI 4+ and above (Table 2).

Three hundred and ninety-one (20%) new cases reported with G2D, of these 21 (5%) were children (Table 3).

Two hundred and thirty (12%) new cases reported with G1D, and of these, four were female children above 11 years of age. The adult G2D proportion was 23% while the child disability proportion was 6·6%. There were no leprosy affected child younger than 4 years and no child below 7 years had disability Grade 1 or 2.

Table 2. Age, type of disease and bacterial index of newly registered child cases ($n = 319$)

New cases of leprosy in children	M $n = 176$	F $n = 143$	Total $n = 319$
Age			
4 to 6	22	9	31 (9·7%)
7 to 9	28	38	66 (20·7%)
10 to 12	49	35	84 (26·3%)
13 to 15	77	61	138 (43·3%)
Disease Type			
Multibacillary	87	72	159 (49·8%)
Paucibacillary	89	71	160 (50·2%)
Bacterial Index			
Negative	157	134	291 (91·2%)
1+ or 2+	4	1	5 (1·6%)
3+ or 4+	9	6	15 (4·7%)
5+ or 6+	6	2	8 (2·5%)

Table 3. Grade 2 disability of registered new cases of leprosy ($n = 391$)

	Adult			Child			
G2D	F $n = 246$	M $n = 124$	Total $n = 370$	M $n = 14$	F $n = 7$	Total $n = 21$	Total $n = 391$
2013	87	52	139 (94%)	5	4	9 (6%)	148
2014	79	43	122 (95%)	5	2	7 (5%)	129
2015	80	29	109 (96%)	4	1	5 (4%)	114

There was a higher disability proportion amongst children with MB leprosy, compared with PB leprosy [MB: 18/159 (11%), versus PB: 3/160 (2%)], amongst smear positive as opposed to smear negative children [BI positive: 6/28 (21%), versus BI negative: 15/291 (5%)], and amongst older children (ages 13 to 15 years) compared with younger ones (ages up to 12 years) [older children: 14/138 (10%), versus younger ones: 7/181 (4%)] (Shown in Table 4).

Among the children with G2D, 15 reported within 6 months of first noticing the symptoms, while six reported more than 6 months later, including one female child who reported 2 years after first noticing the symptoms.

Among the children with G2D, disability affecting the hand was more common than disability of the foot. Paralysis of the intrinsic muscles of hand was seen in 15 children, of whom 11 were boys and four were girls. Palmar anaesthesia was found in 12, of whom eight were boys and four were girls. Among those with hand disability, the majority had right hand ulnar paralysis (10/15), three children had bilateral ulnar-median 'claw hands' and one girl had triple nerve palsy (Table 5).

Eight children had foot drop, among whom three were girls; three children had sole anaesthesia with complicated ulcers and two had sole anaesthesia with deep cracks. Three children had ulcers as their first manifestation of leprosy, and although they were painless the

Table 4. Grade 2 disabilities among newly registered child cases ($n = 21$)

	Age			
Children with Grade 2 disability	7 to 9 $n = 1$	10 to 12 $n = 6$	13 to 15 $n = 14$	Total $n = 21$
Gender				
Female Child	1	1	5	7
Male Child	0	5	9	14
Disease Type				
Multibacillary (MB)	1	6	11	18
Paucibacillary (PB)	0	0	3	3
Bacterial Index				
Negative	1	5	9	15
1+, 2+	0	1	1	2
3+, 4+	0	0	2	2
5+, 6+	0	0	2	2
Duration of delay reporting				
Up to 6 month	0	6	9	15
Above 6 month	1	0	5	6

Table 5. Nerve involvement among newly registered child cases with Grade 2 disability ($n = 21$)

Nerve	Right only	Left only	Both	Total
Ulnar Claw	5	3	3	11
Ulnar-Median Claw	2	1	0	3
Triple Nerve Palsy	0	1	0	1
Foot Drop	6	2	0	8
Total	13	5	3	21

treating practitioner had failed to examine the sensation and diagnose leprosy. Two male children with claw hand were seen by an orthopaedic surgeon before the diagnosis of leprosy had been made; the disability was diagnosed as injury-related and was treated with splints, massage and analgesics.

All the children had leprosy-specific symptoms for more than 6 months and the maximum duration of delay was 25 months. Only three children were detected through a routine institutional based contact survey, although 15 children had a leprosy-affected parent, of whom three children had more than one family member affected by leprosy. Nine fathers and 18 mothers were illiterate, and the primary occupation of most parents was daily labourer or farmer. The reason for delayed reporting is described in Table 6.

Discussion

Hospital statistics are generally based on a very selective group of patients and may not necessarily represent the situation in a community.[11] Patients attending the referral hospital are drawn from a wide area, with an undefined population, so the hospital data does not reflect the local community data. However, the emphasis in this study was simply to describe those children who delayed reporting until visible deformities had occurred, as this is in principle a preventable situation. Hospital statistics have the advantage of greater reliability and validity since the assessments are made by qualified health professionals such as physiotherapists, medical doctors and laboratory technicians.[12–14] The disability proportion (G2D) in this study was less in children (6·6%) than in adults (22%), but in both groups the disability was higher in MB cases and in smear positive cases. While delay in detection could be the main reason for the development of visible deformities before diagnosis, this delay is comprised of two components: patients' delayed presentation to the health services and health workers' delay in making the correct diagnosis.

Table 6. Reasons for delay among children with G2D ($n = 21$)

	Reason for delay	M $n = 14$	F $n = 7$	Total $n = 21$
1	Noticed patch but delayed consultation as it was asymptomatic	4	4	8
2	Failure of practitioner first consulted to recognise leprosy	4	2	6
3	Waited for patch to diminish on its own	2	0	2
4	Did not notice the symptoms	3	1	4
5	Financial constraint	1	0	1

Most of the parents were sad and repentant about their child's condition. Six parents were angry that the specialist medical practitioners they had consulted had misdiagnosed and mistreated the disease. In addition, adverse social factors may have contributed to diagnostic delay since most families were poor, daily wage earners and not well educated.

It is amazing that the gradual development of disabilities among children were not observed by the parents and teachers in schools. Perhaps special education and awareness building of parent community and school teachers are required for voluntary early reporting. Formerly school surveys formed an important and major source for detecting early cases of leprosy among children.[15] The school survey was especially useful in detecting cases in students in the 10–14 year age group.[16] This critical aspect of leprosy control could be utilised in highly leprosy endemic pockets.[16]

According to WHO, children represented 8·9% (11,389) of all new cases registered in India in 2015, indicating continued transmission of the infection.[17] The fact that the majority of children are contacts of known leprosy-affected persons[18,19] (in this study 15/21) who may or may not have been treated properly or adequately, adds to the weakness in our current methods of leprosy control. All child contacts of newly diagnosed adult leprosy cases should be promptly examined for early signs of leprosy. Any default or non-compliance among the adults may increase the risk of infection amongst household contacts.[20] Recent research has pointed out the role of extra-human reservoirs of *Mycobacterium leprae (M. leprae*), and contact of children in unhygienic environments, especially with soil and water must be studied for potential threats of entry of *M. leprae* into the host.[21]

This study shows the great need for further research on children in the field of clinical, epidemiological, social science and for operational studies, to determine more effective ways to encourage voluntary reporting of people with suggestive signs of leprosy at an early stage. The stigma reduction programmes and more awareness building exercises should continue using community-based participatory approaches. Continuing medical education of doctors and other health professionals to undertake passive surveillance for leprosy and to recognise the various manifestations of the disease particularly in young children must be a priority, if we aim for zero G2D among newly detected child leprosy cases.[22] School surveys must be continued in leprosy endemic geographical regions. Headmasters, principals and teachers must be educated and made aware of the need for early detection. Compliance must be encouraged from school, leave granted for hospital visits and admission if necessary. All children suffering from leprosy or its complications must be allowed to write exams and complete school, if necessary with special assistance in the classroom. Both the Ministries of Education and Health must collaborate in ensuring that both education and health services for disabled children are prioritised.

This study clearly shows that social factors are responsible for delayed reporting and prompt starting of MDT. There have been massive efforts made to increase public awareness of the signs and symptoms of leprosy and the current developments through integration and free supply of MDT. However better communication, innovative methods and use of modern technology in persuading families to report early needs to be tested and urgently implemented. Reduction of disability in children to zero has to be a concerted effort at all levels of health professionals. Contact surveys must be systematic and persistent. Parents must be empowered to survey family members periodically. In highly endemic areas, all patches must be considered leprosy until proved otherwise. In doubtful cases an observation period is desirable.

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Authors' Contribution

Joydeepa Darlong, was involved in study conceptualisation and design, preparing the interview questionnaires and preparation of the manuscript.
Pitchaimani Govindharaj, was involved in data analysis, proof reading and revision of the manuscript.
Famkima Darlong, was involved in monitoring the study and comments on the manuscript.
Narayanan Mahato, was involved in identifying the study participants and conducted the interview.

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