Characteristics of children with leprosy: Factors associated with delay in disease diagnosis

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Abstract

Objectives: The objectives of the study were to characterize the clinical profile of childhood leprosy presenting at tertiary leprosy care hospitals in the states of Bihar, West Bengal and Uttar Pradesh in India, and to determine the possible risk factors associated with disabilities at presentation.

Methods: Subjects were children with newly diagnosed leprosy registered for treatment at tertiary Leprosy Mission Hospitals in Muzaffarpur (Bihar), Purulia (West Bengal) and Faizabad (Uttar Pradesh), India, between June and December 2019. Demographic and leprosy characteristics were collected at the time of diagnosis. Parents/guardians were interviewed on reasons for delay in presenting at the hospital. Associations between various factors and delay in diagnosis were assessed.

Results: Among the 84 children, the mean (SD) age was 10 (3) years with a range of 4–14 years. There were more boys (58%) and most children were currently in school (93%), resident in rural areas (90%) and belonged to a lower socioeconomic status (68%). More children were diagnosed with multibacillary leprosy (69%), one-third of them being skin smear positive for *Mycobacterium leprae*. On presentation, 17% had deformity (5% grade 1 deformity and 12% grade 2), 29% had nerve involvement and skin lesions were spread across the body in half of the children. Mean (SD) duration of delay was 10.5 (9.8) months. Delayed presentation was more in boys (43% vs. 17%; $P = 0.01$), those without a history of migration for work compared to those who had a history of migration (40% vs. 9%; $P = 0.008$) and in those children who were from a poor economic status compared with those that came from a better economic status (44% vs. 7%; $P = 0.001$)

Limitations: Because our study was conducted at tertiary care hospitals, the findings are not representative of the situation in the field. Furthermore, a comparison group of newly diagnosed adult leprosy patients with disability could have been included in the study.

Conclusion: Childhood leprosy continues to occur in endemic pockets in India and a substantial number present with skin smear positivity and deformity. Guardians of these children cite many reasons for the delay in presentation.

Key words: Children, disability, leprosy

Plain Language Summary

New cases of children with leprosy are an indication that transmission is going on in the community. Children who are diagnosed late often have progressive disease as multiple patches, nerve involvement and impairment and increased bacteria in the body. Delay in diagnosis can be due to delay in reaching the health facility or inability of the health-care professional to diagnose appropriately. In this study, we found that delay in diagnosis of leprosy in children is still a major problem, resulting in high bacterial load and presence of deformities. There was a 10-month delay in reaching a health facility that diagnosed and treated correctly. Majority of children belonged to a lower socioeconomic strata. Guardians cited many reasons for delay which could have been overcome if they had been aware of the disease and the implications of delay.

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Introduction

Zero disability among new pediatric patients is a top priority target of the global leprosy strategy of the World Health Organization.[1] Despite tremendous success in achieving drastic reduction in the prevalence of leprosy throughout the world, even now, around every 1 in 100 cases are children[1] and 1 in 10 newly diagnosed children with leprosy in India presented with grade 2 deformities (G2D) in 2018.[2] Although data are not available, it is possible that an equal number or more would have presented with grade 1 deformity (G1D) that has an increased risk of progressing to grade 2 deformity.[3,4] In India, which currently has the highest leprosy population, the prevalence rates of childhood leprosy in different parts of the country ranges from 4% to 34 percent.[5-10] The proportion of newly diagnosed childhood cases of leprosy was 8.94% according to the National Leprosy Elimination Program report in 2016.[11] The importance of childhood leprosy is the occurrence of the disease in a vulnerable population that does not have a mature immunity status and exposure to contacts within the family.[12] It is considered a surrogate marker of recent transmission of the disease which can be measured. [13,14]

Patient delay is the major reason for risk of disability (grade 1/2) among adult leprosy patients.[15] Assessing the potential factors associated with delays in seeking care and diagnosis of leprosy is essential to formulating better strategies to promote early diagnosis and prevention of disability. The objective of the present study was to characterize the clinical profile of childhood cases of leprosy presenting at a tertiary leprosy care hospital in the states of (Bihar) Muzaffarpur, (West Bengal) Purulia and Uttar Pradesh (Faizabad) and to determine the possible risk factors associated with the disability (grade 1 and 2) and/or smear positivity. Although slit-skin smears have been discontinued in the public health system, it is routinely done at the leprosy mission hospitals. Smear positivity indicates increased bacteriological burden indicating progression in disease and delay at presentation for diagnosis.

Methods

The study population consisted of newly diagnosed leprosy in children registered for treatment at the tertiary leprosy mission hospitals in Muzaffarpur, Purulia and Faizabad. Consecutive children with newly diagnosed leprosy and registered for treatment during the period between June 2019 and December 2019 were included in the study. The diagnosis of leprosy was made by experienced dermatologists using the World Health Organization definition of multibacillary and paucibacillary leprosy along with skin smears. After obtaining informed consent from parents or guardian, the children were interviewed, and demographic characteristics were collected at the time of diagnosis. A clinical examination was done as also disability grading using the World Health Organization disability grades for eyes, hands and feet. Socioeconomic status (using modified Kuppuswamy scale),[16] education status of parents, history of migration among parents, initial symptoms, duration between first symptom and diagnosis, number and type of visits before leprosy diagnosis and knowledge about leprosy among parents/guardians were among the details elicited. Delay in diagnosis of leprosy was defined as those children presenting with grade 1 or grade 2 deformities and/or smear positivity. Reasons for delay for presenting at the tertiary leprosy hospital were also obtained. Multivariate logistic regression analysis was done to study the associations between demographic and clinical factors and delay in diagnosis, with the level of significance being ≤ 0.05.

The study proposal was approved by the Leprosy Mission Trust India ethics committee.

Results

The demographic characteristics of the children are given in Table 1.

Among the 84 children, the mean (SD) age was 10, with a range of 4–14 years. There were more boys (58%) and most children were currently in school (93%), resident in rural areas (90%) and belonged to a lower socioeconomic status (68%). Over 50% of children had a history of leprosy in their immediate or extended family.

The clinical characteristics of children with leprosy are shown in Table 2. More children were diagnosed with multibacillary leprosy (69%) with nearly one-fifth of them being skin smear positive for *Mycobacterium leprae*.

On presentation, 17% had deformity (5% grade 1 and 12% grade 2), 29% had nerve involvement one or more nerves and skin lesions were spread across the body in half of the children.

Features related to health-care visits before diagnosis and starting multidrug therapy (MDT) are given in Table 3. Two-thirds of the children went either to a tertiary hospital for leprosy or to a private doctor while 5% went to a traditional healer for the first visit related to the disease. Forty seven percent had visited a health provider without getting the correct diagnosis, thereby missing appropriate treatment. Mean (SD) duration in months from the start of symptoms to starting MDT was 10.5 (9.8) months. The mean (SD) duration to start MDT after visiting health facility was 5.3 (6.3) months. Almost 40% of children had to make more than one visit to health facility before diagnosis and start of treatment.

The reasons for the delay in diagnosis are given in Table 4 as stated by the guardians. One-third waited for the symptoms to abate. Less than five percent stated leprosy stigma as the prime reason for late presentation.

Factors associated with delay (defined as presence of deformity and/or skin smear positivity at diagnosis) are given in Table 5. In the univariate analysis, delayed presentation was more in boys odds ratio (OR 3.6, 1.3–10.3), those without a history

Table 1: Demographic characteristics of newly diagnosed children with leprosy

Demographic characteristics	*n*=84 (%)
Age	
4–9 years	39 (46)
10–14 years	45 (54)
Female	35 (42)
Male	49 (58)
Residence	
From rural area	76 (90)
From urban area	8 (10)
Education status	
Currently studying	78 (93)
Not studying	6 (7)
Socioeconomic status*	
Lower and upper lower	57 (68)
Lower middle and upper middle	25 (30)
Upper	2 (2)
Family history of leprosy	
Yes	43 (51)
No	41 (49)

*Assessed using modified Kuppuswamy scale score. The score is based on education and occupation of head of family and total monthly family income. Score of 1-10 is lower and upper lower, 11–25 is lower middle to upper middle and 26–29 is upper socioeconomic strata

of migration for work compared to those who had history of migration (OR 6.8, 1.5–31.5) and in those children who were from a poor economic status compared with those that came from a better economic status (OR 9.8, 2.1–45.2). In the multivariate logistic regression analysis, the lower socioeconomic status was found to be an independent factor associated with leprosy (R^2 = 0.283), where those from lower socioeconomic status were 5.6 (1.1–28.5) times more likely to present late to hospital for diagnosis as compared those from better socioeconomic status.

Limitation of the study

Because our study was conducted at tertiary care hospitals, the findings are not representative of the situation in the field. Furthermore, a comparison group of newly diagnosed adult leprosy patients with disability could have been included in the study.

Discussion

The World Health Organization statistics for 2018 shows that there were 120,334 new cases in India with 9227 (8%) being children below the age of 15 years (2). Bihar, Uttar Pradesh and West Bengal together have more than 30% of newly detected cases in the country.[11]

Our study showed that 12% of the newly diagnosed children presented with grade 2 deformity. Despite the elimination of leprosy in India, children being affected with leprosy are an indication of ongoing transmission in this region. Since these were new leprosy cases presenting at a tertiary leprosy hospital, it is likely that the number of new cases in the community is much larger.

Table 2: Demographic characteristics

Clinical characteristics	*n*=84 (%)
First symptom of leprosy	
Patch	74 (88)
Weakness in limb	4 (4.8)
Loss of sensation in limb	3 (3.6)
Injury/ulcer	3 (3.6)
Type of leprosy	
MB	58 (31)
PB	26 (69)
Bacterial index of skin smear	
Negative	69 (82)
1+ to 3+	10 (12)
>3+	5 (6)
Disability grading	
WHO Grade 0	70 (83)
WHO Grade 1	4 (5)
WHO Grade 2	10 (12)
EHF score 1-2	12 (15)
EHF score 2 and above	2 (2)
Number of nerves involved	
None	60 (71)
1–2 nerves	16 (19)
2 or more nerves	8 (10)
Number of body parts involved (skin lesions)	
Multiple body parts	39 (47)
Face only	11 (13)
Trunk only	1 (1)
Upper limb only	26 (31)
Lower limb only	7 (8)

Table 3: Features related to health-care visits before diagnosis and starting MDT

First health-care provider visited	*n*=84
Tertiary hospital for leprosy	45 (54)
Private practitioner	21 (25)
Over the counter	8 (10)
Public health facility	6 (7)
Traditional healer	4 (5)
Mean (SD) duration to seek health care after first symptom (in months)	10.5 (9.8)
Mean duration of delay to receive MDT after visiting routine health-care provider (in months) *n*=26	5.3 (6.3) Median 3 (1–6)
Number of visits to health facility before receiving MDT	
1	47 (61%)
2–3	31 (37%)
4 and above	6 (8%)

It is alarming that two-thirds of the children were diagnosed[8] with multibacillary leprosy with one-third of them being skin smear positive for *Mycobacterium leprae* indicating a higher bacterial, load and advanced disease prone for complications such as reactions and neuritis. A similar study

Table 4: Reasons for delay as stated by the guardians

Reasons	*n* (%)*
Thought the problem would go away with time	27 (32)
Hospital too far	17 (20)
Managed with self-medication	16 (19)
Preferred local physician	14 (17)
Financial constraints	13 (15)
No help to get to hospital	12 (14)
More urgent priorities, mainly job	10 (12)
Stigma of leprosy	3 (4)
Not sure where to go to when symptom appeared	2 (2)

*Not mutually exclusive

Table 5: Factors associated with delay^

Factors	Category	Delay (%)	Univariate analysis odds ratio (95% CIs)	Multivariate analysis adjusted odds ratio (95% CIs)#
Gender	Female	6/35 (17)	Ref	Ref
	Male	21/49 (43)	3.6 (1.3–10.3)*	2.7 (0.9–8.4)
Residence	Urban	24/76 (32)	Ref	-
	Rural	3/8 (38)	0.8 (0.2–3.5)	-
Family history of leprosy	Yes	12/43 (28)	Ref	-
	No	15/41 (37)	0.7 (0.3–1.7)	-
History of migration	Yes	2/22 (9)	Ref	Ref
	No	25/62 (40)	6.8 (1.5–31.5)*	3.4 (0.6–17.9)
Type of family	Nuclear	5/27 (19)	Ref	-
	Joint	22/57 (39)	2.8 (0.9–8.4)	-
Socioeconomic status	Middle–upper	2/27 (7)	Ref	Ref
	Lower	25/57 (44)	9.8 (2.1–45.2)**	5.6 (1.1–28.2)*
Distance to nearest health facility	4 or less km	12/44 (27)	Ref	-
	More than 4 km	15/40 (38)	1.6 (0.6–4.0)	-
Approximate cost per visit	≤300 Rupees	17/61 (28)	Ref	-
	>300 Rupees	10/23 (44)	1.2 (0.5–3.1)	-
Number of visits to health facility	One visit	14/47 (30)	Ref	-
	More than one visit	13/37 (35)	1.3 (0.5–3.2)	-

^Delay was defined as presentation with Grade 1 or Grade 2 disability or positive skin smears at diagnosis. *P<0.001, **P<0.05. #Adjusted for gender, history of migration and age

from a tertiary hospital in Central India done over a period of five years reported that 40% of the newly diagnosed children had MB leprosy and 11% were smear positive.[8] Although leprosy cannot be easily transmitted, children usually have closer contact for longer periods than adults and the smear-positive children have the potential to spread the disease.[8] The male preponderance of newly diagnosed leprosy in children has been reported from other studies.[10,17,18] The male preponderance is similar in newly diagnosed adult leprosy patients, when comparing patients having deformity to those without deformity.[15]

In a study on risk of deformity among adults by Srinivas *et al*., delayed diagnosis was found to be the major reason for risk of disability.[15] The study found an eight-month delay among patients presenting with deformity compared with a four-month delay in patients without deformity. When patient delay was more than three months, odds of having deformity at diagnosis were 1.6 times higher compared to when patient delay was less than three months.[15] Our study found a ten-month delay (i.e. children with deformity or smear positivity) in seeking health care after the first sign or symptom had been identified. Among those who presented with delay, the mean duration of delay in receiving MDT after visiting a routine health-care provider was five months. More than three-quarters of all the children diagnosed with leprosy were brought to a tertiary leprosy hospital or to a medical practitioner as the initial health-care provider. This could be related to the community's awareness of leprosy and the effectiveness of the information provided by the primary health centers and the leprosy and government hospitals in that area. However, 15% tried over-the-counter and traditional medicines before approaching the allopathic health-care system. In a hospital-based study done by the same authors,[15] development of visible deformities before diagnosis comprised two components of delay: patients' delayed presentation to the health services and health workers' delay in making the correct diagnosis. There is a need to further study the various factors contributing to delay in reporting to hospital for planning an intervention to reduce both patient and health care-related delay to minimize disability among children.

Children are dependent on their parents or guardians to take them to an appropriate place for the diagnosis and treatment and there are several features that lead to postponement in seeking treatment. In comparing these features among adults from a similar environment and the guardians of the children with leprosy. There were more similarities than differences similarities than differences.[15,19] About 32% of guardians thought that the disease would disappear by itself, as compared to 90% of adult leprosy patients. The distance to the health facility was not as much an important factor among adult leprosy patients (8%) as it was to the children's guardians (20%). Family commitments and other pressing jobs or financial constraints did not appear to be different in these two groups.[19]

Conclusion

We found that childhood leprosy is still a public health problem in areas of the subcontinent where leprosy had not been eliminated. Among the newly diagnosed children with leprosy, 18% had smear positivity for *Mycobacterium leprae* and 17% had either a grade 1 or grade 2 deformities. There are multiple reasons for delayed diagnosis and for the most part, they are similar to those found among adult

leprosy patients. Slit-skin smears need to be done to identify high-risk children prone to reactions and neuritis. Continued awareness among all levels of health-care providers is needed so that not a single case of leprosy is missed. Awareness needs to be increased about the variety of typical and atypical presentations of leprosy. Zero disability among new pediatric patients can be achieved if health policies are modified in regions that are still endemic to leprosy and if children are diagnosed early and treated without delay.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Conflicts of interest

There are no conflicts of interest.

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