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Prevalence and risk factors for grade 2 disability among newly diagnosed leprosy in children and adolescents: a record-based analysis from India

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Summary

Objectives Leprosy in children is a strong indicator of disease transmission in the community and the rapidity of case detection. Grade 2 disability (G2D) in children denotes a delay in diagnosis, which could be due to delay either at the health care level or in recognition and referral by the family. The current study determines the proportion of G2D among newly diagnosed leprosy-affected children and adolescents and identifies the associated factors.

Methods A 5-year retrospective analysis of records of children and adolescents aged ≤18 years newly diagnosed with leprosy between April 2014 and September 2019, was carried out with special reference to G2D presentation at the time of diagnosis.

Results Children and adolescents comprised 8.26% (327/3955) of all subjects. Among them, 58 (17.7%) had G2D at the time of diagnosis. G2D occurred more frequently among the 15–18 years age group and was significantly associated with registration delay, presence of household contact cases, having multibacillary leprosy, nerve thickening and neuritis.

Conclusions We report a high rate of G2D among newly diagnosed leprosy cases in children and adolescents, much higher than the reported national average for adults. With such a high occurrence of G2D, the target of having zero disability in childhood cases is unlikely to be met in India in 2020. Early case detection activities with a child-

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focused approach may reduce the delay in diagnosis, preventing leprosy-associated disability in children.

Keywords: Leprosy, children, adolescents, grade 2 disability, registration delay, reactions, neuritis

Introduction

The National Leprosy Elimination Program (NLEP) of India reported 126,164 new leprosy cases during 2017–2018, contributing to over one-half of the global leprosy cases.[1] During this period, 10,287 (8.15%) new child cases were reported, indicating continued disease transmission.[2]

The epidemiology of leprosy in children is complicated by the long and variable incubation period for leprosy.[3,4] Children are believed to be most vulnerable to getting infected with *Mycobacterium leprae* due to their immature immunity and close contact with intra-familial sources.[5] With a long incubation period, leprosy usually manifests during adolescence or early adulthood.[6,7]

Leprosy in children typically presents with equal male/female sex ratios, a higher proportion of paucibacillary cases and reactions. Leprosy related disabilities are supposed to be less common in children because it takes a long time for disabilities to develop.[7–9]

A timely diagnosis is essential for preventing disability and its mitigation if already present. There are numerous reports on the prevalence of leprosy in children (<15 years) from India; however, there is limited data available for the age group of 15–18 years. The occurrence of leprosy and its related disabilities during the adolescent period poses not only physical impairment but also psychological and emotional challenges owing to the inherent adolescent behaviour.

Zero G2D among children diagnosed with leprosy is one of the key targets of the current Global Leprosy Strategy.[10] The development of deformities in children is an indirect indicator of the leprosy burden in a community and delayed case detection. Though it is understandable that delay in diagnosis could be one of the leading causes of disability, it is also important to identify other associated factors to prevent or appropriately manage the disability in leprosy-affected children. With this background, we carried out a record based analysis of children and adolescents diagnosed with leprosy from April 2014 to September 2019 to estimate the frequency and factors associated with G2D.

Methods

STUDY DESIGN

Cross-sectional record-based study.

SUBJECTS

Records of children (0–14 years) and adolescents (aged 15–18 years), who were diagnosed with leprosy and treated at specialized leprosy referral centres (RC) of Lepra society, from Andhra Pradesh, Telangana, Madhya Pradesh and Bihar states of India, between April 2014 and September 2019, were analyzed.

DATA COLLECTION

Data on demography, clinical examination and treatment details with special emphasis on family contact with leprosy, delay (if any) between the occurrence of symptoms and seeking health care, presence of Grade 1 or Grade 2 disability at the time of diagnosis, as recorded in the case sheets were electronically transferred to MS Excel for further analysis. Lepra society referral centres followed standard NLEP guidelines for the diagnosis and treatment of children and adolescents with leprosy.

All the children who presented with clinical symptoms suggestive of leprosy were subjected to thorough clinical examination, including motor and sensory nerve function testing and slit skin smear examination (SSS). Subjects were also examined for the presence of leprosy reactions and neuritis. Confirmed subjects were classified and treated as per the standard NLEP guidelines.[11]

Disability was measured using WHO disability grading.[12] Physical therapy and assisted devices were provided as required.

DEFINITIONS

Family contact

Family contact was defined as a blood relative or the marital partner of the index case (for married adolescents) and residing under the same roof, while cases in the neighbourhood were defined as persons residing in the immediate neighbourhood, other than family contacts.[13]

Registration delay

The time period between the first symptom noticed by the patient and the first visit to any health care provider.

Statistical analysis

Statistical analysis was performed using SPSS statistical software version 20.0 (IBM Corp. in Armonk, NY). Basic descriptive analyses were done for all the variables. Mean (SD) was used to describe the age and registration delay of the participants. The presence or absence of G2D was the dependent variable in the statistical analysis. The independent variables were distributed into two groups: socio-demographic and clinical characteristics. Pearson chi-square test was used to compare proportions of categorical variables. Multivariable logistic regression analysis was done to determine the significance of individual risk factors for G2D. The association between risk factors and G2D was inferred using odds ratios (OR) with 95% Confidence Interval (95% CI) for each parameter. P-values of less than 0.05 were considered to be statistically significant.

Results

A total of 3955 new leprosy subjects were registered during the study period, of which, 327 (8.26%) were children and adolescents. Socio-demographic details of the subjects are furnished in Table 1. A four-year child was the youngest case noted. Most of the children and adolescents were students (57.2%), followed by labourers (21.1%) and school dropouts (21.7%) at the time of diagnosis.A history of contact within the household was observed in

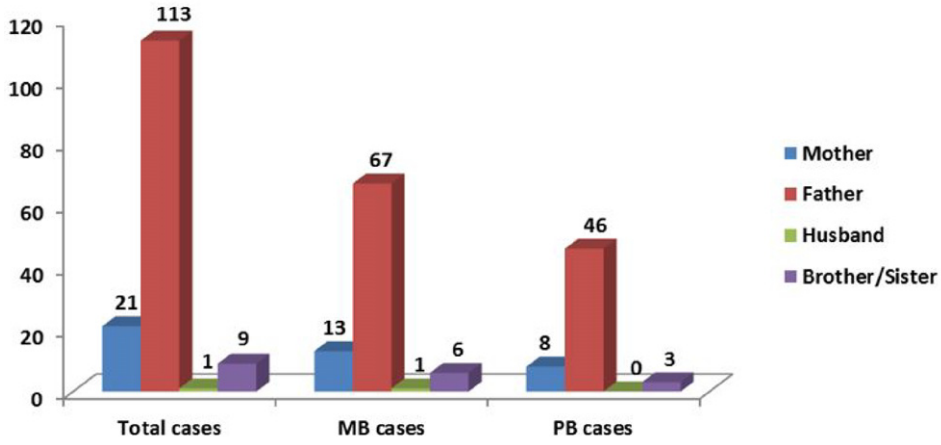

Figure 1. Household contact cases (N = 144).

Table 1. Characteristics of children and adolescents with leprosy (N = 327)

Variables	PB (n = 132) (%)	MB (n = 195) (%)	Total (%)
Age Group			
0–5 years	3(0.9)	2(0.6)	5(1.5)
6–14 years	85(26.0)	86(26.3)	171(52.3)
15–18 years	44(13.4)	107(32.7)	151(46.1)
Contact			
Familial	57(17.4)	87(26.6)	144(44.0)
Non familial	75(22.9)	108(33.1)	183(66.0)
Registration delay (n = 267)			
≤1 year	94(35.2)	147(55.0)	241(90.2)
>1 year	5(1.9)	21(7.9)	26(9.8)
Reactions			
Type 1	1(0.3)	13(4.0)	14(4.3)
Type 2	-	8(2.4)	8(2.4)
Neuritis	8(2.4)	20(6.1)	28(8.5)
Disability grade			
Grade 0	122(37.3)	126(38.5)	248(75.8)
Grade 1	4(1.2)	17(5.2)	21(6.4)
Grade 2	6(1.8)	52(15.9)	58(17.7)
BI value (n = 40)			
≤4	-	27(67.5)	27(67.5)
>4	-	13(32.5)	13(32.5)

44% of subjects; the most common familial contact observed (78.4%) is the father, and most of the primary cases have had MB leprosy (60.4%) (Figure 1). Information on delay in reporting was available for 267 out of 327 subjects. There was more than a one-year delay in seeking treatment in 12 (8.5%) children and 14 (11.2%) adolescents (Table 2). The clinical profile of subjects is shown in Table 2.

Table 2. Clinical and socio-demographic characteristics of children and adolescents with leprosy (N = 327)

Variables	Total (n = 327) (%)	0–14 years (n = 176) (%)	15–18 years (n = 151) (%)
Sex (M:F)	211:116(64:36)	117:59(66:34)	94:57(62:38)
Contact cases	144(44)	83(47.1)	61(40.4)
Registration delay (n = 267)			
≤1 year	241(90.2)	130(48.6)	111(41.6)
>1 year	26(9.8)	12(4.6)	14(5.2)
Classification			
MB	195(59.6)	88(50.0)	107(70.9)
PB	132(40.4)	88(50.0)	44(29.1)
Clinical spectrum			
TT	46(14)	37(21.0)	9(6.0)
BT	159(48.6)	86(48.9)	73(48.3)
BB	41(12.5)	22(12.5)	19(12.6)
BL	54(16.5)	20(11.4)	34(22.5)
LL	22(6.7)	6(3.4)	16(10.6)
Pure neuritic	5(1.5)	5(2.8)	0(0.0)
Nerve thickening	151(46.1)	76(43.2)	84(55.6)
Reaction			
Neuritis	28(8.5)	16(9.1)	12(7.9)
Type 1	14(4.2)	7(4.0)	7(4.6)
Type 2	8(2.4)	2(1.1)	6(4.0)
Deformities			
Grade 0	248(75.8)	137(77.8)	111(73.5)
Grade 1	21(6.4)	14(8.0)	7(4.6)
Grade 2	58(17.7)	25(14.2)	33(21.9)
SSS positive	40(12.2)	13(7.4)	27(17.9)
BI value (n = 40)			
≤4	27(8.2)	10(25.0)	17(42.5)
>4	13(3.9)	3(7.5)	10(25.0)

The slit skin smear (SSS) was available for 174/327 subjects, and 40 (23%) were positive, with BI ranges from 1+ to 6+. Peripheral nerve involvement was observed in 160 (48.9%) subjects; 101 (63.1%) had only one nerve involved, 59 (36.9%) had multiple (>1 nerve) nerve involvement (Table 3).

G2D at the time of diagnosis was seen in 58/327 (17.7%) subjects; claw hand (Figure 2) in 37 (63.8%) and trophic ulcers (Figure 3) in 6 (10.3%) subjects; data are not available for 15 subjects. The youngest child with G2D was an eight-year old male.

We observed a significant association of G2D with registration delay, household contact cases, multibacillary leprosy, nerve thickening, and neuritis. In contrast, no significant association was found with gender, the clinical spectrum of leprosy, reactional state, smear positivity and Bacillary Index (BI) above 4+ (Table 4). The risk of deformity in those with the multibacillary disease was 7.63 times greater than that for paucibacillary leprosy. In comparison, the occurrence of household contact cases increased the risk by 1.87 times (Table 4). At the time of leprosy diagnosis, the presence of neuritis increased the risk by 4.89 times for developing G2D. The children with BI > 4 are at 1.95 times higher risk (NS).

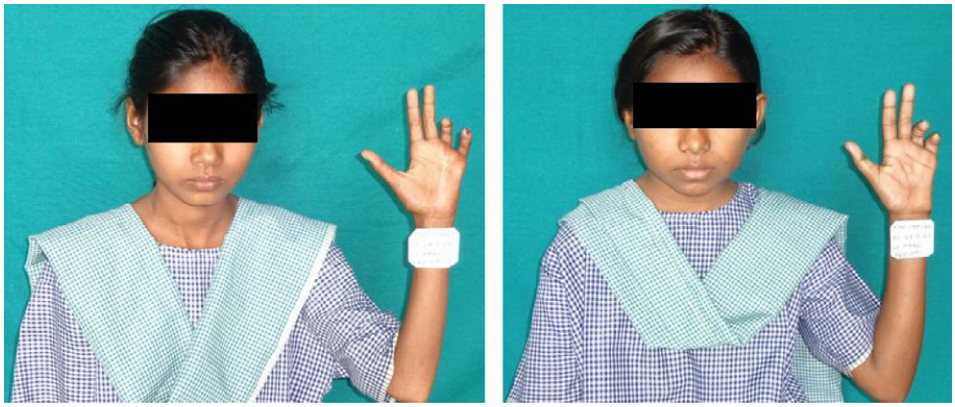

Figure 2. Claw hand in two children.

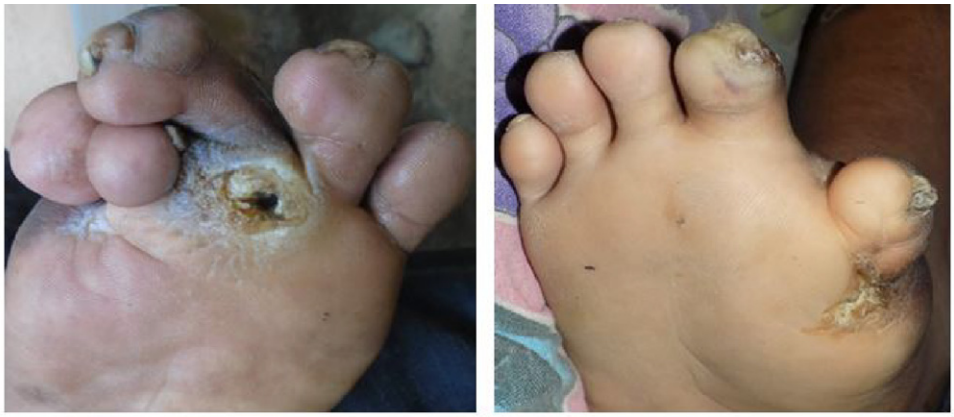

Figure 3. Trophic ulcers in two children.

Table 3. Multiple nerve involvement (N = 160)

	Age group		Total (n = 160)
	0–14 (n = 76)	15–18 (n = 84)	
Types of nerves			
Ulnar	70(43.7)	71(44.4)	141(88.1)
Median	11(6.9)	10(6.2)	21(13.1)
Lateral Poplitial	16(10.0)	18(11.2)	34(21.2)
Post Tibial	16(10.0)	22(13.7)	38(23.7)
Facial	1(0.6)	-	1(0.6)
No. of nerves involved			
1	47(29.4)	54(33.7)	101(63.1)
2	21(13.1)	24(15.0)	45(28.1)
3	7(4.4)	5(3.1)	12(7.5)
4	1(0.6)	1(0.6)	2(1.3)

Table 4. Clinical variables for disability among children and adolescents (N = 327)

Variables	N (%)	With deformity (%)	Without deformity (%)	P value	OR	95% CI
Age						
15–18	151(46.2)	33(10.1)	118(36.1)	0.073	1.689	0.95–2.99
0–14	176(53.8)	25(7.6)	151(46.2)			
Sex						
Male	211(64.5)	40(12.2)	171(52.3)	0.436	1.274	0.69–2.34
Female	116(35.5)	18(5.5)	98(30.0)			
Attend school						
Yes	289(88.4)	52(16.0)	237(72.4)	0.738	1.170	0.46–2.94
No	38(11.6)	6(1.8)	32(9.8)			
Registration delay						
Yes	267(81.7)	58(17.7)	209(64.0)	0.000	-	-
No	60(18.3)	-	60(18.3)			
Household contact cases						
Yes	144(44.0)	33(10.1)	111(33.9)	0.031	1.879	1.05–3.33
No	183(66.0)	25(7.7)	158(48.3)			
Nerve thickening						
Yes	160(48.9)	58(17.7)	102(31.2)	0.000	-	-
No	167(51.1)	-	167(51.1)			
WHO classification						
MB	195(59.6)	52(15.9)	143(43.7)	0.000	7.636	3.17–18.38
PB	132(40.4)	6(1.8)	126(38.6)			
Leprosy reaction						
Yes	22(6.7)	2(0.6)	20(6.1)	0.272	2.249	0.51–9.90
No	305(93.3)	56(17.1)	249(76.2)			
Neuritis						
Yes	28(8.6)	13(4.0)	15(4.6)	0.000	4.892	2.18–10.96
No	299(91.4)	45(13.7)	254(77.7)			
Commonest clinical spectrum						
BT	168(51.4)	31(9.5)	137(41.9)	0.728	1.106	0.62–1.95
Others	159(48.6)	27(8.2)	132(40.4)			
SSS (n = 174)						
Positive	40(23.0)	9(5.2)	31(17.8)	0.132	1.998	0.81–4.91
Negative	134(77.0)	17(9.8)	117(67.2)			
BI value (n = 40)						
>4	13(32.5)	4(10.0)	9(22.5)	0.385	1.956	0.42–8.99
≤4	27(67.5)	5(12.5)	22(55.0)			

The mean (SD) duration of registration delay in children and adolescents was 11.12 (7.52) and 11.5 (6.31) months, respectively. All subjects with G2D had a reporting delay. Most subjects (49/58 or 84.4%) who developed G2D had a registration delay of less than one year, amongst whom 30 had 7–12 months reporting delay (Table 5).

Discussion

We found a high rate of registration delay, G2D and reactions among children and adolescents at the time of diagnosis. Nearly half of the subjects had a history of household contact with

Table 5. Registration delay in children and adolescents with disabilities (N = 79)

	Delay up to 3 months (%)	Delay 4–6 months (%)	Delay 7–12 months (%)	Delay >12 months (%)	Total (%)
All cases					
Grade 1 disability	5(6.3)	3(3.8)	10(12.6)	3(3.8)	21(26.6)
Grade 2 disability	11(14.0)	8(10.1)	30(38.0)	9(11.4)	58(73.4)
Age					
0–14	8(10.1)	8(10.1)	16(20.3)	7(8.9)	39(49.4)
15–18	8(10.1)	3(3.8)	24(30.4)	5(6.3)	40(50.6)
MB cases					
Grade 1 disability	4(5.1)	2(2.5)	8(10.1)	3(3.8)	17(21.5)
Grade 2 disability	11(14.0)	6(7.6)	26(32.9)	9(11.4)	52(65.9)
PB cases					
Grade 1 disability	1(1.3)	1(1.3)	2(2.5)	-	4(5.1)
Grade 2 disability	-	2(2.5)	4(5.1)	-	6(7.6)

MB leprosy parents, indicating the importance of active leprosy case detection for preventing transmission (Table 1). Contrary to some earlier studies,[14–16] we observed a higher proportion of MB than PB leprosy in children and adolescents, indicated a reporting delay as confirmed by our investigation (Table 1). Our observations thus indicate the need for active screening of household and neighbourhood contacts with special emphasis on children and adolescents.

Delay in reporting could be attributed to either inadequate knowledge of leprosy among parents or the stigma attached to leprosy. This is a peculiar problem associated with childhood leprosy cases as they are not aware of health-related issues, are dependent on parents and cannot decide for themselves. Hence, it is essential to make children and their parents in endemic communities aware of the signs and symptoms of leprosy and to encourage appropriate health-seeking behaviour.

The incidence of childhood cases detected in our study was 4.45%, whereas other studies from India ranged from 4% to 34%.[3,17] This variation in prevalence could be due to the ill-defined upper age limit for childhood case definition (ranging from <14 to <19 years) in different studies.[5] Diagnosis of childhood leprosy is inherently challenging, particularly in evaluating peripheral nerve function and assessing clinical aspects of other similar looking skin lesions.

In this study, leprosy reactions were observed in 6.7% of children at the time of presentation. This figure is in line with most research studies where the range of subjects presenting with reactions has been 0–29.7%.[4,18,19]

We observed a higher proportion of G2D at diagnosis in children (14.2%) and adolescents (21.9%) than similar studies reported from India.[9,20,21] These disability rates indicate the possibility of long delays in diagnosis, which may be due to various access barriers to health care. Risk factors that contributed to the development of G2D in this study were MB leprosy, registration delay, nerve thickening, neuritis and the presence of household contact cases (Table 4). According to Kar and Job, the presence of neuritis at presentation, older children and MB disease significantly increased visible deformities in children.[22] We observed that all the cases with G2D were associated with nerve involvement (Table 4).

Disability prevention is of utmost importance for any leprosy patient and more so for children, given its impact on normal childhood and quality of life. Since children and adolescents

are dependent, their parents and other adults in the family play an important role in addressing this concern. Leprosy control programs need to give special attention to prevent disability in the pediatric population through active screening at schools and colleges.

A recent report suggested inadequate knowledge regarding leprosy among leprosy subjects, close contacts, community members and health care workers resulting in under-diagnosis of leprosy cases in the community.[23] Likewise, there is a possibility of similar knowledge gaps in health care workers attending children, which could have contributed to the diagnostic delay. Hence, it is essential to sensitize healthcare workers such as paediatricians, community health workers and nurses involved in childcare about early diagnosis to avoid leprosy related disabilities.

Our data show that the aim of achieving a G2D of zero by 2020 seems to be impossible. Greater awareness of the presentation of leprosy in children by health workers and speedy referral will help reduce this rate. Diagnosing and treating each case of childhood leprosy takes us one step closer to reducing the leprosy burden. Since household contacts are at higher risk of developing leprosy, one strategy for early detection of childhood leprosy could be targeted screening of all children living with adult leprosy cases. Besides, it is also required to adapt child-focused case detection strategies such as school surveys. It is essential to train health care workers across the spectrum to diagnose leprosy. It is important to maintain the services and expertise to continue diagnosing leprosy whilst there are still such high caseloads in children.

Conclusion

The occurrence of leprosy in the pediatric population, especially with a high MB proportion, is an important epidemiological signal of ongoing transmission in the general population. Our findings on G2D in children as a result of registration delays, indicate lacunae in the awareness about the disease. Preventing leprosy related disabilities in children and adolescents is possible only through early detection by targeted screening and increased awareness of leprosy among the general population and healthcare workers.

Ethical approval

This is a record based anonymous study and did not require an ethics clearance.

Conflict of interest

The authors declare no conflicts of interest.

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Contributorship

Study conception and design: BU; data collection: BU, AS, RS, RM and NS; data analysis: NV; initial drafting of the paper: BU; critical revision of the document for important intellectual content: AS; and final approval of the version to be published: all authors.

Patient consent statement

Consent for the publication of pictures has been obtained from the parents.

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