# Childhood leprosy in India over the past two decades

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### Summary

*Objectives:* Clinico-epidemiological pattern of childhood leprosy in India over the past two decades were analysed from the Indian studies conducted during the years 1990–2009.

**Results:** Twelve studies on childhood leprosy were included. Ten were conducted in health institutions and one was a community-based survey. Voluntary reporting was the principal method of case detection; community survey was adopted in two studies. Occurrence of childhood leprosy in tertiary care hospitals varied from  $5 \cdot 1 - 11 \cdot 43\%$ , in one urban clinic and the three leprosy referral hospitals it was  $9 \cdot 81 31 \cdot 3\%$  and peripheral surveys recorded  $7 \cdot 06 - 35 \cdot 5\%$  cases. History of familial contact was present in  $0 \cdot 66 - 47\%$  cases. Borderline tuberculoid was the commonest clinical type, majority with single lesion. Other types were indeterminate ( $3 \cdot 48 - 10 \cdot 1\%$ ), borderline lepromatous ( $1 \cdot 9 - 19 \cdot 4\%$ ), lepromatous ( $0 \cdot 1$  to  $9 \cdot 38\%$ ), and pure neuritic ( $3 \cdot 48 - 10 \cdot 1\%$ ). Single peripheral nerve trunk was involved in  $13 \cdot 63 - 40 \cdot 62\%$  cases and multiple nerve involvement was recorded in  $4 \cdot 54 - 59 \cdot 38\%$  cases. The majority of cases were paucibacillary ( $43 \cdot 28 - 98\%$ ). Multibacillary (MB) cases ranged from  $2 - 56 \cdot 6\%$ . Slit-skin smear positive cases ranged from  $5 \cdot 42 - 25\%$ . Lepra reactions occurred in  $0 - 29 \cdot 7\%$  cases. Relapse rate varied between  $1 \cdot 16 - 7 \cdot 1\%$ . Deformity occurred in 0 - 24% cases.

*Conclusions:* Multibacillary cases were common among Indian children, some of whom were smear positive. Probably these cases were the source of many new cases. Pure neuritic leprosy was frequent among Indian children, so also the lepra reactions and deformities. The presence of familial and extra-familial contact with leprosy cases may be a cause of concern, as it implies continuing transmission of the disease.

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# Introduction

World-wide leprosy prevalence is gradually declining and at present the disease is mostly confined to few countries. Since 2005 India tops the 16 countries reporting  $\geq 1000$  new cases of leprosy annually (WHO).<sup>1</sup> There were 13,387 new childhood cases of leprosy recorded in India in the year 2012.<sup>1</sup> The prevalence of leprosy in children is an useful indicator of current status of transmission of the disease in a country. On scrutiny of the WHO annual leprosy reports (Weekly Epidemiological Records) from the year 2005 to 2012, it is evident that the percentage of childhood cases among the newly detected leprosy patients per year in India remained nearly unchanged (range 9.42–10.14%).<sup>2–8</sup> It implies an existing undercurrent of disease transmission in the country which may erupt any time as many new cases.

Here Indian studies on childhood leprosy published over the last two decades from various parts of India have been reviewed. The purpose of this review is to highlight the salient findings of these studies, so as to have an insight into the characteristics of leprosy in children of this country.

## Methodology

English literature search was undertaken through PubMed, using the key words 'children', 'leprosy', and 'childhood leprosy in India' to find out Indian studies on childhood leprosy. The institutional library was utilised to access the full articles on childhood leprosy published in the journals *Leprosy Review* and *Indian Journal of Leprosy*. Of the available Indian studies, 12 were selected for analysis of clinico-epidemiological data on childhood leprosy in India over a time span of the past 20 years (1990 to 2009). The selected studies were conducted in various states of India, and were published between the years 1998 to 2013 (Table 1).

### Findings & Discussion

The data on childhood leprosy from the above 12 Indian studies were analysed (Tables 1, 2, 3).

Six of these studies were conducted in tertiary care hospitals,<sup>9–14</sup> two in urban leprosy clinics,<sup>15,16</sup> one of which was attached to a tertiary care hospital,<sup>15</sup> three in leprosy referral hospitals<sup>17–19</sup> and one was a community-based survey (urban and rural) conducted by trained health workers.<sup>20</sup>

Voluntary reporting by patients or parents and occasional referral from other health care facilities were the modes of case-detection in all tertiary care hospitals, one of the urban leprosy clinics and the three leprosy referral hospitals. The other urban leprosy clinic had undertaken general community surveys, school surveys and contact surveys as modes of case-detection.<sup>15</sup> The community-based survey had conducted house-to-house visit by trained health workers in defined urban and rural areas in a state of western India.<sup>20</sup>

The occurrence of childhood leprosy during the study period, recorded in tertiary care hospitals varied from 5.1% to 11.43% (Table 1). A higher trend was recorded in one urban clinic and the three leprosy referral hospitals, varying from 9.81%-31.3% (Table 1). Community, school and contact surveys recorded 7.06%-35.5% cases (Table 1). Ten of these studies included patients aged 0-14 or 15 years (Table 1). One study included adolescents in addition  $(0-18 \text{ years})^{12}$  and another one collected data only from adolescents

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Author(s)/year of publication	Study period	Set-up/State of location	Number of childhood leprosy cases detected (%)	Age group	Commonest clinical type (R-J classification)
Prasad PVS (1998) Selvasekar <i>et al.</i> (1999) Jain <i>et al.</i> (2002)	1991–1995 1990–1995 1990–1999	Tertiary care hospital, Tamil Nadu Leprosy Research & Training Centre, Tamil Nadu Urban clinic, Andhra Pradesh	n = 66 (7.2) n = 794 (31.3) n = 306 (9.81)	0 - 14  yrs 0 - 14  yrs 0 - 14  yrs	Not specified Single lesion BT (80%) BT (66.3%)
Grover et al. (2005)	1997-2002	Urban clinic, New Delhi	n = 137 (7.06)	0-14  yrs	BT $(70.8\%)$
John et al. (2005)	1998 - 2003	Leprosy Mission Hospital, West Bengal	n = 258 (18)	10-20 yrs	Not specified
Sardana K (2006)	1992 - 2003	Tertiary care hospital, New Delhi	n = 86.7.71	0-15 yrs	BT $(\tilde{73\%})$
Vara N (2006)	1999 - 2002	Tertiary care hospital, Gujrat	n = 67 (8.4)	0-14 yrs	BT (35.82%)
Rao AG (2009)	2004 - 2009	Tertiary care hospital, Andhra Pradesh	$n = 32 \ (11.43)$	0-18 yrs	BT (68·75%)
Horo et al. (2010)	2004 - 2006	Leprosy Mission Hospital, West Bengal	n = 151 (not quoted)	0-15 yrs	TT (43.7%)
Sachdeva et al. (2010)	2000 - 2009	Tertiary care hospital, Uttar Pradesh	$n = 219 \ (5.1)$	0-15 yrs	Not specified
Singal et al. (2011)	2000 - 2009	Tertiary care hospital, New Delhi	n = 172 (9.6)	0-14 yrs	BT (70.3%)
Shetty et al. (2013)	June-September, 2007	Community survey, Maharashtra	n = 32 (R) (35.5)	0-14 yrs	Not specified (R)
			n = 36 (U) (33)		Not specified, (U)
					Single lesion BT 69%

R = Rural, U = Urban

Table 2. Percent	tage of cases	with familia	l contact,	multibacillary	disease	and smear	positivity in	various	Indian
studies <sup>2-13</sup>	-								

Author(s)/year of publication	Familial contact	Multi-bacillary cases	Smear positivity
Prasad PVS (1998)	6.06%	6.06%	6.06%
Selvasekar et al. (1999)	29.8%	2%	Not quoted
Jain et al. (2002)	36.92%	Not specified	9.4%
Grover et al. (2005)	21.9%	29%	22.62%
John et al. (2005)	Not quoted	56.6%	5.42
Sardana K (2006)	26.74%	37%	28%
Vara N (2006)	14.9%	>50% cases	46.3%
Rao AG (2009)	18%	Not specified	25%
Horo et al. (2010)	0.66%	33%	30%
Sachdeva et al. (2010)	35%	26%	Not quoted
Singal et al. (2011)	11.6%	51.7%	19.8%
Shetty et al. (2013)	47% (R)	34.37% (R)	6·25% (R)
• 、 /	19% (U)	19·44% (U)	8·33% (U)

R = Rural, U = Urban

(10-20 years).<sup>18</sup> Boys predominated in all the studies (gender ratio varying from 1.25:1 to 3:1) except in one, where boys and girls were equal in number.<sup>19</sup>

Borderline tuberculoid (BT) was the commonest clinical type recorded, majority with single lesion disease (Table 1). Presentation with more than five lesions was frequently encountered. Polar tuberculoid (TT) disease varied from 0-43.7%. Horo *et al.* have reported TT as the commonest clinical type, closely followed by BT leprosy.<sup>19</sup> Patients in pediatric age group are known to suffer from tuberculoid disease commonly, but almost all authors have reported occurrence of BL (1.9% to 19.4%) and LL (0.1% to 9.38%) disease in their series. Indeterminate disease was recorded in three studies (3.48%-10.1%). Pure neuritic leprosy has been described as uncommon in children<sup>9</sup> but was recorded in almost all the series of patients (0.3%-4.47%). Cases of histoid leprosy were recorded by two authors.<sup>14,16</sup>

Table 3.	Percentage	of patients	with reaction,	deformity and	l relapse in	various Indi	an studies <sup>2-8</sup>

Author(s)	Reaction	Deformity	Relapse	
Prasad PVS (1998)	0	3%	7.1%	
Selvasekar et al. (1999)	4.03%	0.5%	1.63%	
Jain et al. (2002)	29.7%	0	0	
Grover et al. (2005)	2% (at presentation), 10.9%	24%	0	
John et al. (2005)	14.5%	4.8%	0	
Sardana K (2006)	2.32%	13%	0	
Vara N (2006)	0	10.4%	0	
Rao AG (2009)	6.24%	3.12%	0	
Horo et al. (2010)	11.25%	16%	0	
Sachdeva et al. (2010)	1.36%	Not quoted	0	
Singal <i>et al.</i> (2011)	18.6%	12.8%	1.16%	
Shetty et al. (2013)	0 (R)	9% (R)	0 (R)	
• • •	0 (U)	0 (U)	0 (U)	

R = Rural, U = Urban

Peripheral nerve trunk involvements were encountered commonly. Single nerve trunk was involved in 13.63-40.62% cases in various studies. Multiple nerve trunk involvement was recorded in 4.54-59.38% cases.

The majority of the cases were paucibacillary (43.28%-98%). Multibacillary (MB) cases ranged from 2%-56.6% in various studies (Table 2). In two studies it exceeded the number of paucibacillary (PB) cases.<sup>11,14</sup> The criteria for categorizing PB and MB cases has changed over time. Earlier, at various times, disease type and demonstration of bacilli were used as criteria for categorizing leprosy patients as PB or MB. Presently, this classification is for therapeutic purposes, based upon the number of skin lesions and peripheral nerves involved, irrespective of the bacillary status of the lesions. Hence, the criteria for categorizing patients as PB or MB used by the various authors in these studies might have been heterogeneous and does not give the true picture on the basis of current criteria.

The history of familial contact ranged from 0.66% - 47% (Table 2). Except in one study where data regarding contact was not quoted,<sup>18</sup> all the authors had recorded presence of intrafamilial contact. Parents, grandparents and siblings were the common contacts. Mostly these contacts were multibacillary cases with smear positivity in some cases. Some of the contacts were on regular treatment, some were defaulters, and others did not receive any anti-leprosy treatment at all. Shetty et al had recorded highest number of contacts in the rural area survey in western Maharashtra.<sup>20</sup> Many of the affected children had multiple contacts in the family as recorded in all the twelve studies. However, as Jain et al have recorded 38% paucibacillary contacts in their series of children with leprosy,<sup>15</sup> the threat was not only from the multibacillary cases. Only two studies specifically mentioned regarding presence of non-familial contacts as 1.96% (Jain et al)<sup>15</sup> and 2.9% (Singal *et al.*).<sup>14</sup> Two studies conducted at New Delhi, the capital of the country, reported high percentage of children in their study group (62%-69.6%) who belonged to immigrant families from neighbouring high endemic states for leprosy.<sup>14,16</sup>

Slit-skin smear positive cases ranged from 5.42% - 25% (Table 2). Lepra reactions were not recorded among children in three studies. Among the rest it occurred in 1.36% - 29.7% cases (Table 3). Both Type 1 (1.16% - 28.10%) and Type 2 (0.12% - 5.81%) reactions were recorded. Relapse was recorded in three studies, varying from 1.16% - 7.1% (Table 3).

Deformity occurred in 0-24% cases (Table 3). Most of the studies have measured deformity according to WHO disability grading. Many children had visible deformity at presentation. Sardana K had reported mean disease duration of 1.5 years in children who had deformity at initial presentation, indicating delay in seeking health care facilities among the affected children.<sup>10</sup> Some children had developed deformity after release from treatment.

John *et al.* had conducted in-depth interviews and focus group discussions with 258 adolescent leprosy patients included in their study.<sup>18</sup> The important revelations from interview of this targeted age-group were that they were under dilemma regarding their disease because of lack of overall knowledge about it and dependence upon parents regarding seeking health care facilities.<sup>18</sup> Leprosy-related complications led to school drop-outs and loss of working days for them, and they were ashamed of the deformities leading to social withdrawal.<sup>18</sup> Group discussions involving parents revealed that they were not motivated to adopt modern treatment facilities for leprosy, rather preferred to depend upon indigenous methods and faith healers, leading to delay in diagnosis and complications.<sup>18</sup>

Sachdeva *et al.* recorded absence of BCG scar in 53% of the children with leprosy in their series of cases.<sup>13</sup> Though there was no statistically significant correlation between occurrence of leprosy among BCG-vaccinated and non-vaccinated children, the authors have emphasised

that it is probable that BCG offers some protection against leprosy.<sup>13</sup> This finding has important implication; from the review of the studies it is evident that familial and extra-familial contacts play an important role in the transmission of leprosy in all the regions of India, and in this context, a simple and inexpensive measure like BCG vaccination, though partially, may halt the transmission of the disease.

Studies conducted in two tertiary care hospitals in North India, spanned over a period of 10 years, included patients both from pre– and post-elimination era (before and after the year 2005).<sup>13,14</sup> In one of these studies, when detected cases were charted year-wise, there was no significant difference in the number of new cases in the former half of the study, whereas a downward trend was recorded in the latter half.<sup>13</sup> The other study has recorded a decline in average child proportion in the post-elimination phase (8·48%) as compared to the pre-elimination phase (10·33%).<sup>14</sup>

## Conclusion

As 10 out of the 12 studies were based on the data collected from voluntary reporting by patients, an exact epidemiological picture of childhood leprosy at the community level during this period is not clear. However, some conclusions may be derived from the review of these studies. As evidenced in two studies,<sup>16,20</sup> a community survey is a more effective method to detect cases of leprosy than voluntary reporting and referral services, as it targets the hidden cases.

Contrary to the conventional concept that multibacillary cases are rare in childhood,<sup>21,22</sup> these occur frequently among Indian children. So, childhood leprosy is not synonymous to paucibacillary disease. Children may present with smear positive LL disease and may act as a source of many other new cases in the household, neighbourhood and educational institutions in future.

The presence of both familial and extra-familial contact with leprosy cases may be the reason for high incidence of childhood cases in some studies. These contacts may be an important contributory factor in the present scenario of childhood leprosy in the country. This finding has epidemiological significance and indicates the need for more intense community survey to detect existing cases of leprosy.

Pure neuritic leprosy, which is considered uncommon in children,<sup>9</sup> is actually not so among Indian children.

Contrary to the conclusion of some earlier studies,<sup>23</sup> this review found that lepra reactions and deformities were not uncommon among the children suffering from leprosy. Several socio-economic factors may influence the occurrence of leprosy-related deformity in children in a developing country like India. Illiteracy and ignorance about the consequences of the disease leading to reluctance to avail health care at an early stage,<sup>10</sup> low socio-economic status of most of the families harboring leprosy cases,<sup>18</sup> and often, the custom of entrusting the burden of family income upon young children in poor families are contributory to the problem of leprosy-related deformities.

As per finding from one study,<sup>13</sup> the national protocol of administration of BCG vaccine at birth may be inadequate in some parts of India. BCG vaccination at birth may be encouraged through special campaigns, especially in the states with high endemicity for leprosy and in the families with leprosy patients.

The aim of reviewing the above Indian studies is to get a glimpse of childhood leprosy when the country is standing at the juncture of elimination and eradication.

Little modifications of the existing strategies may mean a lot at this stage in terms of higher case detection, better contact tracing and prevention of deformities. It is distressing to know that in the era of booming information technology, a section of the society is still ignorant about the curability of leprosy and rely upon indigenous methods as the first defensive step. Though awareness creation drives about the disease (through television and newspapers) already exist in the country, these may be further strengthened and frequented to overcome this pitfall.

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