

Survey on child leprosy patients and problems resulted from the disease in China

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Summary

Objectives: To understand the situation of child leprosy patients in the low prevalence situation pertaining in China.

Method: A retrospective survey by questionnaire was carried out in all 32 provinces of mainland of China in 2011. All data concerning child cases detected from January 2005 to December 2009 were collected by professional health workers working at county level.

Results: During the study, only 165 questionnaires were collected for analysis. Among 165 child cases, 96 were boys, 69 were girls with an average age of 11.7 years old. 80% of child cases were members of families with other leprosy affected people. 145 (85%) child cases took their MDT secretly (nobody outside the family knew the child suffered from leprosy), and three (1.8%) children died, one each from dapsone syndrome, suicide and severe pneumonia. During follow-up, four child cases developed new disability increasing the Grade 2 disability rate to 13.3% (22/165). At end of the study, 8.2% of children had discontinued their study at school, and 7.5% had moved to a remote place to do casual work, while 6.3% stayed at home. 31% of child patients thought that leprosy caused a negative impact on their daily life. Two children had a hostile attitude toward society due to the stigma caused by leprosy.

Conclusions: In both high and low endemic areas, as long as there is an infectious source of leprosy in the family, there is a possibility for children to develop leprosy. Contact surveys should be done to detect early disease, especially when there are children in the household.

Introduction

The number of child leprosy cases (aged ≤ 15 years old at diagnosis) is a sensitive indicator of leprosy transmission. Although, China reached the basic elimination goal of leprosy with a prevalence of less than 1/10000 in 1990, many provinces are still reporting

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child cases in recent years, either in provinces with pockets of high leprosy prevalence or in provinces with very few new cases. Why do child leprosy cases still occur? What are the problems in case detection and management of child leprosy? What impact did the disease have on the children affected? We carried out a questionnaire survey in 2011 to study child leprosy patients in China.

Materials and methods

This was a retrospective study. Data from all 32 provinces in mainland China were collected through questionnaires sent to each province. The questionnaire was designed to collect demographic and clinical data, information about the evolution of the disease, treatment and surveillance, and the social situation. The questionnaire was sent through each Provincial Center for Disease Control and Prevention to each county leprosy control unit which has reported child cases during the period of study. All data on child cases (age under 15 years at diagnosis) registered from January 2005 to December 2009 were collected through the questionnaire by the professional health worker at county level, and then sent to National Center for Leprosy Control through each Provincial Center. The data were entered into a computer database at the National Center and analysed using SPSS software version 16.0.

Results

Records show that 191 child cases were diagnosed in 20 provinces during the study period from 2005 to 2009. The proportion of child cases among the all newly detected cases ranged from 2.1–2.9%. From 2010 to 2013, the number of new cases and markedly decreased, but the child cases still occur (Table 1).

The five provinces with the highest number of child cases were Yunnan (reporting 49 child cases), Guizhou (44), Sichuan (28), Guangdong (16) and Guangxi (13) in the 5 years under study; all these provinces are located in the southwest and southern region of China (Table 2).

It is interesting that three provinces (Jiangsu, Zhejiang, Fujian) located in the east of China where the social economy is well developed and leprosy prevalence has markedly decreased with an overall annual detection rate of only 0.04/100000, reported one, three and two child cases in the 5 year period, respectively. Three provinces (Qinghai, Gansu and Xinjiang) located in the northwest of China, where the annual new case detection was as low

Table 1. New case and child case detection from 2005–2013 in China

Category	2005	2006	2007	2008	2009	2010	2011	2012	2013
No. of total new cases reported	1658	1506	1526	1614	1597	1321	1144	1206	924
Detection rate 1/100,000	0.127	0.115	0.115	0.122	0.120	0.099	0.085	0.090	0.069
No. of Child cases reported (% of new cases)	35 (2.1)	43 (2.9)	34 (2.2)	40 (2.5)	39 (2.4)	39 (3.0)	29 (2.5)	29 (2.4)	14 (1.5)

Table 2. New case and child case detection in 20 provinces in China from 2005–2009

Province	Population* X10000	Region in China	No. of new cases detected in 5 years	Mean annual detection rate in 5 years (1/100,000)	No. of child cases detected in 5 years (% of new cases)
Yunnan	4506	Southwest	1893	0.84	49 (2.588)
Guizhou	3975		1147	0.58	44 (3.836)
Sichuan	8127		1210	0.30	28 (2.314)
Guangdong	9449	South	670	0.14	16 (2.388)
Guangxi	5002		555	0.22	13 (2.342)
Jiangxi	4368		290	0.13	8 (2.758)
Hainan	845		138	0.33	7 (5.072)
Hunan	6355		384	0.12	7 (1.822)
Xinjiang	2050	Northwest	38	0.04	4 (10.526)
Zhejiang	5060	East	112	0.04	3 (2.679)
Anhui	6675		135	0.04	2 (1.481)
Tibet	282	Southwest	119	0.84	2 (1.680)
Jiangsu	7624	East	158	0.04	1 (0.632)
Fujian	3581		268	0.15	1 (0.003)
Henan	9869	Central	46	0.01	1 (2.174)
Hubei	6070		187	0.06	1 (0.005)
Chongqing	2822		130	0.09	1 (0.008)
Shaanxi	3748		150	0.08	1 (0.007)
Gansu	2617	Northwest	35	0.03	1 (2.857)
Qinghai	551		15	0.05	1 (6.667)
Total	93576		7680	0.16	191 (2.487)

*According to population data of 2007

as 0.03–0.05/100000, reported one, one and four child cases in the last 5 years, respectively, with a high percentage of 2.8–10.5 among newly detected cases.

One hundred and sixty-five questionnaires were returned for analysis. Regarding the remaining 26 patients, two cases were reported twice, four were misdiagnosis of leprosy, four were not child cases, and the other 16 were not identified for unknown reasons. Among 165 child cases, 96 were boys, 69 were girls with an average age of 11.7 years old. The clinical types were I seven, TT 40, BT 41, BB 11, BL 39 and LL 27. The average delay from disease onset to being diagnosed was 13.8 months. It is noteworthy that in 80% of child cases there were family members who were active leprosy patients in the family before the child was diagnosed as a leprosy case. Five percent of child cases had had contact with leprosy patients outside the family, and 15% did not know of any contact with leprosy.

The top four case detection methods were contact survey (37%), suspect survey (17%), skin clinic (16%) and self-report (16%). At the time of diagnosis, 18 (11%) child patients had a leprosy reaction, including 12 with neuritis; the Grade 2 disability rate amongst all child cases at diagnosis was 11%. During treatment, 145 (85%) child cases accepted MDT secretly (nobody outside the family knew the child suffered from leprosy and was being treated with MDT). Five (3%) child cases developed DDS allergy (dapson syndrome), and three children died, one each of dapson syndrome, suicide and severe pneumonia. In the follow-up period, four child cases developed new disability increasing the Grade 2 disability rate to 13.3% (22/165).

Leprosy was detected below 15 years of age for all child cases, but at the time of the study, the ages of some of the cases exceeded 15 years. The mean age of 165 child patients at the time of the survey was 14.7 years old. Of the 109 subjects who were still under the age of

15 years, 75 (70%) were still going to school, while nine (8%) had discontinued their study at school; eight children had left home to look for work, and seven were staying at home. Amongst child patients, 31% thought that leprosy had had a negative impact on their daily life. Two children even had a hostile attitude toward the society due to stigma caused by leprosy.

Discussion

One limitation of this study is that being a cross sectional retrospective study of records it relies on data which was collected for clinical and public health purposes, rather than direct observation of the cases.

The presence of leprosy in children is a sensitive indicator for leprosy transmission. Usually, the proportion of child leprosy is closely linked with local leprosy prevalence. Among the countries with a high leprosy prevalence, such as Indonesia and Brazil, the proportion of children among new leprosy cases is high, at 11.9% and 7.9% respectively.¹ In 2012, India has 0.13 million cases, 9.7% of which were children.² As compared with these leprosy endemic countries, China is a low epidemic country. However, health workers in China still detect child leprosy cases each year with a percentage of 2.1–2.9 of all newly detected cases. Even in the province with a very low leprosy prevalence such as China's northwest Xinjiang province, there are still a few child patients detected. We find that both in high endemic and low endemic areas, some child leprosy cases are detected. Because the environment of leprosy transmission at the local family level is the same both in high or low endemic areas, as long as there is a leprosy infectious source in the family, there is a possibility to develop a child leprosy case. In addition, in low leprosy endemic areas, there is a trend to detect adult leprosy patients with a long delay,^{3–5} which increases the risk of leprosy transmission to the child in the family.

When a childhood leprosy case occurs, it usually reflects a child having had a long and intense contact with an untreated leprosy patient. Jain *et al.*⁶ reported that among 119 child leprosy patients, 113 (95%) had a family contact history. In our study, 80% of child cases had a family member who once suffered from leprosy before the child was diagnosed as having leprosy. This emphasises the importance of screening children for possible leprosy in leprosy-affected families. In our study, the child case detection by contact survey accounted for 37.4%, and suspect survey for 17.3%, so that we fully agree with many authors' suggestion that contact screening may be an important measure to detect childhood leprosy early.^{7–9} We strongly suggest that whether in high endemic or low endemic areas (due to a same pattern of local family transmission), contact survey for a family having children should be done to detect early disease.

Management of childhood leprosy is very different from that of adult leprosy patients. Guardians of the child patients sometimes neglect care for the child, including regular treatment for leprosy, as well as self care for eyes, hands and feet. Hence the nerve damage caused by leprosy may be more severe than in an adult patient, especially when the child patient develops severe leprosy reaction. In addition psychological injury, due to stigma caused by the disease in communities, is more severe in children than in adult patients. The psychological shadow caused by leprosy always accompanies the child during the period of studying in elementary school, growing up and entering the society. In our study, 8.2% of child patients discontinued their study at school, 7.5% of them left their home and went out to a remote place to do casual work for earning money, and 6.3% of them stayed at home.

Thirty one percent of child patients thought that leprosy caused a negative impact on their daily life, study and work. Two children even had a hostile attitude toward society due to stigma caused by leprosy. We consider that child leprosy patients should be paid special attention. We strongly suggest that if possible the application of appropriate prophylactic measure should be used for children having a long contact with advanced multi-bacillary patients in the family, to decrease the risk of their developing leprosy in the future.

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