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Children and leprosy in southern Nigeria: burden, challenges and prospects

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Summary
Objectives: To describe the trend of leprosy case notification among children from 2002 to 2012 in Southern Nigeria. 2. To identify the challenges faced by the children suffering from leprosy.
Design: A retrospective descriptive desk analysis of leprosy case notification data for children from 0 to 14 years in 14 states in Southern Nigeria. Secondly, a cross sectional study of all children currently undergoing leprosy treatment in three selected clusters (referral centres) in Southern Nigeria. A questionnaire-based interview was used to identify the challenges faced by the children with leprosy.
Results: Notified cases of leprosy among children in southern Nigeria decreased from 110 cases in 2002 to 64 cases in 2012. The median child proportion and MB proportion were 7·0% and 80·5% respectively. Two children (with WHO Grade 2 Disability) interviewed had great difficulty with their education and social life. Others were able to cope well in school and suffered no discrimination probably because their disease remained undisclosed to and unrecognised by the teachers. The school teachers were reportedly unable to recognise the symptoms/signs of leprosy in seven out of the 10 cases. Eight of the child leprosy cases were initially misdiagnosed at peripheral hospitals. The diagnostic delay ranged from 5 to 48 (with a median of 36) months. Notably, five out of the 10 children interviewed reported a positive household contact history.
Conclusion: Notwithstanding the decline in leprosy case-notification in southern Nigeria over the past decade, transmission of the infection appears to be on-going as evidenced by the considerable number of child cases. Innovative approaches in case-finding including school-based activities and robust 'family-contact' management are recommended to address long diagnostic delays and lingering stigma.

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Introduction

Nigeria achieved the WHO leprosy elimination target in 1998. The 14 GLRA-assisted states in southern Nigeria contribute about a third of the total national case-notification. Similar to the control of tuberculosis, diagnosis and management of childhood leprosy is fraught with peculiar challenges. There exists some evidence that children born to leprosy patients (including those affected by leprosy) found in some leprosy settlements in Nigeria faced educational and social challenges.[1] Over the years, children (and adults) are no longer confined to leprosy settlements in the course of their leprosy treatment. These children may face difficulties in education, social life and activities of daily living, which differ somewhat from the problems encountered by adults. How do they cope and how can they best be helped to fulfil their potentials? This study seeks to explore these questions and propose some possible remedial measures.

According to the World Health Organization (WHO), the peak age of onset of leprosy is young adulthood, usually 20–30 years; the disease is rare in children less than five years old.[2] However, the proportion of child cases among new cases is an indicator of ongoing transmission of leprosy in the area. Other indicators of quality of case detection include: proportion of multibacillary (MB) cases and WHO Grade 2 disability rates among new cases.[2] The current WHO strategy is to reduce the number of cases among those less than 15 years old and to achieve a 35% reduction in the rate of new cases with Grade 2 disability per million population relative to that in 2011, and a longer term goal of reducing the number of cases with Grade 2 disability to one in 1,000,000 by 2020.[3,4] Aside from some efforts to encourage leprosy case finding through contact tracing, no specific activities have been directed towards children with leprosy in Nigeria. The objective of this study is to describe the trend of leprosy case notification amongst children less than 15 years old in southern Nigeria from 2002 to 2012. It also seeks to identify the various challenges faced by children diagnosed with leprosy. These challenges ranged from difficulties faced in their educational career and social life to coping with disabilities possibly due to delay in leprosy diagnosis, leprosy reactions, neuritis, adverse drug reactions and other issues.

Materials and methods

A retrospective descriptive desk analysis of leprosy case notification data for children 0 to 14 years in the 14 states in Southern Nigeria supported by the German Leprosy and Tuberculosis Relief Association (GLRA) was conducted. A review of 11-year data described the trend of child leprosy case detection and the proportion of child cases in relation to adults. It also described the Multibacillary (MB) proportion among new child leprosy cases and their gender distribution. The WHO Grade 2 Disability rate among new leprosy cases detected over the period was described. Additionally, a cross sectional study of children currently undergoing leprosy treatment in three out of seven selected clusters (leprosy referral centres) in southern Nigeria was conducted. These centres are Ogoja, Abakaliki and Iberekodo located respectively in the south-south, south-east and south-west geopolitical zones in Southern Nigeria. This study was carried out between August and October, 2013 among children currently receiving leprosy treatment in these centres. A total of 10 children were found in these referral centres during the period of this study: three from Ogoja, seven from Abakaliki and none from Iberekodo. A questionnaire-based interview was conducted to identify the

psychosocial, clinical and educational challenges faced before diagnosis and during the course of their leprosy treatment in the community. These challenges ranged from difficulties faced in their educational career and social life to coping with disabilities possibly due to delay in leprosy diagnosis, leprosy reactions, neuritis, adverse drug reactions and other issues. The study obtained the history of contact with a leprosy case in the family or community and identified the source of information on locating the nearest leprosy treatment centres. The result was collated and analysed using Statistical Package for Social Sciences (SPSS) version 16·0 and presented as ratios, proportions and percentages.

LIMITATIONS OF THE STUDY

The number of subjects studied was very small owing to the declining number of leprosy patients detected in the study population. However, the three referral hospitals were selected each from the three different geopolitical zones in Southern Nigeria to make the data as representative as possible. Slit skin smear and clinical classification of patients into Lepromatous, Borderline and Tuberculoid types are not routinely done in the National Leprosy Control Programme and so were not reported for these patients before treatment was commenced. WHO Grade 2 disability disaggregated by age is not routinely reported to the National leprosy control programme and so it was not possible to analyse the proportion of the Grade 2 disability among new leprosy child cases.

Results

Notified new cases of leprosy amongst children in the 14 states in Southern Nigeria decreased from 110 cases in 2002 to 64 cases in 2012 (41·8% decrease). This represents a proportion of 7·2% in 2002 and 7·0% in 2012 of total new cases (adults and children) notified within the period, with a median of 7·0%. Proportion of MB cases amongst children increased from 79% in 2002 to 90.6% in 2012, with a median of 80·5% (Figure 1). Male to female ratio was 1·2:1 (Figure 2). WHO Grade 2 Disability rate among all newly diagnosed cases (both children and adults) in Southern Nigeria increased from 15·5% in 2002 to 24·4% in 2012.

Among the 10 children studied were eight males and two females aged between 9 and 13 (median age of 12). The cases were all multibacillary (MB); so far, no report of any leprosy reaction or adverse drug effect has been recorded in the course of their treatment. Three of the children had suffered leprosy for 48 months before the diagnosis was made; five had it for 24 to 36 months; while two had leprosy for less than 24 months. (median delay of 36 months). Two of the children had WHO Grade 2 disability at diagnosis; others had no disability (WHO Grade 0). Prior to diagnosis, eight of the leprosy cases were missed (by doctors and general healthcare workers) in one or two different hospitals earlier visited by the patients - including private and tertiary hospitals. Three and five of the patients had earlier visited traditional healers and patent medicine dealers respectively for care at one or more occasions, where they received various herbs and other medications (for an average of 5 months treatment duration) without any improvement. Information on symptoms of leprosy and location of the treatment centres eventually reached seven of the patients through community leprosy campaigns, by health workers or through a family member. Half of

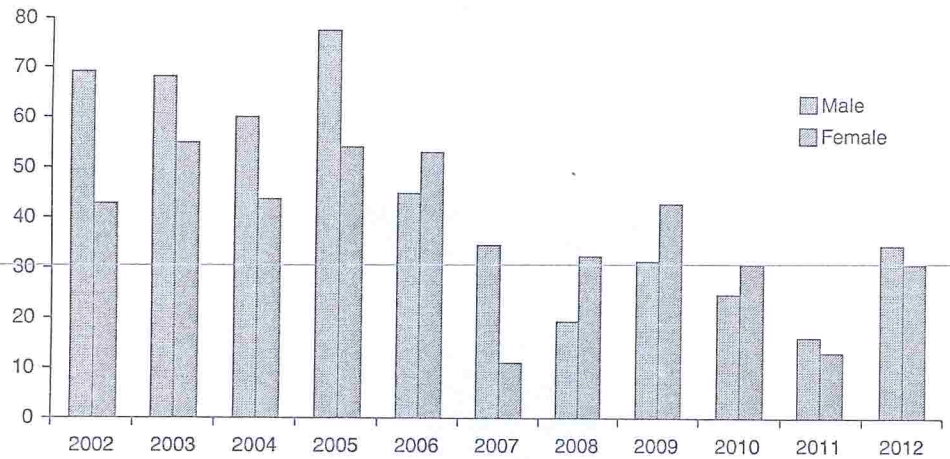

Fig. 1. Male: Female proportions of child cases of leprosy in Southern Nigeria from 2002 to 2012.

the children reported a contact history of a family member who had previously suffered from leprosy.

Two children interviewed (both with WHO Grade 2 Disability) suffered discrimination at school; and one was sent out of school when found to have leprosy. Others were able to cope well in school and suffered no discrimination even though their disease remained undisclosed to the teachers. One of the children interviewed reported a positive and friendly attitude from the teachers when they realised that he had leprosy. In all, it was reported that the school teachers were not able to recognise the symptoms/signs of leprosy in seven out of the 10 children interviewed.

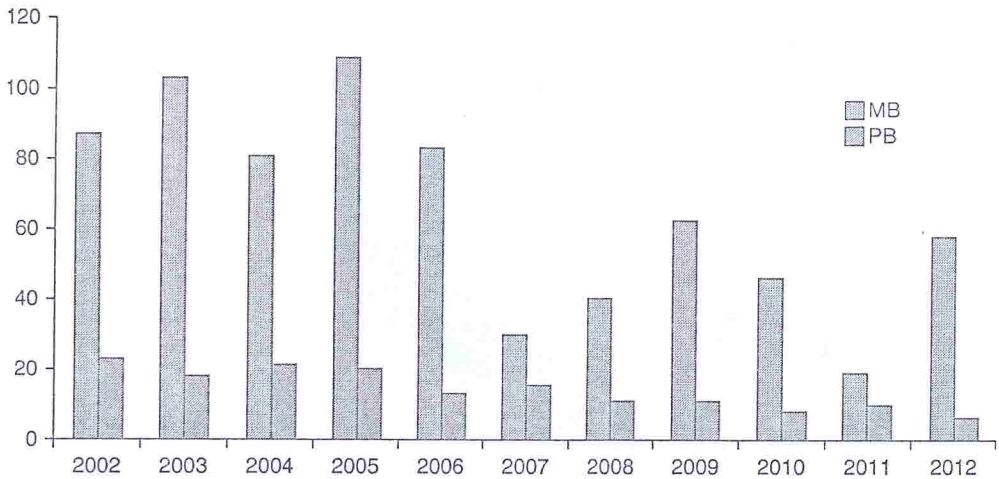

Fig. 2. The proportions pf MB and PB classification among child cases of leprosy in Southern Nigeria from 2002 to 2012.

Discussion

The remarkable decrease in case notification over this period may have resulted at least in part from intensified case finding activities in the country during the WHO leprosy elimination era. Contrary to expectations, the proportion of child cases did not decrease over this period. Nationally, there has been a gradual increase in child proportion from 11·7% in 2002 to 14% in 2012.[5] The increasing trend of child proportion may be connected with intensified leprosy case finding campaigns carried out in communities in high endemic districts in the study area. In these campaigns, a higher proportion of child cases is often detected. This suggests delayed leprosy case detection in southern Nigeria. It is possible that several children who are close contacts of these delayed cases may have undetected leprosy. Some of them may eventually be diagnosed late as MB cases with irreversible deformities, with the consequent social and educational challenges. These results suggest that the strategies for early case finding of leprosy in the country may be inadequate (despite achieving the global leprosy elimination target); and therefore, need to be reviewed.[2] The child proportion of new leprosy cases notified in southern Nigeria is similar to Brazil,[4] but slightly lower than India.[6] This suggests that these countries may share other challenges concerning children and leprosy. The MB proportion of 80.5% (median) among children in this study is much higher than the 51% in India.[6]

The findings in this study suggest that the burden of leprosy was higher in male children than their female counterparts up to 2007. This is similar to the global trend.[2,4,6,7,8] Remarkably, a reversal in this trend was observed from 2008 to 2010 with a preponderance of females. It is not entirely clear why this occurred. Possible explanations include frequent, increased implementation of active leprosy case finding activities during the period which may have contributed to improved access for both boys and girls. Within this period, however, the burden of leprosy remained higher amongst adult males (Figure 3). The reason for this is not clear.

Among the children interviewed, two have already faced difficulties in education and social life. Eight of them are able to cope with their education and social life in the

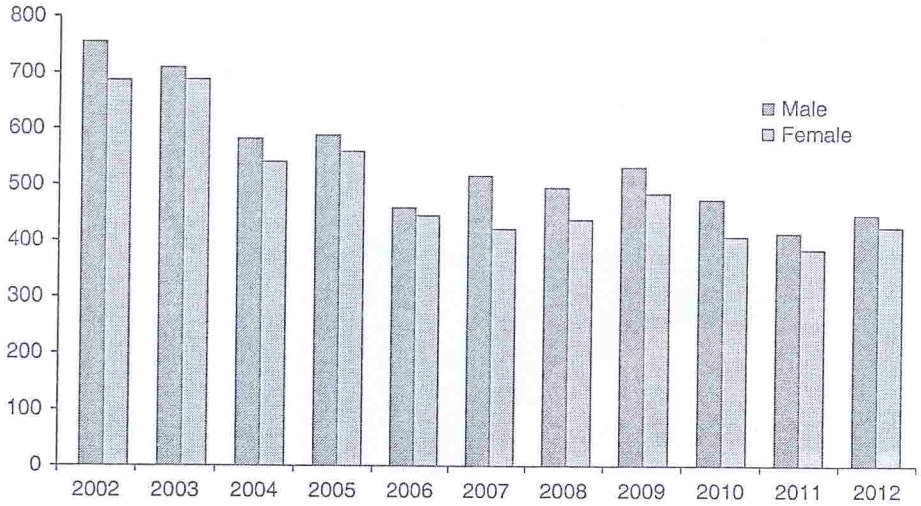

Fig. 3. Male: Female proportions of adult cases of leprosy in Southern Nigeria from 2002 to 2012.

community probably because they have no physical deformities and most of their teachers are reportedly not aware of their disease. The fear of being stigmatised at school appears to be very high in 90% of the cases and this may jeopardise early case detection among other affected young children. Besides, the teachers were reportedly unable to recognise leprosy among seven out of the 10 children interviewed. This clearly suggests a high level of ignorance of symptoms and signs of leprosy among the school teachers. It may also explain the long diagnostic delay of 36 months leading to the high MB proportion and Grade 2 disability rate at diagnosis. Besides stigma and ignorance of leprosy amongst school teachers, delay in leprosy diagnosis was exacerbated by ignorance among healthcare workers including medical doctors, as 80% of the child cases were earlier misdiagnosed in hospitals. Delay in diagnosis is a major reason for most complications and difficulties faced by children with leprosy and therefore should be addressed.

Despite a paucity of data on duration of delay before diagnosis among children, the findings in this study showed that the median delay of 36 months among children in Southern Nigeria did not differ from that of adults obtained in China,[9] however, it represents only a third in Brazil.[10] The findings in this study as well as those from other countries are consistent with the WHO position that leprosy is rare among children less than 5 years.[2,6,8] Unlike other countries,[6] none of the children interviewed had any leprosy reactions, neuritis or adverse drug reactions so far. This difference may reflect the fact that these patients are still taking their medication and may later develop complications before they complete their treatment.

A noteworthy finding in this study is the fact that five out of the 10 children interviewed had a positive household contact history. This underscores the importance of household contact screening as a component of case finding in the national programme[11]. All the children had MB leprosy and two out of 10 presented with Grade 2 disabilities.

Conclusion

The findings in this study suggest that some children affected by leprosy still have difficulties with their education and social life. The long diagnostic delays and high MB proportion suggest inadequate early case finding in the study population. Furthermore, ignorance especially among health workers and school teachers as well as stigma appear to be lingering issues in the community.

Innovative approaches in early case-finding are imperative to improve early case-finding and reduce stigma. These include: school-based activities, robust 'family-contact' management and continued orientation of healthcare workers (including doctors) on leprosy.

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