What parents should know while their child is on MDT: Insights from a qualitative study in Eastern India

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Summary  In order to provide high quality leprosy services to children affected by leprosy, it is necessary to actively engage parents. A qualitative study was undertaken as part of routine monitoring of field activities in West Bengal, India. A non-probability sample of 20 parents whose child was currently undergoing treatment was interviewed to explore the experiences of parents with regard to the diagnosis of leprosy and the treatment of their child. The most common initial symptom was a white patch and the median duration between recognition of the symptom and care-seeking was 6 months. The most commonly reported side-effect was a black discolouration which had led to non-adherence as well as resulting in school absenteeism. None of the parents had any knowledge of reactions. Although current strategies have enabled early case detection, there are challenges related to ensuring treatment completion. Emphasis should be laid on interpersonal communication to empower parents, enabling them to appreciate the side-effects and recognise the complications early and be actively engaged as a treatment partner while their child is on MDT.

Introduction

Childhood leprosy is an indicator of active and recent transmission of the disease and reflects the level of control in a community. Out of the 134,752 new leprosy cases reported in India in 2012–2013, around 10% (13,387) were children; the proportion being much higher in the high burden states (Dadra & Nagar Haveli – 26-09%, Bihar – 15-88%). Moreover, as compared to previous years there has not been a significant decline in the trend for this epidemiologically important indicator.
As envisaged in the ‘Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy by 2015’, there is a need to provide high-quality leprosy services to all including children affected by leprosy. In order to be able to do so, it is necessary to actively engage parents in the management of their children. Despite the importance, however, childhood leprosy has remained neglected and there is a paucity of information on the experience of children while on MDT. The aim of the study was to explore the experiences of parents with regard to the diagnosis of leprosy and the treatment of their child.

Materials and methods

Qualitative research is best suited to explore and understand the beliefs, values and processes underlying behavioural patterns of adherence and non-adherence in the caregiver. We conducted a qualitative study as part of routine monitoring of field-level activities in the state of West Bengal in the Eastern part of India. The state reported endemicity with ANCDR 12.46 per 100,000 population and a child rate of about one per 100,000 population (2012–13).

The study was conducted on a non-probability sample of 20 parents whose child was on MDT. The final sample size was determined by the non-emergence of new themes and data saturation.

The parents were interviewed in their homes using a semi-structured interview guide, after obtaining an informed consent. The interview covered five themes, namely initial symptoms, care-seeking behaviour, experience with MDT, experience with health system and stigma and discrimination in the community.

The framework approach was used for the analysis of transcribed interviews.

Results

A majority of the children were students and belonged to the age group 9–14 years. A white patch was the most common initial symptom which prompted the parents to seek care from the health worker. The median duration between recognition of the symptom and care-seeking was 6 months (range 3–18 months).

Twelve out of the 20 children had been diagnosed as multibacillary leprosy. MDT was usually self-administered by the child. Few children were observed to be taking MDT incorrectly, especially for doses of clofazimine. Some parents complained, “My child has been taking treatment properly for a long time, then why has the patch remained white?”

Black skin discolouration was the most common side-effect. Children were often made fun of at school due to the discoloration. This had led to non-adherence among a few children and also resulted in school absenteeism.

All the parents interviewed were ignorant about the symptoms of reactions and the importance of reporting them early.

During the interviews, two children were found to be suffering from reaction. Their parents expressed anguish and concern that despite being on MDT, the symptoms had flared up. This had lowered their confidence in the health system and therefore they had not sought care from health worker.
Discussion

One of the major successes of the National Leprosy Eradication Programme in India has been the integration of leprosy services with the general healthcare system. This has enabled early case detection. The current challenges relate to ensuring treatment completion and early care-seeking and management of complications in the form of reactions to prevent disabilities.

We found that Clofazimine-induced skin discolouration resulted in interruption of treatment among children and led to discrimination. It is known that the brownish-black discolouration caused by the drug disappears within a few months after stopping treatment. It is also well-known that MDT is a cure for the disease and not the patch; the patch may persist despite successful treatment. In the event of no prior information on these, peoples’ faith on the healthcare system declines significantly.4 The impact of such ‘negative triggers’ on the coping strategies and also on the type of stigmatising actions of others has been elaborated upon.5

It may therefore, not be enough to motivate parents to seek care for their children at the earliest sign of leprosy. Parents should also be empowered to enable them to appreciate the side-effects and recognise the complications early and be actively engaged as a treatment partner while their child is on MDT. The treatment programme should emphasise on interpersonal communication as a key management strategy, building the competence of health professionals to transform such knowledge into information that is easily understandable by the people affected by leprosy. Counselling by trained doctors/health workers available in the health system would be a critical resource that should be available to all those affected by leprosy and to parents in the case of children affected by leprosy. When initiated at the time of diagnosis, this would improve the quality of care and ensure that leprosy services are more acceptable to patients, resulting in better compliance with MDT and treatment completion.6

In the context of a declining disease burden, capacity development and sustaining expertise in leprosy would be critical. Adequate training to make health workers aware of side-effects and complications, an effective referral network, and supportive supervision are essential for timely and effective diagnosis and treatment of the disease and its complications.7

Follow-up strategies for children with multibacillary disease and for early detection of neuritis to prevent nerve damage at an early age have been suggested by other studies.8 Indeed, early management of complications among children should become a top priority. This can be achieved through greater vigilance not only on part of the health system, but of any other child care programmes in education, nutrition, etc.9

Without including such children affected by the disease and disabilities in primary schooling, universal primary education for all cannot be achieved.10 Innovative school-based activities should focus on mitigating stigma and discrimination. As part of the concept of the School Health Programme, teachers are the first point of contact of school children.11 Teachers have a vital role to play in promoting positive attitudes towards these pupils and to provide a safe and supportive environment.

Empowerment of those affected by leprosy and in the case of children, their parents, is the key to ensuring treatment completion, stigma reduction and to the ultimate success of the Programme.

Ethics approval

All the interviews were carried out as part of routine monitoring and therefore formal ethics approval was not required.
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Contributors
All the authors were involved in planning, draft and finalisation of paper. VL and SP were involved in data collection.

References