

CASE REPORT

**A case of stigma in an urban metropolis in India.
What new tools should be used?**

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Introduction

We present here a report from Kolkata, India, which illustrates the persisting deeply anchored roots of stigma in leprosy and our failure to make a significant change in the situation.

Kolkata is a metropolitan city in West Bengal, which is one of the states with a persisting leprosy problem (10 321 new cases were detected in 2010–2011). It is the third most populous metropolitan urban area in India, where many people live in slums and shanty towns scattered through the city.

Background

A rapid house to house survey was conducted in a geographically defined area (Municipal Ward) within the metropolitan area of Kolkata, at the request of the community, after a Focus Group Discussion which was part of a study on new case detection strategies for urban leprosy. The population of the area, according to Municipal records is 28 287 with a literacy rate of 85–95% and about 64% of the population living in slums.

The volunteers, who were given a one day orientation in leprosy, went to each house, explained the reason for their visit and showed a diagnostic card with pictures of leprosy lesions to those present in the house. They would then ask if anyone had skin symptoms and examine anyone who wanted them to check their skin problem, and if necessary refer to the Project Medical Officer who was on site in the area of survey, if so desired by the concerned person.

The survey yielded 10 leprosy cases of which four were new and previously untreated. One of these is the case we present below.

A male aged 50 years, a chauffeur by profession, with a hypo-pigmented patch over the right temple, eye and cheek for more than 3 years, was seen by the volunteers and referred to

the Medical Officer for confirmation as a case of leprosy. The man gave a history of tingling over the patch. He had visited a number of private doctors and applied ointments as prescribed without any sign of improvement, and the patch was growing. On examination, the patch had reduced sensation and loss of hair and the right orbicularis oculi, muscle power was found to be weak. The Medical Officer explained the diagnosis to the patient and arranged for him to be taken to the TLM Referral centre the next day and started on MDT. At first the patient was reluctant to accept the diagnosis; he was counselled and then agreed to go and take treatment.

The next day the patient came to the hospital with the volunteer, and was registered for MDT, but when he realised that the hospital was a referral centre for leprosy he became agitated and refused to accept the diagnosis of leprosy. He was counselled and the risks (including eye complications), of not talking treatment were explained. When he became calmer, he was asked to visit the physiotherapy department for a demonstration of exercises. At this point he suddenly disappeared, and did not return. Since the volunteers were from his locality they went back to him after 3 days, but he refused to accept the diagnosis or come to the hospital again, even after the consequences were explained. The volunteers then requested him to see a private practitioner or visit any other centre, if he did not want to attend The Leprosy Mission Hospital, but he refused.

Discussion

In the struggle against leprosy, stigma has been one of the primary concerns over the years, along with prevention of deformity, and more recently, advocacy addressing patients' rights via legislation.¹ But there is a growing awareness that the efficacy of the tools developed to overcome stigma have not been as effective as the technological advances in the field of leprosy, such as Multi Drug Therapy and Reconstructive Surgery.

During the focus group discussion held in the community, about the best ways to improve new case detection, the majority of the participants were in favour of methods such as surveys and 'skin camps' where people with any kind of skin condition could come for a consultation. When more participatory methods were suggested they felt that they could not spend the time and this should be done by health workers.

It is well known that 'stigma' is one of the main obstacles to early detection, and still persists all over the world in varying degrees, regardless of the educational status of the community or individual and the IEC activities in the area. Both enacted and perceived stigma are greater in communities with lower educational and economic status, older age groups and presence of deformities - but our experience shows that even in urban areas with relatively high literacy rates it is a significant problem.²

Leprosy still evokes fear and distress in people who are told that they have the disease^{3,4} and stigma is both the cause and the effect of delays in management which have tragic results.⁵ The fear stems from an expectation of social restriction and the ensuing family and economic issues,⁶ as well as a dread of disfiguring deformities. There is a general agreement that stigma needs to be addressed at various levels and in combination to be optimally useful, but this too needs further validation.⁷

The case of stigma cited here is especially troubling, because of the high probability that this person's muscle weakness (Grade I disability) will progress to lagophthalmos (Grade II) without treatment and possibly lead to blindness.

It is a failure of our health system that we are not able to combat stigma effectively. We want patients to self-report, as this is the most cost effective method of case detection, but this may not happen while there is a lack of robust measures to reduce stigma. Is it possible to involve urban communities, in stigma reduction as has been shown to be successful in some rural areas in India?⁸ In view of the opinion of the participants from the Focus Group Discussion, this might prove a challenge. High School children are another group who can be used as influencers to combat stigma in the community, as has been shown by programmes for TB, HIV/AIDS as well as leprosy in different parts of the world.⁹⁻¹¹ If so what models should be adopted for these activities?

We are unlikely to succeed in overcoming stigma using the same tools, such as awareness programmes and IEC. The case described demonstrates that effective models and new tools are urgently needed to address these issues otherwise our best efforts of combating leprosy¹² will only achieve slow progress. Urgent concerted and focussed research is needed to address this issue comprehensively if the problem of leprosy is to be solved.¹³

References

- ¹ Failus O. Leprosy – a stigma in the 21st century. *Orv Hetil*, 2011; **152**: 246–251, (Hungarian).
- ² Rao PSS, Raju MS, Barkataki A, Nanda NK, Kumar S. Extent and Correlates of Leprosy Stigma in Rural India. *Ind J Lepr*, 2008; **80**: 167–174.
- ³ Leekassa R, Bizuneh E, Alem A. Prevalence of mental distress in the outpatient clinic of a specialized leprosy hospital. Addis Ababa, Ethiopia, 2002. *Lepr Rev*, 2004; **75**: 367–375.
- ⁴ Tsutsumi A, Izutsu T, Islam, Akramul Islam MD, Amed JU, Nakahara S, Takagi F, Wakai S. Depressive status of leprosy patients in Bangladesh: association with self- perception of stigma. *Lepr Rev*, 2004; **75**: 57–66.
- ⁵ Rao R, Balachandran C. Multiple grade II deformities in a child: tragic effect of leprosy. *J Trop pediatr*, 2010; **56**: Epub 2010 Jan 21.
- ⁶ Lessshafft H, Heukelbach J, Barbosa JC, Riekmann N, Liesenfeld O, Feldmeier H. Perceived social restriction in leprosy-affected inhabitants of a former leprosy colony in Northeast Brazil. *Lepr Rev*, 2010; **81**: 69–78.
- ⁷ van Brakel WH, Augustine V, Ebenso B, Cross H. Review of recent literature on leprosy & stigma. ILEPTechnical Review.
- ⁸ Raju MS, Rao PS, Mutatkar RK. A study on community based approaches to reduce leprosy stigma in India. *Indian J Lepr*, 2008; **80**: 267–273.
- ⁹ Gopichandran V, Roy P, Sitaram A, Karthik, John KR. Impact of a Simple Educational Intervention on the Knowledge and Awareness of Tuberculosis among High School children in Vellore, India. *Indian J Community Med*, 2010; **35**: 174–175.
- ¹⁰ Raizada N, Somasundaram C, Mehta JP, Pandya VP. Effectiveness of various IEC in improving awareness and reducing stigma related to HIV/AIDS among school going teenagers. *Indian J Comm Med*, 2004; **29**: 29–34.
- ¹¹ VandenBroek J, O'Donoghue A, Ishengoma A et al. Evaluation of a sustained 7-year health education campaign on leprosy in Rufiji District. *Tanzania. Lepr Rev*, 1998; **69**: 57–74.
- ¹² Rao PS. Study on differences and similarities in the concept and origin of leprosy stigma in relation to other health related stigma. *Indian J Lepr*, 2010; Jul–Sep: **82**: 117–121.
- ¹³ Porter J, Kessel DH, Anthony S. Needing to know? Ethical Dilemmas in Leprosy treatment and control. *Lepr Rev*, 2001; **72**: 246–249.