

## *EDITORIAL*

### **Hidden leprosy – who is hiding from whom?**

Accepted for publication 1 October 2004

Prevalence of registered leprosy cases has fallen substantially, by about 90%, over the last 2 decades. From 5.4 million cases in 1985 to 0.53 million at the beginning of 2003,<sup>1</sup> the achievement is impressive indeed. Globally, the registered prevalence has reached the strategic milestone of less than 1 per 10,000 population. Out of 122 endemic countries, only six in Asia, Africa and the Americas have a prevalence of more than one per 10,000.<sup>1</sup> While prevalence depicts the success side of the programme, when it comes to new case detection the picture is altogether different. The annual number of new cases detected has remained around 500,000 ever since the introduction of MDT. It has not shown a perceptible decline despite the best efforts by the programme. Even in countries that have achieved the magic figure of prevalence less than 1 per 10,000 population, new case detection has not shown any significant downtrend. Ineffective coverage or delay in the introduction of MDT; intensified efforts at case detection, in the name of enhancing MDT coverage, in some countries, through national or subnational leprosy elimination campaigns (LEC); and problems associated with integration of leprosy service into general health such as less than optimal capacity of the medical professionals to diagnose leprosy correctly, could be some of the factors contributing to sustained level of new case detection.

One of the reasons for the persistent level of new case detection is ineffective coverage of population resulting in a significant proportion of new cases remaining undetected by the health system. Effective coverage means reaching with MDT service every individual in need without constraints in terms of affordability, acceptability, resource availability, provider quality and physical access. These constraints often render it difficult for the health system to detect all the cases that occur in the community and treat them promptly so that they are cured and have no residual impairment. While increasing attention is given to ‘overdetection’ of cases, ‘underdetection’ is ignored for various reasons. Overdetection is not difficult to validate, is manageable and is attractive to programme managers because of its immediate visible impact, whereas underdetection is rather difficult to estimate and is less appealing to programme managers and therefore has no apparent mandate. While we have some idea about overdetection, there is obvious lack of information on underdetection.

Cases that have already occurred and are yet to be detected are commonly referred to as ‘hidden’ cases which can be of two categories: patients with disease who are yet to report to

health facility and patients with disease who have presented themselves at health facilities but not diagnosed as leprosy. Some patients who notice the disease do not report to health facilities immediately, for reasons including that of accessibility, affordability and acceptability. It is difficult to estimate the extent of this problem. There are no simple, scientifically valid methods to get an insight into this category of hidden cases. Sample survey is an extremely complex, resource-guzzling exercise. The few sample surveys conducted using traditional method<sup>2</sup> or Lot quality assurance sampling (LQAS)<sup>3</sup> have revealed sample prevalence 4–5 times the recorded prevalence. Rapid epidemiological assessment methods also have their own limitations. There are indirect ways of getting some information on the problem. During the evaluation of leprosy elimination campaigns (LECs) conducted in India in May to June 2004, the evaluators detected during the exercise an additional 24% (1532) of new cases during the leprosy elimination campaign.<sup>4</sup> The new cases were detected from among the suspects identified by the peripheral staff but not reporting to health facilities and suspects newly reporting to the evaluators during their field visit. Even after five LECs and with a reasonably effective MDT service, the extent of underdetection was very high. In a study conducted in Saran district in Bihar in India, it was found that among the 990 suspects referred by female health workers during their routine work and who did not report to health facilities, 338 (34.1%) were found to be cases of leprosy.<sup>5</sup> Such investigations cannot be carried out as a routine, although they can be employed whenever there is an opportunity. They provide useful information. Attempt may be made to study using disability proportion among MB cases (provided there is no underreporting of disability) as a proxy indicator to arrive at the estimate of hidden cases. An estimation formula could be worked out using the relationship between disability among new cases and new cases, especially MB, in areas with a valid information collection system. The second problem of patients with leprosy reporting to health facilities and not being diagnosed is due mainly to inadequate capacity of health staff, exacerbated by absence of an accepted case definition and procedure for doing sensory tests, and non-availability of a confirmatory smear examination facility for cases with non-anesthetic patches. Evaluation of the fifth LEC in India by ILEP demonstrated an underdiagnosis of 3% among suspects reporting to health facilities.<sup>4</sup> Underdiagnosis is more likely to be seen among borderline lepromatous and lepromatous leprosy cases because of a low degree of suspicion. These are the cases that are likely to transmit infection in the community.

At any point of time, a significant proportion of new cases that occur may remain undetected. These cases, however, do not remain hidden forever. They are likely to be captured eventually by the health system, after a delay. The delay is good neither for the patient because of the possibility of adverse consequences, nor for the community because of the risk of prolonged transmission of infection. What should we do about it? The programme managers should be made aware of this fact. On the one hand, the programme is detecting cases a significant proportion of whom may not be cases, and on the other, it is also missing cases, especially of consequence. In some areas underdetection may be a more serious problem than overdetection. When we know that a significant proportion of cases remain undetected, can we go by the recorded prevalence to assess the seriousness of the leprosy problem? Since the procedures to estimate hidden cases are complex and unreliable, can we ever get an insight into it and use the estimate gainfully? Should there be an effort to reach consensus on the methodology to be used for rapid estimation of hidden cases? These are some of the issues that may be addressed by experts. However, the more relevant question from the public health point of view is how to reach these hidden cases. There should not be

any attempt to resort to surveys to reach them. Instead, activities directed at the community to sustain a high level of awareness should become routine. The role of health workers in this activity is crucial. They can disseminate appropriate information during their routine family visits and also identify and refer suspects to health facilities. They should also make sure that the suspects they have referred reach the health facilities. Delivery of a quality MDT service at health facilities should be ensured. Good service is the best publicity!

We cannot detect all the cases that occur in the community. In addition, we cannot avoid overdiagnosis. There will always be undetected or hidden cases, just as there would be overdiagnosis. We should be aware of these. We should not give undue importance to one or the other. Effective MDT service would ensure that they are not significant.

## References

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- <sup>2</sup> Sample survey in Dharmapuri District (1995), and Kanpur Nagar (1996): Damien Foundation India Trust, India. Unpublished document.
- <sup>3</sup> Murthy BN, Subbian M, Bhoopathi K, *et al*. Lot quality assurance sampling for monitoring leprosy elimination in an endemic district in Tamil Nadu. *Ind J Lepr*, 2001; **73**: 111–119.
- <sup>4</sup> Evaluation of fifth MLEC in eight states in India, 2004: International Federation of Antileprosy Associations (ILEP). Unpublished document.
- <sup>5</sup> Damien Foundation India Trust, 2004. Unpublished document.

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