Leprosy global statistics: beware of traps

ETIENNE DECLERCQ
Damien Foundation, Boulevard Leopold II, 263, 1081 Brussels, Belgium

Accepted for publication 27 November 2009

Global Leprosy statistics for the year 2008 were recently published by WHO. While nothing is presented for the European Region, a total of 121 among 169 countries or territories from the other Regions reported data. The figures presented concern the absolute numbers of registered and newly detected cases, new MB, female and children cases, new cases with grade 2 disabilities, number of relapses and cure rates. Detection trends over the last 7 years per region and for the 17 countries reporting at least 1000 new cases in 2008 are also presented. Efforts have obviously been made by WHO to be as complete and as transparent as possible, since a clear distinction is made between countries reporting no new patients, and those which did not report. According to the report, the number of newly detected cases was 249,007 in 2008, or a 3·5% decrease compared to 2007. Although some countries are missing, their impact on global data would, in any case, be very limited: looking at previous years, one can estimate that a total of about 1000 additional newly detected cases only, almost all from Africa, could have been reported by all these countries and territories together.

In spite of the efforts made, it would, however, be quite dangerous to try and draw many firm conclusions from these data. A number of caveats must be made:

- First, and even if this is obvious, it is important to keep in mind that these are not prevalence or incidence figures, but that these data only concern registered or newly detected cases. How much they differ from one another may vary from place to place and over time.

- No information is available on the completeness of these data. Even for the countries which report figures every year, there is no guarantee that these cover the whole country they are supposed to cover. For Sudan, for instance, a footnote says that in 2007 and 2008, totals include data from southern Sudan. This obviously means that southern Sudan was not included in the data of previous years. Access to health services might be missing for some sub-groups of the population. It might be due to geographical, seasonal or financial (cost of transport or loss of income) factors. In some places, females are not allowed to go to health services on their own. Elsewhere, it might be ethnic minorities which are discriminated against.

- Reliability of the data is another potential problem. It starts with the correctness of the diagnosis. Who is in charge of diagnosing leprosy cases at local level? How is it organised?
What training did the staff receive? Are they regularly supervised? Are all the newly detected cases effectively recorded and reported, including single lesion cases? Is a mechanism in place to check recording and reporting? Concerning classification, on what criteria is it based? On the number of skin lesions only? On the number of skin lesions and the number of nerves involved? Is there a policy of systematic examination of skin smears for new cases? The Philippines give a good example of problematic reporting of MB cases: the MB proportion among new cases was 61% in 2007, and increased to 90% in 2008. Even the reliability or the reproducibility of the data concerning grade 2 disabilities (in principle ‘visible deformities’) is not straightforward. For what proportion of patients was the disability status assessed? What criteria were used? Was it correctly reported? In Brazil, for instance, a change in the coding seems to have influenced the reporting of the proportion of patients with disabilities during the last 2 years: the fact that not all the municipalities used the new coding makes the information not interpretable at national level (M. Leide, personal communication).

- It is difficult, and even dangerous, to try and analyse trends without an in depth knowledge of all the operational factors that might have affected the situation in a country. Is detection active or passive? Is there a policy of systematic evaluation of contacts? How far is it effectively implemented? This could obviously influence the number of children detected. Were there mass population sensitisation campaigns organised? The list of questions is not limitative.

- Trends at regional or global level are primarily influenced by countries reporting large numbers of patients: India first, which reports 54% of the new patients detected globally, followed by Brazil (16%) and Indonesia (7%). The influence of the other countries on global figures is extremely limited. Declining detection trends at global level are essentially due to declining trends in India, and these are largely influenced by operational factors like integration, loss of expertise, abandonment of active case finding, abandonment of detection targets.

- The selection of the 17 countries reporting at least 1000 newly detected cases in 2008 for analysing trends, although interesting, might also be misleading: the countries with the highest numbers of patients are not obligatorily the highest endemic countries: the leprosy problem is, for instance, proportionately much higher in the Comores, with 336 new cases for a population of about 600,000, than in China with its 1,614 cases, or even India with its 134,184 new cases because of its population of more than one billion. However, the Comores are not in the Table, since they detected less than 1000 cases. Another example of how arbitrary a selection can be: Côte d’Ivoire disappeared from the list because they reported 998 new cases only in 2008, which is less than in 2007 (1204 new patients), but absolutely comparable to the prevailing situation during the previous three years.

- Laudable efforts are made to monitor relapses. However, here also, and even more, the completeness and reliability of the data are highly questionable: what criteria were used? Is the staff able to differentiate a relapse from a reaction? Were skin smears taken? It is usually said that for a relapse to be confirmed, results of skin smears must increase by 2 compared to status at the end of treatment. However, in which country are MB patients systematically assessed by skin smears at the end of treatment?

- Data on cure rates for PB and MB cases are published in the reports. These are undoubtedly important data: it is useless to diagnose patients if one cannot treat them till cure. However, no information is given on how these cure rates were calculated: was it on 1-year cohorts? Were the cohorts complete (all the diagnosed patients taken into account)? How confident
can one be to know that all the ‘cured’ patients effectively completed their whole treatment course? For instance, if a PB patient is given a full 6-month treatment at the time of, or shortly after, diagnosis, what guarantee is there that he effectively complied? An interesting point here is the fact that only seven of the 17 countries with more than 1000 new cases could report cure rates, while this is recognised as one of the most important indicators in the WHO Global Strategy.2

The intention is certainly not to say that the data published by WHO are not important. It is however essential to recognise that these data cannot just be taken at face value. As always with epidemiological data, they must be looked at critically before trying to propose any interpretation. Data are important to collect as long as they allow decisions to be taken. It is thus primarily at national or sub-national level, where strategic decisions should be taken, and that they must be thoroughly analysed. It is fortunately at that level also that one can best be aware of the possible influencing factors, and where one should best be able to judge on the quality of the data.

References