

EDITORIAL

Global leprosy statistics: a cause for pride, or frustration?

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Global statistics on leprosy are published annually in the *Weekly Epidemiological Record* (WER) of the WHO, most recently on 11 August 2006.¹ They make challenging reading, including between the lines . . . !

The recent report begins with a comment that the new *Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities (plan Period: 2006–2010)* has been ‘endorsed by all partners’, emphasizing the need for ‘high quality diagnostic services and treatment services using multidrug therapy, and ensuring that they are equitably distributed, affordable and easily accessible.’ Importantly, though the word elimination is mentioned, it is not emphasized, and is used mainly with reference to continued progress towards the elimination target ‘within the next few years’, with no year specified. Importantly, it is acknowledged that eradication is not possible with current tools. Given the many unrealistic comments about leprosy in recent years, that is a useful public recognition. Leprosy will continue for many decades in today’s major endemic countries, even under the most favourable projections, and one is not going to eradicate armadillos from the New World. Leprosy is not an eradicable disease.

Data from 115 countries and territories are reported.¹ Among the absentees are all the nations of Europe, the USA, Australia, and several developing countries, all with endemic autochthonous (or, considering northern Europe, imported) leprosy. However, the major leprosy endemic countries are there; and 12 of the initial absentees, including the USA (but still no European nation – why not?) were reported in a supplementary WER note on 15 September.²

The August 11 report tells us that leprosy declined by about a quarter in the world over the year 1995 – more precisely, that there were 296,499 new cases reported in 2005 [down 111,292 (27%) from 407,791 in 2004] and that the registered prevalence was 219,826 on January 1, 2006 [down 66,237 (23%) from 286,063 the previous year]. We are told that only

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six countries (Brazil, Democratic Republic of the Congo, Madagascar, Mozambique, Nepal, United Republic of Tanzania) have 'yet to reach the elimination goal', i.e. three fewer than last year, with Angola, Central African Republic and India claiming to have satisfied the below 1 per 10,000 threshold over the previous year.

A 25% decline in 1 year of a major global disease is remarkable, something to be proud of – if it were true. But to what extent should one believe such figures? A close look at the data reveals many strange things, and begs questions:

- There are great differences in trends and in year-to-year variations between regions and countries. Despite the apparent global decline, there were increases in new cases detected over the past 2 years in China, Indonesia and Mozambique. To what extent do these various trends reflect changing case detection efforts and policies? We cannot tell.
- The ratios of prevalence to case detection range from 0.6 in India and 0.7 in Brazil, to greater than 5 in Morocco, Cape Verde and Hong Kong. These numbers should reflect the average duration of a 'case', in years, and hence case holding policies (some cases may be discharged immediately after a single dose of MDT, thereby counting only as incidence not prevalence); but they also reflect changes in case detection from one year to the next (as the prevalent cases can include some from previous years) and timing of case detection activities (as paucibacillary cases detected early in the year may be discharged by the year's end). What actually lies behind these inter-country differences? We cannot tell.
- The proportions of MB range from near 30% (Bolivia, Bangladesh, Micronesia) to near 90% (Kenya, Sudan and Philippines). These numbers reflect local policies and classification criteria in use (based, one assumes, largely on numbers of lesions), but may reveal little if anything of regional differences in disease patterns – many studies prior to 1990 indicated lower proportions of lepromatous leprosy in Africa than elsewhere. What is the real classification pattern in the world today? We cannot tell.
- The range in proportions of females is greatest in Africa (from 21% in Chad to 60% in Central Africa Republic) and least in Western Pacific (28% in Cambodia, 36% in Micronesia). This may reflect relative access of females to services in some countries, but also will reflect real differences in leprosy ecology (lepromatous disease is more common in males) and age of the cases (proportions of multibacillary and hence males typically increase with age). What is behind the reported figures? We cannot tell.
- The proportion of 'child' cases ranges from 1–2% (in Argentina and China) to 10–20% (Sri Lanka, Yemen, Dominican Republic) to over 30% (Comores, Micronesia). Does this reflect incidence trends in infection (leading to preferential declines in younger age groups), or differences in case detection (surveys in primary schools), or are different countries using different criteria for the child category (no age is specified)? We cannot tell.

These statistical differences are, one suspects, attributable largely to operational differences between programmes, which make comparisons impossible, in the absence of detailed information on policies in the various countries. That information is not given in this report, and is in fact available nowhere for the vast majority of countries – which means that the data are, in fact, not interpretable.

India provides a major case in point, enhanced because of its predominance in the global leprosy picture. Table 5 of the 11 August WER shows the following: Since 2002, annual case detection in India declined from 473,658 to 161,457. This is a decline of 312,201, or 66%! Over the same 3 years, the global detection figures declined from 620,638 to 296,499,

a decline of 324,139 or 52% ! Thus, 96% of the global decline is accounted for by India! Does anyone believe this reflects trends of actual leprosy in India, or around the world?

Readers of *Leprosy Review* will know why the data are so bizarre: not only is leprosy often a difficult disease to diagnose in the first place, with stigma leading to reluctance to self-report in many societies, but there are insufficient resources for good surveillance in most countries, and inconsistent and changing policies (of case detection, diagnosis, classification, case holding and treatment). And, most importantly, there are the politics, specifically the pressures of the elimination target. It is interesting that WHO recognized the need to discontinue target setting for case detection by peripheral staff in 2003,³ but one suspects that some countries have remained driven by global elimination targets and have been willing to manipulate data in order to appear to achieve them. The subtle move away from emphasis upon the elimination threshold, which is detectable between the lines in this year's WER report, is a step in the right direction. The uninterpretability of global leprosy statistics is an unfortunate legacy of the elimination policy over the past 15 years, and will remain for some years into the future. It is likely to frustrate efforts to evaluate this disease for years to come.

The report contains no critical comment at all, no indication whether any of the figures might be less than valid, or should not be taken at face value. Is this a problem?

It is a problem. It might be acceptable to show dubious data to an audience which is well able to see the flaws, but it is disingenuous to publish data, which one knows to be uninterpretable, to an audience which is not in a position to recognize their weaknesses, without critical comment – and one suspects that the majority of WER's readership (all those outside the leprosy community) is in this latter category. One may assume that the WER is merely reporting what it has been told, by various ministries of health. This may be politically correct, but one may question if it is really helpful for public health. We encourage the WHO to take the lead in not only assembling data but in their critical analysis. It may be a tricky job in today's world, with its many sensitivities between nations. But science and public health depend upon honesty and critical appraisal. WHO should be more proactive in this direction in future.

The new strategic plan calls for quality leprosy services. One indicator of a quality service is accurate data. We look forward to future global reports with straightforward critical appraisal of the available data, with frank comments on how they relate to actual leprosy numbers on the ground, and with recommendations on how both the data, and the reality to which they should refer, can be improved.

References

- ¹ WHO. Global leprosy situation, 2006. *Weekly Epidemiological Record*, 2006; **81**: 309–316.
- ² WHO. Supplementary information on global leprosy situation by WHO region and country/territory (excluding the European region) beginning 2006. *Weekly Epidemiological Record*, 2006; **81**: 349–356.
- ³ WHO. Leprosy elimination campaigns: impact on case detection. *Weekly Epidemiological Record*, 2003; **78**: 9–16.