Leprosy: what is being “eliminated”?

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Leprosy is a well known but poorly understood disease; even its sources and modes of infection transmission are still contentious issues. The World Health Organization has made important contributions to leprosy research and control through inclusion of leprosy in the multi-agency Special Programme for Research and Training in Tropical Diseases (TDR) and by leading a global leprosy elimination initiative.

In 1991 the World Health Assembly (WHA) passed a resolution to “eliminate leprosy as a public health problem” by the year 2000. The implications of this resolution have dominated discussion and activity in the leprosy community in the past 15 years. A footnote to the WHA resolution explained that elimination was to be defined in this context as a reduction in prevalence below 1 per 10,000. This is important. Prevalence at any point in time (e.g. 31 December) is a function of duration, as well as of incidence, and the primary strategy of the initiative has been to reduce prevalence by reducing treatment duration through the institution of short-course multiple-drug regimens. It was also hoped that use of these shorter-term and more-effective drug regimens would reduce infection transmission, and thus effectively reduce incidence of infection and ultimately of disease.

The programme has had a massive effect on reported prevalence. According to data submitted to WHO — the global figures are presented annually in the Weekly Epidemiological Record (WER), most recently in August 2006 — the elimination target was reached globally (using the total human population as a denominator) in 2000, and by the end of 2005 all but six countries reported year-end prevalence below 1 per 10,000.

That much is a success. However, if one looks closely at the published data, it is not clear what has actually happened. The elimination initiative has encouraged some major changes. These include changes in case-finding policies: massive house-to-house surveys inevitably find cases and lead to peaks of case detection, but many cases found early in a year are removed by the end of December, and hence not included in reported prevalence. There have been changes in classification: a new system based upon numbers of lesions is applied differently in different countries, making data inconsistent with previous classification systems. Other changes are in registration, as some countries have not registered cases with single lesions or have required confirmation of all diagnoses by district teams, both of which practices reduce official prevalence. In terms of treatment, some countries have not followed WHO guidelines, instead maintaining cases on treatment for long periods, which inflates prevalence. Information on these changes is not available, though this information is essential for interpreting data from individual countries. These data should be included with the WER annual reports.

Though prevalence has come down, the extent to which there has been a reduction in incidence is less clear. Some analyses have suggested that little or no reduction has occurred as a result of the initiative.1 Incidence declines started in many countries long before this programme; these are attributable to improving socioeconomic conditions and to the Bacille Calmette–Guérin vaccine.

Interestingly, there is no evidence that the global initiative has led to the disappearance (“local eradication”) of infection or disease from any population, and leprosy continues to appear throughout Africa, Asia and Latin America, southern Europe and even in the US states of Louisiana and Texas (where it may be a zoonosis associated with armadillos).

This persistence adds to the list of mysteries about this ancient disease. Perhaps more time will be required to show the recent initiatives’ impact on incidence. Or perhaps there is no effect, because we are failing to understand some important aspect of the disease’s natural history; there is some evidence that the leprosy bacillus may be maintained as a silent transient infection in nasal cavities in endemic areas.2,3 Research is needed to examine these questions.

It is not difficult to argue that the elimination concept has, in this instance, now served its purpose, and that it might even become detrimental to public health. The programme’s rhetoric has led to the impression in some quarters that leprosy no longer exists. This is wrong, but the distinction between eradication and elimination is widely misunderstood.

By encouraging repeated changes of definitions, ascertainment procedures, and diagnostic and registration conventions, the initiative has in effect eliminated our ability to monitor and understand what has actually happened. And it has come close to eliminating leprosy research.4 Neither funders nor young researchers are attracted to an officially “eliminated” disease — even if it is still ubiquitous. The main leprosy journal of the past 70 years (the International Journal of Leprosy) published its last issue in March 2005, and there is now little active research on the disease, despite our continued ignorance of its natural history.

Leprosy and associated disabilities are not going to disappear for a very long time, if ever. As recognized in WHO’s Global Strategy 2006–2010, there will be continued need for leprosy research capability and for specialist clinical expertise.5 WHO should discontinue its rhetoric about eliminating leprosy, lest these essential efforts against the disease be eliminated as well.

References
Web version only: http://www.who.int/bulletin

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