Indian J Med Res 145, January 2017, pp 1-3
DOI: 10.4103/ijmr.IJMR_2027_16

Quick Response Code:

Editorial

Interpreting data in policy & control: The case of leprosy

Leprosy is an ancient disease, and the WHO target of elimination by the year 2000 in 1991 was perhaps ambitious[1]. This ambition was mitigated by a redefinition of elimination to 'elimination as a public health problem', which means, in reality, the reduction of disease to very low levels. The formal definition of control (reduction of disease incidence, prevalence, morbidity or mortality to a locally acceptable level as a result of deliberate efforts, and continued intervention measures are required to maintain the reduction[2]) recognizes that intervention programmes must be kept going[2-4]. The redefinition of 'control' to 'elimination as a public health problem' was presumably to develop a political impetus to a defined endpoint; and political impetus is essential for any concerted public health action.

However, setting targets can have unintended consequences. Targets can be achieved, but result in perverse outcomes. The target of leprosy elimination by 2000 is a good example of how gaps between policy aims and public health delivery can let the original aim escape[5]. The political objective was achieved, but leprosy remained a disease problem, and more importantly, a public health problem. Perversely, the achievement of elimination has meant that many, many cases of disease have gone undiagnosed or unreported[6]. We have learnt that policy has to be driven by real gains in health, not political targets. In public health, the data have to drive the politics, and not the politics drive the data, and the data have to be uncompromised.

This effect is unique to neither India nor leprosy. It is an intrinsic problem for all diseases that are controlled by diagnosis and treatment: so-called intensive disease management (IDM) diseases, including visceral leishmaniasis. Given that leprosy is treatable with a course of multidrug therapy, correct diagnosis of a case is essentially a cure of infection, and results in stopping transmission from that case. So, for IDM diseases, finding cases determines both the number of cases diagnosed and is the measure of the success of the control programme.

One consequence of this duality is that there are two ways of having a low number of cases. If there is little effort or effectiveness in finding cases, then reported diagnoses are low, but transmission continues unchecked, and the true number of cases is large. Alternatively, if the search effort and effectiveness are high, then eventually transmission will be reduced and both the reported and true number of cases will be low. It is clearly the latter situation that policy is aiming for, but there are two ways of reaching the same target.

At intermediate levels of effort or effectiveness, it is possible to have a programme that is good enough to find many cases, but not good enough to effectively control transmission. This looks like the worst situation from a policy viewpoint. But with IDM diseases, cases must be found to be cured, so finding cases is a good thing. Setting a target based on the success of the control programme in finding cases (or not finding them) is always going to be subject to potential problems. It has to be remembered that the true number of cases is never seen, so the effectiveness of the programme cannot be judged by the number of reported cases alone. Without additional information it is impossible to know whether reports of a low incidence of cases is good or bad – does it represent a poor diagnostic system or a very successful one that is controlling disease?

A further complication is that many people are diagnosed and treated outside of organizations in which the diagnosis is captured by official statistics. The current low number of women being diagnosed with leprosy in India suggests that there is underdiagnosis

This editorial is published on the occasion of World Leprosy Day – January 29, 2017

and reporting[7], but private dermatologists might be filling this gap, and it is not being captured in the data.

Improving the programme will increase the number of cases. There is always a group of patients who would be diagnosed if they were put in front of a doctor, but who have yet to seek medical attention or yet to be found, and improving diagnostic effort and effectiveness will find some of them. A more effective programme will eventually result in a fall in cases, so that changes in time can, again, be misleading. There are data analytic methods that can use these changes in diagnostic effort to estimate the underlying population sizes which might be helpful in evaluating the programme effectiveness[8].

From the patient's perspective, the effort and effectiveness of case finding also impact on the delays that patients experience between infection, onset of disease, diagnosis and cure. The lesser the effort, the longer the delays and the greater the opportunity for transmission. In the case of leprosy, the risk and severity of long-term sequelae of infection and disease increase with the length of the delay. The longer the delay, the greater the burden of disability that must be borne after diagnosis. Hence, in the case of leprosy, shortening the delay by putting more effort into effective diagnosis and case finding immediately reduces transmission and in the long term disease burden.

The good news on World Leprosy Day in 2017 is that we are currently controlling leprosy. However, the current child rates of about 11 per cent indicate that there is significant ongoing transmission, and patients infected now will continue to present over the next 20 years[9]. The challenge for the future is to recognize that effective and, sustained suppression of leprosy-related disability will require renewed and sustained efforts to keep diagnosis programmes effective, even when the number of cases being diagnosed is small. Experience from other programmes shows that diagnosing leprosy cases when numbers are low is more challenging. Doctors have fewer skills in recognizing leprosy cases. Leprosy patients present with a range of different skin and nerve symptoms. Maintaining the necessary political and economic case for the investment will be very difficult[3,4]. And if diagnostic effectiveness drops, then any resurgence in cases will not be seen.

What of the future? Current diagnostic technology is relatively basic, but there is impetus to develop the technology to enable diagnosis before clinical symptoms develop[10]. It is also important to recognize that because of the spectrum of immunological responses in leprosy patients there is not likely to be a single diagnostic test. Whether earlier diagnosis would have a further significant impact on transmission is unknown, but it would have a considerable impact on disability, and it would underpin the opportunity to gain a better understanding of transmission.

Elimination of infection (reduction to zero of the incidence of infection caused by a specified agent in a defined geographical area as a result of deliberate efforts. Continued measures to prevent re-establishment of transmission are required[2]) is currently beyond us without more knowledge of the routes of transmission and understanding potential environmental reservoirs. However, in the meantime, we must keep looking for the cases, and the fewer we find, the harder we must look.

Graham F. Medley[1,*], Ron E. Crump[3] & Diana N. J. Lockwood[2]

Departments of [1]Global Health & Development & [2]Clinical Research, London School of Hygiene & Tropical Medicine, London & [3]Warwick Infectious Disease Epidemiology Research, School of Life Sciences, The University of Warwick, Coventry, UK

[*]*For correspondence*: graham.medley@lshtm.ac.uk

Received December 23, 2016

References

1. WHO. Leprosy Resolution WHA 44.9. Available from: *http://www.who.int/neglected_diseases/mediacentre/WHA_44.9_Eng.pdf,* accessed on May 4, 2016.
2. Molyneux DH, Hopkins DR, Zagaria N. Disease eradication, elimination and control: The need for accurate and consistent usage. *Trends Parasitol* 2004; *20* : 347-51.
3. Dowdle WR, Hopkins DR. *The eradication of infectious diseases*. Chichester: John Wiley and Sons; 1998.
4. Dowdle WR. The principles of disease elimination and eradication. *Bull World Health Organ* 1998; *76* (Suppl 2) : 22-5.
5. Lockwood DNJ, Shetty V, Penna GO. Hazards of setting targets to eliminate disease: Lessons from the leprosy elimination campaign. *BMJ* 2014; *348* : g1136.
6. Smith WC, van Brakel W, Gillis T, Saunderson P, Richardus JH. The missing millions: A threat to the elimination of leprosy. *PLoS Negl Trop Dis* 2015; *9* : e0003658.
7. Sarkar R, Pradhan S. Leprosy and women. *Int J Womens Dermatol* 2016; *2* : 117-21.

8. Crump RE, Medley GF. Back-calculating the incidence of infection of leprosy in a Bayesian framework. *Parasit Vectors* 2015; *8* : 534.

9. National leprosy eradication programme (NLEP) Annual Report 2015-2016. Central Leprosy Division. Directorate General of Health Services. Ministry of Health and Family Welfare. New Delhi. Available from: *http://nlep.nic.in/pdf/revised%20annual%20report%2031st%20March%202015-16.pdf*, accessed on December 20, 2016.

10. Roset Bahmanyar E, Smith WC, Brennan P, Cummings R, Duthie M, Richardus JH, *et al.* Leprosy diagnostic test development as a prerequisite towards elimination: requirements from the user's perspective. *PLoS Negl Trop Dis* 2016; *10* : e0004331.