



'Final push of leprosy' in India: What is being pushed?

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In the efforts to reach the target of elimination of leprosy by the end of year 2005, many measures are being pushed by the leprosy agencies of India with the support of WHO and Global Alliance for Elimination of Leprosy (GAEL). We have attempted to analyze three important areas of this 'final push strategy' which we strongly feel are not in the best interest of leprosy program in India at this important period of leprosy elimination process.

The year 1999-2000 was very important for leprosy. The world, as envisaged by WHO, was to reach elimination target of leprosy by the year 2000. (Elimination of leprosy meaning bringing down the prevalence of leprosy (PR) to < 1 per 10,000 population all over the world)

WHO LEPROSY PROGRAM 1999 - 2000

In the year 1999, Leprosy Elimination Advisory Group (LEAG) of WHO acknowledged that about 12 countries would not reach the national elimination target by the end of the year 2000. LEAG felt that strategy should therefore focus on these 12 countries, intensifying efforts of Leprosy elimination campaigns (LEC) in these countries

Final push of leprosy: Final push of leprosy as strategy was initiated by WHO in November, 1999. The objective is to achieve the elimination target in all countries by end of 2005. GAEL was simultaneously initiated by the WHO and comprised member endemic countries and

donor agencies. International federation of anti-leprosy associations (ILEP) also became member GAEL in 1999 although it was not a formal signatory. ILEP consists of NGOs who work for leprosy like The Leprosy Mission International, American Leprosy Mission, LEPRO UK and its branches, Damien foundation and many others. ILEP members spend > \$ 60 Million annually on anti leprosy activities. However, ILEP was expelled from GAEL in December, 2001, probably because ILEP wanted a critical dialogue on certain key issues.^[1] The expulsion of ILEP from GAEL points to the non-conciliatory nature of GAEL/WHO in the matters of leprosy with others who differ with it.

Important observations post 2001: Consistent New case detection rate: In the years after 2001, although the prevalence rate was going down, it was observed that the 'new case detection rate' (NCDR) was remaining constant. In fact, the number of leprosy cases detected globally has increased significantly from 566,567 in 1996 to 622,110 in 2002.^[2]

More new cases were being detected by Leprosy elimination campaigns (LECs) in India, which were recommended and promulgated by WHO towards the end of the last millennium in order to intensify and hasten progress towards elimination of leprosy in India. LECs received widespread government and public support, resulting in the detection of hidden cases of leprosy, whilst providing training to a large number of general health care staff and volunteers and creating widespread awareness about leprosy and the

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availability of treatment free of charge for all cases. This program proved to be one of the most successful health care interventions undertaken in India in recent years, particularly in the states of Bihar and Orissa.^[3]

LEC strategy not only detected new cases but also mobilized substantial resources and political commitment to leprosy. And many workers and organizations felt that NCDR is a better indicator than PR for leprosy control.^[4] The problem faced by the program managers was that LECs were very effective. For example, in West Bengal, 8,181 new cases were detected in 8 day period in a district by LECs.^[5] LECs all over India were finding new cases in good numbers. With these figures, WHO and other leprosy authorities were in quandary. How to bring NCDR down?

To control and report on LECs, WHO introduced the "leprosy elimination monitoring groups" (LEMs). These LEMs developed standard protocols for the validation of leprosy diagnosis and classification of newly detected leprosy cases. One district each from the 12 most endemic states of India was randomly selected. Each district provided the list of recently detected new cases to the validation teams consisting of two experts. Both experts independently assessed each listed patient for the correctness of diagnosis and classification, and for previous history of anti-leprosy treatment. Only a total of 1, 503 patients could be assessed by LEMs.^[6]

LEMs observed that number of new cases detected included a significant proportion of wrong diagnosis, re-registration and non-existent patients in programs (up to 28%). In Effect, LEMs not only brought down the new case numbers, they also brought a bad name to LECs. This was later shown as a basis for the justification to stop / scrapping of LECs from being conducted. The final result was that LECs were totally stopped and active search for new cases was abandoned. In other words, LEMs were used as a means to discredit LECs.

Are the LEM findings right and impartial? What is not mentioned while reporting the findings of LEMs was that similar validation was not conducted in the previous years. In the districts where new cases were assessed by LEMs, the LECs were conducted by the same experienced staffs who were involved in leprosy work

over last few decades, with similar infrastructural facilities and techniques. Moreover not all evaluators found the LECs to be the cause of over diagnosis or re-registration. Some evaluation teams actually diagnosed additional new cases missed by the LEC teams.^[7]

Assuming that there were significant faults with the diagnosis and registration methods of new cases, these should not be considered specific to the period of validation years of 2002-3 alone. They are applicable to all the years when leprosy work is being carried out in those areas, which is for the last two decades or more. By law of averages and by the probability of chance, the over and wrong diagnosis observed would have been same over all these years/decades. And hence the error could be considered as common confounding factor or a common denominator. While increasing attention is given to 'over detection' of cases, 'under detection' is ignored for various reasons. There will always be undetected or hidden cases just as there would be over diagnosis. We should not give importance to one or the other.^[8]

If this argument is tenable, how can one justify the scrapping of LECs, which were actually initiated by WHO in late 90's as one of the methods of intensification of leprosy program?

NEW GUIDELINES FOR LEPROSY ELIMINATION 2005

WHO statistics of leprosy in 2004 were as follows^[9]: Number of leprosy patients under treatment: 460 000. New cases detected: 515 000. Among these, 43% were multibacillary cases, 12% were children, and 3% were diagnosed with severe disabilities. India represents close to 76% of the global burden.^[8] In spite of all the measures taken up to 2004, new cases detected were significantly high. In such a situation, let us examine the leprosy elimination program in India.

Targets and promises: Leprosy directorate of Andhra Pradesh, an endemic state for leprosy in southern India, has assured Sasakawa (Nippon) foundation, in an open forum in January 2005 that Andhra Pradesh would reach elimination target by the end of March, 2005. The problem with this assurance was that the leprosy prevalence rate in Andhra Pradesh was 1.78 on average



by mid 2004 with nine districts with PR between 2- 3 and two districts with PR between 3-5.^[10] Would it be possible to bring down the prevalence rate to <1 in a three months period? What was really troubling was that similar promises were being made in all other endemic states by the authorities in India.

In this effort to reach the elimination target soon, new instructions were being given to the field staff. These are as follows which are called "Katmandu recommendations"

1. *To stop all active search for case detection.*
2. *No registration of cases to be done before reconfirmed by experienced staff* (a member of validation team).
3. *Declare patients as RFT (released from treatment) and delete names of the patients from registers as they receive the last pulse.*

Previously these were made RFT after completion of the therapy which could be a maximum period of 6 pulses out of 9 months for PB therapy and 12 pulses out of 18 months for MB therapy considering that patient misses few months' therapy.

4. Do not register single lesion cases for now

First three instructions are thorough official documents and office orders to the field workers.^[11] The last instruction is the verbal communication / instruction, Instructions such as these are not limited to one state and are being given in other states in India. (Confirmed personally with leprosy workers of other states)

There is no justification in the order to stop search for new case detection, as the whole program of leprosy elimination is based on detection and curing of new cases. There is a strong case to continue to use LEC approaches, as they are a comprehensive and cost effective means of delivering the key elements of leprosy control.^[12]

There are recommendations that LECs should be implemented as an element of the process of integration of leprosy.^[13] In a meeting held at Tokyo to appraise leprosy situation In India, which was well

represented by senior health officials of the Government of India, WHO and the NGO community, it was resolved that the participants agreed to detect as many new cases as early as possible and ensure all of them a complete course of MDT.^[14]

Many important personalities feel strongly about active case detection. Addressing a meeting of the Hind Kusht Nivaran Sangh in March 2005, the President of India Dr. A. P. J. Abdul Kalam, who is also its Honorary Chairman, suggested the organization to prepare an action plan for detecting leprosy cases by using students in Bihar, Chhattisgarh, Jharkhand, Maharashtra, Orissa and West Bengal - the six states with the highest incidence of leprosy. Early identification of leprosy patients would hasten their cure, Dr. Kalam said.^[15]

What is happening to NLEP?: Active surveillance has been discontinued. New case detection is not active any more. Leprosy worker is being replaced by multipurpose / basic health worker, and is attending to TB / HIV work. Other areas of health are being given priority over leprosy. Instead of being intensified, leprosy program has slowed down and diluted.

Do we have a simile for such a national program, which was diluted/made a non-priority and which led to a disaster? Revisit the malaria story, because those who forget history are condemned to repeat it.

REVISIT MALARIA STORY

National malaria control program was started in the year 1953; it was modified as 'National malaria eradication program' 1958. New cases registered in 1961 were 50,000. However resurgence of malaria was reported from 1962 onwards. By 1976 new cases reported were 6.4 million. The program was renamed as 'modified NMEP' in 1977. And presently it is being called 'National anti - malaria program' without mention of control, elimination or eradication.

Some of the important causes detailed for the failure of national malaria eradication^[16] were as follows. *Administrative failures:* Shortage of drugs and workers with diversion of funds in favor of 'more obvious needs'



when greater effort was needed to root out last pockets of endemicity, entrusting work to multi-purpose and basic health workers and above all, laxity in national commitment and determination. *Operational failures:* The third world countries did not fully understand the epidemiological 'rule of the game'. They did not apply the eradication measures with insight. Other causes mentioned were: inadequate surveillance and case detection, premature consolidation and maintenance phase, early dismantling of malaria eradication services and undue reliance on the basic health services who were ill prepared for the task. In short, the present resurgence of malaria is due to the relaxation of effort.

Is leprosy going the same way? Instead of being intensified, leprosy program has slowed down and is being diluted. There is an undue hurry to reach the elimination targets and corners are being cut. There are many indicators, which point to the potential risk of failure of the leprosy program. They are, shortage of staff, no active surveillance, integration of leprosy into general medical services, leprosy workers becoming multipurpose workers and reduction of funds. Added to these are newer priorities such as HIV and tuberculosis. Dilution and relaxation in the efforts of NLEP has already set in. Please note that the majority of the reasons mentioned for the failure of national malaria program already exist in leprosy program.

IT IS TIME FOR ACTION!

It is time for all leaders and workers who have concern for leprosy and those who have power, position and reach to appraise the authorities about this situation. The highest authorities that plan, fund and execute the leprosy program should be appraised of the dangers and possible fallout of diluting leprosy program at this crucial juncture. Please acknowledge that there is no hiding from leprosy numbers, cases and ground situation. There is no need for these short cuts, clever practices to bring down numbers of new cases and monthly or weekly cleaning of registers of leprosy.

Let's face up to the challenges of leprosy with determination and vision for future. Let not some misguided people push us to declare that leprosy is eliminated prematurely by unethical and insincere methods.

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