

Global Leprosy Elimination Programme: Rhetoric or Reality?

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I. INTRODUCTION

KEY objective of this review paper is to trace the evolution of Global Leprosy elimination programme and its important bearing onto National health planning in a regional context. This is illustrated with an Indian case. It brings in contrast between existing data about 'Leprosy Elimination from India in 2005' as claimed by Indian Government and WHO in opposition to resurgence of newer cases. Through this paper I attempt to flag certain key concerns like why leprosy is one among many neglected tropical diseases (NTDs) in spite of causing lifelong morbidity, inadequacy in definition of leprosy elimination set by WHO (prevalence rate of less than one per 10,000 population), systematic neglect in looking at leprosy as a public health problem in an attempt to meet internationally set deadline (There was a marked shift in Leprosy programme strategies from control to elimination in 1983 and programme was renamed as National Leprosy Elimination Programme (NLEP)) with subsequent sidelining of preventive, promotive and rehabilitative aspect of leprosy and an entire thrust on curative aspect through Multi Drug Therapy (MDT), politics of NLEP in India and role of international actors in disease priority setting and funding. Paper ends with analytical concluding remarks about the overall situation with a vision for way forward.

Paper is based on an extensive literature review where secondary literature pertaining to leprosy and National Leprosy eradication programme (NLEP) has been reviewed. Field insights gained from visits to leprosy endemic areas, presenter's own empirical research and key informants interviews have been incorporated to support the argument.

II. NEGLECTED TROPICAL DISEASES AND GLOBAL HEALTH

Peter Hotez et al. (2006) writes about the identification of a select group of 13 tropical infections (Buruli ulcer, Chagas disease, cholera, dengue fever (including dengue haemorrhagic fever), dracunculiasis, lymphatic filariasis, human African trypanosomiasis, leishmaniasis, leprosy, onchocerciasis, schistosomiasis, soil-transmitted helminths and trachoma) as NTDs by WHO, one of them being leprosy which is the subject matter of this paper. It is interesting to note the nomenclature of group of these diseases as 'tropical' and 'neglected' which will be discussed further.

2.1 Communicable Diseases, Non Communicable Diseases (NCDs) and NTDs: A Debate for Disease Priority Setting

NTDs are among what Hunt calls *type III diseases* – the much neglected diseases that “receive extremely little research and development, and essentially no commercially-based research and development in the rich countries” (Hunt.P 2003). These so called diseases of poverty are seen as neglected because they fall outside the purview of Global Fund and other related programs funded and supported by developed nations whose exclusive focus is on the 'big three' - HIV, tuberculosis (TB), and malaria. Too often these diseases are ignored and neglected because they have not yet impacted the lives of those living in affluent areas (LaBeaud AD 2008).

As national public health priorities, NTDs including leprosy typically maintain a low profile and are often left out when public health agendas are formulated. While many of these diseases do not directly cause high rates of mortality, they contribute to an enormous rate of morbidity and a drastic reduction in income for the most poverty-stricken families and communities. These diseases are often found in impoverished populations living in marginalized and poorer areas. And often there is separation of disease from its socio-cultural-economic milieu (Holveck.C.John et.al. 2007).

Another important debate which arises here is – what gets priority between NCDs, communicable diseases and NTDs. Examining funding by disease is critical since diseases are in competition with one another for priority and donors make allocation decisions in ways that do not correspond to developing world's needs (Shiffman.J, 2006). Discussions around global health priorities and funder's choice around diseases like HIV AIDS, Malaria, TB, Cancer, Diabetes, Cardiovascular risks, Polio, Emerging infectious diseases like Swine flu and Avian flu etc are dominant today. On the other hand side,

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advocates of NCDs (Diabetes, cardio-vascular disease, cancer, and chronic respiratory diseases have been recognized as emerging big four killers) as disease priority claim that the proportion of money which is available to deal with NCDs is very little in comparison to 60% of the deaths it causes worldwide. It is estimated that less than 3 per cent of total donor funding (Lancet study found that, in 2005, chronic disease funding from the four largest donors in health was estimated at \$3 per death annually, compared to \$1,030 for HIV/AIDS.) goes to addressing NCDs. In fact, this argument is a catch point of entire discussion today about more funding for communicable diseases and less allocation for NCDs, but amidst this where are NTDs which strike many across the globe. According to Gupta, Indrani and Guin, Pradeep (2010), among all the diseases Japanese Encephalitis, Leprosy and Dengue account for top three diseases with highest percentage among global disease burden in South East Asia as compared to 'big three diseases' which gain the maximum funding. Having said that my question is- Do NTDs really don't exist for global health experts and thus national governments or there is conscious systematic refusal to look at morbidity and mortality caused by NTDs across the globe and not only tropics!

2.2 Geographical Location and Disease Definition

NTDs are said to strike the world's poorest people living in poorer areas of countries in Sub-Saharan Africa and Asia. Remme et al. (2006) categorically states that Tropical diseases (or diseases of poor) are infectious diseases that are found predominantly in the tropics, where ecological and socioeconomic conditions facilitate their propagation. Here I argue that today increasingly 'geographical explanation in association with disease' is being seen as a dominant explanation rather than looking for causal factors ingrained in socio-economic-cultural situations. There is a certain degree of 'simplification and reductionism' in the entire approach which needs to be unpacked.

III. POLITICS OF LEPROSY ELIMINATION: AN INDIAN CASE

I would like to begin the discussion with one question: Was 'leprosy elimination' really a priority of India which is still epidemiologically grappling with high proportions of the disease among its population? It is important to look firstly at what marked transition in leprosy programme strategies from control to elimination (and now eradication) in independent India. Subsequently entire politics of NLEP which embodies internationally set health priorities will be discussed.

3.1 Leprosy in Post Independent India: Control to Elimination to Eradication

Disease control marked the Indian government's initial approach, starting in 1955 with the creation of the National Leprosy Control Program (NLCP) and introduction of Dapsone monotherapy. Based on Swaminathan Committee suggestions (constituted in 1981) and recognising the failures of NLCP, a marked shift in strategies from control to elimination was made with introduction of NLEP in 1983 and a thrust on curative MDT supported by WHO. During the 44th World Health Assembly of WHO in 1991, a global goal was set 'To Eliminate Leprosy by 2000 AD'. This gave an impetus to worldwide efforts to eliminate leprosy as a public health problem. By 2005, very gloriously Indian government declared the elimination of leprosy from the country with a nationwide prevalence of 0.95/10,000 population (Staples James, 2007). And now the entire programme has been renamed as National Leprosy Eradication programme with a special declaration of an action plan in 2012 for 209 high endemic districts in 16 states and UTs (Lancet study found that, in 2005, chronic disease funding from the four largest donors in health was estimated at \$3 per death annually, compared to \$1,030 for HIV/AIDS).

But this is accompanied with much of the criticism regarding accuracy and choice of target parameter (Feenstra Pieter 2003). Data presented subsequently in the paper will elaborate this argument.

3.2 Claims of Leprosy Prevalence coming down in India- Gaps in Claims made and Situations Existing on the Ground

In the years after 2001, although the prevalence rate was going down, but it was observed that the 'new case detection rate' (NCDR) remained constant. According to Lepra (2012) state of Bihar reports around 20,000 new cases of Leprosy every year- the highest NCDR in India. Even post elimination there has been a consistent higher prevalence of leprosy as reported in some areas. One of the factors responsible for emergence of new cases of leprosy is long incubation period of the disease and relatively higher prevalence of leprosy in certain areas of the country as leprosy is known to be a pocket disease. This is illustrated by a report released by Maharashtra state health department, which states that both prevalence and annual NCDR of leprosy in seven districts in Maharashtra are disproportionately high, and surpass the state average. The state's prevalence of leprosy cases per 10,000 population is 0.93. The same is 3.83 in Thane, 2.74 in Chandrapur and 2.50 in Gadchiroli. Similarly, the state's ANCDR is 13 cases per one lakh population. However, the same is 62 cases per lakh population in Gadchiroli, which is highest in the state, followed by Chandrapur (45), Thane (39), Bhandara (31), says the report. (Refer to news report http://articles.timesofindia.indiatimes.com/2011-05-29/pune/29596902_1_leprosy-cases-ancdr-central-leprosy-division)

The national sample survey (NSS) of leprosy 2010-11 reveals that annually 14 new leprosy cases are being detected per 1,00,000 population in the country as against claim made in 2005. The annual NCDR in 11 states, including Maharashtra, is more than 10 per lakh population, which indicates an alarming rise in new cases. Fresh statistics have set alarm bells ringing especially for the states like Andhra Pradesh, Chhattisgarh, Karnataka, Madhya Pradesh, Maharashtra, Orissa, Tamil Nadu, Uttar Pradesh, West Bengal, Chandigarh and the Union territory of Dadra & Nagar Haveli. (Refer to new report http://www.dnaindia.com/mumbai/report_leprosy-rings-alarm-in-11-states-including-maharashtra_1612721) According to latest CBHI 2011 data in relation to leprosy certain states have shown an upsurge in prevalence rate of leprosy while others are well below prevalence rate of 1 per 10,000 population.

Table 1 CBHI 2011

State	Prevalence Rate
Bihar	1.12
D and N Haveli	2.28
Jharkhand	0.65
Maharashtra	0.93
Orissa	0.85
UP	0.79
WB	0.92
Karnataka	0.44
Haryana	0.13
HP	0.27
Kerala	0.27
J and K	0.16
Daman and Diu	0.08
Manipur	0.06
Tripura	0.24

But contrary to this Leprosy Division of Ministry of Health continues to claim a prevalence rate of 0.95/ 10,000 population (Refer to <http://nlep.nic.in/> National Leprosy Eradication programme website). This presents a complex situation where data of two different kinds is present: Government sources show a decline where as data from other sources like NSS show an upsurge in Leprosy situation in India.

It is a high time now to recognize the fallacy in focussing on leprosy elimination (and now eradication) based on just one single indicator at a national level with no account of state variations. Despite the claimed reduction in prevalence, India continues to be one of the endemic countries (those with more than 1000 leprosy patients per year). India registered 134,000 new cases in 2010 accounting for more than 54% of cases globally; one every five minutes. (<http://www.leprahealthinaction.org/lepra-is-to-present-a-new-approach-to-reducing-the-burden-of-leprosy-in-endemic-pockets-in-india/>) It is important to look at leprosy cases and associated disabilities which are mainly a result of late diagnosis. Still there are 'pockets' of leprosy even in states where it has been declared eliminated at a state level. There is a need to address this amicably and focus on continued intervention rather than beating the trumpet of leprosy elimination alone. It is important to realise the control and elimination of Leprosy is very much ingrained in a matrix of structural-cultural-economic-political factors which further speaks about the dubious nature of claims made with regards to 'elimination of Leprosy as a public health problem' and now future efforts for eradication of the disease.

3.3 Biomedicalized approach and Leprosy Elimination

It is significant to note change in treatment regimen in accordance with the one specified by WHO. MDT was introduced worldwide by WHO in 1982 which was incorporated as part of NLEP in 1983. Alongwith this pharmaceutical company like Novartis also gained entry into the National Disease Programme which has created a certain kind of monopoly and dependence in a field which is not level played. WHO programme in relation with MDT has actually failed to reach many of affected people (Rakel 2001 as quoted in Scott R James 2006) In this blind race of eliminating leprosy certain basic factors which are at the crux of entire issue are forgotten and entire thrust is on 'curing through MDT' (MDT is a multi drug therapy consisting of a combination of three potent drugs (Dapsone, Clofazamine and Rifampicin), which need to be taken by patients for six months for Paucibacilliary cases and 12 months for Multibacilliary cases.) and bringing down prevalence and newer case detection rates. Cultural beliefs associated with the disease are totally ignored and if this is not addressed, increased availability of services will not translate into an appropriate increase in utilization and envisioned dream of 'elimination'. Moreover, elimination efforts are often seen as problematic by the afflicted group because they fail to account for their individual needs. Because of existing stigma and inadequate availability of healthcare services their right to engage fully in social life is unfulfilled. Further, community education and medical knowledge of the disease does not immediately dispel stigma (Jesse T. Jacob and Paredes Franco Carlos 2008). Early

diagnosis of the disease and complete rehabilitation efforts are minimal which aggravates the situation in spite of high push for MDT. In many cases diagnosis is at a very later stage when nerve damage has already occurred and disability visibly starts appearing.

3.4 Funding and NLEP: Role of World Bank and other Agencies

Period from 1993-2000 marked the first phase of World Bank funding to NLEP involving a cost of Rs 555 crores of which WB provided Rs 292 crores (more than 50%). During this period, prevalence rate was reduced from 24/10,000 population in 1992 to 3.7/10,000. It is important to bear in mind that this was the period of rapid expansion of World Bank regime through its neo liberal policies with the introduction of Health Sector Reforms in many countries including India. There was an influx of funding and WB supported NLEP is one of the many instances. Second phase of the WB assisted project started for a period of three years 2001-2004 involving a cost of Rs 249.8 crore with a loan of Rs. 166.35 crore. WHO provided free MDT drugs of cost Rs 48.00 crore. 2nd phase not only marked a sharp decline in fund allocation by WB (Rs 126 crore) but also decreased time span as well. In the following years funding by WB was completely withdrawn. January 2005 onwards funding for NLEP is fully provided by Government of India as a centrally sponsored programme. Additional support for the programme is received from WHO, Nippon Foundation and Sasakawa Foundation, Japan, DANIDA and International federation of Anti Leprosy associations (ILEP) organizations. MDT is supplied free of cost by corporate social responsibility wing of Novartis (Novartis Foundation) through WHO.

IV. PREVALENCE AND INCIDENCE OF LEPROSY IN INDIA: SOME CRITICAL ISSUES

WHO's Weekly Epidemiological Record (WER) report published in August 2012 on Global leprosy situation categorically states *Leprosy control has improved significantly due to national and subnational campaigns in most endemic countries. Integration of primary leprosy services and effective collaborations and partnerships have led to a considerable reduction in leprosy burden. Nevertheless, new cases continue to occur in almost all endemic countries and high-burden pockets can exist against a low-burden background.*

As stated in the report, India has registered a prevalence of 83,187 cases during the first quarter of 2012 with 127,295 new cases detected. Out of these new cases detected, 63,562 are MB cases, 47,111 are females, 12,305 are children and 3,834 are with grade 2 disability. 690 cases of relapse have been recorded with cure rate of 95.25% for PB and 90.56% for MB.

WER clearly shows a wide disparity across regions in terms of disease load. In spite of WHO's claims of decline in registered new detected cases annually on a global scale there are regions like African and South Asian which are still recording high disease burden. India has one of the highest number of registered leprosy patients. Majority of endemic countries are still detecting new cases including India. Thus it becomes even more important to revisit the definition of 'elimination' set by WHO which in turn reveals a number of concerns with this internationally shaped approach towards leprosy elimination that still remain under-explored (Staples, James 2007). It is interesting to note that states which are endemic to Leprosy like Tamil Nadu (<http://www.nrhmtn.gov.in/nlep.html> Refer to this link for this statement made on state health society website) have declared on the state health society website that leprosy is no more a public health problem.

How criteria like prevalence rate less than 1/10,000 population can be applied uniformly at a national and state level scale? Is issue of leprosy merely restricted to controlling prevalence rate among populations? Where diagnosis and rehabilitation does find its place in this debate around 'eliminating leprosy' by enhancing cure rate? Leprosy is not a point disease which if cured with MDT can lead to wellbeing. It causes much deeper damage to one's life because of the stigma it produces and disability it causes. This in turn questions the entire declaration of 'eliminating leprosy as a public health problem' which is solely based on numerical criteria and biomedical notion of health. Certainly there is a need to revisit the gaps in internationally set priorities and deadlines which are in dire contrast with national situation. Disease priority setting in any country including India should be based on 'epidemiological needs of the population' with a consciously made sustained political commitment. Globally perceived health needs are not required necessarily to be translated into country specific policies which have a very different context and situations.

V. CONCLUSION: ANALYSIS OF THE PRESENT SCENARIO IN RELATION TO 'LEPROSY ELIMINATION (NOW ERADICATION) IN INDIA'

A number of issues emerge from the discussion under taken above. If looked at analytically each one of them can be categorised under separate headings as discussed below.

Politics of disease elimination: In India an internationally shaped approach to Leprosy elimination set and defined by WHO and other international health agencies has been adopted. There has been a constant push by WHO to eliminate leprosy from India irrespective of the local situations and context. It is important to understand that choosing a disease like leprosy which biologically does not lend itself to principle of elimination is in itself a wrong move. Moreover, leprosy is a disease of pockets and claims regarding its elimination are truly invalid in the current context when there is resurgence and relapse of cases. Co-opting global health strategies does not yield any sustainable result until it is regionally and nationally matched. Marked shift from control to elimination and now eradication in National programme for leprosy was not a sudden decision but it was accompanied with a very settled push by WHO and other international actors.

Larger debates surrounding political economy of disease priority setting in third world nations constantly pushed by international actors. There is a repeated overlooking of national priorities with regards to burden of diseases and international agendas have seeped deep down to national health planning where there is no place for actual epidemiological situations and felt needs of the population. Here global aid and political commitment/agenda of the national governments are detrimental in deciding what gets priority as a disease rather than objective analysis of the situations and sufferings of the people. This politics of funding is clearly illustrated in the case of leprosy. As long as WB support was there interventions were pursued rigorously with active case detection. In 2005 after India declared to have achieved leprosy elimination, WB withdrew all its funding. Impact is visible down the line as there is no sustained intervention now. Leprosy was soon termed as 'Neglected tropical disease', neglected in relation to funding and prominence it gets in the eyes of 'international health experts'. Moreover, WB funding to NLEP was at a time when all over in the 3rd world it was pushing country health systems for health sector reforms. Impact was seen clearly in terms of verticalization of NLEP with an explanation based on increased efficiency and efficacy.

And now the international declaration endorsed by various agencies in London called 'London Declaration on NTDs January 2012' and WHO's Enhanced global strategy for further reducing the disease burden due to leprosy 2011–2015 are playing a vital role in determining and shaping current Global Leprosy Programme including the one for India.

NLEP is a classic case of a reductionist approach where 'achieving numbers' has been the sole target in order to declare elimination as soon as possible to meet WHO set deadline. There is jugglery with disease statistics making false claims which need to be looked at critically since this not only affects the direction of public health programmes, priorities and funding strategies but also refuses to see what is evident and affects lives of people. Certain core issues like Disability and debilitation caused, issue of stigma, social dimensions of the disease etc have been totally overlooked in order to meet these numerical targets. Of course, as per GoI claims leprosy has been eliminated but not the suffering and disability it has caused with no means to address it.

Social dimensions of the disease and intersectionality with caste, class and gender: Broadly speaking, biomedicine is the dominant paradigm determining ways of understanding and addressing any disease including Leprosy. Among the practitioners an understanding that diseases are also socially produced and an approach involving social determinants framework is a rare sight. Although theoretically WHO also very well affirms to existence of social determinants of health and disease but in practice biomedical perspective and reductionism prevails. There is a tendency of looking mind-body separate from illness experience of the patient which Foucault rightly termed as 'medical gaze'. MDT can cure patches but what about accompanying suffering, social stigma and in many cases disability? Even majority of the literature available also excludes this perspective of looking at social dimensions of leprosy.

Thus to summarize, Questioning the very concept of elimination as a political rather than a scientific term is required. To bring back Leprosy into current Public health discourse there is a need for timely recognition of the 'relapse and resurgence of cases and fallacy in the claims of elimination'. Issue is not as simple as achieving a globally set deadline. It transgresses across political economy of disease priority setting in third world nations and funding for neglected tropical diseases at large. This hugely shapes national health planning and priority setting as it is clearly evident in the case of leprosy elimination programme of India. It calls for analysing what one is catering to by blindly adopting such internationally set global health policies and programmes as against regional context and epidemiological needs of the population. An Indian case of leprosy elimination very well captures this dichotomy. It is very much necessary for the government and the health planners to respond to the epidemiological needs of the population with an indigenous planning and holistic approach of looking at preventive, promotive, curative, rehabilitative aspect (Alma Ata declaration 1978) is very much essential in addressing leprosy.

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