SERIES NO. 7

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

February, 2020

FOCUS

‘Elimination’ of Leprosy

- status on the ground
- questionable assumptions

Reducing disease burden

- strategies & best practices
- new approaches & recommendations

Tackling disability and stigma

- missing gaps & predictions
- issues & concerns

INDEX

Focus on learning from experiences and expressions for future leprosy control programme

Declaration

This series contains a compilation of ***views that matter*** from various published articles; reports; reviews; editorials and guidelines (only excerpts with key concerns expressed as title) from journals; manuals and magazines that are available free in the form of print or digital version for non-commercial purposes. The source of these articles / authors are duly acknowledged.

The published material directly or indirectly express ***our point of view*** on strategy and programme related issues of leprosy control.

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Foreword

Sooner or later, a political window of opportunity would open up

This volume of 'FOCUS' is a truly an amazing and erudite contribution to building a public understanding of the state of leprosy control and in shaping the public discourse on the urgent need for a comprehensive review of policy with regard to leprosy.

The methodology of this series is itself innovative, as it draws on different facets of the leprosy problem using extracts from articles by leading authorities and researchers in leprosy control. Even flipping through the headlines of each pages gives the reader a quick catalogue of the diversity and complexity of the issues that are involved.

It would take courage for the establishment to go back on its claims of elimination of leprosy. One article calls for a WHO General Body resolution that states upfront, that leprosy is not eliminated and nor is it likely to be anytime soon. That is not likely to happen, but at least in practice and internally the policy community must admit it to themselves. Sooner or later a political window of opportunity would open up. If at such a time, there is a critical understanding of both the problems and solutions within the policy community then one can hope for the required policy changes.

However, even the current policies allow for considerable action. The second section, on reduction of the burden of disease, is full of suggestions which calls for innovative and creative thinking to re-formulate key tenets of the program. Such design changes are essential to overcome bottle-necks and constraints and move forward.

And the third and last part of the volume describes the problems of life-long disability and stigma management. Even when the disease is no longer a significant communicable disease, it would be one of the most prevalent neurologic conditions with all the features of any non-communicable illness-requiring constant care, special primary care efforts to prevent complications, and adequate tertiary centers that can respond to advanced complications when they do take place. It would also need continued resources and prioritization in health policy.

I congratulate ALERT-INDIA and the editors for bringing this invaluable publication. This series of FOCUS, no doubt, took a long time and a huge effort in the making. But what is needed now is an even greater effort at its dissemination and in using this to facilitate dialogues with politicians, administrators, civil society leadership and even in professional associations.

Prof. T Sundararaman

Presently - Global Coordinator, *Peoples Health Movement, Global Office, New Delhi.*
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Formerly - Professor and Dean, *School of Health System Studies, Tata Institute of Social Sciences, Mumbai.*
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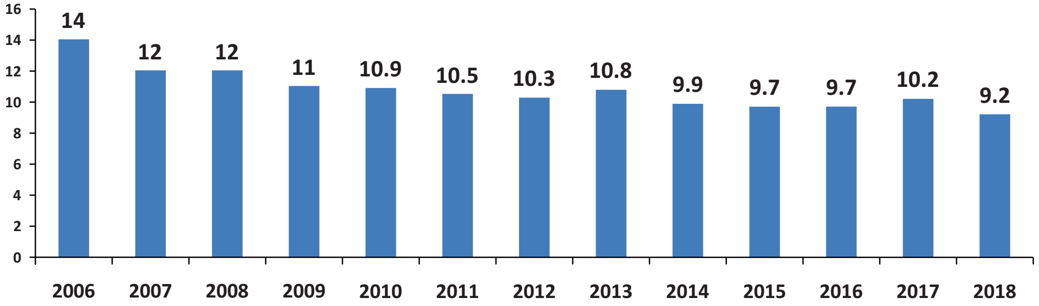
Fact Sheet

Leprosy trend persists in India since 'elimination', 2005


Annual New Case Detection Rate (ANCDR) per 1 lac population : NLEP Reports

Leprosy burden?

- India has long been suspected of deliberately underestimating its leprosy burden so as to attain the "elimination" target.

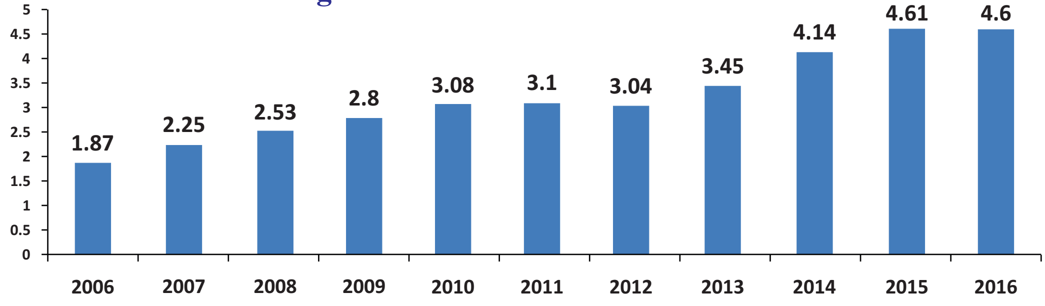
Dr. Diana Lockwood, *Consultant in Infectious Diseases and Tropical Medicine, London School of Hygiene and Tropical Medicine, UK*

NLEP reported 127,509 new leprosy cases (ANCDR of 10.5 per 100,000 population) in 2011

- "Using the inverse sampling methodology, the overall new case detection rate was 27.7 per 100,000 population with a range of 0 - 366 / 100,000. This was higher than that reported in NLEP annually".
- "The estimated cases for the whole country were 334,615 and varied from the lower limit of 287,445 to higher limit of 380,861, as per the inverse sampling methodology".

Dr. Kiran Katoch, *Former Director of National Jalma Institute of Leprosy & Other Mycobacterial Diseases (NJILoMD) under ICMR, Agra, India*

Source: *National sample survey to assess the new case disease burden of leprosy in India. Indian J Med Res. 2017 Nov; 146(5): 585–605.*


Proportion of grade 2 disability (G2D)
among new cases detected in India : NLEP

Source : *NLEP, Revised Operational Guidelines for Leprosy Case Detection Campaign (LCDC), 2016*

Target to reduce disability burden

WHO (2011) sets a target of 35% reduction of new G2D cases by 2015 (baseline 2010). However NLEP data shows 33% increase in G2D among new cases from 2011 to 2015 !

Leprosy is not eliminated in India:
a reality check is critical to redefine strategy

Issues and questions: A proud declaration of leprosy 'elimination' at national level by Govt. of India in 2005 turned out to be misnomer. It is based on a misconstrued definition: intermediate goal based on an arbitrary target - 1 case of leprosy per 10,000 population - set in 1991 by WHO. Press reports hailed the announcement. Health ministry announced it as a 'national achievement' and perhaps we celebrated too early – resulting in loss of focus and funding needed for 'final' push. The public, the polity and other key stakeholders believed it to be factual and welcomed it. A rationale, driven by the success of an effective cure of leprosy by multi-drug therapy (MDT) demonstrated globally since 1982, did not result in a significant reduction in force of transmission over the years as presumed.

Claim versus scientific dictum: The claim of 'elimination' is a superfluous epidemiological triad in which the leprosy bacilli (agent) and the susceptible (host) continue to be active in an unchanged environment in unknown locations. It is scientifically fallacious and a contradiction in epidemiological terms; no validation of prevalence of leprosy based on 'reported' target attainment was done prior to the countrywide declaration.

Repercussions: This faulty public declaration based on numerical target bereft of validation had a huge human investment cost. Public health planners were misled causing post elimination budgets to slacken the leprosy control work by drastically downsizing technical, skilled human resources and dismantling the structure that cured millions of leprosy cases since the introduction of MDT. As reported by the NLEP, average annual detection over the last decade was consistent at 1.3 lacs new leprosy cases. Among them 38% are women; 10% are children and 6% are deformed, which is an appalling state of despair. This confirms continued transmission in unknown hot spots.

Response needed:

- A public denunciation is essential to offset the consequences on the lives of people. A paradigm shift to approach programs from a lens of surveillance and process indicators, not only the final impact and 'elimination target' is the need of the hour.
- A rational determination calls on the policy makers to move away from the 'policy window dressing mode' to a 'reality assessment mode'. It will help the programme to unwrap real time leprosy incidence data and its cohort.
- The NLEP needs to redefine strategies, redirect resources, re-engage trained ground forces and root them in the health care system with planned community outreach interventions to reduce the disease burden and its consequences - disability, stigma and discrimination, based on the evidence gathered.
- *These steps can help to gain an insight and create an impact. It would also serve as an 'enabler' for the stakeholders that toil towards reaching "zero leprosy", the 'aspirational' goal proposed by WHO for the future!*

The purpose of FOCUS (No. 7) is to initiate a dialogue with stakeholders and to urge the Policy makers, health professionals, civil society and public health activists to acknowledge the need to revisit the leprosy control measures in our country under NLEP. It presents the relevant excerpts from the published articles, studies and reports thematically organized in 3 parts. These opinions and experiences reflect the need to tread the future path for a leprosy free India, diligently.

Sion (West), Mumbai
February 2020

A. Antony Samy
Chief Executive

‘Elimination’ of leprosy : *views that matter*

Page

I. Leprosy elimination : status on the ground

II. Leprosy elimination : questionable assumptions!

1

“Fight against leprosy no longer about the numbers”

. . . . focus on numerical targets might be missing the bigger picture . . . .

Talha Khan Burki
Freelance Health Journalist, Karachi, Pakistan

According to WHO, in 2008, there were 249,007 new cases of leprosy, 94% of which were from 17 countries. The figures are dominated by India with 134,184 new cases, down from 473,678 in 2002. ”It's a very substantial decrease”, notes Smith, “it doesn't seem biologically possible.” Several countries reported increases over the same period.

Vijaykumar Pannikar (WHO Global Leprosy Programme, New Delhi, India) stated that whenever leprosy surveys have been done in India, many more cases have been found. **Experts fear that many new cases are not being detected, with resultant delays in treatment, increases in transmission, and the development of disabilities.**

In the 1960s, the worldwide prevalence of leprosy was roughly 11 million cases. There have been enormous improvements since then, but contrary to the impression left by talk of elimination, the disease is not going to disappear.

Instead, numbers are likely to stabilize - vaccine for leprosy is not foreseeable, nor necessarily desirable, given the disease's rarity. **If knowledge of leprosy starts to fade, there will be problems with diagnosis: there is no simple test for infection, and even now mis-diagnosis is not uncommon**.

“If you don't have key indicators and targets, it's difficult to secure political and financial commitment”, concedes Smith. But it is tricky developing eye catching markers for sustainability, equity, and reduction of stigma. Multi-drug treatment—highly effective, and as yet largely resistance-free—has been standard treatment for leprosy since 1981, it is distributed freely, but leprosy treatment does face a funding shortfall.

Experts face questions over how best to pique public and political interest. Smith believes that the 35% reduction in grade 2 disability target will be effective. National programme managers and patients' advocacy groups are in favour. The target encourages early diagnosis and efficient case management, and shares the aspiration of the Millennium Development Goals of reducing disease burden.

“A novel idea”, agrees Fine, but data are poor and there might be difficulties in interpreting statistics. Besides, quality of case finding, reaction control, and rehabilitation are also important long-term issues for leprosy. “I'm concerned that the focus on numerical targets might be missing the bigger picture”, Fine said.

Household contacts are at the highest risk of leprosy; the 2011–15 strategy reiterates a longstanding recommendation to check such contacts - “you're most likely to find early cases there”, notes Fine. But only well-funded programmes can afford such measures, and there are issues of stigma and confidentiality. Meanwhile, two external factors continue to assist: the BCG vaccine, which seems to offer greater protection against leprosy than it does against tuberculosis, and socioeconomic development.

“Integrated diseases are very dependent on the capacity of primary health care”, explains Smith. “In many countries, it's very weak: integration can mean doing nothing at all.” **If control programmes are not sustained and leprosy-specific expertise is lost, the disease could easily resurge.** Experts will have to work very hard to keep leprosy on the agenda for the period of the next global strategy and beyond.

Excerpts - The Lancet Infectious Diseases, News Desk | Volume 10, Issue 2, P 74, February 01, 2010

2

“Can we hope to eliminate leprosy?”

. . . . when elimination is defined as zero incidence, leprosy is definitely not eliminated . . . .

Prasad P V S et al

Department of Dermatology Venereology & Leprosy, Rajah Muthiah Medical College & Hospital, Tamil Nadu, India

It was assumed that MDT would reduce the transmission of M. leprae through a reduction of the number of contagious individuals in the community, but unfortunately there is no convincing evidence for this hypothesis. There were two large-scale studies on trend analysis available to interpret the impact of MDT globally. In the first study published by Meima in 1997, the author concluded that factors such as case detection and treatment would reduce leprosy transmission is reasonable, but the reality may be more complicated. Individuals incubating the disease may already harbor many bacilli, and it is possible that those individuals already transmit M. leprae to others long before the onset of the disease.

More interestingly, a general acceleration of downward trends in the NCDR after the introduction of MDT has not occurred. In the more recent study, the same author showed no general decline in case detection at global level up to 2000. There are no suitable tests to detect the subclinical mycobacterial infections reliably, including M. leprae. **Assessment of results of leprosy control depends on information about disease and not infection. Disease statistics are expressed in terms of prevalence and new case detection.** Disease prevalence in leprosy is measured by counting all patients receiving MDT at a given time and expressing this as a ratio using the population as the denominator (in leprosy, it is per 10,000).

Therefore, the figures are linked to the length of treatment. As the duration of treatment is reduced from 24 to 12 months, the prevalence also is reduced by 50%. For PB group, there is a chance that patients might be missed for that year as those patients on roll only on December, 31 are taken into account. Hence, those patients who completed in the first half of the year may not be included into the figures.

India’s statistics remain difficult to interpret:

The most striking trend in global leprosy in recent years is the decline in India, which reported 137,685 new cases in 2007 when compared to 559,938 in the year 2000. This implies that India’s contribution to the global leprosy burden has declined from 73% to 54% of the world’s newly detected leprosy cases over these years. **It is unclear the extent to which this decline reflects changes in ascertainment and criteria for new cases to be counted in India. At the same time, proportion of new cases with WHO grade-2 disability increased from 1.6% to 2.2% between 2004 and 2007 which is an increase by 38%. This is an alarming situation.**

MDT-based control appears to reduce transmission. The pace of reduction is highly uncertain, but in any case slow. BCG may enhance the pace, but its impact is also uncertain. The gray areas in leprosy control are the role of close contact transmission, the speed of transmission, and the extent of contagiousness during the incubation period. Research addressing these questions is essential to narrow down the uncertainty regarding the impact of MDT - based control.

There are considerable numbers of people who are compelled to live under the threat of deteriorating function due to established leprosy-related impairments. It is predicted that there will be still approximately one million cases with WHO grade-2 deformities in the year 2020. Prevention of deformities does not require advanced technology but will require advanced thinking. When elimination of the disease is defined as the reduction to zero of the incidence, leprosy is definitely not eliminated.

Excerpts - Leprosy therapy, past and present: can we hope to eliminate it? Indian J Dermatol 2010:55(4):316-24.

3

"We don't know who got leprosy and who doesn't"

. . . . reducing the number is a start towards elimination, but it is hardly the end . . . .

Apoorva Mandavilli
Science Journalist, The New York, Times

In 2005, India declared that leprosy was no longer a problem in the country. But that announcement was premature: According to the World Health Organization, India harbors 60% of the world's cases, with more than 100,000 new diagnoses each year. **"Sometimes the program managers start making less effort, so they get less cases, so that they can say that prevalence is going down," said Dr. Anil Kumar, who has led the country's leprosy program since 2015.**

As India's health officials concede, the prevalence of leprosy was low in 2005 not because fewer residents were being infected, but because the government stopped trying to find them. Clarity or no, the World Health Organization has long made the elimination of leprosy one its goals. In 1991, the organization announced that by 2005 leprosy would be "eliminated as a public health problem," meaning that there would be fewer than one case per 10,000 people.

The odds were long — the deadline had been deferred once already — but "sometimes you put intentionally targets which are rather aspirational," said Dr. Erwin Cooreman, team leader of the organization's Global Leprosy Program. But the subtleties of that aspiration were lost on most people in India.

"People actually just completely misunderstood it," said Dr. Diana Lockwood, a leprosy expert at the London School of Tropical Medicine, UK. "For them, elimination means no cases."

People infected with the leprosy bacterium may not show symptoms for 20 years. Meanwhile, they still can infect others, who in turn may remain symptom-free, and infectious, for years. Reducing the number of visible cases of leprosy is a start toward eliminating the disease, but it is hardly the end.

Still, health officials in India took the goal of elimination seriously, and by 2005 the number of symptomatic cases dropped to fewer than 1 case per 10,000 people. **Then the country dismantled most of its leprosy programs and redirected its resources to more urgent priorities such as AIDS and tuberculosis; public awareness of leprosy plunged. But out of view, the bacterium remained active.** The number of infected, disabled people remained low for nearly a decade, and then began to rise. The disease was being detected way too late, generating "lot of collateral damage," Dr.Cooreman said.

Leprosy causes distinct deformities and imposes a heavy social stigma. People with the disease sometimes exile themselves to leprosy "colonies" - there are 700 or so in the country - where they interact only with one another and beg for money.

"In countries like India, people from all classes get leprosy," said Mr. Ashim Chowla, who heads a nonprofit agency called Lepra. "But because of discrimination and prejudice, we don't talk about it. And because we don't talk about it, we don't know who's got leprosy and who doesn't."

Pressured by the organization, India's Supreme Court ruled in September that the government must end discriminatory laws, conduct regular surveillance to detect new cases, provide treatment to everyone who needs it, and promote awareness of leprosy as a curable disease. "We work to make leprosy a disease of no consequence, which is what it should be," said Mr.Chowla.

Excerpts - Health, The New York Times, 17 April 2019.
https://www.nytimes.com/2019/04/17/health/leprosy-india-disease.html

4

"Survey detected more new cases than reported by NLEP"

. . . . survey showed that there was still fear and mis-belief about the disease . . . .

Kiran Katoch et al

National JALMA Institute for Leprosy & Other Mycobacterial Diseases (ICMR), Agra, India

A national sample survey of leprosy

India has achieved the global leprosy elimination target in December 2005, and the average prevalence of the disease at the national level was 0.68/10,000 in 2015. New cases, however, have been detected in about the same frequency in the National Leprosy Eradication Programme (NLEP) in the post-elimination era and have varied from about 1.2/100,000 in 2008 to 0.97/100,000 in 2015. This was not a substantial decline and pointed to the continued transmission and also late reporting of cases. Besides, there were reports about the detection of new cases of leprosy in several tertiary care and service providing centres in the country.

Therefore, despite the declining trends, leprosy continues to be an important public health disease in India both for the professionals and the policymakers. **This study was undertaken in response to the 131st Report of the Committee on Petitions of Rajya Sabha, 2008, which recommended that 'A final survey, involving Panchayati Raj institutions (PRI) may be undertaken so that the government can have realistic figures of leprosy-affected persons (LAPs) to devise a national policy' (Central Leprosy Division, Ministry of Health and Family Welfare, personal communication).**

The Ministry of Health and Family Welfare (MoHFW) along with the Indian Council of Medical Research (ICMR) decided that a multicentric study be undertaken to assess the burden of new leprosy cases, number of these newly detected leprosy patients with Grade 1 and Grade 2 disabilities and determine the magnitude of stigma and discrimination prevalent in the society. Several deliberations were held with the Expert Committee which included programme managers of Central Leprosy Division (CLD), MoHFW, medical statisticians, academicians and epidemiologists, for deciding on the methodology to undertake the aforesaid survey.

The ICMR-National Institute of Medical Statistics (NIMS), New Delhi, was entrusted to carry out a pilot house-to-house survey for the detection of new leprosy cases and comparing the inverse sampling methodology with the conventional method, in Bareilly district of Uttar Pradesh (UP) with funding from CLD. The detailed results of this pilot study were presented4, and discussed at length with the experts.

It was proposed that in the main national sample survey to assess the disease burden of new leprosy cases, all States and Union Territories (UTs) needed to be covered and inverse sampling methodology5 was to be used to detect the new cases. A house-to-house survey was to be undertaken to detect the new leprosy cases with the NLEP staff after re-training and time frame was allotted. Lakshadweep was not included as no new case of leprosy was detected in the area in the last five years.

The main objectives of the national survey were as follows: (i) to estimate new leprosy caseload; (ii) to assess both Grade 1 and Grade 2 disabilities in the newly detected cases; and (iii) to assess the magnitude of stigma and discrimination prevalent in the society.

Methodology of survey and sampling design: Inverse sampling

Inverse sampling is a sampling technique to estimate the proportion 'P' for rare events like leprosy. Briefly, this consists of sampling until exactly 'm' the predetermined occurrences of rare event appear in the population, and the population covered to record these rare events is the denominator. In this methodology, the required sample size 'n' is a random variable and not known in advance. It is contrary to the conventional method where sample size is fixed and the events are noted after attaining the required sample size.

This sampling design was used for the rural and urban settings due to the known differences in occurrence of the disease. These included differences in the system of health providers, variable socio-economic and hygienic conditions, population density per square area, different ways of living and presence of large and variable migrant population.

92 (15%) of the total 612 districts (2011) in the rural clusters and 37 out of 131 urban clusters were selected. Training of staff, IEC as well as the survey was completed in 2011 (cross-verified by validators). The total population screened / examined in the survey was 14,725,525, which included 10,302,443 rural and the rest 4,423,082 urban population.

A total of 2161 new cases of leprosy were detected and put on treatment which included 1300 (60.2%) PB cases and 861 (39.8%) MB cases. Of these, 1474 cases (68.2%) were residing in rural areas and 687 (31.2%) in urban areas. **Using the inverse sampling methodology, the overall new case detection was 27.7 / 100,000 with a range of 0-366 / 100,000. This was higher than that reported in NLEP annually.** The estimated cases for the whole country were 334,615 and varied from the lower limit of 287,445 to higher limit of 380,861, as per the inverse sampling methodology.

Females constituted 46 - 50% of the screened and surveyed population in the various States, which was similar to the census population of the respective States and UTs. About 11 % of cases were of the paediatric age group. It was similar in the rural and urban clusters. Among the new cases, 302 (13.9 %) had disabilities of whom 127 had G1D, while 175 had G2D.

Assessing the stigma prevalent in the new leprosy disabled patients as well as the society

Questionnaire-based method was undertaken to analyze the attitudes and beliefs of patients as well as that of the common unaffected person of the community, as was done in the pilot study at Bareilly. Sample questionnaire was discussed with the Expert Committee members on the ethical issues involved in asking the questions and recording their responses.

It was observed that the extent of self-stigma was small and patient was at ease with his immediate family. However, 30% of the patients still did not tell their family about the disease. Whenever family was told about the disease, they were supportive. It was observed that even after integration of the disease with general health care services, patients got their MDT and care for trophic ulcers as well as disabilities from the government dispensaries/centres and were satisfied with the services.

Stigma in leprosy was largely due to the resulting disabilities and was present both in disabled leprosy patients (self-stigma) as well as the community. Some members of the community were uncertain about the curability of the disease and believed it was hereditary. They still believed that the patients should be kept at a distance, even when on treatment. This showed that there was still fear and misbelief about the disease.

A substantial percentage of community members still felt that patients with residual disabilities, seen begging can spread the disease. A segment of people also gave contradictory and uncertain answers when asked about their social attitudes towards leprosy and needed more knowledge and education to dispel the misbelief.

Excerpts - National sample survey to assess the new case disease burden of leprosy in India. Indian J Med Res. 2017 Nov; 146(5): 585–605.

5

"Thrust on curing through MDT and reducing PR and NCDR"

. . . . crux of the entire issues are forgotten in this blind race of eliminating leprosy . . . .

Neha Dwivedi
Research Scholar at Centre for Social Medicine and Community Health, JNU, New Delhi, India

The national sample survey (NSS) of leprosy 2010-11 reveals that annually 14 new leprosy cases are being detected per 100,000 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. But contrary to this Leprosy Division of Ministry of Health continues to claim a prevalence rate of 0.95/ 10,000 population.** 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 and registered 134,000 new cases in 2010 accounting for more than 54% of cases globally; one case in every five minutes.**

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.

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' and reducing PR & NCDR. 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 health care services their right to engage fully in social life is unfulfilled.

NLEP is a classic case of a reductionaist 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, issue of stigma, social dimensions of the disease etc have been totally overlooked in order to meet these numerical targets. Of course, as per Government of India's claims leprosy has been eliminated but not the suffering and disability it has caused with no means to address it. 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 in addressing leprosy.

Excerpts - Proceedings of International Conference on Global Public Health and Social Work. P 101 to 106. ISBN 978-93-82338-406 | © 2013 Bonfring

6

"In the face of other competing priorities at national level"

. . . . there is an urgent need to rebuild and sustain leprosy expertise . . . .

Casandra Chaptini
Flinders Medical Centre, Adelaide, South Australia, Australia

Although the goal was to eliminate leprosy as a public health problem, the terminology misled many people, including policy makers to believe that the goal was complete elimination. This may partly explain the reduction in leprosy programme funding, the decrease of academic work on leprosy, and why leprosy rarely features in medical school curriculum, even in endemic countries.

Although WHO abandoned the 'elimination' target in 2007, national leprosy rates are still emphasised, which may have unintended damaging consequences, as demonstrated in India. The pressure on outstanding countries to meet the elimination target by 2005 resulted in India meeting the target, however independent studies showed many undiagnosed patients, and it was found that measures were adopted to ensure fewer patients were registered, including not registering single lesion cases and not tracing contacts.

Subsequently, India has reported approximately 130,000 new cases a year, keeping it in the 'eliminated' category. However, from 2004 – 2007 new case detection dropped by 75%, but the proportion of G2D cases increased by 38%. This indicates less active case finding, which may partly be due to a decreased incentive to find new cases, and has a devastating effect on leprosy morbidity.

Although it is important to set targets to provide direction for national programmes and secure political commitment, the targets used are imperative. Evidence has demonstrated that disability-based targets encourage early diagnosis and treatment, and prevent morbidity. Hence, there has been a shift from placing importance solely on 'elimination' and total new cases found, to emphasising disability rates, for instance, new cases of G2D.

Unfortunately, the celebration of the leprosy progress may have resulted in a loss of political commitment. Funding for leprosy programmes has been reducing by 5% per year globally, for the past 5 years. Currently, few countries have a surveillance-response system to provide epidemiological data, and implement required interventions. Moreover, many leprosy programmes have been left unsupported and the skills in diagnosis and management have dwindled. In some countries where marked success has occurred, unfortunately there has been an increase in MB and disability cases.

In the face of other competing priorities (e.g. HIV, malaria, TB), a major challenge is for leaders across all sectors to reaffirm commitment and allocate increased resources at a global and national level. Where facilities are weak, sharing facility control programmes for other diseases should be considered. There is an urgent need to rebuild and sustain leprosy expertise, and to develop strategies globally and nationally, in collaboration with partners, to augment training programmes.

Additionally, national efforts are needed to involve dermatologists in the leprosy control programme to sustain high-quality leprosy services. To achieve this, it is vital that partnerships are solidified between governments, NGOs, private sector, international agencies, professional associations and people affected by leprosy.

We urge all countries, governments, stakeholders, and individuals to reaffirm their commitment to reducing the burden of one of the world's most devastating diseases, so that someday we can say leprosy is truly eliminated.

Excerpts - Leprosy: a review on elimination, reducing the disease burden & future research. Lepr Rev (2015) 86, 307–315

7

“End game is tough: higher index of suspicion for diagnosis”

. . . . ensure that leprosy funds do not find their way to other programmes . . . .

Sunil Dogra et al

Department of Dermatology, Postgraduate Institute of Medical Education & Research, Chandigarh, India

Sustainability is a huge challenge to all leprosy activities everywhere. It is a common problem for all elimination and eradication programmes that have made great progress but now find it harder as the problem appears to get smaller, polio eradication being a good example where the end-game seems tough. The priority of leprosy relative to other health problems in a country diminishes as the number of new cases comes down, and the cost per patient treated increases steadily.

The key approach to sustainability has been integration of the delivery of leprosy services into basic health and primary care. Sustainability is fundamentally an ecological concept, but when applied to health care, it tends to largely focus on financing. We want to ensure that leprosy funds do not find their way to assisting other programmes. Integrated programmes often become what has been termed ‘combined vertical programmes’ rather than truly integrated. However, many previous vertical programmes like leprosy are trying to integrate into the weak, fragile infrastructure of primary health care. Integration can only be successful if the primary health services are strong or competent enough to cope with this integration.

A second view might reveal, for instance, that the leprosy-related portion of a national health budget should not only be based on the current situation, weighing the leprosy burden against that of other diseases. **There is a potential risk that this progress will lessen the perception of the benefit in continuing to spend resources on leprosy, as other competing priorities (e.g., HIV /AIDS, malaria, and tuberculosis) may appear to be of relatively greater importance.** However, management of leprosy requires both treating the bacterial infection as well as minimizing the potential for permanent nerve damage and subsequent impairment. Thus today's window of opportunity requires more resources than a short-term analysis would indicate.

Another possibility that needs to be considered is the paradoxical delay in treatment and subsequent increase in the severity of impairment. **As a disease or condition becomes more rare, it takes a higher index of suspicion for a treating physician to appropriately diagnose or refer a patient for care.**

Leprosy programmes have been slow to develop areas such as integration, multi-disciplinary research, involvement of people affected with and by leprosy, community-based rehabilitation and community participation. Many of these changes potentially threaten the position of those responsible for leprosy activities; we can be as isolated in our thinking and methods as people affected by leprosy.

Prevention of disability is one area that has been innovative, with self-care, community and family involvement, participation of groups of people affected by leprosy, and the use of available, affordable, acceptable appliances such as footwear. For sustainable prevention of disability the ownership of prevention of disability has to pass to people and communities.

Advocacy must play an increasing role to bring about change. It involves influencing those who are responsible to ensure that leprosy is included in health care and social care, and that people affected are fully included in all aspects of society. GIS has become an essential tool to be used with care and wisdom to establish the burden of disease, identify risk factors, and to plan, monitor and evaluate control interventions.

Excerpts - Excerpts - Leprosy - evolution of the path to eradication. Indian J Med Res 2013;137:15-35

8

“Leprosy didn’t promise an overnight magic bullet of glorious success”

. . . . misled people in power and the public to believe that leprosy no longer existed . . . .

Geoff Prescott

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The WHO’s declaration of ‘elimination’ allowed efforts to control leprosy to become neglected, underfunded and, frankly, closed. **Leprosy as an ‘officially eliminated disease’, no matter how nonsensical the definition of ‘elimination’ was, created the impression amongst those in positions of power and the public that leprosy had been eliminated, eradicated or become so marginal that it essentially no longer existed. This was far from the truth.**

Given that after initial infection leprosy can take up to 20 years to manifest itself, it is therefore no surprise that prevalence remains stubbornly high. Over the last decade this has ranged from 210,000 to 249,000 officially reported cases. These official figures are met with a lot of scepticism in the NGO community, as migrants are often not recorded and nor are those treated privately, which is thought to be a significant number, especially in the ‘top two’ countries of India and Brazil. **This matters.**

Leprosy is not very infectious and indeed about 95% of people appear to be immune, but leprosy can result in disability and blindness as peripheral nerves become desensitised and feeling is lost. This is often the result of an immuno-reaction to the disease which can occur before, during and after treatment. So, leprosy is not just a problem of disease, but has potential sequelae of serious disabilities amongst some of the people affected.

The WHO declaration did not define what elimination as a public health problem meant. Yet it is widely accepted that there are currently 3 - 4 million people disabled as a result of leprosy, which by any measure is a significant global public health burden. Yet very little attention has ever been given to disability care, disability management, and provision of pensions and benefits.

Furthermore, an astonishing 50% of leprosy patients develop clinical mental health issues such as anxiety and depression. **This year the WHO brought out new treatment guidelines, and within them there is no advice on these public health matters. So, while there is an effective multidrug treatment available to treat leprosy, there is little but NGO actions to manage the morbidity and disabilities that make leprosy such a tragic disease.**

The tragedy of leprosy does not stop there. If one realises that leprosy funding has been cut, equal access to disability benefits denied, employment curtailed and, in many places, divorce and denial of public services such as transport legitimised, then this is a major concern. Added to this, leprosy has been removed from medical and health curricula and there has been a wholesale loss of skills to clinically and accurately diagnose leprosy. **Surely we have to ask why?**

One of the world’s largest donors admitted that it was because it was a disease that can be incubated for two decades, spread for years and so did not promise an overnight ‘magic bullet’ glorious PR success. Frankly, leprosy is not ‘low-hanging fruit’, and dealing with the disabilities and mental health aspects is not an attractive or simple ‘ask’.

Other diseases may be seen as ‘easier wins’ or have more public support as they are more prevalent in the West. Yet, in reality, giving more resources would make a massive difference to leprosy and those affected by it. There is no other way to beat leprosy than to actively seek and identify those with it, treat them and thus stop the disease spreading.

Excerpts - Health Europa, Special Feature: Infectious Diseases. Qly 08; 14 Jan 2019. www.healtheuropa.eu

9

“No post-elimination policy was envisaged and implemented”

. . . . not much proactive steps have been taken in the past few years . . . .

Abhiruchi Galhotra et al
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We delve into the reasons for this raging persistent enigma; some which might be:

1. The term ‘Elimination’ leads to confusion with ‘Eradication’ among the general public and even in the medical profession. **The leprosy eradication from community appears to have been equated with reaching of the WHO-defined target of elimination as a public health problem, which India reached by the end of 2005.** It was assumed that at this prevalence the disease will disappear from the community.
2. The elimination of leprosy was used as an interim goal to create interest in the neglected disease and raise funds globally. The experts suggest that the meaning of this milestone was not clearly communicated to political leaders. Even today, both Indian and international media often cover the issue while using “leprosy free” as a synonym for “elimination.”
3. The epidemiological definition that is used for the programme purpose is different from the clinical definition. Relapse cannot be considered a new case by epidemiological definition because the patient has been treated before, if re-registered for treatment as a new case.
4. Disability rates in new cases are high. The probable reasons for the rise in disability maybe a delay in the diagnosis of leprosy and lepra reactions that lead to persistent neuritis & ultimately to disability.
5. After the attainment of the elimination status of <1/10,000 in 2005, the vertical NLEP program was integrated with the general health services. The focus of the programme got diverted. **No proper post-elimination policy was envisaged and implemented. A surveillance system should have been in place under the program for quick detection and treatment of new cases to halt transmission of infection in the community.**
6. False sense of security among the health care workers and the public regarding the elimination of the disease. This has created a perception that the disease has been eliminated, and this disease is neither kept as a probable diagnosis nor reported. The skilled manpower, which was instrumental in the 2005 declaration, is non-existent / declining and no refresher training of MPHWs or even doctors exists as of today.
7. Research on leprosy, especially the enigma of its mechanism of transmission, its incubation period, and the effectiveness of MDT among the children is hardly emphasized upon.
8. Leprosy affects the most underserved population; thereby the emerging spread is away from public gaze and governments’ attention. Social banishment adds to the stigma and various heresies regarding the disfigurement and forces patients to seek care in the alternative systems of medicine.
9. Leprosy is primarily a disease of the skin and nerves. Generally, the first lesion to appear is a skin patch and patients often seek help or are referred to dermatologists who are very few in India.
10. Political and financial commitment is declining, and not much proactive steps have been taken in the past few years.
11. Though drug resistance in leprosy is slowly but worrisomely emerging, there is no evidence-based alternative regimen to tackle the problem of drug resistance or for the patients suffering adverse effects of the MDT drugs.

There is a need for a clear cut strategy and an implementation plan to address the problem. Leprosy control requires a multipronged approach towards addressing all aspects.

Excerpts - Leprosy–A raging persistent enigma. J Family Med Prim Care. 2019;8:1863-6

10

“WHO should pass a resolution that leprosy has not been eliminated”

. . . . as the last mile is always the hardest to go, a fresh debate is highly desirable . . . .

Sunil Dogra et al

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It was assumed that MDT would reduce the transmission of M. leprae through a reduction in the number of contagious individuals in the community, but unfortunately there is no convincing evidence for this hypothesis. MDT is also not a perfect tool and it has its shortcomings like poor compliance, long duration of treatment, irregular treatment, minor and sometime serious side effects, rifampicin / multidrug resistance, high relapse rate. All these can have serious implications when we consider the large number of leprosy cases in India. We need to be vigilant and see that the disease does not reappear in the community.

The combination of biological and epidemiological evidence suggests that the leprosy cannot be eliminated by MDT alone. There is an excellent opportunity to improve the compliance to current MDT by ensuring regular intake of MDT amongst leprosy-affected persons through ASHAs at the field level. **Counselling of the patients by the healthcare staff in relation to the disease and its management such as course of the disease, transmissibility of infection, side-effects of the drugs and self-care advice at the time of registration, during treatment and discharge from the treatment should also be stressed upon for better outcome.**

Research addressing the role of transmission is essential to narrow down the uncertainty regarding the impact of MDT-based control. Some people are of the opinion that leprosy should be grouped under the chronic stable diseases that are being successfully controlled. This disheartening scenario has led many to consider the alternative to elimination or the concept of “living with leprosy” but rendering it harmless.

Recognizing the high cost and apparent futility of elimination campaigns in the most highly leprosy-endemic regions of the world, this approach calls for improved tools for management of the infection and its complications and better methods for the prevention and treatment of nerve injury.

Both of these paradigms, as well as the tension between these, reflect the continuing challenges of leprosy. **The evaluation report by Global Alliance to Eliminate Leprosy recommended that the WHO should pass a resolution that makes it clear to the world that leprosy has not been eliminated.**

Eradication of leprosy may be a politically desirable aspiration but the scientific case for such a strategy cannot be justified at the moment. Major research advances in developing new diagnostic and epidemiologic tools, chemoprophylactic regimens and vaccine are needed to develop an eradication strategy.

As the last mile is always the hardest to go, a fresh and future-oriented debate about sustainability is highly desirable at this point in the campaign against this disease. This is a major challenge for leprosy having changed from a well-supported, high priority specialized programme to one that is now mainly integrated within general health and social services.

Radical re-thinking is necessary if we want to sustain early case detection, treatment, prevention of disability, and reduction in the consequences of leprosy including stigma. Anti-leprosy work keeps aiming at rapidly pushing the disease further and further back. Thus, in this context sustaining exactly the same efforts as in the past is not enough and future success will depend on changing familiar patterns and approaches, keeping in mind the resources needed

Excerpts - Leprosy - evolution of the path to eradication. Indian J Med Res 2013;137:15-35

11

"Case detection has flawed as proxy indicator for incidence rates"

. . . . requires a fresh look at policies and strategies for leprosy control . . . .

Jan Visschedijk et al

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Though M. leprae was one of the first microorganisms directly associated with a specific disease, large gaps still exist in our knowledge (WHO 1998a). This applies not only to the pathology and immunology, but also to crucial epidemiological aspects. A simplified model of the transmission of M. leprae, indicating that infection does not necessarily lead to any symptom or lesion specific for the disease leprosy.

In fact, it is assumed that M.leprae is not very pathogenic and that most infections do not result in symptoms. Early symptoms of leprosy can be self limiting and skin lesions can heal spontaneously. Individuals who suffer from the disease, particularly those with MB leprosy, are sources for spread of the infection.

The most important port of entry and exit of M.leprae is the respiratory system, particularly the nose; its dissemination through skin lesions seems to be less important. But what happens to those who are infected but do not develop the disease? Do some of them become carriers? And if so, are they an important source in the transmission of the M. leprae?

Recently, a lively debate has emerged on the significance of the trends in registered prevalence and case detection rates for the epidemiology of leprosy in general and the transmission of M. leprae in particular. Case detection is substantially flawed in functioning as proxy indicators for incidence rates.

In principle, incidence is a better measure for monitoring of trends in transmission. However, virtually no information on incidence rates exists. Case detection rates (all new cases annually registered in health facilities) are substantially flawed in functioning as proxy indicators for incidence rates.

Firstly, not all cases detected are in actual fact recent new cases. Some ostensibly new cases may already have suffered from leprosy for several years, but for various reasons (stigma, inaccessibility of health services, opportunity costs) not visited a health facility. They constitute the so-called hidden 'backlog' of leprosy cases. Defaulting & re-registering ('shopping'), as well as relapses may also inflate the figures for 'new' cases detected. Secondly, detection of new cases depends on the method and intensity of case finding.

Presently, there is no basis for confidence that the incidence and the number of new leprosy patients detected annually will have been substantially reduced in all currently endemic areas after the year 2005, let alone be zero. Hence, leprosy control activities should not be exclusively directed towards a magic target but towards sustainable leprosy control, far into the new millennium. This requires new strategies, rather than questionable assumptions.

Only when, through further research, the gaps in our knowledge of leprosy transmission and epidemiology are closed, long-term strategies for 'real' elimination can be established. Currently, however, the changing circumstances, such as a decreasing registered prevalence, health sector reforms, a diminished commitment and scarcity of resources, require a fresh look at policies and strategies for leprosy control. Such a revision requires an active position by decision-makers, because attempting to carry on as usual is doomed to lead to the evaporation of leprosy control.

Excerpts from article titled - "Review: Mycobacterium leprae – millennium resistant! Leprosy control on the threshold of a new era". Tropical Medicine and International Health; Volume 5; No. 6; 388–399; June 2000

12

“Epidemiological pattern of a waning disease is likely to rise further”

. . . . call for an increased efforts to infuse new vigor in the programme . . . .

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WHO “Global leprosy strategy 2016–2020: Accelerating towards a leprosy-free world” proposes to build on the momentum created in leprosy control at the global and local level. Three key targets were defined (i) zero grade 2 disabilities among children diagnosed with leprosy; (ii) the reduction of new leprosy cases with grade 2 disability to <1 case/million population and (iii) zero countries with legislation allowing discrimination on the basis of leprosy.

These are impressive and well-intentioned targets although they appear too ambitious and difficult to achieve in the next 5 years. **Other goals mentioned include promoting early case detection through active case-finding campaigns in areas of high endemicity, strengthening surveillance for antimicrobial resistance including laboratory networks and taking steps to stop discrimination and promote inclusion of leprosy by society at large.**

These are laudable targets and goals. However, there are areas of concern which need to be considered while proceeding with this action proposal. In this regard, let us first look at the latest global leprosy figures. Southeast Asian region accounts for 74% of the global new case load with India contributing more than 60%.

It is important to note that the global leprosy figures for the year 2014 only encompass annual leprosy statistics received by WHO from 136 countries and does not include leprosy statistics of 92 countries or territories of the world, including 26 African countries, from where no reports were received. **Global leprosy planners need to take these unaccounted leprosy numbers, apart from hidden leprosy cases in high endemic and difficult-to-reach pockets of countries like India into consideration while implementing its strategy**.

Even in the Southeast Asian region, new cases with grade 2 disability showed an increase from 5791 new cases in 2005 to 8572 for the year 2014. These call for increased efforts to infuse new vigor into the program to detect and treat leprosy early, especially in children and those with reactions.

Although there are matters and issues that need attention and renewed focus, by and large, the state of global leprosy program has been healthy. At this stage, it is important to consolidate the gains already made rather than embark on new adventurous modifications in the program based on specious logic and poor evidence. Further, shortening of the duration of MDT is one such endeavor, considered by many to be detrimental to the program. At present, MB patients constitute 60.2% of new cases detected globally, and the current 12-month MB-MDT is a robust regimen proven to treat MB leprosy effectively.

With continued reduction in global leprosy numbers, the reason for shortening duration cannot be budgetary constraints. In addition, there are no valid scientific or administrative reasons to shorten the duration of therapy for MB leprosy by 6 months. **While global leprosy numbers dwindle, the % of MB leprosy cases, a proportion of whom with high initial bacterial load, is likely to rise further in coming years as is expected in the epidemiologic pattern of a waning disease.**

In addition, it should also carefully consider whether there is a real need for shortening the duration of therapy for MB leprosy by half when the existing MDT program has proven to be robust and effective in bringing down the burden of disease globally.

Excerpts - Global leprosy strategy 2016–2020: Issues and concerns. Indian J Dermatol Venereol Leprol 2017;83:4-6.

13

"Leprosy disproportionately affecting the indigenous community"

. . . . what is non-endemic today may turn out to be endemic tomorrow . . . .

Sophie Cousins
Technical consultant for the WHO's South-East Asia Regional Office, New Delhi, India

Today, India accounts for 60% of the global burden of the disease worldwide. In 2016–17, there were 135,485 leprosy cases detected, according to NLEP. That translates to a prevalence of 0·66 per 100,000 people. However, experts believe that this is an underestimation of the true number of cases. A sample survey conducted by the ICMR between 2008 and 2011 found there could be as many as 250,000 new cases of leprosy in India each year. **In stark contrast to the official announcement 13 years ago, India's National Health Policy 2017—set elimination of leprosy as a "national target". It states that the policy "envisages proactive measures targeted towards elimination of leprosy from India by 2018".**

"In 2005, while we were applauding ourselves, we did not look deep enough to see the regional variations. That, in itself, should have given us a pointer that this problem was far from over", said Vineeta Shanker, executive director of the Sasakawa India Leprosy Foundation, an organization that focuses on creating economic opportunities for leprosy-affected people. **"The government is in a state of denial about the levels of leprosy in the country", she said. Experts argue that the "forced elimination" of leprosy in 2005 diminished the country's ability to fight the disease and that the rhetoric led people to believe it no longer existed.** "In our enthusiasm to announce elimination, the government moved leprosy to our public health programme rather than to have a focused mission—a vertical mission—to tackle it", Shanker said. "Unfortunately, what this move did was dilute efforts on the ground. Suddenly, this huge force of people who are trained experts in identifying leprosy were lost. It went down in the government's priorities."

Mary Verghese, executive director of The Leprosy Mission Trust India, the largest organisation focused on the disease in the country, said that after elimination was declared the country moved to voluntary case reporting. As a result, between 2004 and 2007, research shows new case detection dropped by 75%. "Everyone thought leprosy was no longer there, so there was a reduction in resources and funding available", she said.

Oommen C Kurian, a public health fellow at the Observer Research Foundation, has found that, even more so today, leprosy remains a disease of the most marginalised and underserved populations in far-flung areas.

India's leprosy burden is disproportionally affecting the country's indigenous communities—known as Adivasis— which constitute 8·6% of the population, he found. In 2009, Adivasis accounted for 13·3% of new cases; in 2017, that proportion rose to 18·8%. In states like Gujarat and Tripura two-thirds of new patients with leprosy are Adivasis. In addition, Kurian found that the number of districts across India with a prevalence greater than one per 10 000 had increased to 18·8% in 2017 from 15·3% in 2012. "More than 18% of districts [across India] have prevalence above the elimination target and it is increasing rapidly. We are far from elimination at the state and district level", he said.

"No one [in the tribal areas] knows about leprosy. They are not getting treated so there is potential for it to spread", Shanker said. **"We could be successful in bringing down the prevalence level to an insignificant level but a concentrated effort needs to be made across the whole country. Today we can focus on endemic areas, but what is non-endemic today may turn out to be endemic tomorrow. Without mass awareness, it will not happen", Verghese said.**

Excerpts - Experts fear a resurgence of leprosy in India.
www.thelancet.com Vol 392 August 25, 2018

14

“Prospect of elimination has discouraged the research in leprosy”

. . . . approach to elimination should be thoroughly professional and scientific . . . .

Binod K Patro et al
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International Task Force for Disease Eradication evaluated over 90 potential diseases based on these criteria and concluded that only six were eradicable in which leprosy is not included. This questions the rationale of naming our national programme as ‘National Leprosy Eradication Programme’. It seems that the social and political considerations have taken an upper hand for such a declaration.

The terminology reflected in World Health Assembly (WHA) resolutions ‘Elimination of a disease as a public health problem’ creates further confusion. It seems to be a middle path approach between control and elimination of diseases can be best considered as intensified control.

In case of leprosy, elimination efforts were directed to control the diseases rather than infection, by using prevalence instead of incidence of disease. **It appears that people, including health planners and those who fund health care, have not understood the concept of elimination, thinking instead that it means an absence of cases. Though the target of leprosy elimination was achieved at national level in 2006, a large proportion of leprosy cases reported globally still come from India.**

In 2009, of the 244,796 new cases reported globally, 133,717 were detected in India. Among them more than 10% were children which strongly indicate that active transmission is occurring. The reduction in registered prevalence is clearly not based only on a declining incidence, and can be explained by the shortening of treatment duration and cleaning of the registers.

The combination of biological and epidemiological evidence suggests that the leprosy cannot be eliminated by MDT alone as the microbiology of leprosy is still not fully elucidated. Leprosy should be grouped under the chronic stable diseases that are being successfully controlled.

Though the WHO elimination goal created enthusiasm and optimism which galvanized people to work efficiently against the disease, it seems that, actually now, they are hiding the reality. **In fact, the prospect of elimination has also discouraged the research in the field which is the need of the hour.**

Eradication of leprosy may be a politically desirable aspiration but the scientific case for such a strategy cannot be justified at the moment. Major research advances in developing new diagnostic and epidemiologic tools, chemoprophylactic regimens and vaccine are needed to develop an eradication strategy. It might be more productive to work towards overcoming our knowledge gaps with regard to leprosy microbiology and therapy.

The current reality is that there is a need to sustain and provide quality leprosy services to all persons through general health system, including good referral system. Efforts need to be made to reduce deformity through early detection, self care, physiotherapy and reconstructive surgery and developing sound surveillance systems.

The decision regarding declaration of strategies pertaining to eradication, elimination or control of a disease should be left to scientific scrutiny and techno-managerial considerations. The approach should be thoroughly professional and scientific. Only political spicing or value addition in the form of “a strong political will” or “political commitment” may be desirable.

Excerpts - Is leprosy ‘Elimination’ a conceptual illusion?
Indian J Dermatol Venereol Leprol. 2011;77:549-51

B Reducing disease burden *: views that matter*

Page

III. Reducing disease burden : strategies and best practices

IV. Reducing disease burden : new approaches and recommendations

15

“Suspects fail to report for diagnosis and many leprosy cases missed”

. . . moving towards a ‘double’ approach - active screening & routine passive detection . . . .

Laura Gillini et al

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From the interviews conducted, it was clear that health care workers at all levels agreed that the campaigns raised awareness about leprosy and facilitated the diagnosis of new cases. They have also contributed to bringing back into care some patients that had abandoned treatment. The involvement of people affected among the volunteers was reported as a key factor in the success of the campaigns, as well as the involvement of health care workers from central, district and primary health care levels, and NGOs. **However, an important proportion of individuals suspected of having leprosy did not report to the health facility for diagnostic confirmation. Systems to reduce the loss to followup during referral need to be introduced to ensure detection of all leprosy cases in the community actively screened.**

Another consideration to be made is related to the relatively high cost of the campaigns against patients diagnosed that might suggest the possibility of integrated campaigns. Even in countries with higher case notification rates compared to Nepal such as Brazil, active screening campaigns for leprosy are carried out as combined efforts with other neglected tropical diseases. **Detection of TB along with leprosy could also be considered, especially since now TB control is also increasingly moving towards a “double approach” having active screening activities in high risk areas / populations in addition to 'routine' passive detection.** Nepal could consider campaigns that search for both leprosy and TB in the light of the already existing integrated leprosy / TB services delivery model.

Worldwide, several projects funded under the umbrella of the Bangkok Declaration Special Fund have contributed to the organization of active screening campaigns in several countries, e.g. Bangladesh, Democratic Republic of the Congo and Sri Lanka. In addition several 'experimental' active screening modalities have been implemented in other countries, for example in India since 2016. Although such projects were successful, outcomes or challenges faced are yet to be documented by publications in peer-reviewed journals, unlike the experience of the elimination campaigns conducted in pre-elimination era. This report is to our knowledge the first that describes outcomes and challenges of a leprosy campaign carried out under the Global Leprosy Strategy 2016–2020.

The Global Leprosy Programme's active role in monitoring this experience in partnership with its main donors (The Nippon Foundation, SMHF led to the documentation of the experience of Nepal which is one of the 22 global priority countries for leprosy, as classified in 2016. The Nepal experience highlights the fact that many cases of leprosy are still being 'missed' under passive detection modalities so that active detection methods should be considered.

When organizing active case detection campaigns, there is a need to develop tools to ensure adequate monitoring of such campaigns in addition to what is elaborated in the Monitoring and Evaluation Guide to the Global Leprosy Strategy 2016–2020. Those tools should include monitoring of the proportion of people with suspected diseases that access care services for diagnostic confirmation. Also, considerations of cost-benefit and the possibility of integrated campaigns could be explored, even in high burden countries, to reduce costs and enhance public health benefits.

Excerpts - Implementing the Global Leprosy Strategy 2016–2020 in Nepal: lessons learnt from active case detection campaigns. Lepr Rev (2018) 89, 77–82

16

“Alternate ways of screening & assessing contacts based on risk factors”

. . . . need for long-term surveillance of households contacts in the community . . . .

Ruth Butlin et al
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Home visits for active case finding through household contact examinations (HCEs) are an expensive activity. In the area studied it takes about 1 hour to conduct a complete household examination, with mean household size of 4.1 excluding index case, and this may be similar in other countries.

The time taken to travel to and from the home will vary from place to place according to density of population, road conditions and allocated geographical area. If the cost of undertaking home visits for all new cases is prohibitive, alternative ways of assessing contacts will be needed (including well-informed self-examination).

Alternatively, programmes could target HH contact examinations based on specific risk factors of index cases ie. MB / smear positive. Whether the work entailed in doing more than 30 household visits to find a single new case (which might amount to equivalent of one week's work for one health worker) is justified is a subjective decision.

It can be made only after considering the other uses which might have been made of that particular staff's time (which might be disability care for leprosy-affected people, or active case finding of Tuberculosis cases or other primary health care tasks). However, where the index case is in the MB group, it is clear that time spent on HCEs, will be approximately three times more productive in terms of new case detection, compared with time spent on HCEs of PB index households.

It is also noteworthy that the single most productive household contact examination is the first, at year zero, as new case detection rate is highest at that time point (compared with any subsequent examination) especially in PB index households. In MB index households the fall off in NCDR is slower. **Education about leprosy given at that first visit may facilitate subsequent voluntary reporting by contacts with early signs of disease.**

Not many leprosy control projects have reported on very long-term surveillance of household contacts in the community, nor do tertiary centres which follow up cases long after release from treatment usually undertake sequential contact examinations beyond 2 – 5 years.

Extending the routine surveillance periods of annual HCEs beyond the currently recommended 2 and 5 years for households of all index cases is unlikely to be a productive use of staff time. Although some new cases occur late, they are not enough to justify extending the recommended periods of active case finding. The largest number of new cases will be found in early years after index case diagnosis, so annual contact examinations by trained staff should not be continued indefinitely.The number of new cases detected might be increased without any increase in workload, though there would be the potential for a greater delay in diagnosis for some contacts.

Considering the cost involved, managers may direct staff to give first priority to undertaking an initial household contact examinations of MB/smear positive index households. Then, as second priority, to undertake one more examination of MB household contacts after 12 or 24 months and only as third priority to do a single initial household examination soon after diagnosis of each PB index case.

Excerpts - Outcome of late healthy household contact examinations in leprosy-affected households in Bangladesh. Lepr Rev (2019) 90, 305–320

17

“State to prioritize the ‘hot spots’ for better targeted intervention”

. . . . districts or pockets within district could be the actual zone of leprosy cases . . . .

Dhananjay Karkar et al
Consultant, National Leprosy Eradication Programme, Maharashtra, India

Population level elimination strategies highlights the high endemicity district and block approach for the intervention of leprosy. Despite, government programme implementation plan allocating funds to those districts with high PR and trend of PR is stagnant, attributed to the failure of optimum utilization of health care facilities and less focus on actual high risk belts and hot-spot area within the district or state. A two-way priority intervention (district and block) is not sufficient for control and elimination of leprosy.

It is found that very few districts within the state or very few pockets within the district could be the actual zone of the leprosy cases, which need to specific attention to achieve the national target of eradication by 2018. This paper will focus on “high risk pockets” and “tribal hot-spot” in the districts of Maharashtra. 8 years (2008–2015) leprosy data of all 34 districts was obtained and were divided into 2: Tribal and non-tribal and analysis of actual tribal area within districts were done.

Analysis indicates that within the tribal district, those areas are predominantly tribal belts with PR per 10,000 population ranging from 0.5 to 4.5 exceeding the overall PR of districts (0.5–3.5 per 10,000 population). **The highest PR for the overall district is 3.5 while the highest PR for the actual tribal area within the tribal district is 4.5 per 10,000 population.**

PR was found more in Vidharbha region than rest of Maharashtra that may be attributed to lack of health care facilities, skills among health care workers to identify leprosy cases, infection prone area, challenging geographic and tribal areas. **Overall PR of leprosy in actual tribal area is more (2.25 per 10,000 population) as compared to the tribal district (1.66 per 10,000 population). Thus the burden of leprosy is more in the tribal area within tribal district.**

The average ANCDR of actual tribal area shows high number of cases (32 per 100,000 population) as compared to overall district average ANCDR (24 per 100,000 population). Female cases, grade 2 disability cases and all other types of leprosy burden are found within actual tribal area eventually, indicating need of more programmatic focus on actual tribal area's within tribal district for overall control of leprosy burden.

Eventually, it is the responsibility of the state to prioritize these “hot spots” within the state / districts for better targeted intervention. PR at district level might be remain constant for consecutive years but actual case load at ground level varies from state to state, district to district, within district, region to region attributed to; disparities in newly diagnosed cases, tribal, non-tribal, gender-wise, urban-rural area-wise, migration-wise, MB cases etc.

Maharashtra is very much close to achieving the target and for that even a single new case with grade 2 disability / new child / female cases should be treated as evidence of hidden endemicity in tribal belt. Once tribal area of that respective PHC reported zero cases then continuous and sustaining efforts for identification of new cases should be done for at least five consecutive years. So that area / PHC can be called as “Leprosy free zone.”

NLEP should focus on tribal belt for effective control. Without giving extra attention to these tribal areas within high risk district / pockets efforts of eradication of leprosy by 2018 would be unrealistic & impractical.

Excerpts - Epidemiological perspective of National Leprosy Eradication Programme in Maharashtra: Focusing on “Tribal Hot-spot” of Tribal District. Indian J Community Med 2017;42:174-6

18

“Stigma towards leprosy remains despite availability of cure”

. . . . fear of isolation was a strong predictor for delay in diagnosis . . . .

Mary Henry et al

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Brazil contributed 33,955 new cases in 2011, 16% of all new registered global cases, second only to India. In order to break the cycle of transmission and reduce the number of new cases detected with physical deformity, it is essential to diagnose and treat patients early, before these injuries occur. However, significant delays in diagnosis of leprosy have been reported in Brazil. These delays of up to 10 years, are unexpectedly even longer than those observed in some non-endemic countries.

The only study found in the literature search which explored reasons for the delay in diagnosis in Brazil, yielded no significant results and was limited to a small sample size of 40 participants; leaving much further need for research in this area. We therefore conducted our study with the aim of exploring factors that contribute to the overall delay in diagnosis of leprosy.

Such factors can be divided into two categories: **those contributing to ‘patient delay’ (defined as the time between symptom onset and patients consulting a medical doctor) and those contributing to ‘health-system delay’ (defined as the time between first consulting a medical doctor and receiving a diagnosis of leprosy).**

Our study aimed to explore patient and health system delays separately; interested in identifying whether the delay in diagnosis of leprosy is associated with patients not presenting to the health service early enough or whether diagnosis is being delayed by the health service itself.

The findings indicate that stigma towards leprosy sufferers remains despite the availability of a cure, even in endemic regions. Fear of isolation was a strong predictor of longer patient delay, implying that community isolation still exists in Brazil, despite compulsory confinement ending in 1962. Some patients seem to conceal their symptoms and delay in seeking treatment due to fear of social exclusion. Yet only 8.2% of participants delayed due to the fear of isolation. This is likely due to governmental efforts to abolish this stigma; by integrating leprosy care into primary care and changing its name from leprosy to Hansen’s disease.

Many patients appear to still be ignorant regarding leprosy symptoms. Nearly half of the participants (45.1%) waited before consulting a doctor because they did not believe their symptoms were serious. This was supported by the observation that 68.9% of participants consulted a doctor because their symptoms either persisted or worsened.

Participants (44.5%) commonly reported being misdiagnosed with conditions such as rheumatism and skin allergy. This possible lack in clinician suspicion could be explained by the decentralisation of leprosy care in Brazil.

In conclusion, this study highlights the potential need for further patient education regarding disease symptoms and the reduction of stigma to encourage patients to seek earlier medical care. Need for greater education of primary care clinicians with regards to leprosy symptoms. Exploring primary care clinicians’ knowledge of disease symptoms and trialling educational tools could assist in reducing the delay in diagnosis and continued transmission of leprosy.

Excerpts - Factors Contributing to the Delay in Diagnosis and Continued Transmission of Leprosy in Brazil – An Explorative, Quantitative, Questionnaire Based Study. PLoS Negl Trop Dis 10(3): e0004542.

19

“Presence of AFB - forgetting the cardinal sign is a cardinal sin”

. . . . skin smear test remains a gold standard for the diagnosis of infectious leprosy . . . .

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Role of Slit-skin Smear in diagnosis of Leprosy

The WHO (1981) classified leprosy as MB or PB on the basis of Slit-skin Smear (SSS) positivity, in which patients with a bacteriological index (BI) of more than 2 were treated as MB and the rest as PB.

The WHO in 1988 simplified the leprosy classification and included all smear-positive cases in the MB group and all smear-negative cases in the PB group. However, with the development of a highly simplified operational classification of leprosy as PB or MB based on the number of skin lesions and nerves involved, SSS is no longer mandatory for the diagnosis of leprosy in leprosy control programs.

Sensitivity and Specificity of Slit-skin Smear

SSS has a low sensitivity (10%–50% depending on the expertise of the laboratory workers), but it is highly specific (100%). Because SSS depends on the bacterial load, it is highly sensitive in the diagnosis of lepromatous (LL and BL), and histoid leprosy, but its sensitivity is low at the tuberculoid end (TT and BT).

Frequency of SSS test during and after MDT:

Ideally, all patients should have one SSS examination before the start of MDT to decide whether to give PB or MB treatment. With fixed duration treatment regimens, SSS is not needed either to stop treatment or to follow-up the patients after completion of MDT.

Limitations of SSS test:

Because the sensitivity of SSS is low toward the tuberculoid pole, PB cases of leprosy can be missed. It must be remembered that a negative smear does not exclude leprosy. It requires a minimum of 10,000 bacilli / gm of tissue for reliable detection of acid fast bacilli (AFB) by Ziehl Neelsen staining method. Smears may be negative in PB leprosy lesions where M.leprae are scantly present. It is a technician -dependent test and depends on training of the staff.

Relevance of SSS test in the current Era:

Despite the announcement of leprosy elimination in India, new cases of leprosy are being reported regularly from different parts of the country. **Hence, the role of SSS cannot be undermined despite its various limitations and it remains a gold standard for the diagnosis of leprosy until newer, more sensitive diagnostic tools such as polymerase chain reaction (PCR) become available for routine testing.** It is useful in the diagnosis of MB cases and thereby treat them adequately. SSS also helps determine the prognosis of lepra reactions (common in patients with high BI) and to differentiate relapse versus reaction cases.

Excerpts - Forgetting the cardinal sign is a cardinal sin: Slit-skin smear. Indian J Paediatr Dermatol. 2019; 20:341-4.

Is SSS test an essential part of NLEP?

“If there are suspicious signs such as nodules or swelling on the face or earlobes, redness or infiltration in the patch, it is important to do a skin smear to confirm the diagnosis of leprosy”

Where SSS test is to be done?

“Community Health Centre (CHC) and District Hospital (DH) ‘to do skin smear examination for AFB from suspected LL cases and relapse cases”

Who is responsible to do SSS test?

“Medical Officer in charge of CHC / DH supported by Paramedical Worker of NLEP / Health Supervisor of PHC is responsible to do skin smear examination.”

Source: NLEP, Disability Prevention and Medical Rehabilitation (DPMR), Operational Guidelines for Primary, Secondary and Tertiary level centre (2012). Ministry of Health & Family Welfare, India

20

"Slit skin smear : a simple dependable test abandoned altogether"

. . . . possible to achieve good quality skin smear at peripheral field laboratories . . . .

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A valuable investigation in leprosy is the examination of skin smears. Being a very simple technique, it can be performed satisfactorily in the field. Unfortunately, it is being given up because the reports from several field laboratories were not found to be dependable, in the sense that they would not match with the clinical diagnosis. If so, it is necessary to find out the causes for such an unsatisfactory performance of the field laboratories. There could be many causes for such a mismatching, pertaining to several operational factors and skills of the field staff. Such defects could be countered essentially by three steps, (a) training the technician properly, (b) providing minimal facilities, proper reagents and a good microscope, (c) supervision by a periodic cross-checking of the reports.

In all the field laboratories of LEPRA-India enough attention has been paid to the first two steps Supervision by cross-checking of randomly selected slides is carried by an experienced senior technician in the central laboratory. By these means, a field laboratory is well managed and best utilized. The present report proves that by very minimal supervision, and periodic cross-checking, it is possible to achieve good quality and dependable skin smear reports at the peripheral field laboratories.

It was found that out of 36,662 smears cross checked, there was a good concurrence of field laboratory reports with those of the reference laboratory, giving a positive predictive value of 87·7% and negative predictive value of 99·4%. There was a very small degree of under-rating or over-rating. The field laboratories reported a slightly higher rate of positivity.

In conclusion, it can be stated that by following the above suggestions and taking necessary corrective measures, satisfactory and dependable reports can be obtained from very simple field laboratories. The methods suggested for good performance are simple, feasible and cost effective. If sites of smears are not properly selected, it would lead to wrong reports. There can be defects in the preparation of smears if the paramedical worker is not properly trained. **One cannot ignore the fact that the clinical diagnosis can itself be undependable because it is often made by a poorly trained doctor for which the smear report cannot be blamed. All the same, the importance of skin smear examination cannot be underrated.** It is for the programme officers to find out ways and means of utilizing this useful investigation to the extent possible instead of abandoning it all together.

Excerpts - Appraisal of skin smear reports of field laboratories. Lepr Rev (2006) 77, 311–316

Slit Skin Smear examination (NLEP, 2009) : If there is no objective / demonstrable loss of sensation in the skin lesions and no palpably enlarged nerves, but there are suspicious signs, such as diffuse infiltration of the skin, papules and / or nodules on the earlobes, face, back and limbs, it is important to get a slit skin smear test done. A positive skin smear confirms the diagnosis of Leprosy (the third "Cardinal Sign").

Indications for slit skin smear examination:

1. Diffuse infiltration without any sensory impairment or with vague sensory impairment.
2. Innumerable bilaterally symmetrical ill defined macular lesions without any sensory impairment or with vague sensory impairment.
3. Papules, plaques or nodules on the earlobes, face, back and extensor surface of the limbs without any or with vague sensory impairment.
4. Clinical situations where it is unclear whether the person is suffering from PB or MB Leprosy.
5. Person presenting with fresh lesions after release from treatment.

21

"Uniform-MDT can jeopardize the leprosy control programme"

. . . . no valid scientific reason to shorten the duration of MDT for MB leprosy . . . .

P Narashima Rao et al

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WHO is planning to push for implementation of Uniform-MDT globally as a key strategy for the years 2016–2020. It would bring radical change in the duration of therapy for MB leprosy as it reduces the duration of MDT MB regimen by half (6 months). Many leprosy workers in India are apprehensive and distraught about the long-term consequences of implementation of 6-month U-MDT for MB leprosy patients. Many strongly believe that U-MDT in the present form can jeopardize the leprosy program that is already beleaguered due to various administrative reasons.

The WHO open multicenter, non-comparative trial only considered "clinical response" and "cumulative relapse rate at 5 years" as basis for assessment. Neither slit skin smear nor histology was included as parameters for assessing the response. The U-MDT was found ineffective for MB leprosy when it was compared with 12 months WHO MDT-MB where clinical, bacteriological, and histopathological parameters were included.

An open comparative study between WHO MDT and U-MDT regimen with follow-up of 24 months carried out in India concluded that based on clinical, bacteriological, and histopathological parameters, **U-MDT of 6 months duration was effective in PB leprosy but was too short a regimen to adequately treat MB leprosy patients. Other studies too did not find U-MDT superior to 12 months WHO MDT-MB.**

The current 12 months WHO MDT-MB regimen practiced globally is a robust and proven regimen to treat MB leprosy and has been effective in bringing down the leprosy burden substantially world over. Both health care providers and receivers are happy with the present 12-month WHO MDT-MB and as such there is no valid scientific reason or evidence to shorten duration of therapy for MB leprosy by 6 months. With the continued reduction in leprosy cases globally, the reason for shortening the duration cannot be budgetary constraints as well. Based on the limited studies reported so far, the 6 months U-MDT is a good regimen for PB leprosy, but such shorter course was found inadequate for MB leprosy, and it is definitely not superior to presently used 12-month WHO MDT-MB regimen.

Many leprosy workers in India and elsewhere strongly feel that it should not be implemented in the present form until there is substantial evidence of its superiority over the present 12 months MDT MB regimen both in terms of clinical and bacteriological aspects, and not just in 5 years relapse rates.

In conclusion, it can be stated that there is a paucity of evidence at present to support efficacy of 6-month U-MDT in all types of leprosy over current WHO MDT-regimens.

It is imperative that authorities working on this strategy document should have a re-look on long-term damage such a shortened U-MDT regimen can potentially have on the leprosy program in India and worldwide.

Consequently, WHO should re-evaluate its strategy for the good of leprosy programs worldwide and put in abeyance the proposed implementation of U-MDT for MB leprosy in the present form in its proposed action plan for global strategy for the years 2016–2020, until it is studied and discussed thoroughly for evidence of its superiority over the present robust 12-month WHO-MB MDT regimen.

Excerpts - Global leprosy program: Does it need uniform-multi-drug therapy now? Indian Dermatol Online J 2015;6:425-7.

22

“Future measures that can reduce disease burden due to leprosy”

. . . . programme components that need resources and operational research . . . .

Casandra Chaptini

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CONTACT SURVEILLANCE

The risk of acquiring leprosy for individuals living in households with multibacillary patients is 5–10 times higher, and with paucibacillary patients 2–3 times higher, than in people not living in such households. Unrecognized cases and subclinical infections in contacts contribute a significant proportion of all new leprosy cases. **Hence, if case detection campaigns and mandatory contact tracing programmes were implemented nationally, this would undoubtedly reduce the disease burden.**

IMMUNOPROPHYLAXIS

Ideally, disease control is best obtained by an effective vaccine. BCG vaccine, although imperfect, is used globally, with 85% of the world’s infants receiving it. The protection imparted by BCG against leprosy is highly variable for poorly understood reasons. A meta-analysis showed an overall protective effect of 26% in experimental studies, and of 61% in observational studies. In recent studies it was demonstrated that an additional dose of BCG was more protective compared with a single dose, with protection lasting for decades. It has been proposed that an additional dose of BCG be given for all at risk groups in high endemic areas.

CHEMOPROPHYLAXIS

There is much evidence for the use of chemoprophylaxis in asymptomatic contacts. A meta-analysis of 7 RCTs showed that chemoprophylaxis provided 60% protection against leprosy. Rifampicin has an additive effect to BCG. An RCT showed that individually BCG and rifampicin provided 57% and 58% protection respectively, but the combined strategies had a protective effect of 80%. **If national programmes gave one dose of rifampicin and BCG to asymptomatic contacts, it would prevent many potential cases and reduce ongoing transmission**.

PREVENTING DRUG RESISTANCE

Several reports of rifampicin, dapsone and ofloxacin resistance have been published. If chemoprophylaxis were to be introduced, avoiding drug resistance is imperative, and stringent longitudinal observation is required so that timely measures to combat resistance can be developed. Globally, more and more relapses are being reported. Relapse suggests treatment failure, caused by inadequate or irregular treatment. It is vital to continuously monitor relapse cases in relation to treatment completion and drug resistance in all national programmes.

DISABILITY PREVENTION & REHABILITATION

Even after effective treatment, long-term morbidity and disability is problematic. Up to 60% of patients have peripheral nerve damage at diagnosis. Ongoing education of health care workers and the community is vital to prevent damage to hands, feet and eyes in those with peripheral neuropathy. Appropriate referral is important for acute complications and improved rehabilitation services are needed for those with disability to improve quality of life.

REDUCING LEPROSY STIGMATISATION

The stigma of leprosy is still profound in many communities, and increased awareness is necessary to motivate affected individuals to seek treatment. **It is essential for programmes to foster partnerships with people affected by leprosy.** Increased community participation will aid in operationalising policy formulation and achieving successful policy implementation, to increase case finding, improve treatment adherence, and ultimately prevent disability.

Excerpts - Leprosy: a review on elimination, reducing the disease burden & future research. Lepr Rev (2015) 86, 307–315

23 "No worthwhile data on 3 'pillars' of WHO global strategy on leprosy"

. . . . who is accountable to monitor indicators to guide the national leprosy programmes . . . .

World Health Organization
Regional Office for South-East Asia, World Health House, MG Marg, New Delhi, India

The scope of the M&E Guide is to provide tools for national leprosy programmes (NLPs) to allow monitoring of progress towards the Global Leprosy Strategy 2016–2020 targets. It aims to guide them on remedial actions to be taken if the monitoring indicators point out problems with regard to an effective implementation of the strategy.

Overview of the monitoring indicators:

1. Number of children diagnosed with leprosy and visible deformities (G2D)
2. Rate of newly diagnosed leprosy patients with visible deformities (G2D)
3. Legislation allowing discrimination on basis of leprosy

Pillar 1: Strengthen government ownership, coordination and partnership

- Availability of a costed national plan for leprosy (per se or integrated)
- Number of sub-national jurisdictions with a formal alliance between government programme and other stakeholders
- Availability of web-based, case-based reporting system allowing disaggregation by age, sex, place of residence and other relevant criteria

Pillar 2: Stop leprosy and its complications

Case finding

- New case-detection (number and rate)
- Prevalence (number and rate)
- Proportion of G2D cases among total new cases detected
- Proportion of child cases among total new cases detected (or child new case rate)
- Proportion of female cases among total new cases detected
- Proportion of foreign-born cases among total new cases detected
- Proportion of MB cases among total new cases detected
- Proportion of contacts screened

Case holding

- Number and proportion of re-treatment cases over the total leprosy notified cases
- MDT completion for PB
- MDT completion for MB
- Proportion of patients assessed for disability status at least both at beginning and at end of treatment
- Proportion of patients who have developed new disabilities during the course of treatment
- Number of cases with leprosy reactions during treatment
- Proportion of new patients with disability (G1D and G2D) that have received self-care training
- Proportion of leprosy drug-resistant cases among new and re-treatment cases.

Pillar 3: Stop discrimination and promote inclusion

- Number of formal alliances between association of persons affected by leprosy and the government leprosy programme
- Existence of norms and/or regulations facilitating inclusion of persons affected by leprosy and their communities
- Number sub-national jurisdictions where persons affected by leprosy are involved in leprosy services
- Availability of information on prevalence of social stigma and discrimination
- Use by the programme of participation scale to assess the social participation of persons affected by leprosy.

The WHO-led programme reviews are special activities with specific procedures, a team of external and internal monitors and a budget that can allow to supplement routine monitoring information by in-depth information to answer a range of questions about the programme as a whole using quantitative and qualitative data.

Excerpts - WHO (2017). Global Leprosy Strategy 2016–2020. Accelerating towards a leprosy-free world. Monitoring and Evaluation Guide.

24

“WHO guidelines for diagnosis, treatment and prevention of leprosy”

. . . . lacks evidence of efficacy and feasibility in mass leprosy control programme . . . .

World Health Organization
Global Leprosy Programme. Control of Neglected Tropical Diseases, 20, Avenue Appia 1211 Geneva 27, Switzerland

The purpose of this WHO guidelines is to provide evidence-based recommendations on the diagnosis, treatment and prevention of leprosy, utilizing WHO guideline development methods based on the GRADE (Grading of Recommendations Assessment, Development and Evaluation) process.

Summary of the recommendations:

Diagnosis of leprosy:

The clinical diagnosis of early leprosy and PB leprosy can be a challenge. Therefore, a number of serological and other laboratory assays have been developed to supplement clinical diagnostic methods. However, enzyme-linked immunosorbent assays (ELISA) and lateral flow assays are associated with low diagnostic accuracy for PB leprosy. Although some polymerase chain reaction (PCR)-based assays are associated with higher diagnostic accuracy, they lack standardization, are not commercially available, and would be difficult to perform in most primary health-care settings.

NEW GUIDELINES TO DIAGNOSE LEPROSY :

- In 2018, WHO published new guidelines for 'early' diagnosis using sophisticated immunological tests such as PCR and ELISA, which are proven scientifically.
- Problems in practicing these tests in the field for the mass leprosy control programme exist due to paucity of funds and lack of operational application. During integration phase, it is possible to take advantage of these tests to detect leprosy infection in clinically difficult to diagnose cases, which are less in number.
- Routine testing facilities exists nationwide for TB, HIV AIDS and other diseases in the public health system. It is recommended that NLEP to create linkages with tertiary level centres to avail these facilities for 'early' diagnosis of leprosy.

ALERT INDIA team

Treatment of leprosy:

The guidelines recommend ***a 3-drug regimen of rifampicin, dapsone and clofazimine for all leprosy patients, with a duration of treatment of 6 months for PB leprosy and 12 months for MB leprosy***.

This represents a change from the current standard treatment for PB leprosy, which is rifampicin and dapsone for 6 months, due to some evidence indicating better clinical outcomes with a 3-drug, 6-month regimen over a 2-drug, 6-month regimen.

A potential advantage of using the same three drugs for PB and MB leprosy is simplification of treatment (i.e. the same blister pack could be used for treating both types of leprosy) and reduced impact of misclassification of MB leprosy as PB leprosy, since all patients will receive a 3 - drug regimen. For MB leprosy, the current standard treatment is a 3 - drug regimen for 12 months.

Evidence on the potential benefits and harms of a shorter (6-month) 3-drug regimen was limited and inconclusive, with a potential increase in the risk of relapse.

Therefore, the GDG (Guidelines Development Group) determined that there was ***not enough evidence of equivalent outcomes to support a recommendation to shorten the treatment duration for MB leprosy***.

Treatment of drug resistance leprosy:

For ***rifampicin - resistant leprosy***, the guidelines recommend treatment with at least two second-line drugs (***clarithromycin, minocycline or a quinolone) plus clofazimine daily for 6 months, followed by clofazimine plus one of these drugs for an additional 18 months***.

When ***ofloxacin resistance is also present***, a fluoroquinolone should not be used as part of second-line treatment. The regimen of choice in such cases shall consist of ***6 months of clarithromycin, minocycline and clofazimine followed by clarithromycin or minocycline plus clofazimine for an additional 18 months.***

Resistance has been reported from several countries, although the number of patients is small. Evidence on the potential benefits and harms of alternative regimens for drug-resistant leprosy was not available. Therefore, recommendations for second-line regimens are based on expert opinion and the known activity of alternative drugs, including the likelihood of cross-resistance.

Prevention of leprosy through chemoprophylaxis:

The guidelines recommend the use of single-dose rifampicin (SDR) as preventive treatment for adult and child (2 years of age and above) contacts of leprosy patients, after excluding leprosy and tuberculosis (TB) disease and in the absence of other contraindications.

The COLEP-2 (a prospective study on contact and chemoprophylaxis in leprosy) randomized controlled trial (RCT) found SDR in leprosy contacts associated with a 57% reduction in the risk of leprosy after 2 years and 30% after 5–6 years; SDR also appears highly cost–effective, with an incremental cost ratio of US$ 158 (INR 11,375) per additional prevented leprosy case.

The ability of programmes to adequately identify and manage contacts of persons with leprosy is a prerequisite for successful implementation of the recommendation. Because leprosy is highly stigmatized, caution must be exercised when implementing SDR, particularly for contacts outside the patient's family.

Programmes must respect the wish of patients to disclose or not disclose their diagnosis. When patients do not authorize disclosure, the **GDG does not recommend identification or screening of contacts, which is a prerequisite for prescribing preventive treatment**.

In hyperendemic settings, a blanket approach (i.e. treatment of all community members without identifying contacts) might be more feasible and reduce potential harms related to disclosure of a leprosy diagnosis.

Excerpts - Guidelines for the diagnosis, treatment and prevention of leprosy (2018). ISBN: 978 92 9022 638 3

Frequently asked questions

Is there an effective and safe chemoprophylaxis regimen for prevention of leprosy among contacts of leprosy patients and for high-risk populations?

The GDG recommends the use of SDR as preventive treatment for contacts of leprosy patients, in adults and children 2 years of age and above, after excluding leprosy and TB disease and other contraindications, by programmes that can ensure adequate management of contacts and upon agreement of the index case to disclose his/her disease.

Is there an effective vaccine for the prevention of leprosy that could be used under programmatic conditions, with or without chemoprophylaxis, for contacts of leprosy patients?

BCG at birth is effective in reducing the risk of leprosy disease and therefore its use should be maintained at least in all leprosy high-burden countries. Efficacy of M. indicum pranii vaccine, still in production, in preventing leprosy, according to RCTs. Presently, there is insufficient evidence of the efficacy of BCG revaccination among contacts to recommend its use.

25

"National leprosy programmes to ensure an effective referral system"

. . . . need for early detection, treatment of reaction and supportive physiotherapy . . . .

World Health Organization

Global Leprosy Programme. Control of Neglected Tropical Diseases, 20, Avenue Appia 1211 Geneva 27, Switzerland

Nerve function impairment often results from various pathological and immunological processes in leprosy, often termed reactions. Leprosy reactions are considered leading causes of disability because reactions, if left untreated or improperly managed, may lead to irreversible damage causing physical deformities or G2D. Reactions appear to occur in a significant proportion of patients: up to 30% of patients diagnosed with multi-bacillary (MB) disease. Steroids remain the mainstay of treatment of reactions.

Recent WHO recommended course of steroids (Prednisolone)

For Reversal Reaction:		***For ENL Reaction:***	
Dosage	***Duration***	***Dosage***	***Duration***
30 mg / day	*2 weeks*	*30 mg / day*	*2 weeks*
25 mg / day	*2 weeks*	*25 mg / day*	*2 weeks*
20 mg / day	*8 weeks*	*20 mg / day*	*4 weeks*
10 mg / day	*4 weeks*	*15 mg / day*	*4 weeks*
05 mg / day	*4 weeks*	*10 mg / day*	*4 weeks*
		05 mg / day	*4 weeks*
(Total - 20 weeks)		***(Total - 20 weeks)***	

- In the presence of nerve involvement, oral prednisolone is used at a dose of 40-60 mg daily which is gradually reduced weekly or fortnightly.
- Steroid doses may need to be increased if ENL severity increases up to 40-60 mg prednisolone per day depending on body weight.

For treatment of Reversal Reaction (RR), steroids are advised for a period of 12 to 20 weeks starting with an initial dose of 40 mg of oral prednisolone to be administered as a single dose in the morning and gradually tapered by 5 mg every two weeks. **Review of literature showed that 20 weeks of oral prednisolone is effective in controlling RR with recent NFI.**

For treatment of ENL, steroids are advised during the acute phase. For cases which show recurrence or chronicity, the treatment needs to be fortified with clofazimine, which has known anti-inflammatory action. **At start 100 mg of clofazimine three times a day is prescribed; the dosage is subsequently tapered over a period of 36 - 48 weeks depending on the severity and chronicity of the reactions.**

Though many studies have demonstrated effectiveness of thalidomide in treating acute ENL, its use is restricted in many countries due to the teratogenic effects. WHO advocates that NLPs ensure an effective referral system and education of patients for seeking treatment on noticing signs and symptoms of reactions.

In both types of reactions general symptoms should be treated symptomatically. Patients should be screened for conditions where oral steroids are contra-indicated. Treatment of reactions should be supported with physiotherapy and counselling. Nerve function should be assessed frequently to prevent development of disabilities during the course of reactions. Evidence from randomized control trials (RCTs) does not show a significant added benefit of surgery over steroid treatment alone.

The technical guidance on reactions underlines the importance of early detection and institution of the correct treatment and required physiotherapy. Reactions may occur before diagnosis, during and even after treatment with MDT. Patients on MDT are advised to continue while reactions are managed. **WHO advocates that National Leprosy Programmes ensure an effective referral system and education of patients for seeking treatment on noticing signs and symptoms of reactions.**

Excerpts - Report of Informal Consultation on treatment of reactions and prevention of disabilities. SEA/GLP/2019/1

26

“Indicators to evaluate the effects of programme interventions”

. . . . monitoring exercise provide complimentary evidence on program performance . . . .

World Health Organization

Regional Office for South-East Asia, World Health House, MG Marg, New Delhi, India

Monitoring enhanced global leprosy strategy: Purpose

For leprosy control to achieve greater success it is essential to have the concept and practices of monitoring and evaluation well established in the programme. **Monitoring is done through a minimum set of indicators that describe the leprosy services in terms of impact, effectiveness, efficiency, relevance and sustainability. These indicators provide the basis for before-and-after analyses to evaluate the effects of programme interventions.**

Group I: Case detection

1. **Case finding activities**

1.1 Proportion of new cases with Grade 2 disabilities
1.2 Average delay in diagnosis
1.3 Proportion of children among new cases (or age-specific detection)
1.4 Proportion of MB cases among new cases
1.5 Proportion of females among new cases

2. **Prevalence: absolute numbers and rate**

2.1 Reported prevalence
2.2 Prevalence after applying standard definitions (case, completion and defaulters)
2.3 Prevalence trend over the last 5 years

3. **Detection trend: absolute numbers and rate**

3.1 Detection trend over the last 5 years
3.2 G2D trend
3.3 MB detection trend
3.4 Child detection trend

Group II: Integration of MDT services within General Health Services

1. **Proportion of health facilities providing MDT which have been reporting new cases.**
2. **Accessibility to MDT**

2.1 Average distance
2.2 Estimated costs for the patients
2.3 Flexibility in delivering MDT

3. **Availability of MDT drugs**

3.1 Inventory of MDT drug stocks
3.2 Check MDT blister packs for expiry dates.

Group III: Quality of MDT services

1. **Quality of leprosy diagnosis**
2. **Case holding**

2.1 Completion rate
2.2 Defaulter rate
2.3 Proportion of patients continuing treatment after completing MDT standard regimen

3. **Patient satisfaction**
4. **Stigma prevalence**
5. **Community perception**

The monitoring exercise will have to be repeated in order to assess the impact of interventions and changes over time. **These studies should be carried out by independent monitors, who will visit selected units to collect information through standardized methods, and report their findings on compiled data to the national programme managers and WHO.**

The monitoring should be time-limited and the complete cycle should not exceed four weeks. Selected health facilities should be informed in advance of the monitors’ visit so that they have time to mobilize affected persons. Indicators and methodologies described in this document will be adapted/ reviewed as and when needed.

Excerpts - WHO Monitoring Enhanced Global Leprosy Strategy. SEA-GLP-2012.02.

NLEP to collect and analyze data on all these indicators to evaluate the effects of programme interventions as a routine monitoring exercise.

ALERT-INDIA team

27

“The first step - creating a robust surveillance and response system”

. . . . evidence based intervention to implement optimal strategies need resources . . . .

Abhishek Pandey et al

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Despite the severity of leprosy, progress towards elimination has stagnated over the last decade. Status quo approaches rely on patients presenting themselves at health-care facilities with symptoms that can lead to delays in treatment. Such delays are exacerbated by stigma and mis-diagnosis of the initial skin lesions. Accelerating diagnosis and treatment is instrumental both to avoid disabilities and to mitigate transmission.

Even within the most affected countries including India, Brazil, and Indonesia, leprosy risk across a country is often heterogeneous with the majority of cases occurring in high-risk regions. Determining these high risk regions is an essential first step in creating a robust surveillance–response system, which is imperative for making further progress towards a leprosy-free world.

Poverty has often been associated with an elevated risk of leprosy. However, there is inadequate quantification of specific socioeconomic, demographic, and geographical variables that contribute to leprosy risk. Advancing our understanding of these risk factors can be applied to identify the communities in which surveillance and control efforts would be most effectively and efficiently focused.

Ascertaining risk factors is fundamental to implementing such targeted strategies. To investigate the spatial, socioeconomic, demographic, and household factors associated with the risk of leprosy incidence, we analysed the health records and socioeconomic data of more than 23 million individuals, including over 18,000 leprosy cases across Brazil between 2007 and 2014. They introduced a comprehensive classification of risk factors into distal, intermediate, and proximal factors that underlie the hierarchical analytical framework developed in their study. At the highest level, distal factors reflected the broadest variables—eg, geographical location and urbanicity. Intermediate factors considered comprised ethnicity and socioeconomic variables, such as level of education and income. At the lowest level, proximal factors pertained to living conditions, including household size and sanitation.

WHO has established two 2020 goals for leprosy: the elimination of leprosy-attributable disabilities in children and reduction below one per million population in cases of grade-2 disabilities, defined as leprosy-related visible deformities. A targeted, multifaceted strategy is most likely to be effective in realising these goals. To reduce leprosy-related stigma and thereby improve early consultation by patients for diagnosis and timely treatment, possible approaches include improving awareness, particularly within high-risk communities, and introducing socioeconomic rehabilitation programmes for leprosy patients with disabilities.

Strategies aimed at the social development of these high-risk settings can play a crucial role in leprosy control. Despite the availability of effective treatment and impressive progress in reducing the burden of leprosy worldwide, the disease continues to impose significant morbidity and discrimination in affected societies. **Declining global funding for leprosy has left the most marginalised populations at highest risk. Therefore, leprosy programmes need to be reenergised with resources and global commitment.** In concert with bolstered investment, evidence-based interventions are required to implement optimal strategies for leprosy control.

Excerpts - Quantifying risk factors to guide progress towards leprosy elimination.
www.thelancet.com/lancetgh. Vol 7, September 2019

28

“Investment in human resources translates into value of return”

. . . . SDR is not a substitute for contact tracing at family and community level . . . .

Anuj Tiwari et al

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As leprosy recently gained a significant political commitment from the Government of India, it is now back on the agenda of the Ministry of Health and Family Welfare. The 2017 parliamentary budget speech also included a commitment to eradicate leprosy by 2018 (a target that seems unrealistic given the present epidemiological level). However, as the NLEP is in the process of testing feasible strategies for interrupting transmission of M. leprae, economic analysis, particularly costing estimates, is important to guide the decisions that aim to improve financial efficiency.

As costing estimates at primary-care level in leprosy are scarce, our study aimed to estimate the cost of leprosy services at primary care level in two different public-health settings. Because health care in India is organised at the provincial level, individual public-health settings differ in factors such as funding, staffing and infrastructure, which are linked directly to the cost of services and indirectly to service coverage. To gain an overview of the possible variation in costs, we examined two different public-health settings.

The purpose of this study was to mainly provide cost estimates that can aid financial planning of a scale-up and assessing the cost-effectiveness of leprosy control activities, including post-exposure prophylaxis with single-dose of rifampicin (SDR).

Our study shows that a setting with an enhanced public-health financing system invests more in leprosy services and prevention than one with fewer financial resources. **The enhanced public-health system overall appears costly, but in terms of productivity, it no longer remains expensive. Additionally, it also facilitates reduction in out-of-pocket expenditure among households.**

Therefore, we recommend investment in the health system for prevention and increased access to services, which will promote early detection and transmission interruption. According to public-health norms in India, more resources are needed to cover the population at risk, therefore these costs should also be seen as an input that will strengthen the overall health system. Both systems invested mainly in human resources. In both the areas, the investment in human resources translates into active outreach programmes, particularly contact screening.

We found that post-exposure prophylaxis as addition to the control programme is resource intensive. However, once post-exposure prophylaxis has been implemented in a routine setting, the costs are expected to fall. The use SDR for leprosy prevention, which will trigger scale-up of post-exposure prophylaxis.

Our results can immediately guide the fiscal planning during scale-up in India, and SDR role out in other countries after considering the local economies. The relatively low unit cost of contact screening favours its sustainability in the programme; however, this does not mean that contact tracing should be avoided even if costly.

In general, leprosy work is facing financial constraint since the global declaration of leprosy elimination. These results are promising for advocacy and fundraising, especially in support of SDR. The unit costs are of much interest for funding agencies to reimburse on case bases and to plan a flexible investment with a measurable value of return.

Excerpts - Leprosy services in primary health care in India: comparative economic cost analysis of two public-health settings. Tropical Medicine and International Health. Vol 24, No 2. pp 155–165. February 2019

Page

V. Addressing disabilities in leprosy : missing gaps and predictions

VI. Reducing stigma and discrimination : issues and concerns

29

"Actual G2D among new leprosy cases are more than reported"

. . . . reliable data on leprosy related disabilities is lacking in routine NLEP reports . . . .

Anil Kumar et al

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Data on leprosy cases and also on deformities were highly under reported through the passive reporting system. Several cross-sectional surveys have reported high Grade 2 disability rates in new cases of over 10% from Maharashtra and also from Brazil and Myanmar. These wide variations in disability rates have induced interest within WHO to assess the disability burden in India more accurately. A study was therefore started to assess the number of people affected by leprosy and living with Grade 1 (G1D) and Grade 2 (G2D) disabilities, with details of involvement of hands, feet, eyes or multiple disabilities.

Two states in India were selected for the study – one highly endemic for leprosy (Uttar Pradesh) and another of low endemicity (Haryana). In each state, four districts were randomly selected from four geographical clusters i.e. North, East, West and Southern areas of each state. In each district, four sector PHCs were selected randomly using a random number table. In each selected sector PHC area, four sub-centres were randomly selected for a population survey to search for leprosy cases.

This survey sampled 804,534 people and among them 200 leprosy-disabled (old, previously treated) people and 355 new active leprosy cases were detected. Amongst 355 newly detected cases, 56 had disability (18 had G1D & 38 had G2D). The prevalence of disability in Uttar Pradesh was 47·1 per 100,000 population and in Haryana it was 16·8 per 100,000 population. Overall the burden of disability (G1D and G2D) in the population was 31·8 per 100,000 population (47·1 in Uttar Pradesh & 16·8 in Haryana). The percentage disabled among new active leprosy cases detected was 15·8 (15·2% in Uttar Pradesh & 17·7% in Haryana). Of the total disabled among active leprosy cases 5·1% had G1D and 10·7% G2D.

The G2D alone among new leprosy cases was found to be much higher 10·7% (38/355) in the present study than the 1·8% reported in registered data from India 2008–2009. If we assume the percentage with G2D among new active leprosy cases to be representative, this would mean that the figure for the whole country could vary from 5·9 times to 14·5 times the reported figure (NLEP).

One of the reasons identified for the higher disability among leprosy patients is certainly delayed reporting or a longer delay in detection through community surveys. The voluntary reporting system for leprosy patients has some inherent problems related to the low level of community awareness, high social stigma, atypical skin lesions and late presentation of neurological symptoms.

Another reason for a high disability rate could be patients' lack of knowledge about the urgency of treatment for leprosy. It may be coupled with low awareness of the availability of services for such patients and thus the delay in seeking treatment could lead to development of nerve involvement – a precondition or major cause of developing disability.

Despite significant financial and human investment by the Government of India over decades, the impact of IEC seems to be very small. **It is therefore important that leprosy control programmes use such IEC messages more frequently to induce sufficient and effective motivation in the population concerned for self examination and reporting voluntarily to the health system for early detection and diagnosis.**

Excerpts - Burden of leprosy-related disability: results of a population survey in two states in India. Lepr Rev (2018) 89, 353–361

30

“People with leprosy require greater visibility in the political arena”

. . . . multi sectoral policies and strategies are needed to continue surveillance . . . .

Marcos Tulio Raposo et al

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Our findings are consistent with the literature indicating greater risk of nerve damage and, consequently, of permanent disabilities (G1D and G2D) in MB cases. We confirmed the association between MB clinical forms and the occurrence of visible deformities after completion of MDT. However, the lower occurrence of G2D in the PB group does not diminish the severity of the impairment, nor justify taking this group from the focus of priority actions.

In this study, the severity of reactions was in line with the recognized association of nerve damage and disabilities. Leprosy reactions, on a global level, exhibit high variability, and therefore our data are consistent with those of other studies, whose rates range from 20 to 57% and confirm the association between G2D and the occurrence of leprosy reaction at some point (prior to diagnosis, during MDT or after MDT completion) in the patient’s life.

Given the high incidence of leprosy-related complications after MDT and the risk factors involved, lack of follow-up may lead to the need for further healthcare actions to manage potentially preventable complications. The situation is particularly complicated after treatment completion because these patients are no longer monitored by public health services and thus go largely unrecognized by the health authorities.

This study revealed a high prevalence of G2D patients with significant functioning problems after treatment. This patient group requires greater visibility in the political arena and integrated care should be provided. This care involves systematic monitoring of physical disabilities and tertiary rehabilitation, which includes a sustainable long-term approach to physical, psychological and social aspects.

The identified associated factors with G2D indicate the vulnerability affecting this group. The challenges providing integrated care for people affected by leprosy are increased, even after bacteriological cure, if not subjected to systematic follow-up and monitoring. From the wider perspective of care for leprosy and people with disabilities, this study renews discussion on the adoption of health policies promoting integrated care after MDT completion in line with the WHO Global disability action plan 2014 - 2021 and the Global Leprosy Strategy 2016 - 2020.

The situation calls for the implementation of multi-sectoral policies and strategies to continue health surveillance after completion of MDT. Integrated control measures should include the development of ethics protocols, regulation of a system for reporting events post MDT, detection and timely treatment of disabilities and complications (such as leprosy reactions), monitoring factors associated with disabilities, and also the provision of interventions promoting self-care, disability prevention and availability of rehabilitation services.

Given the strong relationship between social vulnerability and leprosy, we may be underestimating the true rates of G2D in this population. On the other hand, it is important to acknowledge that patients with severe disability caused by leprosy are more likely to be in contact with the health service and to have up-todate medical records. In this case, we will overestimate G2D. Either way, this does not detract from the findings in that a significant proportion of patients remain with significant disability after treatment completion.

Excerpts - Grade 2 disabilities in leprosy patients from Brazil: Need for follow-up after completion of multidrug therapy. PLoS Negl Trop Dis (2018) 12 (7): e0006645.

31

“Cumulative data on cases develop new disability each year is lacking”

. . . . resources are urgently needed for management of neuropathy in leprosy . . . .

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Assessing the burden of disability

Leprosy is unusual among the neglected tropical diseases in that the number of new cases detected is reported by countries and these reports give us an annual overview of the leprosy burden globally. However, we do not know how many people have leprosy-related disability. Leprosy disability is measured by the WHO disability grading (DG) system, with three categories: 0, 1 and 2. The indicator can be used as a proxy measure for delay in detection since patients who are diagnosed late will be at risk of more severe deformities. The proportion of grade 2 disability at diagnosis for each country is reported; in 2016, India had a grade 2 level of 5098 among135,485 new cases.

Although the WHO DG system provides a useful measure, it does not reflect changes that may occur in patients following diagnosis. However, cumulative data on patients who develop disability each year are needed but are not being collected. The number of new patients moving into this category each year is estimated to range from 10,000 to 40,000. Since many patients develop leprosy when they are in their teens or early twenties, the possibility for long-term accumulation of patients with disability is significant. This category is dynamic and patients can move into it. Nerve damage is detected by assessing the motor strength of the small muscles in the hands and feet. Sensory loss can be assessed using graded nylon monofilament on the palms or soles. These simple tools were developed so that neuropathy could be detected in low-resource settings.

Economic consequences of leprosy

The economic costs of disability fall on individuals, communities and national governments. In India, we found that families of leprosy patients suffer economic hardship and 33% of such families were tipped into catastrophic expenditures through the costs they incurred. This included direct costs for doctors' visits and medicines, as well as indirect costs because the person was not working. Their families also lost income through having to accompany the relative to the hospital.

Neuropathy has economic costs for communities with affected individuals. Neuropathy has costs for national health programmes because patients need to access services such physiotherapy to help in disability prevention. Patients often need to access services for special shoes to prevent injury; these also have to be provided to people with other disabilities, such as diabetes, so this service can be provided in an integrated setting.

Way forward

People with the medical consequences of leprosy can be treated in integrated health services alongside other patients. Resources are needed for the management of neuropathy in leprosy endemic countries. There is interesting work to be done modelling the numbers of patients with disability. This is a dynamic setting because some patients will become disabled, others may develop disability after treatment and others may improve and will no longer be considered disabled.

I urge the WHO to provide steroids to national leprosy programmes. It should also strengthen optimal management of immune suppression and its complications. **A simple tool for detecting disability needs to be developed. Patients should be screened for neuropathic pain and started on treatment when pain is present. These interventions would help reduce the development of disability and stigma.**

Excerpts - Chronic aspects of leprosy—neglected but important. Trans R Soc Trop Med Hyg 2019; 00: 1–5 doi:10.1093/trstmh/try131

32 "Rehabilitation initiatives go beyond successful employment outcomes"

. . . . combating negative impact of self worth stemming from social stigma . . . .

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People with disabilities (PWDs) often face prejudice and discrimination because of their physical and/or mental deviance from norms subjectively defined by society. The stigma associated with having a disability can have a negative impact on the quality of life. The purpose of this paper is to discuss approaches that PWDs can adapt to overcome and mitigate the adverse effects of a stigmatizing disability. Specifically, the approaches pave way for weaving spiritual well-being, resilience, and optimism into psychoeducation efforts to help PWDs toward the self acceptance; empowerment of their rights to advocate for full integration in society.

Overcoming Disability Related Stigma

According to the labeling perspective, self-perception can often be affected once an individual becomes cognizant of his or her stigmatized label. Thus, how an individual accepts or rejects social labeling becomes highly relevant and important to understanding self-reaction. However, those who reject the stigmatizing label have been shown to produce higher levels of self-esteem and adjustment to a disability. We explore the positive psychology and some of its tenets in relation to working with PWDs with the purpose of overcoming the stigmatizing effects of disability.

Positive Psychology

The ability to transcend through adversity has been of significant interest among researchers and mental health professionals. Positive psychology has been described as the study of optimal experience, acknowledging the low points that transpire in life, and stressing the importance of recognizing the positive outcomes that often occur but are frequently overlooked. The three parts of positive psychology are: (a) subjective experiences–happiness, well-being, hope, and optimism, (b) individual traits–the ability to forgive, persevere, and achieve a certain level of interpersonal skills, & (c) group level–institutions that support, nurture, encourage, and accept responsibility.

Rather than fixating on the pathology of human functioning, positive psychology has been a catalyst for change in the field of psychology by focusing on the positive qualities that each person possesses. Nevertheless, if one of the three parts of positive psychology is absent, the difficulties in overcoming stigma related to having a disability increase.

Rehabilitation professionals often struggle with assisting consumers towards mutually agreed upon goals (i.e., successful employment outcomes) as clients are often combating the challenges of negative self-worth stemming from societal stigmas repeatedly encountered. Although it is undeniable that person-environmental factors interact with the approaches offered in this paper for overcoming stigma, fixating on external forces rather than the intended outcome is counterproductive.

Furthermore, as the rehabilitation practice continues to be filled with passionate and dedicated professionals promoted to supporting independence, elevating subjective well-being, and eradicating discrimination, and prejudice, the need towards providing positive approaches to overcoming stigma is necessary for acceptance and overall well-being. **As a result, individuals working with PWDs in therapeutic setting should assist clients in recognizing their personal attributes by adopting a healthy approach in an effort to empower, self-advocate and reject the negative perceptions of others.**

Excerpts - Positive Approaches to Overcoming the Stigma of Disability. J. Disability Stud. 2018, 4 (1), 3-8

33

“Incorporating rehabilitation into NTD programmes is needed”

. . . . people with disabilities often face stigmatizing attitudes and social exclusion . . . .

Hannah Kuper et al

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Can NTDs be disabling?

There are many parallels between NTDs and disability. Both affect approximately one billion people. Both are more common in the poorest parts of the world, and among the poorest people. There is also a direct link as NTDs are frequently disabling. Trachoma and onchocerciasis can cause blindness. Leprosy, chikuyngunya, yaws, lymphatic filiarisis, and Buruli ulcer can lead to physical impairments. Soil-transmitted helminths and schistosomiasis can cause delayed physical and mental development of affected children, predisposing them to disabilities. The reason for the global attention on NTDs is actually because of their disabling effects, as few are directly linked to mortality.

People with NTDs also often face stigmatising attitudes and social exclusion, which leads to high levels of mental ill health. Even in the absence of vision loss, trachomatous trichiasis can reduce quality of life and participation in activities of daily living because of the pain and discomfort that it causes.

Integrating rehabilitation in NTDs

Since NTDs can cause disabilities, there is a good argument for integrating rehabilitation within NTD programmes in order to improve the quality of life of people affected. Rehabilitation can be defined in a narrow medical sense, such as provision of physiotherapy or assistive devices. It can also be conceptualised more broadly, including programmes to overcome stigma and discrimination, improve employment opportunities, and provide social assistance. **Incorporating this focus in NTDs programmes is also important since disability, poor mental health, shame and stigma can reduce help-seeking and treatment adherence, and so make it more difficult for NTD goals to be achieved.**

Currently, integration of rehabilitation within NTDs programmes is lacking. Focus on NTD programmes is mostly to prevent and treat, in the belief that if these are effective then rehabilitation won’t be needed. However, in today’s world not all cases of NTDs can be avoided, and many people are already disabled as a result of NTDs. This means that incorporating rehabilitation into NTD programmes is still needed.

Two steps are required to achieve this goal. Firstly, the rehabilitation needs of people with disabling NTDs must be assessed, both in terms of medical and broader needs. Secondly, NTD programmes need to be expanded to incorporate provision of rehabilitation, or to link to existing rehabilitation services. This may require tackling physical barriers, providing communications in a range of formats and including images of people with disabilities in campaign pictures to highlight that the programme is for everyone. **It is vital to include people with disabilities in the planning and potentially delivery of NTD programmes to ensure that they are set up to be accessible for all.**

Leaving no-one behind

Expanding the focus of NTD programmes to integrate rehabilitation will help improve the quality of life of people living with NTDs. Ensuring that NTD programmes are inclusive of people with disabilities will mean that a greater proportion of the population is reached, and NTD targets are more likely to be met. Harnessing the current momentum behind both disability and NTDs will make both sectors stronger, and help make sure that 'no-one is left behind' as we move towards NTD control.

Excerpts - Neglected Tropical Diseases & Disability - What is the Link? https://www.ntdsupport.org/cor-ntd. Blog 24 Jul. 2018

34

"Need specific activities to prevent worsening of impairments after RFT"

. . . . social participation in hte community and family help overcome activity limitations . . . .

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A rapid disability assessment (RDA) toolkit comprised of generic methods and instruments, compatible with the International Classification of Functions (ICF) conceptual framework: Screening of Activity Limitation and Safety Awareness (SALSA) scale, Participation Scale, Jacoby Stigma Scale, Explanatory Model Interview Catalogue (EMIC) stigma scale and Discrimination assessment form were used for assessing disability and stigma in 1,358 persons with leprosy-related disability (PLDs) after RFT.

PLDs experience major problems in all four components of disability, body functions and structures, activities and participation, personal factors and environmental factors. The majority had leprosy-related physical impairments (75%). A substantial proportion (39%) of those with visible impairments had developed these after RFT. **This finding indicates a need for specific activities to prevent worsening of impairments also after RFT, especially surveillance of persons at high risk, training in foot and hand care and provision of assistive devices.**

Both felt (anticipated) stigma and community stigma were high in our study population. As a consequence, stigma, activity and participation are usually more important to the affected person and their family than physical impairment. The proportion of people with participation restrictions (60%) was much higher, but was measured in a sample who had screened positive for 'any disability'.

When using social participation as the main outcome measure, increasing levels of impairment and activity limitation increased the risk of participation restrictions significantly. This shows that, to improve social participation, interventions may be needed at different levels. At the personal and physical level this would include measures such as improving education, income and activity, addressing physical impairments and rehabilitation; and at the societal level, reduction of stigma in the community and addressing other environmental barriers.

Our study showed that stigmatising attitudes related to shame were most predominant, followed by problems to find a marriage partner, problems in marriage and problems to find work. Despite this, the majority of people did not feel stigmatised by others. It is possible, however, that these were not enacted and, as a result, people affected did not actually experience stigma very frequently. However, we observed some possible implications of disability or stigma due to leprosy.

38% of the PLDs were unmarried, divorced, separated or widowed. This is significantly more than in a community sample with a similar age-distribution. It may be the effect of community stigma and discrimination, since problems in marriage were reported as one of the major difficulties they faced. Social discrimination in marital relationships should be addressed through counseling and advocacy in the community, with a particular focus on the needs of women.

Our study underlines that PLD are often burdened with social stigma that promotes a cycle of poverty via unemployment, social discrimination and threats to mental health. The findings show that stigma reduction activities and socio-economic rehabilitation are urgently needed in addition to strategies to reduce the development of further physical impairment after RFT.

Excerpts - Disability in people affected by leprosy: the role of impairment,activity, social participation, stigma and discrimination. Glob Health Action 2012, 5: 18394 - http://dx.doi.org/10.3402/gha.v5i0.18394

35

“Women affected by leprosy face high levels of discrimination in India”

. . . . necessary to implement affirmative measures and cross-sectorial policies . . . .

Alice Cruz
UN’s Special Rapporteur on Leprosy, Palais des Nations CH-1211, Geneva 10, Switzerland

Globally, there is a general under representation of women in political and public life. But the absence of women affected by leprosy in programs and policies that directly affect them, as well as in the leadership of NGOs and organizations of persons affected by leprosy, is alarming and indicates that they are certainly not being heard. If there is a current consensus about the need for a wider participation of persons affected by leprosy in making decisions on issues concerning their lives, then there must be a genuine and concerted effort to incorporate gender equality in these demands and participation exercises.

The testimonials of many affected women, we would understand how their vulnerability to discrimination increases as it intersects with poverty, low educational levels, race, religion, disability, and other social conditions. By securing the rights to education, work, and to economic independence - to live a dignified and full life - obstacles to functional and comprehensive access to the right to health could be diminished.

Considering how important women are for overall family health, this increased access could then lead to a decrease in leprosy transmission rates. These women’s testimonials would also speak about an ethics of care as an everyday exercise to generate, reproduce and maintain life that might help decision makers understand why curing is not the same as healing, and that persons affected by leprosy demand full rehabilitation.

Besides affirmative action that secures women’s participation in civil society organizations and decision-making processes at the state level, it is essential that states take immediate action to allow affected women’s voices to be heard. Governments need to ensure the following:

1. the recognition of the stigma and discrimination against women affected by leprosy as a structural and inter-personal violence;
2. the rights of women affected by leprosy at the legislative, executive and judiciary levels of government and administration;
3. the implementation of the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members with a gender focus;
4. the incorporation of women affected by leprosy into national plans for gender equality and gender violence prevention;
5. a response to data gaps with disaggregated data and the implementation of policy monitoring systems;
6. awareness on gender equality in state administrative services, communities and priority groups;
7. empowerment of women affected by leprosy through income generation programs, creation of cooperatives, continued education, and health services that consider gender, culture, and needs for psychological support and integral rehabilitation.

Civic, public and political participation of persons affected by leprosy is the key. However, in order to achieve this, it is necessary to implement affirmative measures and cross-sectorial policies to face both the intersection of leprosy with other processes and social identities subject to oppression (e.g., gender, age, class, race, and disability) and the vulnerability that keeps affected persons inside a spiral of disadvantage. **The voices of women, their knowledge, ethics of care, and practices of resilience will help us to develop better practices for the elimination of discrimination against persons affected by leprosy and their families.**

Excerpts - Battling exclusion: giving a voice to women affected by leprosy. Report to Human Rights Council. Aug 30, 2018

36

“Meaningful engagement of persons affected by leprosy to be ensured”

. . . . need to sensitize policy makers and sustain advocacy initiatives to address stigma . . . .

World Health Organization

Global Leprosy Programme, Regional Office for South-East Asia, New Delhi, India

Recommendations to national leprosy programmes

- National programmes should be strengthened in order to address issues related to stigma, discrimination and other social issues related to leprosy and take appropriate remedial measures.
- A multi-disciplinary and multi-sectoral accountability framework and mechanism should be developed involving relevant ministries, persons affected by leprosy, parliamentarians, NGOs, professional bodies, corporate sector and CBOs to address issues related to stigma and discrimination.
- **Meaningful and impactful engagement of persons affected by leprosy should be ensured at all decision-making levels in leprosy programmes.**
- Any derogatory language and/or expression in national laws, legislations, policies and documents need to be replaced by dignified language in line with the UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members.
- Counselling should be included as an integral part of leprosy services and should be undertaken by professional counsellors, peer-counsellors or persons trained in providing counseling services.
- **A community-based surveillance system should be developed to screen for leprosy and its complications and to identify and report on incidences of stigma and discrimination in the community.**
- Capacity building activities should be undertaken in order to improve knowledge, skills and attitudes of healthcare staff in providing services to the persons affected by leprosy.
- A suitable mechanism should be established to get incidences of discrimination reported and addressed in a systematic manner and also inform facts about leprosy to the community (through a toll-free telephone helpline).
- National programs through a designated qualified focal person should ensure availability of proper documentation and facilitate access to Assistive Technology devices, social entitlements such as pensions, right to welfare measures, etc. for the treated patients in need.
- National programs should reach out to all patients, both residing in the community as well as in self settled colonies.

The group recommended that WHO and all national programmes should make an inventory of discriminatory provisions, laws and policies at national and at sub-national levels which should be disseminated to relevant stakeholders. National programme managers and respective ministries dealing with social justice, equity, law enforcement need to be oriented on the current leprosy situation and informed that such discriminatory laws are obsolete. The need for repealing or amending such laws should also be emphasized.

Policy makers need to be sensitized and the advocacy initiatives need to be sustained. Coalitions need to be formed including persons affected by leprosy, NGOs working in the field of leprosy, parliamentarians and national programme officials and experts from the ministry of law and social justice need to be formed to make concerted effort to get the discriminatory laws repealed / amended.

The Inter-Parliamentary Union may provide a platform for meetings of parliamentarians to discuss repealing discriminatory laws against leprosy.

Excerpts - WHO Report of the Informal Consultation on Stopping Discrimination and Promoting Inclusion of Persons Affected by Leprosy. SEA-GLP-2018.1

37

"Supreme court took cognizance of derogatory laws against leprosy"

. . . . repealing 119 laws discriminating against people affected by leprosy in India . . . .

Dipak Mishra

Hon'ble Chief Justice, The Supreme Court of India, New Delhi, India

Order passed on 5 July 2018

The Supreme Court of India has taken note of the fact that even though leprosy, as on today, is curable yet it remains as a fact that those suffering from it are subject to stigma. This is compounded by the apathy shown by the concerned authorities.

We will in due course deal with the constitutional validity of the laws and the steps taken for repeal by the Union of India and the State Governments. There can be no doubt that a person suffering from leprosy has the right to live with human dignity. His/her status in society cannot be bereft of humanness. Needless to emphasise, there is no reason to discriminate against such persons in any vocation or profession, or for that matter, in the exercise of any civic rights or entitlements under the Constitution or law. It has to be understood that treating persons suffering from leprosy in a stigmatic manner denudes them of humanness.

In view of the aforesaid, there has to be social awakening. Due to the advancement of science in the last four decades, the disease has become curable. Members of society must acknowledge and accept that people suffering from leprosy must be treated with equality. Therefore, we proceed to issue the following directions:

(i) The Union of India and the Department of Health and other concerned Departments shall carry out awareness campaigns at various levels so that people come to know about the curability of the disease and of its not being contagious.

(ii) Some responsible authorities, at least two, shall be exclusively nominated for the said duty.

(iii) There should be specific programmes on All India Radio and Doordarshan, both at the Central and the State level, as also on the regional channels, for educating people about the fact that leprosy is not a communicable disease and not to treat any person suffering from that disease with any kind of stigma or discrimination.

(iv) The programmes shall be shown on Doordarshan, both on the national and the regional channels, to the extent feasible on prime time so that the people can see them.

(v) Hospitals should not decline to treat such patients suffering from leprosy for administering the first dosage and thereafter provide treatment if they suffer from any other disease. It has to be remembered that a person has a right to avail the treatment in the government hospitals.

(vi) The awareness campaign must cover all areas from urban areas to the panchayat level so that there will be a concrete and holistic approach with regard to awareness.

(vii) The Union of India and the States shall take steps to rehabilitate persons suffering from leprosy to bring them in the main-stream. It should be the primary duty of the State to see that this category of persons does not suffer from any kind of stigma.

(viii) We would commend to the Union of India and the State Governments to apprise us about the steps taken with regard to the repeal of the provisions where leprosy has been treated as a stigmatic disability.

A report of compliance shall be filed by the Union of India as well as all the States. The order passed today shall be communicated to the Chief Secretaries of the States and the Lieutenant Governors of Union Territories by E-mail and by speed post for due compliance.

Excerpts - PIL filed by Pankaj Sinha against Union of India and others [Writ Petition (Civil) No.767 of 2014

38

“Supreme court directs Government to treat leprosy affected on par with others”

. . . . ensuring quality education to children of people affected is the first step . . . .

Dipak Mishra

Hon’ble Chief Justice, The Supreme Court of India, New Delhi, India

Judgement passed on 14 September 2018

The petitioners have expressed deep concern over the fact that although a National Sample Survey of Leprosy was conducted by the Union of India, yet the said survey has never been brought out in the public domain. The desired results have not been achieved due to improper dispensation of the MDT drugs through the PHCs established for the said purpose. It is urged that the staff of PHCs display sheer lack of sensitivity while dealing with patients affected with leprosy as a consequence of which the level of stigma and isolation still prevails amongst the said patients.

Several incidents have also been reported which have brought to light the discriminatory treatment meted out by the Government hospitals to leprosy affected pregnant women and cases wherein women have been refused treatment solely on account of being affected by leprosy. Another aspect, that is, the area of education has also been brought forth by the petitioners. It has been urged that lack of adequate education facilities would further magnify the sense of insecurity and stigma prevailing amongst the persons affected with leprosy. For any development to take place, the first step would be in the direction of ensuring quality education for the children who are the wards of people affected with leprosy.

It has been pointed out that several instances have come to fore highlighting that the persons affected with leprosy are being provided with APL cards and not BPL cards which prevented these people from claiming benefits under various schemes brought out by the Government, such as the Antyodaya Anna Yojana (AAY), which again deprives this section of the populace from claiming their right to food. Deprivation of housing and other basic civic amenities, adequate sanitary facilities and rehabilitation programmes are yet other serious concerns which, if not addressed, would lead to the entire reformatory process taking a huge setback. Keeping in view the factual matrix in entirety and the submissions advanced, we think it appropriate to issue the following directions :-

(I) The Union and the States are to undertake periodical national surveys for determining the prevalence rate and new cases detection rate of leprosy and, at the same time, publish and bring the reports of the National Sample Survey of Leprosy conducted in 2010-11 and subsequent thereto into the public domain. That apart, the activities of NLEP must be given wide publicity;

(ii) On leprosy day which is internationally observed every year on the last Sunday of January, the Union of India along with all State Governments should organize massive awareness campaigns to increase public awareness about the signs and symptoms of leprosy and the fact that it is perfectly curable by MDT. The content and information contained in the awareness programmes should discontinue to use frightening images of people disabled with leprosy and instead use positive images of cured persons sharing their experiences of being cured of leprosy;

(iii) The Union and the States are to ensure that drugs for management of leprosy and its complications including the MDT drugs are available free of cost and do not go out of stock at all PHCs or, as the case may be, public health facilities in the country;

(iv) **All-year awareness campaigns should also be run, by the Union as well as the States, to inform the citizenry that under the NLEP, treatment is provided free of cost to all leprosy cases diagnosed through general health care system including NGOs**;

(v) The Union and the States must organize seminars at all levels which serve as platforms to hear the views and experiences directly from the former patients and their families as well as doctors, social workers, experts, NGOs and Government officials;

(vi) The awareness campaigns must include information that a person affected by leprosy is not required to be sent to any special clinic or hospital or sanatorium and should not be isolated from the family members or the community. The awareness campaigns should also inform that a person affected with leprosy can lead a normal married life, can have children, can take part in social events and go to work or school as normal. Acceptability of leprosy patients in the society would go a long way in reducing the stigma attached to the disease;

(vii) Health care to leprosy patients, at both Government as well as private run medical institutions, must be such that medical officials and representatives desist from any discriminatory behaviour while examining and treating leprosy patients. Treatment of leprosy should be integrated into general health care which will usher in a no-isolation method in general wards and OPD services. In particular, it must be ensured that there is no discrimination against women suffering from leprosy and they are given equal and adequate opportunities for treatment in any hospital of their choice. To this effect, proactive measures must be taken for sensitization of hospital personnel;

(viii) Patients affected with leprosy, for whom partial deformity can be corrected by surgery, should be advised and provided adequate facility and opportunity to undergo such surgeries;

(ix) The possibility of including leprosy education in school curricula so as to give correct information about leprosy and leprosy patients and prevent discrimination against them should be explored;

(x) **The Union and the State Governments must ensure that both private and public schools do not discriminate against children hailing from leprosy affected families.** Such children should not be turned away and attempt should be made to provide them free education;

(xi) **Due attention must be paid to ensure that the persons affected with leprosy are issued BPL cards so that they can avail the benefits under AAY scheme and other similar schemes which would enable them to secure their right to food**;

(xii) The Union and the States should endeavour to provide MCR footwear free of cost to all leprosy affected persons in the country;

(xiii) The States together with the Union of India should consider formulating and implementing a scheme for providing at least a minimum assistance, preferably on a monthly basis, to all leprosy affected persons for rehabilitation;

(xiv) The Union and the State Governments must pro-actively plan and formulate a comprehensive community based rehabilitation scheme which shall cater to all basic facilities and needs of the leprosy affected persons and their families. The scheme shall be aimed at eliminating the stigma that is associated with persons afflicted by leprosy.

(xv) **The Union Government may consider framing separate rules for assessing the disability quotient of the leprosy affected persons for the purpose of issuing disability certificate in exercise of the power granted under the Rights of Persons with Disabilities Act, 2016 (No. 49 of 2016).**

Excerpts - PIL filed by Pankaj Sinha against Union of India and others [Writ Petition (Civil) No.767 of 2014

39

"Effective and sustainable stigma reduction interventions needed"

. . . . evidence of effective interventions needs potential funding . . . .

Wim H van Brakel et al

Netherlands Leprosy Relief, Amsterdam, Netherlands

Over the last few years, there has been a growing awareness among policy makers, NGOs, health professionals, and researchers of the importance of stigma reduction interventions. Stigma reduction interventions can target a specific type of stigma (e.g., internalized stigma, enacted stigma), a specific actor (e.g., the stigmatized individual, health professional, family member), or a specific level at which the stigma manifests itself (e.g., intrapersonal, interpersonal). Although targeted at a certain level, particular stigma reduction interventions often produce effects at multiple levels.

Lessons from studies on stigma-reduction interventions:

First, it is important that stigma-reduction interventions are not set up as one-off activities but are developed in such a way that they can be sustained. **Hence, the interventions should be low cost, use materials and methods that are available in and appropriate to local settings, and are designed such that they can be executed by health professionals and the staffs of NGOs and disabled people's organizations (DPOs) in local settings.**

Second, the participation, not merely consultation, of affected persons in the development and implementation of stigma reduction interventions is important. The principle of 'Nothing about us without us' applies from a rights-based perspective, but evidence shows their participation also enhances the effectiveness of the interventions. In the Stigma Assessment & Reduction of Impact (SARI) project in Indonesia, people affected by leprosy co-designed the interventions and were involved in the implementation. For example, persons affected served as lay counselors or made the videos that were screened in the community. The participatory nature of the project was perceived as important for its success.

Third, a thorough understanding of the local context, world view, and knowledge, beliefs, and fears concerning leprosy is important for designing interventions and materials. The materials must be appropriate and effective to address the real needs of the people and to change their attitudes and behavior regarding leprosy.

Fourth, stigma is a sensitive subject. For several reasons (e.g., because people have concealed their diagnosis from family members or neighbors, because of changes in power relations), there may be unexpected, unintended, and undesirable effects of stigma-reduction interventions. It is important to always ask for consent from the persons concerned when there is a risk that their status may be revealed. Furthermore, it is necessary to discuss very carefully how any materials such as photographs and video will be used. Having people and procedures in place that help deal with these issues in an appropriate and timely manner is very important.

Evidence on the effectiveness of interventions is very scarce. Very few studies have attempted to compare methods or to examine the sustainability of the positive changes that have been documented. **Proper data on the effectiveness and sustainability of stigma reduction interventions would greatly enhance the scientific credibility of those interventions and thus increase the potential funding opportunities for implementation.** Appropriate interventions should also be developed, tested, and implemented. There is an urgent need for more studies on the effectiveness of stigma-reduction interventions in other settings.

Excerpts - Stigma Related to Leprosy-A Scientific View. The International Textbook of Leprosy; Part I – Clinical Sciences; Section 4-Rehabilitation & Social aspects; Chapter 4.5

40 "UN Resolution 2010 : Mandate to disseminate the principles and guidelines"

. . . . stakeholders : NHRC, Government and NGOs unaware of India's obligations . . . .

The Leprosy Mission India Trust

CNI Bhavan, 16, Pandit Pant Marg, New Delhi, India

What mechanism has the Government put in place to disseminate the Principles and Guidelines to its citizens? (translation into local languages or any other)

Although the UN resolution was adopted in the year 2010, in which India also participated and accepted, the Government has done nothing concrete within its own mandate to disseminate the Principles and Guidelines document. It is not available either in text or a web-link in either of the concerned central ministries, the Ministry of Social Justice and Empowerment (MSJE) and the Ministry of Health and Family Welfare (MFHW) under which leprosy falls.

Additionally, the document was not referred to by either the MSJE that drafted the initial Rights of Persons with Disabilities Bill, 2011 (RPD) or by MSJE or other concerned officials in the various edited versions of the said Bill in the preceding two years. This happened despite the fact that leprosy cured is a recongnised category of disability under the existing legal structure on disability under the PwDs Act, 1995, which was being reviewed to be replaced by the new bill to bring the main disability legislation in line with India's international obligations on the subject matter of disability.

The only UN document referred to and relied upon in the process of the RPD Bill has been the United Nations Convention on the Rights of Persons with Disabilities, 2007 (UNCRPD). **During our interactions with various officials of the government and its quasi-judicial structures like the National Human Rights Commission and parliamentarians of the government, we found that most people within the system were unaware of the Principles and Guidelines document.** Even a large majority of disability activists and professionals still remain unaware of the existence of India's obligation under the Principles and Guidelines document.

Have any policies, action plans or any other measures been taken at the national level to promote awareness-raising of the issue of discrimination against leprosy affected persons and their family members?

The NLEP has come out with a 'Guidelines on reduction of stigma and discrimination against persons affected by leprosy'. For the purposes of this document, NLEP has identified a close link between stigma and discrimination. The positive aspects of this guideline include the stress of working in collaboration with multistakeholders in the society and reaffirming that the implementing personnel/officers in each region can adopt any other initiatives and means to achieve the goal of reducing discrimination against persons affected by leprosy. However, this document is limited to persons affected by leprosy and fails to include their family members in its scope of application.

In addition to the above guideline, the NLEP came out with a document 'Behaviour Change Communication – Strategy' focusing on the need and use of IEC for raising awareness on discrimination and stigma against persons affected by leprosy. Under this guideline focus is laid on including persons affected by leprosy in village level gram-sabha meetings, health melas and cultural festivities as a means of reducing stigma and discrimination.

The document provides in detail the activities that need to be done at Central, State, District and Block levels to have impact. However, little is known of the implementation and success of these measures. **Yet, self-stigma, stigma and discrimination remain an everyday reality for the higher majority of persons affected by leprosy.**

Excerpts - TLMTI Responses to the UN on the Status of Adherence to A/HRC/29/5 for India

A ‘Elimination’ of leprosy

'Elimination at national level', declared in December 2005 triggered a weak debate and a total unquestioning adherence of the government dictum. The stakeholders had no clear view of its consequences. While 1 case per 10,000 population is good intermediate target to reach, considering it was also an endpoint for leprosy elimination efforts diluted the issues in its very last mile. This last mile is extremely critical, rather uphill and resource-intensive is different ways.

After 15 years, it is a recognized fact that there is no tangible decline in new leprosy cases being detected (and reported) every year. It is indicative of the haste and short-sightedness of the definitions that guided the officials to record and report the attainment of 'elimination' status. This led policy makers and people to believe that the disease has been eradicated completely – zero leprosy transmission – zero new cases, which was far from the truth.

Firstly, the new leprosy cases detected are incorrectly called as 'hidden cases'. These cases in fact represent “an active reservoir of infection in the community” and are responsible for transmission of disease. This situation is 'precariously' close to resurgence of leprosy. *This calls for corrective actions.*

Secondly, 'elimination' has become an eluding phenomenon (as is also evident with the polio, tuberculosis and the very recent HIV stories). This is mainly due to an absence of an effective post-elimination programme strategy to correct and root out the misreporting. *Hence, a serious rethinking on methods of validation and case holding of all new cases in the community.*

Thirdly, the system of case detection based on self reporting and the annual search campaigns involving the public health functionaries had a result indicative of the persisting problem and the inadequacy. NLEP reported 1,20,334 new leprosy cases in 2018, which mean that in every four minutes, one person is diagnosed with leprosy in India. Unfortunately, this regressive 'trend' is unabated since 2006. *Reversing this trend demands intensifying selectively focused community level efforts to identify the hotspots of the infectious cases.*

Fourthly, need to question the system's reluctance to record actual new leprosy cases for fear of losing its 'elimination' status administratively. There is an urgency to reorient the programme based on the objective indicators. A nation-wide sample survey was conducted by ICMR in 2016 on the recommendation of Indian Parliament appointed committee and this revealed a large number of cases that go undetected by NLEP pan-India. *It is high time, we reconcile with reality.*

Finally, a vigilant and proactive actionable programme involving all key stakeholders is needed to pull the NLEP out of the muddle. Decisions on the course of action should be evidence-based to effect a change in reducing the disease burden and subsequently, disability, stigma and discrimination. Collective and concerted thinking can help NLEP to find answers to several critical issues in evolving and clinching a new perspective that can guide us to propel a new strategy towards a leprosy free India.

B >>> Reducing disease burden

In retrospect: The success of SET (Survey - Education - Treatment) strategy (1955) under NLEP with the inclusion of MDT (1983) has undoubtedly contributed to the drastic reduction of disease burden in our country. This has prompted the Government to integrate the leprosy services into general healthcare system in 2002. However, this integration and the assumption that leprosy 'ceased to be a public health problem' countrywide has proven to be short-sighted and erroneous; 15 years of integration failed to build capacity of the general health care staff to carry out the key functions of leprosy control.

Absence of an alternative strategy: The crucial programme components such as active case detection and case holding activities, skin smear examination to diagnose infectious leprosy cases were abandoned during post-elimination. Downsizing the structures and tools for monitoring led to total absence of surveillance and measures of valid data collection from the field. The unrelenting disease burden has placed leprosy control in an unreliable slippery path of resurgence. Scientifically, the continued transmission is at the root of the persistent disease burden. This is due to absence of an alternative strategy that could have effectively stood in the way of weakening of control measures under NLEP in the integrated settings.

All case detection campaigns were ritualistic – too late an effort to prevent disability: Aimed at detecting 'early' leprosy, NLEP launched annual campaigns among selected districts and states without an impact on reduction in disability burden. The 'flip side' of these campaigns is its failure to add any incremental benefit in reducing the disease burden. The large number of cases detected through such annual campaigns didn't alter the overall annual detection rate. The good news is that the NLEP is reported to be rethinking on the effectiveness of this expensive short-term campaigns for case detection. As of now there is an apparent effort to refocus on the public health system and community engagement. However, redefining the objectives and priorities of NLEP is urgently needed with the focus on ground level activities.

New effort: Yet again an attempt to reduce the disease burden with post exposure prophylaxis with single dose rifampicin (SDR) for all contacts of new leprosy cases launched under NLEP merits attention. GoI launched it on 2 October 2018 across the country. However, the scientific community is yet to be convinced on the efficacy and cost-effectiveness of this major intervention in reducing the disease burden.

ALERT-INDIA advocates,

- Need to take on a surveillance-based control mechanism, inbuilt into the programme, by narrowing down on the 'hot spots' through systematic epidemiological enquiry coupled with intensified, selective case detection and allied vital interventions. Alongside these, also focusing on evolving new epidemiological indicators and tools to measure outcome.
- It will be useful to concur with WHO guidelines for treatment and monitoring tools, while assessing programme performance.
- Efficacy of such an approach to reduce disease burden warrants active engagement of stakeholders from public health & civil society to bring about a long-term impact.

C Tackling disability and stigma

Bacterial cure is an easy response, given the access to drugs. The disability and stigma associated with leprosy, which indicate delayed detection are the signs that need closer monitoring, response and tracking. In the current format, the NLEP accords least attention to the concerns of the people affected physically, as a result of leprosy. Once disabilities set in, social rehabilitation becomes very challenging and demanding for those affected whether they are living in the community or are in self-settled colonies and institutions.

Disability: The mid-term evaluation report, 2016 of NLEP estimates more than three million people with deformities caused by leprosy living in our country – this is a direct result of the absence of risk assessment, follow up and counselling. It implies that a substantial number of people among them who live with impairments could have been identified and addressed sooner and that they will now need support through their life span. Interventions required for prevention and care of disabilities, its complications, counselling, training in self-care and other socioeconomic measures essential for quality of life that is often not addressed.

Stigma: The stigma associated with leprosy and seclusion of those affected by the disease persists in different measures. Discrimination and stigma lead to mental affliction - depression and anxiety - with the burden of self stigma and fear of exclusion by the society. Acceptance of the people affected by leprosy in the society will go a long way in reducing the stigma and discrimination.

Discrimination: A significant development in recent times is the public interest litigation that had challenged 119 statutory provisions that are discriminatory of people affected on the grounds of leprosy. In response, the Supreme Court of India has passed directions to the Government to ensure the rights of people affected by leprosy and eliminate discriminatory attitudes towards leprosy. In yet another positive step, the Indian parliament passed an amendment to remove discrimination against leprosy patients in various laws, especially those governing marriage and divorce, across faiths.

What needs to change?

Routine leprosy control programme needs inclusion of tools and methods to detect and treat nerve damage early to prevent occurrence of new disability. Disability Prevention and Medical Rehabilitation (DPMR) programme under NLEP has a lopsided priority of allotting resources only for 'correction' of disability and no programmatic support to 'prevention' related activities. This calls for a decisive review of selective emphasis on surgical corrections that can help patients to overcome the effects of disability and associated stigma.

A community-supported multi-faceted programme is needed for an effective implementation of the directions of Supreme Court. UN guideline to eliminate stigma and discrimination against leprosy are a useful guide in this regard. Real change requires proactive policies and plan to counter stigma with community action, coupled with peer group and family support to ensure ease of social life; this will also include bringing back those stigmatised, ostracised from the society. Above all, a renewed social will and wave to revamp programme priorities at the primary and secondary level by way of education and engagement, thus ensuring appropriate responses to the needs of affected people.

Awareness, Early Detection, Treatment & Training

Leprosy Referral Centre: Disability Prevention & Care Services

30 years later

. . . . A prediction sadly true today!

Can leprosy be eradicated from India?

Prakash Kotecha[1] and Trudy Harpham[2]
1. Medical College Baroda, Gujarat, India and
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In 1982, when the government declared the National Leprosy Eradication Programme (NLEP) after 27 years of the National Leprosy Control Programme (NLCP) - in 1955, the total number of registered leprosy patients - and estimated number about 5 million - was the highest ever recorded since the inception of the programme. This by itself indicated that the country was far from achieving control and, at that stage, to turn to the eradication programme was paradoxical.

Instead, it should have been time for introspection as to why the control programme was unsuccessful. The aim to eradicate leprosy from India was political - no technical expert would have thought eradication by the year 2000 (proposed by WHO) was feasible. The introduction of a timebound eradication programme may have initially brought enhanced resources and funds but has a danger of serious setbacks at a later date when failure looms.

Source: Health Policy and Planning; 6(1): 82-85: Oxford University Press 1991

Anti-leprosy Day (2020) observation by the delegates of the
48th National Conference of Indian Association of Dermatologists, Venereologists & Leprologists at Pune, 30 January to 2 February 2020
Photo courtesy : Dr. Claudio Salgado, President of the Brazilian Hansen Disease Society.