SERIES NO. 6

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

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FOCUS

Integration of NLEP into General Health Care

Operational Challenges and Issues

Leprosy Out-reach (LOR) Camps

Operational Guidelines

Leprosy: Issues and Concerns

Children; Women; Community; General Health Care; Elimination Targets; Disability and Health Policy

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Focus on the decade of integration : Experiences and lessons learnt

III. Leprosy : Issues and Concerns

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Concerns of integration : the right time for mid-course correction

This issue of Focus is timely in the sense it is introspecting the strategy change that happened a decade ago. As we know leprosy control programme has moved from the vertical mode to horizontal mode of integrating with general health care (GHC). A lot of resources spent; capacity building was carried out; and operational guidelines were prepared to integrate to GHC. It was quite logical to adopt this approach at that juncture. While there are some success, there are certain concerns of integration. This issue of Focus delves on these concerns. There are areas where new cases have been detected.

A major concern is new cases of children that remain constant in the decade of integration. Further deformity is also a concern. The articles in this issue specially focus on the leprosy and its social and economic consequences for women patients. One article describes the Leprosy Elimination Action Programme or LEAP of ALERT-INDIA. Under LEAP, Leprosy Outreach Camps were carried out to strengthen and sustain the referral services within the GHC. It is a laudable effort of ALERT-INDIA. It would be better if this strategy is scaled-up all over the country with the technical input from ALERT-INDIA.

Though integration was logical, for me, it is not realistic. The GHC is weak in infrastructure and human resource. It is already overburdened with other health progammes. Primary health centres focus on maternal and child health programme to bring down the maternal and infant mortality rates to move towards achieving the Millennium Development Goals. There are other priority diseases like tuberculosis, and malaria.

Therefore it may be a bit unrealistic to expect them to consider leprosy eradication as a priority. There is need to undertake an intensive evaluation of all the components of integration including the motivation of GHC staff to give priority to leprosy. It is the right time for mid-course correction. Let us not miss the opportunity to develop new strategies to eradicate leprosy.

11th October, 2015

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Crying need for a new approach to resolve the persisting issues of leprosy control

Ten long years of NLEP under the obligation of integration has rendered the critical measures of leprosy control irresolute and ineffectual. The trend of increasing number of new leprosy cases in the country and the deformed among the young people convey to us an adequate warning of yet another generation of disabled population in addition to those who exist already who need care and support.

Persons Affected by Leprosy (PALs) today face ignorance, indifference and apathy of the general healthcare providers in the integrated setting. The lack of knowledge among the health care providers and the wearing away of the fighting force has led to the loss of certain gains of the past decades. This is apparent all over, expressly in the endemic states. *The serious cause of concern at this point is the all pervading weariness that has set in NLEP.* It is important to fathom the factors responsible for the turnabout in the leprosy control programme in the country and take counteractive steps before it is too late.

The present impasse in the integrated leprosy control programme implemented under NLEP prescription calls for a *critical assessment.* Specifically, a realistic look at the performance of the *Modified SET, Disability Prevention and Medical Rehabilitation (DPMR), Special Search Activity (SSA) in high endemic districts and blocks, new NGO Schemes for promoting involvement of NGOs in leprosy services* up to the level of districts, blocks and PHCs. The findings of evaluations in this period and their recommendations are useful inputs for an authentic reassessment of the programme. It can guide us to redefine the policy outlook.

The literature review from a cross section of feedback and views are presented as a compilation in this issue of "Focus" is aimed to help us think effectively - to identify the aspects that are 'positive' and 'feasible' during the 'integration phase' within the present status of general health care (GHC) system. Strengths of the present programme to the extent 'visible' and 'confirmed' need to be recognized as the building blocks for leprosy control under NLEP during the next decade.

A revised NLEP is the need of the hour to direct a comprehensive concerted action for leprosy control.

Sion, Mumbai
11th October, 2015

A. Antony Samy
Chief Executive

I

INTEGRATION OF NLEP INTO GENERAL HEALTH CARE:

Operational Challenges and Issues

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The fight against leprosy

India began the fight against leprosy in the era of effective modern drugs. The bacterial cure is definite and considered favorable to eliminate the disease by a planned vertical national programme: National Leprosy Control Programme (NLCP) / National Leprosy Eradication Programme (NLEP) with Survey, Education and Treatment (SET) strategy with Multi-Drug Therapy (MDT) for five decades. The chronic nature of the disease and the prevailing socio economic situation has stood against achieving long-lasting final success. In 2004, we did have an opportunity by way of 'confirmed' low level of prevalence of leprosy in most parts of the country. This achievement was considered a 'historical opportunity' to integrate the NLEP into general Health Care (GHC) system and 'to eliminate leprosy as a public health problem' at the national level in 2005.

Integration

Integration of health programmes has always been propagated basically for economic and logistic reasons and to achieve optimal results. In the words of Dr. Wardekar (A Window on Leprosy, 1978), the architect of NLCP, "we plan vertical programmes for particular health problems in order to bring down the intensity of the problem to a manageable level whereby it can be tackled as any other disease in the community through the general health care and delivery system i.e., the primary health centers.". Today the numerical intensity may be lower down but no confirmation on the containment of 'infection' and 'transmission'. It is confirmed by the fact that new cases continue to occur throughout the country. Lack of information on locations, actual number of new Persons Affected by Leprosy (PALs) is not known and what is known is alarming.

One of the key assumptions at the time of integrating leprosy into GHC system was that the large contingent of peripheral health personnel would be made available to hasten and sustain case detection activity in routine programme. They would weed out the backlog of hidden cases. This has not happened. Routine Monitoring and Evaluation has come to naught at all levels. The lack of accountability and the all pervading weariness that has set in NLEP is the foremost cause of concern. We have more than enough evidence to show that we failed to contain the problem at a 'meaningful level' even after a decade of experience under integrated setting.

The need for a policy dialogue on leprosy

'Integration' was considered as a sequential policy direction. A policy dialogue on leprosy after a decade of 'integration' need to address all the major concerns that are very conspicuous to all, especially to those who care to see 'elimination of leprosy' in reality. This calls for a critical appraisal of the programme implemented under NLEP prescription. Need to look at different components of NLEP and their implementation up to the level of districts and blocks: Modified SET, Disability Prevention and Medical Rehabilitation (DPMR), Special Search Activity (SSA) in high endemic districts and blocks, new NGO Schemes for promoting involvement of NGOs in leprosy services. The serious cause of concern at this point is the all pervading weariness that has set in NLEP. The momentary, short-lived actions at the GHC level or by NLEP staff do not help to contain the spread. The findings of official evaluations of NLEP conducted during this period and their revelations of the situation need to be part of this policy discourse. They can guide the policy direction. A comprehensive concerted action is need of the hour.

Following are the programmatic analysis of the basic constituents of integration such as 'participation of GHC system', 'retaining human resources' and 'strengthening referral services' that need a serious consideration, if we foresee to attain a 'leprosy free India'!

I. Participation of GHC system:

The Integration of leprosy programme stipulated GHC to take care of all leprosy related services with a brief sensitization / short term trainings, if and when done, and take in leprosy as one of their public health priorities. As mandated by various policy documents, 'participation of GHC system' was envisaged to be accomplished by the trained leprosy personnel. NLEP totally relied on them to take on a specialist role and train medical and paramedical teams with paltry funds and nil training for the new role.

On the other hand, the GHC teams in general an unenthusiastic participant to take on an additional task that demands certain degree of learning. Hence involvement was limited to 'individual interest' of MOs, nurses, and other health functionaries who are 'inclined' to learn and 'motivated' to practice.

Overall, the left over NLEP teams from the 'vertical' era constituted the nucleus for leprosy diagnosis and management. They were considered main stay with requisite skill and expertise. These teams are gradually vanishing in the system due to total absence of an appropriate planned replenishment.

The GHC systems hard shelled indifference and pathetic inadequacies of today are direct result of the 'historical fallacy' of the 'vertical NLEP decades' that kept an unwarranted 'extreme aloofness' with the rest of the public health system until ten years ago.

As a result the social perspective of the health care providers is no different from that of the general public when it comes to prejudices and exclusion and the resultant despicable treatment meted out to PALs till date.

The ignorance and indifference of the GHC staff to the growing incidence of morbidity is further accentuated by the fact of zero mortality. The demanding public health care issues are given the priority in terms of time and resources. The GHC's role as a leprosy care giver and promoter of 'control measures' are negligible and the consequences are grievous in the endemic states and can prove to be the same in others in a relatively short period of time.

CHALLENGES AND ISSUES

1. *Forestalling a permanent disconnect:* The prevailing 'everyone's job is no one's job situation' calls for an urgent underpinning. The requisites for the large number PALs, who are cured, survive in the community enduring with scourge of the disease due to its long term consequences. Forestalling a permanent disconnects between the general medical fraternity and the PALs in the community calls for measures that can bridge the 'knowledge gap' with reliable learning and linkages at all levels.

2. *Addressing concerns:* The GHC staff is largely untrained and clueless to fulfill the critical leprosy control tasks transferred / entrusted to them for the past ten years. The GHC system is reluctant to acknowledge the critical need for identification, training, and selective deployment of designated teams at different levels appropriate skills.

3. *Course setting:* The government's perspective towards the skeleton of vertical leprosy staff available including a handful infused directly by NRHM suffer an unfocused and directionless quandary with reference to financial out lays, the role and scope defining, monitoring methods and tools. The structural readjustments have created mixed reactions resulting in inadvertent neglect of work and a false conjecture that their role has come to an end on reduction of prevalence rate and reaching the stipulated 'elimination level'. An urgent rational mid course correction needed : to introduce new work force persevere in leprosy work; to ensure precise skill set and nuance required to engage proactively with the PALs and community.

4. *Social Communication:* Myths and misconceptions about leprosy affect the social interface and social cognition. It is a scourge on account of trouble free nature of leprosy coupled with lack of scientific knowledge both among the health care providers and the community at large. Further, inadequate information to the leprosy afflicted and the community on the minimally 'available leprosy services' is yet another major factor. The disruption of the 'established referral channels' of the vertical era put the accent on the need to build up a wider pragmatic communication stratagem. The role of voluntary agencies as dedicated communicators and tertiary care providers is limited in terms of resources and the reach. A purposeful interface with civil society organizations and all segments of health care providers can help enhance social recognition.

II. Retaining human resources

The decades of unparalleled success* in leprosy control was largely due to a consistent sound policy proclamation that guaranteed a massive trained human resource under an independent, and dependable admin structure. They aggressively identified and tackled a huge population of affected people with simple tools to diagnose, proven modern drugs to treat, well enunciated down-to-earth SET methodology. Today the small army of specialized human resource is disenchanted and their morale in low ebb. The changes and deplorable underutilization on priority tasks relevant to leprosy control measures has rendered them almost inconsequential despite the crying need in the field for expertise involvement and guidance.

CHALLENGES AND ISSUES

1. *'Transfer' of responsibility:* Governments' policy guidelines that assign the leprosy control tasks to the GHC workforce are yet to meet the requisites. In fact, they are met by the available technical staff from the vertical era are 'appended' to a group of PHCs in a 'taluka' entrusted with responsibility to train and provide technical support. The district level NLEP authority is called to monitor the PHC level control activities. Regardless of guidelines, the responsibility of the programme rests with the vertical leprosy staff (dwindling numbers) whose designations are changed in appreciation of their 'assigned' a new role at the PHC/UHP level' during this phase. This practice for a decade has not changed the GHC functionaries' 'perception' or potential of their role.

2. *Elimination targets:* Unfortunately, directly or indirectly, the LTs and MOs attached to NLEP are 'pushed' to contribute to the 'reduction in prevalence rate' and sustain or reduce it further as their 'main task'. The target oriented performance appraisal confuses the cadre – to detect or not to detect - on how to contribute to leprosy control especially at the time of recording new cases that increase the PR level of the district. The practice not recording of new cases – specifically PALs with disabilities, deformities and complications for the benefit of achievement of short term 'elimination target' in long term blur epidemiological assessment; deny appropriate quality care and services and defeat the goal of leprosy control. There are conscientious officers and workers who are 'exceptions' to this sort of performance committed to the fight against leprosy.

3. *Short term 'campaigns':* The entire effort to 'suspect' and confirm a patient of leprosy under NLEP is limited to short term 'campaigns' and 'voluntary reporting'. PHC health functionaries' role as spokespersons for leprosy in the community is dismal. The policy emphasized and requires that the surveyor or searcher need to explain the signs and symptom of leprosy – the 'suspicious signs' of leprosy and what is not leprosy ('differential diagnosis') at the centre or to the family during SSA in the community. A sound IEC strategy is required to achieve – as the IPC prescribed and practiced is often bereft of communication tools and scheme. A routine entered to fill daily diary when no special task is. Furthermore NLEP fails to focus on promoting routine case detection activity and given up surveillance through technical staff available at its command.

4. *The 'DNT' scheme:* The first decade of integration diluted all the key elements that contributed to a viable control situation in the reduced PR scenario. Essentials for disease control were negated in principle and practice. Noteworthy among them is planned development of new breed professionals for various levels requisite numbers while sustaining the skill, knowledge and the acumen to deal

with disease gained over the past decades. Deploying the available expertise for this purpose under DNT scheme was conceived and implemented ‘mechanically’. Abandoned as special strategy within the 3 years and retained it, as a routine part programme without its core – the technical experts. The aim of the scheme was to systematically train, prepare and equip the GHC medical fraternity turned out to be a diktat on paper and purposeless in practice till date. The know-how and the expertise accomplished over the six decades are on the wane every passing day. The need for retention and replenishment of specialized talent to deal management of exigencies of the disease is almost taken out of NLEP scheme. An alternative appropriate all-inclusive prescription is a desperate need.

III. Strengthening referral services

Following integration, in 2004, GOI envisaged ‘to develop a suitable referral services for providing services to complicated cases, reconstructive surgery, capacity building of needy professionals and supply of footwear by involving established NGO Institutions” The first programme formulation akin to the objective came three years later as a part of 11th Five Year Plan from April 2007 to March 2012 and continued through 12th Five Year Plan from April 2012 to March 2017.

The GOI proposed an operational plan for DPMR as an important component of NLEP to provide quality services to leprosy affected persons. Operational Guidelines were issued. DPMR activities are proposed to be carried out within the existing 3 tier system – the primary, the secondary and the tertiary level care. The secondary level crucial to guide the primary and deliver quality care is noticeable absent.

The GHC services were not equipped technically and operationally to accomplish the tasks handed over to it. It was evident from the start that additional inputs and resources are required to address the problems related to consequences of leprosy during integration phase. There is a dire need to create appropriate support structures and effective referral mechanisms within the GHC system, to make possible sustained quality leprosy services and ensure the rights of people affected by leprosy.

CHALLENGES AND ISSUES

1. *Referral Mechanism:* There is a perceptible absence of system and machinery in place equipped to actualize the objectives of DPMR programme, to manage the referrals and re-referrals between ‘primary’ and ‘tertiary’ levels of public health care system. The impracticality to make a definite proviso for an adequately ‘leprosy trained medical cadre’ at primary and sub centre level calls for alternative human resource development and deployment - a dedicated cadre at the block and district levels to adequately equipped to achieve a referral mechanism.

2. *Quality Care:* ‘Sustaining the quality care at the secondary’ level was assigned to the remnants of vertical system retained care and made accountability the tasks to actualize the objectives of DPMR programme. The District Nucleus Team (DNT) pulled out of them was to engage

and involve the GHC system in provision of quality leprosy services. In practice this proviso failed to address the needs of the backlog of cured patients with disabilities and deformities living in the community and remains utterly uninformed about the addition of 'deformity prone' patients.

3. *Tertiary Care:* The 'partnership approach' to involve the specialties - dermatologist and surgeons got restricted to a limited number of centers at the private and public hospital facilities of the past 'vertical era'. These facilities faced partial or total closure with paucity of funds. With escalation of cost to maintain the facility began to recover part of service cost. Comparatively less number of PALs needs tertiary hospital care. GHC system looks at them merely as surgical correction centers under DPMR. Most specialist centers do not have young leprologist. The need is for a planned investment to nurture a new breed of 'leprosy specialist' at different levels. Further, in point of fact the 'general' tertiary health care services to PALs is often denied in public health facilities due to lack of knowledge and in case of deformed PALs due to prevailing stigma and prejudice.

4. *Training Centers:* Quality care to PALs at the designated tertiary care cum training centers also suffered a serious setback with declining funding or total stoppage of funding for designated training courses to provide for specialized manpower – both medical, paramedical and Physiotherapy has led to larger drawback to provide for technically qualified service providers to PALs spread across the country in need of services. Medical colleges attached to teaching hospitals – both public and private are the potential new tertiary care givers – centers of excellence, besides being the 'master trainers'.

IV. Concluding Remarks

The 'first decade of integration' that followed announcement of 'elimination' of leprosy has paved way for a silent comeback threatening to erode the five decades of historical achievements. This is considerably apparent in the endemic states. It is important to decipher the factors responsible for the turnabout in the leprosy control programme in the country during the last ten years, both in 'endemic' and 'non endemic' states.

On the other hand, it is also equally significant to identify the aspects that were 'feasible' in practice and made 'positive' contribution during 'integration phase' within the present status of the GHC system. 'Strengths' in the programme to the extent 'visible' and 'confirmed' need to be recognized as the building blocks for the next decade. Experience calls for decisive changes. Leprosy control in the country needs a policy review and an appropriate restructuring to achieve our well set goals. ■

II

LEPROSY OUT-REACH (LOR) CAMPS

Operational guidelines

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Sustaining quality services

The integration of leprosy services into general health care system is one of the major focus of NLEP to accelerate the elimination process. The main objectives of this approach are to increase accessibility of MDT services, sustain quality services and reduce stigma and disease morbidity. Key players in leprosy control programme such as WHO, ILEP and NGOs have accepted 'integration' as the most realistic strategy to sustain leprosy control activities. Despite bringing down the overall prevalence of leprosy, new cases continued to surface and a significant number of them are detected / report with disabilities and deformities. Besides, there is a backlog of people cured of disease but with disabilities and deformities in addition to people with leprosy who are prone for developing new deformity during and after MDT. In order to prevent disabilities due to leprosy, there is a need for an effective strategy that supports the existing general health care (GHC) systems at all levels to improve access and utilization of leprosy services by the people affected by leprosy.

Strengthening DPMR services under NLEP

ALERT-INDIA launched a 'Leprosy Elimination Action Programme - LEAP', as a strategy to evolve a sustained leprosy control programme that would eventually strengthen the process of integration through planned interventions. One of the crucial interventions of LEAP is to establish Leprosy Referral Centres (LRCs) that will assist the GHC facilities at the sub-district level to provide quality leprosy services that are evenly distributed and easily accessible by people affected by leprosy. These components are also included in the Disability Prevention and Medical Management (DPMR) guidelines of NLEP.

Purpose: the need to reach out from LRC

Enabling the PHC personnel to diagnose and treat leprosy and its related complications is one of the important tasks of NLEP that need to be achieved before handing over the responsibility as defined in the operational guidelines of DPMR. Although this has been done religiously in all the states, the PHCs are not prepared and equipped to provide appropriate leprosy services to a large number of new and cured leprosy cases needing sustained care with appropriate referral services. This emphasize the need for strengthening the PHC through provision of technical guidance, organizing training for the PHC staff, provision of services for people affected by leprosy with improved referral systems.

'DPMR' link strategy

Therefore, ALERT-INDIA promoted Leprosy Out-Reach (LOR) Camps as a strategic intervention under LEAP that is aimed to promote, strengthen and sustain referral services within GHC system with a special focus to establish linkages between the PHCs and the LRCs established in Rural / Sub-District Hospitals at block level to provide quality leprosy services for the People Affected by Leprosy (PAL). This strategy adopts an approach to strengthen the DPMR services by sensitizing, involving and augmenting the capacity of healthcare personnel at PHCs in the district.

Overall Goal: Ensuring availability of quality services and improving accessibility for PALs through LOR Camps by strengthening the referral systems.

Specific Objectives:

1. To raise the knowledge and skills of the healthcare personnel at PHCs in providing comprehensive leprosy services to all the people affected by leprosy.
2. To establish and promote a viable referral system between PHCs and LRCs at secondary level as well as with other GHC facilities in the district.
3. To update the baseline information of all eligible persons affected by leprosy registered under PHC who need sustained care and services at LRCs that can help to develop specific referral action plans for regular follow-up.

PRE-CAMP ACTIVITIES

1. **Orientation to District Nucleus Team (DNT) and Leprosy Staff of NLEP in the district**
    - The LEAP Technical Team (LTT) of ALERT-INDIA to organize a one-day orientation for the following members of District Nucleus Team (DNT) and leprosy staff of NLEP in respective district.

Participants of the orientation on LOR Camp

a) District Leprosy Officer (DLO)

b) Medical Officer (MO)

c) Non Medical Supervisor (NMS)

d) DPMR Consultant

e) Physiotherapist (PT)

f) Non Medical Assistant (NMA)

Contents of the training (Orientation)

a. Orientation on referral system under NLEP - DPMR strategy & guidelines.

b. Context & strategy of LOR Camps including logistic and budget provisions.

c. Operational methodology of LOR Camps including records / formats & reports.

d. Plan for collecting & updating list of PALs targeted for the LOR camp.

Methodology of the training (Orientation)

a. Audio-Visual Presentations (power-point) and demonstration.

b. Print materials on operational methodology for LOR Camp.

2. **Administrative procedures for LOR camp / deputation orders for training**
    - The DNT to sensitize the respective Taluka Health Officer (THO) of the taluka and Medical Officer (MO) of the respective PHC on the LORC.
    - The DNT to finalize the date for the camp in consultation with THO and obtain official permission from District Health Officer (DHO) and Civil Surgeon (CS).
    - The DNT to undertake administrative

formalities and arrange to issue official circular / orders from DHO / Civil Surgeon for deputation of THO / NLEP / PHC staff.

- The DNT to ensure active involvement of the concerned NLEP staff in the block for the camp and encourage the PHC staff to provide services to PALs.

3. **Training of Trainers (ToT) to health officials and supervisory staff of PHC**

   - The DNT in coordination with LEAP Technical Team (LTT) to conduct one-day block level Training of Trainers (ToT) for the following supervisory health staff in the respective block.

Participants of the training (ToT)

a) Taluka Health Officers (THO)

b) NLEP staff (Non-Medical Supervisor and Non-Medical Assistant)

c) Medical Officer – one each from all PHCs.

d) Health Assistants – two (both male & female) each from all PHCs.

e) Medical Officer – one each from all Rural Hospital / Sub-District Hospital (to be deputed for LOR camp).

f) Staff Nurses – two each from Rural Hospital / Sub-District Hospital (to be deputed for LOR camp).

Contents of the training (ToT)

a. Orientation on referral system under NLEP - DPMR strategy & guidelines.

b. Context & strategy of LOR Camps including logistic and procedures.

c. Operational methodology of LOR Camps including records / formats & reports.

d. Collection & updating baseline information of the PALs targeted for the LOR camp.

e. Orientation on the techniques for POD / POWD in leprosy with demonstration.

f. Preparing action plan for LOR camp at PHC level.

Methodology of the training (ToT)

a. Audio-Visual Presentations (power-point).

b. Demonstration on methods of nerve function assessment / physiotherapy services.

c. Group exercise / methods of counseling and referral services.

4. **Sensitization of peripheral health staff (ANM / MPW / ASHA Supervisor) at PHC**

   - Organize sensitization in the premises of PHC for PHC staff. Maximum 20 participants to be targeted for each of the training session.
   - The trained Medical Officer and Health Assistants of the PHC under the guidance of NLEP staff to conduct a half-day orientation on LORC for peripheral health staff of PHC.

Participants of the training (Orientation)

- Auxiliary Nurse and Midwife (ANM)
- Multi Purpose Worker (MPW)
- Accredited Social Health Activist (ASHA) Supervisor
- Pharmacy Officer (PO)

Contents of the sensitization session

a. Leprosy Referral System under NLEP: Objectives, functions & referral services

b. LOR Camp – Purpose and methodology including the type of services.

c. Roles and responsibilities of peripheral health staff in LOR Camp.

d. Sharing the updated baseline information of the PALs targeted for LOR camp.

e. Preparing a plan of action for mobilization of PALs and assisting in organizing camp.

f. Role and responsibilities of PHC staff in leprosy services & referral system.

5. Collection & updating list (baseline information) of PALs targeted for the LOR camp

- The LTT / NLEP staff posted in the LRC will prepare and update the village / PHC wise list of PALs (Baseline) and identify eligible PALs to be targeted for LORC.

The village / PHC wise list of PALs should include the following:

i. All new PALs with MB type registered at PHC in the past 5 years (LF – 2 Register of NLEP).

ii. All new PALs with lepra reaction either on MDT or completed MDT (Reaction Register)

iii. All new PALs with Grade 1 or Grade 2 disability who are registered at PHC (Deformity Register)

iv. All PALs (High risk / Lepra reactions / Grade 1 / Grade 2) who are registered at respective LRC in the block.

6. Preparation for LOR Camp and arrangement for material and logistic support.

The following are the roles and responsibilities of various functionaries responsible for accomplishing specific tasks for preparation to conduct LOR Camp.

LEAP Technical Team (LTT)

1) The LTT to facilitate all the trainings and provide necessary training materials as well as technical and logistic support for conducting the trainings and LOR camp.

2) The LTT to undertake the following tasks one day prior to the LOR camp.

   - Keep the records (I/D Card, Case Card and Assessment Card from the LRC) of each PAL along with demographic details and arrange in order of village wise (baseline) list.
   - Keep 3 sets of baseline list of PAL due for LORC each one for registration, assessment and report counters including general stationery.
   - Make available the necessary equipments such as EMS and Wax Tub (from the LRC in the respective block) and ensure its functional status with power supply.
   - Make available adequate number of soaking tubs and dressing instruments and other materials (dressing kits and hand splints).
   - Make available adequate quantity of supportive drugs (preferably from the

Pharmacy of PHC) from the LRC stock as per the estimation.

District Nucleus Team (DNT) of NLEP

1) DNT in coordination with NLEP staff (NMS / NMA) to facilitate sensitization sessions in the respective PHCs.
2) The DNT in coordination with LTT to undertake the following tasks one day before the LOR camp in the respective PHC, where the camp is to be held.
   - Convene a meeting of PHC staff to review the preparations for the Camp and involve the Taluka Health Officer (THO) in the organization of LOR camp.
   - Assign specific task to each of the supervisory staff in the PHC and explain their individual role in the camp.
   - Arrange separate counters for the following services with name boards and ensure adequate space and furniture support.
     - i. Reception & Registration
     - ii. Clinical screening / assessment of PAL
     - iii. Physiotherapy services (EMS, Wax Bath, Aids & Appliances)
     - iv. Ulcer dressing
     - v. HOPE demo & self practice
     - vi. Group / Personal counseling
     - vii. Pharmacy (drug distribution)
     - viii. Referrals – record submission & reporting
   - Arrange separate tables and sitting arrangements for ulcer dressing and HOPE therapy. Keep alternate arrangements in place, in case if more number of PALs attends the camp.
   - Arrange desks / cabin / counter for the Medical Officers and Supervisory staff of PHC to conduct clinical examination and nerve function assessment in a well organized manner.
   - Arrange mobility support (Preferably PHC vehicle) for those PALs living in remote villages or those PALs who are immobile due to their physical deformity.
   - Arrange to display banner about the camp in prominent places at the public locations such as bus stand, market including at the entrance of PHC.

Trained supervisory staff of PHC

1) The supervisory staff of PHC to prepare a village wise list of PALs including those registered at PHC (LF-2 & Deformity Register) in the past 5 years and shares it with ASHA.
2) The supervisory staff of PHC to give adequate publicity using print and electronic media as well as by the peripheral health workers of PHC.
3) The supervisory staff of PHC to involve community leaders / NGOs / CBOs to create awareness among the local community in the villages about the camp.
4) The Supervisory staff of PHC to follow-up activity in their respective area of PHC and ensure that maximum number of eligible PALs to take part in LOR camp.

Peripheral health staff (ANM / MPW / ASHA)

1) The peripheral health staff of PHC including ANM, MPW and ASHA workers to mobilize PAL living from his / her area of operation (sub-centre / village).
2) Peripheral health staff of PHC to contact all the eligible PALs by home visit 2 or 3 days prior to the camp and motive the PALs to attend the camp on the specified date and time.
3) Peripheral health staff of PHC to identify PALs whose name is not in the list but require services for disability / deformity due to leprosy and residing in their area of operation.
4) Additionally, peripheral health staff of PHC to promote identification of people with suspect signs of leprosy for confirmation of diagnosis during the camp.
5) Peripheral health staff of PHC to enlist separately PALs requiring mobility support and organize transportation of these PALs to the LORC in coordination with Supervisory staff.

Note: If there are no adequate space / rooms / cabins available in the health facility, arrange to put up a 'pandal' to set up various service counters.

ORGANIZING LOR CAMP AT PRIMARY HEALTH CENTRE (PHC)

- Ensure that all preparations for the LOR camp are completed and checked on the eve of the camp day.

Inauguration of LOR Camp

- Organize a modest inaugural function at the PHC. The duration of inaugural function should be limited to 30 minutes only.
- Invite local leader and PRI members or celebrities as guests at the inaugural function. Make the prominent personalities to inaugurate the camp by local traditional way.
- Sensitize the guests / visitors on leprosy and promote action to eliminate stigma and discrimination of PALs.
- Ensure that district & block level heath officials (DHO and Civil Surgeon) are present at inaugural ceremony.

Functions of the service counters

1. **Reception & registration of PALs attending camp**
   - Arrange the registration counter at the entrance of the PHC. Keep a set of number tokens, baseline list of PALs and prescribed format for registration.
   - Make sure that there is adequate and proper sitting arrangement for PALs awaiting registration at the counter.
   - The concerned ANM / MPW / ASHA to receive the PAL from the village of their area and guide them to the registration counter.
   - The HQ-ANM / local NLEP staff to issue a number token to the PAL along with a set of records (LRC Identity Card, LRC Patient Card, Assessment card).
   - The respective ANM / MPW / ASHA will escort the PAL to assessment counter and other service counters individually or in a group.

2. Clinical screening and assessment of PALs:

By the Medical Officers of the local PHC

- MO to perform initial clinical screening of the PAL and categorize according to the clinical status – High risk cases / Reaction cases / Grade 1 & 2 cases.
- MO to diagnose the case of leprosy (in case of people with suspect signs of leprosy) and refer to NLEP staff for subsequent assessment and registration for MDT.
- Additionally, MO to prescribe appropriate treatment (medicines) as per the clinical complaints such as lepra reactions or infected ulcers.
- MO to give necessary instructions to PAL and refer for other related services that are made available in the camp.
- MO to give health education personally to PAL having risk factors for nerve damage and advice to report promptly at health facility, if such problem arises.

Criteria for cases with 'high risk' factor

- Generally, all the PALs with MB type of leprosy are considered as 'risk' cases for nerve damage and likely to develop new disability / deformity. Following are the criteria for 'high risk' cases:

1. History of Lepra Reaction or Neuritis (acute or silent);
2. Large skin patches on face or on the course of the peripheral trunk nerve;
3. Involvement (thickened / tender) of peripheral trunk nerve/s;
4. Adolescent age group;
5. Female in child bearing age group

By the trained supervisory staff of PHC:

- The Supervisory staff of PHC under the guidance of NLEP staff / LLT to perform nerve function assessment (only high risk cases) or disability assessment (Grade 1 and 2 disabled cases).
- Subsequent to the assessment, the PAL is referred for the respective counter for availing appropriate services.
- Assessment should be done only by the trained health worker in conformable conditions, both for assessor and the PAL.
- Before assessment is begun, explain the need and procedure of assessment to PAL and seek his cooperation for desired results.
- Record all clinical details of the PAL on LRC Patient Card and endorse the services to be provided as per the need.
- Refer the PAL, as per the need and indication, to the respective counter for appropriate physiotherapy services as given below.
- Explain the same to the concerned health worker who will escort the PAL to respective counter and ensure delivery of services.
- Give health education during group self care / practice and provide wound care to the PALs with foot ulcers during the LOR Camp.

By the NLEP staff / LTT of the block / district

- Impart on-job training to peripheral health staff (HA / ANM / MPW) to ensure transfer of knowledge & skills on clinical

Procedure for nerve function assessment

Perform Examination of peripheral Nerve trunks

Palpate the following nerves and record as ‘normal’; ‘enlarged’; and / or ‘tender’.

1. Ulnar nerve at elbow joint
2. Median nerve at wrist joint
3. Lateral Popliteal nerve at knee joint
4. Posterior Tibial nerve at ankle joint

Perform Sensory Testing (ST)

Check for sensation in each limb at pre-defined points (follow the chart) using the tip of ballpoint pen and record as ‘present’ or ‘absent’.

Perform Voluntary Muscle Testing (VMT)

Check for muscle strength of the following nerves and record as ‘normal’; ‘weak’ or ‘paralyzed’.

1. Facial nerve – close eyelids
2. Ulnar nerve – little finger out
3. Medial nerve – thumb up
4. Radial nerve – wrist up
5. Lateral Popliteal nerve – Foot up

General instructions

- Use prescribed assessment format (high risk & disability assessment card) of NLEP / LEAP.
- Record the findings meticulously and use uniform coding system.
- Do not leave any space / column / table blank.

screening & nerve function assessment of PALs.

- Verify and validate the clinical and nerve function assessment of PALs done by the supervisory staff of PHC.
- Inform the PALs about the importance of periodical assessment (once in every six month) and benefits of LRC service.
- Provide appropriate physiotherapy services such as EMS / Wax therapy / Aids & Appliances to the needy PALs.
- Motivate the PALs to report to LRC for follow-up assessment.
- Educate the ‘high risk’ PAL about the early signs of nerve function loss and to report immediately.
- Advise the PALs to report PHC / LRC as soon as they notice any of these signs for assessment and for availing treatment and physiotherapy services.
- Counsel the PALs to attend PHC or LRC periodically to avail necessary follow-up services on his / her own interest.

3. Provision of physiotherapy services

I. Electrical Muscle Stimulation (EMS)

Indication: Any high risk’ PAL having weakness (refer to VMT report) of muscles supplied by any one of the peripheral nerve during the last 6 or less months irrespective of disease and treatment status.

Procedure: Arrange table (near to the electric switch board) of optimum size to keep the **EMS machine** and stool / chair each for PAL and health worker. Arrange electric supply through extension box, if needed. Check all the functions of EMS machine. Keep bowl of water and electrodes covered with gauge cloth ready for EMS service. Ensure that all PALs who receive EMS are also given steroid therapy for nerve function recovery.

II. Wax therapy

Indication: Any PAL with hand deformity with joint stiffness but without any skin abrasion or disease.

Procedure: Keep **wax bath** machine ready with melted wax at optimum required temperature 47-50^{0}C. DO NOT use thermometer. Check the temperature by physically dipping finger in the melted wax. Keep sufficient number of rexin bags with grease coated paper ready to be used during wax therapy to needy PAL. Ensure that all PALs who receive wax therapy undergo passive (stretching) exercises of finger joints. Advise PAL to report to LRC for continuation of wax-therapy, or alternatively practice HOPE at home

III. Ulcer dressing

Indication: Any PAL who is having ulcer on the hand or foot with or without infection, discharge or swelling.

Procedure: Follow TCD technique (Trimming, Cleaning & Dressing) for simple ulcer. Educate the PAL on self-care including protecting anaesthetic feet from developing wounds / ulcers and teach how to dress a wound at home. Provide dressing materials / kit. *In case of infected / complicated ulcer, use aseptic method. Prescribe antibiotics, dressing materials and advice PAL to report to LRC for follow-up.* If required, refer the PAL to tertiary care centre / institute with proper referral note.

IV. Group therapy for HOPE (HYDRO-OLEO-PHYSIO EXERCISE) therapy

Indication: Any PAL who is having dry skin with stiff joints including those with ulcers in hands or feet.

Procedure: Subject all eligible PALs to HOPE therapy at the camp. Keep adequate number of plastic tubs with water ready for soaking hands and feet followed by oil massage & exercise. This activity is to be done in group with proper demonstration / instructions.

V. Provision of hand splints and MCR footwear

Indication: For hand splints - Any PAL who is having hand deformities with or without joint stiffness that are correctable. For MCR - Any PAL who is having sensory loss (Grade 1) or deformities (Grade 2) such as foot drop or ulcers in the foot.

Procedure: Keep sufficient stock of **Hand splints**, in varied sizes, available as per need of the PAL. Provide specific splint as per prescription and demonstrate the use of splints to the PAL. Splints must be used as per the instructions for specific duration in a day regularly till the desired results are achieved. Advise the PAL to attend LRC for replacement of worn out splint.

On felt need, take proper / exact foot measurement for **MCR footwear.** Label the measurement paper properly with PAL name, ID / LRC number and details such as deformity and site of ulcers. Make necessary arrangements for procurement of MCR footwear, either from NLEP Unit or ALERT-INDIA Footwear Unit.

VI. Health education & counseling

Indication: Any PAL who is having grade 1 (disability) or grade 2 (deformity) on hands, feet and eyes IRRESPECTIVE of disease and treatment status. Identify PAL who is having specific social, psychological, economical problems due to leprosy, especially recurrent lepra reaction.

Procedure: Give health education in groups made as per the category of PAL. Use Health Education charts / materials during discussion. Make this session participatory and interesting as well as get feedback from the PAL whether they have understood the matter discussed. PALs with psychosocial problems may be in need of professional counseling. Initial / provisional counseling may be given by social workers if available at the camp. Refer the PAL to a counselor / psychologist at District Hospital for further professional counseling and guidance.

Simple guidelines for Health Education

1. Care of insensitive hands - Use of protective gloves and preventing secondary deformity.
2. Care of insensitive feet - Use of protective footwear and preventing secondary deformity (wounds / ulcers).
4. Care of insensitive eyes – Use protective goggles while walking outside and cover the eyes while sleeping.
5. Care of deformity – Teach simple exercise and oil massage. Use splints and MCR footwear for preventing worsening of deformity.

VII. Distribution of medicines & supportive drugs:

Indication: MDT for any PAL diagnosed as new case of leprosy' Steroid therapy (Prednisolone) and / or Clofazimine for PALs with lepra reaction; Antibiotics (oral or ointment) for PALs with infected ulcers. Supportive drugs such as Antacid, Vitamins, and Calcium to be given as prescribed by MO.

Procedure: Dispensing medicines / drugs at LOR Camp is responsibility of the Pharmacist of PHC as per the prescription given by the MO. It may be done either from pharmacy of the PHC or special counter created at the camp site. Adequate quantity of all essential medicines / drugs should be kept ready in proportionate to estimated number of PALs expected to attend the camp. The pharmacist should keep stock of medicines in prescribed format prepared for the LOR camp.

VIII. Feedback Counter - Records & Reporting

Indication: All PALs before leaving the LOR camp. This counter is to be managed by a team of HA of the PHC and NLEP staff or LTT of ALERT-INDIA.

Procedure: After availing all the LORC services, PAL will be directed to this counter. The staff at the counter to collect the number token along with records from the PALs. Issue identity card back to the PAL. The staff to interact with the PALs and take feedback regarding their satisfaction of services provided at the LOR camp. Give appropriate guidance to PALs on self care and advise to report to LRC or PHC as per the need / requirement. Convey thanks to each and every PAL for attending the LOR Camp. If the PALs expressed desire to attend LRC for follow-up services, give a referral note to LRC specifying the details of services to be provided.

Prepare a LOR camp report using the specially designed reporting form / worksheets. The LTT of ALERT-INDIA will facilitate the report making process. The final report is to be signed by MO-PHC and a copy of the same to be submitted to DNT and LTT of ALERT-INDIA. The following are the LOR Camp report templates

1. List of PAL registered at LOR Camp
2. Service delivery Sheet along with report tally sheet.
3. Medicine stock sheet (Receipts / Issue and balance).
4. Case records / Patients card and assessment cards. (To be returned to LRC after the Camp)

IX. Concluding Session

- At the end of the LOR camp, the District Leprosy Officer of the respective district to thank all the participants – Supervisory and Peripheral staff of the PHC including ASHA – for their valuable efforts and contribution to LOR Camp.
- The LTT and DNT to appeal / motivate all the PHC staff to sustain the leprosy services that are provided to PALs during the camp and to further strengthen the referral system as per DPMR guidelines under NLEP.
- Before leaving PHC / camp premises, ensure that LTT / DNT collect all equipments, materials, medicines and records and arrange to transfer the same to the respective LRC.

Anticipated outcome

Leprosy control activities under NLEP incorporate a wide range of services including diagnosis, treatment with MDT, patient and family counselling, prevention of disabilities, rehabilitation, referral for complications, etc to be delivered at PHC in the integrated settings.

This operational guidelines emphasize the need for conducting ‘LOR Camps’ mainly to strengthen the integration of leprosy control activities including referral services through provision of technical guidance, organizing training for the GHC staff, provision of services for PALs with disabilities and deformities and improved referral systems.

Moreover the LOR camps can improve accessibility of services at LRCs and also enhance the knowledge and skills of the PHC staff in diagnosing difficult cases and in providing certain specialized care to PALs with complications through referral centres.

Further the advocacy in terms of social mobilization through involvement of various community level stakeholders including local leaders, PRI members and NGOs can contribute in creation of awareness about leprosy and promote acceptance of PALs thus reduce stigma and discrimination against leprosy.

It is recommended that the Governments and all agencies, supporting leprosy control work should therefore continue to allocate resources necessary for sustaining leprosy control activities through LOR camps. ■

A pictorial presentation of LOR Camp in Vidarbha & Chhattisgarh at Pg. 57

Report on Leprosy Out Reach (LOR) Camp

I	**Details of LOR Camp**			
1	Name of district			
2	Name of block			
3	Name of PHC			
4	Date of LOR camp			
II	**Outcome of LRC Out Reach (LOR) Camp**			
1	**Total attendance at LOR Camp (2 + 4)**			
2	**Suspects referred / reported for diagnosis**			
3	**Details of leprosy cases assessed and provided services**	**PB**	**MB**	**Total**
3.1	New leprosy cases newly diagnosed among suspects			
3.2	Old leprosy cases (Under MDT / Cured) registered at PHC			
3.3	Total leprosy cases assessed and provided services			
4	**Details of reaction cases assessed and treated**	**Type 1**	**Type 2**	**Total**
4.1	Reaction cases under MDT			
4.2	Reaction cases after MDT			
4.3	Total leprosy cases assessed and provided services			
5	**Details of High risk cases assessed and treated**	**PB**	**MB**	**Total**
5.1	High risk cases newly registered			
5.2	High risk cases previously registered at PHC / LRC			
5.3	Total high risk cases assessed and provided services			
6	**Details of disabled cases assessed and treated**	**Grade 1**	**Grade 2**	**Total**
6.1	High risk cases newly registered			
6.2	High risk cases previously registered at PHC / LRC			
6.3	Total high risk cases assessed and provided services			
7	**Details of services provided**	**New**	**Old**	**Total**
7.1	Nerve Function Assessment			
7.2	Oil massage & Exercises (HOPE)			
7.3	Wax therapy			
7.4	Muscle stimulation			
7.5	Ulcer dressing / dressing kits			
7.6	Health education / Counselling			
7.7	Splints			
7.8	MCR footwear			
7.9	MCR with Foot drop spring			
7.10	Pair of Goggles			

Date: _________ Signature of MO - PHC: _______________ Signature of NMS / NMA (NLEP) :____________

Details of leprosy cases attended LOR Camp and provided services

DISTRICT :	**BLOCK:**	**PHC:**	**DATE:**

Reg. No.	**Name of PAL**	**Disease profile**					**Category**			**Services provided at LOR Camp**								
		Age	**Sex (M / F)**	**Type (MB / PB)**	**MDT (UT / RFT)**	**LRC Registration (New / Old)**	**Lepra Reaction (No / 1 / 2)**	**High Risk (Yes / No)**	**Deformity (Gr.0 / Gr.I / Gr.2)**	**Nerve Function Assessment**	**Steroid therapy**	**HOPE / Self care**	**Wax therapy**	**Muscle Stimulation**	**Dressing / Kits**	**Hand splints**	**MCR Footwear**	**Pair of Goggles**

"Childhood leprosy is a bigger challenge"

1

India being one of the most endemic countries for leprosy, the proportion of children with the disease assumes more importance, particularly as an indicator for monitoring progress. Analysis of National Leprosy Eradication Programme (NLEP) data for the years 2005–2014 show a reasonably constant proportion of children among new cases (9%–10%). However, active community-based surveys and institution-based studies report much higher values of 32%–35%.

This is not a good epidemiological trend, and somewhat indicative of active transmission in the community, rates of which have either remained unchanged or increased over the years post elimination. The likely sources for childhood cases are household members or close contacts, the majority of whom continue to be undiagnosed. A high proportion of subclinical cases also remain a possibility in such a scenario. The proportion of disability in pediatric cases remains many times higher. In fact, about one-third of new pediatric cases are diagnosed with visible deformity, many reporting late in tertiary level institutions. Apparently, their future remains bleak. This is again indicative of delayed diagnosis in this age group. Childhood leprosy is a bigger challenge than health care managers realize, because diagnosis of the disease in children may be a difficult task with many confounders.

Another program-related issue is whether reporting of the proportion of pediatric cases (patients,15 years of age) among new cases is a sufficiently good monitoring indicator, or if it needs to be further refined by categorizing into smaller age groups (of 5, 10, and up to 15 years) to obtain a more precise picture of transmission in the community. With an efficient surveillance mechanism, monitoring the mean age at detection (diagnosis) is another indicator that may provide a clue as to the transmission rate in the community. ■

Reporting year	New cases (n)	Details			
		MB cases (%)	Children (%)	Females (%)	Cases with grade 2 deformity (%)
2004-2005	260,063	104,366 (40.4)	34,524 (13.3)	93,050 (35.8)	4,145 (1.6)
2005-2006	161,457	73,149 (45.3)	16,112 (10.0)	53,083 (32.9)	3,015 (1.9)
2006-2007	139,252	62,647 (45.0)	14,107 (10.1)	47,696 (34.3)	3,130 (2.3)
2007-2008	137,685	64,987 (47.2)	12,942 (9.4)	47,537 (34.5)	3,477 (2.5)
2008-2009	134,183	64,945 (48.4)	13,552 (10.1)	47,188 (35.2)	3,761 (2.8)
2009-2010	134,000	64,990 (48.5)	13,360 (10.0)	47,361 (35.4)	4,154 (3.1)
2010-2011	126,800	61,603 (48.6)	12,463 (9.8)	45,896 (36.2)	3,927 (3.1)
2011-2012	127,295	63,562 (49.9)	12,305 (9.7)	47,111 (37.0)	3,865 (3.0)
2012-2013	134,752	67,268 (40.92)	13,387 (9.9)	50,828 (37.7)	4,650 (3.5)
2013-2014	126,913	65,337 (51.5)	12,043 (9.5)	46,845 (36.9)	5,256 (4.1)

Excerpts from: *Aparna Pandey. Current perspectives on leprosy as a public health challenge in India. Research and Reports in Tropical Medicine 2015:6 43–48*

"Children with deformities must be stopped"

2

Children are most vulnerable to get infected with M.leprae. Given the help-seeking habits in India, they are reported late under the present integrated and voluntary reporting system. It is a tragedy for children to develop disability and deformity and drop out of school and becoming a social and economic burden to the family and community. Incidence of leprosy in children and proportion of children among newly detected leprosy cases are important epidemiological parameters providing an opportunity to treat effectively of reported early. Monitoring childhood leprosy also provides leads to better control of the transmission and assist in the eradication of the disease and its consequences.

Since India has achieved the goal of elimination of leprosy, we should now aggressively progress towards eradication by restarting once again selective leprosy screening surveys, especially in former endemic and hyper-endemic areas. Many innovative cost effective and community based strategies can be developed instead of the former conventional survey done by trained paramedical workers. If leprosy is to be transformed from a disabling disease to a simple disease with effective treatment, it is imperative to begin such screening activities and not rely only on voluntary reporting.

Given the plethora of dermatological conditions that children in developing countries manifest due to unhygienic environment and poor nutrition, leprosy can be easily ignored if not carefully assessed. Fortunately a large number of children report at an early stage when MDT will be effective in stopping progression of the disease. At the same time, a significant number of children have already developed irreversible deformities, which entail life-long care and innumerable tragedies for a growing child. Much education and motivation of the parents and care-givers seems badly needed to protect the child as well as the spread of infection through children.

Capacity building of the professional medical staff as well as the ASHA, Anganwadi and similar development workers will also help in early detection and prompt treatment. The multiple factors in the etiology and the range of clinical manifestations that require careful study to formulate operational guidelines to the PHC and general health staff in diagnosis and treatment of the children suffering from leprosy. The tragedy of children with deformities must be stopped; hospitals and health care institutions should take up this up as a challenge under the national rural and urban health mission activities involving ASHA, USHA, ANM and anganwadi workers. ■

Excerpts from: *Horo I, Sundar Rao P. S. S., Nanda N. K., Abraham S., Childhood leprosy: profiles from a leprosy referral hospital in West Bengal, India, Indian J Lepr., 2010, 82, 33 - 37*

"Childhood leprosy is a cause of concern"

3

Although India attained the goal of leprosy elimination in December 2005, it still contributed 48·54% of total leprosy cases detected worldwide in the year 2012–13.1 Close and prolonged contact with intra-familial sources of infection exposes children to high risk of acquiring infection and manifesting disease as a consequence of their weak immune response.

The child proportion refers to the percentage of children among all new cases of leprosy detected during a given year. It is an important epidemiological indicator as it reflects active disease transmission in the community and the operational efficiency of a given leprosy elimination program. In the South-East Asia Region, 16,337 new cases of childhood leprosy were detected in 2012, of which 13,387 (81·9%) were from India. Children accounted for 9·93% of the new leprosy cases detected during 2012–13 in India.

The proportion of childhood leprosy as evident in this study is a cause of concern for all stake holders in the leprosy control program. This study highlights the presence of a higher percentage of SSS positivity, multiple lesions and thickened nerves in children, thereby pointing to proportionate increase in multibacillary disease in contrast to paucibacillary in the recent past. The higher proportion of multibacillary disease in children suggests the presence of potential contacts among family members of these cases and a shift in epidemiological trends. This in turn reflects the continuing high burden of disease in the post-elimination era. Hence, contact tracing particularly in household members should be carried out. The incidence of complications such as reactions and disabilities, considered less common in children, has also alarmingly risen.

A majority of patients presented late in the course of disease (1–5 years) when they first developed symptoms of reaction, thereby contributing to delayed diagnosis and increased rate of disabilities. If not detected and treated early, childhood leprosy cases would serve as a persistent source of infection in the community. Although the treatment completion rate was satisfactory, the relapse rate was high.

The present scenario emphasises the need for continued efforts for better community awareness in order to self-report and seek leprosy services at an early stage when active case detection has been abandoned. There must be no complacency in leprosy control program in endemic regions. Integration of leprosy services with primary health services should be strengthened so that health workers are trained to suspect and diagnose leprosy at an early stage. They must also establish close links with the referral centres for confirmation of diagnosis, if required and management of reactions and disabilities. ■

Excerpts from: *Sunil Dogra, Tarun Narang, Geeti Khullar, Ramesh Kumar & Uma Nahar Saikia. Childhood leprosy through the post-leprosy elimination era: a retrospective analysis of epidemiological and clinical characteristics of disease over eleven years from a tertiary care hospital in North India. Lepr Rev (2014) 85, 296–310.*

“Programme needs to monitor the number of children”

4

Children with leprosy

It is a sad thing to see a young child with irreversible nerve impairment due to leprosy. We must do all we can to prevent leprosy in children and to prevent disability in leprosy affected children. However, it is important to be confident of the diagnosis of leprosy before giving multi-drug therapy to avoid over-diagnosis and unnecessary treatment. Leprosy in children (under 15 years old) is still common in countries where leprosy continues to be endemic.

In India, 10 states have child proportions of over 10%, while in Daman and Diu it was 30%. Active population surveys give much higher proportions of child leprosy cases, for example 35% in Maharashtra and 32·5% in Agra. Although the number of child cases has decreased in line with a general reduction in case detection, but there is not necessarily a reduction in the proportion of child cases amongst new cases.

The time has come to change the standard indicator (proportion of child cases amongst new cases) and in future to express the burden of child cases as an age-specific rate – the number of cases per 100,000 children under 15 years.

Prevention of impairment and disability (POID) needs special attention in children because of the life time impact of leprosy-related disability. Reconstructive surgery for those with established impairment is feasible even in young patients. Too many children already have disability at diagnosis, although the proportion has decreased over time in some areas.

Delay in diagnosis may contribute to the occurrence of disability and the reasons for this delay may differ in children compared with adults. The occurrence of reactions or neuritis is reported from 20 – 30% of child cases and is commonly the reason for initial presentation, but little has been published on the frequency, management or results of treatment of reaction or neuritis in children.

Similarly, evidence is lacking on the specific difficulties of teaching self care to children and their care givers. When a child presents with new nerve function impairment or overt reaction, his/her body weight should be used to decide on steroid dosage and one must be mindful of the specific risks of steroids in growing children as well as the well-known adverse effects which can occur at any age.

Long-term studies of childhood leprosy, using tools such as the P-scale or a Quality of Life scale, to assess the impact on psycho-social functioning in adult life of a childhood affected by leprosy are needed.

Excerpts from: *Ruth Butlin C. & Paul Saunderson, Children with leprosy, Lepr Rev (2014) 85, 69 – 73*

Public health issues

Congenital leprosy appears to be rare, if it ever genuinely occurs, and transmission through breast milk may be possible. Rare reports of leprosy in infants (including cases confirmed by histology) are mostly from the pre-MDT era. Leaving aside these unusual infant cases, a relatively high rate of leprosy amongst children is thought to indicate continuing transmission in the community.

The source of infection in children is likely to be within the household since young children mix with fewer individuals outside the home compared with adults. Hence household contact surveys should be an especially effective way of case finding when the index case is a child. Conversely, children in a household where a new leprosy case has been diagnosed are at increased risk compared with the general population and even compared with adults in the household.

If transmission to children is still occurring, largely from undiagnosed cases in the community, can it be interrupted? Can progression to leprosy disease be prevented in those contacts more exposed to infection or even in those already infected, but currently in a subclinical state?

Enhanced immunity through vaccination with BCG alone may reduce the incidence of leprosy in the community: this was proposed over 60 years ago and the evidence base for this has expanded recently. BCG vaccination in infants is the policy in most leprosy – endemic countries (as part of tuberculosis control programmes) and might have an effect for 5–10 years, after which it wanes.

Leprosy control programmes need to monitor the number of children (and their ages) being detected and to consider in each case the likely source of infection; ensuring household contact surveys (or, preferably ‘extended contact surveys’ which include near neighbours) are carefully conducted.

The clinician’s response to a new child case should include not only prescribing MDT at appropriate doses, but also a careful assessment for existing nerve function impairment and risk of future impairment, and an assessment of the child’s and the family’s ability to respond to the diagnosis in a way that minimizes the psychological impact and maximizes successful self-care.

In summary, child cases continue to present in substantial numbers and it is suggested that a new indicator be used, number of new cases of leprosy in children per 100,000 children. There are major diagnostic challenges when assessing a child with suggestive signs of leprosy, and if there is any doubt it is generally safer to keep the child under observation (may be 2 – 3 months), then re-examine in the most favourable circumstances possible.

For every confirmed new child case, careful and sympathetic teaching of the parents is essential. This includes the risks of MDT, signs of reaction, and other topics (such as care of sensory impaired limbs) according to the features of the individual case. In relation to each new child case, as for adult patients, household contact examinations need to be arranged. ■

"Deformity in children is an unfortunate tragedy"

5

Majority of pediatric cases of leprosy in our study belonged to the older age group that is above 11 years. A relatively long incubation period of leprosy may be one of the causes, and the chances of misdiagnosing indeterminate skin patches as skin disease in the initial stages may also lead to delayed detection in these cases.

An insignificant male preponderance was seen in probably owing to their greater activity and increased opportunities for contact and neglect of female child in the study area. The proportion of contacts with leprosy is strikingly high, however, the type of disease in children exposed to leprosy contacts did not significantly differ from those unexposed children who developed the disease.

All the positive contacts were intra-familial, and no extra-familial contact history was available which may be due to stigmatic lack of disclosure of the disease in the neighborhood, if any.

Studies have shown that the risk of a person developing leprosy is four times higher when there is a neighborhood contact and up to 9 times higher when the contact is from the household. This emphasizes the need for periodic screening of leprosy contacts specially the children in the family.

Single skin patch was the commonest symptom or sign of leprosy in children. Therefore, a suspicion of a possibility of leprosy should arise in any child presenting with skin patches even if sensation is intact, and such cases should be observed for early detection. Pauci-bacillary disease dominated in children in contrast to other studies that had higher number of multi-bacillary cases where the frequency of finding thickened nerves was high differentiating them into multi-bacillary group. This stresses on a thorough examination of cutaneous nerves at the time of diagnosis to avoid under treatment.

Incidence of neuritis and reactions in children were low however prompt and judicious steroid therapy should be instituted in such cases to avoid development of further neurological damage.

Deformity in children is an unfortunate tragedy. Factors that may contribute to deformities in children are the older age, multiple skin and nerve lesions, multi-bacillary disease, presence of reaction, smear positivity, and delayed diagnosis. This alarms the need to strengthen contact screening, early case detection, and referral activities in the pediatric population to sustain elimination. ■

Excerpts from: *P. Chaitra and Ramesh Marne Bhat, "Post-elimination Status of Childhood Leprosy: Report from a Tertiary-Care Hospital in South India," BioMed Research International, vol. 2013, Article ID 328673, 4 pages, 2013.*

"Women with leprosy - a double jeopardy"

1

Leprosy results in not only physical problems, but also mental, social and economic consequences. In women, these problems are magnified by the gender disadvantage that prevails in many countries. Women are not able to access medical care as easily or as soon as men due to cultural, socioeconomic and psychological constraints. Several articles have referred to 'double jeopardy' in relation to women with leprosy in developing countries.

Holistic health care and quality services

Leprosy affected women are less likely to report early, and not until the disease prevents them from carrying out their domestic responsibilities. Health services are responsible for educating and motivating women leprosy patients to report promptly, adhere to treatment schedules and to provide holistic health care and quality services. They need to respond to the felt needs of women to ensure patient satisfaction and better co-operation between patients and health professionals.

Social worth

In general, the women had to delay going to hospital, till their husband or guardian felt it was necessary. Most women had to complete their household chores before setting out for the hospital. They also had several domestic jobs waiting to be completed when they returned. Over a third of women spent more than 3–4 hours travelling each way. The more time they spent in the hospital, the longer was their absence from home, conflicting with their domestic work, and their social worth in terms of their roles and responsibilities was affected if they are away too long. This de-motivates women from coming to the hospital very often unless the problem is severe.

They found repeated visits to the hospital rather difficult due to the cost, time away from domestic responsibilities, and lack of cooperation from family members. A majority of women revealed that they had no knowledge of leprosy prior to coming to the leprosy centre. Had they known that deformities could be prevented by early treatment they would have tried to come sooner. All of them expected their physical problems to be solved conclusively and were disappointed with the recurrence of ulcers, neuritic pain and reactions. It was difficult for them to follow the medical advice given such as avoiding prolonged walking and standing, and working with hot utensils as they had to care for their families and also augment their family income.

Social and economic problems faced by the women due to leprosy had been addressed in some cases by providing educational grants

Excerpts from: *Annamma Succhanda John, Sundar Rao P. S., Sonali Das. Assessment of needs and quality care issues of women with leprosy. Lepr Rev (2010) 81, 34–40* for children, soft loans for small business ventures, vocational training, and in a few cases reuniting them with their families. The patients appreciated the time given to them by the doctor during the interview. It appeared that just listening to their problems added to their sense of wellbeing and satisfaction even if material benefits were not always possible.

Women come to hospital at great expense of time and cost because of recurring physical problems such as plantar ulcers, reactions or other medical consequences of leprosy. Unfortunately, some of these problems still defy current technical knowledge in prevention or treatment and more research is needed in solving these clinical problems. These female patients face social restrictions as well as perceived and enacted stigma.

Much has been written on the different manifestations of leprosy stigma as it affects women in developing countries. Although stigma affects all leprosy patients, women suffer more adversely. Because of their lack of autonomy or financial constraints, there is a greater need to offer more tangible assistance to promote their early reporting, prompt and regular treatment without unduly disturbing their domestic roles and responsibilities.

Counselling & quality care

Family-based and peer-group counselling could help in boosting their confidence and clearing misconceptions regarding leprosy, its complications and management and facilitating domiciliary care, whether by individuals or family members. There is a great need for health service personnel to be sensitive to the need of female patients. Gender sensitivity in terms of more female staff and trained women volunteers would be helpful.

An important aspect of quality care is the provision of acceptable standards of privacy for women during examination and history taking, in providing basic amenities like separate toilets, and for special services such as prosthesis and orthotics.

Patients have to spend a considerable time waiting at every station in a hospital such as at registration, body-charting, physiotherapy, and at the laboratory, and there are long delays before patients get to see a doctor. These delays adversely affect most women who are expected to return quickly to their homes. Special attention to women patients is needed so that time spent at clinics can be significantly reduced.

Much can be done without increased expenditure, to provide a better quality service to women leprosy patients and to address their needs more effectively. Reduction of waiting times, priority queues, adequate privacy and trained women professionals are just a few examples.

Counselling should be an integral part of holistic care to help patients tackle their needs in a positive manner. Development of culture-specific health education material is a priority. Efforts should be made to promote early detection and treatment, especially under the present integrated set-up, with an increased focus on women. ■

“Women with leprosy - a triple jeopardy”

2

Significant improvements in leprosy control were made in the 1990s following the World Health Assembly Resolution in 1991 to reduce the number of registered leprosy patients to less than 1 in 10,000 by the year 2000.

However since that date, the numbers of new cases being detected has sharply declined and for the last 8 years have remained static. In 2013, there were 215,656 new cases reported to WHO including 79,943 women (37%) and 19,796 children (9%).

Major concern

A major concern for women is delay in diagnosis of leprosy. The disease is slowly progressive so any delay in detection and treatment results in increased nerve damage to eyes, hands and feet. Impairments in sensory and motor nerve function in the hands and feet lead to recurrent injury and irreversible tissue damage. Women who cook using hot utensils or engage in agricultural labour are at high risk of burns and injuries to anaesthetic limbs. Women delay detection because they are afraid of the social consequences of the diagnosis. Women also delay because they do not have ready access to health information and health care.

People are often disempowered because of leprosy, discriminated against in terms of education, employment, housing, use of public transport, and eligibility for elected office. Women are often disempowered due to gender in terms of rights, property ownership and human rights. Women with leprosy experience both. Girls with leprosy will face social discrimination and encounter difficulties in marriage. Leprosy is legally grounds for divorce in many countries, and wives divorced on the grounds of leprosy face destitution.

International Federation

The International Federation of Anti-Leprosy Associations (ILEP) has a strategy to stop leprosy transmission, prevent disability due to leprosy, and break barriers to inclusion. ILEP is currently focusing global attention on the issues of girls and women with leprosy. The World Health Organization is currently developing a new 5 year strategy for leprosy and it is essential that this new strategy addresses the issues of girls and women with leprosy. Similarly, the Neglected Tropical Diseases (NTD) movement needs to recognize the specific issues for girls and women with NTDs. The 3rd WHO Report on NTDs, ”Investing to Overcome the Global Impact of Neglected Tropical Diseases” (2015) mentions gender twice - achieving access to treatment and better outcomes for women and girls affected by NTDs must become a priority. ■

***Excerpts from:** William Cairns Smith, Triple Jeopardy: Girls and women affected by leprosy are discriminated against because of gender, stigma and disabilities, The Lancet Global Health Blog, Neglected Tropical Diseases, 2 March 2015*

"Need for awareness on integration"

1

Successful integration makes treatment for leprosy more accessible and also removes the stigma attached to attending a leprosy hospital. While the emphasis had been on only diagnosis and treatment of leprosy so far, now the general health services are prepared to cope with management of complications of leprosy such as reactions, plantar ulcers and so on. All these improvements are of no avail and wasteful if the public remain ignorant or have misconceptions on how general health care systems can handle leprosy problems.

A study was conducted to determine whether people know that leprosy services are available at PHC and the awareness about treatment. 2942 villagers randomly selected , one male adult and one female adult from each household from 27 villages in Faziabad district of Uttar Pradesh were interviewed using an interview schedule.

Findings confirmed that despite the great benefits of integration, only half of the population aware of the integration. It is gratifying to note that those who are aware of integration also knew MDT is available and free. There are no doubt variations but what is serious is the finding that the uneducated and poor segments have the lower level of awareness and they are the ones who must get the maximum benefit of integration.

NLEP strategy

The NLEP strategy and its operational guidelines place greater weight age in strengthening the general health system and assume that IEC activities and content as planned would suffice. Unfortunately, the present efforts seem grossly inadequate. It may not be just the content but the methodology and the sources of information may need urgent and careful reviews in order that the community awareness and especially of those leprosy affected will significantly improve affect their behavior in terms of early reporting and regular treatment. It has been observed that rural public awareness about integration is quite poor. Younger and better educated persons seemed to be more aware. The source of information seems to be mostly though personal contact and PHC staff.

The non-governmental organizations, local institutions and government should work closely and design a communication strategy to penetrate deeper into masses to make everyone aware about leprosy treatment and services at PHC. Special emphasis should be given to women, old people and less educated as they are difficult to be reached because of cultural taboos and low socio-economic status that prevents the development process. Much greater efforts are urgently needed to increase the awareness on integration especially in the rural areas. ■

Excerpts from: *Verma C, Sundar Rao P.S., Raju M. S., Public awareness on integration of leprosy services at primary health centres in Uttar Pradesh, India, Indian J. Lepr., 2011, 83, 95 – 100.*

"Community's response to sustain the programme"

2

Sustainability in low endemic situations becomes critical, since there are still many pockets in India of high incidence with high proportion of MB cases. Apart from bureaucratic and administrative evaluations, a thorough assessment of community's perception on the problems and possible solutions for improving sustainability will be useful. It was therefore decided to ascertain the community's perceptions about sustainability of integrated leprosy services as carried out in primary health care setting in rural India.

A total of 92 community members of both sex in various age group randomly selected from 3 rural blocks of 3 districts in Uttar Pradesh.

Community's response concerning the adequacy of activities by people with leprosy

As few as 42% and 19% felt that voluntary reporting and early reporting respectively were adequate for the sustainability of leprosy services in PHCs after integration. The difference between male and females is not statistically significant with reference to voluntary reporting and early reporting.

Community's response concerning the adequacy of activities by health services

A majority of the respondents were convinced that 3 activities viz. availability of multi-drug therapy (94%), way of communication by PHC staff with leprosy patients (95%) and treatment of common problems that afflict people with leprosy (98%) were sufficiently satisfactory to ensure future sustainability of the programme. While about 66% of the respondents found ulcer treatment satisfactory, among those who noticed unsatisfactory 70% and 17% identified 'lack of proper facilities' and stigma' respectively as reason for the dissatisfaction. Lack of proper diagnosis is still considered as major problem, only 53% of all respondents felt that the capacity to diagnose leprosy in PHC was adequate. This opinion was voiced by ore females (82%) than that of males (43%).

Opinions were that the main reasons for lack of adequate diagnosis included 'lack of proper facilities' and 'lack of adequate training for staff'. About 47% of respondents reported that they were satisfied with the importance given by PHC to leprosy problem. The community appeared to be least satisfied with PHCs ability in management of leprosy related complications (43%) with strong difference in opinion between males (35%) and females 971%).

Community's response concerning the adequacy of various leprosy control activities

Findings revealed that a majority of the respondents expressed dissatisfaction

Excerpts from: *Raju M. S. Sundar Rao P.S., Sustainability of integrated lerpsoy servics in rural India: perception of community leaders in Uttar Pradesh, Indian J. Lepr. 2011, 83: 87 - 93* concerning the different activities outside PHC i.e. prevention of disability (98%), advocacy (100%), rehabilitation (100%, community awareness (98%) and enlightenment of rights of leprosy afflicted 9100%) with no statistically significant variation between males and females.

Community's response

Suggestions provided by the respondents, include physical, logistic, human resources, behavioural and programme inputs involving the health staff, community and patients.

Physical facilities: The respondents suggested that the sustainability of leprosy services a few physical facilities such as a developed clinical lab specifically for diagnosis of leprosy and operation theatre for surgery (reconstructive surgery) are essential in the existing PHC system.

Logistic issues: The respondents suggested logistic issues like the timely and adequate supply of MDT, other leprosy related medicines and medical supplies for sustainability of the programme in the current setup.

Human resources: The suggestions made by the respondents include staff capacity building through orientation of the existing PHC staff viz. auxiliary nurse midwife (ANM), anganwadi worker (AWW), accredited social health activist (ASHA) and medical Officer, etc. in leprosy work and the utilization of IEC materials. It was also suggested it may be necessary to select and appoint appropriate new staff especially to carry out RCS and other surgeries thereby providing complete PHC level treatment for people adversely affected by leprosy. Involvement of national rural health mission (NRHM) functionaries and village health and sanitation committee (VHSC) in leprosy work with proper training has been suggested to be of vital importance for activities such as case finding, case holding, treatment and awareness / IEC activities in their own village.

Operational inputs at PHC level: Operational inputs that were suggested ought to be taken up in the on-going programme at the PHC level included, improvement of monitoring leprosy work at PHC level, counseling and motivation of PHC staff to accept people affected by leprosy and counseling of leprosy patients and their family members to encourage them to take treatment and make proper use of treatment facilities available from PHCs.

Initiatives to change behavior at community level: It was suggested that behavioral changes necessary in the community to achieve sustainability of the programme make be secured through health education / awareness / IEC programmes. Such programmes in the community and for leprosy patients should be on the topics of leprosy, the disease and for the people affected by leprosy programmes should be about treatment / MDT and their rights. Counselling and motivation should also be targeted at family members and the community to accept leprosy treated individuals. ■

"Adequately functioning general health service"

1

The overall process

Integration requires careful and adequate advance planning and should be introduced on a step-by-step basis (phasing in place, time, and activities). The integration process should be implemented in stages, and it is important to achieve early results. This is necessary to maintain commitment.

Preconditions

- The government should be committed to sustained leprosy control activities, and there should be a national policy for leprosy control. The existence of an adequately functioning general health service infrastructure must be ensured. Staff and public acceptance of leprosy patients in general health facilities and willingness of leprosy patients to attend these facilities is crucial.
- NGOs supporting leprosy control continue to be important partners of governments in integrated leprosy control programs. If donors wish to ensure the establishment of sustainable leprosy services, they must work with and strengthen the national general health services system.
- In order to establish sustainable services, broad ownership of the strategy must be assured, both within the specific leprosy organizations and, equally important, general healthcare system. It is important that the various agencies involved in leprosy control collaborate and coordinate their activities, in order to increase their effectiveness.
- In integrating leprosy control into general health services, equity and quality of care for leprosy patients should be assured. This implies that services for leprosy patients (including diagnosis, treatment, and rehabilitation) should provide the same level of quality (not less, but also not more) as services for other health problems.
- Sufficient capacity in leprosy control must be available within the general health service at the central and intermediate levels for advocacy, policy formulation, technical guidance, training, planning, monitoring, evaluation, and coordination of national and international donor support. Wherever available, dermatologists can play an important role in referral, clinical guidance, and training.
- An adequate, well-prepared support structure at the intermediate level is not only required when leprosy services have been integrated into the general health services, but is also necessary to provide guidance during the integration process.

Excerpts from: *Jan Visschedijk, Anrik Engelhard, Peter Lever, Maria Aparecida de Faria Grossi, Pieter Feenstra. Leprosy control strategies and the integration of health services: an international perspective, Cad. Saúde Pública, Rio de Janeiro, 19 (6):1567-1581, Nov-Dec, 2003*

- With integration, the recording and reporting system will require simplification to allow for appropriate data collection by peripheral multipurpose health workers. Only data directly linked to decision-making should be routinely collected and should be incorporated into an existing general health management information system.
- The tasks of different categories of staff in the integrated program (including previous vertical staff) should be clearly defined and communicated to all concerned long before integration is conducted. The same applies for training: all categories of staff should have completed their training before the integrated program becomes operational.
- A professional advertising campaign to create awareness of the availability of leprosy treatment at all health facilities, as well as to overcome the stigma attached to leprosy, can strongly facilitate a successful integration process.
- Since every region and State generates its own specific context for leprosy control programs, the necessary flexibility has to be observed during the integration process. Furthermore, the process needs to be transparent and must involve all relevant partners. This will facilitate ownership and the commitment to integration. ■

No Shame in Increased Case Numbers

People may be surprised to hear me say that I would like to see an increase in case numbers, but I have my reasons. For many years we have focused on lowering numbers, using the WHO's target of reducing prevalence of leprosy to less than 1 case per 10,000 people in order to eliminate the disease as a public health problem. I remain convinced that setting this numerical target was correct.

Today, the fact that only Brazil and a few small island nations have yet to achieve it is a mark of its effectiveness. However, 'elimination' is only a milestone en route to the ultimate goal of eradicating the disease altogether. But in many countries that have achieved elimination, there has not been a significant reduction in new case numbers in the years since.

One reason, I feel, is that by focusing on reducing numbers we have, without realizing it, come to suffer from a kind of trauma. With attention focused on lowering case numbers, no one has been willing to focus on activities that could result in an increase, fearing the criticism that might come their way. But there is nothing to be ashamed of in seeing patient numbers increase.

An action plan will invariably lead to a temporary rise in new cases, but it will also increase early detection and result in a reduction in new case numbers in the long run. I'll say it again, but an increase in patient numbers is not something to be ashamed of; it should be commended as a sign of an active program. There are still people suffering from leprosy in places we don't know about; there are still leprosy hot spots. Let us go all out and find these new cases.

Excerpts from: *Yohei Sasakawa, WHO Goodwill Ambassador, WHO Goodwill Ambassador's Newsletter for the elimination of leprosy, June 2015, Number 74.*

"Ownership of the programme"

2

For the process of integration to go smoothly, GHC staff were involved by including them in four modified leprosy elimination campaigns (MLECs), between 1997 and 2003. It was presumed that all the GHC staff would be capable of handling leprosy cases independently after the MLEC training. However, these training sessions were more for confirmation of suspect cases by the Medical Officers of the primary health centres, for conducting surveys by GHC staff, for suspecting cases and referring them for confirmation and for IEC activities, rather than for handling leprosy cases independently and maintaining records and reports at GHC centres.

The majority of the GHC staff have started to provide leprosy services independently or at some location dependent on attached vertical staff (now considered part of GHC staff). Quality of services is variable, and in some centres has yet to be improved. To support integration, and to improve quality of services, District Technical Support Teams (DTSTs) have been placed in problem states and districts in India. Though the GHC staff was sensitized for integration, it was accepted as a duty-bound obligation rather than a welcome change. In some states, they have not accepted the change even now. On the other hand, vertical staff were not ready to leave ownership of the programme to the GHC staff. They were not ready and prepared to hand over their records, which they had prepared and maintained with much effort and dedication for many years. In an integrated setup, formats and records maintained by vertical staff were considered to be too complicated and too many in number, and hence simplification was thought to be necessary.

It was presumed that the guidelines were very simple and self-explanatory, hence no formal discussions were held at state and district levels to explain the maintenance of these records and preparation of reports. GHC staffs were expected to be supported by former vertical staff in filling and maintaining these records. Officers from some states did not find this simplicity acceptable, and modified the records and reporting formats. Besides other technical support, major contributions made by ILEP support teams were in the form of transferring of their skills to GHC staff, in maintaining and updating of these records and preparation of reports as per SIS guidelines.

At present in almost all the health facilities, patient cards, treatment register and MDT stock registers are available and maintained as per SIS guidelines, though the quality differs. It has to be ensured now that the quality of maintaining these records and reports does not go down and that supply is uninterrupted. ■

Excerpts from: *Arif M. A. Availability of records and reports in health facilities under Integrated Leprosy Services of India, Lepr Rev (2005) 76, 348–351*

“Manpower training and reinforcements of health care personnel”

3

To assess the training status and program management at the community level, it was decided to interview the medical officers and health workers working in four PHCs (25%) that were selected randomly from the set of 14 PHCs at Kamrup district of Assam. A pre-designed and pre-tested questionnaire contained questions relating to the information on designation of the staff; his / her training status in leprosy; the presence or absence of knowledge about leprosy, its categorization, its treatment modalities; and individual involvement in the National Leprosy Eradication Programme.

Accordingly, 50 medical officers, 40 health supervisors, 66 male multipurpose health workers and nonmedical assistants, 65 female multipurpose health workers and auxiliary nurse midwives, along with 8 policy makers at the district headquarters, were interviewed.

Among the program managers interviewed, only half were organizing training sessions, and 37.5% were involved in supervision of the program activities at the periphery level. Regarding training status in leprosy, 90% of medical officers, 80% of health supervisors and around 87% of MPWs (83% of male MPWs and 89% of female MPWs) had attended training programs on leprosy. 60% of the medical officers had a role to play in Information Education Communication (IEC).

Among the health supervisors, 90% were aware of the cause of leprosy, while 92.5% were aware of the diagnosis, categorization of patients and treatment according to category. All the health supervisors knew about MDT, and 80% of them had an idea about the program. 75% of them played a role in IEC campaign.

Among male grass-root level multipurpose workers, 83.3% were aware of the cause of leprosy; 87.9% could diagnose the disease; 84.8% were aware of MDT, categorization of patients and their treatment duration; 81.8% had knowledge of the program; and 78.8% were involved in IEC campaigns.

Among female MPWs, 66.2% were aware of the cause of the disease; 87.7% could diagnose the disease; 86.2% had an idea of MDT and treatment duration of various categories of patients; 80% of respondents could categorize the patients; 76.9% knew about the program; and 90.7% of the respondents had a role to play in IEC campaigns.

There is still a need to organize training programs at regular intervals to train new recruits, as well as reinforce and update the knowledge of those already trained. In view of the changing logistics, it is very necessary that manpower training and reinforcements should be given serious consideration by health planners. ■

Excerpts from: *Sumit Kar, S Ahmad, and Ranabir Pal. Current Knowledge Attitudes, and Practices of Healthcare Providers about Leprosy in Assam, India. J Glob Infect Dis. 2010 Sep-Dec; 2(3): 212–215.*

"Diagnostic and management challenges"

4

As the clinical management of leprosy is becoming integrated into the general health services, majority of the patients will be diagnosed and managed by non-specialists. Therefore, attempts have been made to simplify the guidelines for diagnosis to be used by field staff taking into account a single sign – the finding of the skin patch or patches with definite impairment of sensations. Others with lesions suggestive of leprosy but without anaesthesia or not diagnosed by this single criterion may be referred to an appropriate center for further examination.

This diagnostic strategy being routinely applied in surveys and many national programs may led to significant under diagnosis, particularly of multibacillary (MB) disease where sensations remain almost intact in the early stage of the disease. This can have serious epidemiological and clinical implications. Firstly, MB patients are the major source of infection leading to further transmission of M.Leprae and secondly they are at greater risk of reactions and consequent nerve damage. Delay in diagnosis may result in preventable disabilities with the accompanying psychological sequale. Over diagnosis on the other hand will result in needless treatment, but, more important are, the damaging psychosocial consequences of the diagnosis of leprosy.

The WHO classification of disease based on number of skin lesions has conspicuously ignored the number of peripheral nerve trunks involved. The obvious reason could be the lack of adequate experience and proficiency among field workers to palpate and identify the thickened peripheral nerve trunks.

Nevertheless, this can have serious implications in PB patients having e" 2 peripheral nerve trunks involved especially in different limbs. It is likely that such PB patients classified solely on number of skin lesions have widespread / disseminated disease and are being inadequately treated with PB regimen and therefore actually being under treated.

Laboratory based tested tools such as slit skin smear and histopathology are sidelined as they are regarded as not very practical or do not add on to the sensitivity of diagnosis. There is no surveillance system to record the number of relapses occurring in the community especially after introduction of short term fixed MDT multibacillary regimens. In addition there is no recording or tracking system in place to access the patients who discontinue their treatment. This poses a public health risk due to the likelihood of infectiousness of active relapses and treatment defaulters. ■

Excerpts from: *Kumar B, Dogra S. Leprosy: a disease with diagnostic and management challenges!. Indian J Dermatol Venereol Leprol 2009; 75: 111-115*

“Factors hampering the success of the program”

5

Gujarat achieved a status of elimination in the year 2004. Certain districts in Gujarat have not achieved the elimination status and Panchmahal, a tribal district is one of them. The objectives of the internal evaluation of NLEP in Panchmahal District were to identify the shortcoming in the program, recognize factors hampering the success of the program, and delineate the problems faced by various stakeholders. A rapid survey of the PHCs of high and low endemic areas, for leprosy, was conducted, by selecting 10 PHCs randomly, out of a total 63 PHCs. The findings are as follows.

Disability cards and LF-01 were not compiled at the sub-center level, LF-04 were not reported by the PHC Supervisor at some PHCs. Overall Records at the PHC such as (LF-01, LF-02, LF-03, LF-04) patient record and treatment record registers were filled properly and were quite good, however, the stock register and suspicious patient register were not filled and most of the information was lacking. In the fortnightly meeting at the PHC, held by the Medical Officer, the issue of leprosy was neither discussed nor had it been compiled in the minutes.

Community level awareness regarding leprosy is lacking. Only 20-30% of the population is aware of the disease. IEC material is not displayed at most of the PHCs. Proper IEC material is also lacking in the villages and the health workers seem least interested in the program. There are no reconstructive surgery centers at the district; 100% of the reaction cases have been managed at the PHC. A very less percentage of people have been given a self-care kit; 15% of the patients have been provided with footwear. Out of the total 316 MB patients, one patient has developed a new deformity after MDT. No patients have been referred for surgery in the district.

The vertical staff does not know the proper guidelines for ulcer care and splint’s are not provided to needy patients. Involvement of the vertical staff in the Disability Prevention and Medical Rehabilitation (DPMR) project is poor; they need special training for sensitization about the project.

Drugs are properly stored and kept in proper racks, well protected from humidity and the sun; however, the drugs are not available according to the needed stock at the PHC and District Level. Stock registers are not maintained properly at certain PHCs. Drugs are not available for patients with reaction in the store, for example, prednisolone. Expenditure for IEC and IPC activity is low. Arrangement of training and workshop for all health staff is very poor. Expenditure under different headings in the urban area is very poor. ■

__Excerpts from:__ Anjali Singh, Internal evaluation of national leprosy elimination program in tribal Gujarat, Indian J Community Med. 2010 Jan; 35(1): 130–133. Year : 2010 | Volume : 35 | Issue : 1 | Page : 130-133

“Integration : Some Concerns”

6

Integration implies that leprosy control activities become the responsibility of the general health services as part of routine day-to-day activities. Thus equity and sustainability, the major components of primary healthcare approach also became the major justification for integration.

Here the challenge is to ensure quality and specialized services to those affected with leprosy but as a responsibility of the general health services. Second, the question of sustainability gains prominence as the reliability and support towards general health services is higher than towards those services provided by a vertical setting. Moreover, integration expects to improve access to leprosy control services through which it reduces stigma and the gender bias attached to it.

The decentralized, health services system that could address the uneven distribution of leprosy cases whereas inadequacy in planning the integration process was identified as a major shortcoming; particularly the processes of training and monitoring. Moreover when disability due to leprosy is on the increase, it indicates that the disease is spreading. Thus, any approach to control leprosy must put a system in place that can ensure prevention of the disease at the primary, secondary and tertiary levels of prevention. These in the context of leprosy can be active surveillance for new cases, effective provisioning of treatment to the patient as near to his/her home as possible with an equally vigorous mechanism to follow-up cases to ensure patient adherence and, last but not the least, prevention of disability and rehabilitation.

In order to ensure horizontal integration sharing of laboratory infrastructure, equipment and technicians amongst various control programmes has been recommended. Developing multiple skills is recommended by NRHM for pharmacists, laboratory technician and other support staff. In addition, it offers space for NGOs / CSOs especially in the field of training, monitoring and evaluation.

It is high time that we develop a reliable and systematic case identification mechanism both in terms of technical and administrative efficiency that can rule out the dilemmas on the number of leprosy cases. Though the NRHM conceptually offers ample scope to build leprosy control into its activities the task here is to ensure that the programme “sails” with the general health services. This can only be accomplished by efforts that can strengthen the health services system thereby ensuring that the components of leprosy control is knit into the general health services system as a responsibility on a regular basis. ■

Excerpts from: *Mathew George, Lessons for Integration of Health Programmes. Economic & Political Weekly, Vol. XLIV, No 14, April, 2009, p 24 - 26*

"Need for sustained political commitment"

7

With integration, the emphasis of the leprosy program in India has changed from a prevalence-targeted approach to improving new case detection rates and retaining cases for completion of treatment. India is a vast country with wide variation in health infrastructure and health status across its provinces, so integration has occurred at a variable pace in the provinces. However, integration demands an efficient and responsive health system and stock management for continued supply of MDT blister packs to timely and completely treat all newly detected, sporadically occurring leprosy cases. Another very important and closely linked issue is ensuring the quality of services, which requires skilled manpower at all levels with supportive supervision, as well as an effective and robust technical monitoring mechanism. The system also needs sustained political commitment to avoid set-backs. A strengthened and streamlined referral mechanism is also crucial in the post integration phase for timely and appropriate handling of the complications and sequelae of leprosy. Follow-up of cases after completion of treatment for reactions and deformity remains the responsibility of peripheral level health care workers. In order to maximize the gains, convergence of resources from various stakeholders, eg, health workers at all levels, donor agencies, and both political and social leaders, is required. These components and activities are all essential steps in the management of leprosy, which has a far-reaching impact on both individuals and society. If these strategies are not implemented, it will be very easy to lose the gains made over many years, and success may remain near but elusive, like the Ziz oasis in the Sahara desert.

Trends over the years post integration suggest ongoing active transmission in the community, delayed diagnosis, and poor monitoring and epidemiological control. The major challenge of hidden leprosy cases remains, and is likely to worsen in the coming years. Analysis of NLEP data over the years shows an increase in the proportion of grade 2 disability among new cases from 1.6% in 2005 to 4.1% in 2014.

The optimist may see this as a good development in terms of eliminating leprosy, but with fluctuating new case detection rates and persistent endemicity, the possibility of delays in diagnosis and initiation of treatment seems more probable. We have still not eliminated the stigma associated with leprosy; rather seems to be increasing as many new cases are diagnosed too late, many with visible deformity. Otherwise, we may lose the remarkable gains made as a result of the hard work of dedicated health personnel over many years, just at a time when success seems so close. ■

Excerpts from: *Aparna Pandey. Current perspectives on leprosy as a public health challenge in India. Research and Reports in Tropical Medicine 2015:6 43–48*

"Categorization of problem districts and focussed activities"

1

During the 12th Plan, provision has been kept for additional human resources in 209 high endemic districts with ANCDR >10 per 100,000 in 2010-11 so that focused activities can be carried out to bring down the endemicity.

However, it is understood that all these districts are not equally problematic and also some other districts may also come under the definition of high endemicity.

The issue was examined by a sub-committee under the Technical Resource Group of NLEP during 2012-13. Based on their recommendation, it has been decided that 'HIGH ENDEMIC PROBLEM DISTRICTS' are those that have recorded in any year:

- ANCDR > 10 per 100,000 population
- Grade II disability rate higher than the national rate.

All such high endemic problem districts will be covered with the following **SIX ADDITIONAL FOCUSSED ACTIVITIES**, in addition to the routine NLEP activities.

i) Survey in selected pockets under strict supervision. Diagnosed cases should receive complete treatment with MDT.

ii) Healthy household contact examination on voluntary basis.

iii) Capacity building of all the health staff for suspecting cases and their management after diagnosis at the PHC and also for DPMR services. Training and retraining should be continuous process for developing their skill.

iv) Awareness campaign regarding early signs of leprosy, role of treatment, reduction of stigma to the persons affected should be undertaken. Involvement of community and persons affected should be helpful. Behavioral change in the community should be the focus.

v) Validation of cases particularly child cases is important to assess skill to the staff involved and to consider remedial action. Child cases should be reviewed, recorded and follow-up actions to be taken.

vi) All cases with disability should be validated and compared with previous years' data. Any upward change in pattern during such disability audit will call for urgent action.

The State Leprosy Officers of all the States / UTs are requested to kindly analyze the district wise situation as on 31st March and identify the high endemic problem districts every year and take focuses action on the suggested lines. ■

Excerpts from: *Directorate General of health Services, Central Leprosy Division, Nirman Bhavan, New Delhi. Circular F. No. L-12012/3/2011-Lep dated 6 June 2013.*

"Elimination is confused with Eradication"

2

Even after a country has achieved elimination of leprosy, the profile of new leprosy might change; for example, in India, new cases of 'histoid leprosy' are still recorded with the same incidence rate. Unless the health service staffs are trained properly, these cases are probably to be missed and interfere with our eradication program.

Based on a rapid population survey in Agra (India), it was shown that a significant number of new patients delay reporting for treatment to a proper place, and mostly they are the multi-bacillary type. They concluded that repeat surveys are essential. This study suggests that repeat surveys on a regular basis are necessary to detect new cases for treatment, and thereby promote leprosy elimination and even eradication.

There have been doubts on the use of the word 'elimination', which is based on prevalence, since it is often confused with the word 'eradication', which refers to incidence or new cases. As mentioned earlier, it has been possible to bring down the prevalence rate to as low a level as 0.6/10,000.

This has caused the following problems: reduction of political commitment, policy support and allocation of resources; and decline in capacity to diagnose and treat cases of leprosy. In fact, an increase in the incidence of leprosy has already been reported in one district in India due to the above causes. Although MDT renders the patient less infectious and stops transmission, infection would have already taken place, and hence new cases will continue to occur for some more years. Constant vigilance is, therefore, required to identify new cases as promptly as possible. It is important to identify any hidden infective source cases, and trace and treat them.

With all the remarkable achievements in the fight against leprosy, the stage is now set for the final assault. Given the recommendations from various international bodies, it is hoped that the disease will be gradually eradicated.

The health authorities are highly capable and are fully armed, and with political will that has sustained the National Leprosy Eradication Program all these years, India could well be leprosy free, and so could other countries with similar mandates to eradicate leprosy, who may have different ecological parameters, but much smaller population and higher development indicators.

However, all these hopes will only remain as dreams unless the countries concerned will heed the wake-up call to engage in meaningful battles against this ancient scourge. ■

Excerpts from: *Sundar Rao PSS, Worldwide Elimination of Leprosy: A Historical Journey, Expert Rev Dermatol. 2012; 7(6): 513-520.*

“Leprosy control in urban areas is a priority”

3

The change in leprosy service delivery from the vertical leprosy staff and specialized leprosy hospitals to general healthcare services has had a number of benefits.

These are

(i) increase in the number of centres from where patients could receive treatment easily,

(ii) patients could collect medicines and consult the medical officer on all working days, instead of a particular day at the leprosy clinics,

(iii) patients could collect their medicines in the more friendly atmosphere of a health centre, as any other patient, which helped in increasing their self-confidence as well as in reducing the stigma, and

(iv) the training given to the general healthcare staff and volunteers such as Anganwadi workers, community health volunteers and teachers helped in spreading positive messages about leprosy, its curability and drug availability in health centres.

However, much more remains to be done in urban areas. The absence of a primary healthcare system in urban areas and the multiplicity of service-providers make programme implementation difficult in these areas, which needs to be addressed on a priority basis.

Integrated services may take another 2–3 years to become fully operational for rendering service to patients with leprosy, but will ultimately help in maintaining a sustainable level of performance. It should be the endeavour of all to help in strengthening the integrated leprosy services through the primary healthcare system.

The leprosy cases that remain in certain states even after the goal of elimination is achieved by December 2005 should receive quality services through the integrated general healthcare system.

In conclusion, India has made tremendous progress towards leprosy elimination during the past decade. Concerted efforts are on to continue the good work done so far, so that the goal of elimination at the national level is achieved by December 2005.

The availability of leprosy diagnosis and treatment services at all primary health centres, free supply of MDT, improved level of awareness among the general population and the reduced level of stigma will help in eliminating leprosy from India. ■

Excerpts from: *Agarwal S. P., Progress in the Elimination of Leprosy in India, Editorials, The National Medical Journal of India, Vol. 18, No. 1, January / February 2005*

"Future of disease eradication and elimination: Issues and opportunities"

4

What lessons can be learnt from smallpox eradication or which other eradication or elimination programmes can be applied to other programmes? Some key lessons include the need to understand the epidemiology and transmission of the disease before targeting it for eradication; the presence of effective tools for diagnosis, treatment and prevention; knowledge of the social, cultural and political factors which may vary from area to area; and the availability of a clear and well thought out strategy.

The eradication strategy should be based on a good surveillance system and on scientific information and evidence. In addition, the biological factors, availability of effective tools and means of their delivery can have an important bearing on the outcome. While the tool in the form of an effective vaccine or treatment could be available, there is a need for continuously and systematically improving the tools and the techniques to deliver them.

Looking into the future, what issues and challenges deem consideration?

First of all, there is considerable degree of confusion relating to the definition of eradication, elimination and elimination as a public health problem. A simple definition that could be proposed includes defining eradication as the absence of disease worldwide as a result of deliberate efforts and elimination defined as reduction to zero of a specific disease in a defined geographic area as a result of deliberate efforts. Such a straightforward definition would help advance the cause of disease eradication or elimination.

Secondly, before embarking on an eradication programme, there should be an agreement on a set of principles that would guide the strategy and action. These include 1) good understanding of the natural history of disease, 2) use of health information or evidence for strategy development; and 3) acknowledging that eradication efforts should not be at the expense of the ongoing programmes such as routine immunization in the case of polio eradication. Considerable attention must be given to planning, setting clear goals and ensuring overall coordination of efforts. Also, care should be taken to make sure that efforts towards disease eradication can supplement and complement the existing health system.

Thirdly, we should be careful not to declare success prematurely as was done in the case of yaws and malaria before the job was done. The last mile is always the hardest and the costliest as we can see in the case of the polio eradication programme. This is a challenge which must be thought through right from the planning stage.

Excerpts from: *Narain JP. Eradicating and eliminating infectious diseases: Past, Present and Future. Indian J Public Health 2011; 55: 81-7*

Fourthly, diseases that are targeted for eradication or elimination should be selected based on a defined and pre-selected criteria which could include disease epidemiology, the natural history and reservoir of infection, availability of an effective intervention tool (biological feasibility), and ability to scale up interventions within a set time frame (operational and technical feasibility). These two criteria should be complemented by a critical analysis of factors such as political commitment, community engagement and trust, availability of funds, and effective communication strategies (economic and political feasibility).

For advocacy and resource mobilization, it would be critical to make a strong economic argument based on the epidemiology and cost-benefit analysis. Achieving eradication or elimination of a disease, if it affects the poorest and most vulnerable populations of the society is also a social and ethical imperative.

Substantial public health and economic benefits make disease eradication a compelling case; while effort is time limited, the benefits of eradication are eternal. However, a careful analysis is needed before embarking on disease eradication. Eradication of some diseases may be possible but it is not easy. For this a good understanding of disease epidemiology, availability of cost effective tools that can be taken to scale, and a broad coalition and partnerships both at the political and community levels are needed which can contribute towards a successful outcome. Most importantly, public health professionals in general and public health workers in particular will have to take a leadership role in making eradication possible. In today's world, the infectious disease agents are dynamic, resilient and capable of spreading across borders efficiently. However, the shared and sustained commitment, political will and dedication of public health personnel can help in achieving the goal. ■

India could well be leprosy-free

Integration of leprosy into the general health service has greatly enhanced the scope of leprosy service.

By integration, discrimination against leprosy has been removed and the patients have access to the services of ophthalmologists, surgeons, physiotherapists, and general physicians.

The most important step in eradication of any communicable disease is to knock out the last case. This can be achieved essentially by community participation for which vigorous IEC activities are required.

It is only the enlightened public that can provide the solution to any social or public health problem.

With all the remarkable achievements in the fight against leprosy, the stage is now set for the final assault. It is hoped that the disease will be eradicated in the near future.

Excerpts from: *Desikan K V. Elimination of leprosy & possibility of eradication - the Indian scenario, Editorial, Indian J Med Res, Year : 2012 | Volume : 135 | Issue : 1 | Page : 3-5*

"Pressure of achieving targets for elimination"

5

Issues related to program strategies

Changing program strategies have affected case detection globally, including in India. The policy of 100% validation of cases detected by primary health care workers and medical officers adopted since 2005 has been unable to be implemented in a number of places; so, many cases have been missed or lost for the purposes of confirmation or examination.

Moreover, the pressure of achieving targets for elimination at the sub-national, district, and block levels had an adverse effect on reporting in many places.

To deal with the issue more effectively, the World Health Organization has twice updated its global leprosy control strategy since 2006, with a focus on strategies to further reduce the disease burden due to the disease, in consultation with national programs of member states, partner organizations, and donor agencies.

Detection of all cases in a community at an early stage and completion of prescribed MDT are the basic tenets of the enhanced global strategy.

India further aims to achieve elimination at the district level by the end of the 12th Five Year Plan (2012–2017). However, given the current resources, this target appears to be too ambitious to be achieved. The critical question remaining here is whether we have declared elimination despite continued high transmission.

Does the hidden challenge remain? Is our health system capable of handling leprosy cases in an integrated program? Diagnosis requires a thorough physical examination of the patient.

Unfortunately, we have a shortage of auxiliary health personnel, making such a thorough physical examination unfeasible.

Adding to this problem is the lack of experience among the general health system staff in diagnosing the disease in the early stages when the patient presents no obvious deformity. Effective training and monitoring of health staff requires constant scrutiny and evaluation.

Are we equipped to manage reactions, complications, and sequelae over time in the integrated system? Are quality checks in place?

Answering these questions and providing appropriate solutions at the highest levels may ultimately allow us to realize the dream of a world without leprosy, even in the near future. ■

Excerpts from: *Aparna Pandey. Current perspectives on leprosy as a public health challenge in India. Research and Reports in Tropical Medicine 2015:6 43–48*

"Government can prove to be a guiding star"

1

Leprosy still remains an important cause of disability even after adopting the resolution by World Health Assembly in 1991 to "eliminate leprosy as a public health problem by year 2000". It was the availability of effective multidrug treatment that led to the thought of leprosy elimination despite little understanding of its epidemiology.

The combination of biological and epidemiological evidence suggests that the leprosy cannot be eliminated by multidrug therapy 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 target of leprosy elimination was achieved at national level in 2006 even then a large proportion of leprosy cases reported globally still constitute from India.

The goal of WHO for the elimination of leprosy has given a boost in this direction but has it been achieved? Global alliance has played a crucial role by publishing its evaluation report and recommended that the World Health Assembly should pass a clear cut resolution to the world community that still the mankind could not be get rid of from the clutches of leprosy as it is not eliminated.

There may be a political agenda, aspiration of the people but the medical and scientific disciplines have not acquired enough base and ground to eradicate this disease.

The delivery of better health care system and management of better quality leprosy services can shoulder to a great extent while good referral system can bring a revolutionary faith in the minds of the masses.

We can achieve a major breakthrough results by reducing the deformity through early detection, self care, physiotherapy and reconstructive surgery and developing sound surveillance systems.

The political will power and vision and mission of the government can prove to be a guiding star and as well as devising strategies for eradication, elimination and prevention of this disease by the scientific and techno-managerial professional community should go hand in hand in perfect harmony with the government. ■

Excerpts from: *Nidhi Yadav, Sumit Kar, Bhushan Madke, Digambar Dashatwar, Neha Singh, Kameshwar Prasad, and Vikash Kesari, Leprosy elimination: A myth busted, J Neurosci Rural Pract. Nov 2014~ 5 (Suppl 1): S28–S32.*

"Need to consolidate the achievement made"

2

Delhi achieved elimination of leprosy in 2008-09. However, being an urban area, it poses unique challenges for health services management. The challenges include social, cultural and economic inequalities and constraints that make vulnerable population segments unaware of or unable to access services. This situation is further complicated by rapid industrialization and increasing density of migrant population in slums.

All this contributes to high endemic zones within the city, which add new cases to our national leprosy data. Out of the total migration to Delhi, 69% are from rural areas, while 31% are from urban areas, the predominant reason being work/ employment. As mostly males migrate to cities in search of employment, this could be an important factor responsible for higher proportion of males in our study.

The percentage of MB cases (86.9%) in our study was significantly higher than PB cases. The high proportion of MB cases in our study could be a sign of existence of inaccessible pockets of population harboring undiagnosed leprosy patients for a long time.

The high rate of reactions observed in our series was alarming. About 30.4% of patients with Type 1 Reaction (T1R), and was seen in BT leprosy (65.9%). The patients present to health care facilities when much damage has already occurred. If detected early by trained health care workers, we could hope to prevent this morbidity associated with the disease.

Our study showed a much higher incidence of WHO grade 2 deformity at presentation (30.79%) as this could be commensurate with high rate of the occurrence of T1R in our series, which significantly increases the risk of deformities, especially in MB leprosy. The need to improve early detection of reactions as well as the role of careful neurological examination in patients with T1R to help reduce deformities is clearly highlighted.

The Enhanced Global Leprosy Strategy 2011-2015 aims to reduce the global rate of new cases with Grade-2 disabilities per 100 000 population by at least 35% by the end of 2015, compared with the baseline at the end of 2010 through early detection and improving management of leprosy reactions. The experience from our tertiary referral center suggests that though great strides have been made in elimination of leprosy, we still cannot celebrate. The high rate of multibacillary disease or patients presenting with reactions and deformities, as compared to the national averages is a cause for alarm. Its time when we need to consolidate the achievement made and intensify on the aberrations discovered. ■

Excerpts from: *Chhabra N, Grover C, Singal A, Bhattacharya SN, Kaur R. Leprosy scenario at a tertiary level hospital in Delhi: A 5-year retrospective study. Indian J Dermatol 2015; 60: 55-9.*

"Need for a strong, efficient referral system"

3

Sustaining adequate and effective leprosy services in the light of low endemic situations and changing policies of health sector reforms is a challenging task. Disease Control Systems must be sustained as long as the need exists, until the disease and its complications are totally eliminated. Such sustainability depends not only on political wills but the administrative aspects of training and capacity building of service staff to provide quality care, as well as on the availability of necessary resources, especially drugs and other therapies.

Beyond these grassroot requirements, under the integrated health settings, successful sustainability requires a feasible, acceptable and efficient referral system that provides the necessary support to grass root staff in managing complex issues in patients as well as to provide education to the staff and the community. For developing countries, strategies that give greater focus on strengthening referral systems will assist better use of scarce resources.

Establishing such a referral system seems acceptable and a good concept, but in many developing countries the health services have failed in its implementation. An effective referral system seems to be the weakest link in successful health delivery under the integrated setup, especially in rural areas. In India, referral systems planned for most urgent health problems such as maternal and child care, communicable diseases and many life-style diseases are dysfunctional, and leprosy services are no exception. If leprosy services are to be sustained in countries such as India, adopting contemporary and technological innovations and full community involvement is crucial.

Functions of a good Referral System

As leprosy becomes less common, the ability of peripheral general health workers to suspect cases of leprosy and to make appropriate referrals becomes the most important skill. The referral unit should not only be capable of dealing with such cases, but also handle patients with complex and complicated leprosy, providing the necessary feedback to the referring unit for education and follow-up. Thus, referral is a two-way process and must be facilitated by minimal, essential paperwork.

As in any successful management protocols, periodical reviews will enhance their effectiveness and efficiency. This is lacking at present. What is urgently needed is a clear directive to the health/medical personnel on what to refer, where and how, what directions should be given to the patient/family and the provision of both the upward and downward flow of information, as well as constantly reviewing the mechanism to ensure the

Excerpts from: *Sundar Rao P.S.S., Referral system: A vital link in the sustainability of leprosy services, Lepr Rev (2010) 81, 292–298.*

system works to the benefit of the patient. Such a directive must include guidelines on: referring patients for diagnosis and classification of leprosy, prescription of the right type of MDT and additional drugs such as steroids where indicated, the referral for prosthetic and orthotic aids for reconstructive surgery, the referral in cases of superimposed infections such as tuberculosis, referrals for specialized services such as ophthalmology, occupational therapy, and counselling.

Appropriate referrals for disability management and any laboratory investigations may also enhance medical care. Although the WHO Operational Guidelines on Global strategy for further reducing the Leprosy Burden and sustaining Leprosy Control Activities (2006–10) provide some details, professional staffs are not given sufficient orientation and training in making efficient referrals, and there are no proper systems for feedback that will improve the practice.

Such a comprehensive plan will no doubt yield good outcomes, and are applicable for leprosy referral systems as well, in a much simpler fashion. The essential functions of a referral unit at different levels in an integrated leprosy service critical in sustaining the quality and coverage as well as community support, so important in any public health programme.

There is no doubt that the Government alone cannot handle any public health programme without the full cooperation of the public as well as the active collaboration of various like-minded non-governmental and private enterprises. In the case of National Leprosy Eradication Programme of the Government of India (NLEP), there are many instances of such Public-Private collaborations during the pre-MDT era in terms of case detections, case management and provisions of IEC or other supporting services such as provision of footwear, etc. Although they don't strictly qualify as partnership, such collaborations continued during the MDT era as well, but after integration, the Government decided that they can manage the bulk of NLEP activities, leaving only some marginal issues and covering of unreachable areas to leprosy NGOs. The identification of some institutions for Reconstructive Surgery and offering monetary benefits do not by themselves become successful in managing the grade 2 disabilities, unless, the process and paperwork for proper feedback is in position.

At present, there are no authentic records of how many were referred for RCS, how many responded, and how many were operated. Details on how the operated patient was facilitated to resume his occupation and re-settled economically and socially are essential for further progress and sustainability of RCS services.

After all, the health must become the responsibility of the people for a programme to be successful, with necessary inputs from the government and nongovernmental agencies. Therefore, the need of the hour is to establish PPPP for provision of an effective referral system. The initiative for such partnerships must come from the government in a big way, and the bureaucratic tangles eliminated, to get the programme on the way. This is an urgent and strategic issue for the government if it has to continue its progress towards eradication, removing all biomedical and social obstacles. ■

"Leprosy patients are not sidelined"

4

The technology of physical care of the disabled leprosy patients, which is confined to hospitals and institutions, has not penetrated into the community. Though the PHCs have accepted and even appreciated the services offered to patients, it may still take far more time for the health workers to perform the disability care activities themselves. There are some instances of "ASHA" workers (of the "National Rural Health Mission") who have assisted our volunteers, but we cannot generalize on the basis of limited experience.

There is a clear indication, however, that provided such programs are encouraged to function consistently as models for longer periods in PHC areas, the handing over of technology to the PHC is possible. This will ultimately meet the policy of WHO and the government aiming at total integration.

The magnitude of problem posed by leprosy patients with disabilities and their rehabilitation is highly challenging and is expected to pose a heavy burden on the community as well as unprecedented strain on the PHCs managed by government. The health planners should rethink on future strategies in such a manner that human rights of the downtrodden patients suffering from the "neglected disease" of leprosy are not sidelined. ■

Excerpts from: *Ganapati R,. Community care of the physically disabled due to leprosy. Indian Dermatol Online J, 2011; 2: 70-4. Available from: http://www.idoj.in/text.asp?2011/2/2/70/85994*

"New G2D cases is constant"

5

Information about new Grade 2 Disabled (G2D) cases is collected as absolute numbers, proportion of new G2D cases among new cases, and rate of new G2D cases per 100 000 population. At global and WHO region levels, the new G2D rate per million population is also calculated. Reduction of G2D cases in the community is also measured by reduction of disease burden due to leprosy.

The enhanced global strategy for further reducing disease burden due to leprosy set a target of reduction of new G2D cases by 35% in 2015, taking 2010 data on new G2D cases as baseline.

The numbers of new G2D cases have been found to be higher than in the previous year at global level in all WHO Regions except WPR. The number of new G2D cases was found to be constant in the range of 13,000 to 14,000 for the past 10 years. The new global G2D case rate is 2.5 per million populations.

The WHO expert committee called for a target of reduction of new G2D cases to >1 case per million population by end of 2020. The trend in new G2D cases shows definite levelling and warrants improved active case finding to detect new leprosy cases before disabilities develop. ■

Excerpts from: *WHO Weekly Epidemiological Record, No. 36, 4 September 2015, 90, 461–476*

“Need for an accountability framework”

1

The health policy, while being holistic, focuses on the need for enhanced funding and an organizational restructuring in order to facilitate more equitable access to the health facilities. Also, the policy is focused on those diseases which are principally contributing to the disease burden. This is not to say that other items contributing to the disease burden of the country will be ignored; but only that the resources, and also the principal focus of the public health administration, will recognize certain relative priorities.

The policy aims to achieve an acceptable standard of good health among the general population of the country and has set goals to be achieved by the year 2015. However, from a global perspective India’s public spending on health is extremely low. The 12th five-year plan (2012–17) aims to increase the public health investment from 1.1 per cent to 2–3 per cent of GDP.

The 12th plan envisages that every district would announce as part of its five year strategic district plan, the package of services each facility would guarantee such that taken together the district health system would ensure universal access to good quality of comprehensive health services. Such a district plan would become the instrument to be used for programme audit by the government and for social audit and community monitoring purposes. One of the most important areas where persistence and quality is needed is in the state level institutions of management and governance. Governance institutions need to function as good governance and need to have the necessary separation from management functions. The governing boards of the State and District Health Societies and Rogi Kalyan Samitis must perform different functions from the executive committees.

An accountability framework needs to be built with clearly defined responsibilities for all officers at all levels. Involvement of communities should be strengthened to ensure that the accountability framework is implemented effectively. The principles of good governance are to be emphasized and practices such as the display of expenditures on the district and state websites on a monthly basis could be mandated to ensure transparency in the 12th Plan.

One direction of change would be to integrate the various steps undertaken by the Ministry of Health and Family Welfare over different periods into one integrated ‘National Health Survey’ with a periodicity of three years. Meanwhile, programme evaluation of specific strategies would be continued using appropriate methodologies to assess the contribution of each programme to the overall goals. ■

*I**Excerpts from:** ndia’s Healthcare System – Overview and Quality Improvements. Swedish Agency for Growth Policy Analysis, April, 2013*

"Acceptability and sustainability of public health policies"

2

Another important contribution of primary health care to leprosy control policy was that it provided a platform for the integration of leprosy control and treatment services into the general health system. The integration of leprosy into primary health care initiative was strengthened by empowerment of people affected by leprosy to take active part in the management of their disease. The integration process was a difficult initiative, given high levels of leprosy stigma and perception among a significant proportion of staff that integration of leprosy into primary health care might lead to situations in which targets cannot be met, supervision would be difficult, knowledge of the staff was inadequate, and leprosy would be accorded low priority in the mix of primary health care functions.

Despite formidable challenges, the integration strategy was largely successful globally because it was substantially reinforced by the global health policy of Health for All by 2000. This global policy was adapted to leprosy in remarkably effective ways, including funding support. In some nations, leprosy funding was sufficient enough to develop vertical leprosy control programs to such an extent that it was feasible to integrate some primary health care functions into vertical leprosy control Programs.

Three themes which are evident in this review are: the need for strong leadership, effective health activism, and inclusive public health platform, in assuring consistency in international leprosy control policies. The healthcare leadership styles demonstrated by proponents of various public health eras have important implications for consistency in global policy development. Although the need for health leadership was highlighted in the World Health Report [2008], consensus on health leadership competencies is lacking, and this lack of consensus has contributed to inconsistencies in global health policy implementation.

Second, health activism, defined as "energetic advocacy in a civil society," has been instrumental to the success of many health promotion activities on stigma reduction and should be preserved as one of its important leprosy control legacies contemporary public health era. The social marketing and other health activism approaches incorporated into "World Leprosy Day" activities exemplify the important role of active advocacy in contemporary leprosy control. Renewed leprosy control-related activism, involving people affected by leprosy is needed to complement current approaches to reduce leprosy incidence and prevalence, as well as effectively socio-economically rehabilitate individuals and groups affected by leprosy. Finally, the public health platform on which international health policies are formulated and disseminated is an important determinant of the acceptability and sustainability of public health policies. ■

Excerpts from: *Niyi Awofeso, Leprosy: International Public Health Policies and Public Health Eras, Adm. Sci. 2011, 1, 32-44*

“Indian healthcare : a glass half empty or a glass half full”

3

The Indian healthcare sector can be viewed as a glass half empty or a glass half full. The challenges the sector faces are substantial, from the need to reduce mortality rates, improve physical infrastructure, necessity to provide health insurance, ensuring availability of trained medical personnel etc. There has been a rise in both communicable/infectious diseases and non-communicable diseases, including chronic diseases.

There are considerable shortages of hospital beds and trained medical staff such as doctors and nurses, and as a result public accessibility is reduced. There is also a considerable rural-urban imbalance in which accessibility is significantly lower in rural compared to urban areas. Women are under-represented in the healthcare workforce. The health needs of the country are enormous and the financial resources and managerial capacity available to meet them, even on the most optimistic projections, fall somewhat short.

India’s National Health Policy, 2002 had to make hard choices between various priorities and operational options. It does not claim to be a road-map for meeting all the health needs of the populace of the country. Furthermore, it has to be recognized that such health needs are also dynamic, as threats in the area of public health keep changing over time. The policy, while being holistic, focuses on the need for enhanced funding and an organizational restructuring in order to facilitate more equitable access to the health facilities. Also, the policy is focused on those diseases which are principally contributing to the disease burden. This is not to say that other items contributing to the disease burden of the country will be ignored; but only that the resources, and also the principal focus of the public health administration, will recognize certain relative priorities.

The policy aims to achieve an acceptable standard of good health among the general population of the country and has set goals to be achieved by the year 2015. However, from a global perspective India’s public spending on health is extremely low. The 12th five-year plan (2012–17) aims to increase the public health investment from 1.1% to 2–3% of GDP.

While states are responsible for the functioning of their respective healthcare systems, certain responsibilities also fall on the federal (Central) government, namely aspects of policy-making, planning, guiding, assisting, evaluating and coordinating the work of various provincial health authorities and providing funding to implement national programmes.

The 12th plan envisages that every district would announce as part of its five year strategic district plan, the package of services each facility would guarantee such that taken

Excerpts from: *India’s Healthcare System – Overview and Quality Improvements. Swedish Agency for Growth Policy Analysis, April, 2013* together the district health system would ensure universal access to good quality of comprehensive health services. Such a district plan would become the instrument to be used for programme audit by the government and for social audit and community monitoring purposes.

One of the most important areas where persistence and quality is needed is in the state level institutions of management and governance. Governance institutions need to function as good governance and need to have the necessary separation from management functions. The governing boards of the State and District Health Societies and Rogi Kalyan Samitis must perform different functions from the executive committees. The programme management units must function as secretariats of the executive committees. An accountability framework needs to be built with clearly defined responsibilities for all officers at all levels. Involvement of communities should be strengthened to ensure that the accountability framework is implemented effectively.

The principles of good governance are to be emphasized and practices such as the display of expenditures on the district and state websites on a monthly basis could be mandated to ensure transparency in the 12th Plan. One direction of change would be to integrate the various steps undertaken by the Ministry of Health and Family Welfare over different periods into one integrated 'National Health Survey' with a periodicity of three years. Meanwhile, programme evaluation of specific strategies would be continued using appropriate methodologies to assess the contribution of each programme to the overall goals. ■

Leprosy control offer several challenges

On January 30, 2005 India celebrated the elimination of leprosy as a public health problem after achieving the nationwide prevalence of 1 case per 10,000 population, though not without criticism regarding the accuracy and choice of target parameter.

This is a remarkable achievement given that in 1981, two years before NLEP, there were nearly 4,000,000 cases with a prevalence of 50 cases per 10,000 population. However, in a population of more than a billion people, up to 100,000 people with leprosy remain, representing approximately half of the world's disease burden.

Some regions, mostly rural, still have up to five times the national average of cases; these areas have become the next targets in leprosy control. The future of leprosy control and elimination offers several challenges with both structural and cultural dimensions.

Efforts to decrease health inequity due to poverty, especially in rural areas with limited access to health care, may help with leprosy control. However, if cultural beliefs are not addressed, increased availability may not translate into an appropriate increase in utilization. Cultural aspects of leprosy affecting its control include traditional medicine and stigma.

Excerpts from: *Jesse T. Jacob, Carlos Franco-Paredes. The Stigmatization of Leprosy in India and Its Impact on Future Approaches to Elimination and Control, PLOS Neglected Tropical Diseases, Jan 2008.*

LOR Camp: An approach to sustain the quality leprosy services and ensure the rights of PALs.

A glimpse of activities

Inaugural : sensitisation

PALs : peer group motivation

Access : enquiry on cure & care

Screening for requisite service

Clinical assessment

Counselling on self care

'HOPE' therapy

Wound dressing by PHC staff

TOWARDS A LEPROSY-FREE WORLD

We, the Ministers of Health from the 17 high-burden leprosy countries in all WHO regions, with relevant stakeholders, and the World Health Organization;

1. ***declare*** that it is time for the leprosy-endemic countries, as well as their international and national partners, to reaffirm their commitments and reinforce their participation towards addressing leprosy in order to ensure a leprosy-free world at the earliest;

2. ***urge*** governments and all interested parties to accord higher priority for activities towards a leprosy-free world, and allocate increased resources in the coming years, in a sustainable manner, and in doing so:

   a. ***aim*** to reduce the burden of leprosy and ultimately move towards a leprosy free world;

   b. ***apply*** special focus on high-endemic geographic areas within countries through vigorous and innovative approaches towards timely case detection and treatment completion aiming to achieve leprosy elimination as a public health problem at sub-national levels;

   c. ***achieve*** the global target of reducing the occurrence of new cases with visible deformity (grade 2 disability) to less than one case per million population by the year 2020;

   d. ***prevent*** occurrence of disability through early detection as well as limiting disabilities among already disabled persons;

   e. ***involve*** communities and the forums of persons affected by leprosy in the process of strategy formulation and implementation of leprosy care, including physical, social and economic rehabilitation and social integration, as per WHO guidelines;

   f. ***promote*** empowerment of persons affected by leprosy and ensure effective implementation of United Nations resolution, Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members; and

   g. ***monitor*** the progress towards attainment of targets through a mechanism at the national level with technical support from WHO and other relevant partners;

3. ***Reaffirm*** our political commitment and guidance towards a world free of leprosy.

International Leprosy Summit – Overcoming the Remaining Challenges,
Bangkok, 24 July 2013