Dear Friends

It’s my pleasure to present the newsletter from the Knowledge management domain encompassing research, training and evaluation. This issue focusses on transmission and we have a case study of eleven year old Niranjan affected with leprosy. Children are still getting leprosy and while on treatment with MDT, they are getting deformities that will cripple them for their entire life.

I ask these questions to myself and my readers – His father was treated for leprosy, did he not know the symptoms? Why did he not recognize the patches on his son’s body and report early? Is there a disconnect between knowledge and practice? “What the mind does not know, the eye does not see”! Or is it apathy? Is it failure of our medical education? In Delhi, fortunately someone diagnosed him, and was started on MDT. From the number of patches, did anyone not anticipate that he was at risk for reactions and neuritis? Did he not deserve special attention from health care providers? What was going on when he was developing eye, hand and foot impairment? Anesthetic feet demand an entire life time of self-care and use of MCR sandals to prevent ulcers. Do we understand the burden we are putting on this little child who wants to run, play and live? He does not understand, but we do! And yet allow it to happen, time and again. It’s time we resolve to care for individuals, with ethics and a sense of justice, the people affected with leprosy.

At TLMTI, we are concerned about the dwindling leprosy expertise nationally and globally. This year we conducted training programmes to address this gap. The department also endeavors to build the capacity of staff. 2 staff participated in advanced statistical package and one staff underwent whole genome sequencing training at NHDP, USA. There was also representation of TLMTI staff in various national forums.

We hope this edition of the newsletter will be thought provoking. We would love to hear from you.

Joydeepa Darlong
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Stable ANCDR rate at national level since eight years

Reducing transmission of leprosy

Leprosy continues to be one of the most important burning issues plaguing the health of our country even in the post elimination era, in spite of India having achieved elimination status well over a decade ago. Though no longer the scourge that it once used to be, the burden of the leprosy is still alarming enough to draw attention of leprologists and health professionals across all sectors. As recently as March 2017, the annual new case detection rate (ANCDR), considered to be proxy indicator of the burden of the disease was found to be 10.17 per 100,000 population, and prevalence of leprosy (PR) 0.66 per 10,000 population, according to the National Leprosy Eradication Programme (NLEP) monthly progress report for the year 2016-17. In the same report, the proportion of childhood leprosy among the new cases detected, regarded as an indicator of the transmission of leprosy in society, was 8.71%, of which 2.46% belonged to the multibacillary spectrum.1 These figures and statistics are alarming in their own right, though they constitute just the tip of the iceberg as there still remain many sufferers who still do not come forward to seek medical help for fear of the stigma and being discriminated against. Transmission of leprosy is thus clearly not a problem of the past, yet one of the persistent problems is further reducing the disease burden since after achieving elimination in 2005. The fall in ANCDR and PR has since almost plateaued falling from 1.2 and 0.72 in 2006-07 to 1.02 and 0.66 in 2016-17 respectively.

Continued on page 2
A major hurdle to interrupting this transmission is the lack of adequate and accurate information about where and to what extent transmission is occurring. A large number of hidden cases continue to occur and reducing transmission of the disease is the need of the hour. However, this is not possible to be achieved only through multi drug therapy and new tools are needed to prevent new cases. Though our country has an effective surveillance system that provides epidemiological data to map high-risk areas for leprosy, and to monitor the changing epidemiological pattern of the disease, effective prevention and intervention strategies need to be in place to bring about a significant change in these figures. The section of people who need to play the most active role in gaining this information include people working at the grass root level of the national leprosy programme. The importance of raising awareness about signs and symptoms of leprosy so that people recognize that they should seek help cannot be overemphasized. It is also extremely important to destigmatize the disease by emphasizing on the fact that it is curable with appropriate and adequate treatment.

Measures for early detection of cases constitute a major tool towards reducing transmission of the disease. Seeking out cases by rigorous contact tracing and community surveys among high risk groups are a prerequisite to detect new cases and treat them early in the course of the disease in order to reduce transmission. Implementation of contact-tracing programmes is not only imperative but also feasible, especially in high-risk groups. However, it should be integrated into local healthcare services to ensure their long-term sustainability. Local healthcare workers should be trained in carrying out basic on field bedside tests like slit skin smear. Involvement of local workers will also help in improving outreach of these facilities as language barriers will be overcome. Adequate funding must be maintained throughout the implementation and volunteers should be appropriately rewarded. Contact tracing programs also need effective surveillance systems to enable appropriate follow-up and outcome evaluation. Symptomatic contacts should also be treated with multi drug therapy. Epidemiological studies have shown that the chance of finding previously undiagnosed leprosy is much higher in household contacts of leprosy patients than in the general population, and increasing proportion of new cases are from household contacts. School surveys are especially important because the detection of leprosy in school-age children is a strong indicator of ongoing transmission and failing control measures. Every case detected should receive information and counselling regarding the disease and the importance of adherence to multidrug therapy.

The use of chemoprophylaxis or immunoprophylaxisin asymptomatic contacts remains an issue of debate, the main hurdle to their implementation being that intensified, population-based approaches to case detection are not cost effective. Chemoprophylaxis with single-dose rifampicin (SDR) is efficacious in reducing the transmission of leprosy, although the protective effect appears to be smaller in contacts closer to the index patient than in more distant contacts. Post exposure chemoprophylaxis with SDR has shown to reduce incidence of leprosy and reduce detection rates of new patients—and there by transmission of infection—by about 50–60%.

Alternative prophylaxis regimens and the role of post-exposure immunoprophylaxis need to be further investigated. Vaccine trials have been conducted with BCG, often in combination with Mycobacterium leprae and related Mycobacterium species like Mycobacterium Indicus Pranii (MIP) as immunoprophylaxis for contacts of leprosy patients. Meta-analyses have confirmed the protective effect of BGG against leprosy. A recent review described variable protection of BCG vaccination against leprosy indifferent study sites, ranging from 20% to 90%, and presented evidence for protection given by the vaccine at a young age.

These shortcomings underline the need for research into alternative regimens. A serious obstacle, however, to contact tracing is the absence of a reliable and simple diagnostic test for early detection of both disease and subclinical infection in contacts. Such a test would not only help with research into the mechanisms underlying the transmission of leprosy, but also enable better measures for prevention and earlier treatment. Clinical diagnosis of leprosy is dependent on the recognition of disease signs and symptoms and also depends on the skills of the health care worker. One of the available tests based on antibody responses to the M lepraephenolic glycolipid (PGL) 1 is a marker for higher bacterial load, and may identify potential infectious sources among patients with few clinical signs. However, it is only effective for detecting infection in MB patients and does not accurately predict the development of disease in subclinical cases. It would not prove to be very useful to establish whether leprosy contacts are infected with M leprae or more likely to develop disease, in which case they could receive prophylactic treatment. However, screening of contacts for presence of antibodies against PGL-1 by ELISA might again be fraught with practical difficulties in implementation because of feasibility and cost factors. It is important to develop tests that are based on bio markers that can differentiate between infection and disease and at the same time are simple and cost effective.

It is high time now for policy makers and the society at large to collaborate and formulate both innovative and feasible intervention strategies for the prevention of leprosy. Interruption of transmission of leprosy is achievable, provided the governments and the people working for the national program commit, politically and financially, towards an effective and fool-proof, multi pronged strategy. Surveys of high risk groups like contacts and schools and epidemiological mapping should be done regularly. Both active and passive contact tracing should be systematically implemented, followed by post-exposure prophylaxis and treatment, if necessary. An effective and fool proof surveillance system should be in place. These strategies form the basis for effective reduction in the transmission of this debilitating disease and could finally result in its end game.

References
1. National Leprosy Eradication Program, Annual Progress Report 2016-17
2. National Leprosy Eradication Program, important maps and graphs
Niranjan Darlong attended Dermatology and Allied Sciences (DAAS) SUMMIT – 2018 which was held on 29th June 2018 to 1st July 2018. Dr. Joydeepa was invited as a Panelist for the Theme: Leprosy and Topic - Challenges in the treatment of Leprosy – reactions, adverse reactions to anti-leprosy drugs, drug resistance, and alternate MDT regimens.

Dr. Utpal Sengupta, Dr. Joydeepa Darlong and Dr. Loretta Das were invited in the National Leprosy Symposium Scheduled for August 24th in Delhi. The topics for the symposium were – UMDT, Chemoprophylaxis and Immuno-prophylaxis. Dr Joydeepa was the rapporteur for UMDT session, Dr Sengupta spoke on Immuno-prophylaxis and Dr Mary was a panel member in the Chemoprophylaxis session.

Mr. Karthikeyan was a facilitator in the Operational Research workshop at 2018 Global fellowship workshops for programs, June 11-15, 2018. There were total of 23 participants in the operational research workshop, including facilitators. The facilitators were, Dr Deanna Hagge (TLMI/TLM Nepal); Mr Karthikeyan Govindasamy (TLMTI); Mr Suren Singh (TLMB) and Ms Shabina Sadiq (TLMEW). The workshop was designed and delivered with the intention that participants would identify research questions relevant to their own programs, select topics, develop a proposal and employ tools introduced during the workshop to come up with operational research projects by the end of the workshop.

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He developed type 1 reaction 4 months ago and was given a course of steroids. His preop physio is continuing and soon he will be able to undergo corrective surgeries and return to normal functional life.

Niranjan reported to TLM hospital after completing 12 months of MB-MDT. At that time he was studying in class 5 in one of the schools run by Delhi government.

In the hospital, his body charting was done which revealed multiple anesthetic patches on back and large big hypopigmented patch on left side of the face, and some small patches on the forearm. His BI was negative.

He had following impairments:
1. Left eye lagophthalmos of duration around eight to nine months.
2. Partial Sensory loss on soles of both feet but no ulcer...
3. Left hand impairments - Sensory loss, Ulnar median claw, Ape thumb deformity.

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Capacity building & participation in national forums

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Dr. Ravindra P. Turankar and Mr. Karthikeyan attended Hands on training of statistical software in medical research from 1st August – 3rd August, 2018 in Division of Biostatistics & Epidemiology, I-7, Sector 39, National Institute of Cancer Prevention and Research (NICPR), Noida.

Dr. Mallika Lavania successfully completed her 2 months (August - September) training in National Hansen's Disease Program (NHDP), Louisiana University, USA.
TLM Naini
83 persons were trained at the Training Unit Naini during the past 6 months through workshops, In-service training, Orientation and certificate courses. Topics addressed were Leprosy, Disability, Project Development, Inner Well Being etc.

The Certificate course in Leprosy for Doctors was conducted thrice - March, May and August 2018 and trained 33 Medical officers including 8 Delhi DLOs & 1 SLO. Workshops: Four workshops have been organised and conducted by Training Domain and CREATE & CIU projects TLMTI

Inner Well Being:
◆ A 5 day workshop was conducted for lay counsellors of TLMTI, Karuna Project Mumbai, TLM Myanmar & Bangladesh to address the need to address mental health of people affected by leprosy and learn the basics of counselling 27 participants attended.
◆ This program was led by Dr. Joydeepa Head, Knowledge Management and Mr. Immanuel Jacob counsellor, TLM Vadathorasalur with the support from facilitators from Sangath, Goa and Ms Jubin Varghese, clinical psychologist from.

Non-surgical management of motor disabilities in leprosy
◆ A 4 day workshop was conducted for 12 TLMTI therapists & technicians to upgrade their skills & knowledge in prescribing / designing / fabricating thermoplastic and POP splints for hand deformities.
◆ Exercise therapy, Gait Scan, Latex, Research and Leadership in Disability management were discussed during the workshop.
◆ The facilitators were Mr. Karthikeyan, Mr. Vijayasekar Mr. G. Babu and Mr. Bino Berry.

TLM Miraj
Restarted the PMW Training in Leprosy. This is a new initiative to rebuild skills in clinical care of leprosy affected, in the country. TLM Miraj is currently running the first course and 50 trainees are enrolled. They plan to conduct 3 more such courses, the next one beginning in November 2018.
Workshop on “Customized Insole Fabrication using Online 3D Scan & CAD/CAM Technology

This workshop was conducted in February 2018 for physiotherapists of TLMI. The topics covered were paradigm’s of Pathology and Treatment, The Tissue Stress (TS) theory of foot assessment and treatment, fundamentals of gait, the importance of the foot impression and patient compliance, foot impressions using 3D LFS scanner, using CAD to replicate and enhance the traditional methods of manufacture, assessing and prescribing orthotics in patients, designing of insole with specific modifications using CAD technology, milling of the insoles using CAM Technology with finishing and a team approach to agree on orthotic and insole protocols to treat common foot conditions. It was a very fruitful learning experience with the excitement of learning how to adapt 3d printing technology in prosthetics.

Leprosy and Champions development workshop:

◆ This training was organised by CREATE & CIU Projects on Methods of developing ‘champions’, by Mr. James George Program Manager CREATE & Ms. Phoebe Program Manager CIU.

Training in Preparedness for Disaster Mitigation

Training and disaster mitigation plan for 6 locations have been done so far. 1-Vada (VTC& Hospital), 2-Shahdara, 3-Naini, 4-Faizabad, 5-Muzaffarpur, 6-Purulia. This involves- training of staff what to do/not to do in case of any disaster e.g. fire/earthquake/riot/mob attack etc. Evacuation plan and 6 monthly mock-drill, making incident command system and keeping it functional.

Changes in infrastructure involves simple, no cost to costly e.g.- additional stairs/ramps to reinforcing buildings wall.

Training of master trainers will enable formation of a team capable of training others as well as preparing disaster mitigation plan for hospitals.

The First Master Trainers program for Hospital Disaster Management was held in TLM Purulia in May 2018. There were 24 participants representing 11 hospitals and 2 each from VTCs and projects of TLM. The 3-days training program was quite rigorous with theory, hands on practice and assignments.
The International textbook of leprosy is available online. Over a period of time, the number of leprosy cases has decreased, and fewer resources, including textbooks, are available that focus on it. The International Textbook of Leprosy (ITL) is a comprehensive online and open access reference text. The book was written by more than fifty international experts from fourteen countries and co-edited by David Scollard and Tom Gillis. The primary audience of this book is medical doctors and scientists, particularly those who do not have access to a major medical library or the funds to purchase such a specialized text.

The textbook can be accessed at www.internationaltextbookofleprosy.org

After “Hidden Challenges” in Brussels in 2013 and “Unfinished Business” in China in 2016, the 20th International Leprosy Congress definitely gives us the opportunity to turn to future challenges with ambition and realism. After discussions with the Philippines authorities, the International Leprosy Association (ILA) is pleased to announce the organization of the upcoming International Leprosy Congress from 10th to 13th September, 2019 in Manila, Philippines.

Since the introduction of effective multi-drug therapy (MDT) some 30 years ago, the prevalence rate of leprosy has been reduced by 95%. In contrast, the number of people reported with newly diagnosed leprosy has consistently remained above 200,000 per year over the past decade. Yet new scientific advances and strategic approaches have brought the vision of “zero leprosy” into focus. They have created a sense of urgency to accelerate progress towards this vision and have clarified the need to work collaboratively in innovative ways. The World Health Organization Global Leprosy Strategy 2016–2020 now includes in its vision statement “zero transmission of leprosy infection”.

There is no doubt that the global picture of leprosy is different than it was 30 years ago. In this new context, innovative approaches and initiatives are necessary for truly stopping leprosy transmission, preventing disability, and promoting inclusion.

The 20th International Leprosy Congress is a privileged opportunity for scientists, researchers, health staff, partners, and individuals affected by leprosy to interact, discuss, and share experiences in a variety of fields.

Taking into account these different elements, this Congress, resolutely turned towards “Future Challenges”, has as its main objectives to:

- Review progress made in implementing the 2016–2020 WHO strategic plan since the 19th ILC in China
- Foster a global partnership to stop the transmission of leprosy

This partnership is meant to be inclusive in order to pool all resources, all opportunities, and to achieve the ambitious goal of stopping the transmission of leprosy.

Full details of the congress will be provided later.

Dr. Roch Christian Johnson,
President, International Leprosy Association

Source: Lepra
A pilot study using participatory, translational, social science research methods to explore stakeholder perspectives on preventing delayed diagnosis in leprosy

Kuipers P, Joy A, John A and Raju MS

Summary

Objectives: This study sought to enhance and complement existing knowledge on preventing delay in diagnosis of leprosy, through the application of inclusive research methods which incorporate perspectives of multiple stakeholders.

Study Design: An innovative, sequential, qualitative and participatory method was used comprising interviews with people affected by leprosy, reflection and discussion groups with multiple community level stakeholders and research translation meetings with management level staff of a major NGO and the relevant state government department.

Results: Enhancing the skills and roles of people affected, lay people and grassroots community workers was identified as a foundational strategy. Targeted and active case finding approaches are required.

A broad-scale dissemination approach to public education and awareness on leprosy is also recommended, using ubiquitous and high profile media. Intervention planners must ensure alignment between general aspirations or goals, and more practical and specific strategies.

Conclusion: The current findings align well with the Behaviour Change Wheel, and provide a worthwhile framework to guide multifaceted and holistic service development to address delayed diagnosis.

Screening household contacts of children diagnosed with leprosy in a tertiary referral centre, Chattisgarh state, India

Ramasaamy S, Kumar A & Gonvindaraj P

Summary

Objective: The study aimed to screen the household contacts of children diagnosed with leprosy in a tertiary referral centre.

Methods: This hospital based study involved 117 children, aged up to 14 years and newly diagnosed with leprosy, who attended a tertiary referral centre Hospital, Champa, Chhattisgarh, India. We enumerated all the household contacts of the registered child cases and invited them to attend for screening.

Results: Of the 117 children, 72 (62%) were male and 45 (38%) were female with ages ranging from 3 to 14 years. Nearly half of them (47%) were diagnosed as multibacillary cases. A total of 358 household members was enrolled for screening. Of these, 214 (60%) were examined for leprosy. Ninety-three household members were found to have signs of leprosy, and among these, 17 were identified as new cases, 30 were known cases currently on treatment and 46 had been previously treated for leprosy.

Conclusion: The study showed that a household contact survey is an effective method for case detection in leprosy control programmes. Continued health education and motivation of household contacts will enhance the voluntary reporting for periodical screening.

The symposium was organized by The Leprosy Mission Trust India (TLMTI) on the 29 November, 2017 at India Habitat Centre, Lodi Road, New Delhi, India. The meeting was organized for the stakeholders who are engaged in the leprosy elimination programme for an exposure to the recently emerging scenario on relapse and drug resistance in leprosy. A total of sixty three participants including representatives from Government of India, WHO, ILEP, GLRA, LEPRO India, NLR, DFIT, BLP, FMR, NIMHANS, ICMR-NJIL & OMD and ICMR gathered in the symposium. Most of the famous advisors of the country, leprologists and dermatologists of TLM, Safdarjung, Guru Tegh Bahadur hospitals, PGIMER (Chandigarh, India), DLO and SLO of Delhi participated in the symposium. Leprosy researchers and scientists from different organizations across the country also gathered for the deliberations and discussions. The symposium began with a welcome address from the Executive Director, TLM which was followed by inaugural keynote addresses by the experts of the country. Scientific deliberations by the leprologists, dermatologists and laboratory researchers were divided in four main sessions. This symposium had presentations on most current areas of importance such as goals and achievements of NLEP; diagnostics with focus on different forms of disease including neuritic leprosy; newer methods such as imaging for studying CNS involvement; response to therapy; drug resistance in the context of relapses, poor responders, reactions and multibacillary leprosy, transmission, methods and strategies for detection of drug resistance and its surveillance; national and global perspective etc. The Symposium concluded with a plenary session for the road map of a future strategy with recommendations which include molecular detection of drug resistance with focus on relapses, reactions and MB leprosy; confirmation of relevance of novel mutations in animals; networks for drug resistance surveillance and epidemiology of drug resistance in leprosy.
### The New WHO Leprosy Guidelines on diagnosis, treatment and chemoprophylaxis is out.


<table>
<thead>
<tr>
<th>AREA OF THE RECOMMENDATION</th>
<th>RECOMMENDATION</th>
<th>STRENGTH</th>
<th>QUALITY OF EVIDENCE</th>
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<tbody>
<tr>
<td><strong>DIAGNOSIS</strong></td>
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<tr>
<td>Diagnosis of leprosy</td>
<td>The diagnosis of leprosy may be based on clinical examination, with or without slit-skin smears or pathological examination of biopsies.</td>
<td>Conditional</td>
<td>Low</td>
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<tr>
<td>Diagnosis of leprosy infection</td>
<td>There is currently no test recommended to diagnose leprosy infection (latent leprosy) among asymptomatic contacts.</td>
<td>Conditional</td>
<td>Low</td>
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<tr>
<td><strong>TREATMENT</strong></td>
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<tr>
<td>Treatment of leprosy</td>
<td>The same 3-drug regimen of rifampicin, dapsone and clofazimine may be used for all leprosy patients, with a duration of treatment of 6 months for PB leprosy and of 12 months for MB leprosy.</td>
<td>Conditional</td>
<td>Low</td>
</tr>
<tr>
<td>Treatment of drug-resistant leprosy</td>
<td>Leprosy patients with rifampicin resistance may be treated using at least two of the following second-line drugs: clarithromycin, minocycline or a quinolone (ofloxacin, levofloxacin or moxifloxacin), plus clofazimine daily for 6 months, followed by clofazimine plus one of the second-line drugs daily for an additional 18 months. Leprosy patients with resistance to both rifampicin and ofloxacin may be treated with the following drugs: clarithromycin, minocycline and clofazimine for 6 months followed by clarithromycin or minocycline plus clofazimine for an additional 18 months.</td>
<td>Conditional</td>
<td>No evidence retrieved (based on expert opinion)</td>
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<td><strong>PREVENTION</strong></td>
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<tr>
<td>Chemoprophylaxis for contacts of leprosy cases</td>
<td>Single-dose rifampicin (SDR) may be used as leprosy preventive treatment for contacts of leprosy patients (adults and children aged 2 years and above), after excluding leprosy and tuberculosis (TB) disease, and in the absence of other contraindications. This intervention shall be implemented only by programmes that can ensure: (a) adequate management of contacts, and (b) consent of the index case to disclose his/her disease.</td>
<td>Conditional</td>
<td>Moderate</td>
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