Dear Friends,

As the unbearable heat of summer declines and the monsoons are welcomed all across India, it is already time for another edition of our Newsletter.

This time we are privileged to have a message from Dr. V M Katoch, Former Director General of ICMR and Former Secretary of the Department of Health Research, Govt. of India, who has supported leprosy research. He describes the present leprosy situation in India very lucidly and challenges all involved to work together to find the solutions to the ongoing tragedy of disability in leprosy, especially in children.

Dr. Helen Roberts shares an interesting case study on eye involvement in leprosy, and Astha Nigam reports on her experiences at a conference on Infectious Diseases in Malaysia. We also present our usual journal scan; this time focusing on delay in diagnosis and detection of leprosy.

On the Training front we have completed a Refresher Course for doctors from TLM. The subjects covered were Leprosy, Podiatry, Human Rights & Advocacy, and Dermatology, along with NTDS & WASH. The training – a new initiative – was a success, and you will find a report from the participants on page 3. We aim to have two more sessions so that all the doctors in TLMTI will have the opportunity to attend.

Apart from this we include a link to some new material from WHO on POID, which can be used as posters or for other Health Education efforts.

We would welcome your comments, feedback and any interesting material or article on training and research.

Happy Reading!

Annamma S. John
Editor & Head (Research & Training)

EDITORIAL

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transmission in a progressive rapid manner and should target zero deformity as the main goal. Data from National Sample Survey to assess the burden of leprosy (report submitted in 2012) and midterm evaluation of NLEP supported by WHO would be useful to plan afresh. Information generated from several studies supported by Indian Council of Medical Research during the last 10-12 years would also be relevant for this purpose. Scientific data generated in the recent years should be properly analysed in the context of the needs of our national programme.

International NGOs like the Leprosy Mission (TLM) and others can play a significant role in the capacity building and also providing referral services. Government also needs to partner with professional associations like Indian Association of Leprologists (IAL), Indian Association of Dermatologists, Venerologists and Leprologists (IADVL), associations of Orthopedicians, Plastic Surgeons etc and national / international NGOs to develop and implement continuous medical education programmes, to train our doctors and other health professionals to tackle the problem, specially when the disease becomes low endemic. Focus on medical students for diagnosis and management should be back as cases may continue to occur for several years and they should be diagnosed and treated early if we want to prevent deformities. All of us should be in a hurry to overcome the current situation as fast as possible because continued childhood transmission and child cases with deformities should be totally eliminated in the very near future. It is the time for synergy and time for unified action.

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LEPROSY IN CHILDREN  
a growing concern

The fact that leprosy is still being transmitted and children are affected in large numbers was brought home to us again while at a training programme at TLM Community Hospital Naini. We were having sessions on leprosy and asked for new patients to be sent from OPD to the training unit for demonstration of clinical signs. It was an eye opener just seeing the number of children among the new cases at Naini.

The significance of leprosy occurring in children is well known. It indicates active transmission in the community, but for the child it poses a host of problems and obstacles to healthy participation in normal life, unless diagnosed and treated early. Many children develop disabilities as evidenced by the number admitted for reconstructive surgery. As time passes after the declaration of Elimination of Leprosy in India, leprosy workers are increasingly concerned at the evidence of ongoing transmission and the high numbers of children affected, especially in endemic areas. In TLMTI hospitals the numbers are indicative of the persistence of disease activity in the areas the patients are coming from. The following table gives us an idea of the problem.

<table>
<thead>
<tr>
<th>Hospital</th>
<th>No. of Children</th>
<th>% of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Purulia</td>
<td>151</td>
<td>23.4</td>
</tr>
<tr>
<td>2 Muzaffarpur</td>
<td>104</td>
<td>22.9</td>
</tr>
<tr>
<td>3 Chandkuri</td>
<td>66</td>
<td>15.8</td>
</tr>
<tr>
<td>4 Naini</td>
<td>246</td>
<td>14.1</td>
</tr>
<tr>
<td>5 Champa</td>
<td>46</td>
<td>12.7</td>
</tr>
<tr>
<td>6 TLMTI</td>
<td>6114</td>
<td>13.8</td>
</tr>
</tbody>
</table>

* Mentioned the 5 hospitals with highest number of children among new cases.

Now, as we think of taking on Neglected Tropical Diseases along with leprosy, there are a number of issues which need to be studied and solutions found to improve the lives of the communities where we work. Helminthiasis, sanitation and water supply being a few, high on the list. A study on Transmission among children in Multi Case families is in progress in Purulia and Champa. This is being carried out by SBL and is
supported by effect: hope (previously TLM Canada).

We hope this article might give our readers some insights/ideas on studies to shed light on transmission and eventually reduce the numbers of children affected by and suffering needlessly from leprosy.

The conference “Infections 2015”, covered various aspects of infectious diseases with particular attention being paid to the current research related to host pathogen interactions, challenges in diagnostics, emerging infections, antibiotic resistance and the alternative therapeutic approaches for infectious diseases.

The conference was very interesting and gave delegates the opportunity to share and learn about many issues related to infectious diseases. It was a very enriching experience for me to attend the conference. The conference was well attended. Many clinicians and researchers, representatives of government and private institutions were present from Malaysia and across the globe. There were total of 9 sessions in which presentations were rendered by experts on clinical and technical aspects like Microbial Pathogenesis-Prof. Alistair Brown, UK, Antimicrobial resistance and new antimicrobials- Prof. Richard V Goering, USA, Current scenario with emerging infections- Prof. Jamal I-Ching Sam, Malaysia along with some very interesting clinical case presentations.

I gave a presentation on “Characterization and molecular analysis of drug resistant mycobacterium leprae isolates of relapsed Leprosy patients from The Leprosy Mission Trust India hospitals in India”. My paper focused on the emergence of drug-resistant strains of M. leprae and identification of mutations within the Drug Resistance Determining Regions (DRDR) of the M. leprae genome in cases that were clinically determined as being unresponsive to MDT.

A total of 150 relapsed leprosy cases from different TLM hospitals across India were analyzed for the genes associated with drug resistance in M. leprae. More than 90% of the patients relapsed as multibacillary (MB) cases. Among these we were able to amplify only 114 samples. Till date 13/114 of the DNA samples showed mutations associated with rifampicin resistance. Along with 9/114 of the DNA samples with mutations that can cause resistance to Dapsone and quinolones.

Discussions with experts suggested that with the reduced duration of MB-MDT it is now important to decipher the viability of M. leprae in slit skin smear positive patients irrespective of their bacillary load (1+ to 6+) at RFT and after 12 months of MDT. Further surveillance and necessary actions are needed to ensure successful control of the disease that has reached a stage of elimination.

Ms. Astha Nigam
Research Fellow, Stanley Browne laboratory
A rejuvenating experience – it was good to realise new ways to implement our knowledge and experience in our practise’ - Dr. Timothy Maximus (TLM Faizabad)

This was the opinion shared by all the participants of the ‘Refresher course in leprosy, dermatology and NTDs’ a 2 week course held in TLM Naini from June 1st – 12th.

The course started with an introduction to the history of leprosy and a few lesser known facts about the disease. This was followed by a detailed presentation in microbiology and pathophysiology by Dr. Sen Gupta. The next few days entailed a series of interactive sessions with Dr. Loretta Das, regarding approach to the leprosy affected. These were augmented by several practical sessions, assessing patients with the occupational and physiotherapists, to improve clinical skills.

The course was unique in the way that, the students became the teachers and vice versa, with the participants leading sessions in their areas of expertise. This included sessions on NLEP, differential diagnosis of leprosy, community based rehabilitation and leprosy related ophthalmology. Podiatry, ulcer management, reconstructive surgery and prosthesis and orthoses were some of the areas that Dr. Jerry Joshua elaborated in his practical sessions. Visits to the septic theatre, ulcer wards and plaster casting stations set the stage for a novel experience in the management of leprosy. Seema Bacquer, an attorney working with Humman Rights and associated with TLMTI shed light on human rights and disability, stigma and advocacy from a leprosy perspective.

‘I have been reoriented and sensitised’, said Dr Ruby Marshalla (Anaesthesiologist, TLM Naini) following the series of lectures.

WHO consultant for Uttar Pradesh, Dr Rashmi Shukla, took illuminating sessions on Neglected Tropical Diseases (NTDs), Water Sanitation & Hygeine (WASH) and NLEP. These comparatively new areas opened up a whole vista of opportunities for growth and learning for TLMTI.

The course ended with a glimpse into the essentials of dermatology with updates on the newer interventions available.

According to the organisers of the training, it was satisfying to see that the participants enjoyed the experience and the diverse teaching methods and learnt, so the objectives of the course were fulfilled.

Dr. Kruthika Benjamin & Dr. Diya Koikkara
TLM Naini
CONJUNCTIVA IN Lepromatous Leprosy

It is a general assumption that eye complications are rare in the Multi Drug therapy era. The description of the following case will make us rethink our opinions on the issue.

40 year old Sankar Biswas, who hails from 24 Paraganas (North) district of West Bengal, walked into our Out Patient Clinic in the month of November 2014, with a fearsome looking red eye with multiple nodules on the Face. (Photograph I; top, left) He is an atypical case of untreated Leprosy with high smear positivity, showing the tell tale signs of advanced Hansen’s disease. He has severe bacillary infiltration involving both eyes, along with facial skin. On his first visit, when he was examined I had seen the Conjunctival infiltration extending upto the middle of the Right cornea and the limbus on his Left Cornea. (Photograph II; top, right)

At present he is on MDT/MB 7th Pulse. His conjunctival infiltration has regressed from the Cornea of the Right Eye. Both eyes are quiet and responding clinically to MDT. (Photograph III; below)

We had done a PCR study for any drug resistance and found that he is sensitive to all three drugs.

Lessons learned:
- As Leprologists, we need to be aware of Eye complications in Leprosy and be able to recognize them.
- Most Eye complications in leprosy are due to bacillary invasion and respond well to MDT.
- Close monitoring of Eye lesions would give an idea, whether the treatment given is effective.

Dr. Helen Roberts
Ophthalmologist & Medical Superintendent
TLM Kolkata

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DELAY IN DETECTION & DIAGNOSIS

Healthcare seeking behaviour and delay in diagnosis of leprosy in a low endemic area of China

Furen Zhang, Shumin Chen, Yiping Sun & Tongsheng Chu.

Lepr Rev (2009) 80, 416–423

Summary: Delay in diagnosis of leprosy can increase the risk of nerve function impairments and promote the transmission of the infection in a community. In order to understand the factors associated with the delays in diagnosis of leprosy, a questionnaire-based interview was conducted to collect information on the delays among 88 newly diagnosed leprosy patients. The results showed that delay was common and associated with the high rate of disability in the study population. The total mean delay was 50±18 months (median 36 months). The mean patient delay was 24±4 months (median 9±5 months) and the mean health service delay was 25±7 months (median 12 months). Patients with leprosy reported a variety of symptoms/signs at an early stage of the disease, particularly numbness and tingling. Ignorance of the illness was reported to be the main reason for the patient’s delay. Health seeking actions ranged from 1 to 50 with a mean of 7±2 after becoming aware of the first symptom/sign. The effectiveness of early diagnosis of leprosy through health promotion in the population needs to be validated and continuous training on leprosy among healthcare providers is needed.

The relationship between detection delay and impairment in leprosy control: a comparison of patient cohorts from Bangladesh and Ethiopia

Natasja H. J. Van Veen, Abraham Meima & Jan H. Richardus


Summary:

Introduction It is acknowledged that longer delays
between first symptoms and diagnosis result in increased impairment in newly detected leprosy patients. However, it is unclear whether detection delay in relation to impairment can be used as a general or absolute performance indicator of leprosy control programmes. It is unknown whether similar delays always result in similar proportions of impairment. Therefore, the present study examined the quantitative relationship between delay and impairment in two different patient populations.

**Methods** Patients from two study cohorts (BANDS and AMFES) who reported voluntarily were included in the analysis. Data on detection delay, WHO impairment status, type of leprosy, age and sex were analysed using descriptive statistics and multivariate logistic regression analysis to identify significant risk factors for impairment and to quantify the relationship between detection delay and impairment status at intake.

**Results** Detection delay was an independent risk factor for impairment at presentation in multivariate analysis. The AMFES cohort reported more impairment at detection than BANDS. In multivariate analysis, this difference was significant among PB patients (51% in AMFES versus 15% in BANDS), but not in MB patients (56% in AMFES versus 45% in BANDS). In fact, for every delay category PB patients from AMFES had much higher proportions of impairment than PB BANDS patients. Impairment rates in MB patients from AMFES were higher in every delay category, but the differences between the two cohorts were much smaller compared to PB patients.

**Conclusions** Our analysis confirms earlier findings that with longer delays, the risk of impairment at presentation increases. With the same reported delay, however, the proportion impaired can vary considerably between different patient populations, in particular for PB leprosy. Delay can therefore not simply be used as a general or absolute performance indicator for programme evaluation. Achieving short delays remains important in general, but understanding and addressing the underlying mechanisms of delay specific to a patient population adds substantially to the effectiveness of leprosy control.

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**Interventions addressing patient-related delay**

P. G. Nicholls, L. Ross & W. C. S. Smith


**Summary:**

**Objectives** The objective of the literature review was to identify proven and potential interventions to promote early diagnosis and start of treatment in leprosy, specifically, forms of intervention addressing needs at the local or primary level. Design Using a structured search procedure, we identified recent leprosy-related publications describing proven interventions. To identify potential interventions the search was extended to publications assessing knowledge and attitudes towards leprosy and extended again to identify publications relating to patient-related delay in the context of other infectious diseases.

**Results** The review identified just 19 publications reporting leprosy-related interventions that included a form of evaluation of which only 10 directly addressed patient-related delay. These included health education interventions focussed on people directly affected by leprosy, their family members and other key individuals or groups within the local community. We identified no reports of interventions focussed specifically on the needs of women.

**Conclusions** Our conclusion is that the evidence base available to inform the choice of small-scale interventions to promote early detection at the primary level is extremely limited. There is an urgent need to develop and extend the range of proven interventions, specifically those that address the needs of women, those that explore and develop the health promotion potential of people previously affected by leprosy and those that exploit the potential of individuals with leadership roles within the community. This will require careful attention to planning, implementation, evaluation and reporting of interventions.