Dear Friends,

We are already halfway through 2013, and events are moving along at such a rapid pace that we hardly have time to stop and think! However, unless we take time out to think and plan we will be unable to work effectively and utilise our resources optimally.

In the last three months we have been considering the evaluation findings from the review of the Research domain along with the Stanley Brown Laboratory. We received positive feedback as well as helpful recommendations for the strengthening of research and its future directions. We also present an account of the meetings held in Delhi along with the International Research Committee of TLM in early May, and the emerging issues and priorities identified in the field of leprosy research.

Rebecca Kattikaren has recently taken over as head of Knowledge Management and her message is about the relationship between research and knowledge, and how research contributes to the intellectual resources in the organisation. We look forward to working together to find answers to some of the urgent unanswered questions regarding leprosy.

Paul Saunderson, Research Director, TLMI, writes about the new ILEP focus on Contact Tracing, its rational, relevance and issues to be considered, in the present leprosy scenario. We hope that this will encourage you to consider how contact tracing could be implemented, even as a pilot study in your own situations.

An abstract of a paper recently published in the Indian Journal of Medical Research demonstrates the appalling loss of productivity and working years in people affected by leprosy and serves to emphasise the importance of the work we are engaged in - to eradicate these negative impacts of leprosy.

We have also been gearing up for the ILC in September and will be holding some preparatory sessions at NOIDA in the first week of July, to give presenters an opportunity to present and discuss their work before the ILC. Dr. Sundar Rao has graciously agreed to be the facilitator for this.

We hope you enjoy this issue of the newsletter and would welcome any feedback, articles or letters from you, and maybe to meet some of you at Brussels in September!

Happy reading!

Annamma S John

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The Two strong Pillars of TLMTI

Through wisdom is a house built. By understanding it is established. By Knowledge shall the chambers be filled with all precious and pleasant riches. Proverbs 24:3-4

Knowledge is an actual asset of any organisation rather than something intangible. The unit of Knowledge Management and Development (KMD) in TLMTI will protect and exploit “what it knows”, and improve and focus its knowledge development efforts to match its needs. This is one pillar of TLMTI.

Knowledge management is the systematic management of an organization’s knowledge assets for the purpose of creating value and meeting tactical & strategic requirements; it consists of the initiatives, processes, strategies, and systems that sustain and enhance the storage, assessment, sharing, refinement, and creation of knowledge. (Alan Frost M.Sc., 2010)
Innovative strategies for contact tracing in leprosy.

It is well known from studies in Malawi in the 1970s and 80s, and more recently in Bangladesh (the COLEP study), that household and other close contacts of people with leprosy have a higher risk (typically up to 8 times the risk) of developing leprosy themselves, compared with others in the general population. This leads naturally to a search for new cases amongst contacts, and now to the possibility of preventing leprosy in contacts through chemoprophylaxis and/or immunoprophylaxis. It is increasingly clear that treating the index case with MDT does not interrupt transmission to contacts, most likely because cases present too late, after transmission has occurred.

There is therefore an increasing interest in how we actually do contact tracing, and how we deal with certain practical issues. As with other case-finding methods, contact tracing can be done ‘passively’ with an invitation for a new patient to bring other household members to the clinic for examination, especially if they have any suggestive signs of leprosy; or ‘actively’ through a home visit, with enumeration of all household members and – in an ideal world – examination of all contacts annually for 5 years.

Passive contact tracing is cheaper for the health services, but costly for the patients and their contacts; actual attendance for examination may be low, so this would not be a robust enough methodology on which to build a prophylaxis program. Active contact tracing is more expensive for the health services, so combining with other programs in the community would be worthwhile.

The practical issues surrounding active contact tracing can be grouped under three headings:

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**It is the glory of God to conceal things, but the glory of kings is to search things out.**
Proverbs 25:2

Our Research unit helps TLMTI to search for the knowledge that is concealed to create the asset – Knowledge. Thus Research forms the second Pillar of TLMTI. One major aspect where Research could support KMD is investigating Knowledge Management capabilities within TLMTI in a changing environment. As TLMTI is going through a change, it is important to understand the influence of change readiness on knowledge management processes and knowledge management effectiveness. The process of managing organisational knowledge requires interaction among all members of TLMTI - a holistic view of readiness at individual and organisational level needs to be developed.

*And the Lord went before them by day in a pillar of cloud to lead them along the way, and by night in a pillar of fire to give them light, that they might travel by day and by night. The pillar of cloud by day and the pillar of fire by night did not depart from before the people.*
Exodus 13:21-22

**Policy**

To do routine active case finding, it must be official government policy, with published guidelines indicating how each of the practical issues mentioned here will be managed. Pilot studies can be done before the policy is established, in order to provide evidence for the detailed provisions of the policy. If active contact examination is already government policy, as in Indonesia, pilot studies can be used to show how chemoprophylaxis for contacts can be introduced in a cost-effective and acceptable manner.

**Ethics and acceptability**

Stigma is still a major issue in many settings and some people suggest that active contact tracing cannot be done in these areas. This needs to be examined and innovative solutions developed. In some places the true diagnosis (leprosy) is not mentioned, or a different term suggesting a mild condition that might eventually lead to leprosy is used; this is probably not a strategy that could or should be used on a wide scale. In some settings, the whole street or village may be the contact group, in order not to identify the index case as a person with leprosy. Whatever methods are used, the index cases should give informed consent for their contacts to be seen.

For success in a routine program, it is essential that the general public is informed about it and that there is broad acceptability. The possibility of preventing leprosy through chemoprophylaxis is likely to add considerably to the acceptability of the program.

**Definitions and procedures**

It is very important that the terms used and the procedures for recording and reporting contact examinations are clearly spelt out in the guidelines. Different categories of contact need to be defined and recorded: blood relatives and non-blood relatives, unrelated household contacts, social contacts and neighbours, etc. How many contacts should be included per case? What information should be given to the contacts? How should they be examined and managed – for example, what to do about other skin or medical conditions found, that are not leprosy?

Is a written record to be made for each contact examination? This may be useful when chemoprophylaxis is introduced, in order to make sure people do not get repeated doses of rifampicin, if they are contacts of several different index cases.

In conclusion, there is a new interest in promoting contact examination, especially because there are new interventions to prevent leprosy in contacts. Innovative solutions to the problems caused by stigma must be sought through pilot studies, but eventually a routine program of active contact tracing can only be developed when it becomes government policy, with officially sanctioned operational guidelines.

Paul Saunderson
Research Director, TLMI
Research Events

In early May, three important leprosy research meetings were held in the Leprosy Mission India Trust Media Centre.

The first (Collaborative meetings of laboratories working on leprosy) convened members from TLM’s International Research Committee with representative leprosy researchers from India and Nepal, both NGO and Government institutions. Presentations aimed to increase collaborative learning between labs and clinical services, with topics including: neuropathy models, efficacies of current and trialed treatment regimens for reactions and neuropathy, biomarkers for diagnostics development, detection of neuropathy by ultrasound, histology, relapse, drug resistance, transmission, nerve pain and perceptions in seeking and utilization of health services. Discussions highlighted the strategic need for multi-centric collaboration to effectively provide globally relevant answers, especially in mouse foot pad and ENL studies. ILEP strategies for contact-centered prevention strategies with coordinated research potentials were also discussed, as was a clear need for promoting stronger links to public health alongside clinical and laboratory researchers to sharpen relevance and impact to field applications. There is a critical need for developing next generation histologists with leprosy expertise, and options were considered for how to best use current human resources in training others.

TLM’s International Research Committee (TIRC) met again on the 10th. of May. Recent external evaluation results of the Stanley Browne Laboratories (Shahdara Hospital, New Delhi, India) were presented for TIRC consideration; while the Mycobacterial Research Laboratories (Anandaban Hospital, Kathmandu, Nepal) presented a progress response to the 2007 external evaluation in preparation for their upcoming external evaluation. Continuing discussions from the first meetings influenced conversation, directing TLM research to progress further in strategic innovations answering clear needs. In addition, research efforts were encouraged in patient counseling, implementation of innovations in orthotics and surgery, child leprosy and integrated services to improve pathways of patient care. TLM centers provide care for roughly 3% of new leprosy cases in India. Strengthening public/private partnerships could broaden that influence for improving leprosy patient care nationally.

Deanna Hagge, MRL, Anandaban

During the same week, TLMTI also held a meeting to enable staff engaged in research and some senior staff to interact with TLM’s International Research Committee. Staff from centres presented some of their work and had an opportunity to discuss their projects and get inputs from experts.

Ethics Committee - The Leprosy Mission India Ethics Committee, met in Delhi on the 20th. June. Ethical considerations for three new proposals were discussed and are to be incorporated before the projects are finally started.

"Forget it Mister! You’re not going anywhere until your room is clean and you figure out why my computer keeps crashing.”

"A trifle can encourage because it takes only a trifle to discourage us.”

- Blaise Pascal

"It does not do to have only a large powerful spotlights. It’s true: they send their beams a long way; but we need the small lights for warmth.

– Karl Heinrich Waggerl
Disability Adjusted Working Life Years (DAWLYs) Of Leprosy Affected Persons In India


Abstract:
Background & Objectives: Disability-adjusted life years (DALYs) have been accepted as a useful method to estimate the burden of disease, and can be adapted to determine the number of productive years lost due to the disability. DALY has been reported for many studies but not for leprosy. Hence this study was carried out in three States of India. In view of the fact that in this study, productive working years are used, the term is modified as DAWLY.

Methods: A representative random sample of 150 leprosy affected persons, 50 from each States of Uttar Pradesh, West Bengal and Chhattisgarh, was chosen, and data were collected on detailed work-life history, occupation, time when leprosy was discovered, reported and treatment started, break of job/loss of income due to leprosy. The loss of wages and durations were used to compute the life-years lost due to leprosy, and summarized over the average total duration of 42 years of productive work-life from 18 to 60 years. The percentage losses were determined and differences tested for statistical significance.

Results: The overall mean (± SE) disability adjusted working life years was 28.6 (±0.67), a reduction of 13.4 yr from the ideal productive working life period of 42 yr. The youngest patients with disability had a reduction of 41.4 per cent, as compared to the oldest patients. There was a significant increase in loss based on year for those whose disability started earlier (P=0.0024).

Interpretation & conclusions: On an average, 30 per cent of the leprosy affected person’s work life is lost due to disability.

Key words DALY - DAWLY - India - leprosy - working life.

Elimination Of 4D's In Leprosy
(DELAY, DEFAULTING, DEFORMITY AND DEHABILITATION)
M S Raju and PSS Rao

With a primary objective to diagnose the medico-psycho-social pathology of the leprosy afflicted after occurrence of symptoms, a network analysis was carried out on the 4 D's (Delay, Defaulting, Deformity and De-habilitation), estimating conditional probabilities and their relationship to specific demographic, social and economic factors. Secondary objective of this ICSSR sponsored 2 year research project is to involve the communities in developing acceptable strategies to reduce or eradicate the links among the 4 D’s.

Secondary data which includes lists of patients registered in the years of 2007-2011 from TLM treatment centres at Purulia (WB) and Barabanki(UP), demographic information and data on the diagnosis, disease symptoms, treatment etc were collected. Primary data were collected from all the available patients from the list of those registered during 2007-2011, thus a total of 450 members have been in-depth interviewed, pertaining to their perception about the 4D's and their experiences with their Family/Community/Friends/Relatives/colleagues etc.

The detailed analyses of the four D's conclude that, while deformity is biological and the result of mycobacterial invasion into human tissues, delay, which seems to be the primary and crucial factor in preventing deformity through early reporting and prompt treatment, is a psycho-social variable. Defaulting is shown to be associated with delay, but defaulting could be due more to ignorance, misconceptions and lack of faith in MDT, that contributes to inadequate treatment, relapses and continued transmission of the disease. The final, D, dehabilitation is entirely sociological, but a criminal neglect of an affected person has no place in today’s family structure. For, in no other disease does dehabilitation take place, this may be the first D to be eradicated. The community's activities that have been proved to be successful and replicable in similar situations are of three broad categories viz. PICA (Patient Involved Community Actions), NICA (Non-patient Involved Community Actions) & ASI (Action of Social Institutions).