Dear Friends,

We are already three months into the New Year and so much is happening. This new issue of the RRC newsletter brings you a variety of thought provoking articles and snippets of interesting news.

Dr. Pim Kuipers, a member of the TLM International Research Committee, who has been involved in community based work and research in leprosy writes about ‘complexity’ and newer ways to approach and solve complicated problems. Leprosy has been with us for centuries and is medically, systemically and situationally a complex disease and we need to think in new ways to facilitate the search for solutions to the myriad problems of leprosy. He stresses the need for a more participatory, values – based approach which supports the flow of information and draws on the talents of all the stakeholders. He stresses that TLM appears to be in a good position to do this and make significant contribution to efforts to eradicate leprosy.

RRC has already held two mini workshops at Kolkata and Naini, and hope to hold another at Kothara to encourage staff to engage in research at their own centres and get them enthused to make research a part of their daily life.

The 28th Biennial Conference of the Indian Association of Leprologists was held at Mumbai at the end of January and Stanley Browne laboratory made us proud (Details inside).

We present briefly the findings of the national sample survey held in 2011. The findings seem to cry out for more attention and a strong movement to address the situation where we may be looking at 3 lakh new patients, a significant number with disabilities. This reinforces the need for an effective response and research into newer methods for early case detection and prevention of NFI.

Dr. Sundar Rao, Head RRC, explains about sampling methods and how important it is to choose the right method for each study. There is news from the TLM International Research Committee and a Journal Scan giving some interesting papers on varied topics.

Mr. Karthikeyan, an Occupational therapist from TLM Naini, writes about research opportunities in TLM hospitals.

Please do send us any interesting articles or case reports and give us your feedback on how we can improve this newsletter.

Wishing you a Blessed Easter Season!

Happy Reading! Hope you enjoy the Newsletter in its new avatar!

Annamma S. John
Complexity

One of the interesting topics of current discussion and action in many circles globally (including health care, as well as international development) is the issue of “complexity”. It has been described as one of the hallmarks of the 21st century. Those who adopt a complexity-type theory, tell us that many of the difficult issues and intractable problems we face in many walks of life do not follow linear, cause and effect patterns. They often affect a broad range of stakeholders at many levels, they are often highly interlinked with other issues, and they usually result in unpredictable change processes. Most importantly, thinkers in this area tell us that traditional mechanistic ways of thinking (which rely on taking a problem apart, examining the components, and trying to ‘fix’ broken parts) are inadequate for resolving complex issues.

It seems to me that the prevention, treatment and care of people affected by leprosy is an area which demonstrates many hallmarks of complexity. Clearly leprosy is medically complex. There are many great minds struggling with issues of treatments, medications, reactions, interactions, resistance, transmission, ulcers, prevention, vaccines and other complex scientific and medical treatment issues. Leprosy is also situationally complex. People’s situations including their housing, work, income, the stigma that impacts on them, their social setting, culture, beliefs, resources and access all contribute to the complex reality of leprosy prevention, care, control, and rehabilitation. This complex reality of prevention, care, control, and rehabilitation also reflects that leprosy is also systemically complex. There are many service and system dimensions in support of people affected by leprosy from media to community care, hospitals, laboratories, vocational training, and research activities. Also importantly, the current rapid changes in these systems further contribute to complexity. The challenge is how to respond to that complexity without becoming overwhelmed or focusing on simplistic responses.

Fortunately, there are some cues for how to respond. Complexity-based approaches tell us we should prioritise the following:

- Small steps and diverse small-scale actions (which are more likely to address complex issues than “grand solutions”).
- Local actions and working with local solutions (which have considerable influence in addressing key aspects of complex problems).
- Ensuring a broad range of stakeholders, and encouraging self-organisation and reflection.
- Creating conditions that unleash the talent of all the people involved in a situation (because the capacities to deal with complex problems are often distributed across all players).
- Supporting the flow of information, connections between people, and reducing power inequalities.
- Fostering a values-based approach, including openness and integrity.

The Leprosy Mission Trust India would appear to be well positioned to harness and employ such responses to complexity in many aspects of care and service delivery (and they appear quite consistent with current strategic planning). A key challenge is to find a way to integrate these with our research.

Complementing the existing scientific, social and service research with participatory approaches would seem a constructive step. Greater use of participatory methods integrated with traditional research approaches may be beneficial. Likewise, more emphasis on stand-alone participatory studies to understand social and service delivery dimensions may be warranted. In general though, multiple and diverse research initiatives would seem to be required if we are to address the complex reality of leprosy.

Dr. Pim Kuipers

Scope for Research for health professionals in TLM

Prevention of Impairments and disability (POID) is one of the most important components of any leprosy programme. POID activities are aimed at preventing the occurrence and worsening of disabilities among leprosy affected people by addressing the issue in a comprehensive way – promoting early detection and effective management of leprosy and its complications such as reactions, nerve function impairment, promoting self care activities etc.

Physiotherapists and occupational therapists play an important role detection, assessment and Management of impairments and disabilities caused by leprosy and its complications. There are constant changes in these fields and the search for more effective methods continues. TLM offers excellent research opportunities for health professionals who want challenging fields to find better methods and tools for the management of complications of leprosy. These include use of quantitative sensory and motor power assessment in detection of early NFI, role of nerve conduction studies, role of adaptive/assistive devices in enhancing functional abilities, comparative assessments of different self care teaching methods and many others.

As TLM places more and more emphasis on research as learning form our daily work and using evidence based medicine we hope all our young professionals will be encouraged to engage in research on a routine basis.

G Kartikeyan
Occupational Therapist, TLM Naini
The International Research Committee (TLM & ALM) meets twice every year and discusses leprosy research issues globally; Annually two meetings are held, one face to face and one a teleconference over skype. The last meeting was held in Cebu, Philippines on 17th. February 2012.

The meeting, chaired by Prof. W. Britton (Chairman), was attended by prominent research figures: Dr. Paul Saunderson (ALM), Dr. Pim Kuipers, Dr. Sundar Rao, Prof. J.H. Richardus, Geoff Warne, along with observers.

There were several interesting presentations which we mention briefly below.

Dr. Gigi Ebenzer, formerly of Karigiri, and now at Johns Hopkins University, reported her research on the use of 3mm punch biopsy to assess nerve damage and regeneration using immuno histochemistry. According to her study nerve re-growth may occur from the injured nerve itself or through collaterals sprouting from uninjured nerves, the process is comparatively slower in humans than in monkeys. In armadillos an increased density of Schwann cells are seen while axons are degenerating. Valuable research would be to compare these changes in different kinds of leprosy.

Dr. Richardus spoke about the efficacy of chemoprophylaxis using single dose rifampicin (SDR). He said research priorities in this area include diagnostic tests, prophylaxis for high risk groups, improved modelling, operational research on the logistics of contact examination and the combination of SDR and immune prophylaxis.

Bob Bowers reported on the impact of CBR in NW Bangladesh. The Committee noted that very little CBR research is going on and this needs to be addressed. Dr. Kuipers referred to the WHO World disability report, which is itself a useful checklist for priority setting in research.

Dr. Sundar Rao spoke of the urgent issues addressed by three ongoing ICMR projects in India, the positive impact of Dr. Sengupta's appointment and improved clinical laboratory collaborations. He also stressed that in spite of the funds crunch in TLM alternative funding sources such as the Departments of Science & Technology, Bio technology and ICMR were available in India and could be tapped into.

Every Investigator asks the question: How many should I study? Almost all studies are based on samples. There are good samples and bad/invalid samples. In Logic, inductive inference is defined as generalizing from a part (sample) to the whole (population); this is fraught with uncertainty as opposed to deductive inference, from population to sample.

Designing a proper study and choosing the correct sampling plan and size, are fundamental and crucial for a valid study. No amount of statistical juggling and sophistication can compensate for a bad study design!

To be valid, a sample must be random (unbiased) and of adequate size to capture the variability in the population. Precision and confidence in generalizing from a sample to the total are also essential in determining the minimum sample size. Nowadays, ready-reckoners are available for determining the sample sizes, but a discussion with a good biostatistician will be better and more useful. Many studies have compound and multiple hypothesis, and several studies have dropouts and defaulters which can vitiate the results, and all these require careful attention.

Several types of samples: simple, stratified, multistage, cluster, systematic, etc. are possible and a good decision must be taken on which sample would be the best for your study, and cost-effective too. Many methods of random sampling are available and must be used for better efficiency. Some studies, may require nonrandom or purposive sampling, and this requires careful consideration, especially in qualitative studies.

Abstract of Dr. Mallika Lavania’s paper

Molecular typing of Mycobacterium leprae strains from Northern India using short tandem repeats

Due to the inability to cultivate Mycobacterium leprae in vitro and most cases being paucibacillary, it has been difficult to apply classical fingerprinting methods to this organism. The objective of this study was therefore, to analyze the diversity among M. leprae strains from North India, by targeting ten short tandem repeats (STRs) as molecular markers.

Diversity was observed in the cross-sectional survey of isolates obtained from 90 patients. Similarity in fingerprinting profiles observed in specimens from the cases from same house or nearby locations indicated a possible common source of infection. Such analysis was also found to be useful in discriminating the relapse from possible reinfection.

This study led to identification of these markers eliciting polymorphism in North Indian strains of M. leprae. The data suggest that these STRs can be used to study the sources and transmission chain in leprosy, which could be very important in monitoring of the disease dynamics in high endemic foci.

The 28th Biennial Conference of the Indian Association of Leprologists

The 28th Biennial Conference of the Indian Association of Leprologists, was held at Mumbai from 27th to 29th Jan 2012, in coordination with Novartis and ICMR. The Theme was: Science of Leprology for Benefit of Society.

TLMTI had 3 Oral presentations, from the Staley Browne Laboratories, and Dr. Mallika Lavania won the Acworth Leprosy Hospital Society for Research, Rehabilitation and Education in Leprosy Award, for Best Publication in Leprosy in the peer reviewed National / International Journal.

National Sample Survey on Leprosy

As you are all aware a National Sample Survey on Leprosy was carried out in 2011 with the following objectives:

- To estimate new leprosy case load in the country
- To assess the leprosy burden of disability cases both grade 1 and grade 2
- To assess the stigma and discrimination prevalent in the society

The survey was completed last year and the results show that the actual incidence of leprosy is much higher than shown by the annual ANCDR. The total number of people examined was 15427363 and 2177 new cases were found. There are 13 states/UTs with ANCDR > 10. Beginning with the highest, these are Dadra & Nagar Haveli, Chandigarh, Bihar, Uttar Pradesh, Andhra Pradesh, Tamil Nadu, Maharashtra, Chattisgarh, Madhya Pradesh, West Bengal, Orissa, Karnataka, and Assam, in descending order. The Mean ANCDR was 14.20/100000, while weighted estimates were observed to be 25.70/100000.

Andhra Pradesh, Arunachal Pradesh, Assam, Bihar, Chattisgarh, Haryana, Himachal Pradesh, Karnataka, Madhya Pradesh, Nagaland, Sikkim, Uttar Pradesh and West Bengal have higher than 2/100000 deformity rate with Uttar Pradesh reporting the highest deformities. So more emphasis in these states needs to be given to prevention of deformities and care of hands, eyes and feet in these areas. It is interesting that No cases with deformities were detected in Dadra & Nagar Haveli which had the highest ANCDR.

The distribution of cases in rural and urban population varies according to the population distribution. The proportion of PB and MB cases in both these populations is also similar.

Regarding Stigma, it was seen that 20 to 30% of the leprosy patients suffered from some amount of stigma due to leprosy, though most patients were well accepted by the family members, at their work places as well as in the community. A few community members still felt that the disease was hereditary and patients should be isolated while on treatment.

Conclusions:
- Considering the 2011 census it is estimated that about 2 to 3.5 lakh new cases will be detected.
- Measures are needed for detection of cases without deformities and prevention of deformities progressing to grade 2 type.

Adapted from the NSS Report

RRC Events

- Azathioprine Meeting at Kolkata on 24th. & 25th. February 2010
- Urban Study Review Meeting at Delhi 29th. February & 1st March 2012
- Predem Study meeting at Kothara 21st. to 24th. March 2012
- Mini workshops at Kolkata, Naini & Kothara Ethics Committee meeting at Delhi 20th. March.