Dear Colleagues,

One of the major objectives of our Organizational Development initiatives is for us to become a Learning Organization, where every opportunity is utilized to glean learnings and feed them back into our systems, so as to be more effective. Research is an important activity that contributes to much learning. Though we have been involved in research for sometime now, we have not capitalized on the learnings from our research activities.

If we want to be relevant and sustainable then our outlook on research needs to change. It can no longer be viewed as an activity done occasionally by a select few. It needs to become a mandate for each one of us which ever field we are involved in. The challenge is for a culture of research to set in where every problem we face becomes a research question, where each one is involved in finding answers to those problems, where such answers are disseminated, discussed and applied, and where there is innovation. Are we up to that challenge?

With best wishes,
Sunil Anand

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Message from the Director

Dear Friends,

Greetings from TLMTI's Research Team.

2013 is well under way and we are all fully occupied with our various activities of patient care, vocational training, community development, capacity building and so many other initiatives, which we hope will improve the lives of those we serve. As we progress in this struggle to end leprosy the last part is the hardest and the same effort does not seem to produce the satisfying results we saw earlier. Now we need to find new ways to address these issues and find solutions to the problems we face with our patients management, field programmes and other projects.

Trying to solve our problems and questions based on evidence we gather systematically is research, and that is the need of the day. As our Director mentions in his message we all need to engage with our work, simultaneously trying to find answers to the challenges we face; whether it be the high proportion of new child, or highly positive cases, the referral system not working as it should or continuing social stigma.

Dr. Ruth Butlin in her article, encourages us to think of and try to develop new regimes of treatment which would increase compliance and help us to be prepared for the emergence of drug resistance. She also informs us that there is an opportunity to use our vast stores of clinical material and data, and invites papers on leprosy in children for a leprosy review issue next year.

This first quarter has been an eventful one for Research in TLMTI. The Evaluation of RRC was conducted recently. We had the Research Committee meeting in February, at which the Director General of ICMR emphasised the importance of the research TLMTI is doing, as the only organisation doing dedicated leprosy research, and how our contribution keeps the interest and commitment to leprosy alive among leprosy workers and even among scientists at ICMR. There was a period of hectic activity just before the final dates for submission of abstracts for the ILC in September, and we are happy that around 60 abstracts have been submitted.

Our young colleagues continue to participate in professional fora and win recognition.

We look forward to a year of fruitful combined work, which positively impacts those affected by leprosy.

We hope you like the newsletter in its new avatar. Please send us your feedback and suggestions.

Happy Reading,
Annamma S John
Use of “ROM” as chemotherapy for leprosy

This article is based on an editorial published in Leprosy Review Sept 2012: “Developing new MDT regimens for MB patients; time to test ROM 12month regimen globally” by Diana N J Lockwood and Maria Gracia Cunha.

When WHO-recommended MDT was first introduced into leprosy control programmes in 1982, staff were anxious about the possible adverse effects of rifampicin, whereas dapsone was considered to be a relatively safe and well-tolerated drug. It is now clear after 3 decades of MDT use that the monthly rifampicin doses in standard MDT rarely cause problems, and the commonest cause of serious adverse reactions to MDT regimens is the dapsone component (in some studies as many as 43% patients have an untoward response to dapsone). Clofazimine causes skin discoloration in most active cases of leprosy but it is not always perceived by the patients as a major problem, and other more dangerous adverse effects of clofazimine are rare.

Compliance with MDT continues to be a worrying issue; although many programmes have abandoned the attempt to supervise every monthly dose of rifampicin, we cannot be complacent about the patients’ correct intake of drugs dispensed to them for home consumption, even when they attend voluntarily to collect medicines. In some reported studies, there was evidence of 30% or more patients not taking the dapsone regularly.

These factors together with the evidence that – in the mouse footpad model and in clinical trials- minocycline and ofloxacin are more bactericidal than dapsone and clofazimine, suggest that new regimens should be considered.

In 1997 a randomised controlled trial (in which I believe some TLM India centres participated) showed that a single dose of a rifampicin/ofloxacin/minocycline (ROM) combination, could be almost as effective for “single lesion PB leprosy” as conventional WHO-recommended PB MDT. As a result the WHO expert committee in 1998 advised routine use of this combination for PB patients including children) with a single skin lesion and no nerve involvement. There is by now considerable experience of this use of “ROM” therapy in different locations, with fairly long follow ups having been reported to show low relapse rates. A few small trials, some with methodological problems, have been carried out using single dose ROM therapy for other PB cases, with more lesions.

The7th report of the WHO expert committee on leprosy (1998) repeated what the Study group had recommended in 1994, that “for special situations” such as “patients who do not accept clofazimine”, ROM could be used as a monthly dose for 24months for MB cases. To date 2 small trials have been published providing limited evidence for the effectiveness of this regimen compared with conventional MBMDT.

The authors of the editorial mentioned above strongly advocate large randomised controlled trials of monthly doses of ROM compared with standard MBMDT (using rifampicin, clofazimine and dapsone), in 2 durations namely 24 months for those with initial BI > 4+, and 12 months for other MB cases. They say there should be a follow up of 10years, which though difficult in practice is a reasonable requirement since relapse rate is the only truly appropriate outcome measure for effectiveness of a chemotherapy regimen, and in other chemotherapy trials relapses have often been found to occur late (more than 7 years after release from treatment). Trials would probably need to be multicentre, to obtain adequate numbers of subjects, and must be done using stringent definitions of relapse and good quality data collection including data on incidence of reactions.

There is a need for some prior investigation into the safety and acceptability of repeated dose of minocycline in children before monthly ROM could be used widely in this age group.

If it should prove to be as effective, albeit a little more expensive that conventional MDT for MB cases, then monthly ROM would be a very welcome alternative: it may be easier to ensure high compliance rates, as well as achieving lower adverse reaction rates with this regimen. The sad fact is that it may be 15 years before we have the evidence (by the time the proposed trials are planned, funded, implemented, analysed and published!). However many times it has been noted that some previously recommended regimens were introduced without waiting for the trial evidence to be produced. Now that we are more aware of the need to practise evidence-based medicine, we will all watch with interest to see the outcome of the proposed trials comparing ROM with rifampicin/dapsone/clofazimine... and maybe some of the readers of this Research newsletter will be involved in producing the evidence!

C Ruth Butlin

Chaplin meets Einstein

“What I admire most about your art”, Albert Einstein said, “is its universality. You do not say a word, and yet ... the world understands you.”

-”It’s true”, replies Chaplin. “But your fame is even greater: the world admires you, but nobody understands you.”
International Federation of Societies for Hand Therapy and International Federation of Societies for Surgery of the Hand

This year the IFSSH and IFSHT conference was held in India at the India Expo Centre in NOIDA from 4th. to 8th. March. It was an unique opportunity to showcase our work to the world and learn more about current concepts in rehabilitation of the hand. This conference is very relevant to us, as leprosy is closely related to hand therapy and therapy, as many concepts for tendon transfers for paralysed hands were derived from knowledge of leprosy related deformities. Therefore, it was a privilege to represent The Leprosy Mission Hospital, Naini with various presentations from leprosy related topics.

The conference was outstanding from a scientific perspective and the exposure has been educational and deeply enriching. The new concepts in hand rehabilitation learned from this conference can be applied in leprosy related rehabilitation to maximize the outcome of our interventions. The conference was attended by Dr. Premal Das, and 5 therapists Mr Manivannan & Mr Karthikeyan from Naini, Mr Sathish Paul, Mr Pankaj Gupta from Shahdara and Mr Suresh from Purulia.

The papers presented were:

1. Half Flexor Digitorum Superficialis (FDS) lasso surgery for correction of claw hand in leprosy (Dr Premal Das)
2. Short extension outrigger Splint to release Proximal interphalangeal Joint contracture in clawed fingers in Leprosy (Mr Karthikeyan)
3. Effect of Early resistance to restore Grip strength in Lasso surgery among leprosy patients (Mr Manivannan)
4. Low cost aesthetic prosthesis using Latex for the absorbed digits due to Leprosy (Mr Manivannan)
5. Selection criteria for reconstructive surgery in correction of claw hand and thumb deformities in Leprosy (Mr Karthikeyan)
6. Correction of bilateral claw hand and thumb deformity in motor neuron disease: case report (Mr Karthikeyan)

Karthikeyan, Occupational therapist, TLM Naini.

Journal Scan


Early Revelation of Leprosy in China by Sequential Antibody Analyses with LID-1 and PGL-I.


Abstract

Leprosy is a disabling chronic infection, with insidious onset that often evades early detection. In order to detect new leprosy cases in a timely manner, we conducted surveillance visits in some difficult-to-reach mountain areas in South West China where the disease is still prevalent. Our data confirm that Chinese multibacillary (MB) leprosy patients have strong antibody responses against Mycobacterium leprae antigens ND-O-BSA and LID-1. Contacts of clinically diagnosed patients were then monitored at regular intervals by both physical examinations and the laboratory determination of antibody responses in sera collected during these examinations. Elevations in antibody titers indicated the onset of MB leprosy in one of the contacts, and diagnosis was subsequently confirmed on physical examination. Our data indicate that rising antibody titers can be used as a trigger for physical examination or increased monitoring of particular individuals in order to provide early leprosy diagnosis.


Recognition of the phenotype of thalidomide embryopathy in countries endemic for leprosy: new cases and review of the main dysmorphological findings.


Abstract

Thalidomide is the best-known teratogen worldwide. It was first marketed as a sedative in the late 1950s, but the birth of ~10 000 children with birth defects resulted in the withdrawal of thalidomide from the market in 1962. Thalidomide embryopathy affects almost all organs but the main defects are concentrated in the limbs, eyes, ears, and heart. Shortly after the withdrawal of thalidomide from the market, its effectiveness in the treatment of erythema nodosum leprosum, an inflammatory condition resulting from leprosy, was reported and since the mid-1990s, the drug has been used widely in the treatment of cancers and autoimmune diseases, among other conditions. 40 000 new cases of leprosy are diagnosed every year in Brazil. Although there is a strict legislation for the prescription and use of thalidomide in Brazil, cases of thalidomide embryopathy have continued to be reported. Here, we present two new cases of thalidomide embryopathy identified in 2011 and review the major clinical findings in the literature that can aid the identification of the embryopathy.

Bino Berry, of TLMTI attended the 50th National Conference of All India Occupational Therapists Association held at Trivandrum during Feb 26th- 28th, and was awarded with the AOITA Trophy for the best scientific paper in mental health.

His paper is entitled “Human Resource professional’s perception on disability related barriers to employment of Persons with intellectual disability”. We congratulate him on this achievement.
News from the Research Domain

TLM India Research Committee was held on 9th. February at ICMR Headquarters and presided over by the Director General of ICMR.

The Scientific Advisory Committee of SBL was held on the 8th. February 2013 at TLM Shahdara. It was attended by Dr. Sujai Suneetha, Dr. Krishna Prasad, Dr. Sunil Anand, Dr. Mary Verghese, Dr. U. Sengupta, Dr. Annamma John and laboratory staff as well as representatives from TLM Shahdara Hospital.

Evaluation of RRC conducted from 18th. to 22nd March, by Dr. Mannam Ebenezer and Dr. Shyamala Anand. The report is eagerly awaited.

Review Meeting of the Urban Study held at TLM Shahdara on 19th. March, and attended by both teams from Kolkata and Delhi and Dr. Sundar Rao.

Call for papers:

In March 2014 there will be a special issue of Leprosy Review journal focussing on “Leprosy in Children” with Dr C R Butlin as guest editor. We need plenty of material to make it a good issue! Topics might include trends & patterns in epidemiology, clinical presentations, frequency and management of complications, social aspects, cost effective methods of improving awareness/compliance amongst children, long term outcomes of children affected by leprosy when young, novel methods of managing children affected by leprosy to reduce the impact on their lives, effect on healthy children of parental leprosy…… or anything else which would be worth sharing. Although all types of paper are welcome, including reviews and original research, the type of paper which I believe TLM India staff are most likely to be able to contribute would be Case Reports or papers analysing epidemiological/operational data derived from leprosy control work over a period of years. I suspect there will be very few clinical trials which specifically enrolled children, but if people have data on long-term outcomes of ROM given to children for single lesion leprosy, that would be very useful, or if anyone has data on outcomes in children of giving steroids for new nerve function impairment, please do write it up. Papers can be submitted to Irene Allen (assistant editor) at irenea@leprahealthinaction.org, but please read the Instructions to Authors (inside back pages of a recent issue of Leprosy Review) before sending your paper, to ensure you are complying with requirements such as length of manuscript, and –if you are doing a case report- attach a copy of the patient’s consent to publication.

Dr. C R Butlin

The Burden of New Leprosy Cases in India: A Population-Based Survey in Two States

Anil Kumar and Sajid Husain, SRN Tropical Medicine Volume (2013), Article ID 329283,

Abstract:

Objectives. To assess the burden of new leprosy cases in India and the efficiency of case detection work by ASHA in general health system.

Methods. A sample survey of 804,536 persons was undertaken in 8 districts during 2009-2010: 4 each in Haryana (low endemic for leprosy) and Uttar Pradesh (high endemic for leprosy). About 20% population was covered from urban areas.

Results. The survey suggested that burden of new case detection rate of leprosy in India per 10,000 population could be 4.41 in comparison to 1.09 as per government records. When present observation is adjusted to team performance in rural area, the NCDR increased to 10.64 per 10,000. This leads to suggest that NCDR in India could further increase to 9.76 times when adjusted to team performance. This data suggest that large numbers of early leprosy cases do not reach the health facilities where leprosy treatment is provided, although some chronically ill patients reach late, and thus multibacillary disease is found more in passive reporting. This could also be an indicator of a large number of established cases not being sufficiently self-motivated or lacking knowledge to utilize the free diagnosis and treatment services. Thus, the programme needs to be designed to meet these objectives effectively to better utilize the available services to reduce the leprosy burden.

Conclusion. Active survey detected many folds higher leprosy cases in community, and this suggests that the information, education, and communication based approaches have a very minimal effect. If the programme continues to be based on IEC activities, the information should be designed in such a way that most persons suspected to have leprosy can know about free treatment, place of availability, and its effectiveness. However, leprosy elimination campaign surveys may be used as a tool to filter large pool of cases from community.

Courage does not always roar, sometimes courage is the quiet voice at the end of the day saying, "I Will Try Again Tomorrow"