Dear Readers,

The latest issue of our Newsletter brings you articles and news from the Research & Training Domains of The Leprosy Mission Trust India. Six months of the year have passed, and TLMTI is in the initial stages of actively implementing our new Country Strategy.

The main article is on GIS, or Geographical Information Systems. This is a tool increasingly used in medicine, and specially in Public Health Initiatives to map various diseases, and related parameters and contribute to planning interventions. The article gives clear and simple information for those who are unfamiliar with GIS.

Apart from this, ‘Sudha’s Story … Another instance of ignorance and neglect’, highlights again the problems which beg solutions, through research and focused attention.

There is an interesting Case History regarding involvement of the eye from Shahdara, and the other usual features such news of the activities and a journal scan.

This issue is being put together by a new team of Research Scientists, and we would be delighted to have your feedback and suggestions.

Happy reading!

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

TLMTI AND THE USE OF GEOGRAPHIC INFORMATION SYSTEMS (GIS)

Definition

Geographic Information Systems (GIS) – what is it all about? Simple – it’s all about maps! In our complex world, maps play a vital role. GIS essentially multiply the power of maps through the use of multiple map layers. What are these layers? Well, for someone analysing traffic accident data, a basic base layer might be a street map. On top of this could be a layer with points / dots showing the location of all the recorded traffic accidents in the town in the past five years. Another layer might show all the pedestrian crossings for major roads. The final layer could show the locations of all the medical facilities in the city.

When all these layers are ‘turned on’, the GIS allows for some powerful analysis, and this could lead to action that could reduce accidents and save lives.

A GIS is just a piece of computer software. Today, this kind of software is widely used by many different organizations, companies and NGOs – large and small. The software can be simple and essentially free of cost, like Google Maps, or complex and expensive like ArcGIS or MapInfo. Fully fledged, free, open source GIS are available to download from the Internet; a popular one is QGIS.

The following are just a few brief examples of how GIS can be useful:

- A local authority may want to notify all residents of a town living within 5 km of, say, a proposed factory. The GIS will mark that factory as a point and will then generate a 5 km buffer zone around it. Through the use of an address layer all the addresses within this buffer zone will be generated.

- Medical researchers looking at mosquito borne disease can estimate the number of people at risk by
mapping many environmental variables. See the link to this topical article: http://www.dipterajournal.com/vol1issue3/august2014/22.1.pdf

• GIS can be used to predict the severity of impacts from natural disasters. For example, a GIS could show exactly how many villages in Bihar would be affected by flood events of differing severity.

GIS can help us locate or record where things are, but they also let us visualize, question, analyze, and interpret data to understand relationships, patterns, and trends.

**How could a GIS be used by TLMTI?**

A GIS could be used to:

1. Map the locations / addresses of leprosy affected people coming to TLMTI hospitals and VTCs. Historical address data could be used as well as live data. The made up map example (below) shows TLM Naini Hospital as a square red symbol. The purple dots could be leprosy cases (e.g. new child cases treated at Naini in the past 6 months). The red polygon highlights a significant cluster which maybe an area that needs targeted intervention. By turning on another map layer, this area (in the polygon) might also be shown to have a particularly high population density and many polluted water bodies. In the GIS, each dot will have an attribute table attached to it. By clicking on the dot a range of information about the person can be displayed.

![Figure 1: TLM Naini Hospital and points showing hypothetical leprosy cases (visitor to the hospital).](image)

2. Map the location of leprosy affected people (or those with other NTDs or disabilities) through village surveys – using, say, the KoBoCollect app on mobile phones and tablets. As a person is interviewed, their exact location is recorded by the GPS (Global Positioning System) on the mobile device. This person will be displayed as a dot on a map available in KoBoToolbox, or the point data can be transferred to a GIS which will allow for more sophisticated display and analysis.

3. Map Primary Health Centres (PHCs) in a district or block. (The map could show symbols for PHCs: e.g. green = fully functional / orange = semi-functional / red = not functioning. At a TLM hospital this would be very useful information in terms of directing patients (e.g. for ongoing MDT) to a PHC that is reasonably close to where they live and to one that is functioning.

4. Map environmental features, like villages with a polluted water supply, no toilets, a high number of stagnant ponds, gross overcrowding etc.

5. Map villages with high BPL or SC / ST populations, and / or those which are a significant distance from any health facility.

**Will a GIS really be useful?**

The answer is emphatically yes! A GIS could:

1. Assist research into the transmission of leprosy and other NTDs.

2. Allow for evidence based, targeted interventions, like focusing on certain villages showing high prevalence of leprosy or other NTDs. Interventions could include health camps, awareness campaigns, and community projects from TLM hospitals.

3. Provide an excellent evidence base for funders. TLMTI could confidently approach Water, Sanitation & Hygiene (WASH) donors on the basis that surveys and GIS analysis have highlighted probable links between dirty water, lack of sanitation and high levels of a certain disease.

4. Allow for increased collaborating with others fighting organisations fighting the NTD battle. See https://www.infontd.org/

5. Showcase good practice to government i.e. what can be achieved using this technology.

6. Contribute to an accurate assessment of leprosy prevalence in India.

**Points to conclude**

- GIS are here to stay. They are powerful tools that have become indispensable to many organizations. Software is increasingly accessible even at low cost through open source providers.

- It can get complex. A GIS needs to be useable;
not 'crazy' technical. A simple system that works and is well understood is best.

- Quality of data is key. However good the GIS, the maxim 'rubbish in - rubbish out' applies. There is no point in having fancy maps showing a spread of disease points if 80% of the addresses are wrong. Good and accurate surveys are crucial to success.

- We know that the National Leprosy Eradication Programme (NLEP) is starting to use ArcGIS and that the Indian Council of Medical Research (ICMR), supported by the World Health Organisation (WHO) is also working in this area.

- TLMTI is about to embark on a NTD/disability survey in blocks close to TLM Champa hospital and TLM Vadathorasalur hospital. This will be a good opportunity to conduct a high accuracy survey and to display and analyse the results using a GIS.

- This is just the start!

David Ingleby
Volunteer and City Planner

A CASE OF OCULAR HIV WITH NO SYSTEMIC MANIFESTATIONS

A 38 years old patient presented to OPD with chief complaints of diminution of vision and seeing floaters in both eyes for the past one month. He was apparently alright one month back when he suddenly noticed intermittent floaters associated with progressive vision loss in both eyes. He reported only being able to make out shadows in the left eye and blurry figures in the right eye. He denied painful vision, headache, photophobia, neck stiffness, nausea, vomiting, and focal neurological deficits. No history of systemic illness.

On examination

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Right Eye</th>
<th>Left Eye</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual Acuity</td>
<td>6/12</td>
<td>6/60</td>
</tr>
<tr>
<td>IOP</td>
<td>16 mm Hg at 11:30AM</td>
<td>18 mm Hg at 11:30AM</td>
</tr>
<tr>
<td>Anterior Segment</td>
<td>Cells 2+ Flare + Pupil round regular reacting to light</td>
<td>Cells 3+ Flare + Pupil round regular reacting to light</td>
</tr>
<tr>
<td>Posterior Segment</td>
<td>Disc 0.3:1 cup normal NRR Multiple hemorrhages with cotton wool spots at macula and peripheral retina.</td>
<td>Disc 0.3:1 cup with normal NRR Macular edema present. Sheathing of retinal vessels present. Multiple hemorrhages with cotton wool spots with 360 degree peripheral necrosis of retina.</td>
</tr>
</tbody>
</table>

Fundus picture of both eye showing vascular sheathing with hemorrhages and peripheral necrosis of retina
Patient was advised investigations both systemic and ocular. On systemic investigation complete blood count was within normal limits, ESR was 45 mm/hr. LFT and KFT were within normal limits. HIV 1 and 2 was reactive.

Fundus fluorescein angiography was done which showed extensive retinal vasculitis with numerous microaneurysms with marked areas of capillary non perfusion and blocked fluorescence.

Patient was referred to ART Centre where CD 4 count was done which was 114 cumm and started on ART therapy. Patient was also started on oral valganciclovir 900 mg BD, and intravitreal ganciclovir was given 2.0 mg/0.1 ml.

On follow up, patient’s vision gradually improved from 6/60 to 6/9 in Left eye. And is now continuing on ART Therapy along with oral valganciclovir 900 mg OD.

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Dept. of Ophthalmology
TLM Shahdara

SUDHA’S STORY

Another instance of ignorance and neglect...

Meena Gupta is 30 years old and comes from a middle class Brahmin family. She completed her high school studies and then a marriage was arranged for by her parents. She has two daughters and was living a normal happy life with her husband and his family.

She first noticed symptoms of fever, pain, numbness and nodules while pregnant with her second child. She was taken to a hospital nearby for treatment but there was no improvement. A round of fruitless trips to different private and government hospitals followed, but no diagnosis was made and her suffering continued. Her in-laws began to lose patience and were unsympathetic, they started to
neglect her and she continued to have fever, pain in her limbs and joints and nodules on her arms and legs. She was told by her in-laws that “they were waiting for her to die” so that her husband could get married again to a healthy person. She was at her wits end trying to find a way out of her illness and to save her family life.

Desperate, she informed her parents of her plight, and her mother came and took her for consultation to some more hospitals but to no avail. Finally she heard of TLM and came to Naini Hospital with hardly any hope for the future. By then she had moved out of her in-laws with her daughters and was living with her parents.

At Naini she was diagnosed with multi-bacillary leprosy with severe Type2 reaction. There was no significant nerve function impairment, but she had extensive ENLs. Now she is admitted and being treated for leprosy and reaction, and is also attending counselling sessions to help her cope with her situation. Now she is slowly regaining her strength of mind and hopes to get well and go back to her husband for the sake of the future of her children. She hopes the family will accept her in spite of the diagnosis of leprosy.

This incident highlights the major social obstacles to all of us who are working towards elimination of leprosy from our country. The doctors who are unable to recognise and diagnose leprosy due to their inadequate training and exposure to leprosy may be missing many such cases - causing prolonged suffering and increased transmission of the disease in the community. The in-laws, who were unsupportive, demonstrate the ignorance and stigma in our society, pushing sufferers who already have so many physical problems to the end of their tether.

There is a great need of further research and continued efforts to educate both society and the medical fraternity about the different aspects of leprosy so that we can all work together towards a world without leprosy.

Symposium on emerging needs in leprosy research in the post elimination era: The Leprosy Mission Trust India.


Recommendations

1. Increase attention to training of young medical professionals so that they can diagnose leprosy and early nerve damage, and treat them.

2. Creating and maintaining leprosy expertise by Empowerment of PHC staff, health care workers and all medical care professionals for suspecting and bringing in early cases of leprosy for diagnosis.

3. Empowerment of the community in facilitating accessibility of treatment and reduction of stigma.

4. Introduction of immunotherapy and immunoprophylaxis (by Leprovac inoculation) in the NLEP; especially for MB cases.

5. Reintroduction of practice of slit skin smear in the PHCs and NLEP to facilitate identification of Relapse, Resistance and MB cases with no visible patches (Infiltrative).

6. Patient should not be released from treatment until MI ‘Zero’ is attained.

7. NLEP should not accept UMDT for MB patients.

8. MB leprosy patients with high BI/MI (.4) often do not respond adequately to 12 months MDT MB Regimen. Long term follow up should be done for them.

9. Detect early reaction and nerve damage for high risk group of leprosy patients with the help of bio-marker like IP-10 and if any other biomarkers are found.

10. Leprosy cases with BI 4+ or more should be kept on longer follow up while on a drug trial.

11. Focused brainstorming sessions comprising of dermatologists, immunologists, bacteriologists and other experts to discuss and develop strategies to combat Drug resistance, which should be led by GOI, WHO, ILEP and ICMR.

13. Initiative need to be taken for development of second line anti leprosy treatment.

14. Have inter-sectoral and inter-ministry plans and activities for improvement of services to leprosy patients.

15. Attention to Advocacy initiatives.

16. Empower people affected by leprosy suffering from reaction to tell doctors about the subtle symptoms of reaction.

17. Improve and increase IEC campaigns, developing them in a scientific manner with communication experts.

18. Create a system to identify high risk individuals for developing leprosy.

**CHILDREN AND ADOLESCENTS’ ATTITUDE TOWARDS HAVING LEPROSY IN A HIGH ENDEMIC DISTRICT OF INDIA**


This is the first study using the CATIS scale to investigate the attitude of children and adolescents with leprosy. The results indicate that the children and adolescents had a positive attitude towards having leprosy. However, one-third of children and adolescents experienced internalised stigma. Further research should be multi-centric in nature, in order to more accurately analyse CATIS scores in a broader setting.

Information gained from research may help guide local and national policy on leprosy treatment, such as health education, allowing targeted approaches to benefit the psychosocial wellbeing of leprosy patients.

**DETECTION OF MYCOBACTERIUM GILVUM FIRST TIME FROM THE BATHING WATER OF LEPROSY PATIENT FROM PURULIA, WEST BENGAL**


In this present study for the first time the authors are reporting the isolation of *Mycobacterium gilvum* from the accumulated water in the drain connected to the bathing place of leprosy patients residing in an endemic region. The identification and characterization of this isolate was carried out by various conventional and molecular tests, including 16S rDNA sequencing. These findings might shed further light and association with amoeba in the leprosy endemic area of this rare Mycobacterium species.

**TLMTI CONDUCTS REFRESHER WORKSHOP FOR ITS NURSING STAFF**

The Leprosy Mission Trust India conducted a refresher workshop for its nursing staff at TLM Miraj Hospital, from June 14 - 16.

Sixteen nursing staff from TLM hospitals in Champa, Chandkhuri, Dayapuram, Kothara, Miraj, Naini and Vadathorasalur attended the workshop.

Some of the topics covered in the workshop were:

- Diagnosis and treatment of leprosy
- Early detection and management of reaction and neuritis
- Management of deformities
- Importance of health education (inspection,
soaking, scraping, oiling)

- Importance of MCR protective footwear in people with anaesthetic foot

- Self-dressing for simple hand/foot ulcer by the patients

- Methods of rest for hands and feet (slings, crutches, PoP cast, wheelchair, etc.)

- Diabetes, neglected tropical diseases (NTDs) and water, sanitation and hygiene (WASH)

Dr. Suresh Verghese, Superintendent, TLM Hospital, Dayapuram; Dr. Rohini Suryawanshi, Consultant, TLM Hospital, Miraj; Mr. Shrish Shegaonkar, Sr Programme Manager, CHANGED project; Mr. N. R. Raja, CHANGED Project; Mr. Harsha Gudasalamani, Team Leader, CREATE Project; and Mrs. Irudayapurana Kumar, Nursing In-charge, were the resource persons for the workshop.

A four day workshop on ILC 2016 was conducted from 21st – 24th June 2016 at TLM Naini Community Hospital. The purpose of the workshop was to provide technical support to the TLMTI staff who will be presenting their work at the ILC in Beijing later this year. There were 11 participants from the field – hospitals, VTCs and projects, and the Principle facilitator was Dr. Ambarish Dutta from Indian Institute of Public Health, Bhubaneshwar.

The workshop was totally practical and participatory, giving the participants an opportunity to focus and sharpen their work making it more technically sound and improving the standard and quality.

The Leprosy Mission Research Newsletter is published by the Head (Research & Training) on behalf of TLM. It is available in two versions: electronic (pdf) and hard copy. If you would like to receive either, or have any questions, comments or suggestions, write to us at tlmrrc@tlmindia.org.