The Leprosy Mission Community Hospital, Naini.

Leprosy is curable...

Reconstructive Surgery
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The Problem of Deformity in Leprosy:

Leprosy is a cruel disease. While it doesn’t kill directly, it deforms and stigmatizes, leading to rejection by communities, and consequent impoverishment, disease and early death. Leprosy causes both disfigurement and disability especially of hands, feet and eyes. While disfigurement often leads to social rejection, disability reduces the possibility of undertaking productive work. Together, they are a life sentence without surgical intervention. Leprosy is also a neglected disease, ignored or denied in many countries and communities. This denial increases the negative impact of the disease as it is often not treated early enough.

**Leprosy**
- is one of the oldest diseases known to mankind.
- 50% of the world’s leprosy cases are in India.
- is caused by a bacteria - Mycobacterium leprae
- is treated with MDT - Multi Drug Therapy for 6 – 12 months
- starts with a skin patch and if not treated promptly can lead to deformities
- is a disease which has several complications like Deformity, Reaction, Neuritis, ulcer etc.

Among all the complications, deformities are the commonest and restrict activities. The main cause of deformity in leprosy patients is nerve damage. This occurs because the leprosy germs grow in the cooler parts of the body, such as skin and nerves which are close to the skin. The body tries to get rid of the germs and the resulting inflammation compresses and destroys these delicate fibres with more or less complete loss of function. So feeling is lost and muscles paralyzed, thus paving the way for disability/deformity, anaesthesia, ulceration, damage through injury and eventual fixed in-correctable deformity. The Leprosy affected who develop deformity have several problems - physical, social, economic, psychological etc

**Physical:**

Deformity in leprosy makes the person vulnerable. Any deformed patient (hands or feet or both) becomes increasingly dependent on others for his daily activities as well as his livelihood. A person with deformity cannot do his work properly. Deformities like clawed fingers or wrist drop do not allow a patient to even hold a glass of water. Similarly other deformities due to leprosy make life even more difficult.

They come to the hospital when they feel that there is no option other than surgery. Often the delay is because of a lack of awareness. It takes one to two weeks physiotherapy before surgery and three to four weeks of post – operative physiotherapy.
**Psychosocial:**

Deformities in leprosy do not just limit mobility; they also cause the patient to be isolated from society. The common perception of people is that a person with clawed finger may spread the disease and hence they prefer to keep a distance from them, do not talk to them and even drive them out of the house.

Most general and government hospitals in UP do not provide comprehensive care for the leprosy affected. They have only MDT which is not always available, knowledge of deformity care is not widespread, stigma prevails – and patients are discriminated against. This causes the patient to lose dignity and also a host of negative emotions, depression and even suicide. Hence they need not only medical and surgical care but also psychological care.

**Economical:**

The most expensive and probably the worrying factor today is the cost of health care. The relatively well off find it difficult, the poor impossible. The patients admitted in TLM Naini for deformity correction are mostly the rural poor. They are the children of or are themselves farm labourers earning daily wages and the monthly income is less than Rs 2000/month. They have large families and several expenses hence medical treatment gets a low priority. They often avoid it and accept the consequences. This is even truer for the leprosy affected.

There are very few (one or two) Government hospitals that provide Reconstructive Surgery (Deformity correction) for leprosy in Uttar Pradesh. Private hospitals charge a high fee (> ₹50,000) only for the surgical procedure and most do not include physiotherapy, food or stay. They would have to borrow from money lenders and be in debt for a very long time. This often causes them to decide to die with the deformity at home rather than to spend their hard earned money.

**SOCIAL IMPACT:**

There still exists a social stigma against leprosy, mainly due to lack of knowledge and the misconception that it is a curse from God. This is worse when the patient gets deformity or ulcers. Patients try to hide their deformity from others so that they may escape from social ostracism. But gradually when the deformity gets worse it cannot be hidden from others in the home and community; hence many of the patients have been driven out of their homes and villages just because of their deformity or ulcers. They cannot afford treatment in private hospitals and are usually not accepted/treated properly in government hospitals so they continue managing at home with local quacks and come to TLM Naini when they find no other way. Here they are welcomed, admitted and cared for unconditionally. They get compassionate, holistic care – medical, surgical, psychological. TLM Naini fills a gap existing in the society for these people who have nowhere to go. We have a policy that ‘no leprosy patient should be denied treatment just because he cannot afford it’.
Surgical reconstruction for the correction of deformities due to leprosy is now well and firmly established. For a leprosy patient, appearance is very important since his deformity not only separates him from his family, friends and relatives but it causes a stigma against him in the community. So the main aim of Re-constructive surgery is restoration to normality.

The commonest deformities in leprosy that can be corrected by surgery are Claw Hand, Ape thumb, Lagophthalmos, Foot drop, Claw toes, etc. Reconstructive surgery facilities are available in TLM Naini hospital.

**Process of Surgery.**

Patients eligible for surgery are selected and motivated. All patients are explained the procedure to build and gain their confidence. The muscle that is to be transferred is isolated and strengthened for about a week or more based on the condition of the muscle and joints. Regular assessment is made by the operating surgeon as well as the physiotherapist during rounds, and once fit they are posted for surgery. After surgery a Plaster is applied for 3 weeks (hands) and 5 weeks (feet). Patients are encouraged to go home with the plaster and return for re-admission on its removal date.

The physiotherapy management involves re-education by Exercises, Splinting etc. and lasts for 3-4 weeks. The first step in re-education is to teach the patient, how to use his old muscle for a new job, and train them to apply it unconsciously. In the second step, the Occupational therapist trains patients to use their limbs effectively and safely in their day-to-day life.

**Rehabilitation Plan.**

A Rehabilitation plan is made for each individual patient who underwent corrective surgery, and they are followed-up. The plan will take into consideration, his occupation before admittance for surgery and what he intends to do after surgery, whether going back to the same occupation or not. Based on his academic/technical qualification, previous experience, interests, disabilities and needs of the community they are referred for programmes like CTY, CBR, VTC, etc.

**Outcome of Surgery:**

**Physical Outcome**
- Improved Function
- Cosmetic appearance restored.

**Psychological Outcome**
- Increased Self-Confidence in Patients to face the community
- Build Self-esteem of the patients to have a desire to be a productive member of society.
Social Outcome
- Increased Work output
- Eligibility for Education
- Re-union with family
- Marriage
- Employment / Employability
- Improved Socio-economic Status & Social participation.

Progress of TLM Naini in Deformity Correction:
TLM Naini is continuously battling to remove the stigma and discrimination against people affected by leprosy. The Out patients Department serves approx 300 patients daily, both leprosy and others, all seated together in the same hall. It never segregates leprosy affected. The Leprosy Patient with deformity coming first to the hospital, visits various departments for assessment like Laboratory, Body charting, Physiotherapy, counselling and finally the doctor. Doctor examines the patient and based on the other departments report and recommendation they decide to admit the patient for surgery.

Surgeon:
Surgeon conducts rounds twice a week where he posts the patients for surgery in suitable cases and recommends further pre-operative physiotherapy for the ineligible patients. During rounds the surgeon also oversees the treatment (medical & physio), post operative physiotherapy for patients who have had surgery.

Physiotherapy unit-
All the inpatients admitted for surgery (Pre-operative & Post-operative) undergo physiotherapy treatment for around 6-8hrs per day.

PRE-OPERATIVE PHYSIOTHERAPY.
In the Surgical Physiotherapy department, the therapists make the patients suitable for surgery by the following ways.

- Pre-operative Assessment that includes Range of Motion, Muscle power, Functional difficulties, ADL etc
- Contracture (tightness) released by splints and stretching exercise.
- Strengthen the weekend muscle by resistive exercise.
- Skin softness maintained by Soaking, Scraping and Oiling.

For all patients pre-operative physiotherapy will decide the outcome of the surgery. Therefore, minimum of 7-10days of pre operative physiotherapy is essential for almost all of the patients.
POST OPERATIVE PHYSIOTHERAPY;

After the 3weeks (Hand)/ 5weeks (Foot) of post surgery plaster period, patients has the POP removed and physiotherapy treatment for 3-5 weeks where they meet following things.

- Improve the range of motion
- Muscle re-education
- Regain the functional activities
- Improve the activities of daily living (toileting, bathing, dressing etc)
- Vocational rehabilitation

After the post operative physiotherapy treatment patient will be discharged by the surgeon with follow up care.

PICTORIAL PRESENTATION OF A RECONSTRUCTIVE SURGERY PROCESS OF HAND...
Patient with Lagophthalmos due to leprosy, not able to close his eyes which leads to blindness if surgery is not performed in time.

Surgeon performing surgery (Temporalis Muscle Transplant).

Patient after surgery can close his eyes and can save himself from blindness.
Counsellor:
TLM Naini understands the need for counselling of a patient before reconstructive surgery. Most of the patients reporting to TLM Naini belong to the rural population and often have a lot of fear & misconception regarding surgery. At the same time thoughts of family and livelihood also occupies their mind. Therefore convincing such patients for surgery requires counselling.

Deformed patients are admitted for about 1-2 weeks before the surgery and 3-5 weeks after the surgery. In both admissions patients need a lot of psychological support. Group counselling is also done for the surgical patients. This helps to boost their morale and motivates them to get back to their community with full confidence.

Statistics:-

The above graph is showing the number of patients operated for Reconstructive Surgery at TLM Naini hospital from the year 2006 to 2010.
PROPOSAL TO REVERSE DEFORMITY IN LEPROSY

Deformity in Leprosy is the reason for stigma to the disease. Reversing this deformity in the early stages will eventually get rid of the dread of Leprosy.

The Leprosy Mission Hospital, Naini, Allahabad, does among the largest number of Leprosy Reconstructive Surgery (Tendon Transfer) procedures in the world, each year.

This includes:

- 7 – 10 day Pre-operative Physiotherapy
- The Surgical Procedure
- 21 days of POP (Plaster) immobilization (usually at home)
- 21 – 30 days of Post-operative Physiotherapy

<table>
<thead>
<tr>
<th>Proposal Request for CSR</th>
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<tbody>
<tr>
<td><strong>Approximate number of Re-constructive surgeries done each year</strong></td>
</tr>
<tr>
<td><strong>Estimate (details below) for each procedure including IP stay, Food, Physiotherapy, Surgery, Medicines &amp; supplies</strong></td>
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<td>Proposal Request for CSR</td>
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### DETAILED COSTING

<table>
<thead>
<tr>
<th>Description</th>
<th>Cost</th>
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<tbody>
<tr>
<td>Hospital Bed Charges</td>
<td>Rs. 6,200</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>Rs. 2,000</td>
</tr>
<tr>
<td>Surgery Fees</td>
<td>Rs. 5,000</td>
</tr>
<tr>
<td>Anaesthesia Charges</td>
<td>Rs. 1,000</td>
</tr>
<tr>
<td>Post-Operative Drugs</td>
<td>Rs. 200</td>
</tr>
<tr>
<td>Pre-operative drugs</td>
<td>Rs. 100</td>
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<tr>
<td>Nursing/Support staff cost</td>
<td>Rs. 2,000</td>
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<tr>
<td>Surgical materials</td>
<td>Rs. 2,000</td>
</tr>
<tr>
<td>Administrative expenses*</td>
<td>Rs. 3,500</td>
</tr>
</tbody>
</table>

Total cost of RCS Surgery per patient: Rs. 22,000

### Explanation of Administrative expenses*

- **Registration/Pre-Post counselling**: Rs. 800
- **Office/Accounting expenses**: Rs. 500
- **Audio/visual documentation**: Rs. 1,000
- **Monitoring and evaluation**: Rs. 1,000
- **Miscellaneous**: Rs. 700

Pre-operative drugs: Rs. 500

Total: Rs. 3,500

No. of days of hospitalization, Pre/Post surgery is taken as 40 days
Physiotherapy includes the pre and post surgical physio activities
Shweta (name changed) is a young girl of 17 years from a village called Attara in Banda district (name changed). Her father is a farmer and mother is a housewife. She has one brother and a sister. Both of them are older than her. Her family income is Rs 2000/- per month. She studied till 12th standard and is now studying General Nursing & Midwifery from a well known private nursing college.

Shweta came to TLM Naini in the year 2002 when she found her left wrist dropped, fingers clawed and paralysis of her left foot. She consulted many private doctors but could not get relief from her ailment. Her father was very puzzled and upset as he was already short of money and over that his daughter was diagnosed with leprosy which none of his family members had in the past. Shweta was very interested in studies but her long stay in the hospital raised several questions at the school and also in the community. She got very good support from her father. Even though her father was under stress he never reflected his anxiety to Shweta.

Shweta was operated for her left foot and wrist drop in 2001 at TLM Naini. She was unable to return for follow-up surgeries till 2004. The ‘Catch Them Young’ programme of Comprehensive Rehabilitation Project recognized her desire for education. After discussing with her father the project started providing financial assistance for her studies from the year 2005 onwards. In the year 2007, Shweta came back to TLM Naini for further corrective surgery of her left hand. This time Shweta was under more stress as she was now a grown up young girl, intelligent but had fears for her future due to the stigma of leprosy. Shweta was interested to be a Nurse but somewhere in her heart she knew that she cannot study nursing with the income of her father.

During her stay in TLM hospital Naini (for RCS of left hand) she expressed her desire of studying nursing to some of the hospital staff and the social worker. Since the cost of the 4 year Nursing diploma is high, Catch Them Young Programme had to take special permission from higher authorities for education.

Shweta is now in the Nursing school and doing her second year of diploma in General Nursing & Midwifery. She is very confident and happy too to find herself one among the nursing students. She has made friends among her class mates. Her father was in tears when she got admission in the Nursing College. Shweta says *I have got feathers to fly and touch the sky. This is only because of TLM.*
Rima (name changed) is a young girl of 17 years from Varanasi, Uttar Pradesh (name changed). She has 2 brothers and a sister. Her father works in a carpet company in Bhadohi. The total family monthly income is less than 3000 rupees per month. She had studied till 10th standard but after that due to her clawed fingers she was not even able to hold a pen so she stopped studying.

She was very upset when she came for surgery because all her classmates and friends were in higher classes and would avoid her. She was not able to do the house hold work like cooking; washing clothes etc. all this made her psychologically stressed.

Rima came to TLM Naini in the year 2009 for the correction of her deformity (clawed hand). Before coming to TLM Naini she had completed her MDT treatment from outside.

While she was admitted in the ward the counsellor talked to her several times and tried to console her psychologically. She obtained a very good result of reconstructive surgery of her right hand.

Now she can hold a pen, wash clothes and even helps her mother in cooking. In her latest revisit to TLM Naini hospital May-2011 she expressed her willingness to study again. She is very happy now and seems more confident.

The Community Rehabilitation Project staff are in the process of assessing her need for support and will be getting her back into the 11th Standard.
Ramakant Patel is a young man of 34 years from a village called Beerapur which is around 55 kilometres from TLM Naini. He studied till 12th standard and now has a water service centre at Bhulai Ka Pura (on Gorakhpur Highway road). His monthly income is between 3000/- to 4000/- rupees per month. His father is an old ‘care after cure’ leprosy patient of TLM Naini. Ramakant has five children and his wife is a housewife. All his children are studying.

Ramakant turned to TLM Naini in the year 1989 when he found some anaesthetic patches on his body. He was under DDS mono therapy for long time and finally he found his left hand getting clawed. This became a major problem for him as his family was already stigmatised by his relatives because his father had leprosy and getting clawed fingers added to his stress. He was psychologically stressed because of his disease and his future looked bleak due to the deformity.

There were several problems in Ramakant’s life

- The disease of Leprosy
- his physical condition, deformity
- Stigma (Self/society)
- Career and Livelihood

In the year 1994 he underwent Reconstructive Surgery of his left hand at TLM Naini. At that time Ramakant was only a young boy of 18 years and had absolutely no idea about what to do in the future? After his reconstructive surgery Ramakant was very happy and encouraged. He decided to go for vocational training at the VTC in Faizabad of TLM Trust India.

After successfully completing his training in ‘Diesel Mechanic’, Ramakant started his own service centre. This was the turning point in his life and that service centre has now helped him establish himself and he is accepted by his family. Ramakant is the sole bread winner of his whole family. Because of this come back, both he and his family are now recognized by the entire village. He is very happy with what he has achieved. He says “Today whatever I am is all because of TLM”
APPENDIX

Annual Report 2010
(Attached separately)

Donation Appeal
(Attached separately)

Training Unit Brochure
(Attached separately)