# Preventive Strategies and Practices to Avoid Disabilities in Leprosy Patients

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Leprosy is a chronic infectious disease caused by the Mycobacterium Leprae which primarily affects the skin, the peripheral nerves and other tissues.

Nerve impairment is the main cause for disabilities to develop in leprosy patients if no preventive measures are taken. Damage to the nerve due to influx of inflammatory cells and their mediators is generally responsible for nerve function impairment.

Impairments may be present or absent at the time leprosy is diagnosed. During the multi-drug therapy (MDT), new impairments may develop, and existing impairments may become worse, remain the same or improve. <sup>1</sup>

# Symptoms of nerve impairment can be:

Impaired nerve	Primary Impairment	Secondary Impairment	Third Impairment
Autonomic	Dry, hard skin	Callus, crack, ulcer	
Sensory	Sensation loss	Blister, burn, injury, ulcer, blindness	Bone and soft tissue damage and loss
Motor	Muscle	Contracture, crack,	
	weakness/paralysis	ulcer	

Much of this disability can be prevented and the new WHO *Global Strategy for reducing the Burden of Leprosy and Sustaining Leprosy Control Activities* calls for the increased efforts to reduce this "burden" by preventing disability in new cases, by helping to rehabilitate those with disability and by fighting stigma wherever it exists. <sup>1</sup>

The grading system used in this paper is the "Maximum WHO Impairment Grade". In 1988 the WHO introduced a system, <sup>2</sup> which has been adapted in 1998, <sup>3</sup> where impairment was reflected by grades assigned to each eye, hand and foot using a scale of three possible outcomes (0, 1, 2). The maximum of these six grades, the Maximum WHO Impairment Grade, specifies the patient's overall score. The Maximum WHO Impairment Grade recognizes both first onset of impairment and total recovery of existing impairment\*. It is widely used in Bangladesh and LEPRA Bangladesh uses it as its measure tool for the achievement of the work strategies utilized. <sup>4</sup>

# WHO Impairment Grade

Grade 0	No anaesthesia. No visible deformity due to leprosy
Grade 1	Anaesthesia present No visible deformity due to leprosy

Grade 2	Anaesthesia is present	
	Visible deformity due to leprosy	
	Lagophthalmos, corneal ulcer, iridocyclitis	
	Visual acuity < 6/60	

Whereas the primary impairments are preventable, the secondary impairments are avoidable; the third impairments should not happen at all.

- ► For the prevention of primary impairments the following steps are to be taken:
- <u>1. Early diagnosis:</u> in order to be able to diagnose leprosy in a patient, basic knowledge about the cardinal symptoms is crucial:
  - Hypopigmented or erythematous skin lesion(s) of characteristic appearance with definite reduced sensation.
  - Enlarged nerve(s) at the sites of predilection.
  - The finding of acid-fast bacilli in slit skin smears.

For the prevention of disability (POD) LEPRA Bangladesh also uses the tools of quick muscle testing (QMT) and sensory testing (ST) to detect suspects at the earliest possible stage.

<u>2. Early detection:</u> to make as many as possible people aware of the cardinal signs and symptoms of leprosy. Patients may be detected passively (voluntary reporting or self-reporting) or actively. LEPRA Bangladesh uses a broad and varied system for early case detection.

## Passive case detection:

Awareness raising is done in the following ways:

- Mass information (miking, film show, drama, folk songs, radio, TV, etc)
- Group information (using flip charts)
- School information

\*Note author. According to the article: "Monitoring impairment in leprosy: choosing the appropriate tool", the ISF scale is a better way to monitor the changes in impairment, both in numbers and in severity. The author has made a start to review the tools used by LEPRA Bangladesh

- Networking with and orientation of the other GOs, NGOs and BGOs is particularly important for the awareness raising and spreading of the message on leprosy and its treatment, as the other organisations cover large groups of different people.
- During the Mobile Team Clinics (MTC) teams, consisting of a medical officer, a lab technician, a physiotherapy technician, an orthopedic & foot wear technician and a driver, travel to different districts on monthly bases, and have exposure to significant groups of patients and general health workers. Returning to the clinics regularly has made the people more aware of the organisation and the services it offers. It also has opened the doors for people with doubts and questions and in this way LEPRA Bangladesh has been able to detect more cases.

#### Active case detection:

Active case finding is done by contact survey, house to house survey, village survey and school survey. Contacts are defined as household contacts of known leprosy cases. <sup>5</sup>

<u>3. Adequate treatment:</u> the adequate treatment of leprosy patients is detrimental for the prevention of disability.

The adequate treatment consists of:

- Proper medication and compliance. One needs to explain the treatment to the patient: the reason for treatment, the correct dosage of the medication, duration of the treatment, what to do if pain or loss of feeling increases or strength decreases and the possible side effects of the treatment.
- Adequate leprosy-reaction treatment. (Type 1 and Type 2 reaction)
- Health education on self care and prevention of disability. The priority is to stop
  permanent nerve damage or primary impairment developing into secondary impairment.
  To do this, one must inform and empower the person affected so that they can act to
  prevent further damage.
- Exercise program adapted to specific needs of the patients.
- Supervision of the assessment and treatment of the patients.
- Strict follow up system: -reaction neuritis every 2 weeks
  - -ulcer every 2 weeks-UT/MDT monthly-disability yearly
  - -whenever indicated follow up will take place earlier
- ▶ For the avoidance of secondary and third impairments the following steps are of importance:

### 1. Health education:

The health education consists of three parts and well special self care, exercises and the use of protective wear. Corner stones of health care are knowledge, attitude and practice.

- Special self-care: concerning the fact that leprosy patients can lose the sensitivity in the hands, feet and eyes self care is extremely important to prevent disabilities. All leprosy patients with loss of sensation are taught the way how to conduct self control and self care and how to prevent injuries. Staff should help the patients to recognize the dangers and practice wound avoidance. Patients have to be aware that they need a daily routine of eye, hand and/or foot inspection, skin care and exercise. If an ulcer already exists, patients have to be taught how to take medication in a proper way and how to perform ulcer care. Patients should know the cardinal signs and symptoms of nerve function impairment and take proper steps to avoid worsening of the condition. In each follow up session, problems and other issues are discussed with the patients. To encourage compliance the patient should be praised if no skin lesions occur or if the existing skin problems/ ulcers have improved. The responsibility for looking after the sensitive areas lies principally with the person affected. Health workers may advise, help and encourage, but they can never take over this task.<sup>6</sup>
- Exercises: a daily simple exercise program is imperative in case of loss of muscle power and/or mobility changes. In this regard a limited but regular practiced amount of exercises is better than having a broad workout program which overstretches the patient. The exercises should be adapted to the severity of the problems and according to the needs of the people affected. It is important that patients realize the purpose of the exercises. When patients understand that they can maintain or improve their situation, they will be better motivated to do the exercises every day.
- Protective wear: since the patient has loss of sensation he/she will not be warned by the
  normal physiological system when there is an irritation, a burn or injury. Therefore
  he/she will not be able to take protective measurements. LEPRA Bangladesh uses
  special material for shoes to avoid blisters on the feet and teaches the patients how to

produce their own protective wear in order to avoid injuries caused by daily duties. It is important that the patient can produce their protective wear from local material to make its use sustainable. Protective wear should be used for the eyes, hands and feet.

### 2. Follow up schedule:

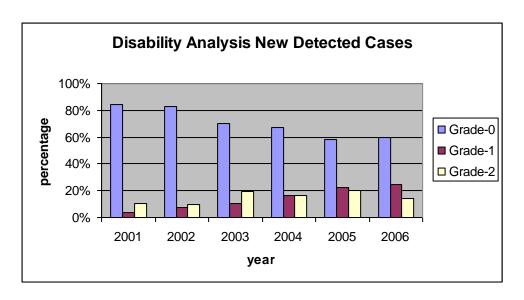
- Control: without proper control system an evaluation of the process is not possible, success or failure cannot be detected and the program will not be sustainable. L EPRA Bangladesh has very clear guidelines on the follow up schedule and what to do during such a follow up. For all involved the tasks are clear and therefore we have a very low default rate. The use of Baseline Disability Records and Follow up Disability Records ensure the right action plan.
- Motivation: motivation of all involved is one of the major corner stones towards a successful program. Having sensory loss for a leprosy patient means a life long danger of getting Level 2 and 3 complications. <sup>7</sup> This implicates that the people affected have to follow a life long program of self care, exercises and protection. As for all chronic problems, it is difficult to find the motivation to continue, especially since the results obtained are most of the time limited on keeping damage at bay and does not show clear improvements. For staff involved motivation is also a problem, for the same reasons. It is much more interesting to work with patients where clear results can be observed, instead of being satisfied when the patients just maintains and injury free life or keeps worsening of the situation under control. Leprosy is not anymore a "fashionable" disease and many people have lost their interest in this health issue and the patients still suffering from the impairments caused by the disease.
- Involvement family, community: the acceptance and the cooperation of the family are very important for a good and long-lasting result of the treatment. Ideally the patient and the family will take ownership of the treatment and the life-long self care to avoid dependency on outsiders. To be able to observe, that a satisfactory life despite the leprosy is possible, will also positively influence the community where the patient lives. Stigma is still one of the major reasons why a patient would not disclose the nature of the disease and with that possibly closing the doors on further case detection. If the community shows the acceptance towards the patient, avoidance of the development of secondary and tertiary impairments can be reached.

#### 3. Medication

Patients and health workers should have knowledge about the medication regime for all aspects of leprosy, with its complication, in all different stages. Without proper medication and compliance of medication intake, good results cannot be achieved.

<u>Disability Analysis:</u> if the above mentioned strategies are followed strictly, a reduction of disabilities in leprosy patients can be observed.

The statistics below shows the outcome of the preventive strategies and practices of LEPRA Bangladesh to avoid disabilities in new detected leprosy patients over a period of 6 years. The working area of LEPRA Bangladesh for leprosy is in three districts: Sirajgonj, Pabna and Natore with a population of 7.204.897 people. WHO target is to reach less than 5% Grade 1 and/or Grade 2 disability cases in new detected leprosy patients.



The first two years of the project showed improving results where LEPRA Bangladesh reached the WHO target of 5% Grade 1 in the year 2002. (Grade 2 was 7%) In November 2002 LEPRA Bangladesh started another program and attention was drawn to the new project. The result has been that the WHO target for the leprosy patients could not be reached anymore and in the year 2005 both the Grade 1 and the Grade 2 rate was 20% and more. This has been an alarming development and LEPRA Bangladesh has started to focus again more on the leprosy patients, and for the Grade 2 detection rate, a significant improvement can be observed in the year 2006.

## Conclusion

The preventive strategies and practices of LEPRA Bangladesh have been proven to be effective to avoid disabilities in leprosy patients (2001-2002) and these strategies could be beneficial for other organisations as well. However, if attention on prevention and early detection is lost, the results are harmful for the patients. (2003-2005)

#### References

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