UPDATE
CONTINUING MEDICAL EDUCATION
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COMMUNITY INVOLVEMENT IN MANAGING LEPROSY-AFFECTED PERSONS WITH DISABILITIES

There is social stigma attached to leprosy mainly because of the disabilities one sees among persons affected with the disease. Society tends to treat persons with leprosy-related disabilities in a way that makes them feel unimportant. This is due to fallacious and unfounded perception about the disease brought about to some extent by impoverished efforts at dissemination of right information about the disease among the population. We cannot find fault with the programme for not converging on this facet of leprosy control because of the legitimate emphasis given to early diagnosis and treatment. The definitive intervention has brought down apparently the number of new cases and also those being detected with disabilities. But one should not forget that even though the number of new cases with disabilities has come down there is a significant pool of patients with disabilities who are left to fend for themselves without any tangible assistance from any quarter. The problem is compounded by the fact that we do not have an exact idea of the magnitude of the problem. The number of persons with leprosy-related disabilities in a leprosy-endemic district with an average population of 1.5 million may vary from 100 to 1500 depending on the age of the programme, existence of referral services and efficiency in managing the information system. In order to change the image of leprosy as perceived by the community it is essential that these persons with disabilities are looked after and cared for and their physical and social needs are attended to. They rarely present themselves at health facilities because they do not get any service titred to their needs. This is due to the fact that personnel at health facilities are not trained and therefore not competent to deal with them. Patients themselves do not do anything because they do not know how to take care of their disabilities. They are ignored by their families, dismissed by the community, overlooked by the programme and neglected by themselves. This unsavoury situation needs to be hauled around.

One of the objectives of leprosy control is to identify every leprosy affected person with disability, learn about his/her problems, understand them and work out appropriate solution. This may look a tall order for the programme. It is not. Each Peripheral health worker will have

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COMMUNITY INVOLVEMENT IN MANAGING LEPROSY-AFFECTED PERSONS WITH DISABILITIES *- Contd. from page 1*

3 to 10 patients with disabilities. During the routine village survey the health worker can identify these persons. The workers need to be trained on how to identify persons with disabilities, and also on counseling and monitoring. The worker needs to be trained to engage the community in assisting the patients' self-care needs. The patients should be helped to take care of themselves with the help of their families and the community. Management of persons with disabilities without the involvement of families and community will be difficult to sustain. While the involvement of the family is understandable, one may wonder how the involvement of the community would help the patients. Community involvement is needed in spreading the correct information, identifying persons with disability and referring them to health facilities for necessary assistance, providing advice, counseling and monitoring patients on self care, arranging for special footwear or prosthesis for patients in need as the case may be and finally as change agents to change the image of leprosy. The health worker in consultation and discussion with village panchayat can identify volunteer(s) interested in helping the patients and the programme. These volunteers can be given short training in spreading appropriate messages in the community with the intention of making them accept leprosy-affected persons with disability with alacrity.

In Salem town in Tamil Nadu one may be surprised to see young volunteers arranging street plays, group talks and slide shows on their own to spread correct messages about the disease and to dispel misconceptions and wrong attitudes. The volunteers can assist the programme in identifying persons with leprosy-related disabilities and in need of help. These persons can be referred to primary health centres or hospitals and on the advice of Medical Officers they could help the patients in taking care of their disabilities. Involvement of the community in counseling patients with disabilities on self-care and in monitoring these patients would be really useful to foster positive attitude about Leprosy among the community and also to promote better compliance among patients. When people see that the horrible looking ulcers can be healed with simple self-care practice it encourages them to understand better the problems of these patients and removes from their mind the cobwebs of misconceptions. This type of community engagement is seen in Salem and Fathimanagar (Trichy).

Community can also be involved in mobilising resource for providing MCR footwear or prosthesis to patients with disabilities in the foot. In Salem the Government health workers could motivate the community to raise Rs. 77000 towards provision of footwear to disabled persons! The image of leprosy has changed with the sharp reduction in the number of persons affected with the disease, and it can be further changed by reducing the number of those with disabilities. This can happen to a large extent if community is engaged in key areas of leprosy control.

To serve is Human, to reach out is Divine

Thalaivasal block in Salem district has 25 Health Sub centers and covers a population of 11,200. It is heartening to note that the Village Health Nurses in these sub centers are actively involved in National Leprosy Eradication Programme. They disseminate the messages about Leprosy to the community and try to help persons with Leprosy related disabilities.

Mrs. Tamizharasi, a Village Health Nurse of this block is fully committed to the cause of Leprosy. After getting the orientation training from a local NGO she traced 52 disabled patients including 20 patients with plantar ulcers. One may be interested to know that she closely monitors these patients on self-care. What is really interesting is that she has mobilised community resources for providing MCR footwear to 25 patients!.

Mrs. Thamizharasi like her colleagues in the block is a sterling example for dedication, commitment and service to people affected with Leprosy.

How good is prevalence rate as an indicator in Leprosy?

First of all, prevalence rate is not a rate because of the problem with the denominator (the numerator is not part of the denominator). It should be referred to as “Prevalence”.

Prevalence of leprosy is influenced by so many operational factors that it is often difficult to control them. When the indicator is used as a target the influence of operational factors is accentuated. Here is an example:

In district ‘X’ prevalence which is 3 per 10000 comes down to 1 in four months. Case detection drops by almost 75% during this period. About 85% of the 200 cases detected are PB cases. There is not a single case with disability. There is no active case detection in the district.

One of the possible reasons for this scenario is non-registration of MB cases.

SUPERVISION

Supervision aims to provide guidance and support to people working in an organisation. Good supervision encourages people to bring out the best. To be a good or effective supervisor one needs to be familiar with the two most important tools of supervision: job description and check list. While job description helps to understand the tasks and responsibilities of individuals in an organisation, checklist elaborates the means of looking critically at the tasks, identifying problems in performance and finding appropriate solutions. Checklist is simply a list of items related to tasks and responsibilities of an individual with definite set of criteria and scale for each measurement variable.

For example:

- Measurement variable - Awareness about the leprosy problem
- Measurement Criteria - Magnitude of the problem
  - Basic facts about Leprosy
- Measurement scale - Aware / not aware.

Starting with this issue, we will be giving checklist for supervising the general health staff involved in NLEP, one in each issue.

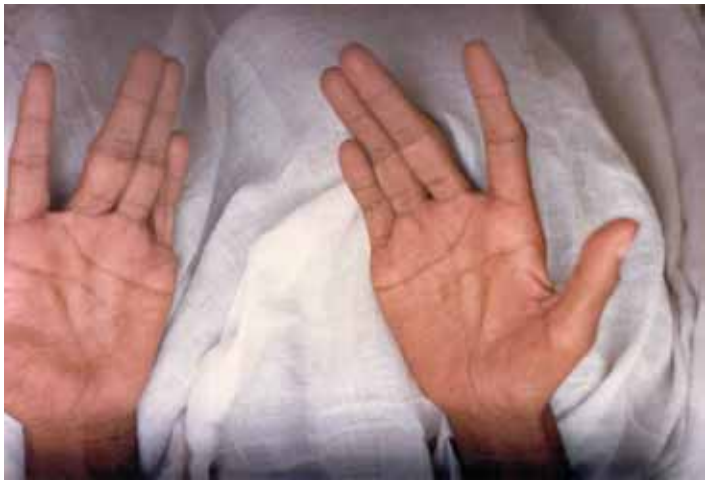
I. Checklist for Supervision of peripheral health worker:

1	Clarity of perception about his / her role	Clear / Not clear
2	Awareness about the Leprosy problem and Programme (NLEP) • Magnitude of the problem in the area • Basic facts about Leprosy – caused by bacteria, curable, MDT • Programme – What is done at each point (SC, PHC, Block, District)	Aware / Not Aware
3	Knows about regimens (MB / PB)	Yes / No
4	Knows about the messages to be conveyed to the community (Leprosy is caused by a germ; is curable; MDT available free, where; no discrimination)	Yes / No
5	Knows the key points to be stressed during patient counseling – Assurance, basic facts about Leprosy, treatment regimen, regularity, curability, side effects, when to report and where.	Yes / No
6	Has referred suspects in the last 2/3 months	Yes / No
7	Maintains suspect referral slips	Yes / No
8	Maintains patient card / register (Correct, accurate & up to date)	Yes / No
9	Knows when to refer patients under treatment	Yes / No
10	Number of patients under treatment who are regular	……|……
11	Has adequate stock of drugs (for cases under treatment)	Yes / No
12	Updates the master register at PHC	Yes / No
13	Knows the self-care practice for managing persons with disabilities.	Yes / No

How big is the problem of disability in Leprosy ?

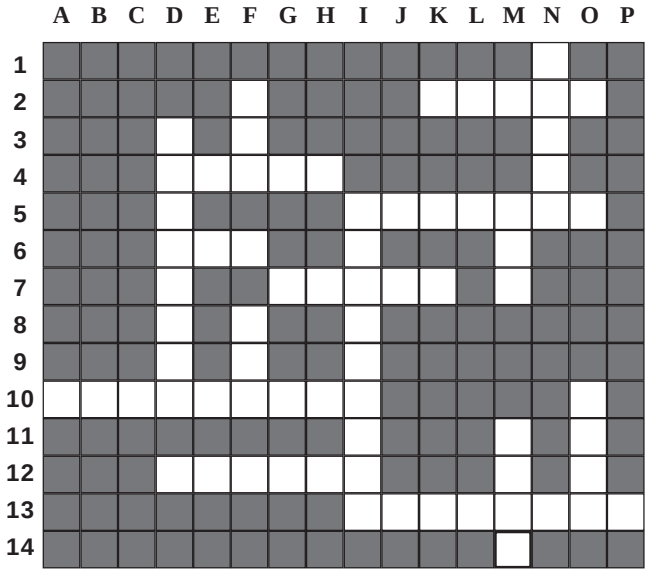
"Everybody talks about POD, but nobody seems to do anything about it" to misquote Mark Twain. Basically, the problem is that we don't get baseline data which gives us an idea about the magnitude of the problem. Unless we know the size of the problem it would be impossible to prepare a plan. The NGO project at Amda in Saraikala district which has been doing Leprosy work for more than 15 years has very effective POD programme in at least two blocks in the district. An attempt was made to screen all the living cases in Kharswan block in the district (population about 150000). The block has 2724 patients on record from the beginning of the project of whom 98 had grade two and 91 had grade 1 disability. This works out to about 1000 cases with grade 2 disability in a district with about 1,500,000. What is interesting is the grade 1 disability which is as much as grade 2.

Out of the 2724 cases 898 were screened by the project in 3 months from January 2005. Among them were 28 cases with grade 1 disability and 70 with grade 2. None of the cases with initial grade 1 disability had any disability at the time of screening. Of the 28 cases with grade 2 disability 20 were not available, 5 had left the control area and 3 had temporarily left the area. Similarly, of the 68 cases with grade 1 disability 50 were not available, 6 had migrated and 7 had left the area temporarily.



Lessons learnt:

1. In an endemic district one could expect about 1000 cases with grade 2 disability and an equal number with grade 1 disability.
2. About 3-5% of the living cases would have grade 2 disability and another 3-5% grade 1 disability.
3. It is interesting to note that about 77% of the patients with G2 disability were staying in the area and were available, whereas only 30% of cases with G1 disability were available.



CROSSWORD - L2 (Leprosy)

ACROSS:

2K Ignorance is blister
4D No delay is the message
5I To write with a sense
6D Reverse the residual consequence
7G A wristy fall
10A Negativeness is a sure indication
12D No sweat
13I A sure cure for tender nerves

DOWNWARDS

D3 It is the nerves, I believe
F2 A brace for the sole
F8 Stretch it to test it
I5 Exposure keratitis if not treated leads to
M5 Harbours seed
M11 12 inches
N1 Involvement leads to disability
O10 Self care practice

ANSWER TO CROSSWORD - T1 (TB) (April 2005 Issue)

ACROSS

1D AFB
2 I MDR
4 C PULMONARY
7A SLIDE
7 G IP
9 D CP
9 G DOTS

DOWN

B 5 STLS
C 3 EP
D 7 DTC
E 1 FAILURE
G 2 DTO
H 4 NTCP
K 1 XRAY
J 4 RELAPSE

TB CONTROL PROGRAMME

'Why's in Tuberculosis Control Programme

Why there is often delay in starting treatment?

	Reasons	Action required
1	Patient is not aware of • Where to go with sputum results • Distance to PHC inconvenient to patient • Treatment facilities • DOT provider	➢ Adequate counseling of patient ➢ Allot adequate time. ➢ Cover all the important points. ➢ Ensure that patient has understood. ➢ Explain DOT and provide information on who is the DOT provider.
2	Delay in sending sputum results to PHC	➢ Organise channel to send sputum results to PHC. ➢ STS to check at least sputum positive patients & provide feed back to MO-PHC and MOTC ➢ MO-PHC to supervise organisation of DOT for newly detected TB patients. ➢ MOTC to supervise PHC. ➢ DTO to verify during review meeting.
3	None identified to coordinate at PHC	➢ Identify one of the staff at PHC for receiving sputum results and co-ordinating DOT through MPHW. ➢ On the job training to PHC staff.
4	No drug stock at PHC	➢ STS to periodically supply RNTCP medicines. ➢ Assist PHC to prepare correct indent.
5	No drug stock at DTC / problems in distribution system	➢ Prepare correct drug indent. ➢ Maintain adequate drug stock. ➢ Organise drug distribution system.
6	Delay in contacting MPHW	➢ Organise a system to intimate MPHW (weekly meeting / vaccine collection day).
7	Delay in identifying DOT provider	➢ On the job training of MPHW ➢ Supervision by Health Supervisor
8	Non availability of x-ray facilities – delay in diagnosis of P-negative	➢ TU is situated in referral centres which have x-ray unit. Make it functional.
9	Lack of supervision	➢ MO-PHC to supervise organisation of DOT for newly detected TB patients. ➢ Review of RNTCP in monthly meetings at PHC. ➢ MOTC to supervise PHC. ➢ DTO to verify during review meeting. ➢ On the job counseling of health staff during supervisory visits by MO-PHC, MOTC, DTO.
10	Lack of feedback	➢ Organise feedback system at different levels

Where there is suffering, there is succour

Pakiranima from Korrapadu in Anantpur is a patient suffering from pulmonary tuberculosis (new, sputum positive). She was identified by Aswathu, a community worker. After diagnosis he has been providing the drugs under his supervision.

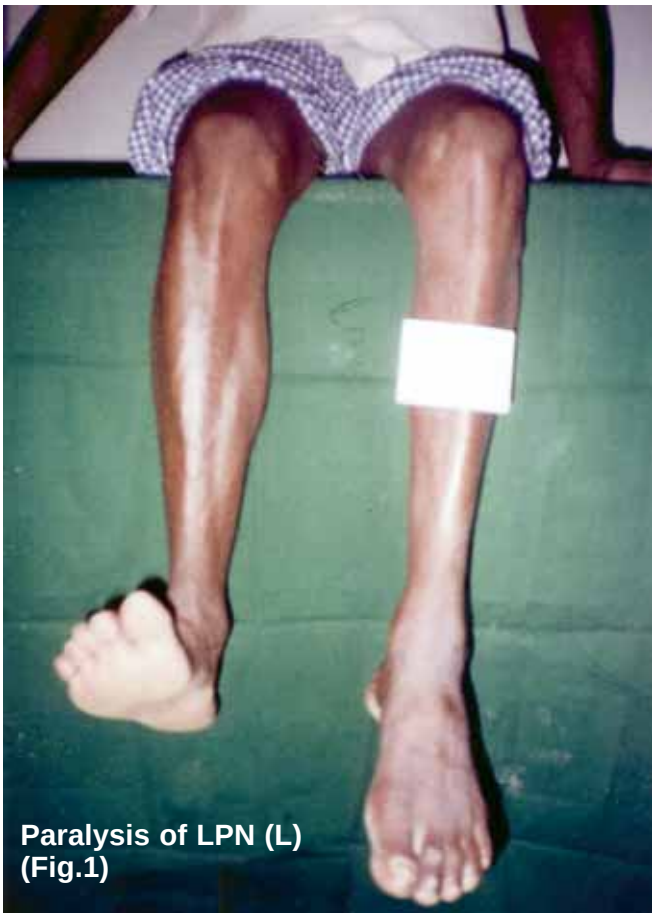
The patient is profusely thankful of Aswathu's service. It is gratifying to note that he has been the DOT supervisor for 8 patients, so far and out of 15 suspects referred by him 8 have been found to be cases of Tuberculosis.

Achari Pothulaiah from Shivapuram village in Anantpur district suffers from pulmonary tuberculosis (new, sputum positive). His treatment is supervised by Mr.Veeriah, an ironsmith.

Ram Vilas Paswan from Fitkychak village in Gaya district in Bihar is a patient of pulmonary tuberculosis. His treatment is supervised by the Panchayat leader Ashok Paswan. His understanding of the problem of tuberculosis and the need for supervision of treatment is very good. When asked to give reason for his involvement, pat came the reply "Service to fellow human being is worship".

It is the committed involvement of people like Aswathu, Veeriah and Ashok Paswan that contributes to the success of RNTCP.

Voluntary muscle testing for Lateral Popliteal Nerve



Paralysis of LPN (L)
(Fig.1)

Voluntary muscle testing for Lateral Popliteal Nerve (LPN) (Fig. 2)

1. Patient should be comfortably seated with the legs hanging loose.

2. The examiner should sit in front of the patient for doing the VMT.

3. Lift the foot off the ground and support at calf region.
   (The right leg of the patient should be supported with the left hand of examiner)

4. Ask the patient to lift the foot fully.

5. To test for weakness push the foot down while the patient tries to hold it in the test position.

6. Grade the muscle power as “S”, “W”, or “P”. (Strong, Weak, Paralysed)

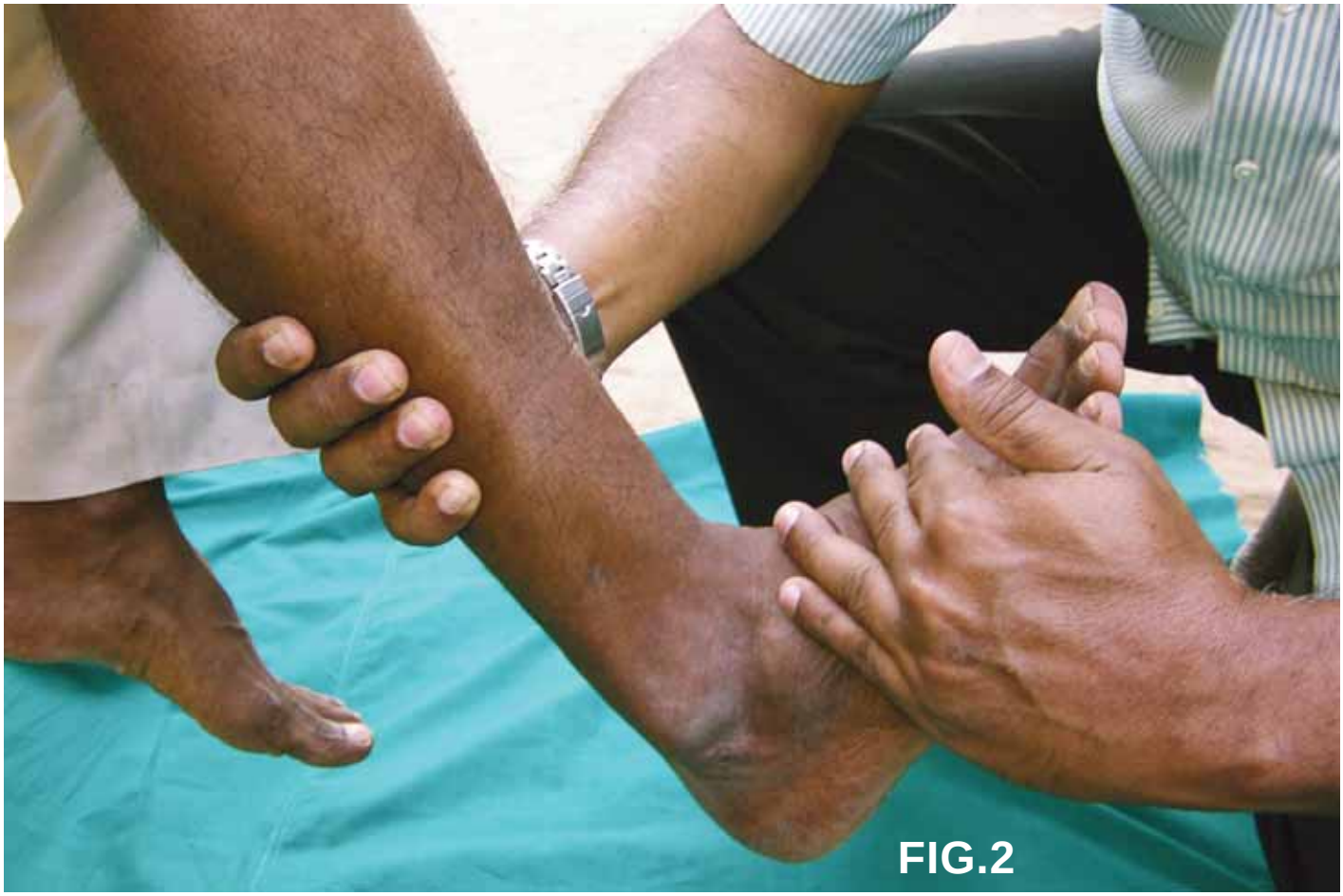


FIG.2