



*Integration of leprosy rehabilitation services
into the mainstream of physical medicine & rehabilitation*

National Workshop
10th October 2005

Jointly Organised by
ALERT - INDIA & AIIPM&R, Mumbai

Inaugural Session



Dr. R. K. Srivastava, Addl. DGHS, GOI releasing 'Task Today', a LEAP Publication



Dr. G. P. S. Dhillon, DDG (Lep), GOI delivering Special address



Dr. H. Srinivasan, WHO Consultant delivering Theme paper



Dr. P. P. Doke, DHS, GOM delivering Inaugural Address



Inaugural Session Dr. R. K. Srivastava (delivering Keynote address),
Dr. P. P. Doke, Dr. B. D. Athani, Dr. G. P. S. Dhillon, Dr. H. Srinivasan &
Mr. A. Antony Samy



Dr. S. C. Gupta, JDHS (Lep), GOM, delivering special address



Dr. B. D. Athani, Director, AIIPM & R, Mumbai, delivering Status paper



Mr. A. Antony Samy, C. E., ALERT-INDIA recounting purpose of the Workshop



Dr. P. K. Oommen, Director, CLTRI delivering Status paper

INTEGRATION OF LEPROSY REHABILITATION SERVICES INTO THE MAINSTREAM OF PHYSICAL MEDICINE AND REHABILITATION

Organisers : ALERT-INDIA and AIIPM&R, Mumbai

National Workshop

held on 10th October 2005

at

Hotel Kohinoor, Prabhadevi, Opp. Siddhi Vinayak Temple, Mumbai

 **ALERT-INDIA**

27th Foundation Day Commemorative Workshop

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Foreword



Dr. W. G. Rama Rao

Former Director, AIIPMR ; Past President, IAPMR.

I was excited and enthused at the theme of the National Workshop on Integration of Leprosy Rehabilitation Services in the mainstream of PMR, which I attended on 10th Oct' 2005, at Mumbai. As a former Director of AIIPM&R, I could not venture to take it up. Albeit the desire and conviction to do so.

When Mr. M. K. Gandhi was requested to open the first asylum for leprosy patients in India at Dattapur, near Wardha, Gandhiji observed "I would be too pained at heart to do so, that in fact I would like to see it closed down as soon as possible. It almost came to be so. Government of India redesignated the NLCP (National Leprosy Control Programme) as National Leprosy Eradication Programme (NLEP) in 1983 and hoped by 2000-2005, leprosy would be eradicated. The issue is not that the leprosy eradication is possible or probable. Let it be debated by the leprosy experts. But it is the policy decision and involving the NGO is important in achieving leprosy elimination. Prevention and early detection of probable deforming factors helped to bring about palpable outcome. Such patient can be now referred for interventional programme, and the PMR infrastructure is capable of taking it up.

The UK Royal College Report of 1972 concluded against specific specialisation in P.M.R. Yet considering the spectrum of neglected physical disability, the GOI persisted with continuation of the speciality a nebulous attempt. With the realisation of the need to prevent morbidity in the highly technical integration now possible. UK now started specialisation in rehab medicine. PMR in India too do the same. New areas and technique must be explored.

The DGHS in his keynote address pointed out a MOU was signed between ILEP and GOI on 8th Feb 2005

for continuation of partnership from April 2005 to March 2007.

Besides 5 medical colleges in the country, Reconstructive Surgery will be continued in 41 hospitals and institutions, without any reimbursement from GOI. So, this Workshop came at an appropriate moment for PMR.

Dr. H. Srinivasan and Dr. Dinakar D. Palande, stalwarts in the field showed the PMR experts, how to go about. This needs prioritisation and referral facilities by NLEP in the prevention programme. Dr. B. D. Athani gave his view vis-a-vis CBR and PHC. The Committee on recommendations concisely pointed out 16 areas. This needs to be discussed in depth. PMR institutions should play a role in this.

It is unfortunate despite international organisations recommending alternatives, the much stigmatised word "leprosy", persists in every discussion in this area. True it may not make a difference now but to the generation next, may be. PMR should think about clinics for chronic ulcers, plantar ulcers, claw hand, intrinsic minus hand and such. The etiological stamping of the entity is better confined to the academic discussions if need be.

ALERT-INDIA rightly devoted time to bring to the notice of the less informed the state of art through this landmark workshop. It is sincerely hoped ALERT-INDIA thinks about the dynamic concept and plan a sequel to discuss, conclude and implement it.

19th January, 2006,
Mumbai.



Inaugural Session

Invocation

Welcome address - **Mrs. Veera Rao**, Director, Resource Mobilization Unit, ALERT- INDIA

Purpose of the Workshop - **A. Antony Samy**, Chief Executive, ALERT- INDIA

Inaugural Address: "Disability situation and the welfare schemes in Maharashtra"
Dr. P. P. Doke, Director of Health Services, Govt. of Maharashtra, Mumbai, Maharashtra

Background Paper : "Leprosy scenario in the country"
Dr. G. P. S. Dhillon, Dy. Director General of Health Services (Leprosy), Govt. of India, New Delhi

Guest Lecture : "Leprosy scenario in Maharashtra state"
Dr. S. C. Gupta, Jt. Director of Health Services (Leprosy), Govt. of Maharashtra

Release of 'TASK TODAY - Series No.2 - A LEAP Publication'

Keynote address by the Chief Guest : "Partnership between National Leprosy Eradication Programme and Physical Medicine and Rehabilitation institutions: New vistas"
Dr R. K. Srivastava, Additional Director General of Health Services, Govt. of India, New Delhi

Theme Paper : "Incorporating disability management and rehabilitation of leprosy-affected persons in the agenda of PM&R institutions and departments"
Dr. H. Srinivasan, WHO Consultant & Former Editor, Indian J. of Leprosy, Chennai, TamilNadu

Status Paper: "Leprosy disability situation in the country :Backlog and strategy for care in the integration phase"
Dr. P. K. Oommen, Director, Central Leprosy Training & Research Institute, Chengalpattu, Tamil Nadu



Purpose of the Workshop

Integration of leprosy services into P M & R - better today than never

Respected guests on the dais; Dr RK Srivastava, Addl. Director General of Health Services, Govt. of India; Dr GPS Dhillon, Dy. Director General of Health Services (Leprosy), Govt. of India; Dr PP Doke, Director of Health Services, Govt. of Maharashtra; Dr H Srinivasan, WHO Consultant; Dr BD Athani, Director, All India Institute of Physical Medicine & Rehabilitation; Representatives from PM&R institutions; Representatives from the national and international leprosy organizations; Medical colleges, research institutions, government units, municipal corporations; Representatives from leprosy organizations / institutions in Mumbai; Ladies and gentlemen,

Integration is a challenge !

ALERT-INDIA accepts this challenge and works towards actualization of objectives of integration. One of the main objectives is to integrate leprosy rehabilitation services into the General Health Care system. Had we designed deformity and rehabilitation services as an integral part of the mainstream of PM&R during the past 5 decades of vertical programme, we would have had specialist of specialist for leprosy in PM&R today. PM&R and other disciplines such as surgical, physiotherapy and rehabilitation would also have had capabilities necessary to meet the rehabilitation needs of all the leprosy patients in India. Had this happened, we would have specialists of specialists spread out across the country in both public and private hospitals.

What kept us away from such a policy that looks to us most rationale thing to do today?

First and foremost reason was, the reality of tradition driven social fear kept the victims of leprosy from seeking the services in the mainstream. Decades ago, the policy makers and programme pioneers opted for a vertical programme to meet the needs of over five million patients in the country. The main focus remained reduction of number and breaking the chain of transmission.

The huge task demanded special expertise and exclusive manpower. We must acknowledge this as it was a necessity of the times and a correct thing to do in a country like ours.

What prompted the change in the 5 decade old policy?

We were fortunate to have had effective drugs for short duration treatment in the last two decades. In the last two decades, we cured 11.5 million people afflicted by leprosy. Thanks to MDT and its multiple sponsors. 5 decades later today, we find it difficult to accept the wisdom that justified vertical programme that kept away the surgeons, physiotherapists and rehabilitation experts of the public health system.

Following integration, the large number of technical manpower in the vertical system is being discontinued for reasons of economy. Prevalence reduction has resulted in massive reduction of this manpower and the budget. It is today, we realize that we are still left with several unfinished tasks to combat the disease and its consequences with a small-specialized manpower. To tackle a large problem of disability management and care for leprosy patients - whose exact number is unknown - who are widely spread out in all corners of the country, we need a matching number of wide spread well trained manpower.

Where do we find them?

Instead of blaming the past, ALERT-INDIA through its Leprosy Elimination Action Programme – LEAP attempts to promote and complement the integration policy.

LEAP is aimed to make integration a reality for the people. Charged with this vision, instead of being laid back by the present predicament, LEAP calls upon every one to respond proactively to face the challenge. The need of the time is to look ahead and identify multiple strategic interventions to rectify the past and effect a change. We can move ahead only with participation of all the players from the field of surgery, physiotherapy and rehabilitation services, both in public and private health sectors. We have highly skilled specialists throughout the country who are capable of providing these services to leprosy-affected persons.



This capability can be built up easily, provided we perceive and pursue the need seriously.

It is the vertical policy that had kept them all away till now. The leprosy organizations have to accept the fact that we need to rally all the available resources for services to the leprosy affected today. Leprosy can no longer be a specialization of the leprosy specialist only. It has to become a partnership programme provided we are open to look at the potential that exist in our country. Today, we need to recognize that there is an opportunity to train and involve departments, institutions, body of surgeons, physiotherapists and occupational therapists in the country. We will miss the opportune time, if we fail to acknowledge and involve all specializations in the health sector. We must consider them all as our reliable ally for the future, in service of the leprosy affected.

Futuristic first step

This workshop on “Integration of Leprosy Rehabilitation Services into the Mainstream of Physical Medicine and Rehabilitation” in collaboration with the All India Institute of Physical Medicine and Rehabilitation (AIIPM&R), Mumbai is a very small first step towards achieving a greater partnership needed in the future.

Such a partnership should not stop with joint Workshops alone and should practically change the way we look at the issues and act till the goals of integration is achieved.

ALERT-INDIA records its due appreciation to AIIPM&R, Mumbai for accepting this partnership venture and taking this futuristic first step. We hope this joint step can pave way for many more debates, discussions and eventual policy change and necessary action needed in our country. We are also glad that many key players from the PM&R, Medical education and other disciplines are attending this landmark workshop in response to our invitation. It is your participation in the Workshop and its deliberations that can make a difference. It is you who can effect a change in your respective areas of your discipline and institution. ALERT -INDIA is confident that we can collectively bring about a change. The recommendations we will make today, at the end of

this workshop, can definitely influence the policies and bring about changes in the curriculum and subsequent practice.

We are convinced of this, by the virtue of the fact, that today we have with us all concerned authorities from the Centre, State Governments and their institutions willing to deliberate on the subject. We also have a representation from the wide spectrum of leprosy world to interact with them.

Mainstream of PM&R

This Workshop today is not about mainstreaming of leprosy services. It is about integrating leprosy by incorporating rehabilitation services into the mainstream of PM&R. It is time, we acknowledge this fact. We also need to acknowledge all physiotherapy, rehabilitation institutions and services are also part of the PM&R mainstream.

This alone can pave way for a long-term change. It is leprosy that has been away from the mainstream for the reasons I stated in the beginning. This recognition can go a long way only if we work towards to bring about a change in the teaching curricula of the mainstream disciplines. Taking cognizance of this is the need of the hour. This workshop should initiate a new thought process and change our mind set.

This workshop looks forward to a new policy frame both from leprosy and the PM&R. This workshop also looks forward to a consensus on the need for a new curriculum change in PM&R and in all allied disciplines. All players participating in the workshop can effect and complement the process initiated today.

Let us together make this small beginning today, a stepping-stone for a larger change tomorrow !

A Antony Samy
Chief Executive
ALERT - INDIA



Disability situation & welfare schemes in Maharashtra

Dr. P. P. Doke

Director of Health Services, Govt. of Maharashtra

The State of Maharashtra came into existence on 1st May, 1960. It is made up of 35 districts with a population of 96,752,247 and area of 307,713.00 sq. km. It is the second largest state of India in terms of population. Because of its geographical location, Maharashtra exhibits the features of a cultural mix of the north and the south which is reflected in the ethnic groups in the population, their habits, rituals, customs and language. This makes the state rich in its social and cultural heritage. Maharashtra makes a significant contribution to the Nations political, social and economic development.

Disability Situation in Maharashtra

With the help of health, education & ICDS department assessment of disabilities due to various causes in the state has been made. According to this assessment, highest are orthopaedic disabilities (56%) followed by visually handicaps (16%), ENT/deaf & dumb disabilities (13%) & mental & others are about 15%.

Deformities in leprosy

As per WHO guidelines only Gr II deformities are reported in leprosy. Various deformities are occurring in leprosy which include Claw-hand, wrist-drop, ulcers, absorption of digits, thumb-web contracture, hollowing of the interosseous spaces and swollen hands, Plantar Ulcers, Foot-drops, inversion of the foot, clawing of the toes, absorption of the toes, collapsed foot, swollen foot, & callosities, Logophthalmos, loss of eye brows/eye lashes, Corneal Ulcers & opacities e.g. nodules on the ear and elongated lobules.

Benefits available under Prevention of Disability Act 1995

“Leprosy Cured Person” is included in the definition of disable person. The act defines “Leprosy Cured Person” as any person who has been cured of leprosy but is suffering from :

- i) Loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eye-lid but with no manifest deformity,
- ii) Manifest deformity and paresis but having sufficient mobility in his hands and feet to enable him to engage in normal economic activity,
- iii) Extreme physical deformity as well as advanced age which prevents him from undertaking any gainful occupation.

At the same time act defines “Person with Disability” as a person suffering from not less than 40% of any disability as certified by a medical authority.

Welfare Schemes available in Maharashtra

This includes following benefits in addition to benefits available under Prevention of Disability Act 1995 :

1) Sanjay Gandhi Niradhar Yojna : This scheme is implemented since 1980 in Maharashtra State. The main purpose of this scheme is to give financial help to disable person, old, blind, mentally & physical handicap persons. Every beneficiary is given financial help of Rs.250 per month under this scheme. This scheme is implemented by social-welfare department all over Maharashtra. The benefit of the scheme is given to eligible females below 60 years & males below 65 years.

2) Financial Help : Financial help from Rs.500 to 1000 given to disabled cured leprosy patients for business or self employment in the form of material & machines. This help is provided in kind viz. supplying sewing machine, raw material for production of chalks, electric winding, watch repairing etc. This scheme is being implemented by social-welfare department.

3) Bank loan : Disabled persons are given financial help for their business as a capital. The disabled persons are given cash loan of Rs. 25,000/- of which 80% is to be refunded with 20% subsidy for self employment,



supplementary business, farming etc. This scheme is being implemented by social-welfare department through Bank loan.

4) Indira Awas Yojna : The benefit of this schemes is given to the people of SC,ST & people below poverty level in terms of grant for construction of new houses & for repairing of old houses by Govt. of Maharashtra.

5) Help from other dept. : The benefits like travel concession for ST/ Railway, to issue identity card for benefit given to disabled persons.

6) Vocational Training : Vocational training like iron-smith, carpentry, hair cutting saloon, dairy, printing press etc. are given to leprosy patients to earn and become economically self sufficient.

7) Recommendations of Kushthapitid Samasya Nivaran Samiti : This samiti was established by Govt. of Maharashtra in Oct. 2002 to look into the problems of leprosy afflicted persons residing in self settled colonies of Maharashtra (34 colonies in 13 dists.) The final recommendations of this samiti submitted to the Govt. for further action are as follows:

- i) All self settled colonies in the state established before 1995 are to be given the benefits of Valmiki Ambedkar Awas Yojana and Maharashtra Slums Act. 1971 which includes issuing BPL cards, photo passes, construction of new houses and renovation of existing houses.
- ii) Municipal Commissioners of respective Municipal Corporations should review on priority whether the residents are getting benefits under the above act.
- iii) Govt. of Maharashtra Cabinet to consider the issue of reservation of Govt. and Semi-Govt. jobs to wards of leprosy persons under the 3% reservation available under PWD act 1995.
- iv) Self employment department of Govt. of Maharashtra to plan special guidance sessions for the leprosy cured persons and their dependants.
- v) Wards of leprosy afflicted persons to be given scholarships, concession in fees in professional colleges as available for children of backward communities.
- vi) Families of leprosy afflicted to be given benefits of Antyodaya Anna Yojana
- vii) All municipal corporations to give jobs to leprosy afflicted on priority considering their eligibility.
- viii) Modification of GR of Public Health Dept. regarding hospital fees ensuring that no charges

have to be paid by leprosy patients for whatever hospital services they need from all Govt. and Semi-Govt. hospitals.

- ix) Amendment of GR of Social Justice Dept. regarding cancellation of age, precondition of wards of leprosy patients as regards the benefits under Sanjay Gandhi Niradhar Yojana

Services Provided by Govt. / NGO to Disabled Leprosy Patients :

- 1) **Reconstructive Surgery :** Eligible deformed leprosy patients are operated for deformity correction by performing reconstructive surgery free of cost. Surgery is performed in all civil hospitals, medical colleges, Acworth Leprosy Hospital Mumbai, Nanded Leprosy Mission Hospital, Kothara, Bandorwala Leprosy Hospital Pune, Vimla Dermatology Center Mumbai, free of cost.
- 2) **Supply of MCR Chappals :** MCR Chappals are supplied to needy leprosy patients for protection from wounds or cuts to aesthetic foot of leprosy patients or patients already having ulcers. Funds for MCR Chappals are provided by District Leprosy Society.
- 3) **Supply of Goggles:** Goggles are supplied to needy leprosy patients having eye deformity like iritis, iridocyclitis patients having continuous tears in their eyes. The grants for goggles are given by District Leprosy Society.
- 4) **Supply of Splints:** Splints are given to needy leprosy patients having claw hands. The grants for splints are given by District Leprosy Society.
- 5) **Ulcer Treatment:** Ulcer treatment is given to eligible patients according to the need in all Govt. Hospitals, PHCs, Municipal dispensaries free of cost. These services are also given in self settled colonies.
- 6) **Physiotherapy:** Physiotherapy services are given free of cost to eligible leprosy patients having deformity or not to develop deformity, in all Govt. Hospitals. These services are also given in self settled colonies.
- 7) **Rehabilitation of Cured Leprosy patients by NGO :** There are 16 NGOs working for rehabilitation of cured leprosy patients having total capacity of 2075 beds. Govt. of Maharashtra is giving grant-in-aid at the rate of Rs. 450 / month / bed.

Similarly there are 18 NGOs working on hospital pattern. The total bed strength of these NGOs is 3171 beds. Govt. of Maharashtra is giving grant-in-aid at the rate of Rs. 480 / month / bed.



Leprosy scenario in the country

Dr. G. P. S. Dhillon

*Dy. Director General of Health Services (Leprosy),
Govt. of India, New Delhi*

India was one of the endemic countries of the World, which could not attain the WHO's goal of leprosy elimination, i.e. to reduce the prevalence of leprosy less than 1 case per 10,000 population by the year 2000. With the wide coverage of multidrug therapy (MDT), all over the country, the leprosy elimination has become an achievable goal by the end of December 2005. The prevalence of leprosy in 1981 was 57 per 10,000 population and after MDT came into wide use since 1983, the PR has dropped down to 1.1 as on August 2005. The country's fight against leprosy is a combined effort of Govt. of India (GOI), the State Governments and a number of partners. Reaching the goal of elimination at the national level in itself is not the end of the problem of leprosy in the country.

Milestones of NLEP

- 1955 - Government of India launched National Leprosy Control Programme
- 1970s - Definite cure through MDT was identified
- 1982 - WHO study group recommended use of MDT and Government of India launched National Leprosy Eradication Programme (NLEP) and introduced MDT
- 1991 - WHO declaration to eliminate leprosy at global level by 2000.
- 1993 - 2000 - World Bank supported NLEP - I
- 2001 - 2004 - World Bank supported NLEP - II
- 2005 - 2007 - NLEP to continue till 2007 with GOI support.

The National Health Policy - 2002 of Govt. of India has adopted the goal to achieve elimination of leprosy at national level by December 2005.

Major initiatives of NLEP

Several major initiatives were taken up by NLEP during the 2nd Phase of World Bank project towards achieving the goal of leprosy elimination in India with the following strategies:

1. Decentralization of NLEP to States & Districts
2. Integration of leprosy services with General Health Care System
3. Leprosy Training of GHS functionaries
4. Surveillance for early diagnosis & prompt MDT, through routine and special efforts
5. Intensified IEC using Local and Mass Media approaches
6. Prevention of Disability & Care
7. Monitoring & Evaluation on regular (Monthly / Quarterly / Annually) basis as well as with special efforts such as Independent Evaluation, Leprosy Elimination Monitoring (LEM), Annual Survey and Validation of progress towards leprosy elimination.

Partners in NLEP

The NLEP works with several partners comprising of State Governments, WHO, ILEP agencies and NGOs and encourages them to play key roles on various



leprosy elimination activities in the country. All partners have indicated their willingness to continue the support till elimination goal is achieved. The following are the details of assistance provided through partner agencies:

- Govt. of India provides 100% [Centrally Sponsored Programme] financial assistance for training, IEC and operational support to State Govt. through provision of health infrastructure and technical manpower.
- WHO, Sasakawa Memorial Health Foundation, The Nippon Foundation & Novartis provides support for technical manpower, drugs and evaluation of programme.
- ILEP agencies provide support with districts technical support teams training of district nucleus staff and facilities for Reconstructive Surgery.
- Local NGOs provides services under Survey Education and Treatment (SET) Scheme for prevention deformities and care of patients.

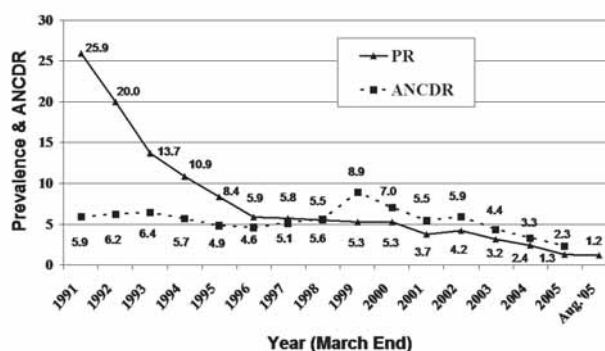
Current epidemiological situation of NLEP

Prevalence rate has declined to 1.34 leprosy cases / 10,000 population as on 31st March 2005 compared to 2.44 as on 31st March 2004. Disability among new cases was about 20% when NLEP was started in the year 1983-84, which has brought down to 1.6% in the year 2004-05.

24 States/ UTs have achieved the level of leprosy elimination i.e. PR <1 case 10,000 population and they include: 1.Nagaland, 2.Haryana, 3.Meghalaya, 4.Himachal Pradesh, 5.Mizoram, 6.Tripura, 7.Punjab, 8.Sikkim, 9.Jammu & Kashmir, 10.Assam, 11.Manipur, 12.Rajasthan, 13.Kerala, 14.Arunachal Pradesh, 15.Daman & Diu, 16.Andaman & Nichobar Islands, 17.Pondicherry, 18.Karnataka, 19.Gujarat, 20.Tamilnadu, 21.Lakshadweep, 22.Andhra Pradesh, 23.Uttaranchal and 24.Madhya Pradesh.

Another 4 States/UTs are very near towards this goal of leprosy elimination i.e. (PR between 1 and 2). These are 1.Bihar, 2.Maharashtra, 3.Uttar Pradesh and 4.Goa.

Trend of Leprosy Prevalence & Annual New Case Detection (ANCD) Rates in India



Year-wise endemicity status of States

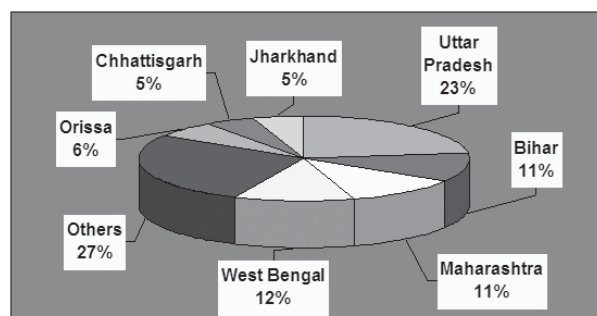
Endemicity (PR/10,000)	No. of States				
	2001	2002	2003	2004	2005
< 1	13	12	15	17	24
1 – 2	4	3	6	7	4
2 – 5	13	14	9	9	7
5 – 10	4	2	5	2	0
> 10	1	4	0	0	0
Total	35	35	35	35	35

Year-wise endemicity status of Districts

Endemicity (PR/10,000)	No. of Districts				
	2001	2002	2003	2004	2005
< 1	171	181	212	250	337
1 – 2	82	80	88	105	131
2 – 5	179	156	172	163	118
5 – 10	91	108	90	68	8
> 10	40	51	28	4	1
Total	563	576	590	590	595



Of the total recorded leprosy cases as on 1st April 2005, 73% cases been contributed by 7 states as shown hereunder:



Comparative progress in seven key endemic States

States	PR as on		Districts achieved elimination as on	
	Mar 04	Mar 05	Mar 04	Mar 05
Bihar	4.97	1.81	0	2
Chhattisgarh	5.91	3.60	0	3
Jharkhand	4.38	2.68	0	0
Maharashtra	2.87	1.57	0	7
Orissa	3.49	2.14	1	7
Uttar Pradesh	3.52	1.86	9	11
West Bengal	3.06	2.11	5	7

Present initiatives of NLEP

The GOI has decided to carry on the NLEP as at present till the end of the 10th plan period i.e. 31st March 2007. The following are the initiatives which will help to maintain the activities without any laxity in quality and quantity.

- Formation of district nucleus in all districts. Training for all the district nucleus staff is in hand with support from ILEP organizations.

- The learning material for Medical Officer's training has been updated and supplied to all the states with ILEP support. Learning material for other categories of GHS staff are in the process of updating.
- Under NLEP-2005, one day re-orientation of all the Medical Officers in 552 blocks is being conducted. This one day re-orientation to be made a regular practice covering all other PHCs under the programme.
- IEC activities have been considerably increased with provision of nearly 30% of the NLEP budget during the current year. IPC is given higher priority.
- The States/ UTs have been advised to develop a referral system involving the district hospitals for diagnosis and management of difficult cases.
- Training to GHS staff on POD care and also self care practices to patients under treatment is being imparted through the POD camps being organized at block level.
- ILEP has agreed for capacity building to facilitate RCS in five Medical Colleges during the current year. Process already completed in Patna Medical College, Patna, Bihar.
- Supervision and monitoring of the programme activities have been suitably increased during the current year.



Partnership between National Leprosy Eradication Programme (NLEP) and Physical Medicine & Rehabilitation Institutions (PMR): New Vistas

Dr. R. K. Srivastava

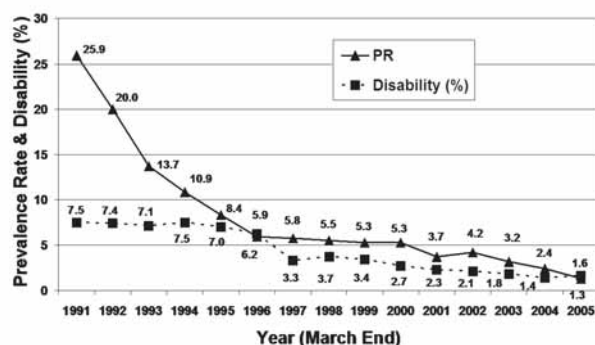
*Addl. Director General of Health Services,
Ministry of Health & Family Welfare, Govt. of India, New Delhi*

The National Leprosy Eradication Programme – Background:

With the introduction of Multidrug Therapy (MDT) as a tool to cure leprosy, the Govt. of India re-designated the National Leprosy Control Programme (NLCP) as National Leprosy Eradication Programme (NLEP) in 1983. In view of substantial progress achieved with MDT, the WHO in 1991 resolved to eliminate leprosy at the global level by the year 2000. The prevalence rate in 1983 was 44.73 per 10,000 population and it was brought down to 1.34 as on March 2005. None of the state had achieved the goal of leprosy elimination till the year 1997-98. Nagaland was the first state to achieve elimination in 1998-99. As of now, 24 States/UTs have achieved the goal of leprosy elimination.

Magnitude of disability:

Leprosy is known to cause physical deformities and subsequently lead to social dismay. During the year 1983-84 around 20% of new cases are detected were having Grade-II deformity. In the year 2004-05 this proportion has come down to 1.6%. During the last 21 years a total of 0.73 million patients were recorded with Grade-II deformity under the programme. At present, every year approximately 4000 new cases are being detected with Grade-II deformity.



Trend of leprosy prevalence and disability rate in India:

Out of 4144 new cases detected with visible deformities from 25 States / UTs, 2515 (60%) cases were reported from 6 states during 2005. Remaining 10 states did not record any disability.

State / UT	New cases with disability (Gr - II)	%
Bihar	345	8.3
Chhattisgarh	327	7.9
Maharashtra	425	10.2
Orissa	391	9.4
Uttar Pradesh	594	14.3
West Bengal	433	10.4
Total	2515	60

Disability specific activities under NLEP

Under the 2nd Phase of World Bank supported project, NLEP has implemented well-planned activities in association with various NLEP partners. The following activities are promoted by NLEP :

- Conducted POD camps at 'Block' level.
- Training of PHC Medical Officers also covers "Disability and its management".
- MCR procured by District Leprosy Societies for needy patients.
- ILEP organizations also supply MCR footwear from their institutions.
- Reconstructive Surgery (RCS) is being carried out by NGO institutions funded by International



Federation of Anti-Leprosy Associations (ILEP) on their own since long.

GOI used to reimburse Rs. 2500/- per major RCS to 30 recognized NGO institutions till December 2004 under World Bank assisted project. This scheme has been now stopped. However, ILEP organizations agreed to continue RCS through 41 institutions from April 2005 to March 2007. During 2nd NLEP project period (2001-04), RCS were carried out in 13,789 leprosy patients, i.e. about 3500 cases per year.

Substantial amount of programme funds (25% approx.) is spent on Information, Education & Communication (IEC) campaigns. Messages aimed at spreading awareness about leprosy, its curability with MDT, early detection & treatment to prevent the deformity and free availability of Medicine from all Govt. institutions.

Memorandum of Understanding with International Federation of Anti-Leprosy Associations (ILEP)

ILEP is one of the main partners in India's effort to eliminate leprosy and 10 international organizations working for leprosy under the banner of ILEP. A Memorandum of Understanding (MOU) was signed between ILEP & GOI on 8th February 2005 for continuation of partnership from April 2005 to March 2007. Among other activities, ILEP had agreed to provide support towards reducing leprosy disability and assist in establishing Reconstructive Surgery Services at five Medical Colleges in the country.

1. Patna Medical College, Bihar
2. Ranchi Medical College, Jharkhand
3. Bhopal Medical College, Madhya Pradesh
4. SCB Medical College, Cuttack, Orissa
5. King George Hospital, Lucknow, U.P.

Besides this, the RCS will be continued in the ILEP sponsored 41 Hospitals and Institutions without any reimbursement from GOI.

GOI has also identified 4 Central Govt. leprosy institutions responsible for undertaking RCS in their region.

1. CLTRI, Chengalpattu (Tamilnadu)
2. RLTRI, Raipur (Chhattisgarh)
3. RLTRI, Aska (Orissa)
4. RLTRI, Gauripur (West Bengal)

Map : ILEP Institutions - 41 ILEP institutions having existing facilities.



It is also proposed that the 46 Physical Medicine & Rehabilitation (PMR) Institutions can be involved for providing RCS to leprosy disabled persons.

Map : State wise No. of Medical Colleges / Tertiary Institutions with PMR services



11th Five Year Plan Period

The NLEP will remain as a 100% centrally sponsored scheme from December 2004 and it is envisaged that Prevention of disability and also reconstructive surgery services should be given more priority. It is proposed that the number of institutions for RCS should be increased, which include:

- 4 Central Govt. institutions
- 41 ILEP institutions
- 46 PMR institutions
- Medical Colleges (Identified and trained)

It is also suggested that the State Leprosy Societies to ensure up gradation of facilities and capacity building of these institutions for conducting RCS operations.

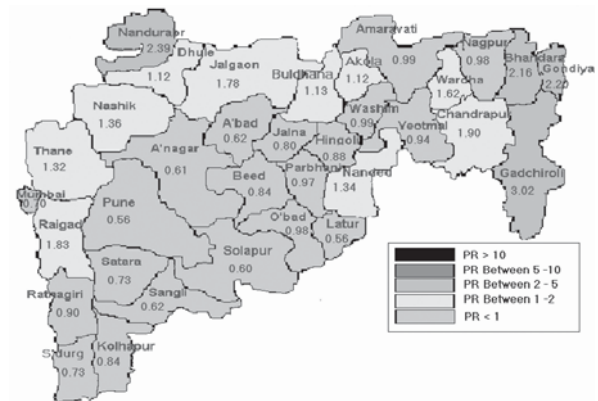
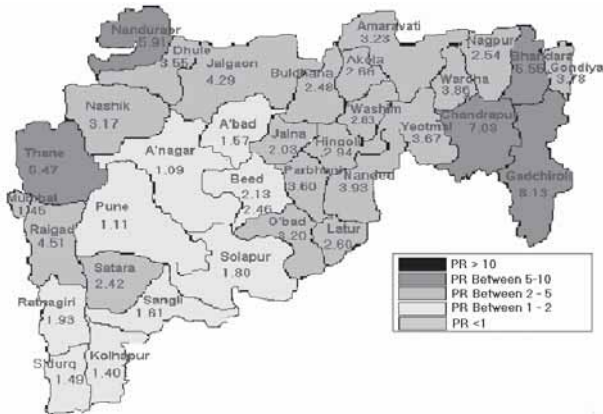


Leprosy scenario in Maharashtra State

Dr. S. C. Gupta

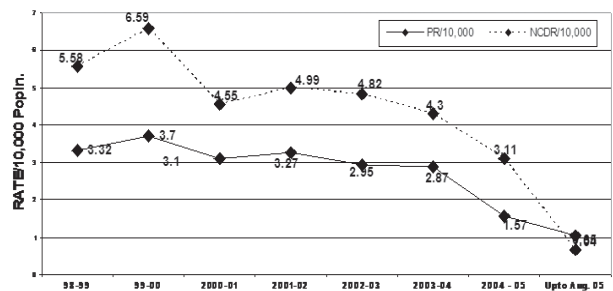
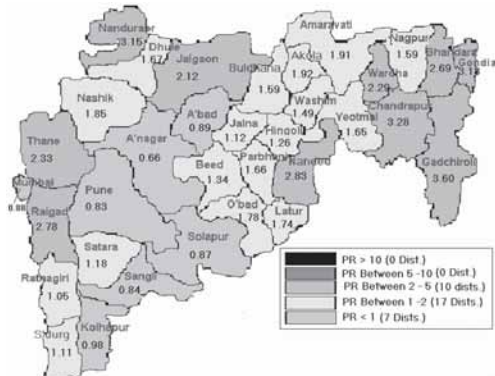
*Jt. Director of Health Services (Leprosy),
Govt. of Maharashtra, Pune*

Maharashtra State is one of the 7 endemic States, which contributes 11 % of the case load in the country as on March 2005. The PR of the State is 1.57 as on March 2005. The rate of decline (PR & NCDR) in the State is similar to the PR of the country. The current PR is 1.04 as on August 2005.



Based on the past record, the Govt. of Maharashtra proposes to achieve the leprosy elimination target at the State level by the end of December 2005 and at the district level by the end of March 2007.

The process of Integration began in April 2004 and the MDT services are made available at all PHCs and UHPs in the State. As on August 2005, there were 10,941 active cases under treatment. The NCDR has declined from 4.99 in March 2001 to 3.11 in March 2005.





Indicator	Achieved			To be achieved		
	3/04	3/05	8/05	12/05	3/06	3/07
PR/10,000	2.4	1.8	1.04	<1	<1	<1
Dist. achieving goal	44.2%	50%	58.7%	60%	65%	80%
NCDR/10,000	3.3	300	0.65	2.8	2.5	2.0
MB %	39	41	44.35	43	45	48
Disability %	1.4	1.3	0.96	1.2	1.1	1
Female %	35	38	41.11	40	44	45

By the end of August 2005, only 4 districts are having a PR between 2 – 5 (1.Gadchiroli, 2.Nandurbar, 3.Gondia and 4.Bhandara and 10 districts (1.Chandrapur, 2.Nanded, 3.Raigad, 4.Wardha, 5.Jalgaon, 6.Thane, 7.Dhule, 8.Nasik, 9.Buldhana and 10.Akola) are having a PR between 1 – 2 per 10,000 population. The remaining 20 districts are having a PR less than 1 per 10,000 population.

Among the 14 endemic districts, 51 blocks were identified having high PR and special efforts are being

taken to intensify the activities in order to reach the goal of leprosy elimination.

The programme has also covered all the 15 tribal areas although the PR is higher as compared to PR among the non-tribal areas of the State. Since the beginning of Phase 2 of NLEP project, training programmes were also undertaken to all the GHC personnel on POD activities and conducted 710 POD camps at the PHC level.

Dists	Dist. Level trainers trained	Block POD camps		Patients training			GHC Staff Trained			
		Planned	Executed	M	F	Total	MO	HS	HWs	Total
34	69	710	710	9155	4398	13553	975	2268	4220	7483



Physical rehabilitation activities were also undertaken by the Govt. of Maharashtra with the help of NGOs in the State. The details of services are as follows.

Years	Reconstructive Surgery	Distribution of MCR Chappals	Distribution of Goggles	Distribution of splints	Treatment of Trophic Ulcers	Physio Therapy
1999-2000	428	8014	673	2899	27670	23548
2000-2001	1009	7499	3619	313	39968	140743
2001-2002	1155	5999	815	1897	28517	19161
2002-2003	1060	4508	655	2298	29844	45137
2003-2004	1572	6449	933	5805	56203	51928
2004-2005	759	7123	984	3860	41665	34417
2005 (June 05)	115	1155	232	605	4213	5369

Besides, the Govt. of Maharashtra has also extended socio-economic rehabilitation assistance to leprosy cured persons and the details of services are as follows.

Years	Sanjay Gandhi Niradhar Yojana	Financial Support	Bank Loans	Indira Awas Yojna	Help from other depts	Any other help	Vocational Training	Health Education
1999-2000	6542	631	275	507	509	6123	1005	76941
2000-2001	467	178	151	298	662	370	411	178382
2001-2002	1296	629	119	170	967	743	677	490846
2002-2003	1029	319	52	72	188	222	1023	226636
2003-2004	1377	3556	29	274	173	1021	339	310709
2004-2005	3921	4252	101	877	8130	1043	700	222799
2005 (June 05)	855	8	20	152	5	447	2	11644



Incorporating disability management and rehabilitation of leprosy-affected persons in the agenda of PMR (Physical Medicine and Rehabilitation) institutions and departments

Dr. H. Srinivasan

*Senior Orthopaedic Surgeon &
Member, WHO Expert Committee on Leprosy*

Distinguished delegates, dear professional colleagues and fellow workers in rehabilitation and leprosy, ladies and gentlemen,

1. Let me at the outset thank the organizers of this National Workshop, the authorities of ALERT-India and AIIPMR, for giving me the privilege and pleasure of participating in this important workshop and placing some of my views before you for your consideration.
2. I congratulate ALERT-India and AIIPMR for holding this workshop on an issue, which, to the best of my knowledge, has not ever been discussed in any forum in the 43 years of my life in leprosy. But, there are reasons for that. I will revert to that in the second part of my talk. First, let me give you an overview of what is expected of us regarding disability management and physical rehabilitation of leprosy-affected persons.
3. A proportion of leprosy-affected persons continue to need help, periodically, from the medical services, for the rest of their lives, although they have been completely cured of their disease. This proportion is not large but significant, especially now because of accumulation of a large number of backlog patients. There are reasons for this situation.
4. During the course of their disease, a proportion of patients suffer damage to one or more of their peripheral nerve trunks of the extremities. Sometimes the face is also similarly affected. Their eyes may also develop recurrent or chronic iridocyclitis and other complications unrelated to leprosy as such. These are persistent problems and they often give rise to other serious other secondary impairments.
5. These impairments in turn give rise to deformities and disability. In many cases, the combined stigma of leprosy and disability proves to be a formidable handicap to the affected persons, causing their progressive devaluation and exclusion from family- and societal affairs leading to their debilitation and even destitution.
6. We, therefore recognize that leprosy-affected persons need, besides cure of their disease, prevention of worsening of their deformities and improvement of their disabilities to enable them carry out their activities at home and at workplace and also social acceptance to ensure their social status and economic security.
7. I have put the above in the order of priority as we in the medical profession see it. It is well to remember that patients have their own priorities, which often differ from those of ours. From their point of view, social acceptance and socio-economic security has the highest priority and “cure” of the disease has relevance to them only in that context, since they are not, usually, very much disabled or disturbed physically by the disease as such until late in the course of the disease. The leprosy patches don't even itch !
8. Damage to the sensory nerves of the limbs causes loss of sensibility, particularly in hands and feet. In some individuals, eyes may lose corneal sensibility. Damage to motor nerves of limbs, usually below the elbow or below the knee, gives rise to paralysis of intrinsic and / or extrinsic muscles of hands and feet. Sometimes, the eyelid muscles become weak or paralysed.



9. These results of nerve damage have certain consequences. The anæsthetic hands and feet get damaged as they come into forceful contact with the external world and the damage is neglected because of lack of pain, which is the “damage recognition mechanism and warning system” of our body. Continuance of this state of affairs leads to the development of a variety of serious secondary impairments collectively known as “anæsthetic deformities”. In late stages, the affected part becomes a useless liability and may even be lost. The eyes may be similarly affected with the patient ending up with blindness.
10. The paralytic deformities of leprosy, which are consequences of motor nerve damage, are well-known. They include partial or complete claw-hand, drop-foot, claw-toes and lagophthalmos.
11. It is worth noting here that, whereas anæsthetic deformities are more easily prevented than corrected, it is the other way round regarding paralytic deformities. The former are avoided by protecting the anæsthetic parts from injuries, and taking care of the injuries without delay. On the other hand, we have standard and time-tested procedures for correcting the paralytic deformities of leprosy.
12. Nevertheless, leprosy wards are filled with patients having advanced secondary impairments consequent to acral anæsthesia. This is not because we do not know how to avoid their occurrence or worsening. The reason is the asymmetry in the location of the problem and its solution. The affected persons have the problem; but the solution namely, the relevant knowledge of preventive practices is available with the medical sector. What is needed is the solution to be located where the problem is, i.e., the affected persons, their families and well-wishers.
13. Correction of this asymmetry requires that the technology of prevention of secondary impairments be transferred from the medical sector to the patients, their families, in a planned manner. Secondly, the medical sector should at the same time actively support patients’ efforts by providing easy access to specialists’ services and necessary supplies.
14. In this context of disability prevention, “technology transfer” primarily involves counselling and training. In order to be successful, the efforts of affected persons should be monitored and corrected as and when necessary besides supporting them with necessary supplies and specialist services.
15. Counselling and training (the affected persons to carry out the activities of daily life at home and at workplace, safely despite having insensitive extremities) has three purposes: 1) to restore and enhance the self-esteem of affected persons, 2) to make them realise the full significance of having insensitive hands, feet and eyes (with or without muscle paralysis) and learn how to live with these disabilities without damaging the affected body parts; and 3) to practice in daily life what they have learnt. In other words, counselling and training is needed to empower the affected persons learn to lead a life applying the disability prevention methods that they have learnt. In this context I must stress that mere admonition and handing out clichés and impossible advices like “don’t touch hot objects” and “don’t walk” are counterproductive. The message is lost as the patients simply ignore them as trite, impractical or plain stupid.
16. In order to derive full benefit from practice of disability prevention, it is essential that the patients receive, besides counselling and training, support from the medical sector by way of supplies and expert assistance. The supplies include protective footwear for those with insensitive feet, physio- and occupational therapy for those with muscle paralysis and splints and orthoses for those with deformities. Further, medical help and corrective or rehabilitation surgery for treating their physical problems that cannot be managed at their own homes or peripheral medical facilities should be made available.
17. The most common conditions that would demand our attention are chronic or frequently recurrent plantar ulceration, paralytic drop-foot, disorganized denervated foot, and paralytic claw-hand with varying degree of stiffness. I shall briefly touch upon these conditions indicating what is expected of us.



18. Plantar ulceration, often referred to as “trophic ulcers”, and sometimes as “perforating ulcers”, is the most common condition for which patients desperately seek relief. They are also the most common cause of morbidity in leprosy-affected persons. If we can relieve the patients of this problem we would have solved the problems of more than 75% of leprosy-affected persons.
19. When the posterior tibial nerve is damaged, and this nerve is the second most commonly damaged nerve in leprosy patients, the “tissue damage warning system” of the foot is lost because of loss of pain sensibility in the sole. In addition, the plantar intrinsic muscles, which are supplied by this nerve, are also paralysed and the foot is structurally weakened. The foot thus rendered weak and defenceless is unable to bear the normal stresses and strains of walking and it breaks down at its most vulnerable part, the subcutaneous fat pad, initiating a process of ulceration. If we remember that the foot with damaged posterior tibial nerve is actually a weight-bearing anaesthetic stump that has the shape of a foot, we will understand the patient’s predicament and the seriousness of the problem.
20. That does not mean that ulceration of such feet is inevitable. These ulcers are eminently preventable with diligent practice of “foot care”. There is also a feeling of hopelessness among many medical personnel that they are difficult if not impossible to heal and that even if one manages to heal them, they will invariably recur. I can assure you on the basis of my experience that one can heal almost all cases of plantar ulceration. And their recurrence can be avoided with simple precautions in more than 80% of ulcers. I am saying only 80 % in view of the backlog cases, the old veterans with severely damaged feet. We can achieve prevention in almost all the others. More importantly, as rehabilitation specialists, we have the expertise in this area and the needed technological support is also there. This is our job and we need only the will to take up this problem as a challenge to our expertise in order to achieve success.
21. The other fairly common problem you may have to tackle is drop-foot due to common peroneal nerve paralysis. Tibialis posterior transfer, a relatively straightforward procedure within the competence of any one with average surgical ability and is easily done under local infiltration anaesthesia, satisfactorily corrects mobile drop-foot. Orthoses is not advised as a permanent solution for drop-foot in leprosy-affected persons, as tibialis posterior is always available for transfer in these persons. Secondly, surgery provides a permanent solution eliminating the need for periodic repair and renewal of an orthosis. An appropriate type of triple arthrodesis to provide a plantigrade foot is the solution for long-standing, neglected drop-foot in which the foot has become stiff in the plantarflexed and inverted position (acquired equino varus foot).
22. The denervated disorganized foot (somewhat as in Charcot’s neuroarthropathy) is managed conservatively, in the true sense of that term, with the aim of conserving the foot for as long as possible while keeping the patient ambulant. The treatment consists of repeated POP casting, graded weight bearing in custom made footwear or orthosis and carefully selected surgery for stabilizing the foot. Amputation is postponed for as long as possible; for, it is not a real solution for those with anaesthesia of the leg. In such persons, by amputation, even if it is below-the-knee variety, we are only shifting the problem of ulceration to a more difficult proximal level. I will recommend B-K amputation in patients with denervated feet either for saving their lives or if the patient will be better off after amputation even without having a prosthesis. If one has to amputate, do it as far distally as possible. One can do trans- metatarsal, Syme’s or Boyd’s or a similar conservative amputation, when that is possible, rather than B-K amputation.
23. From time immemorial leprosy has been viewed with anxiety, fear and disgust as it was considered as divinely ordered, capriciously contagious, hideously deforming and hopelessly crippling disease. Leprosy patients were thought of as carriers of this scourge. They were shunned, segregated, isolated, expelled from normal society and even exterminated. Thus the public health aspect of the disease has loomed large in societal perception and victims of leprosy have always been thought of as danger to the public rather than as persons having a difficult disease needing compassionate consideration.



24. The situation regarding curability of leprosy took a dramatic turn for the better when dapsone was discovered to be an effective anti-leprosy drug during the mid 1900s. It is noteworthy that an enthusiastic and ambitious anti-leprosy campaign based on domiciliary dapsone treatment was started at the earliest opportunity as a public health programme. This programme sought to minimize the danger of spread of leprosy by using dapsone to treat as many leprosy patients as possible, for as long as possible. The avowed aim of this National Leprosy Control Programme was to render the patients smear-negative for *M. leprae* so that they cease to be a danger to the community at large. Thus leprosy-affected persons became the “property” of public health departments and managing the disease in general and providing chemotherapy to these persons in particular became the responsibility of public health officials under the National Leprosy Control Programme. This suited the medical profession as well for they could now continue to ignore leprosy as a medical problem with clearer conscience. This “non-involvement with leprosy” was not confined to treating leprosy as such, but it also extended to treating its complications like deformities of hands and feet, plantar ulceration and neuropathic disorganization of the foot although these conditions required specialist attention. Thus, the expertise in dealing with these problems also developed outside the main stream of medicine, as unavoidable extraneous fringe developments within the vertical leprosy services and not as developments in appropriate specialities like orthopaedics, plastic surgery, hand surgery, physical medicine and rehabilitation.

The discovery of rifampicin as a very potent mycobactericidal drug gave further fillip to the leprosy programme, which blossomed into the National Leprosy Eradication Programme in 1980s. The success of rifampicin-containing drug multidrug regimens in obtaining maximum bacterial kill within a very short time persuaded the World Health Assembly to declare, in 1991, “elimination of leprosy by the year 2000” as the global goal of all national leprosy programmes. We expect to reach that goal at the national and at many sub national levels before the end of this year. Already, more than 12 million leprosy

patients have been cured under our National Leprosy Elimination Programme. The vertical leprosy programme has become highly uneconomical because of the drastic reduction in the number of persons needing anti-leprosy treatment by a factor ten or even more. In many States, therefore, the vertical set up has been disbanded and the responsibility for management of leprosy and its complications has been shifted to the general medical services and health facilities. Now, the leprosy programme comes under the patient care programme; and we in the general medical services have to tackle these problems.

25. This “patient care approach” differs fundamentally from the ‘Public health approach’ that has governed leprosy management all these years. Public health programmes are mass programmes having the aim of protecting the public and they strive to benefit maximum number of persons possible with the resources available. Further, they are field-oriented programmes, often seeking and going to the beneficiaries. Lastly, because of that reason they also work under many constraints, like minimal, poor or non-existent support services. Patient care services function on “service-on-demand” basis. They are individual-oriented and they are run for the benefit of individual clients and seek to provide maximum satisfaction to each client. Quality rather than quantity is their guiding principle, although they may like to have as many clients as possible. They also often have much better support services.
26. Till now the special vertical National Leprosy Programme has been dealing with all leprosy-related problems. However, that programme has been wound up now, and many ‘leprosy hospitals’ have closed down or have started diversifying their interests to other areas like tuberculosis. And any general medical or health facility is expected to deal with the problems of leprosy-affected persons.
27. In the previous set up while leprosy patients had access to sound and adequate anti-leprosy therapy, there were many deficiencies in dealing with the other problems like deformities and secondary impairments for lack of facilities of the required quality in adequate numbers. The



PMR departments have the required expertise in many areas relevant to the patients' needs. They are in a good position to satisfy the needs of leprosy-affected persons, at least those residing in urban and metropolitan areas where these departments and institutions are located.

28. It is likely that many PMR departments and Institutions are already catering to leprosy-affected persons. I am assuming for simplicity's sake that they are not and will be opening up only from now on. In order to successfully discharge this responsibility, the personnel working in these departments and institutions will need to be sensitised to the problems of leprosy-affected persons: Secondly, their knowledge base in this area will need to be refreshed and possibly up-dated. I have indicated in the first part of my talk the possible areas that may come within the purview of PMR departments and institutions. I have not touched on socio-economic rehabilitation of the leprosy-affected as that is not an area of my expertise. Probably, that will also come within the ambit of your field of activity.

29. You may expect to meet some challenges when your clientele includes leprosy-affected persons. I would say that besides being challenges, they may also be considered as opportunities to expand your vision, mission and practice. You may expect an initial increase in the workload because of the accumulated backlog patients who have residual problems managed hitherto indifferently, if at all they have been cared for. But that workload should decrease sharply once they have been taken care of, because the number of new patients seeking your help is likely to be extremely small. Right now, hardly 3% of new cases of leprosy seem to be having significant impairments as leprosy patients are being identified and cured with MDT in the very early stages of the disease, long before they develop any impairments.

The second type of challenge I expect you may face is pressure from higher authorities and from the public to reach out to rural public and people living in small towns. You may have to develop outreach programmes and may be even develop mobile services for that purpose – “something like PMR on wheels” – for which you may have to innovate new approaches and methods.

30. You may also have to develop expertise in managing plantar ulcers and that experience should come in handy to manage ulceration in persons having denervated feet and hands due to any cause, including diabetes. The situation is simpler in leprosy than in diabetes and in leprosy we have accumulated experience of over half a century on the management of this vexing problem with low tech approaches. That should be useful at this juncture.

Secondly, incorporating management of leprosy-related problems in your agenda opens up opportunities, for the surgically ambitious staff among you, for increasing the scope of rehabilitation surgery beyond amputations and, may be release of contractures in polio cases. Some of the exciting areas that will be thus made available include procedures for resurfacing the sole of the foot and surgery for correcting paralytic deformities of hands and feet including surgery for their complications. Existing orthopaedic and plastic surgery departments are so heavily overloaded with acute problems that they are unable to do much rehabilitation surgery and may be the staff of PMR departments and institutions could step into this area, hopefully without stepping on other people's dreams and corns and without being considered as encroaching on their turf.

I once again congratulate ALERT-India and AIIPMR for holding this workshop and thus blazing a new trail. I would, if I may be permitted to do so, suggest that the National PMR association could have a session on this topic in their next Annual Conference so that the professionals that matter in this specialty can consider the issues involved and come to a consensus and develop guide lines on how to proceed further. I thank you all for the patient hearing you have given me and I thank the organizers once more for providing me this wonderful opportunity to interact with members from a sister speciality and enabling me to participate in this historic National level workshop. Thank you.



Leprosy disability situation in the country backlog today and strategy for care in the integration phase

Dr. P. K. Oommen, M. S. (Ortho) Consultant (Orthopaedics)

Director, Central Leprosy Teaching and Research Institute (CLTRI), Chengalpattu - 603001, Tamilnadu.

It is a privilege to be here amongst you all and I sincerely thank Mr.A.Antony Samy, Chief Executive ALERT-INDIA, Mumbai and other sponsors of this Workshop for making it possible.

My talk will be in two parts. Let me commence the first part on disability data by projecting WHO Grading of Disabilities which is being followed by NLEP.

WHO Grading of Disabilities Hands and feet:

- Grade 0 - No anaesthesia, No visible deformity or damage
- Grade 1 - Anaesthesia present but no visible deformity or damage
- Grade 2 - Visible deformity or damage present

Eyes :

- Grade 0 - No eye problems due to leprosy, No evidence of visual Loss.
- Grade 1 - Eye problems due to leprosy present, but vision not severely affected as a result (Vision 6/60 or better, can count fingers at 6 metres)
- Grade 2 - Severe visual impairment (Vision worse than 6/60, Inability to count fingers at 6 metres), Lagophthalmos, Iridocyclitis and corneal opacities.

In India about 11.5 million cases were registered for treatment from 1984, and among them there were 6.7 lacs Grade-2 disability cases reported among registered cases from 1984 to 2005. This indicates that 5.8% of total registered cases were having Grade-2 disability. Statistically it is expected that a total of 2.5 to 3 lakhs Grade-2 disabled cases (2.5 per 10000 population)

are living in India considering the death rate and re-registration of cases.

The distribution of Grade-2 disability cases in India as on March 2005



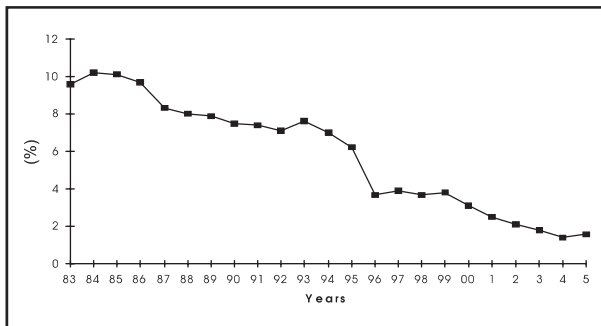
States	No. of disab. cases
Bihar and U.P.	> 25000
A.P., M.P.,Maha., T.N., Orissa and W.B.	> 10000
Gujarat and Karnataka	> 5000
Assam, Chattisgarh, Jharkhand, and Delhi	> 2000
Kerala, Punjab, Rajasthan	> 1000
Chandigarh	> 500
Goa, Haryana, H.P., Jammu & Kashmir, Manipur, Uttranchal, Tripura	> 100
Arunachal Pradesh, Meghalaya, Mizoram, Nagaland, Sikkim, Pondicherry	> 1



To give all of you an idea of Grade-2 disability cases detected and trend each year in the 35 States/Union Territories, I will project the registered disabled cases from 1995-96 to 2004-05 being for the last 10 years.

Looking at these figures one can state that over the last 5 years effective 2000-01 to 2004-05 there has been a definite drop in the numbers of Grade-2 disabilities detected year wise.

In the year 1999-2000 Grade-2 disability cases detected were 18,638 cases and in 2000-01 deformed cases detected dropped to 12,955. In the subsequent years there has been a progressive decline with the year 2004-05 showing number of deformed cases detected as 4145 for whole year. The Grade 2 disability among new cases is considered as one of the indicators of whether the National Leprosy Eradication Program is a success. The trend of disability among new cases has been declining at a faster rate than New Case Detection Rate (NCDR). Presently the deformity among new cases is less than 2%.



The Graph shows the declining percentage of Grade 2 disabilities among new cases in India.

This declining trend in Grade 2 disabled cases I attribute to the impact of MDT.

The NLEP introduced the Simplified Information System (SIS) in 2002 all over the country. In this information on Grade 2 disability is only reported with no categorization as to whether hands, feet or eyes are the affected parts.

A study was carried out recently in 6 States viz. Maharashtra, Gujarat, Karnataka, Bihar, Orissa and Andhra Pradesh by different teams from C.L.T.R.I., Chengalpattu, to assess the capabilities of the General

Health Care System to deliver Prevention of Disability(POD) services at PHC and referral centres. Data collected from these 6 States on disability characteristics revealed that hand, foot and eye disability percentage was 65%, 50% and 5% respectively with 20% of cases having multiple deformity. The female cases having disability among total disabled cases were 33 per cent. These figures I feel are a reflection of disability characteristics all over the country.

The reported data on disability has not been validated and I feel to draw up concrete programs for POD disability data has to be got from all over the country and validated.

STRATEGY FOR CARE IN THE INTEGRATION PHASE

In leprosy Grade 1 disability and status of nerve involvement is extremely important in the prevention of disabilities and deformities. However we do not have any figures in this regard.

Reflecting on the figures showing a declining trend in Grade 2 disabilities it is obvious that the best way to prevent disabilities is early diagnosis and treatment with MDT. The next step is to recognize Signs and Symptoms of leprosy reactions and nerve involvement and to initiate treatment with prednisolone.

All this sounds very simple. But the important question is whether this rather basic expertise exists in the General Health Care System. Although integration has been effected all over the country I am sure the leprologists here will agree with me that ground reality is in the fact, that the General Health Care system is to a very good extent dependent on the Vertical program workers for the diagnosis and management of leprosy. Further I am told in Tamil Nadu by the year 2007 seventy percent of vertical program staff will retire. This is I presume probably true in all other states.

Such being the case when one ponders about the strategy for care I feel TRAINING of General Health Care Staff in the basics of diagnosis , management of reactions and neuritis in leprosy is absolutely vital.

Further and here again my leprologists colleagues will agree that it is among medical professionals themselves that the stigma of leprosy is most prevalent. Training of General Health Care Staff should be taken up as an



continuous process both theoretical and hands on training with patients to examine, for at least the next 5 years. The medical curriculum for undergraduates should incorporate leprosy in its syllabi with a direction from the Medical Council of India that at least a short note on some aspect of leprosy should be present for the Final Year Medicine paper in all Medical Colleges and if possible at least one Short Case for practical examination.

If the above 2 suggestions are seriously taken into consideration we can hope that the General Health Care System in the next 5 years will certainly incorporate leprosy into the mainstream of General Health Care, thereby making integration a success.

As pointed out earlier detection of Grade 1 disability is vital in the prevention of disabilities and deformities in leprosy. For this the General medical professionals should examine the patient detect Grade 1 disability and then transfer 'Disability Prevention Technology' to affected persons and their families. This in effect means Health Education on Care of the hands, feet and eyes is the basis of Community based Rehabilitation to prevent further deterioration.

In essence all this means first level of intervention in leprosy to prevent primary impairments. This requires early recognition of disease, effective and adequate treatment and proper patient counselling. Further to prevent secondary impairments resulting from use of anaesthetic deformities it is absolutely important to identify patients at risk, train patients in the safe use of hands and feet, provide simple protective footwear and educate family and neighbours (Community Based Rehabilitation)

The second level of intervention in leprosy aims to prevent disability i.e. prevent impairments of the eye and nerve damage becoming permanent. This requires identification of affected patients, appropriate and prompt treatment with medical and Surgical Specialist Care requiring individual attention and frequent and regular assessment.

The third level of intervention to prevent handicaps requires reablement procedures. This is where Physical Medicine and Rehabilitation Centres can play a very important role. The Orthopaedic departments in Medical Colleges and district hospitals needs to be reined in. However attempts made in Kerala Medical Colleges by

G.L.R.A. and myself, and by DFIT in Bihar and Jharkhand has not met with much favour. They are overburdened with trauma. However both NLEP and certain NGOs are persistently trying to enter medical colleges and I am sure we will succeed in the near future.

The tragedy with regards to the complications of leprosy is that among the disabled population itself there is resistance in including disabled leprosy cured persons from entering their arena of rehabilitation. The departments of Physical Medicine and Rehabilitations will by taking up the management of leprosy disabled help in removing this stigma.

Presently one of the most challenging problems with regards to complications of leprosy is plantar ulceration and total disorganization of feet. The PMR departments have the expertise in managing insensitive feet and they can certainly play a major role in the prevention and management of plantar ulcers. This is a most urgent need. I say this because at my institute there is increasing number of patients coming with severe recurrent plantar ulceration with septic disorganization and they themselves are requesting amputation. The feet are so badly disorganized and invariably needs amputation. This is no solution and we have to take urgent steps to prevent this rather deteriorating state of affairs.

In summing up I would like to highlight the following points:

- 1) At a National level both Governments and NGOs need to cooperate to gather relevant data on the number of disabled leprosy patients to draw up realistic programs for their rehabilitation.
- 2) To prevent a resurgence of leprosy and increase in the number of disabled, Training of GHC personnel is to be taken up on a National Scale. I would even recommend the NLEP be changed to National Leprosy Training and Surveillance Program – NLTSP. If done this would go a long way in effecting integration successfully.
- 3) Motivate Physical Medicine and Rehabilitation departments to take up the cause of the leprosy disabled.
- 4) To eliminate the stigma of leprosy through intensive IEC on visual media to change societal perception that persons with deformities and ulcers arising as a complication of leprosy is not in any way a source of transmission.



Disability care today, the changing role of workers in leprosy and in the discipline of Physical Medicine and Rehabilitation

Dr. Dinkar D. Palande

Vice Chairman, LEPRO India, Secunderabad, Andhra Pradesh

The title of the workshop and that it is taking place, suggests that the concept of “Integration of leprosy rehabilitation services into the mainstream of physical medicine and rehabilitation.” is an urgent need that is being recognized.. I agree, with the proviso that much more than that needs to be done to successfully tackle the problem of disability in general and that due to Leprosy in particular.

“Disability Care” is a long standing problem in our country, not because the technology and knowledge how to deal with it is not available but, because it has a low priority, both in Govt. and non-government organisations.

We continue to have a large number of persons whose functional ability in their personal and social life is markedly affected because we are allowing disability to continue and may be to worsen in those already disabled due to different causes including Leprosy. At least in leprosy we are preventing future disability by a well organized program of early diagnosis and treatment. But we are doing hardly anything to diminish the functional disability in those already disabled.

The way out then could be for the people and the community at grass root levels to take up the challenge with support of persons/organizations with the technical and theoretical know-how. Organisations working in different disabilities could come together more effectively and pool their resources.

In the meantime, slowly the established organizations may also start giving more priority to this subject. This needs advocacy, increased demand, and activism on the part of those concerned. 'Alert' has been playing

an important role as an activist, giving a “wake up” call to all of us, leprosy workers as well as those in general Physical Medicine and Rehabilitation.

The Present Position:

Let us first briefly summarise the present position of disability care in Leprosy. The main method of preventing disability in Leprosy is by ensuring early treatment of the disease and of nerve involvement. This is either being achieved or on the way. The care of the already disabled is however random and unsatisfactory.

The focus today should be holistic, on the prevention of worsening of disabilities –physical, mental, social, and economic and their amelioration to the maximum extent possible. The methodology is available, in theory, in books and manuals and there are some successful examples. There are many small pockets here and there where some NGOs employ skills like, splinting, education in care of insensitive limbs, maintaining joint mobility of affected fingers and joints, economic empowerment by self-employment schemes and others.

In a few places the family and community are involved to take the responsibility. The objective is attainment of functional independence by the affected individual and his family. The effect is return of dignity- individual, social, and psychological to the affected person and his/her family.

I would like to repeat that in general there is no well planned rehabilitation effort on a large required scale in any region. And now in the post integration era



rehabilitation of persons affected by leprosy is no one's priority, neither the Government's nor the NGO's and so everyone talks about it.

The worker in Leprosy rehabilitation, (I am not sure where he is now!) knows more than the P.M. and R. professional about the disease, the physical, social, economic and psychological disability caused and to an extent what to do about it. He may recognize that there is something common between all disabilities. But now he has to learn other skills in probably unrelated fields. The distance between him and a leprosy affected person needing rehabilitation is increasing rapidly, every day. He also does not necessarily have the means, the resources available because of change in his role. And he is not quite sure of his new role.

The P.M.R. worker, especially the one working in the field, has known about the leprosy affected person, the disabilities and the need of rehabilitation but usually from a distance, leprosy being never in his ambit up to now. He would be willing to bring these persons with leprosy affected disabilities under his umbrella, under his care. He would need convincing and then a short refresher.

Let us now come back to this workshop

The persons attending this workshop, I believe, fall into three groups, the two major groups being:

1. Leprosy workers, especially those in rehabilitation services knowing something of P.M. and R. and
2. Workers of Physical medicine and Rehabilitation knowing something of leprosy.
3. The third very small group would be of those knowing more than something of both disciplines and these persons should act as facilitators.

The purpose of the workshop, I hope, is to bring the two big groups together aiming at eventual assimilation into one common group. Such a common group, convinced of the need for this integration, shall work to achieve it by different means like advocacy and

planning, training programs and community participation..

The first task of such a group would be to convince the leaders, influential persons, power brokers and true advocates in organizations, regions, states and centre.

The second task should be to help in training of the general health workers, especially in the Primary Health Care units, in methods of rehabilitation and the third would be to activate and facilitate community participation

For this we have to identify the organisations who have worked in Leprosy Rehabilitation and bring them in contact with the PMR organizations, departments and workers –doctors, technicians, and others similarly identified in different regions. These two now have to evolve a pragmatic rehabilitation policy in their zone of influence and work.

The main features of such a policy would have to be worked out rather urgently. In different areas the strategy could be different, some places would be ideal for an institutional based program with field extensions, in others there could be a community based program with inputs by local NGOs. There are many possibilities.

The main concepts to be discussed would be -

1. A common rehabilitation program for the disabled –irrespective of the cause
2. Availability of resources locally– like splints, ways of empowerment for earning livelihood etc.
3. Involvement of family and community, (village councils ..)
4. Transfer of information and simple technology by training programs, institution based and on going in-service programs.
5. Adequate Documentation and feed-back mechanisms.



Session 1

Status of Physical Medicine and Rehabilitation (PM&R) curriculum, training and services in India today with reference to leprosy

Chairman: Dr. B. K. Girdhar,
Dy Director, Central JALMA Institute for Leprosy, Indian Council for Medical Research, Agra, U. P.

Co-Chairman: Dr. P. K. Gopal,
President, IDEA INDIA, Erode, Tamil Nadu

Status Paper : "Utilization of NLEP resources for initiating CBR programme at the Primary Health Care level"
Dr. B. D. Athani, *Director, AIIPM&R, Mumbai, Maharashtra*

Panel members:

Dr. Ajit Kumar Varma, Prof. & Head, Dept. of Rehabilitation, Patna Medical College, Patna, Bihar

Dr. Navnendra Mathur, Prof. & Head, Dept. of PM&R, SMS Medical College, Jaipur, Rajasthan

Dr. V. Ramamoorthy, Consultant Psychiatrist, Director, PSG College of Physiotherapy, Coimbatore, Tamil Nadu

Dr. Kurien Zachariah, Associate Prof. & Head, Dept. of PM&R, St.John's Medical College, Bangalore, Karnataka

Dr. George Joseph, Prof. & Head, Dept of PM&R, Govt. Medical College, Calicut, Kerala

Dr. Kunjabasi Wangjam, Prof. & Head, Dept. of PM&R, Regional Medical Institute, Manipur

Presentation 1: "Preventive and therapeutic rehabilitation services for the general disabled and leprosy disabled provided at the PM&R institutions in the country"
*Dr. Sanjay Wadhwa, *Additional Professor, Dept. of PM&R, All India Institute of Medical Sciences (AIIMS), New Delhi*

Presentation 2: "Secondary and tertiary rehabilitation services for the general disabled and leprosy disabled provided at the PM&R institutions in the country"
Dr. U. Singh, *Editor, Indian Journal of PM&R and Prof. & Head, Dept. of PM&R, All India Institute of Medical Sciences (AIIMS), New Delhi*

Presentation 3: "Review of PM&R training curriculum with reference to leprosy integration strategy of Govt. of India"
Dr. George Anderson, *Prof. & Head, Dept. of Hand and Leprosy Re-constructive Surgery Unit, Christian Medical College, Vellore, Tamil Nadu*

Brief intervention by the Panel Members

Views from the participants

Remarks from the Co-Chairman and Chairman

* Text version of the presentation not received, despite repeated request.



“Utilization of National Leprosy Eradication Programme (NLEP) resources for initiating Community Based Rehabilitation (CBR) programme at the Primary Health Care Level”

Dr. B. D. Athani

Director, All India Institute of Physical Medicine & Rehabilitation, Mumbai

Introduction:

Since the Alma-Ata declaration, Govt. of India have taken significant steps to establish health systems in accordance with the strategies of Primary Health Care (PHC), emphasizing on decentralization and district health system development, community participation and volunteerism in local health actions, including the involvement of the private sector in providing health care services to the people. Leprosy patients with disabilities have always been viewed as a disadvantaged and marginalized group because their condition is associated with the poverty and stigma. The greatest challenge is to restore as many functional abilities of the leprosy affected persons and enable them to overcome physical and social barriers. Leprosy disabled are more at a disadvantage that many of them have not had the benefit of disability prevention and care services for which the feasible solution is community-based rehabilitation (CBR). CBR is a common form of service delivery to people with disabilities in underserved areas. This concept emphasizes that a new direction in CBR need to be put in place in order to maximize the realization of the ultimate goal. CBR programmes need to function with a holistic approach in the context of social, cultural and physical changes existing within the community and by engaging different groups - including all leprosy and health workers - as is currently taking place.

Prospects of integration between NLEP and GHC system

There is clear evidence that the leprosy elimination strategy is successful over the last 20 years as the global prevalence has fallen by almost 90%, and more than 14 million patients have been cured. In India, leprosy now remains a public health problem in only nine endemic states in the beginning of 2005. Improved

access to diagnosis and the widest possible availability of good quality MDT remain the cornerstones of the leprosy elimination strategy, and this was achieved by integrating of leprosy services into the national primary health care system. This was mainly due to scarce resources available at international / NGOs / government levels to utilize for full development of people affected by leprosy. A structural concern, specific to the NLEP, will be functional with modification in the context of integration with the GHC system. This is likely to continue till March 2007, i.e. the end of 10th year plan according to Govt. of India.

Current leprosy scenario in Maharashtra State:

Although there has been considerable decline in the prevalence and incidence of leprosy in the State, there has been no appreciable change in the disability proportion among the newly detected leprosy cases. In Mumbai, it has increased from 6.8 % in March 2004 to 8.9 in August 2005. Moreover, there is a backlog of 40,000 people disabled due to leprosy in the State. There is scarcity of financial resources for implementing integrated rehabilitation services. This indicates that there is a need to regulate the integrated services in order to provide appropriate rehabilitation services to these disabled persons.

Present level of prevalence, incidence (New case detection) and proportion of visible disability (WHO, Grade II) among new leprosy cases

Year	Maharashtra State		
	PR/10,000	NCDR/10,000	Disability %
03-04	2.9	4.3	1.3
04-05	1.5	3.1	1.3
Aug '05	1.04	1.56	0.96



Year	Mumbai District		
	PR /10,000	NCDR /10,000	Disability %
03-04	1.48	2.5	6.8
04-05	0.88	1.38	7.93
Aug '05	0.70	0.36	8.9

Source: Mumbai District Leprosy Society, 2005

Range of disability prevention and rehabilitation services provided by NLEP:

At present, the disability prevention and rehabilitation services are not the priority in NLEP. However, the State Government and NGOs are providing a wide range of rehabilitation services to the needy leprosy patients in their jurisdiction. Govt. of India has coordinated with other partner agencies for providing the disability prevention and rehabilitation services through its relevant stakeholders.

Type of disability prevention and rehabilitation services provided by NLEP

- Medical intervention to prevent the occurrence of new disability / deformity
- Surgical intervention to prevent and correct existing disability / deformity
- Provision of aids and appliances such as splints and special footwear
- Counselling to achieve social integration
- Vocational training to increase the earning power
- Economic assistance to generate income

Strengths of NLEP

Since the 1950s, the Govt. of India has accorded a high priority to the control of infectious diseases including leprosy through a series of centrally administered disease control programmes. Prior to

integration, the specialized NLEP infrastructure in the country had a total of about 8,500 establishments including 719 leprosy control units, 244 district leprosy units and 49 training centres. Leprosy elimination programme has had a positive spill-over effect well beyond the disease itself as the progressive integration of leprosy into general health services is aimed to strengthen the local health services as well as increased the confidence of general health care workers by being part of a global initiative and sharing the burden along with other health programmes. The human resource capacity available for leprosy services under NLEP is enormous, which can be utilized for allied rehabilitation services. Besides, the NLEP enjoys increased community access and involved all grass root level auxiliary workers. In Maharashtra State, 1270 persons constitute 'health manpower' under NLEP and these categories of workers will be performing different activities of leprosy control. In the currently declining phase of leprosy endemicity, engaging conventionally trained paramedical staff for delivering preventive and restorative rehabilitation services is operationally feasible. It also covers all matters related to disability prevention and rehabilitation needs of all disabled persons including leprosy disabled to be carried out in an integrated manner.

District and Sub-district level operational structure of NLEP: Pre-Integration

NLEP personnel	State	District	Total
NMS	165	474	639
PMW	126	505	631
Total	291	979	1270

Source: Mumbai District Leprosy Society, 2005

Redeployment of NLEP work force during Post Integration

In Maharashtra State, after integration all the 1270 NLEP personnel have been redeployed to the General Health care system and will perform the NLEP activities in their respective PHC area (Rural) and Urban Health Post area (UHP). These NLEP personnel are currently engaged in assisting the general health care personnel to diagnose and treat leprosy with MDT. The absence of specific tasks related to rehabilitation services to be



performed by the different health workers will create a vacuum and may hamper the efforts of leprosy elimination. The provision of rehabilitation services for the leprosy disabled now fully rely on the Medical colleges and the Civil Hospitals at the district level. There has been no increase in the budgetary provision under NLEP after integration.

Restructuring secondary and tertiary level specialized leprosy centres for disability due to other causes:

There are number of NGOs managing specialized leprosy centres, now called as 'Leprosy Referral Centres', besides 7 specialized leprosy centres that are recognized by the State government offering secondary and tertiary level care for the disabled leprosy patients. In order to secure the commitment of donor agencies, several NGOs have extended their services to treat the people suffering from other diseases like HIV-AIDS or Tuberculosis or people with disabilities due to other causes. Such 'reverse' integration process may have positive influence in arresting social stigma attached to leprosy. When the skill and knowledge has been already available with NLEP, it can be utilized to promote allied disability related services. The enthusiasm of NLEP personnel will be essential in order to contribute in a substantial way to accomplish new tasks that can be developed and implemented in a phased manner.

Need to train the NLEP personnel in CBR

A common consensus has emerged that community based services offer the best prospect of meeting the needs of people with disabilities and their families including those affected by leprosy. However, the shift away from specialized centres and institutions has not been accomplished as yet by a reappraisal of the training required by NLEP personnel to deliver new forms of rehabilitation services. There is a need to train the leprosy workers and professionals in the non-medical expectations of any rehabilitation programme. Estimating the commitment of vertical leprosy workers in offering comprehensive rehabilitation services, it is

ideal to engage these personnel to assist in the empowerment of all disabled people including those affected with leprosy in an integrated manner.

Integration of leprosy disability services with PM&R services

In general, the rehabilitation services to the leprosy-affected persons are provided at the community level, but more difficult cases, which require more sophisticated approaches, are referred to institutions more closely allied to physical medicine and rehabilitation (PM&R). Such referral system also gives the leprosy disabled person access to more specialized personnel and services available at PM&R institutions. This integrated approach have emphasized the restoration of the physical function of the leprosy disabled, while others have looked beyond to psychological and social well-being. Several leprosy institutions have built on the expertise of professionals while the grass root level leprosy workers have laid emphasis on the caring capacity available with them and sought to reinforce it. The uneasy process of building CBR partnership can be made easier through an understanding of meeting a common goal involving the community level health workers.

Experience of AIIPM&R

- Physical medicine and rehabilitation services has multiple inputs for medical interventions.
- Entire range of services of disability prevention and rehabilitation with PMR institutions can be offered to leprosy patients as well in various phases of treatment.
- Need to pool resources of PMR institutions and NLEP.
- Capacity building of district/civil hospitals.
- Establishment of rehabilitation unit at district Raigad and Durg.
- Manpower development.
- Sensitization and training of personnel including central and state health administrators, district and PHC. Doctors, health & grass root level functionaries, school teachers, members of village panchayat, parents, etc.
- Translation of WHO Training manual "**training in the community for people with disabilities**" into five regional languages.



- Designing, translation and printing posters on “**disability prevention and rehabilitation**” for community awareness.
- Disability detection and service camps.

It has been widely argued that community based programmes offer considerable advantages to the traditional forms of institutions in health and rehabilitation services delivery. With about 10 years of experience in operating CBR projects for the disabled, the experience points to potential collaboration with other health programmes in delivering rehabilitation services. As a continuing process, several activities have already been carried out by AIIPM&R on pilot basis in selected districts. This project is attempted to make it possible for disabled people to receive the help they need and to be able to go about their daily activities aided by trained personnel from their own communities.

Rationale for utilizing the leprosy manpower for CBR:

GOI is fully committed to the integration of leprosy services and recommended a plan for sustaining leprosy control efforts in the post-elimination phase. The phasing out of vertical leprosy programmes was planned and executed within a reasonable time. However, despite the challenges that still remain, we can be confident that the responsibility of providing the rehabilitation services for the disabled people including the leprosy affected persons can be undertaken in a cohesive manner. This leaves a scope to utilize the NLEP manpower and other resources to practice an integrated CBR programme within their area of operation. This would enable the PM&R institutions to ensure wider geographical coverage of treatment and improving service efficiency including those with disabilities due to leprosy. At best, this has been a rudimentary management tool, which improves the performance of leprosy workers and this will facilitate integration of leprosy disability services with PMR services. This could be organized based on the real extent of the leprosy problem and on the feasibility of the elimination strategy itself.

Meeting the challenge

These activities, in turn, are unfolding within a broader context of diminishing government resources for health and social programs. There is a need to provide a

framework and future strategic directions for utilizing the NLEP resources to meet the new challenges towards leprosy rehabilitation and to maximize the opportunities of changing technology and evolving partnerships. The role of NLEP personnel and other stakeholders is well recognized as one of allies and resources in the rehabilitation process. Moreover, the participation of community in the rehabilitation process needs to be assured. The integration of NLEP with PM&R would benefit by consolidating on the positive aspects in utilization of available resources, transfer of knowledge, strengthening referral services and multisectoral coordination. This would obviate the gradual marginalization, rejection and debilitation of the leprosy affected persons and reduce stigma. These factors need to be appropriately taken care while planning rehabilitation and disability prevention programme in leprosy control programmes.

A framework for action

The overall objective of the integrating leprosy disability services with the PM&R services is to strengthen the general public health as a major part of health systems development in the country. This initiative will first attempt to improve preventive rehabilitation and training capacity in the region, as well as promote an active network of PM&R institutes. Along with the strengthening of NLEP personnel, this initiative will also strive to support and strengthen disability services within the context of health systems development. To that end, the essential functions of the NLEP personnel are to be examined within the context of each public health policies, infrastructure, human resources and service capacity. Providing practical insights into the application of CBR within the NLEP structure and exploring the current practices in CBR with reference to leprosy disabilities is essential to offer appropriate rehabilitation services for the leprosy disabled persons. It is hoped that this initiative will lay the foundations of integration of leprosy disability services with the general rehabilitation services in future, which is people-oriented, sustainable and directed towards ensuring equity and balance.



Secondary and tertiary rehabilitation services for the general disabled and leprosy disabled provided at the PMR institutions in the country

Dr U Singh

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Secondary and Tertiary Rehabilitation Services

At the beginning of the talk, let me confess that I was a little confused with the topics to be covered with my talk. Am I supposed to talk on the secondary and tertiary level of health care delivery system or the secondary and tertiary Rehabilitation services. Further to this there is a little dilemma in my mind about the secondary and tertiary rehabilitation services offered to the patients of Leprosy. I am a bit more comfortable with the terms secondary and tertiary disability prevention, which mean early diagnosis and treatment and interventions aimed at rehabilitation of the patients with leprosy respectively. However, further in my talk, I shall try to clarify both my doubts and throw a little light on both these aspects.

Talking of the Level of Rehabilitation Delivery Services

As per the existing Rehabilitation (for the persons with disability) delivery services run by the government of India, there is a Community Based Rehabilitation (CBR) Scheme (under the Ministry of Social Justice and Empowerment, MOSJE), which works at the grass root level with a volunteer (not a paid worker) as the key person (grass root level functionary). In this scheme there is a referral system that goes along with it to the Primary Health Centre, District and state or apex level. We may call this to be an effort of the secondary and tertiary level rehabilitation services. Unfortunately, there are only a couple of states, namely, Kerala and Karnataka, which run these services but even there the whole of the states are not covered. These services are not run by the government but only by the Non-governmental organizations (NGO) even though not completely but to a certain aspect as per the guidelines of the World Health Organization (WHO). The functionaries are not (un-paid) volunteers but workers of the NGOs. The referral system is not that developed. Perhaps the government is not funding the

CBR. There are efforts by the WHO to spread these services to the areas where people are interested and the WHO is willing to help by training the workers, middle level functionaries and the tertiary level functionaries besides providing the training material to them. The efforts have not been great to have this take off literally or effectively. There has always been some conflict about who should provide rehabilitation services to the persons with disability. The MOSJE provides some services while some are provided by the Ministry of Health (MOH), even though the main Ministry dealing with the welfare of the persons with disabilities is the former. The MOSJE runs another scheme with foreign funds called the District Rehabilitation Centre (DRC) Scheme. Even the DRC Scheme runs in 10 states and has only 11 DRCs and four Regional Rehabilitation Training Centres (RRTC). The future fate of these DRCs and RRTCs is not known after the funding stops though there is a move by the MOSJE to continue the DRCs. The original scheme aimed to have atleast one DRC at each District in India with four RRTCs, but it was contained. The DRC has all the basic needs of a full-fledged rehabilitation center and it is the first secondary level rehabilitation center. Instead of having more DRCs, the MOSJE is now opening up Composite Rehabilitation Centres (CRC) and also District Disability Rehabilitation Centres (DDRCs) and quite a few are in place. At the CRCs more or less a complete team of Rehabilitation is available though the services are not comprehensive at DDRCs but still they provide some facilities for the rehabilitation of the disabled at the secondary level. The numbers of CRCs and DDRCs is growing gradually. The MOSJE is funding the establishment and initial expenses for running the DDRCs and aims at transferring them to the state to run with the passage of time. The tertiary level hospitals in the states, some medical colleges and hospitals and apex level



institutions, including the All India Institute of Physical Medicine and Rehabilitation, Mumbai, under the MOH and four national level institutes under the MOSJE are a few centers providing comprehensive Rehabilitation services for the persons with disability. The Government of India is making all out efforts at this stage, in the present five year plan, to start at least five rehabilitation centers in different medical colleges and hospitals each year. The tertiary level rehabilitation centers or Physical Medicine and Rehabilitation (PMR) institutions are very few in number though growing gradually. To top it up, though not in the organized health care delivery services or the services for the rehabilitation offered by the MOSJE, there are a few private hospitals, private clinics and those run by the NGOs. Some of them can also be said to be contributing to the provision of secondary and tertiary level rehabilitation services.

Secondary or Tertiary Rehabilitation Services or Disability Prevention

By secondary and tertiary rehabilitation services do we really mean disability prevention, which itself is a tertiary level of prevention in the three tier prevention of disability as was advocated by the WHO: primary prevention meaning prevention of disease itself, secondary prevention meaning early detection of the disease and early treatment and tertiary prevention meaning prevention of disability once an impairment or functional limitation has already occurred. The tertiary level of prevention is also called rehabilitation, which prevents the person from getting disabled even if the patient has some structural or functional deficits caused by any illness. Another term: prevention of secondary disability really means preventing secondary effects of an impairment or functional limitations on the person leading to further complications, e.g. development of contractures, deformities or ulcerations in the presence of motor paralysis and sensory loss, that could be prevented by appropriate positioning, exercises or protective devices etc. Rehabilitation cannot be termed as primary, secondary or tertiary, as far as I know or can imagine or think. The terms impairments, functional limitations and disability etc. have been replaced with structural and functional deficits, activity limitation and participatory restriction. The structural and functional deficits are the deficits at the tissue or organ level in an illness, whereas the activity limitation in a person is at the individual level denoting

how the structural and functional deficits affect the activities that could be performed by an individual having such deficits and participatory restrictions imply the restrictions faced by an individual in a society due to his deficits or activity limitations. To have prevention of disability and to achieve rehabilitation of the person suffering from a disabling condition, one would like to prevent the limitation of activity and participation restriction in an individual so that he can remain to be an active member of the society and be integrated in it. While we talk of Rehabilitation intervention of an individual suffering from any disabling condition, the modus operandi of the rehabilitation services is irrespective of the level of services and is not dependent on the type of illness or the diagnosis (say leprosy or poliomyelitis) causing the functional deficits even though the prognosis of the illness might matter to an extent. To have a better understanding of the rehabilitation of the patient with leprosy, let us now learn how are the patients with leprosy are affected.

Specific Problem Areas for Patients with Leprosy

The patients with leprosy typically present with the following problems as perceived from the point of view of rehabilitation: sensory deficit, paralysis, deformity, ulcerations, amputations, visual impairment, segregation and stigma. As per the teachings of rehabilitation of the patients with leprosy, segregation and stigma are a problem with those having deformities and ulcerations, if we are able to prevent these two with early treatment and appropriate management, the major battle of segregation and stigma is won. The patient can easily be restored in the society.

Facilities Available at PMR Institutions and Role of the Medical Doctors in PMR

The PMR institutions work with the basic theme as in the definition of rehabilitation given by WHO: Rehabilitation means combined and co-ordinated efforts to restore a disabled person to his fullest physical, mental, social and vocational aspects to as far extent as is possible. The doctors who specialize in PMR co-ordinate the rehabilitation team and provide the patient with the understanding of the disease and its prognosis. The importance of medication in the cure of the disease is given to the patient with an emphasis on the prevention of spread with the help of medication. In most PMR institutions, including the one at AIIMS and Safdarjang Hospitals in Delhi, dermatologists work in close



collaboration with the doctors in PMR. The patient is advised to be sensory conscious to prevent ulcerations and avoid the occurrence of more ulcers by giving an insight into the causation of ulcerations. The role of prevention of deformities by way of positioning, splinting and prescription of specific exercises is emphasized to the patient. Integration of the patient into family and society is stressed both to the patient and the family members by alleviating their fears of spread to other members of the family. The importance of continuing productive work commensurate with the deficits in the particular patient is advised. The doctors also give appropriate advise to the patient about the ulcer care. Plaster management of the foot ulcers, surgery for ulcers and deformity corrections etc. are also done at some PMR institutions, at others in the departments of Orthopaedics. One of the major roles of the PMR doctors in the rehabilitation of the leprosy patients is certification of disability and for various benefits including railway concession certificates.

Physical Therapy is aimed at maintaining joint range of motion, maintaining muscle power and prevention of deformity by way of exercises. **Occupational Therapy** helps the patient achieve independence in activities of daily living and also achieving the goals of maintenance of muscle power, co-ordination and joint range of motion by way of therapeutic activities in addition to provision of splints and self help devices. Splints are the mainstay of the management of hand deformities in patients with leprosy

The **Prosthetic & Orthotic** devices are necessary in patients having paralysis, sensory deficits or amputations. Protective foot wear, special foot wear with or without orthotic devices are fabricated by the Prosthetists and Orthotists as are deemed necessary. The patients having amputation require specially designed sockets to allow adequate weight bearing in the prosthesis and avoiding ulcerations in the insensate skin of the stump.

Psycho-socio-vocational counseling would include making the patient aware about the illness, coping up in the family and society and issues related to integration of the patient in the family and society. The facilities for disabled persons including those with disability due to leprosy are explained to the patients and help is given to them on availing these. The vocational guidance, training and placement including that in the sheltered workshops is done for the patients.

The advantage with the PMR Institution is that they provide facilities for rehabilitation integrated with rest of the disabled while giving emphasis to the specific problems of the patients with leprosy. The PMR doctors in their curriculum have leprosy rehabilitation as part of their curriculum. It is obvious from the above that there are a number of professionals involved in rehabilitation, called the rehabilitation team. Let us now have a look at the typical rehabilitation team in a PMR institution.

Typical PMR (Rehabilitation) Team comprises of:

- Medical Doctor (PMR Specialist)
- Physiotherapist
- Occupational Therapist
- Clinical Psychologist
- Medical Social Worker
- Vocational Counselor
- Prosthetist and Orthotist

The number of PMR Institutions is inadequate in India.

Wherever there are PMR institutions, majority are already providing services for the patients with leprosy and they are more or less well equipped to handle the rehabilitation of the patients with leprosy. The trouble is that there are only a few centers at the secondary and tertiary levels. The number is growing slowly with the intervention of the MOSJE trying to open up more departments of PMR in the existing medical colleges and opening up more CRCs and DDRCs. If we depend on rehabilitation of leprosy patients only on these centers, they may provide services where they are available but in certain states e.g. in Gujarat, there is not a single facility for rehabilitation at any level of health care delivery services, leave aside any PMR institute. Besides, most of the DDRCs do not have PMR specialist doctors or at places no medical doctor at all on their roles but they might have a visiting medical officer in DDRCs.

Even though the government of India has directed through the Medical Council of India to have a department of PMR, all the medical colleges still do not have one, since it is not mandatory to have a department, it is only desirable. Hence, if the services for the integration of the patients suffering from leprosy are equated with the general disabled by the PMR institutions, the good thing is that the existing PMR



institutions are equipped to handle them, at the same time it would also mean that services may be inadequate for the time being where PMR institutions are not there. If we talk of the CRCs and DDRCs and wish to provide something under the MOH, say an extension or auxiliary of the National program for eradication of Leprosy, the institutions under MOSJE may not be obliged to take up the issue unless there is a clear cut and well defined understanding in achieving the targets besides distribution and utilization of funds. At present, CRCs and DDRCs are also not enough though efforts are on to augment those or may be have them under the common MOH so that there is no conflict with the services to be provided.

Medical Manpower Development Requirements

To achieve the manpower requirement for the PMR centers being opened, more specialist doctors with the degrees of MD (PMR) and DNB (PMR) or DPMPR will be required. Since there are only 11 institutions providing teaching facilities for doctors in PMR at present, mere opening of the PMR centers without doctors would not solve the problems for the immediate future. Training of Service Doctors in Health Care Delivery System as is being done by the Rehabilitation Council of India should be augmented. The doctors who are working in PMR institutions would require further training in surgical techniques for leprosy that can be done as in-service training.

Para-Medical Manpower Development Requirements

Physiotherapy institutions are plenty and at the moment most of the fresh graduates in Physiotherapy are not able to find jobs, despite having new jobs created for them. The number of trained and qualified physiotherapists is sufficient at present though some components of skills of physiotherapy management in patients with leprosy may need to be emphasized in their curriculum. Occupational Therapy education has not taken off in such a scale as those of physiotherapists though there has been some increase in the institutions imparting degrees in Occupational Therapy. The jobs for occupational therapists have not increased in the same scale as those of physiotherapists. If we look from the point of view of leprosy, more occupational therapists would be needed compared to the physiotherapists. The Prosthetists and Orthotists' training is not that far lagging behind and the job availability is still not commensurate with the number

qualified. A little emphasis in their curriculum would be welcome to include components of special orthotic devices, shoe designing and its modifications would be a welcome step. It has been observed that the Prosthetists and Orthotists are reluctant to design and modify shoes, which should be made a compulsory component of their curriculum and practical training so that they are abreast with the problems to be tackled for the patients with leprosy. Sensitization of Medical Social Workers, Vocational Counselors and trainers is needed so that they can accordingly handle the socio-economic-vocational problems of the people suffering from leprosy.

Summary

Leprosy Rehabilitation is being done as a routine at most PMR Institutions and is already integrated with the rehabilitation of the general disabled. Leprosy Rehabilitation is already included in the curriculum of the post-graduate degrees and diplomas of the medical doctors pursuing PMR. However, there is a gross inadequacy of the PMR doctors and PMR Institutes in the country. The MCI should make it mandatory for all the medical colleges to have departments of PMR in the country. There is an urgent requirement of PMR teaching institutes to fulfill the manpower requirements of medical doctors. The service doctors can be trained in rehabilitation, specially for persons with leprosy. The doctors in PMR should be given additional training in reconstructive surgery in leprosy. There is a need to have some modifications in the curriculum of para-medical courses like Physiotherapy and Prosthetists and Orthotists. Training of more Occupational Therapists would be required and sensitization of the Medical Social Workers, Vocational Counselors and Vocational Trainers need to be done to give them better understanding of rehabilitation of persons with leprosy. Though the government is making efforts to augment the manpower as well as the PMR institutions, it might take a while before the persons with leprosy can have the benefits of availing full services of rehabilitation integrated with other disabilities at the PMR institutions all over the country. The beginning can however be made immediately.



Review of PM&R training curriculum with reference to leprosy integration strategy of Govt. of India

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Introduction

Physical therapy and Rehabilitation tailored to the leprosy afflicted has long been an inseparable part of the comprehensive care rendered to them. Introduced in a simple form several decades ago, even before proven antileprosy therapy was put to routine clinical use points to some inexplicable attention leprosy patients attracted, in all probability, a devotion to God for some who cared or was considered as a duty to work towards a common goal in reducing deformities and disabilities for certain others. Both forms of commitment remain a valuable legacy of our land in alleviation of suffering in leprosy patients in some way possible.

Leprosy Physical therapy and rehabilitation training originated in a non-formal 'education' of simple physical techniques and splint-making imparted by physical therapists and/or surgeons to some interested 'Aides'. The positive impact of this led to the realisation of a formal training programme that came to be known as 'Leprosy Physiotherapy Technician' training course with a simple curriculum spanning 9 months duration. The DGHS, the Hind Kusht Nivaran Sangh, and many NGOs successfully promoted this 'paramedical course'. Dr Paul Brand, the pioneer in leprosy reconstructive surgery and leprosy rehabilitation started the LPT certificate course in CMC Hospital Vellore in 1958. This course was enlarged to a 15 month Diploma course in 1984 by this author in consultation with CMC Hospital Medical Superintendent's Office after including basic Hand Therapy, and upgraded again in 2004 by this author through the Allied Health Sciences Committee of CMC Vellore. The criteria for admission into the LPT training programme in CMC Vellore was a pass in SSLC in those who also knew about leprosy or were cured of leprosy or had been previously

working with leprosy patients in some capacity. In 1984, the criterion was a pass in the Plus 2 exam with selection through an interview, and from 1996 the requisites were a pass in Plus 2 with a minimum of 50% in Biology, then passing a common MCQ entrance exam and final selection through an interview. Right through from LPT to DHLPT and DHLPT (Upgrade), these graduates pursued a career providing simple professional and technical treatment for Leprosy patients in Hospitals / Clinics with components of their work supervised by their seniors, a physiotherapist or a surgeon. They were not exclusively under the supervision of staff from the department of physical medicine and rehabilitation, an arrangement that permitted the latter to concentrate on general, i.e., 'non leprosy' patients. The general Diploma in Physiotherapy (DPT) and later its transition to the Bachelor's degree in Physiotherapy (BPT) had a sizeable curriculum inclusive of aspects of Leprosy and physiotherapy care as could be seen below.

The intent to integrate leprosy physical therapy and rehabilitation service into the general health care (GHC) would also mean the augmentation of the physical medicine and rehabilitation curriculum, especially in relation to physical therapy skills that need to be responsibly given by all who are to engage in this diverse and enlarged system. Also challenges are bound to be aplenty in accommodating the rehabilitation component of the curriculum for a diversely disabled clientele. While promoting this integrated approach, the Physical Medicine and Rehabilitation graduates in training can be expected to acquire more hands-on skills in the care of leprosy patients now that there is a substantial reduction in the infectivity of even multibacillary cases as a result of the proven efficacy of Multidrug therapy (MDT), if this was a reason for only a few opting to



train in an exclusive leprosy physiotherapy programme. And with patient isolation and protracted confinement in institutions being low, the available patient numbers and thus, their attendance would appear adequate for the integrated training programme to be put in place at regional centres. The facilities and paraphernalia required for practical training in leprosy physical therapy techniques in all probability already exists in most departments which cater to 'general' disabilities in a big way. The success of training for this integrated service will largely depend on the leprosy patients themselves feeling confident in accessing these centres. Here the social scientists will come into their own in devising or putting in place measures that enhance the proper utilisation of the services. It is beyond the mandate of the author's designated subject matter to delve further into the nitty-gritty of such issues.

Curriculum Review of Leprosy Physiotherapy and Rehabilitation.

On reviewing the curriculum of the original LPT programme, 2 major objectives were:

1. To inculcate essential knowledge of leprosy, help trainees identify primary and secondary deformities (impairments), help trainees evaluate impairments in patients, help them understand neuritis and reactions, recording findings on standard charts, acquire knowledge about protective footwear and prescribe the same at the appropriate time, awareness of the advantages of simple orthosis and prosthetic devices, providing health education to patients, imparting home self care skills and other simple exercise techniques that could be applied safely by patients themselves in protecting anaesthetic hands, feet and eyes, and
2. In providing physical therapy technical skills for applying them directly on non-surgical patients and where surgery services are not available as in field conditions as part of the prevention of impairments and deformities programme for the hands, feet and eyes., being actively involved in the referral system for surgery or rehabilitation at bigger centres, and for being a team member in covering surgical rehabilitation - pre and post-operative physical therapy programmes and follow-up evaluation.

Regular tests /assessments were conducted for the trainees so that the system could generate proficient workers with the required knowledge and skills to do adequate work and be gainfully employed. Further training was reserved for those in service and who had an aptitude to take on additional responsibility.

Curriculum of Term I:

Essential basic sciences in anatomy of the limbs, eyes, peripheral neurological system, and physiology were taught to the student to understand the techniques of physical therapy. Faculty included: Senior trained physical therapy technical staff, Anatomist and Physiologist.

1. General structure and function of i) skin, ii) bones, iii) joints, iv) ligaments, v) muscles, and vi) peripheral nerve system.
2. Hands – structure and function: i) Description of all bones and joints, ii) description of normal movements in the joints, iii) muscle groups, and iv) main nerve trunks and v) the common deformities resulting from leprosy neuropathy.
3. Movements of the hand: i) Labelling bones and joints on chart diagrams of the hand and on demo skeletons, ii) Ability to name terms used in describing normal movement at the elbow, forearm, wrist and hand, and understanding normal range of motion in all joints.
4. Muscle groups: Describing muscle groups producing normal movement in the hand, stating their origin and insertion, and the function at joints over which they pass.
5. Voluntary muscle testing (VMT): i) Describing starting positions and methods of VMT for each of the muscles, in particular on patients selected with deformities, ii) method of carrying out VMT and assigning muscle grades to be checked by experienced observers.
6. Nerve supply and effects of their damage in the hand: i) Describing and marking the areas of skin supplied by the ulnar, median and radial nerves, ii) Naming muscle groups supplied by each nerve and movements (function) brought about by such nerve supply, iii) Naming the deformities arising from damage to each nerve trunk.
7. Foot- structure and function: i) Naming and describing bones of the ankle joint, tarsal and tarso-metatarsal joints, ii) naming anatomical movements at these joints and the normal range of movements at these joints, and iv) nerve supply and deformities arising in the joints as a result of such nerve damage.
8. Muscle groups in the foot: Naming and describing the general location and action of the muscle groups of the leg, foot and toes, ii) origin and insertion of muscles producing movements at all the joints of the foot.
9. Nerve supply and effects of damage in the foot: i) Describing and marking the areas of skin supplied by the common peroneal nerve, tibial nerve, lateral and



medial plantar nerves, sural nerve and saphenous nerve, ii) Naming the muscle groups supplied by each nerve and the movements (function) brought about by each muscle group, iii) Naming early and late deformities arising from damage to each nerve, especially in relation to the sole of the foot.

10. Eye: i) Describing the eyelids, conjunctiva, sclera, cornea, iris and pupil, lens., ii) orbicularis oculi muscle and temporalis muscle., iii) normal movements of the eye, iv) results of nerve damage- sensory loss and muscle paralysis, v) facial nerve and facial paralysis.

Curriculum for Term II

The focus is on special problems in the management of leprosy, with emphasis on its chronic nature, and the responsibilities of the LPT for providing physical therapy and rehabilitation.

1. Types of leprosy: i) Knowing the main types of leprosy, ii) Describing differences in skin signs, iii) Describe signs of different reactions

2. Nerve trunk palpation: i) Naming and locating on human figure charts the 8 nerve trunks most commonly affected in leprosy patients, ii) palpating ulnar, median, common peroneal and tibial nerves on normal people and then palpating and feeling for enlarged nerve trunks in particular patients, guided by experienced staff.

3. Nerve fibre function: i) Naming the three types of nerve fibres present in nerve of the hands, feet and eyes, ii) describing the normal functions controlled by each, iii) describing signs of damage to each type of nerve fibre.

4 Skin sensitivity testing: i) describing procedures for testing skin sensitivity, use of the threshold tests- Von Frey monofilament nylon / Semmes-Weinstein standardised nylon monofilaments method and supra-threshold tests using ball-point ii) detecting areas of insensitivity present in particular patients, iii) recording insensitive areas on a chart of the body, iv) determining presence or absence of protective sensation in the hands and feet.

5. Benefits of early leprosy treatment: i) Describing benefits of early diagnosis and adequate treatment, ii) enabling LPT trainees to convey these benefits to leprosy patients, iii) identifying patients with nerve damage before treatment was started, iv) identifying these from records of patients with and without nerve trunk damage, v) nerve trunk damage as a sign of progression of impairment.

6. Extent of movement loss in the Hands and Feet: i) describing the normal movements and the signs of

reduced or lost movement in the hands and feet of specific deformities in leprosy patients, ii) importance of range of motion, iii) recognizing the absence of normal movements and other abnormalities in i) hands, and ii) feet of particular patients, in early and late stages.

7. Eye changes in leprosy: i) reviewing the normal appearance of the external eye, review functions of conjunctiva, cornea, lens, vitreous ii) description of signs of damage to conjunctiva, sclera, cornea, lens, iii) observing signs of damage in eyelids and eyeball in particular patients especially with lagophthalmos and patients in reaction, preferably when of slight degree, iv) describing pain and loss of vision, v) identifying eye emergencies in the field- conjunctivitis, iritis, exposure keratitis, poor vision, loss of vision leading to blindness, vi) instructions on prevention of eye complications, vii) testing vision with suitable Snellen's chart based on patient's level of literacy (for regular use, "open C" chart), iii) identifying patient's needing tarsorrhaphy, lagophthalmos correction.

8. Neuritis: i) defining neuritis, ii) listing early and later signs of neuritis, iii) describing differences in types of neuritis, iv) explaining their onset, severity and frequency, v) recognizing signs of neuritis in particular patients as early as possible and by palpating each nerve commonly affected, vi) identifying early and late signs of neuritis in the commonly involved nerves of the upper and lower limb, and face. vii) recommending rest and splinting of the part as early treatment in the field, and referral for anti-inflammatory medication, viii) describing severity of neuritis as a marker for appropriate attention in field conditions, ix) providing skills for essential care of leprosy patient with acute neuritis.

9. Primary and Secondary impairments: i) description of untreated neuritis, ii) primary impairments, iii) secondary impairments, iv) ways to prevent secondary impairments, iv) identifying early primary and secondary impairments in the field in particular patients whose neuritis remained unrecognized early, for appropriate treatment.

10. Wounds and Ulcers: Description of different types of wounds and ulcers, ii) signs, symptoms, and causes of ulcers, iii) early management in the field, iv) recognition of closed wounds / blisters, v) methods of resting extremities with wounds, vi) the role of sterile dressing, taping, POP application, pharmacological agents, minimal surgical intervention, corrective footwear and their modification, vi) role of health education.



11. Essential exercises: i) Description of simple exercises to prevent contracture in i) claw hands, ii) adducted and supinated thumb iii) drop foot, and iv) weak eyelids, v) muscle strengthening to improve function.

12. Complications: i) recognizing signs of complications in the hands, eyes and feet in particular patients, ii) identifying which conditions constitute emergencies in the field in the hands, feet and eyes, iii) selecting the specific methods for each patient iv) listing signs and / or symptoms which can be improved by physical therapy and home self care, v) description of steps in prevention of deformity and disability. .

Curriculum in Term III

1. Goals of physical therapy: defining and describing the goals of physical therapy, ii) ways in which LPTs reach these goals, iii) differences between deformity and disability, and iv) prevention of deformity and disability.

2. Responsibilities of physical therapy technicians in the field, local clinic and a hospital.

3. Details of Plantar Ulceration: frequency and long term effects (separate subject matter)

4. Physical therapy techniques: describing supervised physical therapy and self care techniques useful to retain and restore function, including i) active exercise against resistance, ii) active exercise against gravity, iii) active exercise with gravity eliminated, iv) active assisted exercise, v) passive exercises, vi) skin care, vii) treatment of wounds, viii) footwear and safety in work, ix) plaster casts for foot ulcers, x) body positioning, xi) below knee amputation walking exercises, xii) crutches and crutch walking, xiii) other modalities of physical therapy for hands and feet- wax bath, oil massage, hydrotherapy, different thumb and finger splinting techniques, xiiii) special attention to anaesthetic areas of the hands and feet, and the ability to provide wax bath without complications, xv) application of hand and thumb splints without pressure sores, improving ROM, and amputation stump bandaging.

4. Assessment and Record maintenance: Reviewing procedures for assessing and recording i) early nerve trunk damage, ii) skin insensitivity, iii) muscle weakness, iv) eyelid and eyeball abnormality, vi) joint contractures and inflexibility, v) several types of hand deformities- swan neck, boutonniere, mallet, guttering,

web contractures, absorption vi) disability evaluation using the World Health Organization Disability Record.

5. Goniometric measurements / template measurements: describing method of taking and recording measurements with hand held goniometer, there application for hand and foot joints, ii) goniometric measurements of normal range of motion in the joints of the hand and foot, iii) measuring ROM limitations in particular leprosy patients with deformities iv) importance in surgery and follow-up review.

6. Indications, contraindications, limitations and complications of modalities used in physical therapy: describing these for every technique used in physical therapy of particular leprosy patients, ii) selecting most practical technique with good value, iii) naming techniques which are contraindicated in particular situations and knowing the reasons, iv) listing possible limitations in techniques and knowing the reason, and v) listing methods of avoiding complications in routine techniques.

7. Problems in patient cooperation: listing known reasons for patients not taking regular medications / carrying out treatment instructions as advised i) patient and community ignorance regarding infectivity, treatment and prevention of deformity, ii) feeling of rejection by family members, iii) submission to fate when neighbours / known society reject them, iv) financial problems resulting from employer's pressure / termination, v) despondency about life and their families future, and vi) failure of concerned leprosy workers in understanding/providing patients' specific needs,

8. Successful patient cooperation: listing steps to be taken in getting patient's cooperation in therapy, the role of community leaders, the community, health workers, and i) teaching patient cooperation for deformity prevention, ii) successful cooperation and the association of restoring hope for the patient's future

9. Planning patient's treatment: outlining steps in planning of physical therapy, health education and home self care for patients, including i) identifying realistic goals to improve conditions in the patient's work area, his family and his community, ii) choosing the best and practical physical therapy techniques in reaching these goals, iii) describing methods for evaluating success, iv) choosing methods for follow-up after discharge from good care.



10. Evaluation of treatment: i) describing signs when a patient is unlikely to make any further improvement, ii) describing actions that can be advisedly taken in particular patients, iii) recognition as to when treatment cannot be expected to result in further improvement and iv) when treatment is no longer needed.

11. Organization skills: describing of an organization, responsibilities, staff relationships and conditions of working to satisfaction, as in most common assignments: i) in a hospital physical therapy section, ii) as a physical therapy technical staff role in field conditions, iii) as in-charge of a leprosy physical therapy and rehabilitation clinic, iv) and when working under supervision

12. Patients for surgery: describing goals of surgery, identifying particular patients for surgical assessment, identifying potentials problems, identifying patients unsuitable for surgery.

13. Physical therapy for surgical patients: i) role of physical therapy, ii) describing physical therapy contribution to the success of surgery, iii) listing common surgical techniques used for leprosy patients- a) tendon transfers, b) contracture release, c) capsulotomy, d) arthrodesis, and e) tenodesis, f) skin grafting., iv) describing essential pre and post-operative physical therapy goals in each surgical programme.

14. Goals in specific operations: i) pre-operative description of most common surgical corrections used in leprosy patients with claw hands, foot drop, wrist drop, contractures, lagophthalmos, foot deformities., ii) indicating surgical goals for each, and describing goals to be achieved through pre and post operative physical therapy, iii) observing common operations in the OR, iv) identifying structures exposed and answering questions asked by surgeon, vi) making a plan for post operative physical therapy.

15. General guidelines of physical therapy techniques in post-operative period: role of protection, control of swelling, muscle re-education, maintaining suppleness and joint movements, maintaining and improving strength, safety in ADL, and home self care.

16. Physical therapy schedules for specific surgeries: describing day by day goals in physical therapy for specific procedures used in claw correction, opponensplasties, foot drop correction, using knowledge and skill to obtain deformity correction under supervision.

Structured teaching of special subjects / aspects related to leprosy physical therapy and rehabilitation: (added on gradually from 1984)

Sociology: 10 hours

Socialization: influence of social factor on personality change in leprosy afflicted, socialization within hospitals during investigations, therapy and surgery, socialization in the rehabilitation of leprosy patients in the hospitals or in selected centres

Social groups: concept of social groups and influence of formal and informal groups on health and sickness, the role of primary group and secondary groups in the hospital settings.

Family: influence of patient's sickness of leprosy on family members, discussion of changes in function within the family. Influence of the family on the patient's health and future well being, the psychosomatic disease syndrome.

Community: role of rural / urban communities having leprosy afflicted individuals, role of community in determining beliefs in treatment, practices and home remedies in proper treatment, continuation of normal relationship and contacts.

Social change: social changes and stress, deviance, health programmes, the role of social planning in the improvement of health and rehabilitation of the leprosy, individual.

problems of the leprosy disabled

Consequence of leprosy: relationship and the remedies in preventing social problems associated with leprosy-poverty and unemployment, beggary, vagrancy, alcoholism. *Estrangement:* definition and its prevention, leading an independent life, responsibility to oneself and self respect.

Social security and social legislation: affects of these in relation to Leprosy disabled

Occupation: continuation and adjustments with former occupation, alternate employment options, training for new vocations, appropriateness of vocations in relationship to deformity and anaesthesia.

Health psychology: 10 hours

Psychological reaction of a patient in diagnosis, in admission, in investigation, describing anxiety, shock, loneliness, rejection, fear, withdrawal, depression,



emotional over reactions, confusion, anger, hostility, loss of hope.

Communications: barriers to good communication, effective communication and the specific communication techniques used for leprosy patients.

Emotional needs: psychological factors in relation to leprosy handicapped patients, long stay patients, peripheral nerve paralysis, disfigurement.

Psychological support for the leprosy disabled, family visits, reassurance, health workers attitudes

Compliance and motivation: describing factors contributing to non compliance in medical, physical, vocational and rehabilitative therapy sessions, ways of improving compliance, enhancing motivation of individual leprosy patients, enhancing motivation of groups of patients.

Counselling: principles in counselling leprosy patients, and the qualities of a good counsellor in leprosy.

Dermatology: 10 hours

1. History, Aetiology, Epidemiology of Leprosy.
2. Pathology and Immunology of Leprosy.
3. Signs and Symptoms of Leprosy, differential diagnosis of Leprosy
4. Classification of Leprosy, differentiating Paucibacillary and Multibacillary leprosy.
5. Peripheral nerves involved in leprosy in the upper and lower limbs, and peripheral and central nerves in the face, palpation of nerves for signs of enlargement and tenderness, associating nerve involvement with distal impairments
6. Neuritis and reactions in leprosy and changes in the musculoskeletal system
7. Complications in peripheral nerves and other systemic changes.
8. Definition of Impairment: Primary and Secondary: WHO categorization of disabilities
9. Bacteriological Index and Morphological index.
10. Medical aspects including Paucibacillary and Multibacillary drug therapy.
11. Preventive aspects, Antileprosy medication, Multidrug therapy (MDT)
12. Practical Classes on Skin smear and Nerve Biopsy.

It is incumbent on this course being introduced where there is a full compliment of personnel like Physician,/ Dermatologist, Rehabilitation Officer/ Vocation Guidance Officer, Social Welfare Officer, Physiotherapist, Occupational Therapist and Surgeon.

Plantar ulcers in leprosy

Instruction hours: Theory 25 and Practicals 52,

Clinic Attendance: 208 hours. Total 285 hours.

1. Definition of Plantar Ulcer and synonyms, explain traditional "Trophic ulcer"
2. Incidence, location of ulcers - forefoot, mid foot and hind foot
3. Pattern of plantar ulcers in different types of Leprosy, comparison with anaesthetic ulcers seen in Diabetic Neuropathy.
4. Relationship: explanation of misconception with duration of leprosy, presence of mycobacterium leprae or activity of leprosy
5. Aetiology: listing all inherent causes, listing all exciting and aggravating causes
- 6 Stages in plantar ulceration: inflammation, blister, frank ulcer
7. Features and Classification: elaborate and demonstrate Superficial and Deep ulcers, Types of ulcers- sub-acute and chronic, explain and demonstrate Simple and Complicated ulcers.
8. Aspects in Ulcer examination and recording in ulcer chart: the edge, base, depth, discharge, presence / absence of Slough (demonstrate), association with tenosynovitis, joint involvement and infection , brief explanation of bacterial flora in plantar ulcers
9. Constitutional changes in patients with ulcers: as signs of acute spread, additional infection, and cellulitis, prompt actions to be taken in the clinic / field
10. Differentiating early ulcer and recurrent ulceration
11. Plantar ulcer and secondary deformities (anaesthetic deformities)
12. Plantar ulceration and squamous-cell carcinoma: incidence
13. Malleolar Ulcer: causes, treatment , prevention
14. Treatment: a. Outline outpatient treatment techniques, b. Mention treatment in the Inpatient setting,



c. Minor procedures in the outpatient setting, d. Indication for admission, surgery and special footwear, e. Indication for POP cast, types of casting- below knee walking cast, moulded double rocker cast, f. List advantages of casting, g) total contact casts.

15. Sinuses and fistula: definition of sinus and fistula and explained with diagrams, ii) causes, locations, identification, explanation of 'Probing' and 'Laying-Open', time when these are done, after care.

16. Squamous cell carcinoma: definition, the incidence, description of suspicious features, discuss causes of malignant change of plantar ulcers, significance of examination of lymphadenopathy, significance of jaundice in plantar ulceration, treatment- local, ablative, follow-up care, special prosthesis for particular ablation and type of foot after treatment of squamous cell carcinoma

17. Chronic foot deformities in plantar ulceration: describe foreshortened foot, absorbed toes, claw toes, hammer toes, inverted foot, everted foot, flat foot, rocker-bottom foot, associated foot drop, neuropathic degeneration of ankle and foot.

18. Local and general treatment: Local dressing – applications, indications for sterile dressing w/ gauze and gamji pad, saline, fresh sodium hypochlorite solution, indications for soaking of ulcerated feet, Zinc tape application and indication

19. Briefly: Surgery in plantar ulcers- minor including pairing, curetting, excision of slough, trimming, laying-open sinus and fistula tracks., major including tenosynovectomy, arthrotomy, sequestrectomy, osteotomy, wedge resection, tendo-Achilles lengthening, limited fusion, triple arthrodesis, amputations- deformed toes, trans-metatarsal, mid-foot, trans-tarsal, Boyd, Symes, BK.

Basic Surgical Nursing: Instruction hours: 10.
Lecture and Practical Demonstrations.

Introductory class:

1. Defining Clinical nursing. Principles in Nursing.
2. Describing good inter- personal relationship
3. Observation, reporting and recording of Temperature, Respiration and Pulse,
4. Simple Aseptic Techniques of wound care
5. Bandaging of extremities: injured / ulcerated. Stump bandaging

Triangular Bandages, their application in injured upper limbs

6. Preoperative limb preparation
7. Disinfection.

General inpatient & outpatient care:

1. Definition of Sterile handling of hand and leg wounds, Cleansing of wounds,
2. Use of Surgical glove: a. protective gloves and b. Sterile gloves
3. Dressings: Gauze dressings, Gamje pad dressings and bandaging.
4. Needle stick Injuries: Prevention, early attention and subsequent care.
5. Handling of compromised patients, etc., eg: HIV patients.
6. FIRST AID: Syllabus as for Certificate of Red Cross Society and St. John's Ambulance Brigade.

Health Education in leprosy

Instruction hours: 30, Interactive session of students with participation during Ulcer Clinics: 104 hours

1. Explain Health Education Importance to treatment and Control of Leprosy
2. Health education directed towards: Receptive relatives, to the public and patient
3. Importance to school teachers, school students, and medical personnel
4. What is Team Work in Health Education ?
5. Explain the advantages of rendering health education at any setting
6. Explain Staff conscientiousness required for success of Health Education
7. Methods of teaching these facts: w/ visual aids of all kinds, simple talks on specific aspects of Leprosy and causes the disease, practical sessions on the negative influence of carrying heavy objects with anaesthetic hands, standing for a long time with ulcerated and anaesthetic feet, Cooking classes with improvised tools
8. Motivation of people to change old habits, explaining benefits of changing certain habits
9. Explain need for delivering short 10-15 minutes talk in the vernacular
10. How to Prepare a teaching session: as in introduction, important teaching points, summary, entering details of progress made after each session



11. Details of the way of Actual Presentation to be made: measured talks with reasonable speed for all to understand, allow some pauses, provision of only 2-3 new ideas in a talk, illustration with local story, skit in a popular movie, focussing on all individuals in the audience, attracting the inattentive, ambience: seated audience with comfortable spread each participant is seen ,greeting the group, making things pleasant, keeping talks short, allowing enquiries from audience, encouraging discourse.

12. Aspects for Health Education and facts about leprosy, the absolute necessity for Medical treatment, emphasis that leprosy is curable, anti leprosy tablets cure leprosy and injections are not better than tablets, taking of medicines exactly as instructed, explain advantages of MDT and that patches disappear slowly even as treatment is stopped.

13. Teach general hygiene, washing of hands, bathing fairly regularly, boiling water before drinking,

14. Explain about Loss of feeling / sensation. Inform them that there is no medicine to bring back the feeling. Practicing to be careful not to touch hot objects, sharp objects, not getting any wounds will prevent against shortening and destruction

15. Explain about Neuritis: the sites, the early loss of sensation and other Signs of weakness, explain about Reactions; about sudden change in nature of skin patches, pain in the eyes and specific areas of the nerve, joint pains, lymph node enlargement, fever and the need to report to the health worker of hospital

16. Explain about early recognition of leprosy, the signs: patches, loss of sensation, nerve thickening, weakness of the hands or feet or inability to close eyes, and the need to go immediately to the hospital or clinic

17. Explain causes of deformity: primary and also especially about the secondary deformity: burns and cuts getting neglected and infected, leading to loss

18. Explain importance of soaking feet and inspecting hands and feet atleast once a day. Explain use of vegetable oil for dry skin

19. Explain ways of preventing plantar ulcers, including foot wear and its importance. Teach care of blisters, and talk about rest to the feet. Teach handling of hot utensils with cloth, padded or wooden handles, mitten gloves. Use the 'mother-child simile' for the eyes (the mother) to take care of her hands (the child)

20. Eye care: To go to the clinic or hospital if there is burning,redness, watering, pain around the eyes, loss of vision, and inability to look at sunlight. Advise not to rub with cloth but to use a eye shade or dark glass. Immediately visit the hospital for examination and preventive treatment.

21. Teach about washing eyes every day, exercise the eyelid and gently massage all around, use a mirror to inspect the eye if it is difficult to close it fully, keep the eyes covered with a clean cloth at night, and not to sleep in a dusty room or in the open.

22. Explain the simple aspects of General Hygiene: a. body, b. clothes, c. the house environment, and 4. the compound and neighbourhood. Teach simple first aid for burns, cuts, blisters, splinter that enters hand or feet, cracks on the feet. Teach importance of washing, protecting and resting

23. Provide specific health education about Care of the Walking cast, and protecting plaster applied on the hand after surgery

Occupational therapy for leprosy physiotherapy technology

Instruction hours 25: Theory 10 and Practical demonstrations 15, Written and Oral Examination in the IV Semester

1. Definition of Occupational Therapy, importance of psychological & functional aspect of OT care for patient
2. Aims and Reasons for returning patients back to a useful place in society.

3. Various functions of the Hand: every day used patterns in the hand, provide examples for explaining Hold, Grip and Handling of objects, emphasize requirements for hand function to be successful: Sensation, Mobility and Stability.

4. Two basic ways of using hand: a) Prehensile functions and b) Non-Prehensile function:

Define Prehension and the use of thumb in opposing four fingers to hold objects

Explain the 2 main prehensile functions; Grasp and Pinch, explain and provide suitable examples

5. Define Non prehensile function and the use of whole hand without the thumb playing an opposing role (thumb in the plain of the palm). Explain common non prehensile functions- Pushing, Clapping, explain and provide suitable examples

6. Define Grasp: the ability of the hand to surround objects and hold them between palm and fingers, mention types of Grasp- Cylindrical grasp as in holding



a tumbler, Diagonal grasp as in holding a racquet, Transverse (Hook) grasp as in holding a suitcase

7. Define Pinch: the ability of opposing thumb against one or more fingers. Mention types of Pinch- Pulp-to-pulp pinch using all fingers as in holding a marble, Tripod pinch using the index and middle finger as in holding a pen, Lateral Pinch by using the radial border of index finger as in holding a key, Tip Pinch by using the tip of the thumb nail against the index nail, picking up a pin

8. Define Cupping of the hand: the ability of cascading the four fingers against the opposing thumb. Mention the traditional common cupping actions in our culture. Explain the importance of eating rice with the hand. Give simple examples of how this action may be lost in ulnar nerve paralysis in leprosy

9. Define Dexterity in hand function: emphasize importance in fine movements and provide examples, emphasize its importance with regard to accuracy and speed and provide examples.

10. Versatility: define and mention a suitable example like playing musical instruments.

11. Mention main areas of Occupational Therapy for HLPT patients:

Explain and give Details for the following:

1. Functional ability evaluation before and after surgery
2. Psychological evaluation and orientation of the patient to functional possibilities after reconstructive surgery
3. Teaching of practical training of prevention methods relevant to the patient
4. Retraining correct hand functions post-operatively
5. Building patient's confidence in herself / himself.
6. Assessment of the patient's ability to return to work or a possible change of employment
7. Introducing adaptive methods for carrying out work and activities of daily living by:

Devising adaptive tools and making splints for patients with more severe deformities.

8. Adapted Methods: padded handles, wooden handles for handling hot objects, MCR sandals, adapted methods - Gloves, mittens, adapted splints - palmar pocket, opponens splint

9. Evaluating functional ability: Evaluation of various Hand Functions, Evaluation of vocation of the patient, Evaluation of Self-care abilities

10. Injury prevention: Through "on the Job" training in avoiding injuries, Injury chart

11. Description of Functional problems of anaesthesia: in being prone to injury by repetitive use of hand even

for routine use. Mention common types of injuries: scratches / pricks, friction blisters, cuts, burns, cracks. Stress on the need for patient to understand causes of hand injury / ulcers. Emphasis on the Care of anaesthetic extremities

12. Explain consequences of paralysis not adequately attended, explain reasons for these leading to deformities, emphasizing the important points for deformity prevention, elaborate on training methods used in preventing injuries in the deformed

13. Explain the need for involving patient in his / her own care, awareness of the specific causes, mention the need in understanding the individuals work & ADL.

14. Knowledge that patients require for protection: Mention about looking & thinking ahead, and mention about uses of protective devices.

15. Practical Trial of suitable methods: testing out various methods by their uses & acceptability. Stressing on required understanding by therapist of all the possible causes of injuries in relation to particular aspects of a patient's lifestyle. Discussing methods patients must use or get training in for the certain way in preventing similar injuries occurring in the future. Conduct evaluation of the success / failure of the chosen protective methods through injury records.

16. Define Injury chart: used by therapists to record injuries sustained on anaesthetic hands, describe all the features recorded on these charts. Describe conventional symbols used in denoting adverse features on a picture of the hand: eg., © for clawing, (b) for blister, etc. Describe conventional shading / lines used in denoting features on the picture of a hand: Eg., Dark shade for Absorption, Shade with slanted lines for Anaesthesia

17. General principles followed in Assessing functional problems in patients: i). recording the steps / stages involved in the job or task, ii). Analysing them in small steps

iii). Tools used by the patient at work, iv). Positions adopted by patient while working, whether seated or standing, v).the place of work itself.

18. Simple explanations of Ergonomics & Environmental work-site factors in prevention of: i). Overuse 'syndrome', ii). Repetitive strains, iii). Tendinitis

19. Simple approach of preventing Anaesthesia problem in the hand: i) use of eyes in becoming aware of danger areas, ii) the practice of examining own hands & feet every day, iii). use of moulded handles for accurate distribution of pressure to whole of palmar surface,



iv). Padding of handles to make them bigger for pressure distribution over a large area, use of micro-cellular rubber, Sponge piece or Used cloth piece, v). Protection by use of cotton gloves while working
20. Discuss importance of Foot wear for anaesthetic feet: Explain about lost sensation on the sole of the feet and paralysis of small muscles of the foot that lead to ulceration. Explain principles of Protective Footwear:
i) Covering as prevention against injury from heat, sharp stones or thorns, ii) Padding to lessen effects of muscle wasting and to give soft surface for bony prominence, iii). Moulding to increase weight-bearing area, and to take weight off a danger spot, iv). Rigidity to stabilise the foot

Simple Orthoses and Prosthesis used for deformities in leprosy patients

1. Hand: Knuckle bender splint, PIP extension splint, Thumb abduction splint, Various wrist drop splints, rest splints, D-ring dynamic splint

2. MCR sandals: modifications are described including Types of MCR Slippers for anaesthetic feet- V-model (Village model), X-model with cross over straps at forefoot section- commoner for modification, Y-model with Y-shaped strap at the forefoot level to accommodate dressings, Sole additions: Metatarsal Bar, tyre rubber bar underside of sole at metatarsal heads, Medial arch support placed on the inside of the sole to raise the arch, Thomas heel

3. Details of Indications: listed for MT bar, Medial arch support and metacarpal pad, Thomas heel, Heel counter and cushion, Double bar

4. Suitable footwear for specific foot problems: Grade I - Anaesthesia & small muscles paralysis- MCR sandals with back straps, Grade II - Several forefoot scars- MCR sandals with metatarsal bar (MT bar), Grade III – Short foot due to loss of bone- Moulded shoe, v. Grade IV – Unstable foot with inversion at the mid foot- FAB walker or PTB

D. Anterior Foot drop spring: indication and uses. Compare with static moulded splint

5. Description and Indications for - Moulded boot, Fixed ankle brace, Weight relieving brace, Patella tendon bearing (PTB) prosthesis, Symes prosthesis, Sethi's BK Prosthesis

6. Practical classes for devising simple orthoses in field conditions: example using covering materials: rubber and leather, Padding materials: layer of soft rubber like Microcellular Rubber (MCR), rest splints.

Rehabilitation in leprosy

Instruction Hours: 12. Oral examinations in Final Semester

1. Definition, psychological aspects to rehabilitation,
2. General principles of Rehabilitation, the need for rehabilitation
3. Special problems in Leprosy. Compare with other diseases, discuss the role of stigma and ostracism as impediments to rehabilitation
4. Assessment and application of method of rehabilitation
5. Role of physical therapy, role of surgery, splinting, special footwear / prosthesis. importance of early surgical rehabilitation when the deformities are established.
6. Rehabilitation through social means and psychological well being.
7. Rehabilitation through vocational means- i) traditional as in poultry, piggery, sewing shoes, woodwork (carpentry), knitting, weaving, other handicraft making, etc., ii) modern options in the more industrious and the motivated.
8. Team approach to rehabilitation
9. Future of rehabilitation
10. The need for Care after cure

Record book

Hours for completion: 12.

Recommended to be done in Last Semester

- Emphasis on Record Book presentation, originality and neatness.
- Marks for consideration in Final Internal Evaluation in IV semester.
- Selective Anatomic diagrams from Grant's, Cunningham Manual of Anatomy
- Diagrams of the Different Types of Cells, Skin, Nerve cell,
- Selected physiology Diagrams
- All hand Physical therapy techniques
- Brand's Volumeter
- Wax Bath, FEPS apparatus
- Selected hand Exercisers, splints
- Selective illustrations with labelling of common footwear for Leprosy patients



Curriculum on Leprosy followed by CMC Vellore, for **Bachelor of Physiotherapy (BPT) Degree**, Dr MGR University, Tamil Nadu

Under Microbiology – during 2nd Year end of 3rd Semester: [25 Instruction hours for a total of 12 Topic headings], Topic under **J.6:** Leprosy, Tuberculosis & Miscellaneous infections (**2 hours**)

Under Pathology – during 2nd Year, end of 3rd Semester: [25 Instruction hours for a total of 17 Topic] Topic under **K.** Skin, Leprosy (**2 hours**)

Under Ophthalmology: during 2nd year 3rd semester. Topic under **1.** Eye lesion in Leprosy including causes, Treatment and complications of lagophthalmos

Under Community Medicine. during 3rd Year, 6th Semester. [55 hours Instruction hours for a total of 15 topics], Topic under subheading '**J. f** hours not specified', Description of Leprosy, Mode of transmission, route of entry, Levels of prevention.

Under Orthopaedics for Physiotherapists:

during 4th Year 7th Semester. [Instruction hours 55 for a total of 19 grouped Topics], Topic under subheading '**S**'. Leprosy: Outline of Clinical features and Management, Complications of Neuritis, Muscle Paralysis, Trophic ulcer of hand and feet deformities.

Under Physiotherapy in Orthopaedic Conditions

during 4th Year end of 8th Semester. [Instruction hours 120, for a total of 19 varied topics], Topic under subheading '**S**': Define Leprosy. Review incidence and mode of transmission. Review clinical features, common deformities and medical management. Review tendon transfer operations and describe physiotherapy management before and following tendon transfers. Describe risk of anaesthetic limbs and outline its care to prevent complications. Review plantar ulcer in leprosy and its management (including foot wear)

Observation and Suggestion

The different curriculum on leprosy physiotherapy and rehabilitation as can be seen above places different degrees of emphasis on the aspects of such care. This had come about from the unique position that leprosy Physiotherapy technicians had taken on / were given - the actual responsibility of providing day to day basic care with Physiotherapists and Reconstructive surgeons guiding them.

Probably there is a need for a Leprosy Physical therapy and Rehabilitation Curriculum committee that can restructure the curriculum and programme from the known objectives and knowledge already available in this field of leprosy care, to ensure larger inclusion of preferred skills to be acquired uniformly by all therapists.

Conclusion

Physiotherapy and Rehabilitation will continue to remain the inalienable right, or rather be rendered to every individual affected with leprosy at every stage of the disease. Now the input from all categories of health workers in ensuring that leprosy services are integrated in to the GHC would contribute immensely to leprosy being labelled honestly as 'just another bacterial disease' and probably this may come about ahead of the 'leprosy is eradicated' sign, our ultimate goal.

Normal relationship of leprosy patients with their relatives and contacts are on the rise and this trend is likely to improve even further if the integrated programme were implemented with due attention to several factors. Commitment of all hospitals in promoting integrated services is the key, and a well thought of curriculum with all category of physiotherapy graduates committed to practicing leprosy physiotherapy and rehabilitation wherever they work, will be a good example of rising in unison to the next higher ideal in leprosy services: a seamless integration of leprosy care into the general health services.



Status of PM&R curriculum, training and services in Bihar today with reference to leprosy

Dr. Ajit Kumar Varma,

MBBS Hons., MS., DNB (Physical Medicine & Rehab.)

*Physiatrist & Co-ordinator, Leprosy Reconstructive Surgery and Rehabilitation Program,
Professor and Head, PMR Department, Patna Medical College, Patna*

In Bihar, having its **38 districts** so far, with a total estimated population of **91482684** as on March 2005 with (**SC figuring 14398928 and ST 1122208**) the number of Leprosy cases reporting at the end of August 2005 figures 16937 only. It is significant to note that the prevalence is 1.85 and the existing number of Sub-Centres in Bihar is 8930 whereas the **number of Sub-centres providing MDT is only 8590**. The Damien Foundation, India Trust (DFIT) in Bihar with its Technical Support Team (One Doctor and one supervisor) covers only 22 districts and makes a great contribution. Rest 14 Districts are being covered by the Lepra India(9), Netherlands Leprosy Relief Association (NLR) (5) and The Leprosy Mission International (TLMI) (1) respectively.

The Status of PM and R curriculum, training and services in Bihar today with reference to leprosy has reached a new height and has assumed its own dimension . The **“Leprosy Reconstructive Surgery and Rehabilitation Program”** has been launched at Patna Medical College, Patna in January 2004 in the department of PM and R. The PM and R department is the nodal centre for leprosy services in Bihar. The Principal and the Medical Superintendent, Patna Medical College, Patna are the Chairman and the Vice-Chairman of this Program respectively & co-ordinated by Professor & Head of PM and R department. Till now 45 cases have been operated for the hand and foot deformities (42 hand cases and 3 foot cases). This program is jointly conducted in collaboration with the State Leprosy Officer, Bihar. A committee has been constituted under the Chairmanship of the Principal, Patna Medical College, Patna to review the ongoing events from time to time. The members of this review committee includes State Leprosy Officer, Bihar, Patna, Head of the Skin, VD & Leprosy Deptt., Head of the Orthopaedics, Associate and Assistant Professor of PM and R Department of Patna Medical College, Patna. Since this department fulfills all the infrastructure for rehabilitating Leprosy cured persons

for their hand and foot rehabilitation, the program goes on successfully. A Physiotherapist has exclusively been deputed from the SLO, Bihar, Office, Bihar, Patna to the department of PM and R, Patna Medical College, Patna for pre-operative & post-operative exercises program. All such activities are being supervised by the Physiatrists too. A visiting **Reconstructive Surgeon, Dr Jacob Mathew** and his team demonstrated newer surgery techniques and also assisted to assess the pre and post operative activities and evaluation. This courtesy is being extended by the Damien Foundation, India Trust (DFIT) to PM and R Department at Patna Medical College, Patna

The Post Graduate students and the House Surgeons of PM and R Department are also being trained in the pre operative evaluation, selection of right cases for operation, post operative tendon re-education and rehabilitation program. The Leprosy Rehabilitation has well been accepted in PM and R curriculum at Patna University also. One candidate doing his **Ph.D thesis**, is also carrying out his research activities at PM and R Department, Patna Medical College, Patna. The undergraduate students (**MBBS**) of Patna Medical College, Patna, posted at PM and R curriculum, are also well covered on Leprosy Rehabilitation topic along with their routine class lectures. The Govt. sector in Bihar, NGO's and the University level all have extended their supportive hands in making this program a great success by collaborating with the department of Physical Medicine and Rehabilitation, Patna Medical College, Patna, Bihar.

I feel confident that, all states and PM and R Departments of this country will include the training, services in their PM and R curriculum with reference to Leprosy.



Status of PM &R curriculum, training and services in Rajasthan today with reference to leprosy

Dr. Navnendra Mathur

Prof. & Head, Dept. of PM&R, SMS Medical College, Jaipur, Rajasthan

Leprosy work in Rajasthan started as Leprosy control programme in 1970 – 71 and then was converted to eradication programme in 1981 – 82.

Up to July 2005, 55,488 patients of leprosy has been detected and 53,542 patients have been completely cured and the rest 1946 are still under treatment at various centers.

The following units are working for leprosy eradication programme :-

1.	Directorate	one	State leprosy eradication programme
2.	State Leprosy units	four	Nagaur, Jodhpur, Jaipur, Bara
3.	Leprosy control Units	Six	Bharatpur, Bundi, Jhalawad, Kota, Udaipur, Ganganagar.
4.	Temprary Hospital wards (20 beded)	Four	Jaipur, Jodhpur, Udaipur, Bikaner
5.	Urban Leprosy centers E.S.I. Hospital Jaipur	Five	Jaipur, Kota, Udaipur, Jodhpur,
6.	Leprosy Hospitals	Two	Jaipur, Jodhpur.

Following this programme the disease prevelance rate has been decreased from 0.82 / 10,000 persons in 2000-2001 to 0.31 / 10,000 persons in 2004 -2005.

The worst part is that there is no rehabilitation programme going on in leprosy eradication programme.



Status of Physical Medicine and Rehabilitation (PM&R) curriculum, training and services in Tamilnadu today with reference to leprosy

Dr. V. Ramamoorthy

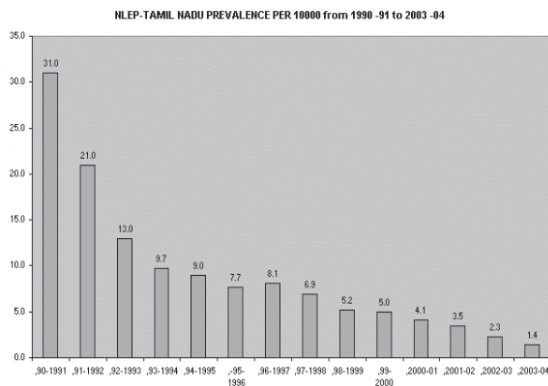
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Consultant Psychiatrist, PSG Medical College and Hospital, Coimbatore, Tamilnadu

In India, leprosy is known since ancient times as *Kustha roga* and attributed to punishment or curse from God. Leprosy is widely prevalent in India. Although the disease is present throughout the country, the distribution is uneven. As of March 2004, the PR is 2.3 cases per 10000 population, reduced from 57 per 10000 in 1981.

As the prevalence of leprosy has come down, integration was designed to change over from service delivery through the vertical leprosy staff and specialized leprosy hospitals to that of GHC services. TamilNadu has been the first state in our country to have implemented the scheme since 1997.



NLEP – TamilNadu: Prevalence of Leprosy

Year	Prevalence per 10000 population
1983	118
1990	53
1995	9
2001	4.1
2002	3.5
2003	2.3
2004	1.4

Ref.: Department of Public Health and Preventive Medicine

Leprosy situation in TamilNadu

April 2002 – March 2003

Total No. of cases	:	24757
MB%	:	28.85
Female%	:	38.50
Child (0-14 years)	:	17.84
Grade II Disability	:	1.78
Detection rate / 10,000	:	39.04
PR/10,000	:	2.34

Deformities:

As a single disease entity, leprosy is one of the foremost causes of crippling deformities. It is estimated that approximately 25% of the patients who are not treated at an early stage of disease develop anaesthesia and or motor deficits with deformities of the hands and feet.

The strategy to achieve control of leprosy consists of four major elements:

- early case detection
- adequate chemotherapy (MDT)
- prevention of leprosy related impairments and rehabilitation

The WHO Expert Committee on Leprosy in its Second Report defined rehabilitation as:

“the physical and mental restoration, as far as possible, of all treated patients to normal activity, so that they may be able to resume their place in the home, society and industry”.

Rehabilitation is, therefore, an integral part of leprosy control. It must begin as soon as the disease is diagnosed. The cheapest and surest rehabilitation is to prevent physical deformities and social and vocational disruption by early diagnosis and adequate treatment. The measure that are taken in this direction are known



as “preventive rehabilitation”. The approach to rehabilitation should, therefore, begin with preventing debilitation. We should never allow debilitation to take place and afterwards take up the uphill task of rehabilitation.

The measures to prevent disabilities include actions to take care of the dry, denervated skin of palms and soles, heal the wounds, ulcers and skin cracks in palms and soles, prevent injuries to hands and feet by using protective gloves and footwear, protect the eyes, and assess periodically the commonly damaged nerves for loss of nerve function and its progression, using simple tests that can be carried out in the field.

Improvement of disabilities is achieved through the use of prosthetic and orthotic devices, including corrective splints, as well as by corrective surgery. All these measures however, require special expertise and facilities. Rehabilitation measures may appear to be simple; they require planned and systematic actions – medical, surgical, social, educational and vocational – consistently over years with sustained counselling and health education for training or retraining of the individual to the highest possible level of functional ability.

Physiatrists and Comprehensive Leprosy Rehabilitation:

The Physiatrists have a significant role in leprosy rehabilitation. The Physiatric history and physical examination are quite different from conventional history and physical examination and are in many aspects unique. The physiatrist has special skills not only in the evaluation of neuromuscular, musculo skeletal and cognitive systems, but also the functional, social and vocational impact of the deficits. The identification of functional problems allows for the assignment of functional goals that become the basis for development of the therapeutic management plan.

Current Scenario

Current thrust of Leprosy management is restricted to General Physicians, Dermatologists, Plastic surgeons and some paramedical personnel. With diminishing incidence, low prevalence and relatively high disability rate of about 2% among the leprosy affected population, there is a need for a bigger role of PMR specialists in the prevention and management of disabilities due to leprosy.

Against this backdrop, the current level of leprosy related curriculum, training and services in Physical Medicine and Rehabilitation in TamilNadu is to say the least- grossly inadequate. PMR Institutions in the country have a definite role to play in the strengthening of integration phase.

I. Present Curriculum:

In PMR curriculum, leprosy is restricted to a single chapter on

Leprosy:

Classification
Clinical features
Diagnosis and treatment.

Recommended Text book

Leprosy : Ridley & Jopling

Recommended Journal

International Journal of Leprosy

II. Present Training:

The training consists of just 1 week postings to a Department of skin and Leprosy in a government general hospital, where the majority of cases would be general Dermatology rather than leprosy.

III. Present Services:

At the moment, rehabilitation services are currently being offered through a scattered group of NGO's, GO's and private institutions.

Need of the hour

With the integration of leprosy into the General Health Care system, and the large number of leprosy disabled persons, there is an urgent need for more comprehensive training in management and rehabilitation of leprosy for Physical Medicine and Rehabilitation specialists.

I. Proposed Curriculum

The syllabus on leprosy in PMR curriculum is insufficient and leprosy is not a priority for the current generation of PMR students. There is a need to revamp the syllabus/ curriculum on leprosy for PMR students in the context of the integration of leprosy with GHC. The curriculum should be expanded to address the following major problems of the leprosy patients:



Physical	–	Deformities, Ulcers, and Disabilities
Social	–	Discriminations, isolation, Martial disharmony
Economical	–	Unemployment, Under employment, Poverty, Illiteracy, Ill housing
Psychological	–	Low self esteem, Dependency, depression, tension, anxiety, anger, hatred, aggression, suicidal tendency etc.

Medical aspects to be covered:

- Cause
- Pathology
- Symptoms and signs
- Diagnosis
- Treatment
- Reactions and their management
- Complications.

Health education in leprosy to be taught:

- Care of the skin
- Prevention of plantar ulcers
- Dressing the wounds
- Hand care, Foot care
- Eye care
- Walking plaster application
- Foot and hand clinic

Training in Reconstructive surgery

PMR being a surgical speciality, the following surgical training to be provided to PMR students.

- Tarsorrhaphy
- Tendon transfer surgery and
- Cosmetic procedures

Training in Prosthetic & Orthotic fabrication

Prostheses and Orthoses fabrication relevant to leprosy patients.

II. Proposed Training:

Training period should be increased to one month in specialized centers like SLRTC/Thirumani (Chengalpattu).

Training includes,

- Prevention of deformities and complications
- Corrective methods
 - Splinting
 - Surgical correction
 - tendon transfer
 - contracture release
 - tarsorrhaphy
 - minor reconstruction procedure

Post operative follow up and functional retraining.

III. Proposed Services:

Fully equipped Physical Medicine and Rehabilitation departments under qualified physiatrists should be started in all teaching and District Head Quarters hospitals.

The Physical Medicine and Rehabilitation department should conduct specialized leprosy rehabilitation clinics like foot/hand/eye clinic on a weekly basis.

NGO's involved in leprosy care can tie-up with private institutions having established PMR departments to provide specialized comprehensive leprosy rehabilitative services.

I congratulate and appreciate ALERT – INDIA which has been focusing on urban leprosy elimination programmes by supporting NLEP initiatives and developing an appropriate approach to integration.

Let us join hands and contribute our might in strengthening the integration of leprosy into the GHC and ultimately achieve the goal of leprosy elimination.



PMR curriculum, services and training in Karnataka with respect to leprosy

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The use of 'multi-drug therapy' (MDT) introduced by the WHO in 1981 dramatically reduced the prevalence of leprosy globally. The World Health Association's commitment in 1991 to eliminate the scourge of leprosy from the world was followed by the free distribution of MDT via the WHO free of charge in 1995. As a result of all these factors, the global case load has fallen by almost 90% over the last two decades, and elimination levels (prevalence rate less than 1 per 10,000 population) have been reached in more than 100 countries.

These figures are mirrored in India and Karnataka. According to the annual report of the Ministry of Health and Family Welfare for the year 2005, from a nationwide prevalence rate of 57.6 cases per 10,000 population in 1981, the figure last year stood at 2.44 per 10,000 per population. Karnataka is one of the states close to the elimination target with a prevalence rate of 1-2 per 10,000 population, a target which 17 of the Indian states has already achieved.

These facts show that the scenario with regard to leprosy elimination is changing. While the main principles of leprosy control, viz. early detection of new cases and treatment with MDT drugs will continue to be the essential to ensure continuation of success, organizational changes are also required. The process of integrating vertical national leprosy programmes into the general health care system already existing in cities and towns has been met – like many new initiatives – with a certain amount of resistance from both sides. This needs to be resolved at the earliest to ensure that leprosy is eliminated globally.

Holistic rehabilitation can be the key to unify the various threads of leprosy control. For this greater emphasis has to be paid to the Physical Medicine & Rehabilitation

under-graduate curriculum. The Medical Council of India had passed a circular to the Principals of all Medical Colleges in 1999 based on the resolution of the Central Council of Health and Family Welfare that all medical colleges in the country are to start a Physical Medicine & Rehabilitation department. Yet even today in 2005 only one out of the 32 medical colleges in Karnataka has a PMR department, which is at St John's Medical College Hospital, Bangalore.

Physical Medicine & Rehabilitation has been recognized as a distinct specialty by both the Medical Council of India and the National Board of Examinations. However the Rajiv Gandhi University of Health Sciences only mentions Physical Medicine & Rehabilitation as a subsection under Cold Orthopaedics, with no guidelines whatsoever on what topics need to be covered.

When it comes to leprosy, the under-graduate student in Dermatology is exposed mainly to the diagnosis and treatment of leprosy, including complications such as neuritis and plantar ulcers; in Orthopaedics to the surgical correction of deformities and in Community Medicine to the social consequences of contracting leprosy and information related to the National Leprosy Eradication Programme.

The services that PMR offers to leprosy patients – strengthening of muscles, range of motion exercises, re-education following tendon transfers, sensory re-education, hand splinting, providing of orthoses and casting are not experienced first hand by the under-graduate as the curriculum sadly does not presently allot a posting in the department.

While the specialty of PMR is handicapped by being a late entry into the field of medicine, it has much more to offer in ways of comprehensively treating the patient as well as holistically training the under-graduate as well.



Apart from all the above, the areas of great importance to the patient - and which are the domain of Physical Medicine & Rehabilitation - but which tend to get neglected by other specialties are income generation, self care, and health education to prevent getting deformities. The psychological aspect in the rehabilitation of leprosy patients, many of whom have low esteem, feelings of guilt or inferiority is probably best addressed in a PMR setup as well.

Thus the two central issues are:

1. The objective of the Medical Council of India (MCI) is to train doctors versatile in basic skills to treat patients independently and in a holistic manner
2. Leprosy is a public health problem which needs to be tackled in a holistic fashion to eliminate it from states such as Karnataka

The facts that stand out clearly are:

1. The MCI believes that PMR is an essential component of under-graduate education to achieve the first objective mentioned above
2. The M.B.B.S. curriculum in Karnataka does not reflect this
3. Holistic training and treatment is not occurring as could be hoped for

Suggestions for a PMR curriculum for under-graduate training in leprosy

- A) What an under-graduate must know related to leprosy.
1. Diagnosis and prescribing treatment with the MDT regimen
 2. Recognition and management of reactional stages
 3. How to advise the patient from getting secondary complications
 4. Management of pressure sores
 5. Principles of physiotherapy, including electrical stimulation
 6. Principles of occupational therapy, including hand therapy
 7. When to refer a leprosy patient to the ophthalmologist
- B) What would be good for an under-graduate to know related to leprosy.
1. Principles and practice of splinting and application of casts
 2. Psychological aspects of disability to the patient and the family, and how to counsel them

C) What would be nice for an under-graduate to know related to leprosy.

1. How to assist in surgical procedures in deformity correction and pressure sore management

It is recommended that PMR be made a 2 week compulsory posting during the under-graduate course (preferably in the fifth semester) and a two week compulsory posting during internship to ensure that the student's above requisite knowledge and skills translates into a service delivery that benefits the patient maximally

The above could be taught to the students via practical demonstration, hands on experience, bed side clinics, and didactic classes

Suggestions to improve the services:

1. Twinning with one of the existing vertical programmes to enrich the department in leprosy related management issues
2. Subsequently to incorporate staff from these vertical programmes into the department, including a hand surgeon
3. Rotation of Primary Health Care doctors through the department for gaining experience in the holistic management of leprosy and other disorders

Suggestions to improve the training:

1. Upgrade the department into a post-graduate course as only if there are more physiatrists (PMR specialists) in the country can MCI achieve its goal of every medical college in the country having a PMR department for the purpose of training middle and grass root workers in the principles and practice of holistic rehabilitation.
2. Posting of post-graduate students from the departments of Community Medicine & Health, Dermatology and Orthopaedics each for a period of one month in the Department of PMR would mutually benefit the concerned departments and enhance the training of the post-graduates.



Leprosy rehabilitation in Kerala present status and the role of PMR

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Kerala has one of the best health care delivery systems in the country. This is reflected in the efficient control of many communicable diseases including leprosy and the state has achieved the level of leprosy elimination in the year 2000. The prevalence of leprosy has been steadily declining in the state over the past few years and during 2003 it was only 0.71 per 10,000. But in 2004, the prevalence showed an increase to 1.5. This was probably only a temporary trend and the available data till date during the current year points to a fall to around 0.5 per 10,000. Calicut district, where

the incidence was one of the highest in the state few decades ago, may be projected as a sample district in the state. In the district, there is a steady decline of the disease during the recent years, as shown in the table below.

Leprosy health care delivery in the state

The state level coordinating officer is the State Leprosy Officer (SLO), under whom there is a District Leprosy Officer (DLO) and an Assistant Leprosy Officer (ALO) in each district. The leprosy Inspectors (LI) are directly involved in the detection

LEPROSY PROFILE IN CALICUT DISTRICT							
Year	New cases detected			Population	Prevalence per 10,000	No. of cases deleted	No. of cases cured
	MB	PB	Total				
2003-04	94	158	252	28,78,494	0.71	239	235
2004-05	68	121	189	29,64,574	0.38	273	262
2005-06 (upto 8/05)	28	42	70		0.385	76	76



and monitoring of the patients at the community level. These LIs are attached to the primary health centres. The cases detected by the LIs are reported to the DLO through the Non-medical supervisors and the ALOs. Treatment is initiated at the community level or through referral centres after the diagnostic tests. All drugs and footwears / orthoses are provided free of cost. The leprosy physiotherapists posted at the district level hospitals help to minimise the deformity and impairment. Those requiring further rehabilitation are referred to the PMR units in the teaching hospitals or District Hospitals.

All the 5 Government Medical Colleges in the state are having PMR departments and two of them (Calicut and Trivandrum) have postgraduate courses in PMR, including training in surgical rehabilitation. In addition, 12 of the 14 district hospitals are also having PMR units. The services rendered through PMR departments include special footwears, various lower limb orthoses, hand splints and ADL assistive devices, ADL training in the occupational therapy and electrophysiological studies for assessing the status of the nerves. Surgical procedures are mainly carried out by the Orthopaedic and Plastic Surgery units and follow up rehabilitation by the PMR.

The present strategy in the state is to be changed to an integrated approach where the multipurpose health workers will be entrusted with the task of leprosy work as well.

Leprosy Rehabilitation in PMR curriculum

The issue of leprosy rehabilitation is not adequately covered in the present PMR curriculum in the state, even though the PG trainees get chance to see a lot of patients with various impairments resulting from leprosy.

It is included along with other peripheral nerve lesions and we need to incorporate more aspects of the problem to equip the postgraduates to deal with the issue. Surgical rehabilitation, including reconstructive hand surgery has to be given more emphasis. Few of the faculty members can be sent to any of the advanced leprosy rehabilitation centres to get preliminary training in surgical rehabilitation before incorporating this in the curriculum. Organisations like ALERT may be able to help in this training. It is also useful to include Plastic Surgery and Dermatology among the specialty postings for the PG trainees.

Further scope for PMR in leprosy rehabilitation

The PMR specialty with the available infrastructure has the potential to participate in leprosy rehabilitation in the following manner.

1. Early intervention and prevention of deformities
2. Periodic electrophysiological studies of those on MDT, especially the MB category to detect progression of nerve involvement while on treatment
3. Early splinting, physiotherapy and protective footwear based on the above studies to reduce impairment
4. Vocational Rehabilitation of leprosy cured – PMR is already engaged in vocational rehabilitation of the disabled. Vocational rehabilitation of the leprosy cured also can be integrated with that of patients with other disabilities.



Session 2

Present status of leprosy rehabilitation measures and the avenues for integrating with Physical Medicine & Rehabilitation services

Chairman: Dr. S. C. Gupta
Joint Director of Health Services (Leprosy), Govt. of Maharashtra, Pune, Maharashtra

Co-Chairman: Dr. T. Sreedhar
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Status Paper : "A review of integration of leprosy rehabilitation policies and efforts in the past & lessons for the future"
Dr. B. K. Girdhar, Dy. Director & **Dr. Anil Kumar**, Dy. Director,
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Panel members:

Dr. R. Premkumar, Head, Training, Schieffelin Leprosy Research & Training Centre, Karigiri, Tamil Nadu

Dr.B.P. Ravikumar, Superintendent, Richardson Leprosy Hospital, Miraj, Maharashtra

Presentation 4: "An overview of strategies and plans by ILEP agencies for sustaining leprosy services in the integrated set-up beyond 2005"
Dr. Rajan Babu, Dy. Director, Evaluation Cell, The Leprosy Mission - India, New Delhi

Presentation 5: 'Preventive and therapeutic methods of treating disabilities in leprosy – The changing roles of PM&R personnel and the need for training GHC personnel'
Dr. G. N. Malaviya, Head, Reconstructive Surgery Unit, CJIL, Agra, Uttar Pradesh

Presentation 6: 'Surgical interventions and functional aids for the management of disabilities in leprosy – The scope for integration with PMR services'
Dr. A. Salafia, Senior Surgeon, Vimala Dermatological Centre, Mumbai, Maharashtra

Brief intervention by the Panel members

Views from the participants

Remarks from the Co-Chairman and Chairman



A review of integration of leprosy rehabilitation policies and efforts in the past & lessons for the future

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Why Rehabilitation?

M. leprae is the only bacteria that affect the nerves, apart from skin and some other organs. If not detected and treated early, nerve damage is the natural consequence. Sensory loss occurs early and motor power deficit follows. Neglect in care and/or delay in treatment results in development of disabilities (Functional Impairment). This may lead to loss/absorption of the normal body parts (Disfigurement). If timely corrective measures not taken, it can result in stigma and ostracism within the family and the community. This may lead to exclusion of the patient from family and community, affecting supply of their daily needs and thus misery and difficulties for survival of the individual which is against the human right. This raises the question, is leprosy curable? The answer is clearly "yes". However, awareness, early detection and treatment are essential. Disability is an outcome of individual patients' ignorance about disease and treatment or arrogance for not getting treated or treatment not being available. Of the deformed or disfiguring individuals few may go to destitution requiring community support. Rehabilitation is thus required by them to lead normal life. However, rehabilitation may not be needed in leprosy, if dehabilitation is prevented. This can be done if;

1. Leprosy cases are diagnosed early.
2. Regular, effective (adoptable) and full treatment of each patient is ensured.
3. Proper and periodic health instructions for care of affected parts/skin is imparted and followed.
4. Surgical support and correction at appropriate time is available and care of the corrected parts ensured.

This is feasible only if community awareness and involvement is there. This requires intensive health education, correct and practical information, education of persons at all levels - both formal and informal communication to the society and health instructions to the affected individuals. It is important that the IEC

activities must tickle down to the most peripheral level and not be limited to dispensaries or/and district hospital. In some of the areas evaluated, it is seen that IEC activities are clearly insufficient to spread the message and thus unable to draw individual attention of the community and the affected persons.

Magnitude of the problem:

Not too long ago, leprosy affected nearly 5 million persons in our country. Though the prevalence rate (PR) has drastically come down, the number of leprosy deformed individuals has accumulated over the years. Many have minor problems but a few with severe disabilities continue and need help. For the planners, it is essential to know, how many of them need help and of what kind. No correct estimates in this regard are available. Some scattered studies have indicated that leprosy patients with deformity of grade ≥ 2 come under the pressing need of rehabilitation. However, definition of deformity of grade ≥ 2 varies from country to country and from place to place within the country.

In India, about 2-5% of field detected cases are reported to have such deformities. However, among self reporting/referred patients to institutions, it can be about 20% as majority of the patients presenting at these institutions come at much later stage when the consequence of the disease becomes unavoidable. A field study from Vellore (TN) however indicated that about "half of the 14% Grade ≥ 2 deformity patients" probably needed rehabilitation services (Thomas & SudarRao, 2000). Their social and psychological status was not defined. Psychological factors are particularly relevant to lepromatous patients who may not have functional disabilities or deformities but disfigurement of face including nasal depression, facial wrinkling and occasionally loss of teeth and alveolar bone.

Even among this the group of leprosy patients, only a small proportion becomes physically disabled / deformed, as many of them have correctable deformities that are treatable by means of medical, physical or surgical help. Thus only a small proportion,



who have uncorrectable deformities and did not have necessary treatment or correctible procedure at the appropriate time need help under community based rehabilitations (CBR) services. Among these, many get support and manage with their families. This leaves only a small proportion of individuals who need to be rehabilitated. More important than rehabilitation of disabled individuals is the prevention of disabilities. For this, the understanding as to who are at risk of developing deformities is important. Several studies have indicated that longer is the duration of untreated leprosy disease, higher is risk of developing disabilities in leprosy. Patients can have the disease affecting one or more nerves without having visible skin lesions. A study, done at JALMA (Kumar et al. 2004) has indicated that among these patients of neuritis leprosy (N)', the delay of over 5 years in starting treatment is an important risk factor (adjusted for age/sex) .

Delay (Yrs)	OR (95% CI)
<1	1.0
1-3	1.8(0.2-18.7)
3-5	1.4(0.1-20.5)
5-8	17.5(1.3-230)
>8	14.7(1.3-167)

It is well established that the chances of reversal reaction (RR) often associated with nerve damage, increases with increasing number of skin lesions, more than one body segment and being more common in BL/BB cases than in BT/TT patients. Likewise in patients with skin lesions, thickening of ≥ 3 nerves and neuritic leprosy per se are important risk factor (adjusted for age/sex).

No. of Thicken Nerves	OR(95% CI)
0	1.0
1-2	2.7(0.29-24.6)
3-4	33.4(4.0-280)
≥ 5	18.7(2.1-169)

All this indicates that to prevent disabilities it is essential to diagnose and treat leprosy early - both in duration and also type/extent of disease –in particular before thickening of more than 2 nerves trunk.

Rehabilitation -Whose Responsibility?

Under NLEP, there is no provision/programme for rehabilitation. All that we see is only a scattered self supported effort by patients, often helped by NGO's. This is mostly in the form of leprosy colonies, where leprosy patients of all grades get sheltered accommodation and food and are more or less cut-off from the society at large. This is not rehabilitation in true sense. Under the NLEP, services are limited to active patients and aimed at reducing/blocking

transmission of the disease with limited therapy. For reaction and nerve damage during treatment, steroids are provided. Limited surgical help for the patients is available in few centres only. Thus, once the patient is declared cured or released from treatment (RFT), even if he has residual disabilities at the time of being declared RFT, he is taken as cured and no more a case of leprosy and thus remain uncared for even if they develop reactions and new NFI in the post treatment follow-up period. Such persons and others with leprosy related disabilities whether treated or burnt out old patients of leprosy are to be dealt with programmes under Ministry of social justice (MOSJ). This ministry has the responsibilities to create the image of the balance of justice needing rehabilitation.

To help in rehabilitation of the needy, the Government of India enacted a law labeled as "The Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act, 1995". This came into force on February 7, 1996. This was a significant step in the direction of ensuring equal opportunities for people with disabilities and their full participation in the nation building. The act provides for both preventive and promotional aspects of rehabilitation like education, employment and vocational training, job reservation, research and manpower development, creation of barrier-free environment, rehabilitation of persons with disability, unemployment allowance for the disabled, special insurance scheme for the disabled employees and establishment of homes for persons with severe disability etc.

It is seen that the law requires steps on;

1. Prevention and early detection of the disabled by conducting surveys, investigations and research concerning the cause of occurrence of disabilities
2. Promote various methods of preventing disabilities
3. Identify "at risk" cases for developing disabilities
4. Sponsor awareness campaigns to create awareness amongst the masses through television, radio and other mass media on the causes of disabilities and the preventive measures to be adopted

Though, the law is meant for physically handicapped/ disabled persons, visually and mentally challenged individuals, leprosy disabled individuals fit in well within the scope of the service provided under the law and thus should be entitled to all the facilities under the rehabilitation programme of MOSJ.

Now that the integration of leprosy services with General Health Care system (GHS) has been done through out the country, rehabilitation integration should be functionally possible. However, the act indicates the



need for undertaking the surveys to detect person at risk of disabilities. But in leprosy, this has been discontinued following integration of NLEP with GHS, the slogan being “no surveys - only IEC”. This is meant to encourage voluntary reporting. This is contrary to what MOSJ aims to do.

The crux of the matter thus remains in finding ways to help disabled leprosy patients to get rehabilitation support by encouraging them to seek help by approaching MOSJ themselves or through NGO's.

Under the Act, the disabled persons in the country have been given following facilities:

- a. **Right to free education**
- b. **Employment:** 3% of vacancies in government department have been reserved for people with disabilities (1% each for persons suffering from blindness or low vision, hearing impairment, locomotor disability or cerebral palsy).
- c. **Non-Discrimination** from general able bodied individuals of the society.
- d. **Research and Manpower Development :**
Prevention of Disability
 - Rehabilitation including CBR
 - Development of assistive devices
 - Job identification
 - On site modifications of offices and factories to make the disabled friendly
- e. **Affirmative Action :**
 - Aids and Appliances shall be made available to people with disabilities.
 - Allotment of land shall be made at concessional rates to the people with disabilities for:
 - 1) house, business, recreational centres
 - 2) special schools, research schools
 - 3) factories by entrepreneurs with disability
- f. **Social Security:** Financial assistance to NGO'S for rehabilitation of persons with disabilities for insurance coverage and unemployment allowance to registered persons with disabilities.
- g. Special Mechanism of **grievances redressal :**
As a pilot project, the government has set up 11 District Rehabilitation Centres to provide complete rehabilitation services at door step in the following districts across the country. These are 1. Bhubaneshwar (Orissa), 2. Bilaspur (Madhya Pradesh), 3. Kharagpur (West Bengal), 4. Mysore (Karnataka), 5. Chengalpattu (Tamil Nadu), 6. Sitapur (Uttar Pradesh), 7. Jagdishpur (Uttar Pradesh), 8. Vijaywada (Andhra Pradesh), 9. Bhiwani (Haryana), 10. Kota (Rajasthan) and 11. Virar (Maharashtra).

Importance of Leprosy related Disabilities vis-à-vis Other disabilities : How much importance to rehabilitation of leprosy disabled patients is being given can be measured in terms of proportion of budget allocation, institutional infrastructure, facilities for physical, surgical correction and assistance vis-à-vis other disabled individual having orthopedic, ophthalmic (blindness) or hearing problems, Job reservations/community help and the availability of Occupational therapists for leprosy across the country and training opportunities for sustainable self development. Understandably, the physical numbers of disabled of each group has to be taken in account for due importance.

What is needed in the current situation?

First we should emphasize on empowering leprosy disabled by way of counseling/ training, to enable them to become useful work force so that they develop self esteem and live a normal and respectable life.

Second there should be a mechanism to advertise and popularize places providing training to these persons. Institutions at Duttapur, Poona, Miraj etc have job oriented training programmes particularly for leprosy disabled. These centres can be helped to play lead role in CBR of leprosy disabled. This calls for dissemination of information about the centres providing suitable training and help in independent settlements within the community.

Three, this process will help to identify those persons who are not in a position to become functional or self supportive and thus need to be rehabilitated and supported to lead a reasonably comfortable and disinfected life.. Finally, the resources are limited and the disabled population very large in our country, clear criterion and approach must be evolved to help create self dependence among the disabled and not total dependence on the public resources.

To conclude, it is high time that rehabilitation of leprosy disabled becomes part and parcel of general rehabilitation services. Leprosy disabled need to be educated about the training opportunities and the places these can be had. They should be encouraged to seek the same so that they can gain useful employment or self settle themselves. This Would not only make them self dependent and useful members of the society but also improve their self esteem.

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An overview of strategies and plans by ILEP agencies for sustaining leprosy services in the integrated set-up beyond 2005

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Introduction:

The main principle of leprosy control is “morbidity control”, i.e. timely detection of new cases, their treatment with effective chemotherapy in the form of Multi Drug Therapy (MDT), prevention of disability and rehabilitation.

The prevalence of leprosy in India is reduced from 25.9 per 10,000 population (March 1991) to 1.3 per 10,000 population (March 2005). About 69% of the leprosy cases in the world are found in India. One of the main objectives of National Leprosy Eradication Programme (NLEP) India is to achieve elimination of leprosy at national level (1 per 10,000 population). Elimination of leprosy as a public health problem is only an interim goal aimed at reducing the disease burden. New case of leprosy will continue to occur. There will still remain a considerable number of cured leprosy patients with disabilities who will need physical, socio-economic and psychological rehabilitation. In view of this, leprosy services needs to be continued in a sustained manner.

The major challenges are:

- To maintain quality of leprosy services in the integrated set up.
- To build the capacity of general health workers in carrying out leprosy control activities.
- To establish a sustainable efficient referral network.
- To assess the magnitude of the disability burden

due to leprosy and develop appropriate tools and procedures to address issues related to prevention of disability and rehabilitation in integrated settings.

- To strengthen Information, education and communication (IEC).
- To further reduce stigma and discrimination against affected persons and their families and promote correction or deletions of outdated legislation.
- To build effective partnerships based on mutual trust, equality and unity of purpose.

International Federation of Anti-Leprosy Associations (ILEP):

ILEP is a federation of autonomous non-governmental organizations working together in India in close partnership with the Government of India for the common goal of “A world without leprosy”.

In India, ten ILEP members are active through their local bodies working in close collaboration with Government of India, directly supporting NLEP.

Keeping the goal of ILEP a world without leprosy, the aim of ILEP members working in India is to eradicate the causes and consequences of leprosy by-

- Assisting the NLEP to provide sustained leprosy services through general health care system.



- Strengthening the partnerships with those working for the leprosy control programme and care of leprosy-affected persons.

ILEP members signed a MoU with Government of India to support NLEP for sustaining effective leprosy services in general health care system.

The activities for the support are:

1. Support to sustained capacity building of the GHC staff:

- Production of learning material (leprosy) for GHC staff.
 - Training of District Nucleus staff (590 Districts).
2. Provision of technical support at National, State and District level:
- Support through District Technical Support Teams (DTSTs) at district and sub district level to facilitate and maintenance of adequate quality integrated leprosy services.
 - Provision of NLEP consultant at National level to assist Central Leprosy Division in planning, in implementing and monitoring of activities of NLEP.

3. Strengthening of an adequate referral system:

- Assist in developing secondary and tertiary referral system at the district and sub- district level, for management of leprosy and its complications, including disability care of leprosy affected persons by appropriate capacity building activities.

4. Establishing Reconstructive Surgery services in Government Medical College Hospitals:

- Assist in establishing reconstructive surgery services at five Medical College hospitals in Bihar, Jharkhand, Orissa, Madhya Pradesh and Uttar Pradesh.

- Reconstructive surgeries will be continued in the ILEP supported hospitals, where facilities exist.

5. Support in establishing urban leprosy control:

- Assist state Governments in implementing adequate urban leprosy services as per the guidelines issued by Government of India.

6. Participation in community education and advocacy:

- Assist in developing specific IEC materials in local languages and replicate them for effective dissemination of information to educate the community on the integrated approach of leprosy services.

- Participate in advocacy meetings at appropriate levels.

7. Support to (operational) research:

- Research may be taken up covering specific aspects of common concern related to leprosy with focus on clinical, epidemiological and applied research.

8. Support to Community Based Rehabilitation:

- Participate in Community Based Rehabilitation activities to enable people affected by leprosy gain a sustainable and improved quality of life.

9. Supports to NGOs:

- Support existing projects (NGOs), which are functioning in accordance with GOI guidelines.

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- MoU signed between Government of India and ILEP Members active in India 1st January 2005 to 31st March 2007.



Preventive and therapeutic methods of treating disabilities in leprosy – Changing roles of PM & R personnel and the need for training GHC personnel

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Introduction

Leprosy is feared for its deformities and associated disabilities. The consequences of deformities not only affect the quality of life of those affected with disease but also generate stigma and social ostracism. Prevention is always better than cure is an old dictum. Prevention of impairments and disability (POID) is integral to leprosy control program be it vertical, integrated or organized in any other way. The objectives of managing disabilities in leprosy, therefore, are –

- (i) Preventing the onset of new disabilities and
- (ii) Prevention of worsening of existing disabilities.

Strategies for preventing the development and progression of impairments are based on the experience accumulated over years through individual observations or planned studies¹⁻⁵. The components of disability prevention are detection of disability, its measurement in a quantitative / semi-quantitative manner and management. Anticipation of impending nerve function impairments (NFI) is very important because it helps in preventing the precipitation of impairment. Approach to the problem in clinical and field based situation are different only in the methodologies applied, basic concepts remaining the same. However in our enthusiasm to examine hands and feet we tend to forget about eyes which are vital for survival and probably only source of sensory inputs / feedbacks available to persons with anesthetic extremities.

Protective sensations

Sensory system functions at subconscious level and therefore we take it for granted. It is only when there is sensory loss in palm and soles that we realize the importance of sensory inputs from these areas which perceive the environment around and keep the brain duly informed. These sensory inputs help the brain to develop a motor strategy to respond. If the stimulus is interpreted to be injurious, there is an immediate

withdrawal. To appreciate finer details of an object – texture etc. intact sensory modalities are necessary. However to appreciate noxious stimuli certain minimal sensory abilities are enough. This is called as “Protective Sensation”.

The sensory modalities expected to be tested in a clinical setup are – touch (moving and static), pain, temperature and vibration. In many setups especially in the field only pain and touch are tested. Monofilament nylons though criticized for their deficiencies are still in use because of their reproducibility⁴⁻⁶ and convenience.

Normal perception thresholds for nylons at finger pulps are 0.217 gms/mm² and levels of protective sensations are double the normal thresholds i.e. 0.434 gms. / mm². For sole these values have been worked out to be 2.35 Gms. /mm² and 5 Gms. /mm² respectively^{7,9}. Some other reports take responses to 10 Gms as cut off point to define protective sensations in sole⁸. Tip of ball point pens are used by majority of field workers to evaluate sensory loss and these have been reported to be comparable to monofilament nylons^{6, 10-11}. Periodic assessment by voluntary muscle testing and response to graded monofilament nylons can be used to monitor progress of the patients though inter-observer variations do exist¹²⁻¹⁴. Of the various testing methods compared for their efficacy to detect early nerve damage nerve palpation and testing with 200 mgs monofilament nylon were found better¹. Palpation of nerves and testing with graded nylons gave comparable results as observed in another study also¹⁵⁻¹⁶.

Prevention of development of disabilities in a fresh case

A newly detected case of leprosy may not have clinically manifest sensory impairment or autonomic nerve function impairment though he might have thickened nerve trunks. The process of nerve damage



starts much earlier before the disease manifests clinically. It has been quoted by several workers that for nerve damage to clinically manifest at least 25-30% of the nerve fibers must get damaged^{16, 17, 28, 30}. This suggests that the damage is relatively advanced in terms of pathology though it is an “earliest” presentation. Most of the early manifestations of nerve damage are not very intense. The appearance of a clinical deficit in the form of anesthesia or muscle weakness brings the patient to clinic. The treatment unfortunately is done for the manifest disease and not for the tissue pathology which may or may not manifest clinically. The nerve damage has been reported to occur before, during and even after the chemotherapy is over. It may occur insidiously or as a part of reactional episode¹⁷. All impairments are not preventable. In a study it was noted that 37 % MB and 3% PB patients developed new impairments¹⁸. These studies suggest that early detection and treatment may reduce the frequency of NFI but all impairments can not be prevented by MDT alone. The potential of MDT to prevent nerve function impairments is further reduced if cases are not detected early enough.

Anticipating nerve function impairment – We have to anticipate the impending neural damage and therefore identify high risk patients. These patients can then be given some form of prophylactic treatment to bring down the numbers of those developing deformities. Risk factors have been identified which can help in pointing out cases that are more likely to develop reactive episodes and NFI¹⁸. Previous nerve damage, clinical MB disease especially borderline leprosy, pregnancy, inter-current illness like tuberculosis, aggressive MDT, multiple nerve trunk involvement - all can precipitate a reactive episode. Predicting the onset of a reactive episode based on serological changes have not been successful so far¹⁹ and diagnosis of reaction is a clinical exercise based on the changes appearing in the skin lesions, neural swelling, pain and tenderness and nerve function changes.

Role of steroids - Steroids have been used to treat NFI, reactive episodes and also as a prophylactic agents against reactions^{3, 4, 20-23}. In a report it was concluded that 60 % of patients who were treated with steroids for NFI had useful recovery of sensory-motor functions. It might be possible that if detected in early stages of NFI, patients can have full recovery. However defining early has its own problems – early in terms of

duration of clinical manifestations or early in terms of severity of clinical manifestations. Some studies have suggested that steroids if given along with MDT can prevent NFI and reactions^{4, 23}. Optimal steroid regimens still need to be worked out. Alternative forms of immuno-suppression are under investigation.

Role of nerve trunk decompression - The waiting period before calling for surgical intervention in the form of nerve trunk decompression is not very clear²⁴⁻²⁷. It has been reported to be 3 months or less and with muscle strength of MRC grade 3 or more.

Prevention of progression of disabilities:

It involves detection of nerve damage, early in terms of duration and severity both and also the care for existing disabilities. Of these, severity is of more importance because it decides the actual clinical outcome. More severe damage of shorter duration some times has better prognosis in contrast to a less severe damage of longer duration viz. silent neuropathy which is chronic insidious type of nerve damage and has variable response to therapy²⁸⁻²⁹. Problems faced by the patients having insensitive extremities (hands and feet) are many –

- (i) Problems of disuse or under use
- (ii) Problems of misuse and overuse
- (iii) Problems of protection

Problems of disuse are seen in hands in cases of unilateral palsies especially where non dominant is affected. Patients avoid using affected limb even if it surgically restored until it is absolutely essential for them to it³¹. This results in disuse atrophy of the muscles. In growing children disuse results in hypoplasia of the limb. The limb is neglected by the patient resulting in skin and joint contractures.

Problems of misuse and overuse are different in hands and feet. In hands, even if motor capability is there, efficiency is reduced. The paralyzed hand adopts unnatural postures due to muscle imbalance and functionally adapts to convenient movement patterns for activities of daily living. This leads to contractures and posture gets some what fixed. In median palsies pinch is badly affected. Even with simple anesthesia patients complain that they can not hold the objects properly and have a feeling that object will fall down. They tend to use much force than actually needed ending up with gradual absorption of their finger tips. Fine manipulative activities can not be performed. In cases with bilateral involvements the handicap is much



worse. Patients walk briskly over long distances without resting their feet and keep standing on the same foot without changing postures for quite some time. Even if they have plantar ulcers they walk and injure the foot more in the process. Singular absence of pain is the root cause for all such misadventures. Surgically restored limbs are prone to injuries because patients are likely to carry a false impression that their limbs have become normal and do not require care any more.

Problems of protected use are peculiar. Even if patients are aware of their deficiencies, psychological and social pressures come in their way. Also, there is an inherent desire in these patients to perform and behave like normal persons. As a result they are likely to damage their hands and feet. The patients are shy to use appliances. At times it is because of social compulsions (to hide their disease and avoid social embarrassments) that they indulge.

Management – The patient needs to be properly examined and evaluated before a scheme for his rehabilitation can be worked out³². The evaluation includes, besides age and occupation, assessment of residual sensory-motor functions and psychological state to find out his reaction and attitude towards his problems.

Sensory evaluation begins with mapping of the area of sensory loss by the patient on his palm and sole. The presence or absence of protective sensations and use of hand by the patient for daily activities is assessed. Since no single test can completely assess the complexity of sensibility and dysfunctions, it is better to apply a battery of tests selected after initial examination. The approach has to be tailor made. A need based program has better chances to succeed. Proper counseling is done in several sittings and options are suggested. It is for the patients to decide and choose the one that suits him best under the circumstances.

Health education is an important component of the management scheme and is key to success. It should start from the day patient is brought under MDT umbrella. and continue until he is ready to be released from control. Patient has to be told about the causation of injuries and ulcers. The role of sensory loss in this context has to be made clear. The patient should be explained the cause of anesthesia and also the methods to protect their hands and feet if affected. Simple easy

to follow instructions are important to ensure compliance.

The patients must understand their physical limitations due to disease and accept that. Once this has been achieved, they can be empowered to adapt to the new situations. Self-care is the responsibility of the individual who has NFI and they are expected to carry this out on daily bases. The health care workers are expected to educate and guide patients in the self-care practices. The hydro-oleo therapy and passive exercises are prescribed to keep the skin supple and mobile. Care of hands and feet, looking for injuries and impending ulcers, if found promptly treating them goes a long way in preventing mutilations. The physical, functional and social improvement seen with self-care practices improves the quality of life.

Patients are taught protected use of hands and feet. They are advised to use visual feed back while using their hands for different tasks and use both hands with conscious effort. Use of tool and appliances with protective (molded) handles at home and at place of work can be suggested. Similarly, constant use of protective footwear is encouraged. Footwear is a cost effective intervention in preventing plantar ulcers and its recurrences and along with self-care practices has done wonders for the patients. There might be some initial hesitation but with time patients accept it realizing the benefits of its use.

Sensory re-education program can be tried in those cases that have some residual sensibility, especially in younger patients. With some training protective sensibility can be restored and those who have protective sensations can be taught to differentiate textures. Attempts have been made to restore sensibility in some key areas of the palm using surgical procedures.

Surgical procedures to correct deformities and restore function can be performed on those who need it. Day to day surgical problems like ulcers, wounds etc can be and should be managed at the nearest available facilities. Restorative surgery requires skilled hands and should be restricted to some centers. Even though early detection and provision of MDT are the primary means but the process of POID has to address at every level of care. A comprehensive concept of POID needs to be developed involving all areas of leprosy control viz.



early detection, MDT, nerve function assessments, identification of high risk patients, prophylaxis, treatment, reconstructive surgery and rehabilitation. POID at the initiation and during MDT call for proper recording of base line data and regular follow-up information about nerve function, detection of high risk cases and management of reactions.

Health education training of general health care staff and resource persons are essential for the success of POID. Referral options for specialist POID care are imperative to make an integrated leprosy control system work. For POID, once chemotherapy is over, the patients need to be empowered to understand when and where to request for care of the complications arising due to leprosy if these develop. High risk patients need extra care and more frequent examinations. Patients with established disabilities should receive continued care preferably at the community level but referral facilities for the specialists care should also be available if the need arises. The PMR activities needed for a successful POID program can be grouped as follows:

- Stage 1. Palpation of nerves / nerve trunks
- Stage 2. Testing for sensory and motor functions
- Stage 3. Health education – cause and mechanism of damage
- Stage 4. Self-care practices - massage and exercises
- Stage 5. Splinting, orthoses and other protective appliances
- Stage 6. Surgical Interventions to restore appearance and function

As is obvious, all above activities require an understanding about disease (read leprosy) in addition to the special skills for managing specific disabilities. PMR persons have been managing polio and cerebral palsy cases very well but their capabilities have been largely eclipsed. People think of them as a person who prescribes and delivers orthoses especially to amputees. PMR people are better equipped to handle leprosy related disabilities because they are well versed with biomechanical aspects of deformities, can assess sensory motor functions and deformities and competent to provide splints, orthoses etc to the needy persons. Polio is expected to be eradicated soon except for some back log palsies. They can divert their attention to leprosy disabled persons. The residual problems keep

haunting leprosy affected persons for a considerable period, if not life long, after bacteriological cure. If PMR personnel (read surgeons) can be trained in deformity correction they can become a valuable resource person for secondary and tertiary care of leprosy affected persons. Unfortunately they are shying away to hold the knife and leave this job to the leprosy surgeons.

We all know that orthopedic surgeons are busy with fractures and trauma even in small towns and so are plastic surgeons that spend their time managing burns from various causes or in beautifying persons. PMR persons, therefore, have the opportunity to volunteer themselves for this job which I am sure they will find interesting and satisfying. There has to be some one to fill the void created by the fading out breed of leprosy surgeons. People operating occasionally on leprosy induced deformities can not do justice and quality of work suffers.

PMR persons will also have to bear additional responsibility to train general health care workers so as to empower them to look after the needs of leprosy disabled persons many of whom will continue to be on screen for number of years to come. These health care workers can share the knowledge with patients telling them to recognize the signs of reaction, assess muscle strength and report for remedial measures when certain danger signs are noticed by them. Self-care practices – care of hands and feet are also an important part of health education and patients should practice it from day one. The patient empowerment will reduce the load on follow-ups once the patients are released from control. A study from Africa has reported benefits of such a strategy in field. In our country it can be tried in difficult terrains to begin with. But before such modalities are resorted to, confidence building measures are needed. Patients should feel assured that if they report with a problem, care will be available. Only then the process of integration will have some meaning.

The relapse of disease particularly in bacillated MB patients has been reported from several places. We have already done enough adventures and played with treatment schedules in our enthusiasm to eliminate leprosy as fast as possible. I keep my fingers crossed and pray that nothing untoward happens. If the relapses of some magnitude appear after 10- 15 years, leprosy specialists will no longer be available. In this context the involvement and enablement of PMR and general health workers is very important.



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Present status of disability and the rehabilitation needs in two rural areas of the Vellore district, Tamil Nadu.

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Introduction

This national workshop focuses on the important question of integrating rehabilitation of leprosy into the main stream of Physical Medicine and Rehabilitation. The Schieffelin Leprosy Research & Training Centre, Karigiri, (SLR&TC) is situated in Vellore District, Tamil Nadu and it pioneered leprosy rehabilitation in physical, socio-economic, psychological and spiritual aspects since 1955. The A.I.I.P.M & R – Mumbai was also established in the same year and both these institutions are celebrating their golden jubilee anniversary this year. Since 2000, the rehabilitation infrastructure of SLR&TC-Karigiri had been extended to all disabilities by initiating a Community Based Rehabilitation programme in 15 *panchayats*.

The rehabilitation and health planners have to be aware of the existing prevalence of disabilities in their communities and as well as the rehabilitation needs of the people whom they are serving. We made an attempt to accurately evaluate this with the specific objectives of:

- (a) Determining the prevalence of both physical and mental disabilities among different age groups, gender and castes and explain the outcomes in relation to the scenarios presented by other studies.
- (b) Knowing more about the rehabilitation needs of the physically and mentally disabled in the community.

Methodology

Study population

Out of 15 *panchayats* that were allocated for community based rehabilitation work in our project, two *panchayats*, one large and another small were randomly selected for this study. They were situated in the Katpadi taluk of Vellore district in Tamil Nadu, and each of

these were geographically separated approximately 20 kms from one another. All the hamlets that were under these *panchayats* were taken for the data collection. The total study population in both these *panchayats* was 7454, comprising 5585 from the large *panchayat* Vandranthangal (Total number of houses 1316. Average size of the family – 4.24) and 1869 from the small *panchayat* Eranthangal (Total number of houses 422. Average size of the family – 4.42). The demographic characteristics depicted in Table 1 showed that they were nearly similar in gender and age distribution and as well as both *panchayats* had a high percent of lower caste population.

Age group:

The population was classified into three age groups, namely, 0 – 14 years (children), 15 – 59 years (adults) and, 60 and above (old age).

Measure of disability

The Rapid Rural Appraisal (RRA) helped the investigators to identify the disabled in a community. This was followed by the post verification visits by experts, which confirmed the disabilities by professionals.

Classification of disabilities was according to the Person with Disability Act, 1995¹.

Needs assessment

The domains listed under the activity limitation and the participation restriction of the International Classification of Functioning, Disability and Health – 2000² was taken for the enquiries into the physical, social and psychological rehabilitation needs existing in these two villages.



RESULTS

Table – 1. Gender, age and caste distribution in two study panchayats

	Large <i>panchayat</i> population	%	Small <i>panchayat</i> Population	%
Male	2681	48.00	925	49.49
Female	2904	52.00	944	50.51
Children (0-14 years)	1257	22.51	401	21.46
Adults (15-59 years)	3607	64.58	1225	65.54
Old age (60+ years)	721	12.91	243	13.00
Upper caste	3903	69.88	985	52.70
Lower caste	1682	30.12	884	47.30
Total population	5585		1869	7454

Table 1 shows that the two *panchayats* taken for the study were identical in all aspects like male and female, children, adult and old aged population percentages. Besides, more than half of the total population in both *panchayats* belonged to the upper castes.

Table – 2. Disability burden in the community

	Total population	Disabled	%
Males	3606	167	4.6
Females	3848	188	4.9
Children (0-14 years)	1658	34	2.1
Adults (15-59 years)	4832	190	3.9
Old age (60+ years)	964	131	13.6
Low caste	2566	152	5.9
High caste	4888	203	4.2
Disabilities in large <i>panchayat</i>	5585	238	4.3
Disabilities in small <i>panchayat</i>	1869	117	6.3
Total population	7454	355	4.8

Table 2 showed that among the study population, 4.8 per cent of its members were suffering from some form of disability. It ranged in between 4.3% to 6.3% in large and small *panchayats*, respectively. A marginal higher percentage of females (4.9%) than males (4.6) suffered from disabilities. Age specific prevalence of disability has shown that disability burden increased with age; in adulthood twofold, and in above 60 years it increased more than four fold than the adulthood. The disability burden among low caste was higher (5.9%); whereas in higher caste it was only 4.2%.



Table – 3. Age specific disabilities in the community

Disabilities	Children			Adult			Old age			Total	%
	M	F	%	M	F	%	M	F	%		
Locomotor	6	3	20	30	33	27.8	29	31	33.0	132	29.1
Visual	1	3	8.9	22	43	28.6	24	46	38.5	139	30.6
Speech & Hearing	8	4	26.7	15	8	10.1	16	10	14.3	61	13.4
Fits	2	1	6.7	4	7	4.8	1	1	1.1	16	3.5
Difficulty in learning	9	2	24.4	2	3	2.2	1	0	0.5	17	3.7
Strange behaviour	1	0	2.2	9	10	8.4	3	2	2.7	25	5.5
Insensitive hands and feet	0	0	0	6	3	4.0	7	2	4.9	18	3.9
Hand dysfunction	2	1	6.7	10	6	7	2	2	2.2	23	5.1
Other disabilities	1	1	4.4	6	10	7	1	4	2.7	23	5.1
Total	30	15		104	123		84	98		454	

Table 3 showed that about one fourth of disabilities among children were learning, speech and hearing defects; while in adults and old aged disabled it was visual and locomotor problems. Male children were predominantly affected than females with learning, speech and hearing defects. In general the disability ratio between male and female children were 2:1; however, with the progress of age, females had more disabilities than males. Difficulty in learning and fits decreased with the progression of age.

Table – 4. The rehabilitation needs of the rural population

NEEDS	No	%
Physical	314	66.9
Self care	55	11.7
Mobility	128	27.3
Domestic life	60	12.8
Communication (verbal and non-verbal)	71	15.1
Social	36	7.7
Community, social and civic life	2	0.4
Attitude of the community	6	1.3
Marriage prospects	2	0.4
Participation restriction	26	5.6
Economic	68	14.5
Welfare schemes	31	6.6
Vocational	31	6.6
Education	6	1.3
Psychological	51	10.9
Learning and applying knowledge and special school	16	3.4
Psychiatric problems	20	4.3
Interpersonal interactions and relationships	5	1.1
Counseling	10	2.1
	469	100.0



Total numbers of persons with disabilities	355
Total number of persons with disabilities who require rehabilitation	284
Percentage of persons with disabilities who required rehabilitation	80%

Table 4 showed that among the needs of the persons with disabilities (PWDs), two third of them (66.9%) had physical well-being requirements with mobility as their major concern (27.3%). Need for economic assistance came second (14.5%), psychological, the third (10.9%) and the last was the social aspects (7.7%). In these communities 80 per cent of the disabled required some form of rehabilitation.

Discussion

Prevalence of disabilities:

There is a mild difference in prediction of the over all prevalence of disabilities within India. For example, the figures from South India in 1999 suggest that it was 6.7 per cent³. The data provided by UNFPA in 1995 showed that the prevalence of disability in India is estimated as 4.6%⁴ and this study depicted it around 4.8%. Interestingly, while comparing the results of disabilities between two *panchayats* in our study itself showed a difference of 2 per cent in the rates of prevalence of disabilities; the lowest being 4.3 and the highest 6.3. Therefore, comparing other similar studies, we conclude that the prevalence of disability in our communities ranges between 4 to 6 per cent.

Disability and gender:

Though there were a marginal higher percentage (4.9%) of females than males (4.6%) to have disabilities, we conclude that disability rate is almost equal in both gender and the reason is that both gender are equally exposed to hardship and toil as men.

Disability and age:

Learning and speech & hearing defects were predominant among children while visual and locomotor impairments among adults and those above 60 years. The reason is, learning and speech are being closely related to growth and development, therefore children were more prone towards these disabilities. Table - 3 also depicted that difficulty in learning and fits decreases with the progression of age. The environmental stimulation and age factor plays a better role in

promoting learning.

When this study looked into the cause of other disabilities it was mainly due to systemic diseases like asthma, chronic obstructive airway diseases, various heart problems and tuberculosis. A previous study also corroborated with our findings⁵.

Rehabilitation needs:

Table-4 showed that 20 per cent of PWDs do not require any rehabilitation. Among those who required rehabilitation, the prime needs of the PWDs and their families were the physical well being, especially the mobility. This shows that improving the physical ability satisfies PWDs and their families more. It is estimated that the rehabilitation needs of 80% of the people with disabilities could be satisfied at the community level itself and the remaining 20% are likely to require referral to some kind of specialist facilities⁶.

Conclusion

Prevalence of disability in rural community in the Vellore district of Tamil Nadu ranged in between 4% to 6%. Males and females are being equally affected. Difficulties in learning, speech & hearing are the commonest disabilities among children and it decreased with the progression of age. The major rehabilitation need of the disabled is the functional independence. Among the disabled and their families 20 per cent do not have any rehabilitation needs despite the physical and mental impairments.

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Surgical interventions and functional aids for the management of disabilities in leprosy – The scope for integration with PMR services

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The surgery that deals with deformities caused by leprosy is the dominion of both orthopaedic and plastic surgery; as a matter of fact both specialties integrate with each other.

An orthopaedic surgeon will find congenial to deal with hand and foot deformities while the plastic surgeon will be better equipped to deal with facial deformities. Both the Plastic and Orthopaedic Surgeons will deal with hand deformities as per their training and experience.

While some deformities are rather easy to tackle – like a mobile claw-hand and a foot drop – a mitten hand will pose a challenge to the best hand-surgeon.

The Bombay Orthopaedic Society conducts every year – for the last 30 years or so – advanced training programs in various aspects of surgery, one of the yearly courses is hand surgery; our team of Vimala Dermatological Centre (VDC) is member of the faculty for the last 15 years.

Our experience tells us that any Orthopaedic or Plastic surgeon can be trained to deal with the finer point of surgery as related to leprosy; it is all a question of time, opportunities and will.

In view of the general tendency to integrate leprosy work into the main stream of Government health services, we believe that Orthopaedic and Plastic Surgeons attached to such centres can deal with deformities caused by leprosy. Apart from a good training, experience and the right judgment is necessary to achieve good results.

We at VDC, with our past experience, are ready to cooperate with the Government in training young surgeons.

A sort of curriculum should be prepared and centres, which excel in this field, should be visited by young surgeons in order to get the maximum exposure to various techniques. This will equip them with the ability to deal with simple and complex problems.



Present status of leprosy rehabilitation measures and avenues for integrating with PMR services - Sangli perspective

Dr. B. P. Ravikumar

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Medical Superintendent, Richardson Leprosy Hospital, Miraj, Maharashtra

Introduction :

Richardson Leprosy Hospital was started in 1896 and two blocks –Miraj and Kavathe Mahankal were allotted for leprosy control work. However, it was handed over to Government after integration in 2002. In 1976 the PR in the district was 18/1000 and the deformity rate was 36% which is only next to Solapur. The PR in 2003 was 2.43 per 10000 and the new case detection rate was 3.9 per 10000 and new disability rate was 0.7%. The cumulative deformed patients in the district are 1197 in 2003.

Present Status of leprosy rehabilitation and avenues for integrating with PMR services (The Sangli District Perspectives). Sangli District has an area of 8601 Sq. KM with an estimated population in 2001 of 24,34,380. The urban population in the district is 5,01,447. This district has 741 villages out of which 668 villages have the population above 1000. The PR in 2003 was 1.53 /10000 and new cases detected from 1st April 2002 to 31st March, 2003 were 641. Today the PR is 0.89 per 10000. There are three NGO's including Richardson Leprosy Hospital in the rehabilitation of the leprosy sufferers.

- 1. WanlessWadi :** There is a Weaving Unit wherein six leprosy sufferers are being rehabilitated. They produce Bags, Shoulder Bags, Bed sheets, Towels, Dusters etc.
- 2. Paulus Leprosy Rehabilitation centre:** Their focus of rehabilitation is through training in agriculture.
- 3. Richardson Leprosy Hospital, Miraj :** It has a weaving unit where Shoulder Bags, Bed sheets, towels, table mats, runners, napkins etc. are produced and seven leprosy patients are rehabilitated. It assists students through sponsorship at Kothara and now through the financial assistance programme. Students are referred to VTC, Nashik where the following trades are available: A) Motor Mechanic, B) Diesel Mechanic, C) Welding, D) Stenography, E) Computer, F) Secretarial Practice, G) Tailoring, H) Offset Printing, I) Printing & Composing, J) Desk Top Publishing etc. Richardson also provides non formal training course at Hospital in I) Tailoring, II) Weaving III) Carpentry, IV) Shoe Making etc.

Houses were provided to those who are without proper habitation through loans from other sources like nationalized banks and we stand as a guarantor. Now self help groups are provided loans to start their enterprise. Once money is recovered by self help groups, the money is paid back. The individual functions as decision maker in relation to loan disbursement.

Richardson Leprosy Hospital has been on the forefront of Reconstructive Surgery providing ulcer care and MCR chappals to the leprosy patients. It has performed 1132 reconstructive surgeries from 1982, made and distributed 8189 pairs of MCR chappals from 1994. The leprosy patient needs physical rehabilitation [including reconstructive surgery, management of ulcer, appliances and aids for ADL (Activities of Daily Life)], social, vocational and economical rehabilitation.

The role of PMR professionals :

- A. Considering leprosy as a possibility in case of mono neuritis multiplex/sensory peripheral neuropathy.
- B. Protocols for care of the disabled.
- C. Research in prosthetic, orthotics, appropriate foot wear.
- D. Measures to reduce weight bearing in ambulatory patients (in short foot)
- E. Specialized vocational appliances and their modification.
- F. Training of other professionals like Physiotherapists, Occupational therapists, Prosthetics, nurses and others.
- G. Measures to assist in ADL for burnt out case.

Avenues for integration :

1. Mutual visits to specialized centers.
2. Change in the curriculum giving due weightage to the needs of leprosy sufferers.
3. Joint research ventures: - Study of biomechanics of hand and foot in disease and strategy for restoration of function.
4. Education of leprosy experts on what PMR professionals can contribute.
5. Development of Management protocols and appropriate technologies where relevant.
6. Evaluation and validation of reconstructive procedures.



Session 3

Recommendations for review of PM&R training curriculum / courses and the services in the context of integration of leprosy into GHC system

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Interventions by panel members and participants

Drafting recommendations by the Co-Chairman

Reading and passing of recommendations by the Chairman

Rapportuers : Dr. Sachin Salunkhe, Consulting Dermatologist, LEAP, ALERT-INDIA
Dr. M. Y. Achrekar, Medical Officer, CCDT, Mumbai
S. Kingsley, Epidemiological Monitoring Unit, LEAP, ALERT-INDIA

Vote of Thanks: Joy Mancheril, Director, General Administration, LEAP, ALERT-INDIA



Recommendation

The following recommendations were made and unanimously approved by a panel of experts.

The recommendations were divided into two parts:

I. Integrating leprosy rehabilitation services into the mainstream of PMR services

1. The integration of leprosy services into the mainstream of PMR services should be done gradually and in a coordinated manner with all those concerned with the rehabilitation services including NGOs and private health sector.
2. The leprosy patients having various functional and structural deficits would require interventions to prevent activity limitations at the personal level and participatory restrictions at the societal level and such interventions should be made available at all the PMR institutions.
3. A directory containing the details of the services that are available with the PMR institutions for leprosy affected persons should be made available with the health workers at the PHC level.
4. The Leprosy division of Govt. of India should conduct a regional level meeting with the PMR experts and the State Leprosy Officers and include PMR experts as a part of the District Leprosy Nucleus team.
5. A realistic estimate on the magnitude of the leprosy related disabilities including the grade 1 disabilities (WHO, 1988) should be collected at the taluka level to plan the necessary interventions.
6. Integration of the leprosy rehabilitation services should be made at all the level of general health care delivery system and not only at the GHC level.
7. The health workers at the GHC system should be trained in the early identification and simple intervention of leprosy related disabilities and their rehabilitation.
8. The leprosy institutions providing tertiary care to leprosy affected persons should extend their services to the persons with other chronic disabilities due causes other than leprosy.
9. The media should be adequately used to achieve integration of patients in the community and to dispel the misconceptions about the fear on infectivity.

II. Review and propose modification in the training curriculum for medical and paramedical graduates.

1. The trained rehabilitation manpower as well as the PMR institution is limited hence it cannot meet all the rehabilitation needs of leprosy affected persons. Therefore the teaching of disability prevention and rehabilitation with focus on leprosy rehabilitation should be included at under graduate level.
2. At the post-graduate level, (MD / DNB) for the doctors, PMR curriculum approved by Medical Council of India (MCI) / National Board of Examinations (NBE) is already inclusive of leprosy rehabilitation. Surgical skills should be enhanced at this level. The medical specialists working in PMR already should be given training in the surgical skills on appropriate reconstructive procedures for leprosy.
3. Training of medical officers at PHC and district level should be done as is being under RCI programme to bridge the gap of requirement of available resources keeping in view of the paucity of the PMR institutions in the country.
4. Paramedical courses such as Physiotherapy, Occupational Therapy and Prosthetic and Orthotic curricula should include adequate coverage of leprosy rehabilitation components.
5. The training programmes organized by the Rehabilitation Council of India (RCI) for the medical officers working in the general health sector should include leprosy rehabilitation services.
6. The professional bodies such as Indian Association of Physical Medicine & Rehabilitation (IAPMR) in coordination with the MCI need to review the existing curricula for medical and paramedical undergraduates and suggest suitable curriculum with more focus on leprosy rehabilitation.
7. The Leprosy division of Govt. of India in coordination with the PMR experts should recommend a revised curriculum on leprosy rehabilitation to the MCI for MBBS and other paramedical courses by forming a Consultative committee and through a Curriculum Development Workshop.



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Session - 3

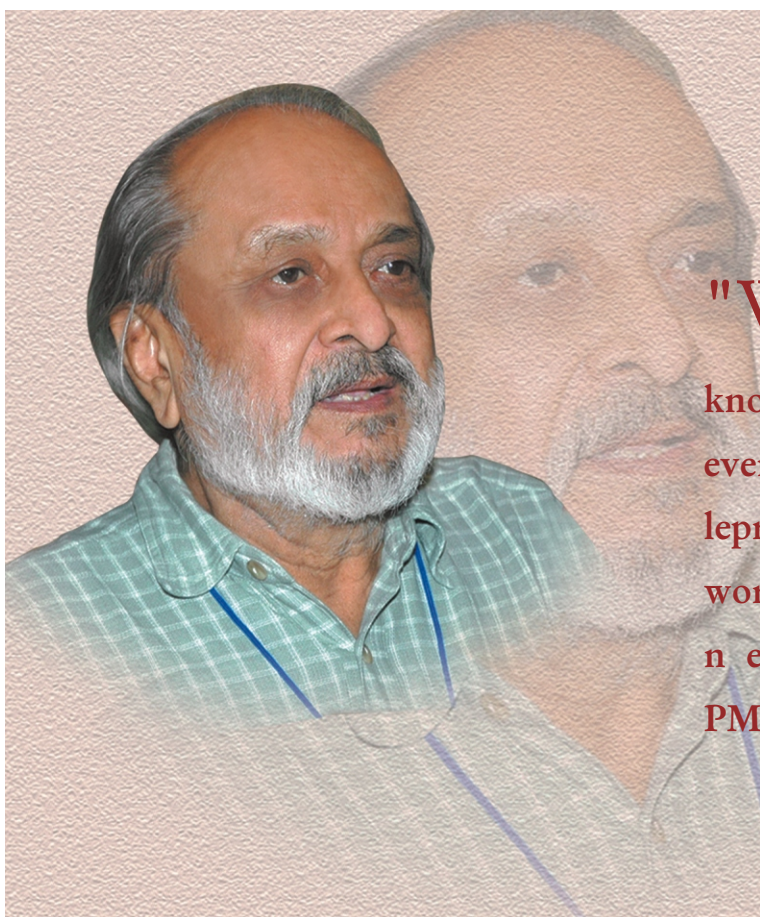
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"We must shed, rather irritating, 'only I know what is best for leprosy patients' and the even worse 'You don't know what to do for leprosy patients' attitude that many people working in leprosy have. We must spread the news that PMR departments are capable of taking care of

Dr. H. Srinivasan

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

ALERT-INDIA

strives towards
programmes focussing on
community partnership strategies
to achieve the goal of leprosy elimination
during the integration phase,
in partnership with all stakeholders,
to make elimination a reality for people.



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