Community Dermatology

Community Care of the Physically Disabled due to Leprosy

R Ganapati

Director Emeritus,
Bombay Leprosy Project
rganapati@gmail.com / rganapati@yahoo.com

Introduction

Leprosy "elimination" based on mass chemotherapy is believed to be one of the most successful public health programs in India. However, dependence on bactericidal drugs alone and expectation of any significant impact in preventing nerve damage and sequelae proved to be unrealistic from the point of view of reaching the objective of "eradication" or ultimately the goal of "World Without Leprosy". Still the health planners seem to be quite complacent. Unfortunately, devising a mass strategy to save the affected nerves and the devastating complications was not their priority. Though the subject of Leprology is a part of Dermato-Venereology in India, the neurological aspects of leprosy have not received the attention they deserve at the hands of most dermatologists. Lack of field experiments on comprehensive community based comprehensive leprosy work especially with reference to disability prevention is a set back for reaching the goal of CBR (Community Based Rehabilitation) [1]. This preliminary presentation portrays the alarming dimensions of the disease burden felt by rural communities and recommends a cost effective field model.

Field Observations (Phase I & II -2007 to 2008)

A crash drive of rapid surveys was organized in Thane district by using community volunteers who identified visible disabilities due to leprosy (Grade 2, WHO) in rural "talukas" (sub division of district) adjoining the megalopolis of Bombay in 2007-2008. Physical care was limited to provision of simple splints and foot wear only, as long term care was not the object off the study.

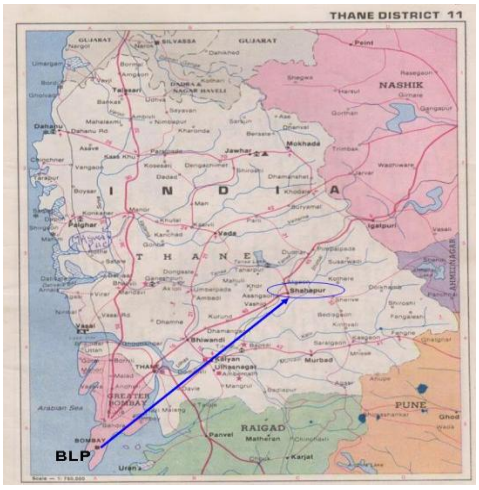


Figure 1

A startling figure of 3000 (approximately) such patients living in some pockets led to intensive observations on a population of 480,000 in three talukas. 1250 patients were identified in this population covered by 11 Primary Health Centers (PHCs). PHC of the government was taken as a unit because leprosy is integrated with primary health care in India and leprosy disabled are expected to be the offered service at these centers. The mean prevalence rate (PR) of deformities was 26 per 10,000, PR of active disease needing specific chemotherapy was about 3 per 10,000 (see Figures 1 and 2).

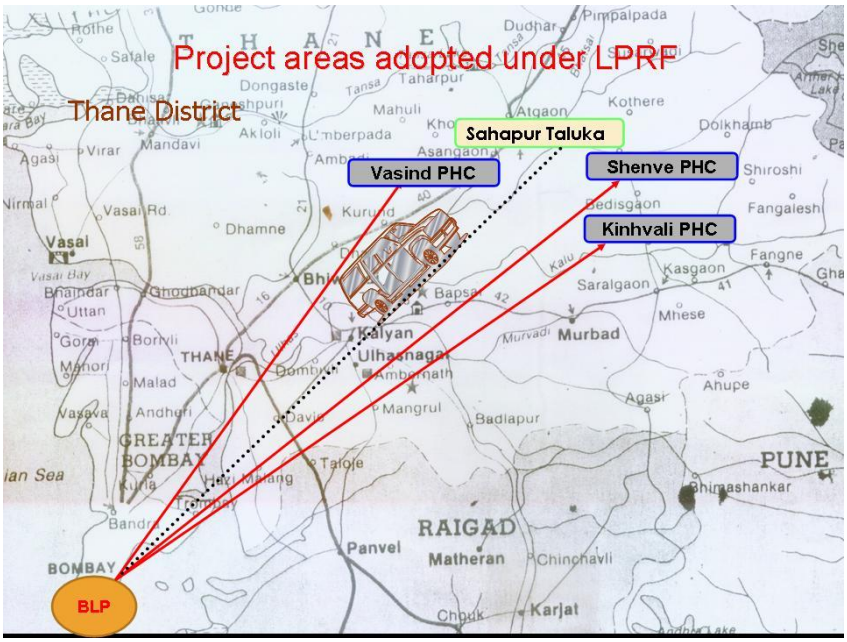


Figure 2

Focused Surveys followed by Limited Services in Shahapur Taluka (Phase II-2009)

The next objective was to limit the surveys and to focus on just one taluka called Shahapur which has 8 PHCs covering a population of 212,104. Over 500 patients were unearthed during 2009, the PR being 27 per 10,000. The PR in four PHCs in particular in this taluka has been documented[2]. It was realized that to provide ideal services at the community level to such large number of patients in the whole of Shahapur taluka most of them being tribals living in hilly terrains will pose tremendous financial and logistic problems. It was therefore decided to intensify services to already identified patients in one of the PHCs.

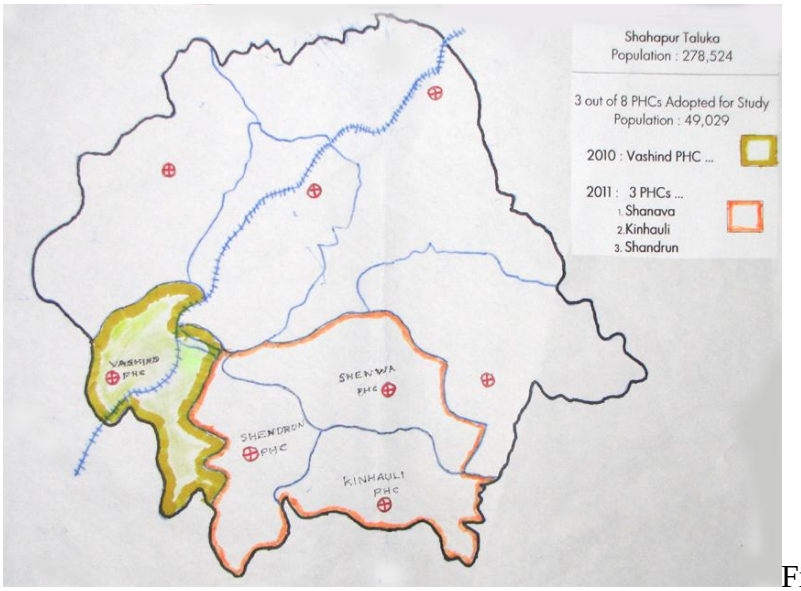


Figure 3

Intensive Physical care at the community level in Vashind PHC (Phase III-2010)

The aim of the study was now to concentrate on a manageable number of patients and transfer the disability care technology to the community with the ultimate object of reaching the concept of CBR. One PHC called Vashind with a population of 52,466 was adopted in 2010 and 140 patients were targeted for intensive physical care and long-term follow up.

Doorstep Services offered

- Pre-fabricated low cost aids and appliances with physiotherapy
- Wax therapy by physiotherapists and volunteers in village centers
- Grip aids for mutilated hands for a few selected cases (Prepared out of easily available cheap Araldite material mixed with Hardener)
- Standard micro cellular foot wear for simple and moderately advanced plantar ulcers
- Moulded foot wear for complicated deformity
- Ulcer dressing kits for home self care and dressing of plantar Ulcers at door step by Experienced Dressers.
- Dressing of plantar Ulcers at door step by Experienced Dressers
- Care of intractable foot Problems, including application of plaster of Paris casts by trained dressing teams.
- Amputation in highly specialized institutions in rare cases.

Maintenance of proformas and documents, calculation of cost of service to each patient***,** album of photographs of every patient, field maps of location of patients to understand the epidemiological and logistic implications, computerization of data etc. form the special features of this unique investigation. The impact of the intervention on the clinical condition of patients is studied at specific intervals.

*****The analysis of cost of services offered to patients will form the subject of a separate communication.

Extension of Services to Patients in 3 more PHCs (Phase IV-2011)

It was felt important to gain more personal experience and that of the supervisory team and service providers, and confidence in establishing a "Cost Effective Field model of Community Service to Disabled Leprosy Patients" .The model should be sustainable and the technology should be transferred to the government staff of PHCs. The study therefore is extended to a population of about 90,000 housing about 300 patients. The 140 patients already recruited in Vashind PHC will be followed up for ensuring compliance.

SUMMARY

PHASE	METHODOLOGY	PERIOD	STUDY AREA : THANE DISTRICT	POPULATION	NO of PHCs	NO OF PATIENTS	Prevalence Rate 10,000
I	Crash Surveys with Limited Services	2007 to 2008	Southern Talukas	Not Considered	Not Considered	3000 (approx)	Not Considered
	Rapid Surveys + Services	2008	Three Talukas	480,000	11	1250	26
II	Door to Door Surveys + Services	2009	Shahapur Taluka	212,104	7	587	27
Phase III : Intensive Physical Care at The Community Level							
III	Intensive Physical Care	2010	Vashind	52,466	1	140	25
Phase IV : Intensive Physical Care at he Community Level							
IV	Intensive Physical Care	2011	Shenawa	27,474	1	79	24
	-Do-	-Do-	Kinhauli	24,714	1	120	36
	-Do-	-Do-	Shendrun	37,375	1	91	25

Conclusions

The complacency over the decline in prevalence rates of leprosy which prompted the government to integrate total leprosy management with general health services is not justified. Though leprology is included in the specialty of dermato-venereology, the importance given to the neurological sequelae at the community level by the experts is not quite satisfactory. The technology of physical care of the disabled leprosy patients which is confined to hospitals and institutions has not penetrated into the community and doorstep of patients.

The magnitude of the problem posed by leprosy patients with disabilities and their rehabilitation is highly challenging and is expected to pose a heavy burden on the community as well as unprecedented strain on the PHCs managed by the government. The health planners should rethink on future strategies in such a manner that human rights of the downtrodden patients suffering from the "neglected disease" of leprosy are not sidelined.

Acknowledgement

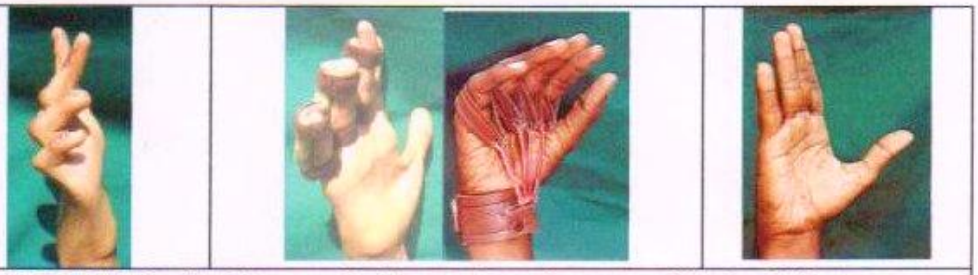
I am indebted to the Managing Committee of Bombay Leprosy Project (BLP) for recognizing the research wing of the Project called "Leprosy Patients Relief Fund" to raise donations for the field investigations as well as the Director and all the staff of BLP for their cooperation. The rural volunteers working under the supervision of Mr BO More provided efficient field services.
Mr Rahul Gupta and Mr Sanjay Kulkarni offered competent computer assistance.

References

1. Ganapati R, Community Based Comprehensive Leprosy Work in Rural Maharashtra, *Indian Association of Leprologists (IAL)* 2010; Chapter **41** . 542 – 544

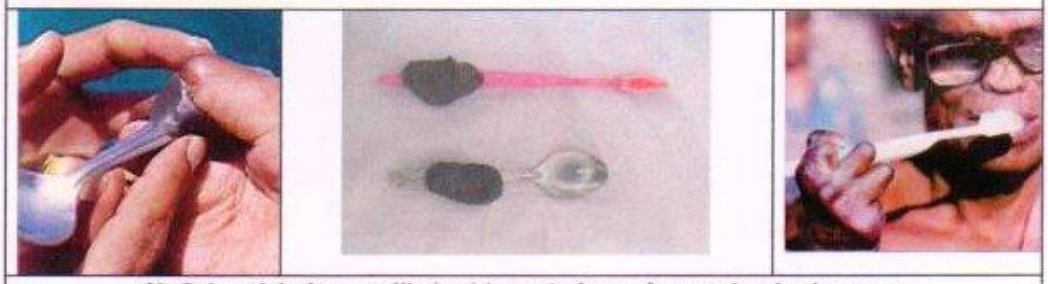
2. Ganapati R, Pai VV, Tripathi A. Can Primary Health Centres Offer Care to the Leprosy Disabled After Integration with General Health services? – A Study in Rural India, *Lepr Rev* 2008; **79**: 340-341

SERVICES OFFERED AT THE COMMUNITY LEVEL



1) Pre-fabricated low cost aids and appliances with physiotherapy

2) Wax therapy by physiotherapists and volunteers in village centers



3) Grip aids for mutilated hands for a few selected cases
(Prepared out of easily available cheap Araldite material mixed with Hardener)

4) Standard micro cellular footwear for simple and moderately advanced plantar ulcers

5) Moulded footwear for complicated deformity

Figure 4

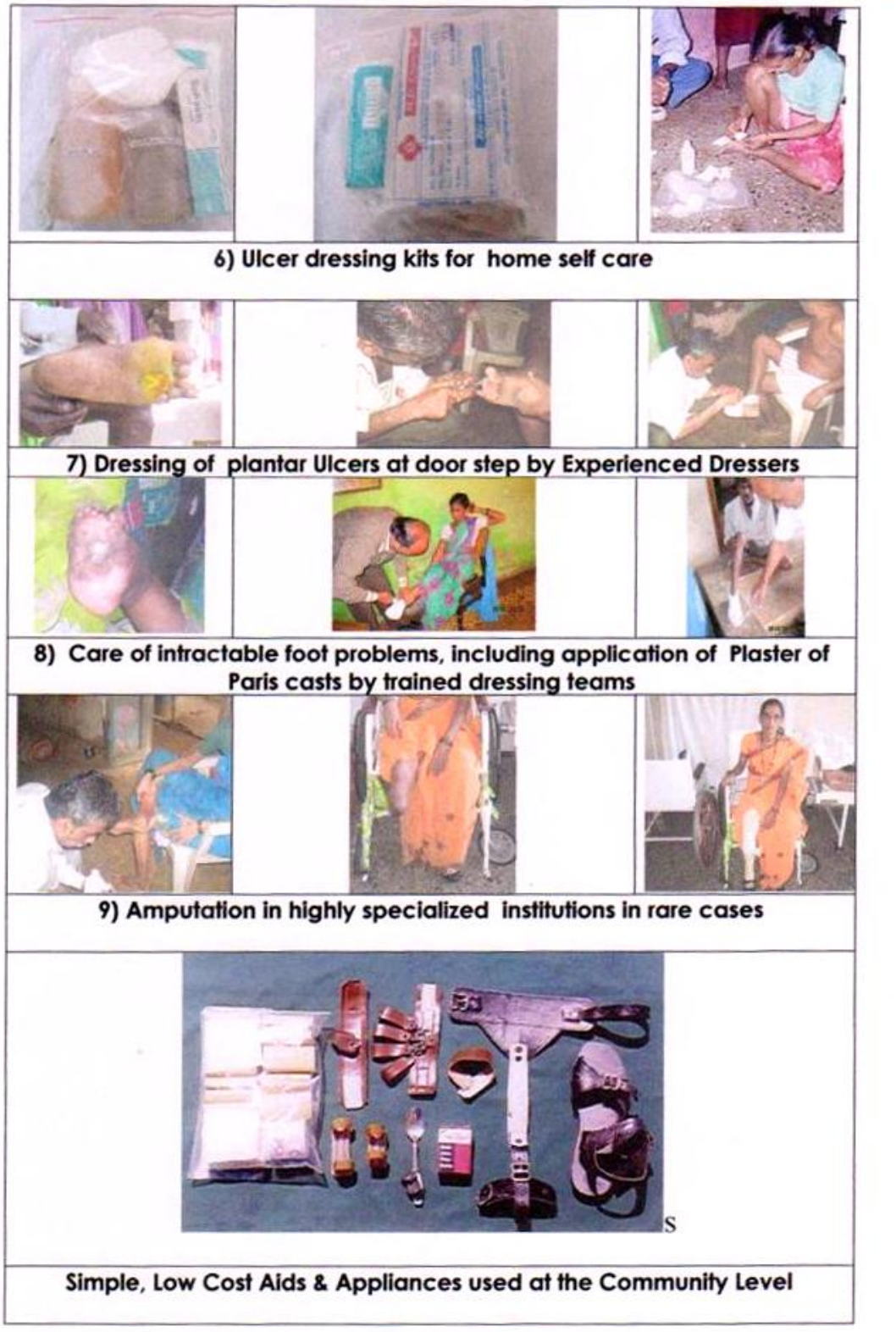

6) Ulcer dressing kits for home self care
7) Dressing of plantar Ulcers at door step by Experienced Dressers
8) Care of intractable foot problems, including application of Plaster of Paris casts by trained dressing teams
9) Amputation in highly specialized institutions in rare cases
Simple, Low Cost Aids & Appliances used at the Community Level

Figure 5