LEPROSY CONTROL

A REPORT FOR KAP STUDY

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by : QUEST QUALITATIVE RESEARCH

BOMBAY

BACKGROUND

Anti-leprosy work in India dates back to 1925, but it is only with the announcement of the National Leprosy Eradication Programme (NLEP) in 1983 that the movement received the right focus and momentum.

Given the unabating magnitude and geographic dispersion of the incidence of leprosy, the NLEP has been shaped by the following considerations:

(a) Priority should be attached to those areas where incidence of leprosy is high

(b) Voluntary agencies already active in the field of leprosy control as well as the public health system should be extended all possible support

(c) Leprosy control should form a part of a wider primary health care approach.

As an answer to the problem of drug resistance that had become a serious threat to all leprosy control activities, Multi-Drug Therapy (MDT) has recently been introduced to bring down the infectivity expeditiously and to thwart the emergence of drug resistance.

UNICEF assistance has been extended to the NLEP over the past few years, and this has included the supply of dapsone tablets, vehicles, training and health education material. 43 leprosy training centres have been set up to disseminate knowledge about leprosy and train the leprosy control staff. While UNICEF will continue to support the health education and awareness campaign at the national level, the MDT programme will concentrate on specific districts, moving simultaneously on all three fronts - medical, social and individual.

Out of the 98 hyper-endemic (over 10 cases per 1000 population) districts that qualify for MDT treatment, MDT has been introduced in 15 districts. Out of these, in three districts - Vishakapatnam (Andhra Pradesh), Puri (Orissa) and Chingelpet (Tamil Nadu), MDT is being implemented with the financial assistance of UNICEF.

UNICEF is aware that leprosy is as much a social problem as a medical one. Increasingly, the objectives of early detection, diagnosis and regular treatment are being defeated by strong social non-acceptance. There is, therefore, a need to develop an effective communication strategy to help break through the attitudinal barriers that currently inhibit the control and eradication of leprosy.

It is against this background that UNICEF wished to initiate research that is sensitive enough to provide fresh insights into the social, cultural and psychological aspects of the problem and thereby assist in establishing the objectives, approach and methodology of the communication programme. To this end, they commissioned QUEST QUALITATIVE RESEARCH to conduct a ten-district study.

RESEARCH OBJECTIVES

The major objectives of this study were to:

- investigate knowledge, attitudes and practices with regard to leprosy
- generate data to aid the development of a relevant communication strategy
- identify what needs to be communicated, how and to whom.

GEOGRAPHICAL COVERAGE

DISTRICTS	STATE	CHARACTERISTICS OF DISTRICTS
1.Vishakapatnam	Andhra Pradesh	Hyper-endemic, MDT districts in the most highly endemic states
2.Deoghar	Bihar	
3.Ganjam	Orissa	
4.Chandrapur	Maharashtra	Highly endemic districts with mono-therapy
5. Periyar	Tamil Nadu	
6. Uttarkashi	Uttar Pradesh	
7. Dangs	Gujarat	
8. Tuensang	Nagaland	Low endemic districts with mono therapy
9. Alwar	Rajasthan	
10.Kanpur	Uttar Pradesh	Hyper endemic, entirely urban district, monotherapy

SAMPLE

INTERVIEWS

	No. of interviews per Rural District			No.of interviews for urban district	Total no.of interviews
	Urban	Rural	SubTotal		
Patients	7	8	135	15	150
- with family	(3)	(4)			
- away from family	(4)	(4)			
Medical Arm	5	4	81	9	90
- doctors	(2)	(1)			
- paramedics	(2)	(3)			
- medical students	(1)	-			
Families of patients	2.5	3	50	5	55
- patients with them	(1)	(2)			
- patients away from them	(1.5)	(1)			
Voluntary Organisations	1		9	1	10
Opinion Leaders/ Influencers	1.5	2	32	3	35
- school teachers	(1)	(1)			
- village elders	-	(1)			
- journalists	(0.5)				
TOTAL NO. OF INTERVIEWS					340

SAMPLE CONTINUED

Group Discussions Amongst General Public

	Sex	Age	Education	Monthly	Urban	Rural	Total
1.	Men	25-45 years	Graduate	Rs.1000-2000	1	-	(10)
2.	Women	25-45 years	Upto SSC	Rs.1000-2000	1	-	(10)
3.	Young Adults (Boys, Girls)	13-17 years	-	Rs.1000-2000	1	-	(10)
4.	Men	30-50 years	Illiterate	Rs. 350-750	-	1	(9)
5.	Men	30-50 years	Upto SSC	Rs. 500-1000	-	1	(9)
6.	Women	30-50 years	Illiterate	Rs. 350-750	-	1	(9)
7.	Young Adults (Boys, Girls)	13-17 years	-	Rs. 350-750	-	1	(9)
					3	4	(66)

RESPONDENT CATEGORIES

A. General Public

* Men, women, adolescents
* Rural, urban, tribal
* Literate, semi-literate, illiterate

B. Patients

* With family, away from family
* Paucibacillary, Multibacillary
* Mono- and Multi-drug therapy
* Male, female, adolescent

C. Patients' Families

* With patient, patient away
* Paucibacillary, Multibacillary patient
* Mono- and Multi-drug therapy
* Male, female, adolescent patient

D. Voluntary Organisations

* Indian
* Foreign

E. Leprosy Training Centres

* Dehradun
* Ganjam
* Vishakhapatnam

RESPONDENT CATEGORIES (CONTINUED)

F. Medical Arm

* Doctors (MOs at LCU, PHC; Homoeopaths; Allopaths; Vaids; Private Practitioners; Specialists)
* PMW
* NMS, Health Educators
* LT

G. Influencers/Opinion Leaders

* School Teachers
* Village elders
* Mahila Mandal members
* Journalists
* Religious Heads

METHODOLOGY : FIELDWORK AND ANALYSIS

Selection of Villages

Within each district, two taluks were selected so that they:

i) were not adjacent

ii) did not represent an atypical community

iii) had differing degrees of incidence/prevalence of leprosy

iv) had differing leprosy control mechanisms such as LCU, SET, etc

Within each taluk, 2-4 villages selected on similar criteria as for taluk selection

Selection of Respondents

Patients:

- differing degrees of disease and treatment progression
- PB and MB
- Mono and MDT
- varying castes, communities, occupations, literacy and income levels

Patients' Families

- included families with patients staying with them, as well as patients away from them

Doctors:

- MOs at LCU
- MOs at PHC
- Private Practitioners
- Homoeopaths
- Vaids
- Specialists

Paramedical Arm: spread among:

- PMWs
- MPWs
- NMSs
- LTs

Voluntary Organisations and LTC Staff:

- Executive head
- Doctor
- PMWs as applicable

Classification Data

For every respondent, data was classified on the following basis:

- Age, sex, educational level, caste, religion, household income, marital status, occupation, family size and type, details of family members, type of leprsoy, stage and treatment, places of treatment, etc.

  It was used as a reference for check-back and analysis

Storing and Collection of Data

All depth interviews and groups were conducted by executives, consultants and specialist interviewers of QUEST

All depth-interviews and group discussions were conducted in the local language

All depth-interviews and group discussions were recorded and transcribed verbatim in English

Enabling techniques such as personification, analogy, metaphor and role play were employed, wherever applicable, in order to overcome rationalised responses

Analysis and Interpretation

The data in the transcripts were content-analysed by a team of qualitative analysts into a number of relevant categories

Outputs of enabling techniques were decoded with the help of the concerned research executive to interpret their significance in the particular social context.

LIST OF ABBREVIATIONS

GPM	-	General Public Men
GPW		General Public Women
GPB	-	General Public Teenage Boys
GPG	-	General Public Teenage Girls
PWF	-	Patient with Family
PAF	-	Patient away from Family
FWP	-	Family with Patient
FAP	-	Family away from Patient
OLJ	-	Opinion Leader Journalist
OLT	-	Opinion Leader Teacher
OLV	-	Opinion Leader Village Leader
VO	-	Voluntary Organisation
MO	-	Medical Officer
PMW	-	Para Medical Worker
NMS	-	Non Medical Supervisor
LT	-	Lab Technician
PB	-	Paucibacillary
MB	-	Multibacillary
UT	-	Under Treatment
C	-	Cured
DT	-	Discontinued Treatment
D1	-	Periyar
D2	-	Vishakapatnam
D3	-	Deogarh
D4	-	Chandrapur

AN OVERVIEW OF THE DISTRICT-WISE ASSESSMENT OF KNOWLEDGE AND ATTITUDES

LIST OF ABBREVIATION (CONTINUED)

D5	-	Ganjam
D6	-	Dangs
D7	-	Alwar
D8	-	Kanpur
D9	-	Twensang
D10	-	Uttarkashi

1. KNOWLEDGE - DISTRICT PROFILE

In this section we have endeavoured to provide a picture of the varying levels of knowledge about leprosy across the districts and have commented on the factors that cause this variance. When commenting on the districts, we have looked at them as various 'clusters', specifically, high, medium and low knowledge districts. Within each group of districts, we have highlighted the varying levels of knowledge among the different respondent categories.

High Knowledge Districts

The districts with fairly high levels of knowledge were Kanpur, Viaskhapatnam and Ganjam. The factors that brought about this commonality have been discussed below.

Common Features that Impinge on Overall Knowledge

Urbanisation: Kanpur is the only urban centre in this group, while Visakhapatnam and Ganjam are districts with a rural component. However, unlike the other districts, Visakhapatnam and Ganjam do not have a tribal populace and the villages also display greater signs of urbanisation. The effect of urbanisation on knowledge levels is nowhere more clearly highlighted than in the case of Kanpur. There seems to be a greater level of exposure to sources of information in the urban situation and education levels are higher. This leads to a much better informed public. In Visakhapatnam and Ganjam, access to sources of information and to media seems to be higher, interestingly, also as a result of the MDT program, a factor which has been discussed later in this section.

Further,Visakhapatnam district seems to display a gradually increasing level of industrialisation when compared to the other districts. Our respondent profile had a fair admixture of farm labourers, industrial/ quarry workers and also many who were involved in municipal work. This has improved access to and the need for knowledge and resulted in the growing away from traditional myths, foklore, etc., and an opening up to the outside world.

Ganjam is not so urbanised and is mainly agrarian. Therefore, it is comparatively backward. However, the fact of the high level of knowledge about leprosy can be attributed to the MDT program that is in full operation in Ganjam.

Drug regime: One of the major factors that has influenced levels of knowledge has been the MDT program. This program seems to (gathering from respondent comments) come with a package of information and education in addition to the drugs. The medical arm is kept rigorously educated and motivated to consciously impart this information to patients whom they contact. Thus, both Visakhapatnam and Ganjam, where

MDT is fully in progress, displayed higher levels of knowledge about leprosy. With regard to Kanpur, it is pertinent to note that the knowledge levels are high not only because of the fact of urbanisation, but also because MDT has been introduced here by the Damien Institute and has been in progress for a couple of years.

The news of the visible results of MDT's efficacy and the stress on education in this program have succeeded in creating a change in a Monotherapy district like Kanpur. Although Deogarh is also under the MDT schedule, it does not, however, come under this high knowledge category, a fact that we have discussed later.

Media: The presence of mass media and the levels of exposure to them has clearly had an impact on people's knowledge about leprosy.

Kanpur, by virtue of being a mini metro, has full exposure to mass media and other media sources. Consequently, a greater part of the populace is exposed regularly to the media than in other districts. Thus, whenever messages about leprosy have been beamed out, these have found an audience in Kanpur.

Visakhapatnam and Ganjam displayed stepped up media activity relating to leprosy, as a part of the MDT program. Pamphlets, wall paintings/ posters form the main sources of information about leprosy. It was interesting to note that many respondents in these districts actually verbalised that leprosy can be cured and that it is merely a disease, not a divine curse. In doing so, some tended to mention having read the media messages. In the section on Media, we have discussed the details regarding the various sources and respondents' perceptions of these sources.

Medical infrastructure: One of the reasons for the high level of knowledge in Kanpur, Ganjam and Visakhapatnam could also be the large medical infrastructure here. Compared to the other districts, these three have a complex and far-reaching system for leprosy treatment.

The LCUs, SETs and ULCs are better represented here than in the low knowledge districts. Kanpur has 22 PHCs and Ganjam has 29 PHCs where leprosy treatment is a regular feature. Visakhapatnam does not have PHCs for leprosy but has, instead, 4 LUCs and 4 ULCs and a record 49 SETs and a Temporary Hospitalisation Ward, which the others do not. This stepped-up activity on the medical side has made some impact on the overall awareness and knowledge of this disease. These medical centres are well manned and have penetrated deep into the districts, thereby ensuring that the awareness is widespread and intensive. As a result, the populace is beginning to view leprosy as another disease that can be treated and cured by the medical arm. The leprosy training centre at Aska has also greatly contributed in bettering levels of knowledge among the medical arm. Its presence in Ganjam affords constant recourse to information and enhances interest.

Further, the presence of voluntary organisations in these districts (especially in Visakhapatnam and Kanpur) has enhanced the infrastructure and their comparatively heightened levels of activity in this area have contributed immensely to improving knowledge levels in these districts. By contrast, in Ganjam the voluntary organisation plays no role in disseminating knowledge or training leprosy personnel. The Daughters Charity merely distributes medication and provides material aid. In comparative terms, the medical arm in Ganjam are not as motivated as those in Visakhapatnam and do not bother to actively impart knowledge about leprosy to the patients and their families.

Categorywise Knowledge Levels : An Overview

While there have been certain common factors that have influenced the levels of knowledge across the districts, it would be interesting to assess the extent to which and the manner in which this has percolated across the various respondent categories.

Medical Arm: Obviously, the medical arm was the most highly informed about leprosy and leprosy treatment. They receive the information directly and continuously from the Government (Health Ministry) or from voluntary organisations. They are also highly involved in putting this knowledge to practice and have learnt a lot more in this process. However, even within the medical arm, there were variances in levels of knowledge. The MDT areas, for instance, revealed a more deeply-informed medical arm when compared to the Monotherapy districts. Visakhapatnam and Ganjam, therefore, had a team of doctors and paramedical workers who were aware of the nuances of leprosy treatment and cure, and had regular access to new data in this field. In the Monotherapy districts, in contrast, the medical arm were knowledgeable but were not up-to-date on drug/treatment related information.

In Kanpur, which is a Monotherapy district, there was a difference between the government team's knowledge levels and those of the Damien Institute (who administer MDT). However, the presence of the MDT regime and its effective results have prompted renewed interest among the government team too. However, it was interesting to note that it was at the PMW level that this interest and desire for new information was more strongly manifest. The doctors tended to be more inflexible about wanting to change, fearing this would reveal the lacuna in their knowledge level and perhaps lead to loss of face or self image among junior staff. The PMWs, however, were more enthusiastic and were yearning to be exposed to more information about the new regime - to them, this was the best way to render their function more effective, to strengthen their hands, to basically `get on with the job'. Across all the 10 districts, we found that the medical students and practitioners of homoeopathy and ayurveda were very poorly informed about leprosy.

General Public: Of all the respondent categories, the general public was the least informed across all the districts, as they seem to have poor access to sources of information. Moreover, mass media has not communicated messages relating to leprosy very effectively to this segment.

However, we noted that in the high knowledge districts, even the general public seemed more knowledgeable than in the in other districts. While they may not know the exact scientific/medical details, it was heartening to note that at least they sought and put forward more pragmatic, more scientific and health-related explanations and tended to view the traditional beliefs and myths as unrealistic and untrue. Most of them were still not fully conversant with the medical facts about leprosy but at least were open to new ideas. It was mostly in these districts that the lay public was increasingly beginning to believe that leprosy is curable.

Opinion Leaders: This segment comprised teachers, journalists, village elders and religious leaders. Among these, we found the journalists most knowledgeable about leprosy as also about the new MDT regime and its advantages over Monotherapy. The teachers and religious leaders displayed poor levels of knowledge and most often perpetrated ancient beliefs, misconceptions about the disease and the prescribed interaction with patients. Some of the village heads were fairly well informed wherever they had been harnessed by the PMWs to help with the leprosy programme in their village.

Patients/Patients' Families: The patient's level of knowledge about leprosy is directly proportionate to the inputs of the medical personnel he comes into contact with. In Visakhapatnam, the MDT program, which is in full implementation, ensures that the PMW keeps patients and their families accurately informed - in fact, they see this as part of their function. Thus, these patients saw their affliction in the right perspective and were hopeful of cure and resumption of normal life.

In Kanpur, the exposure of many patients to the information-oriented MDT program at the Damien Institute has led to a better grasp of facts. Even those under the Government's Monotherapy Program came into contact with PMWs who, having heard of MDT at the Damien Institute, were enthused to instil their patients with hope. Further, we cannot discount the fact that Kanpur is an urban centre and so, exposure to media and sources of knowledge is greater. This could affect the patients/patient's family directly or be percolated to them via the PMWs.

However, in Ganjam, the scenario is quite different. We found that the patients here displayed lower knowledge levels when compared to Visakhapatnam and Kanpur. The medical arm, however, is well informed as they have been administering MDT for a while. However, the factors that seem to have impinged here are the attitudes and practices of the medical arm. The MDT program is being run by the government here, and we discerned a difference in the attitudes of this medical arm when compared to Kanpur and Visakhapatnam. We shall discuss this in detail in the Attitudes section. Suffice it to mention here that the patients do not receive enough information from the medical functionaries. The voluntary organisation here - run by Mother Teresa - has not made any impact in this direction either, as it is more involved with material aid, rehabilitation and assisting the medicos, rather than any active dissemination of information. With regard to the patient's family, it is necessary to point out that in Kanpur and Visakhapatnam, the PMWs took the trouble to keep them equally well-informed as the patients themselves.

Medium Knowledge Districts

Those districts that we would classify as displaying medium levels of knowledge are Chandrapur, Periyar and Deogarh.

Common Features that Impinge on Overall Knowledge

Urbanisation: The levels of urbanisation in this set of districts tended to be lower than in the high knowledge districts. Within this 'cluster', Chandrapur and Deogarh were more rural when compared to Periyar. In Deogarh and Chandrapur, the profile of the populace tended to be mostly agrarian, with a few industrial workers in Chandrapur (Deogarh was wholly agrarian) and so access to information sources was limited to that extent. The urbanisation levels in Uttarkashi and Periyar were higher in comparison. Periyar registered the highest levels of knowledge among these medium-level districts. While this can be attributed to a number of other factors, we cannot overlook the fact that this district, like Visakhapatnam, is increasingly becoming urbanised and rural folk have begun seeking occupation as labourers in the various dyeing mills or other small-scale industries that have sprung up in the rural areas. The villagers find gainful employment here and their standard of life and earnings seem better than with agricultural workers. We discerned an increase in the levels of education among the younger generation in these households, more signs of modernity and urban symbols like radios and other semidurables such as furniture and other household appliances, etc. Their new found awareness has led them to constantly seek information on more topics.

Interestingly, during the interviews in this district, we discerned a tendency among this populace to doubt traditional explanations and a need to replace these with more pragmatic, 'scientific' lore. Also, the presence of a large town like Erode in this district has helped speed the process of urbanisation.

Drug regime: Interestingly, of the medium knowledge districts, Chandrapur and Periyar, while they belong to the Monotherapy regime, have all just begun the administration of MDT. These drugs have just been introduced and their palpably remarkable success has been noticed and, therefore, there is a heightened level of awareness of the treatment and cure of leprosy. Deogarh is wholly an MDT district but this has been in progress only for about a year. Respondents in these three districts were aware of the fact that this is a new drug regime and have witnessed its stepped-up activity when compared to Monotherapy. Their interest has been aroused and, more importantly, there is a nascent knowledge of more scientific facts about leprosy and the possibility of its cure. Traditional knowledge still has a hold over this populace, but there is a sense of ambivalence as to its veracity.

However, in these districts, the level of knowledge was not equal among all respondent categories. Since the MDT program has been introduced in a limited manner (e.g. in Periyar, only in Erode town), the patients/patients' families were well-informed. The others, i.e. the lay public, was either unaware or just beginning to hear about this drug regime. Even the medical arm in these districts, with the notable exception of Periyar, were not highly knowledgeable about leprosy. We have discussed this in detail in the section on categorywise differentiation in knowledge.

Media: By and large, the media has not been adequately utilised in all these medium-knowledge districts. The findings indicate that, by and large, it was the 'static' media, viz. posters, wall paintings that were being used to disseminate knowledge about leprosy. Further, even these media were being underutilised in that these were displayed only at the LUCs, nowhere else. As a result, only patients and sometimes, their families, were exposed to these sources of information. The effect of these cannot be assessed, however, as the patients we interviewed recalled these messages, sounded hopeful of a cure and were emotionally reassured by the messages that advocated an attitude of acceptance towards leprosy sufferers.

The lay public is largely unaffected by these messages and has no other source of information about leprosy. This was also the case in Deogarh, which is an MDT district and this is, therefore, at variance with the other MDT districts like Visakhapatnam and Ganjam. The radio, T.V., film are all media that do not seem to have been utilised for leprosy-related information.

In Periyar, the film medium is used regularly by the Family Planning Department and has created great levels of awareness and recall of the FP message. However, this has not been harnessed by the leprosy personnel here. In Chandrapur, the Baba Amte Ashram is endeavouring to spread the message verbally by delivering regular talks at local schools, thereby clearing misconceptions among the younger generation.

Medical Infrastructure: These districts have a fairly well-represented medical infrastructure in the area of leprosy. This infrastructure is not as intensive as in the high knowledge districts, in that it is not well-represented in the entire district.

In Deogarh, there is a 20-bed government hospital that is supposed to be for leprosy patients. However, we found that the reality is different - the functioning of this medical centre is not as impressive as it sounds. We heard stories of doctors and medical staff who refused to touch patients or who took paying patients on priority.

There were voluntary organisations in addition to the government leprosy arm in Doegarh and Periyar. Deogarh has the Santhal Pahadiya Seva Mandal and the Rajkumari Kusht Seva Ashram. The former is very active in this area and is making a concerted effort to curb the disease. However, in terms of other related activities like dissemination of information, they do not seem to have done too much. Nor has the government done anything in this direction.

Periyar has the ASSISI, a Christian missionary organisation that works primarily among the tribals and also administers MDT. Other than hard work at treatment and rehabilitation, nothing is specifically done to disseminate knowledge to any one other than the patients and their families.

Categorywise Knowledge Levels : An Overview

Medical Arm

The knowledge levels among this segment were the highest in Periyar. This district has had the MDT regime introduced in the last year or so by the government. As a result, the entire medical arm has begun undergoing training in this area, a drastic updating of knowledge on leprosy and its cure. This was clearly reflected in our interviews, where most of the medical arm were able to talk knowledgeably about the details of treatment and cure and of the MDT program as well. With the beginning of this regime, the doctors as well as the paramedical staff have begun to focus attention on the treatment of leprosy with greater interest and are desirous of knowing all the details of this drug regime, in order to attain success with their cases. Since only a few had actually gained first-hand experience with MDT, overall knowledge in this district was still not yet as high as in Visakhapatnam.

Chandrapur has also begun MDT in a small way and this, again, has resulted in the medical arm being better informed. They were definitely moving away from old beliefs and gearing themselves to be an MDT district.

In Deogarh, however, knowledge levels were lower than in Periyar, despite it being an MDT district. This could be attributed to the fact that other than the voluntary organisation, the government medical arm had nothing much to do with leprosy. As a result, all the knowledge and the activity in this field was confined to the Santhal Pahadiya Seva Mandal and the government medical arm was not up-to-date on this disease.

General Public

By and-large, the level of knowledge pertaining to leprosy was fairly similar across these three districts.

The general public has not yet witnessed or heard about the impact of the new drug regime and the resultant hope it has brought to patients. Consequently, the old beliefs persist and the lay public are still not aware that leprosy, like other diseases, is caused by a germ and has nothing to do with one's misdeeds or karma. However, these districts differed from the low knowledge ones in that the populace is beginning to be ambivalent rather than rigid in their misconceptions about leprosy. They have begun to see some renewal of activity in this area by the medical arm, have had stray exposure to media messages (a case in point : the posters stuck on the marketplace and outside the LCU in Periyar) and are beginning to review their ancient belief system. They attempt to put forward reasons like poor sanitation or contagion as more likely causes of leprosy (which, though not accurate, are still more 'scientific').

In Deogarh the knowledge levels plummet, as the people are not exposed to any media, propaganda or activity in this field, despite the MDT regime being in progress here. We can include the category of opinion leaders here, as they were equally misinformed about leprosy and propogated the same myths.

Low Knowledge Districts

The districts that displayed poor levels of knowledge overall were Dangs, Tuensang, Alwar and Uttarkashi.

Common Features that Impinge on Overall Knowledge

Urbanisation: Interestingly, all these districts were marked by their high tribal populace. Levels of urbanisation were very low and all were also fairly economically backward as a result. It is hardly surprising, therefore, that tribal customs, folklore, traditional beliefs hold sway and exposure to modern thinking, to factual, scientific information is low.

The traditional misconceptions about leprosy hold sway in these districts and this is starkly reflected in their practices as well.

Drug regime: All the four districts follow Monotherapy and have done so for years. The slow rate of treatment has disillusioned some patients and led them to resort to traditional medicine, while others are lackadaisical about their drug routine. This has led to the perception among the populace that leprosy really has no cure. Further, Tuensang and Alwar are also low endemicity areas and thus the involvement with and the desire to know more about leprosy is low. This poor level of knowledge has, in turn, led to the most appalling practices and customs being meted out to patients in these districts.

The Raphael Ryder Cheshire International Centre located at Dehradun appears to have introduced the MDT drug regime. The centre attracts urban patients from Uttarkashi and other neighbouring districts. However, this organisation, while it administers MDT,does not have any interaction with the rest of the district (Uttarkashi) where Monotherapy is the main regime.

Media: The low level of urbanisation and the economic backwardness have also led to poor exposure to media. The audio or audio-visual media are virtually unknown in these districts, while illiteracy renders the printed medium redundant. Moreover, even the medical arm here has not utilised other information sources (talks, demonstration, etc.) to propogate the right messages either. In Dangs, the government has made a beginning in this direction - at the local fair, the Dangs Durbar, they have begun displaying posters about this disease, talking about it. Interestingly, this had registered and was recalled by a few respondents. It has served to arouse curiosity at least among these few, even if it has not brought them away from their misconception and superstition.

Medical infrastructure: In Dangs, there are no LCWs or LTCs only a number of SETs, while in Alwar there are some Family Health Centres and the multipurpose here double up for leprosy. The virtual absence of medical activity in this field has resulted in poor levels of knowledge even among the patients, who are normally best informed because of their constant interaction with the medical arm. Nor are there any voluntary organisations here that help step up interest with their supportive activity in this area.

In Tuensang, the medical infrastructure is such that the majority of the patients are at the commune at Longleng and are treated with Dapsone there - the concept of treatment at home is one that the medical arm in Tuensang obviously does not subscribe to.

Categorywise Knowledge Levels : An Overview

Medical Arm

As in the other districts, the medical arm in the low-knowledge districts was the best informed among all the respondent categories. However, there was a difference between Alwar, Tuensang, Dangs and Uttarkashi.

In Uttarkashi, the medical arm was best informed of these four districts and this, we feel, is because it is a hyperendemic area. As a result, the doctors and PMWs here are treating more leprosy patients regularly and their experience in this field is greater. However, since they follow Monotherapy completely, they displayed poor awareness of the details of treatment. They were not too sure about the best way to handle drug resistance or contraindications, the kind of diet or hygiene standards to be prescribed, etc. In this regard, we found that in Dangs,the PMWs are poorly informed on all these aspects as they have forgotten quite a bit of what they had learnt during their training program years ago. Thus, they tended to be unnecessarily strict and advised patients against consumption of quite a range of foods, believing them to be `heating' and, therefore, likely to aggravate the disease.

In Tuensang, Alwar and Dangs, the medical arm displayed abysmally low knowledge levels - they saw themselves as mere dispensers of medicines and were unmotivated to apply themselves beyond that in the treatment and cure. Other than the doctors, the PMWs were unsure of the facts and this has been picked up by the patients who, consequently, lose faith in their PMWs. The doctors, too, knew all about Monotherapy but not read of new advances in this area and so, had a limited supply of knowledge. Among the medical arm in these districts only those directly involved in leprosy work knew anything about it. The other GPs, homoeopaths, Vaids, etc. knew little and were, by and large, misinformed.

General Public

If the medical arm is so inadequately informed, it is not surprising that the lay public in Dangs, Tuensang and Uttarkashi is either ignorant of any facts or hoplessly misinformed. Local misconceptions, superstitions and customs abound and the populace is really characterised by a low interest in this disease. These people firmly believe that leprosy is caused as a result of a divine curse for one's past sins. Interestingly, in Dangs, which is a hyperendemic area, some people also tend to attribute this disease to more 'scientific' causes, such as the consumption of certain foods or drink (e.g.pork,alcohol) or through air/water contamination. The rural and the tribal folk believe strongly in karma or witchcraft practices as being the cause of this dreaded disease.

The general public in these districts does not seem to recall any messages relating to leprosy, is unaware that the government is involved in this field and so continues to mystify and dread this disease.

The so-called opinion leaders, viz. teachers, religious heads, village heads,can be categorised with the lay public as far as their knowledge of leprosy is concerned - they have the same misconceptions, reiterate the same customs, with perhaps the exception of the Christian priests/ pastors in Tuensang, who, despite their poor knowledge, do not condone the harsh customs.

Patients/Patients' Family

The patients and their families were a little more knowledgeable than the lay public, to the extent that they understood the symptoms of leprosy, its progress, the signs of cure, the extent of contagion, etc. However, they were ambivalent about the cause and could not really accept traditional beliefs as their own experience did not reiterate these. They found the medical arm - at least the PMWs whom they come in contact with - unable to provide satisfactory explanations and were, therefore, curious to learn the truth. Their common complaint is that the lay public refuses to accept any sensible explanation and due to this lack of knowledge, ostracises and harrasses patients. Patients' families are also open to more scientific explanations as they are close to the patients and the medical arm, but in the absence of any convincing explanations, tend to revert to folklore.

2. ATTITUDES : DISTRICT PROFILE

When discussing attitudes across the districts, we have categorised them as Hopeful (i.e. those with a more positive and open attitude to leprosy), Ambivalent and Negative districts.

Hopeful Districts

These districts were Kanpur, Visakhapatnam and Ganjam. They were characterised by their overall attitude of hope and an attempt at positive, forward thinking rather than easy acceptance of traditional misconceptions. This does not, however, mean that the populace in these districts displays a greatly positive and the 'right' attitude - rather, they are more open and willing to be positive rather than wholly negative and closed.

Our findings reveal that the factors that have brought about this attitude were those that affected knowledge levels too. We have discussed these factors and their influence on attitudes in the section below.

Common Influencing Factors

Urbanisation: It cannot be denied that a more urban populace is more open and positive in its attitudes than those in rural or semi-urban areas.

Kanpur is a case in point : in terms of knowledge, it is not as high as Visakhapatnam but in attitude terms, it excels, simply because of its urbanisation. This is a mini metro and displays urban values which are a result of increased education, industrialisation and exposure to mass media. Consequently, antagonism towards a sect is publicly frowned on and, overtly at least, one learns an attitude of acceptance of differences, tolerance and learns to display humanitarianism. The 'black and white' attitude of the rural areas is not prevalent here and, at least for social acceptance, one learns to mouth humanitarianism and a social spirit. This has resulted in a more pragmatic and enlightened attitude to health and the treatment of diseases. The scientific basis of any disease and its successful treatment is more readily acceptable. Furthermore, traditional health care has given way to a greater reliance on scientific medi-care. Thus, overall, people in Kanpur were more hopeful about leprosy being cured and were desirous of doing their bit not to ostracise patients. They believed medical science, by its activity in this area, has created the feeling that everyone can do his bit to reduce the suffering of patients - material help is the first (and easiest) to be offered, while a few were convinced they also needed to render moral and emotional support. However, this does not encompass more than verbal gestures, as the innate fear of contagion still lingers as people are unsure about the medical facts pertaining to this disease.

In Visakhapatnam, where knowledge levels are better, the overall attitudes are not as good as in Kanpur, as the rural component is greater. Their low level of exposure to urban thinking has led to the same traditional beliefs and misconceptions being handed down even today. The more urban areas in Visakhapatnam or those with increasing urban facilities have led to a growing change in attitudes. People here display the hope that leprosy will be cured and tend to reject the concept of karma, of divine curses as traditional and impractical, definitely not beliefs they are willing to subscribe to. Further, the urban need for presenting the right social `face' leads them to discard ideas of ostracism and accept patients if facts prove this to be the right thing to do.

Ganjam is not as hopeful as those two districts, but this is also because the urbanisation levels are lower here. However, the attitudes here are good despite this, as a result of the MDT regime in progress here, an aspect we shall deal with in the following section.

Drug regime: Visakhapatnam and Ganjam are wholly MDT districts while in Kanpur, the MDT regime has only been introduced by the Damien Institute.

The interesting factor of the MDT regime that we noticed is, that the personnel trained in this program have learnt to lay great stress on imparting knowledge, counselling, advising and take pains to mould attitudes as well. In the Monotherapy districts, in contrast, the medical personnel are not as knowledgeable and also, perceive themselves as dispensers of treatment and discount the importance of emotional/attitudinal guidance. We know that in the area of leprosy, the social stigma and the negative attitudes have been more deleterious to progress than anything else. The MDT-trained personnel in Visakhapatnam and Ganjam have recognised this and are succeeding in filling patients with great hope, an attitude that rubs off slowly on other people as well. Secondly, the dramatic results of MDT - when compared to Dapsone - have had an equally important role in raising hope in these districts and improving attitudes to this disease. The promise of a cure acts as an impetus to be cured with minimum fuss and, even to the lay public, acts as proof that the leprosy patient can be treated like other disease-sufferers, i.e. as someone with a temporary problem but with the hope of regaining normalcy soon.

In Kanpur, MDT is not the mass-scale regime but, nevertheless, the effective results it has produced have begun to be talked about and the patients are open to revamping their attitudes and beginning to replace fear and despair with hope and determination.

Media: This is perhaps the most important factor in influencing people's attitudes to leprosy. Mass media communication of factual and positive messages cannot fail to create an impact. In the few cases where it has been done, one has witnessed results - the LCUs in these Hopeful districts have utilised posters/wall paintings to communicate the message of hope and this has changed the attitudes of its target

audience, viz. patients and, sometimes, their families who accompany them to the LCUs. However, by and large, this very influencing factor has not been harnessed in these districts. The change in attitudes can, thus, be attributed to a great extent to levels of urbanisation and to the yeoman service rendered by the medical arm in these districts.

Medical infrastructure: The medical infrastructure in Visakhapatnam and Ganjam is well organised and intensive. The MDT regime has reached everywhere and the heightened activity this regime demands has been communicated to the people. The patients have definitely picked up this achievement-oriented, hopeful attitude and the lay public has not been slow to recognise the efforts by the medical arm, as also the results.

In Kanpur, the government infrastructure follows Monotherapy and is not as intensive in terms of personnel. However, the Damien Institute has an active presence here, a team of PMWs who fan out everywhere with their drugs, counselling, etc. The government, however, has a good infrastructure in terms of facilities such as clinics, physiotherapy clinics, hospitals, etc. where leprosy patients are regular visitors. This has led patients to feel they are being well handled by an efficient, modern system and so, are hopeful of cure and willing to undergo treatment.

The presence of voluntary organisations is also a major contributing factor in these districts. In Visakhapatnam their presence is most powerful (GREVALTES, UNICEF, GMLF) and most people are aware of the efforts they are expending for leprosy patients. This has fired the government medical arm to try and match them. The patients who come into contact with the voluntary organisations are full of praise for their zeal and efforts and display a far more positive and determined attitude. The impression of a dedicated, hard-working, determined and enthusiastic medical arm was strongest among voluntary organisations such as the GREVALTE and GMLF, who run model institutions there.

The Damien Institute in Kanpur is of the same calibre and its effects on patients are palpable. In Ganjam, the Missionaries of Charity are noticed by most people for their selfless and enthusiastic efforts at helping patients.

Categorywise Attitudinal Levels

While Kanpur, Visakhapatnam and Ganjam are overall Hopeful districts, we found that this attitude did not exist in equal measure across the respondent categories.

Medical arm: The medical arm in these districts was most positively predisposed to working with leprosy patients. They were of the opinion that leprosy is just another area of work. Since their knowledge of the facts about leprosy and its transmission was also high, they had

few qualms about handling these patients. However, the medical arm in the rural areas confessed that though they were themselves of this attitude, other members of their profession who were not involved in leprosy, tended to perceive not just the patients but the doctors and PMWs as `outcastes' of sorts.

In Kanpur, the medical arm engaged in the area of leprosy have a fairly no-nonsense attitude and are, as is typical in an urban situation, desirous of achieving successfully cured cases. The introduction of MDT and its palpable results have created greater interest among the government doctors and they are pushing for this drug regime for their patients as well. In Visakhapatnam and Ganjam, the medical arm have the aid of the MDT regime and are highly motivated to work in this area, now that modern technology has brought in hope.

General public: The attitudes of the general public are the poorest when compared to the other respondent categories. They have not been affected very much by the new strides taken in the cure of leprosy and continue to view it with horror and dread. They have heard or seen some glimmer of this hope and so are not rigid but willing to know more and willing to accept a change in attitudes. However, as discussed earlier, no efforts have been made to educate them or mould their attitudes.

Opinion leaders: While the attitude of the lay public can be excused as arising due to lack of knowledge, the attitude of the opinion leaders is difficult to justify. These are people who are supposed to be more knowledgeable, pragmatic, in a position to ring in change among the masses. However, we found that they were of the same level as the masses, in that they condoned traditional beliefs and customs as the only ones they were aware of. There were many instances of journalists or teachers who, despite their education, could only offer pity and charity rather than an attitude of acceptance and support towards patients.

In Visakhapatnam we found a few of the village heads were more positive attitudinally, as they had been harnessed by the PMWs in detecting and counselling patients in their villages. They had, therefore, been counselled in turn by the PMW and so were positively predisposed and willing to `educate' the villagers.

Patients/Patients' family: The effect of the MDT and the attitudes of the medical arm have had the most directly positive result on patients and some of their families.

The patients in these three districts were characterised by their hopefulness and determination to be cured. The palpable effects of MDT have led them to envisage total cure and a quick return to normalcy.

Further,the role of the PMWs in these areas also cannot be underplayed; they constantly check on the patients, ensure they have their medicines, counsel them and their families, offer advice or help in rehabilitation and offer emotional encouragement. This constant prodding and attention have led these patients to slowly move away from despair, to work towards regaining their self-confidence and the determination to overcome their situation.

AMBIVALENT DISTRICTS

The districts we have termed Ambivalent are Periyar and Deogarh. Periyar is a Monotherapy district, hyperendemic, with the MDT being gradually introduced. Deogarh is also hyperendemic but follows MDT wholly.

Common Influencing Factors

Urbanisation: Periyar is mainly agrarian but has begun the process of urbanisation gradually. To that extent these people are attitudinally just that much more open than in the fairly rural Deogarh district.

The levels of education and the general standard of living also seemed better in Periyar and this has led to a revamping of old attitudes and a desire to be more pragmatic and sensible. But it is still between two worlds in its attitudes and this is reflected in attitudes to leprsoy as well - a reluctance to give up the old and the stirrings of curiosity in the new. Deogarh is not among the Negative districts, mainly because of the MDT program in progress there and due to the efforts of the voluntary organisation there - we have discussed this in detail later. However, it is otherwise a strongly rural area, where attitudes are still harder to change. This process has begun with the new drug regime.

Drug regime: The MDT program is fully in implementation in Deogarh. The effective results of this drug regime and the efforts expended by the PMWs in this regime have raised the hopes of the patients who come into direct contact with them. There is the beginning of hope now among patients. This feeling is only prevalent among the few who are involved in the MDT regime - as discussed earlier, only the Santhal Pahadiya Sena Mandal does this work and it has a limited reach.

In Periyar, the MDT program has just been introduced in parts and so the results are not yet fully known. As a result,most patients and the medical arm are ambivalent; they are no longer fully frustrated as there is the hope of a new drug. Nor are they as hopeful as in Kanpur or Visakhapatnam since the effects of MDT have not yet been witnessed in Periyar.

Media: There have been very few efforts made to harness media to help spread the message of hope further. Thus, these districts rely only on the few posters put up at LCUs for any mass communication and change in attitudes. This has begun with the patients as only they are exposed to these posters. However, they do not see these messages supported in other mass media and thus their stirrings of hope are not really encouraged further.

The other sections of society (general public) do not receive any media messages pertaining to leprosy and have not changed old attitudes. The medical arm has begun receiving information through pamphlets, training programs on MDT and have begun the slow process of change in attitudes.

Categorywise Differentiation

Medical Arm: In Periyar, the MDT has been introduced in small phases and the actual results have not yet been fully experienced. Thus the medical arm here is still ambivalent in its attitude - they are willing to leave behind the frustration of their Monotherapy experience but unsure of being too hopeful till MDT is fully in progress.

In Deogarh, the government has nothing to do with leprosy and the voluntary organisation, Santhal Pahadiya Seva Mandal, works alone in this field under the MDT regime. Their task is, therefore, uphill, as they lack the on-going infrastructure of the government and it is commendable that their attitudes are still highly hopeful and enthusiastic. The government doctors were uninvolved and yet curious about the steps being taken by the voluntary organisation.

General public: The lay public in Periyar and Deogarh displayed a negative attitude, not even ambivalence. Very few effort has been made to bring about a change in their attitudes. Therefore, they still believe in traditional folklore and superstition and perceive leprosy patients as being doomed for life and outcastes of society. The opinion leaders here were of the same attitude.

Patients/Patients' families: The patients were more hopeful. In Deogarh the effect of MDT and the counselling and moral support offered by the voluntary organisation have resulted in a slow but certain growing of more positive feelings among patients. Most were hesitant and wary of being too hopeful, but eager to give it a try.

In Periyar, the patients who had come under the MDT program echoed this attitude, while the others were either ignorant of this new hope or else had begun to hear of it and paused in their despair, ready to be gently prodded back to a more positive attitude.

NEGATIVE DISTRICTS

These were Chandrapur, Uttarkashi, Dangs, Tuensang and Alwar.

This attitude was brought about by common factors such as the high rural and tribal content in these districts, the poor media sources, the inadequate medical infrastructure (and absence of voluntary organisations except the Amte Ashram at Chandrapur) and the fact that Dapsone is the main drug regime here. We have discussed these factors in the knowledge area, and here we have only highlighted the differences among the various respondent categories in these districts.

Categorywise Differentiation

Medical arm: Except in Tuensang and Alwar, the medical arm in the other three districts displayed a remarkably hopeful and positive attitude. They seemed fairly involved with their cases since they had been treating them for years and were desirous of bringing about some change.

In Tuensang and Alwar, the medical arm is uninvolved and frustrated by years of an apparently slow-working drug, the constant shortage of drug supplies and the transportation problems they face. They seem to have developed a lackadaisical attitude to their patients and this has been picked up by the latter. The most basic norms of leprosy treatment are not maintained and there is a palpable feeling that these medical workers have given up.

General public: On the whole, the attitudes of the lay public were at their worst in these districts. They have no involvement with leprosy and patients have not heard of any new thinking or scientific/medical advances in this area. Thus, the taboos, ostracism and rigid attitudes were most palpable here, making these patients' lot a terrible one. The rural/tribal/backward classes segments are high in these districts and their poverty and illiteracy are still major barriers to any health education or revamping of attitudes. Nowhere was this more apparent than in Tuensang, where a separate colony for patients exists at Longling. We could find only six patients outside Longling and that too, at the early, patch stage and so unknown to society.

Social ostracism of patients and their families is high in these districts, as the lay public is driven by unfounded fears, superstition and rigid adherence to custom. The attitude of tolerance or a willingness to learn is lacking. Most often, in these districts, this attitude of the general public has had a deleterious effect on the patient and even hindered the medical arm from making headway with their cases.

Patients/Patients' families: The unfortunate aspect of these Negative districts is that even the patients (who come into contact with the medical arm and pick up the right information and attitudes) display a not too hopeful attitude. In fact, they were characterised by their attitudes of despair, hopelessness and resignation to their unhappy lot. They have undergone long periods of treatment with Dapsone with little apparent improvement and even the few who have begun MDT in Uttarkashi and Chandrapur have not yet witnessed any change (the drugs have been introduced very recently). Thus, even though the medical arm in these districts (except Tuensang and Alwar) is hopeful, this attitude has not percolated to the patients. The other reason for their dejection is the extremely negative attitude of society here - cases of severe social ostracism are rampant and this has served to dampen the hopes of patients and even their families. The latter, rather than being supportive, came under the social pressure and rejected the patients, thus deepening their negative attitude. Unlike the other districts, in these Negative districts, fewer patients lived with their families.

3. MEDIA

The media plays a considerable role in disseminating knowledge about leprosy. While a qualitative study can at best provide an insight into people's relationship with the various media, it cannot provide a comprehensive or accurate assessment of the reach or effectiveness of each mass communication medium. Hence the observations in this section must be viewed as indicative of people's perceptions and the researcher's observations rather than as a definitive understanding of media habits and effectiveness of the various media.

It was observed across the districts that the audio-visual and other media such as posters, pamphlets, etc. appear to have a better reach in urban areas than in rural areas.

In rural areas, the spoken word is more effective as senior village members can also be utilised for this form of health-education - this requires no norms of lteracy on the part of the audience and no investment or cost either. Further, we noticed that to most villagers, the messages received with the participation/`sanction' of their own village heads/elders are viewed as gospel. We have discussed below perceptions of respondents of the various media sources available. In doing so, we have found it pertinent to comment specifically on rural vs urban audiences.

Radio

In both the rural and urban scenarios, the radio/transistor is almost ubiquitous. Most homes own one and it blares a variety of `noises' through the day. Or else, it is blaring in someone else's home or in other public places for the benefit of the neighbourhood. The radio forms a sort of background to daily routine.

Both rural and urban respondents mentioned that they heard a variety of health-education programs on the radio and these have, obviously, been of some use, as respondents were able to recall many. However, it was interesting to note that although the radio is currently <u>not</u> being utilised for leprosy messages, many people who had registered some stray messages (either through hearsay or through doctors), professed to having heard these on the radio. "I heard that one must treat leprosy patients with understanding and that leprosy can be cured these days ... I think I heard it on the radio, you know they have all these health programs, innoculation and family planning and all that on the radio ...". This quote sums up the extent to which the radio is entrenched in people's perceptions as the doctor's/government's welfare `tool'; thus, any health related message must, to their minds, have come from the radio.

The rurally backward areas as in districts like Dangs, Alwar, Tuensang and even Deograh, to some extent, do not seem to have this easy access to the radio. In fact, they have no access to most media forms and are far removed from mass communication. While the radio can be used for leprosy messages, due to its wide audience, there is also the drawback of the health message `clutter' on this medium now. Further, the need of the hour is a bold impactive foray in moulding attitudes to leprosy and the radio lacks the ability to make a strong impact.

Cinema

The cinema is more an urban medium than rural, simply because of the logistics involved in regular screening (theatre, equipment costs). However, rural audiences are exposed to the travelling cinema. The government has been screening health education films to rural audiences, often with a bonus feature film as an incentive.

The impact of this larger than life audio-visual medium is obviously very powerful. Urban respondents, who have easy access to cinema, were able to recount the various health education documentaries they have seen on the screen - most spoke of family planning films. The few rural respondents who had remembered seeing health education documentaries, also remembered the family planning film.

Currently, this medium is not being utilised for leprosy, but we feel this should be remedied, as it has a powerful impact on audiences.

Television

This is even more wholly an urban phenomenon and rarely, if ever, reaches the rural audiences. Respondents seem to recall many health related messages from this medium as well and it is obviously the most impactive in the urban situation. Like the radio, people are so addicted to, and conditioned by, TV that we also had some (urban) respondents telling us that they vaguely recalled seeing documentaries on leprosy on TV - currently, no such documentaries are being screened on TV nor have they been for a while. Respondents remembered the various social/health messages beamed at them by TV and some even suggested that communication on leprosy should find a place in this medium. They believe it would create a lasting impression if they were exposed to regular talk-shows and case histories on leprosy via this powerful, in-home, audio visual medium.

Posters/Wall paintings

This fairly `static' medium is being extensively used by leprosy workers in both urban and rural situations. The common practice currently is to stick these on the walls of the LCUs or some clinics or hospitals run by the government/voluntary organisations. Thus, they are seen

only by visitors to these places and these tend to be mostly the leprosy patients and, sometimes, their family members who accompany them. The posters have had some impact on patients specifically in terms of creating the feeling that cure is at hand and that there is an entire system that is geared to help them.

The drawback, however, is, that in the rural areas and among the urban poor, illiteracy is rampant and,thus, the message in these posters/wall paintings is lost to them. Mere visual depiction conveys nothing, as this is an area of some complexity and requires explanation.

Pamphlets

It is only the medical arm, and that too mostly those in the MDT program, who receive pamphlets with information on leprosy. This forms part of their training process and they have a constant supply of printed information that explains the details and complexities of the MDT program.

However, the common complaint was that the PMWs rarely gain access to this medium and they have to rely on the medical officers for most information. The doctors/medical officers, it is believed, rarely hand out these pamphlets to the PMWs, who are always eager for formal training of any sort.

Pamphlets are not handed out to patients or the lay public and are treated as medical literature. In any case, most of the audience that the medical arm reach out to is illiterate and pamphlets are, therefore, of no use to them.

The government medical arm receives these pamphlets from the Ministry of Health while voluntary organisations have access to printed material on the subject from a variety of sources.

Folk Theatre/Plays

The folk theatre is used regularly in villages to convey religious or social messages. In the urban areas, plays with social messages are also common.

In the rural set-up, this is a very effective medium for various reasons. Firstly, this is an ancient art form and villagers look forward to education through these plays - the symbols used are interpreted with ease and are familiar and, therefore, communicate messages successfully. Secondly, the villager's illiteracy is no barrier to receiving education via this medium. Thirdly, folk theatre is a big event in villages and, since they are normally combined with a fair or a festival or a religious event, command a large and varied audience.

This form has not at all been utilised so far for leprosy-related communication.

SUMMARY OF MAIN FINDINGS

At the outset, it should be pointed out that this KAP was a qualitative one. Thus, while it was ideally suited for exploring the range of attitudes and examining the various patterns of behaviour, it was not geared to making projections on factors such as knowledge levels and the extent of prevalence of various behavioural patterns. However, such a qualitative KAP is much more insightful. This is of particular relevance when one of the major objectives of the research was to aid in the development of a communication program. In the course of a qualitative research study, the researcher is exposed to the manner in which respondents express themselves about the causes and treatment of the disease. Consequently, the researcher is in a better position to recommend communication strategies that are more in consonance with the beliefs and modes of expression used by the respondents. It also assists in identifying local terminology which makes communication both more comprehensible and more credible.

In this section, we shall endeavour to answer the various questions to which the research addressed itself.

1. Is the level of knowledge about leprosy similar across the districts and the various respondent categories?

   Knowledge levels varied sharply across the ten districts. Based on their knowledge levels, we could classify them into three categories, viz. High, Medium and Low Knowledge districts.

   The High Knowledge districts were Kanpur, Visakhapatnam and Ganjam, the Medium Knowledge districts were Chandrapur, Periyar and Deogarh, while Uttarkashi, Alwar, Tuensang and Dangs comprised the Low Knowledge districts.

   The difference in knowledge in these districts was mainly the result of factors such as urbanisation, exposure to media, the drug regime and the medical infrastructure. Thus, we found that the more urbanised districts featured among the High and Medium categories, while districts with a high tribal/rural content tended to display a dip in levels of knowledge about leprosy. Misconceptions and lack of understanding or information about this disease characterised the districts with low levels of urbanisation.

   Media presence and pressure does affect knowledge levels. It was not surprising to note, therefore, that the Medium and Low Knowledge districts had lower or negligible exposure to mass media communication.

   The drug regime in a district, i.e. whether it is MDT or Monotherapy, did have a strong role to play in influencing knowledge levels. Thus, High and Medium Knowledge districts were either totally or partially under the MDT program, while Low Knowledge districts were the Monotherapy areas. The MDT program seems to have a built in information-dissemination component and this has apparently paid off, in contrast to the mere drug-dispensing culture of the Monotherapy program.

Not all the efficacy of the drug regime nor the support systems of an urban situation can, however, make much of an impact without an efficient medical infrastructure. Thus, in the districts where the medical arm is poorly represented or lacks the support of a voluntary organisation, we found that the knowledge levels dipped - this, in some cases, despite a fully ongoing MDT program.

In the 'District Profile' section of the Main Report, we have commented on the differences in levels of knowledge across the districts.

Among the respondent categories too, the level of knowledge pertaining to the disease varied sharply. The medical arm (MOs, PMWs, NMSs) was the best informed in all the districts except Tuensang and Alwar. However, medical students, practitioners of ayruveda and homoeopathy were grossly under informed about leprosy. Medical students felt that the study of leprosy did not merit and was not given adequate emphasis in their curriculum. While the Vaids recognised the disease and were able to prescribe a course of treatment, the practices followed by them suggested that they reinforced some of the common misconceptions about leprosy, e.g. leprosy was a result of impurities in the blood and that its cure required dietary control, etc. The Homoeopaths, on the other hand, clearly acknowledged that their science was not equipped to deal with this disease.

As the medical arm is in frequent contact with the patients and their families, these two categories of respondents tended to be better informed than other 'publics' interviewed. The traditional beliefs concerning the cause and transmission of the disease seem to have given way to the modern, scientific approach communicated by the medical arm. However, the interaction between the PMW and the patient/family concentrates more on the treatment and the cure than on the causes of the disease. This lack of knowledge about the causes of the disease results in some scepticism about the ultimate curability of the disease and about the patients ability to live together with his family without infecting them.

The findings suggest that there is very little difference in the low levels of knowledge of the various facets of the disease between opinion leaders (village headmen, teachers, journalists, etc.) and the general public. These are also the categories where all the misconceptions about the causes and the transmission of the disease abound. Consequently, they displayed a high level of dread and abhorrence of the disease. In fact, they considered ostracism as a normal and natural action to stop the spread of the disease. Among members of the general public, it was clear that the levels ofliteracy and urbanisation had an impact on the level of knowledge. The more literate and urbanised segment of the general public tended to be better informed, as did literate males and adolescent boys (who tended to attend school longer than girls) about the various aspects of the disease. The higher level of knowledge among the literate and the urban public could also be attributed to their wider exposure to media.

2. What are some of the most common misconceptions about leprosy?

The cause/transmission

The cause and the transmission of the disease are shrouded in mystery. Outside the members of the medical arm (MOs, PMWs, NMSs), there was a fairly high level of ignorance about the causes and the transmission of leprosy. There were the traditional beliefs that suggested that leprosy was hereditary or that it was a blood disease or that it was an act of retribution of the Gods. Then there were the quasi-scientific mis-conceptions which related the disease to poor levels of hygiene and to some bacteria and where the transmission was believed to be caused by contact. Further, respondents were unaware of the fact that leprosy could only be contracted from the infectious, multibacillary type of leprosy patient. In fact, the common misconception was that patients with wounds, ulcers and deformities were the most infectious. It was not common knowledge that leprosy was an airborne disease; it was perceived as a disease which was transmitted through blood (genetic), sputum, sexual contact and ingestion of contaminated food. Thus, it was believed that close physical or social contact with a leprosy patient would result in the transmission of the disease. As a consequence, segregation of the patient was perceived to be a necessary precaution to restrict the spread of the disease. There is also the belief that men are more prone to contract leprosy than women. This misconception is borne out of the misconceptions about the cause of the disease - that it is contracted through sexual transgressions and that it is a blood disease. Since men are believed to be the greater transgressors, it is believed that men are more prone to this disease.

The symptoms/progression of the disease

Knowledge levels pertaining to the symptoms and the progression of the disease were higher than the knowledge of the cause and transmission of the disease. Respondents were able to chart the progression of the disease and specify distinctive symptoms that characterised the disease. An anaesthetic patch was commonly associated with the onset of leprosy but, in people's classification, it signified an early 'dry', 'raw' stage which was entirely curable and not contagious. The major misconception pertaining to the progression of the disease related to the association of deformities, ulcers and the leonine face with the penultimate stage of the disease - "rotting and wasting away". These symptoms were not viewed (as they really area) as a results of the patient's negligence but regarded as a symptom of the later stage of the disease.

It is pertinent to note that patients often confused the side-effects of the drugs with the symptoms of the disease. For instance, dizziness, feverish feeling, debility, etc. were perceived to be manifestations of the disease rather than side-effects of the drugs.

Curability and treatment

There is widespread awareness of the claim that leprosy is now curable. In the MDT districts, this claim is felt to be credible because of the cures that have been effected through MDT treatment. Moreover, the medical arm also reinforces this feeling of hope. In the Monotherapy areas, on the other hand, the message of curability lacks conviction primarily because of the long duration of the treatment and the absence of any tangible proof of the cure. People, in fact, continue to associate the deformed patient with an active infection.

3. Do attitudes to leprosy vary?

Across districts

As with knowledge levels, the attitudes that were manifest across the districts also varied. Thus, we had Hopeful, Ambivalent and Negative districts.

The Hopeful districts (Kanpur, Visakhapatnam and Ganjam) were marked by an open attitude, a willingness to replace old beliefs with pragmatism and hope. The Ambivalent districts (Periyar, Deogarh), as the very name suggests, were still unsure, still holding on to their traditional beliefs but more as a habit than out of conviction. They were uncertain and desired to bring more pragmatism to bear on their attitudes. The Negative districts were most prejudiced towards patients and the levels of hope were low. Further, these districts were characterised by their rigid, close attitude, an attitudinal 'blinker' to any mention of this disease.

Across respondent categories

Of the respondents categories across the districts, we discerned that the attitudes of the lay public, the opinion leaders and the patients' families, to some extent, were always comparatively negative.

The lay public/opinion leaders were the worst actually, as they were poorly informed and harboured/perpetrated the misconceptions, ostracism etc. It is here that attitudes need to be revamped if the NLEP is to make headway, as their negative attitudes are imposed on patients and patients' families.

The patients' families are attitudinally more positive than the lay public, mainly due to the efforts of the medical arm. Unfortunately, however, they are most often pressurised by society and are not allowed to strengthen this attitude. Due to the pressure brought to bear by the general public, families sometimes have to ostracise the patients or go to pathetic lengths to hide the fact of the affliction.

The attitudes of the medical arm to leprosy were not uniform. Those involved in the treatment of leprosy displayed a matter-of-fact attitude to the disease. Those in MDT districts, in particular, were more enthusiastic and tended to communicate this enthusiasm to patients and patients' families. Among the senior officials, the attitudes varied between those working for voluntary organisations (who were highly motivated) and those working for the Government (who saw themselves in a dead-end job). Homoeopaths, Vaids and medical students admitted that they did not know much about the diseasee and had not come into contact with leprosy patients. They perceived the job of a specialist in leprosy as one of low status and, in general, tended to display low involvement in the disease.

Basic attitudes to leprosy

The basic attitudes, common to all categories of respondents, are ones of fear of the disease, of social ostracism, of charity and, finally, one of indifference.

As people are not aware of the manner in which leprosy is caused/ transmitted, the general public is fearful of contracting the disease and tends to isolate and ostracise the leprosy patient.

There is a segment of society which feels that leprosy patients deserve support. These people (who generally belong to the better educated segments of society) in most cases believe that they have done their duty if they contribute to a charitable organisation working in the field of leprosy.

The vast majority of the lay public displays an attitude of indifference. Most of them have not come into contact with leprosy patients and, in any case, believe that it is for the Government to tackle this disease. Their ignorance of the causes of the disease and their fears about it contribute to this feeling of indifference.

Overall, society's attitudes is the most protective and supportive towards children who contract leprosy. By and large, they are not isolated and an attempt is made to conceal the disease from the child and from society at large. Society is also supportive of female patients because they are seen as economically unable to fend for themselves. Thus, they are only partially ostracised and are fed and clothed by the family. However, it is in case of the male patients that ostracism comes into full play. It is believed that they are capable of looking after themselves and it is considered a part of the social obligation of the patient that he moves away from his family.

4. What are the factors that influence patients' attitudes to the treatment of leprosy?

The existence of the medical infrastructure in the community for the treatment of various diseases has itself been a considerable force in promoting a favourable attitude to the treatment of leprosy. Moreover, the efforts of the PHWs, who carry out regular surveys, keep in touch with patients, provide them with hope and solace, also contribute significantly to a positive attitude on the part of patients.

Another factor that influences a patients' attitude to treatment is the extent of support that the family provides to the patient. Where the family does not ostracise the patient, the patient feels obliged to follow the course of treatment, not infect anyone else and hope to regain his place in the family. However, an air of fatalism pervades those cases where the patient is ostracised by his family and his attitude towards treatment is frequently not positive.

Finally, the state of the disease also influences the attitude to its treatment. At the early patch stage, the patient is keen to treat the disease so that he does not fall prey to its later manifestations and deformities. At a later stage, he is branded as a leper and he is, to some extent, resigned to his fate and not so enthusiastic about the course of treatment.

5. What are the factors that deter patients from seeking or continuing with medical help?

Ostracism: The fear and abhorrence that leprosy engenders is so great that when a person knows he has leprosy, he tends to blank it out. This results in his shying away from taking medication in an attempt not to come to terms with his affliction. This practice is actually rooted in the fear of social ostracism and rejection that almost all patients face. Further, the process of seeking medical help involves having to go to a 'public' location and, thus, reveal one's affliction to society. Most leprosy treat-ment centres are located in the skin diseases and VD clinics/departments and this further embarrasses patients. Even in MDT districts, the patients go to a centralised collection point and are checked by a visiting squad who are identified as leprosy workers. Some patients are fearful of being so publicly associated with this disease and hesitate to collect medicines or visit these centres.

Side effects: The drugs administered often have palpably uncomfortable side effects. This is particularly true with regard to MDT, where reddening of the skin, weakness, nausea, giddiness, excess body heat, etc. are common. These cause too much discomfort or else scare off the patient and he refuses to continue with the drugs. This reluctance to thereapy can sometimes occur despite being forewarned by the medical personnel about possible side effects. At this stage, it is important for the patient to be motivated and prodded constantly by the medical personnel to overcome this reluctance.

Length of treatment: The Dapsone drug regime for leprosy is a lengthy, tedious one that stretches over months, with slow or little apparent improvement in the physical condition. This is one factor that very often demotivates patients and causes them to discontinue treatment or become irregular in following the regime.

Time and effort: In most cases, the rural patient has to travel out of his village to collect the drugs, meet the PMW or NMS for checking, monitoring etc. The time, the physical effort (this is exacerbated in the case of patients who are weakened by the drugs) and, of course, the expense involved in this travel tends to lead patients to become irregular. Often, in the MDT districts, the PMW or NMS notices this drop out and visits the patient at home, in order to remotivate him. In some districts, Visakhapatnam notably, the PMW takes the trouble to continue visiting the patient and dispensing drugs.

Recommendations

1. What are the major messages that need to be communicated to all publics?

Whether the communication is aimed at the lay public or the patients or even the PHW/NMS cadre, it seems to be critical that some messages are beamed at all of them, as these are nebulous areas with most.

Firstly, it is important to clear firmly and conclusively the misconceptions and apprehensions regarding the cause/transmission of leprosy. Except for the medical arm, the fact of mycobacterium lepare causing the disease is unknown. With regard to the transmission, however, the misconception regarding heredity seems to prevail even among some of the PHWs. There is a strongly held belief that leprosy is a 'blood' disease. This belief tends to reinforce the view that the disease is hereditary. It is necessary to communicate the fact that leprosy is a skin or a nerve disease. The 'location' of the disease in the correct perceptive would assist in countering the notion that it can be spread across generations in the same family. The communication task here is to firmly disassociate leprosy from 'blood' diseases and thus remove the fear of hereditary factors. Rather, it should be understood clearly to be a disease that affects the nerves and the skin. Only then will leprosy be viewed as just another disease and not a scourge or blight.

Secondly, with regard to the cure of leprosy, so far the communication has not been definite in its tone. It needs to convey that leprosy can be cured and is a disease well within the purview of medical science. So far, except for the medical functionaries, the others are still ambivalent about whether leprosy can be fully cured.

Thirdly, with regard to the symptoms and progression of the disease, it appears that most people - other than the medical arm - harbour the overwhelming opinion that leprosy is almost invariably associated with disfigurement. Currently, the medical arm uses terminology to describe the patch stage of the disease (e.g. Lakshan) which tends to delink it from the deformities stage. It is important that the communication capitalises on this indigenous classification and reinforces this de-linking, which would result in the early stage of the disease being viewed with much less abhorrence and fear. Also, this de-linking is likely to result in a more positive attitude to taking the treatment and prevent ostracism of the patient.

Fourthly, there has been a belief - still held even by some members of the medical arm - that leprosy spreads through contact. It is important that the communication combats this misconception by advocating the 'right' practices, e.g. treatment of the patient at home, lack of isolation, etc.

The communication should also stress that deformities - which lead to most of the abhorrence and ostracism - are not infectious but are the burnt out remnants/scars of a disease that once did exist. In fact, one could draw an analogy with small pox, where pox marks remain long after the patient has been cured.

At present, to the general public, oozing ulcers and pus are sure signs of leprosy. It is vital to educate the general public and other sections of society that these ulcers have nothing to do with the disease but are a result of negligence on part on the patient who, because of anaesthesia, is unable to prevent injury to himself.

Overall, to sum up, the accent should be on steadily developing an alternative, modern, scientific, cohesive and hope-providing 'mythology' to replace traditional mythology about leprosy. Thus, the focus of the communication should be on demystifying the disease and positioning it squarely where it belongs among other infectious diseases. One of the ways of doing this would be by using analogies with other major diseases that have, due to medical help, lost their dreaded aspect today, such as small pox, tuberculosis, cholera, etc. Another way to 'demystify' the disease is through the medical arm. The PMW is already doing a good job of informing the patients and their families. However, it is important that the PMW understands both the physiological and social implications of the disease better. The research findings suggest that the educational material used by voluntary orgnisations is more effective in training and motivating leprosy workers. It is imperative that workers in the Government sector also have access to similar information and training, so that in their survey work as well as in the treatment of patients, they can communicate more effectively with patients, patients' families and the lay public. Finally, it is important that the infrastructure for leprosy not be separate or be linked with sexually-transmitted diseases. The current infrastructure not only embarrasses the patients and makes them less willing to take treatment but also 'locates' the disease wrongly. Leprosy is an infectious disease like many others and it is important that it is not seen as a blight.

It may be argued that a separate medical infrastructure and trained personnel for leprosy would ensure a more focussed and effective disbursement of expensive medication, funds and reflect a more concerted effort on the part of the Government to control and eradicate the disease. However, at the same time, the segregation of leprosy treatment and infrastructure from the Public Health infrastucture has, to some extent, underscored the fact that leprosy is the 'untouchable' disease and must be handled apart from other health issues. Leprosy patients receiving medication at leprosy centres are aware of their 'outcast' status and believe that their disease is so dreaded that it cannot be treated at a common public health centre or hospital. Similarly, in the medical arm, leprosy workers believe that they are

the 'outcasts' within their profession and not accorded the same respect as public health workers. We believe that segregation of leprosy treatment has, to some extent, reinforced current attitudes to the disease and enhanced its 'dreaded', 'to be kept apart' status vis-a-vis other diseases.

2. With regard to mass media communication, what are the various target segments that need to be addressed?

The general public and the opinion leaders are two segments where misconceptions abound. Their lack of knowledge about leprosy and the resultant negative attitudes cause the social stigma that is attached to leprosy patients. It creates a negative social climate which prevents the effective rehabilitation of leprosy patients and demotivates patients from availing of the medication.

In the general public category, the males (both adult and adolescent) appear to be more exposed to the various media and could become important initiators of a change in attitudes towards leprosy. They are also likely to disseminate knowledge within the family and, hence, the communication strategy must address its efforts to this segment of the general public.

Opinion leaders, such as village elders, teachers and journalists, can play a major role in influencing attitudes within the social community. This influential segment must be harnessed via the communication efforts.

Upto now, the program of imparting knowledge and changing attitudes has concentrated on the PHWs. The program has not exploited the full potential of the traditional schools of medicine (ayurveda, unani) which have significant 'reach' in rural areas.

3. What is the mode of communication that would be suitable in this regard?

The communication, in order to be most effective, should be simple, easy to understand and beam a limited (but critical) list of messages. The intention should to erode the most debilitating beliefs and not to be a treatise of facts. The message should be couched in metaphors and analogies that are commonly used and have been discussed in the report.

While selecting the media, the reach/popularity of the media should be borne in mind. Thus, the radio and popular cinema are immediate choices. Folk theatre, we believe, has not been adequately utilised and is a medium that has considerable reach in the rural scenario. The other advantage with folk theatre is that it uses familiar analogies and symbols and is easily understood by the rural populace. Posters, wall paintings and other outdoor media forms should have a ubiquitous presence, but much in the manner in which the family planning program does - with simple, eye-catching symbols and high visibility at public places.

Another mode of communication that should be activated is the segment of opinion leaders. This is a very credible and effective medium for propaganda and should not be ignored as it currently appears to be.

4. What are the current need gaps in the functioning of the NLEP?

The need gaps in the NLEP seemed to be specifically in two major areas, firstly, with regard to the personnel implementing it and, secondly, in relation to the facilities offered by this program.

The Personnel: We found that the doctors and the medical officers, i.e. the upper echelons of the medical arm, did not seem to face as many problems as the lower level, i.e. the PMW or the NMS.

The PMW is the mainstay of the program and the problems he faces seem to be demotivating him. These could be categorised under the following aspects:

NLEP implementation: In order to motivate him and also to strengthen his hands and increase his efficiency, it is necessary to keep him well informed. The common complaint was that PMWs do not receive enough by way of training and ongoing education in this area. The PMWs desire to remain in contact with the latest developments in this field, as they are keen to be more efficient and to gain greater credibility among their patients. Thus, they need to be trained prior to entering the field. At present, many of them are just thrown into the field and have to learn 'on the job'. In this regard, the more 'seasoned' PMWs also desired exposure to refresher training courses that revamped their knowledge and practices. To that end, they also need to be supplied with pamphlets, leaflets etc. that apprise them of the latest developments in the area of leprosy. This not only enhances their information base but also creates the feeling that they are part of a well-planned, active system, not merely backwoods functionaries.

The PMWs also expressed the desire that the NLEP training be extended to include basic health care. Often the PMW becomes the 'doctor sahib' in the patient's family and is expected to offer counsel on other minor ailments such as diarrhoea, fever, etc. Lack of knowledge and training in these areas erodes the PMW's credibility among his patients.

Career cycle: The PMW is involved with the NLEP but does have his fair share of long-term career prospects. He aspires to move upwards, as well as gain in terms of financial and job-related promotions. Thus, a career plan is important; the PMW must be moved 'upward' with time and the posting in 'hardship' areas should be reduced. To him, this is a career and must provide the perquisites that go with one.

Personal: At the personal level too, the PMWs often complained that the Government is slow in repaying expenses incurred on the job, providing the support of basic facilities like housing, help with schools for their children, etc. It is this willingness to ease their day-to-day problems that inspires loyalty in an otherwise difficult job.

Facilities: In the survey and detection, as also in the treatment of female patients, the problem faced is that the medical arm lacks women workers. This poses a problem in rural areas as the male PHW is rejected by female patients. To overcome this problem, it is necessary to have more women among the field force. Further, the local people could also be induced to participate in the work, e.g. the older women in the village could help in detection and survey, as also in counselling. To avoid giving rise to a 'watchdog' attitude, however, it would be important to ensure that the public is induced to be supportive and participative.

Regarding facilities for treatment, the need is to move leprosy clinics away from those where sexually transmitted disease are treated, so as to reduce embarrassment and motivate patients to visit the clinic. This does not mean, however, that the clinic/ department be publicly earmarked as being for leprosy, as it defeats the very purpose. Even within these leprosy treatment centres, it would be desirable if 'patch' stage patients could be treated separately from the more advanced cases - thereby, mitigating the horror for early patients, creating the hope of cure and also further reinforcing the idea that leprosy need not always be an abhorrent affliction.

SOCIAL ASPECTS OF LEPROSY

findings from rural maharashtra

Sponsored by the Damien Foundation

RAVI DUGGAL
AMAR JESANI
MANISHA GUPTE

SUMMARY

MARCH 1988

frch Foundation for Research in Community Health

SUMMARY OF FINDINGS

The present study began as an add on to an ICMR research project which focused on the NGO health sector in rural Maharashtra. The main objective of this project was to critically evaluate NGO intervention from a comparative perspective. The opportunity that this major study offered in establishing direct contact with a representative rural population led to the inclusion of a study to look into the 'social aspects of leprosy'. The Damien Foundation willingly agreed to provide additional funds to conduct the leprosy study.

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Leprosy as a disease has a unique feature in the sense that unlike most other diseases it stigmatises the afflicted person. This study aims at exploring and critically understanding the socio-cultural, economic and political correlates of this stigmatising disease. The study has been carried out in both leprosy high endemic and low endemic areas and focuses around differentials, if any, due to endemicity.

The study places stigma in the context of political economy and the entire social structure. It rejects the behaviourist approach and examines the stigma against leprosy in terms of the general discrimination existing in an exploitative society - a society in which the basis of relations of production are differentiation, discrimination, domination, alienation and ostracism.

It is often suggested that the main cause of stigma, historically, has been the inability to tackle the disease in any significant manner. And the disfigurement that is often associated with it has only helped cement the stigma. This explanation is rejected by the authors. Stigma is socially acquired and is reproduced in society as a part of the process of reproduction of inequality. For instance stigma against leprosy cannot be viewed independent of casteism and untouchabillty, racism and skin colour, class society and the working class. Health education that is aimed at modifying behaviour by appealing to rationality has failed to eliminate stigma, because like inequality persists in a society of abundance so irrationality persists in the modern scientific age. Therefore the fight against stigma of leprosy has to be a fight to change radically the social reality itself.

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The National Leprosy Control Programme started in 1954 has over the years failed to make any significant dent in controlling leprosy. The Survay Education & Treatment (SET) approach adopted under National Leprosy Control Programme (NLCP) to run a vertical programme of national importance has paid poor dividends, except in small pockets of a few states often with active participation of some NGOs. The top-down approach of the programme and a disinterested bureaucracy is the first stumbling block. Policies and programmes are formulated on the basis of ideas that have little or no connection with the context of socio-cultural and economic aspects of the placement of the disease in people's lives. The status accorded to the leprosy programme and as a consequence to those who work in it is very low. This low status is directly related to the stigma associated with the disease as well as to its low priority in the health system. There is a deep-seated stigma against the leprosy programme within the health service organization, and postings to the leprosy programme are considered as a "punishment -posting". The weakest element of NLCP's SET approach is the education component.

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The survey was carried out in 22 villages spread over six districts. Four villages of two districts (Wardha & Chandrapur) have high endemicity of leprosy and 18 villages from four districts (Ratnagiri, Pune, Aurangabad and Dhule) have low endemicity. The prevalence rate in the high endemic sample was 14.68 leprosy patients per 1000 population and 1.6 per 1000 in the low endemic sample.

The principal objective of the study was to explore and understand stigma assoicated with leprosy, both from the perspective of the patient and the general population. This has undertaken in a comparative framework between the high and low endemic samples, as well as evaluating the effects of intervention of a NGO in the high endemic area. All the registered patients from these 22 villages and persons from randomly selected households were interviewed using quasi-structured interview schedules.

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Characteristics of the Sample: The high and low endemic area populations differ significantly on the basis of two important characteristics - caste distribution and landholding distribution. These two variables are prime determinants of social and economic status. In the low endemic area the middle castes (Marathas) constitute the dominant group but in the high endemic area the occupational castes (balutedars) constitute a large majority. This distribution has resulted in a highly significant chi-square value. Similarly in the case of landholding the chi-square value is highly significant because in the high endemic area the landless form a large proportion in comparison to the middle peasantry in the low endemic area. These two differentials are very important indicators in understanding and explaining differentials if any, regarding leprosy stigma and related aspects. Educational achievement is also an important variable but between the two areas there is no significant difference in the spread of this characteristic. However, when education is seen in the context of caste and landholding status it presents significant differences showing a direct relationship i.e. a better recognised social status (high caste) and a higher economic status (large landholding) are important determinants for access to higher levels of education.

Knowledge of leprosy: As anticipated knowledge of leprosy is significantly different between the low and high endemic areas. Respondents from the high endemic area were better informed about the disease. They not only knew about the disease but cited its symptoms and signs correctly more often. High endemicity is largely responsible for this difference. Because of the high prevalence people get to see a lot more leprosy in the high endemic area. The distribution of other socio-economic factors (caste, landholding and education) show that with regard to knowledge about leprosy these factors don't matter in the high endemic area but are very important in the low endemic area. This is because high prevalence of the disease makes the knowledge universal - cutting across socio-economic factors. Whereas in the low endemic area the "upper" castes, the richer peasants and the more educated classes have better knowledge about leprosy simply because their position in society makes access to information, whether correct or incorrect, more possible.

Stigma against leprosy: We began with the hypothesis that because of high prevalence in the high endemic areas (as every other household may have a leprosy patient) the stigma against leprosy (at least physical expression) would be absent or significantly lower as compared to the low endemic areas where we also expected secrecy about the disease to be higher. This hypothesis has been disproved. Even when we control the distribution for socio economic factors we find that no significant differences show. This helps us in reaching the conclusion that stigma against leprosy is almost universal: that not only people living in high and low endemic areas share similar attitudes and feelings with regard to leprosy but also stigma is shared similarly by people from different economic, social and educational backgrounds.

The main reasons given by respondents with regard to why they uphold stigma against leprosy are fear of contracting leprosy and the fear of being ostracised or socially boycotted for associating with leprosy patients. The reasons given in both the high and low endemic areas is similar.

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PATIENT AND SOCIETY

Characteristics of patients: In the high endemic area the mean age of the patient was significantly lower than the low endemic area. This is because high prevalence affects a wider range of population and in a low prevalence area the disease manifests itself in a higher age group. Similarly a larger proportion of women (though not statistically significant) have contracted leprosy when compared with low endemic area patients. However males constitute as a significant majority of patient population in both the areas. Eighty-two percent of the patients had "ever-married" and out of those who were "never-married" 31% said that they could not get married because they had leprosy. Further, on the basis of caste and landholding the two patient populations are significantly different. In the high endemic area the scheduled caste and tribes and the small peasantry as a class have a significantly higher proportion of patients, whereas in the low endemic areas the "upper" castes and the landless class have a higher proportion of patients.

Patients Experience of the Disease: Experiences of patients pertaining to the onset of the disease, the symptoms and signs experienced, treatment of the disease, advice about disease, treatment, diet, cure, deformity etc, given by the health staff, have been discussed in this section. The findings reveal that the experiences of the patients in both the areas is not very different. "Patch" is the most important onset symptom reported in both areas and a similar proportion of patients in both areas have reported it. However, surprisingly, the proportion of those reporting deformity as an onset symptom is higher in the high endemic area inspite of the fact (as seen earlier) that knowledge is significantly better in the high endemic area.

The patients from both areas have shared similar experiences vis-a-vis advice given to them about the disease, its treatment and cure, diet etc. More than 3/4ths of patients in both areas have stated that no advice or information whatsoever was given to them by the health staff who examined and treated them.

The only significant difference was with regard to regularity of treatment. In the high endemic areas where an LCUS operated the regularity of treatment was significantly better than the low endemic areas. This is expected because of the special emphasis provided for leprosy control in the high endemic area. However, inspite of the high profile leprosy activity in the high endemic area only 51.4% of the patients were taking treatment regularly. In the low endemic area 31.5% of patients were regular. The main reason given for irregularity of treatment or "no treatment currently" is irregular supply of drugs or an inconveniently located health centre. In the low endemic area 80% of the irregular patients gave this reason and in the high endemic area 46% did so. This reflects on the poor performance of the NLCP, even in the high endemic areas where special inputs are made available. Infact, of the SET approach the survey and education components are conspicuous by their absence.

Patient's Interface with society: We have seen earlier that stigma against leprosy is almost universal. But when we asked patients about their interactions in society in different situations they said that things had not changed after they got leprosy. This would appear contradictory. But maybe not, because like the harijans the leprosy patients take their defined position for

granted or accept it as normal, and therefore don't regard the discrimination, if any, as unusual. Also, the limitation of the survey method to study a problem like leprosy when compared to life-history analysis (which we haven't done) could be responsible for this contradiction.

However, interestingly, the only change that the patients have reported has been with regard to interaction with the health staff. Over one-third of the patients in both areas have reported negative changes in interaction with the health staff. The changes were of two types i) refusal to examine or see the patients and ii) not giving proper information or advice about the disease.

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NGO INTERVENTION

The Gandhi Memorial Leprosy Foundation, Wardha, has been taken up as a case study of a NGO which has done significant work in controlling leprosy.

The GMLF has been running a LCU in that area since 1951, besides a Leprosy Referral Hospital, Training and research centre for leprosy started in later years.

In what manner has the GMLF's intervention effected significant changes in controlling leprosy and destigmatising it?.

The findings reveal that the GMLF has successfully controlled the prevalence of leprosy. They have brought down the prevalence from 25 per 1000 population in 1954 to 8 per 1000 presently. In our survey we recorded a prevalence rate of 6.36 patients per 1000 population in the GMLF sample.

In the government run LCU at Brahmapuri, with which we have compared the GMLF performance, the prevalence rate was 22 per 1000 population. Further, early detection in the GMLF area has been

facilitated by regular surveys. This is substantiated by the fact that not even a single patient in the GMLF area reported the onset symptom as deformity unlike the Brahmapuri LCU area where 16% of the patients had reported deformity as an onset symptom.

With regard to regularity of treatment all the GMLF area patients reported regular treatment whereas only 41% in the Brahmapuri LCU area did so.

However with regard to knowledge, stigma and related aspects, aspects there were no differences between the GMLF and Brahmapuri area. This is another unexpected result. Knowledge of leprosy, stigma, related variables, attitude of health worker towards patient have a more or less similar pattern in both the areas. This shows that the only significant difference that the NGO has made is in making the delivery system more effective. Therefore its contribution has been largely of a techno-managerial nature.

This also raises questions regarding the much talked about health education. GMLFs intensive information and education campaign to change the behavioural response of people towards leprosy and its patients has not paid any significant dividends. This provides evidence for the failure of the behavioural approach to tackle the problem of leprosy stigma. It calls for a need to look at more radical changes - changes that eliminates the discriminating and differentiated social structure itself.

SECTION ONE : INTRODUCTION

1. A CRITIQUE OF STIGMA AND LEPROSY CONTROL

The Political Economy of Stigma

What is stigma?

Stigma in the Social Context

Social Aspects of Leprosy

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A Note on the National Leprosy Eradication Programme

2. OBJECTIVES, STUDY DESIGN AND METHODOLOGY

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A CRITIQUE OF STIGMA AND LEPROSY CONTROL

Cultural traditions and social practices pertaining to health and medicine have, in recent years, acquired a great significance. This is consequent to an increasing interest in the social sciences about health related issues. Infact the primary health care approach and 'community health' are results of this interaction between the health and social sciences.

Historically, every social system has evolved its healing system providing for sick roles, healers and an accompanying ideology (see Parsons, 1951). Invariably the process of healing has been associated with values of the sacred and divine; as a consequence it has been operated and controlled by an elite class (priestly class in India). Even secularization into the modern system of healing has not demystified the healing system and neither has it rid itself of its elitism.

Every healing system has had its limitations in that it has been incapable of coping with every affliction. But there have always been explanations for grey areas. Whatever was incurable was assigned a metaphysical (or supernatural) cause and was left to the practitioners of the supernatural (sorcerers, exorcists, faith healers etc.) to deal with and offer solutions. **Leprosy** is one such disease which, even today when its cure is well known, is surrounded with awe and is considered generally as manifestation of 'god's wrath'.

Is lack of knowledge or lack of technology the only reason why leprosy enjoys a special (sic) status within our society? Is the stigma and ostracism or isolation associated with leprosy a simple result of this inability to tackle the disease adequately? The answer is no.

The Political Economy of Stigma

What is stigma?

The origin of the term stigma is credited to the Greeks. In their worldly view, it referred to bodily signs designed to

expose something unusual and bad about the moral status of the stigmatised - a blemished person, ritually polluted, to be avoided, especially in public places (Goffman, 1963, p.11). Goffman further adds that later, in Christian times, two layers of metaphor were added to the term : the first referred to bodily signs of holy grace that took the form of eruptive blossoms on the skin, the second, a medical allusion to this religious allusion, referred to bodily signs of physical disorders. Thus, stigma while segregating the stigmatised individual, invites compassion for such individuals.

Medical historians have paid considerable attention to the stigma attached to leprosy patients. Much of the discussion centres around the time of Biblical antiquity and the early Middle Ages to understand the roots of society's response to leprosy. In Biblical times "lepers" were segregated for it was believed that all impurities were contagious. The "lepers" were considered both unclean and impure. In the early Middle Ages when leprosy became endemic and no treatment proved effective, the Bible was resorted to and segregation became mandatory (Sudhoff, 1917) Similar segregation is also reported from Japan where Buddhism became the dominant religion after its introduction into that country in the 7th century A.D. (Veith, 1947). In India since ancient times, the concepts of purity and pollution were central to the dominant religious and cultural value system and practices.

Goffman classifies three gross categories of stigma:

(1) abomination of the body-the various physical deformities,
(2) blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, dishonesty etc., and
(3) the tribal stigma of race, nation and religion (Goffman, 1963, p.14).

These notions of stigma are socially acquired and the `normal´ are expected to observe them. The process of socialisation, and consequently social control, is so encompassing that even the stigmatised (who have been marginalised by society on some count) tend to hold the same beliefs about their identity as the `normals´. This says Goffman, is a pivotal fact. So pivotal that it is the `hook´ on which the stigmatized hang all inadequacies, dissatisfactions, procrastinations and all unpleasant duties of social life, depending on it not only as a reasonable escape from competition but as a protection from social responsibility (Baker and Smith, 1939). The `normal´ accept these `shortcomings´ of the stigmatized and encourage its perpetuation

because stigmatization apparently functions as a means of removing those minorities from avenues of competition. Further, if the stigmatized don't 'behave' in the manner in which they are expected to they arouse suspicion and are brought to book. Thus, stigmatization also becomes a means for social control. The vehicle of stigma are symbols or labels. Labeling is a very powerful social mechanism through which not only attitudes, beliefs, norms and complex behavioral patterns are ingrained but also the entire basis of a class and exploitative society is preserved and reproduced. Stigmatizing of leprosy is part of this larger complex. In one sense the disfigurement that may result from the disease may be directly responsible for the stigma but when we look deeper, it appears as a malaise of the social structure itself.

Stigma in Social Context

There is a broad agreement among sociologists and anthropologists that stigma is a social phenomenon. Stigma is a complex social response to the concrete social reality which is reproduced and changed in the course of historical development. The social basis of stigma is the unequal relationship between individuals and or groups of individuals whose social identity is defined from the stand point of economic and social status, race, sex, health and so on. A social structure based on inequality provides for an economic, social and ideological mechanism to reproduce unequal relationships in the daily life of people. In the course of development, the practical manifestation of stigma changes in accordance with the stage of development, the continuous realignment of socio-economic forces within the structure, and in response to the need to cope with the crises. In the process, new symbols of stigma are added, some of the old ones are modified or discarded. In the society as a whole, various types of stigma co-exist, they influence and modify each other, and all of them together help reinforce inequality in the social intercourse.

Historically, societies have evolved on the basis of the development of their productive forces. Culture, folkways, norms and attitudes have developed as a consequence of these productive forces and the relations of production that dominate within that society. Primitive societies have given way to those whose value systems are based on structural differentiation. This was a result of a new and increasingly complex divison of labour, development of private property and the consequent greater

concentration of ownership of the means of production in fewer hands (see Morgan 1877; and Engels, 1894). The modern capitalist society is based on a newer method of economic exploitation which is continuously reproduced with the help of the political structure evolved from the need of such a society.

Though modern society has evolved modern means of exploitation and oppression, the older forms are not summarily discarded. Rather, the relevant older forms are integrated with the newer ones in such a way that both the forms give a picture of on integrated whole. This also helps in providing an apparent continuity and justification to the modern social order. That is why in a society which has enough productive capacity to meet the needs of all people are deprived of those needs not only on the basis of economic stratification but also in accordance with caste, sex and racial status. The same is true in the field of health where the inability to control diseases, provide safe water, nutrition etc. are termed as "lack of political will", which is nothing but a manifestation of a social system based on inequality.

Inequality in practice is expressed as deprivation and discrimination. Discrimination is deeply ingrained in the daily life in such a way that the perpetrator and the sufferer develop a behavioural pattern to suit the needs of the discriminatory social system, unscientific and irrational nature of such behaviour not with standing. Further, in daily life, all types of discrimination and stigma arising from them are not given equal importance at a given time and place. For example, in racial relations the blacks are discriminated/stigmatised. But in sexual and family relations, women are discriminated irrespective of race. Similarly amongst women, we find the black women discriminated against by the white women. This brings a complexity in the discriminatory relationship.

How does stigma against some diseases articulate within such a discriminatory system? As in the case of economic and/or social status, the stigma against diseases is not uniform, so the intensity of discrimination and stigma against a diseased state depends not only upon the type of disease, it's communicability, ability to treat etc, but above all, the overlap of the disease's manifestation with the cultural and social practices and economic needs. In the case of leprosy, the religio-cultural overlap is the highest and hence the universality and high intensity of stigma.

As human beings evolved from the primitive stages, they brought with them various diseases and in the process acquired new ones. Even presently, the development of modern civilisation is introducing newer diseases and stigma attached to them. Thus, in the course of human development, the diseases ceased to be purely biological phenomena, they acquired social and cultural dimensions as well.

How do human beings respond to diseases? Rubin says, "By necessity man has undoubtedly always been concerned with questions of health and survival, and has sought within the framework of his knowledge solutions to problems of illness" (Rubin 1960, p.785) Therefore, the diseases which not only threatened the biological safety of the individuals but also the social and economic life of the group, and for which no rational solution was available at that time, human beings reacted by isolating themselves, by outcasting the sufferers and so on (Foster and Anderson, 1978, p.34). Infact there are instances in history when such measures helped in controlling epidemics. For example, isolating leprosy patients in leprosaria brought about a sharp decline in the incidence of leprosy in Western Europe during the fourteenth century. This was because in the crowded leprosaria, the undernourished and weak leprosy patients were easy targets for secondary infections. (Sigerist, 1943). Of course this measure actually eliminated leprosy patients rather than leprosy!

How can one explain such human behaviour of eliminating patients and not the disease? Sometimes this is seen as the animal instinct inherited by the humans. After all "Social Darwinism" or the "nothing but" school in anthropology and sociobiology emphasises instinctual continuity of humans with their animal ancestors. We feel that one should refrain from applying biological explanations and theories to social phenomenon; for human evolution introduces the overwhelming social discontinuity to the biological continuity with the animal world. (Reed, 1978). The formation of human society is a unique phenomenon in the living world. The human biological instinct has got more or less reduced to the involuntary processes in the human body. The so-called biological behaviour is in essence the social behaviour of individuals. An animal defense reaction of discarding the diseased is not the same as human social behaviour of depriving and stigmatising some diseased people.

What is important to understand here is the distinction that one ought to make between a social necessity of isolating a

diseased individual in order to reduce or control infection when no good cure is available, and stigmatising or depriving or discriminating an individual for his or her diseased state. This becomes glaring when the cure is available but the society's structure does not allow it to reach to the diseased individual, and when such isolation is not scientifically necessary. **Thus such behaviour is only as much instinctual as is poverty or untouchability or racism.**

To sum up, there is not one reason to explain the relationships of domination. Similarly there is not one reason to explain myths and stigma attached to sufferers and dominated groups, for instance in India to the low caste groups. However all such relationships, myths and stigmas condemn the target individual or groups of individuals to exploitation, oppression or isolation for their taking birth in such oppressed groups or for acquiring certain characteristics, including diseases in the course of living.

The case of leprosy falls in this framework. The isolating and outcasting of the sufferers, misconceptions, myths and stigma attached to it and so on were natural reactions of humanity for its survival. But they also got ingrained in the societal life to be continuously reinforced in the process of reproduction of inequality, exploitation and oppression of groups of people in the society at its various stages. As inequality persists in a society of abundance, similarly irrationality persists in the modern scientific age.

In short, the fight against stigma towards leprosy cannot be an isolated fight. It must be conceived as a part of the attempt to change social reality as a whole.

Social Aspects of Leprosy

Leprosy as an illness exposes those afflicted to a long and protracted experience with pain and sufferring and deformity, as well as social ostracism. Death alone is not the frightening element; the major threat is bodily deterioration and assault on the body-ego (Gussow and Tracy, 1968). Therefore, "it appears reasonable to postulate that it is this complex and its uniqueness which is responsible for the unique social reactions to leprosy (Skinsnes, 1964). Deformity and disfigurement then **appears** to be the main associate of leprosy to stigma and invariably, deformity is classified as a symptom of the disease (Rao, 1982). Society

and Culture "have seen leprosy as incurable, resulting into deformities, ulcers, changing the very identity of a person into something which is aesthetically devastating and against the cultural image of the body....(afflicting) sinners, worthy of divine punishment".(Mutatkar, 1981).

This then is the dominant view not only in society generally but also among those who have enquired into the 'social aspects of leprosy'. However, stigma towards leprosy cannot be looked upon as an independent occurence because its basis is the discriminating, exploitative social system itself. It is thus an ideological issue. The system defines the responses (of its adherents) towards the disease in the same manner as it determined social distance among various groups within its fold. Thus, stigma towards leprosy occurs in the same way as stigma towards the "untouchable" under classical Brahminism, of Stigma towards blacks through racism in South Africa and the USA and most of the "white" world. Moreover this socio-cultural inequality and oppression is reproduced in economic and political relations within society strengthening the adverse relationships between the domineering and the dominated. Consequently a leprosy patient, like the harijan or black, is not only a social outcaste but also suffers economically and politically, being forced into beggary and other activities that are socially looked down upon.

For many years attempts have been made to explain social stigma of leprosy almost exclusively in terms of peoples' adaptive behaviour. But behaviour is the effect and not the cause of the stigma. All strategies that aimed at merely changing peoples' behaviour towards leprosy have met with partial success, and these successes have not turned out to be permanent. More importantly, the control of the disease (say bringing its prevalence rate to one or less than one per thousand) has not ushered in societies with people banishing stigma towards leprosy. In Western societies for instance, leprosy is no longer a public health problem, but the masses still harbour stigma towards the disease and its sufferers. The existence of leprosariums and the social, economic and psychological problems faced by their inmates in their societies is documented, although such studies concentrate on the adaptive behaviour to stigmatised illness (Gussow and Tracy, 1968). This also puts to rest the argument that disfiguration of the body is the chief cause of the stigma towards leprosy. In fact, disfiguration is a contributing factor in enhancing the stigma. Hence, the need to eliminate it. But that still does not touch the roots. The social and psychological

problems that leprosy patients face are substantially due to societies defective view of the disease (Ibid), but more importantly due to the defective (discriminating) social system itself.

The **Leprosy Eradication Programme** in India is based on the strategy of Survey, Education and Treatment. The surveys identify the sufferers who are then treated. The role of education is conceived as giving scientific information about the disease to the people and help the sufferer to adapt to the diseased state. The underlying assumption is that once scientific information is received, the people will realise the irrationality of treating leprosy patients as outcastes or untouchables. Change in the attitude of the people can be affected by health education. Health education aimed at informing people about the irrationality of stigma and various superstitions and misconceptions about leprosy may reduce the intensity of stigma and earn lepro patients some sympathy, but experience shows that it has not been able to eliminate stigma : neither in societies with universal education nor in societies where leprosy has ceased to be a significant disease. As it is often stated by the people involved in leprosy control work, "people receive information, but that doesn't mean they accept it". Furthermore at it's worst, the scientific information in absence of any radical change in social relationships, introduces new symbols to identify stigmatised individuals. To obvious deformities are added skin patches, thickened pinna of the ear and so on. Thus, while giving scientific information, the programme exposes the suffering individual to stigma even earlier. **The purpose of scientific information thus does not turn out to be a social fight against stigma, but a medical decision to detect leprosy.** This is not to argue that early detection is not necessary or scientif' information should not be given to the masses. We only intend to point out that social malaise cannot be fought medically alone.

At the same time, social and economic compulsions force groups of people to associate and work with leprosy patients, although they may not believe that there is no harm in associating with them. In brief, such behavioural complexity has its foundations in the socio-economic and cultural reality. Therefore, in order to bring about far-reaching changes in the behaviour, i.e.elimination of stigma, corresponding changes in the socio-economic and cultural life are required to be brought about by eliminating the "stigma" in the social relations itself. In absence of this, imparting of scientific information learnt from

scientific and technological advancement, will at the most reduce or modify the behaviour to generate another complex behavioural pattern.

In order to go into the depth of the problem arising out of stigma towards leprosy, it is necessary to understand it in its innumerable connections, particularly in its relation to various socio-economic conditions. It is necessary to relate various forms of stigma towards leprosy to the social and economic position occupied by the individuals manifesting such stigmatised behaviour. The present study does make efforts in this direction with the objective of acquiring a better understanding of the social basis of leprosy and its stigma.

Leprosy Control

An estimate by WHO (1977) indicates that there are over 12 million leprosy patients in the world, half of which reside in South-East Asia. India accounts for about one-third of all leprosy cases in the world, an estimated 3.95 million cases in 1981. The number of cases of leprosy is expected to increase further as case detection improves; for example, between 1971 and 1981 the number of cases detected in Maharashtra have almost doubled.

India's fight against leprosy began after independence in 1954-55 with the launching of the National Leprosy Control Programme (NLCP). This was based on DDS, a sulphone, discovered as a cheap and effective drug against leprosy. In 1983, following the recommendations of a Working Group appointed under the chairpersonship of Dr. M.S. Swaminathan, the then Member, Planning Commission, the NLCP was converted into the National Leprosy Eradication Programme (NLEP). The Eradication strategy was adopted in reponse to two developments : The advance in chemotherapy with the advent of Rifampicin which reduced the duration of treatment, and the widespread reach of mass media.

The NLEP strategy is based on three components - Survey, Education and Treatment (SET). The very inclusion of education in the strategy of leprosy control shows that health planners recognized its importance early enough. The role of education is conceived as giving scientific information to people about the disease and to help the sufferer adapt to the diseased state. The underlying assumption is that once people receive information they will realize the irrationality of looking upon leprosy patients as

outcastes or untouchables. However, experience of people involved in leprosy control indicates that reception of information is no guarantee to its acceptance.

Thirty years of NLEP have not made any serious dents in the problem of leprosy in India, except in a few isolated pockets in some states through the active participation of a few NGOs, (like the GMLF which has been included as a case study in the present study). This is not to say that the NLEP has achieved no positive results, but to underline the fact that there is more leprosy today than in 1955 and the problem of stigma is as serious. Efforts are presently being made by health planners as well as NGOs and researchers to reevaluate and reconsider the strategy for the control of this as well as other diseases with special emphasis on socio-cultural and economic factors. Even the WHO in 1979 established a scientific working group on social and economic research which includes sociologists, anthropologists, psychologists, among others. These scientists probe peoples' attitudes, perception and behaviour in relation to disease and disease transmission; economists assess, from national and international perspectives, not only the cost-effectiveness of control programmes but also the economic rationale behind decision-making in the household and how it is influenced by and influences disease transmission (UNDP/WB/WHO, 1985). Prof. Mutatkar has summarized this appropriately, "A greater realization is coming to the medical scientists, that the human being can no longer be treated only as an anatomical and physiological entity, but that his individuality should be understood in terms of his culture and belief system. In fact, the individual perceptions of the body image are moulded by the cultural determinants. These factors have necessitated a dialogue between the medical scientists and social scientists, even though the extent of dialogue is limited in nature" (Mutatkar, 1979). This change in perspective was also observed in the last International Congress on Leprosy held in Delhi in 1984. For the first time a whole day was devoted to social and human aspects in the control of leprosy. Whether this changed approach has an impact on the leprosy control programme and in what direction, is yet to be seen.

Prof. D. Banerji commenting on the political economy of leprosy control in a paper presented at the 1984 International Leprosy Congress pointed out that this area of study was practically untouched by social scientists. Political economy concerns the analysis of forces which influences decisions concerning policies, plans and programs .... the low "Status" of

the leprosy program and its workers in the health services ... and the stigma against leprosy in the health services themselves (Banerji, 1984).

The top-down approach of the vertical leprosy program, and its accompanying disinterested bureaucracy is the first stumbling block in the leprosy program. The bureaucratic design inhibits a proper modelling and operation of the leprosy programs, like any other activity of a health care delivery system (Foster, 1982). Policies and programs are formulated on the basis of ideas that have little or no connection with the context of socio-cultural and economic aspects of the placement of the disease in people's lives.

The status accorded to the leprosy program and as a consequence to those who work in it is very low. This low status is directly related to the stigma associated with the disease as well as to its low priority in the health system. As a result implementation of the leprosy program suffers grossly.

This neglect of implementation perhaps offers an explanation of the paradoxical situation in leprosy programs in India : there is a deep-seated stigma against the leprosy program within health service organization and because of this health workers avoid getting posted for leprosy work and those who are unable to avoid doing so, have a low motivation - even antipathy for leprosy work (Rao, 1982). Our discussions with those working in the leprosy program reveals that leprosy is considered a "punishment posting" and leprosy workers, especially physicians, are not only most disinterested in their work but also exhibit stigma towards the disease.

Though education constitutes a significant component of the leprosy program the main focus continues to remain with case-finding and case-holding. This inspite of the realization that socio-cultural and economic factors need to be looked into to bring about changes in community attitudes and practices.

In this study, we have elicited responses from the people on certain forms of stigma. The responses on knowledge of leprosy and leprosy patients has also been elicited. Apart from relating the knowledge of leprosy with their behaviour towards leprosy patients, we have also related both, the knowledge and behaviour to their socio-economic position in society. It should be noted that this attempt is not to provide a very comprehensive

understanding, but within the limitation of the study, to outline one of the methods to study stigma - as a part of the socio-economic structure and to describe it as it exists in the study area.

A NOTE ON THE NATIONAL LEPROSY ERADICATION PROGRAMME

In the last year of the First Five Year Plan (1955-56) the National Leprosy Control Programme (NLCP) (now renamed as the National leprosy Eradication Programme without any change in the overall strategy) was launched in the country. The programme is based on three **principles** :

(i) Detection of all cases, especially those of the infectious types, at as early a stage as possible.
(ii) Provision of treatment facilities to all patients so detected, and
(iii) Health Education to create a favourable atmosphere which will help both in case detection as well as case holding programmes.

The stated **objectives** of the NLEP are :

(a) To reduce the load of infection in the community by converting the bacteriologically positive cases to bacteriological negativity inorder to interrupt the transmission of infection in the community.
(b) To reduce the prevalence rate of leprosy to a level when leprosy will no longer pose major health hazard i.e. less than one case per 1000 population.
(c) Ultimately to rid the country of the disease.

To achieve the objectives, following types of centres have been established:

(1) Survey, Education and Treatment (SET) Centres: They are generally established in rural areas with a prevalence rate of less than 10 per 1000 population and covering about 20,000 to 25,000 population. It is manned by a Leprosy Technician and is supervised by the Medical Officer of the PHC as well as the District Non-medical Supervisor.

(2) Leprosy Control Unit (LCU) : They are generally established in areas with prevalence rate of 10 or above. They cover population of 2 to 4 lacs in rural areas. A medical officer, supervisors and other staff is provided with a vehicle. The main field workers are leprosy technicians, each covering 20 to 25 thousand population.

(3) Urban Leprosy Centre (ULC): Workers on the SET pattern, covering 30 to 50 thousand urban population. A senior para- medical designated as Non-medical Assistant is appointed there with attachment to a Government or Municipal Dispensary/Hospital.

In addition, Temporary Hospitalisation Wards, Reconstructive Surgery Units, Voluntary SET Centres and Leprosy Control Units, Leprosy Training Centres, Leprosy Homes and Hospitals, etc. are set up in the rural and urban areas. The achievement of the physical components of the NLEP in Maharashtra State are given below

NLEP INFRASTRUCTURE IN MAHARASHTRA STATE

PARTICULAR	ACHIEVEMENT (NO.) TILL MARCH 1984
Leprosy Control Unit (LCU)	42
Urban Leprosy Centre (ULC)	211
Survey Education & Treatment Unit (SET)	970
Temporary Hospitalisation Ward	23
Reconstructive Surgery Unit	11
District Leprosy Officer	25
Non-Medical Supervisor	192
Statistical Assistant for SLO	-
Leprosy Training Centre	7
Upgradation of Old Unit	17
Upgradation of Urban Leprosy Centre	23
Upgradation of district Leprosy Office	7
Upgradation of Leprosy Training Centre	5
Maintenance of Voluntary Leprosy Beds	2250
Leprosy Rehabilitation Promotion Unit	2
Sample Survey-cum-Assessment Unit	1

Source : Government of India, Ministry of Health and Family Welfare, "Health Statistics of India - 1984", New Delhi")

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NATIONAL LEPROSY ORGANISATION, INDIA

The National Leprosy Organisation, India (NLO) was established in 1965 to remove the sense of isolation among leprosy institutions and leprosy workers and to bring about brotherhood among all those fighting and supporting the cause of leprosy.

"The membership of the NLO is open to such leprosy workers, persons interested in leprosy work and leprosy institutions as believe in secularism and subscribe in writing to the objects of Organisation and the Policy Statement made from time to time." *Rule 2(a) of NLO's Rules & Regulations.*

The membership of NLO is of two kinds: Annual membership and Life membership. It is open both to individuals as well as institutions. The fees are:

	Annual	Life
1. for individuals	Rs. 10/-	Rs. 100/-
2. for institutions	Rs. 25/-	Rs. 500/-

The NLO Bulletin, a quarterly journal is supplied free to all members. For institutional non-members, the annual subscription of the Bulletin is Rs. 20/-.

Life membership is accepted in easy monthly instalments.

NLO's OBJECTIVES

1. Serve as a federation of leprosy institutions, leprosy workers and sympathisers who believe in secularism *(Sarva-Dharma-Samabhava)*.
2. Bring closer such institutions and workers and foster brotherhood.
3. Provide a forum (through regional and all India conferences) to leprosy institutions and workers to come together and discuss problems and find solutions.
4. Take up matters and issues of common interest to all institutions and workers.
5. Help them in improving their work by giving technical guidance so that they render better service to patients of leprosy.
6. Bring out a quarterly Bulletin to give information about the events, newer thoughts and developments in anti-leprosy field.
7. Bring out material and aids helpful to field leprosy workers in undertaking health education of the community.

EXECUTIVE COMMITTEE of The National Leprosy Organisation, India

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15. Shri. D.S. Wele, Wardha, 442 103	*Organising Secretary*

Source: Mini Leprosy Guide - 1987 (Diary) Report - National Leprosy Organisations India.

PATRON MEMBERS OF NLO

1. Dr. B. Mukhopadhyaya, Patna
2. Shri I.C. Patel, Baroda
3. Shri L.M. Patel, Bombay

LIFE MEMBER INSTITUTIONS OF NLO

1. Maharogi Seva Samiti, Anandvan, Warora (Maha.)
2. Gandhi Smarak Nidhi, New Delhi
3. Vidarbha Maharogi Seva Samiti, Amravati (Maha.)
4. Kustha Seva Samiti, Dattapur (Maha.)
5. Santal Pahadiya Seva Mandal, Deoghar (Bihar)
6. Gandhi Memorial Leprosy Foundation, Wardha (Maha.)
7. Sacred Heart Leprosy Centre, Sakkottai (TN)
8. Assissi Seva Sadan, Allapalli (AP)
9. Rajendra Kushta Ashram Research & Training Centre, Mairwa (Bihar)
10. Kushta Sevashram, Gorakhpur (UP)
11. Sreemanta Sankar Mission, Nowgong (Assam)
12. Acworth Leprosy Hospital, Bombay (Maha.)
13. Damien Social Welfare Centre, Dhanbad (Bihar)
14. Poona District Leprosy Committee, Poona (Maha.)
15. Trust for Leprosy Affected People, Bombay (Maha.)
16. Shram Mandir Trust, Baroda (Gujarat)
17. Bhagwan Mahavir Kushta Ashram, Doraha (Punjab)
18. Anand Gram Society, Poona (Maha.)
19. Gandhi Kushta Nivaran Pratisthan, Akhalaspur (Bihar)
20. Vimukti, Kakinada (AP)
21. Leprosy Health Centre, Nalgonda (AP)
22. M/s Suhrid Geigy Ltd., Bombay (Maha.)
23. Leprosy Relief Rural Centre; Settipatti (TN)
24. Katharina Kaspar Leprosy Control Scheme, Bangalore (Karna.)
25. Purva Khandesh Kushta Seva Mandal, Bhusaval (Maha.)
26. GRECALTES, Calcutta (WB)
27. Jhargram Leprosy Project, Jhargram (WB)
28. Central Leprosy Clinic and Home, Ponnur (AP)
29. Hansen Society, Howrah (WB)
30. Lok Seva Sangham, Bombay (Maha.)
31. GREVALTES, Visakhapatnam (AP)
32. BAM (INDIA), Calcutta (WB)
33. Leprosy Relief & Rehabilitation Centre, Nimbhora-khurd (Maha.)
34. St. Joseph's Hospital Leprosy Control Unit, Prathipadu (AP)
35. The Society for the Eradication of Leprosy, Bombay (Maha.)
36. Maharashtra Lokhit Seva Mandal, Bombay (Maha.)
37. Leprosy Patients Welfare Society, Chingmeirang (Manipur)
38. Glady's Schumacher Memorial Leprosy Hospital, Guntur (AP)
39. Greater Tenali Leprosy Treatment Education Scheme, Tenali (AP)
40. Dr. Heythornthwaite Memorial Service, Kagal (Maha.)
41. Christian Hospital, Madarapakkam (AP)
42. Bharat Sevashram Sangh, Jamshedpur (Bihar).
43. Leprosy Hospital & Free Treatment Centre Solapur (Maha.)
44. ALERT India, Bombay (Maha.)
45. Hind Kushta Nivaran Sangh, Haryana State Branch Chandigarh.
46. Marathwada Lokseva Mandal, Nerli, (Maha.)
47. Kushta Seva Samiti, New Delhi
48. Asha Gram Trust, Badwani (MP)
49. Damien Leprosy Centre, Vegavaram (AP)
50. Hemerijckx Rural Centre, Rawattakuppam (TN)
51. St. Joseph's Leprosy Hospital, Mangalore (Karna)
52. Word & Deed, Hyderabad (AP)
53. Bombay Leprosy Project, Bombay (Maha.)
54. ELEP Leprosy Control Project, Dhrmapuri (TN)
55. AMG International, Vijayavada. (AP)
56. Viswa Karuna Sangham, Warangal, (AP)
57. HKNS, Leprosy Project, Jammikunta (AP)
58. Gram Nav Nirman Samiti, Hyderabad (AP)
59. Shakti Brahmashram, Jalna (Maha.)
60. Ramdeobaba Satsang Mandal, Deshmukhwadi, Wani (Maha.)
61. Kedia Vanaspati Ltd. Hyderabad (AP)
62. Kushtarog Nivaran Samiti, Wakdi (Maha.)
63. Udyog Dham, Badrikashram, Pune (Maha.)
64. Vanvasi Seva Kendra, Kusht Nivaran Samiti, Adhaura (Bihar)
65. Sree Srinivasa Leprosy Vimukti Organisation, Tirupati (AP)
66. Prema Samajam, Vijayanagaram (AP)
67. Holy Family Hansenorium, Fatimanagar, Tiruchirapally (TN)
68. Prema Samajam, Visakhapatnam (AP)
69. Vimala Dermatological Centre, Bombay (Maha.)
70. Asha Sadan Leprosy Centre, Kalheri (UP)
71. Grameen Sarbatmak Kalyan Kendra, Calcutta (WB)

Institutional Members 1986-87
(Till August 1986)

1. OXFAM India Trust, Nagpur, (Maha.)
2. Phoenix Seva Sangh, Subhashwadi, (Maha.)
3. Hubli Hospital for the Handicapped, Hubli (Karna.)
4. Swami Vivekanand Kusht Seva Samiti, Bijapur (Karna.)
5. CULTES, Cochin, (Kerala)
6. Shri Gurudev Kushta Seva Mandir, Amla Vishweshwar, (Maha.)
7. Kushta Kalyan Samiti, Charichaka, (WB)
8. DANIDA Leprosy Coordination Unit, New Delhi
9. Geeta Arogya Bhavan, Bhagwanpur (WB)
10. Swami Vivekanand Seva Trust, Jamshedpur (Bihar)

International financing agencies participating in leprosy work in India

1. American Leprosy Missions, Inc. 566, Morris Avenue, New Jersey, 07901 (USA)
2. Leprosy Relief Work Emmaus Switzerland, Spitalgasse, 913011, Berne (Switzerland)
3. International Co-ordinating Committee of the Leprosy Associations (ILEP) 106, Rue Steven, Brussels, 4 (Belgium)
4. OXFAM, 274, Banbury Road, Oxford-OX2 7 DZ UK
5. Associazione Italiana "Amici de Roul Follereau" 44135 Bologna, Via Borselli 4 (Italy)
6. German Leprosy Relief Association, Dominikanerpiatz 4 Wurzburg (Germany)
7. Leprosy Relief Organization, Munich e.v. Zenettistrasse 45 D 8000, MUNCHEN 2, (West Germany)
8. International Society for Rehabilitation of the Disabled, 219 East 44th Street, New York N.Y. 10017 (USA)
9. Damien Foundation, Rue Steven, 16, B-1040 Brussels, Belgium.
10. The Leprosy Mission 7, Bloomsbury Square, London, W.C.I. (U.K.)
11. Rehabilitation International, 432, Park Avenue South New York, N.Y. 10016 (USA)

LEPROSY

I. DEFINITION

"Leprosy is a chronic, specific, infectious disease caused by a germ called *Mycobacterium Leprae*. It starts insidiously and progresses slowly. It can be easily diagnosed. It is curable without any deformity, but if neglected it may lead to deformities."

Dr. P. Kapoor

II. SUGGESTIVE SIGNS

Suspect leprosy when any person complains of or is seen with one or more of the following signs and symptoms and then examine thoroughly for a definite diagnosis:

(A) SKIN

1. Non-itching, non painful—

(i) HYPO-pigmented or erythematous patch or patches

(ii) Disseminated diffuse erythema.

(a) In the patches, following are additional helpful suggestive signs of leprosy—

(i) Numbness in the patch
(ii) Loss of hair
(iii) Loss of sweat causing dryness of patch.

(b) In diffuse erythema the skin looks erythematous, smooth, oily and shiny. It may have a velvety or greasy or waxy appearance; in addition, there may be—

(i) Small nodules on the earlobes, face and extremities.
(ii) Thinning of eyebrows due to partial los of hair.
(iii) Thick and elongated earlobes.

2. Sudden appearance of painful nodules on the face and extremities, with fever, nerve and joint pains. Skin is erythematous smooth, oily and shiny.
3. Painful, swollen hand, particularly the base of the fingers.

(B) NOSE

Sometimes a patient may come with the complaint of nose block and bleeding from the nose. On examination, the skin will be found erythematous, smooth, only and shiny.

(C) NERVE CHANGES

1. Sensory changes

(a) Tingling sensation in the course of the nerve or ants-crawling sensation.
(b) Numbness of the skin
(c) Painless blisters and ulcers in hands and feet.
(d) Pain in the nerves behind big joints like inner side of elbow, outer side of knee and inner side of ankle joints.

2. Motor changes:

(a) Weakness and/or wasting of the muscles of hands and feet.
(b) Paralysis of muscles of hands, feet and eyes causing clawing of fingers, foot drop and lagophthalmos.

III. DIAGNOSTIC CARDINAL SIGNS

Presence of any *ONE OR MORE* of the following:

1. Complete or partial loss of sensation in an area.
2. Thick and/or tender nerves.
3. Presence of *'M. Leprae'* in smears taken by standard slit and scrape method.

If a definite diagnosis cannot be arrived at, refer the case to an appropriate authority for examination or keep the patient under observation for 3 to 6 months by which time either the lesions will heal or very clear signs of leprosy or some other disease will appear.

When under observation, the patient should be very carefully examined once every month.

IV CLASSIFICATION

(As approved by Indian Association of Leprologists in its XII Biennial Conference held at Agra from 9th to 12th September 1981)

I. Indeterminate Type

The indeterminate type represents those cases where leprosy is in the very early stages of evolution. The skin lesions consist of macules. The clinical characteristics of the lesions are given below: *a. Skin lesions:* One to three; Size: Small (5 cm or less in diameter): colour: Hypopigmented; Elevation: Flat and flush with rest of the skin; Margin: Ill defined; Surface-smooth, occasionally dry; Sensory changes-Impairment of pain or touch sensation.

b. Nerve Lesions Nerve thickening not necessarily present.
c. Skin smears by slit and scrape method: Negative
d. Lepromin reaction: Negative to doubtful.

II. Tuberculoid Type

a. Skin Lesions: Number—One to three; Size—Could be of any size; Colour—Hypopigmented or varying shades of erythema; Elevation—Raised or flat. In the raised lesions the entire lesion may be raised or only the edges may be raised; Margin-well defined. The edges in the raised lesions are abrupt; Surface—Dry, rough, anhydretic. Consistency in raised lesion-Firm; Sensory changes-Analgesia and/or anaesthesia.

b. Nerve lesions: In cases with raised lesions, cutaneous nerves leading to the skin lesion and regional nerve trunks are often enlarged. In cases with flat lesions such nerve enlargement may not be observed.

c. Skin smear by slit and scrape method: negative

a. Lepromin: Positive (1+ to 3+)

III. Borderline Type

The borderline type of leprosy represents a clinical spectrum reflecting the immunological gradation from the tuberculoid at one end to the lepromatous at the other. Both flat and raised skin lesions are found throughout the spectrum.

a. Skin lesions: Number—4 or more, sometimes satellite lesions may be observed near the larger ones: Size-Could be of any size; Colour-Hypopigmented or varying shades of erythema; Elevation Flat or raised. In the raised lesions the entire lesions may be raised or only the edges may be raised. There could be thus various patterns e.g. uniformly raised, dome shaped circinate, concentric or irregular. Margin—In the flat lesions margins may be ill-defined, partially defined or well defined. In the raised lesions edges are sloping. Surface-smooth to different grades of dryness. Consistency of raised lesions-Rubbery to soft. Sensory changes-Modalities of sensation may be lost to varying degrees.

b. Nerve lesions: In cases with raised lesions, cutaneous nerves leading to the skin lesions and regional nerve trunks are often enlarged. In cases with flat lesions, such nerve enlargement may not be observed.

c. Skin smears by slit and scrape method Moderately positive to negative.

d. Lepromin: Moderately positive to negative.

Note : Borderline leprosy could be divided into macular and infiltrated types. In the hands of experienced workers it would be possible to subdivide it into Borderline on Tuberculoid side (BT) and Borderline on Lepromatous side (BL) both in the raised and flat lesions.

IV. Lepromatos Type

a. Skin lesions : The skin lesions in lepromatous vary according to the stage of the disease. In the early stages the lesions could be seen as macules which are small, numerous, symmetrically distributed, hypopigmented or coppery red, ill defined, smooth and shining with no sensory loss. As the disease advances, the lesions get infiltrated with a smooth shining surface and with colour varying from coppery red to reddish brown, involving the skin of the entire body except for certain areas like the axilla, groin and flexures where lesions are relatively inapparent. In the more advanced stages, papules nodules appear.

b. Nerve lesions : Some of the nerve trunks are enlarged on both sides and are soft in consistency. Loss of sensation is found in the distal parts of the limbs.

c. Skin smears by slit and scrpe method : Positive.

d. Lepromin : Negative.

V. Pure Neuritic Type.

In this type of leprosy, there are no skin lesions. Larger nerve trunks or their branches are enlarged. There is sensory loss in the areas of distribution of the nerves. A single nerve or multiple nerves may be involved. The enlarged nerves are generally firm, but may also be soft. Skin smears are negative. Lepromin reaction is generally positive, but sometimes may be doubtful or negative.

V. TREATMENT

Dapsone still continues to be the sheet anchor in the treatment of leprosy. Dapsone is cheap, easily administered, safe, effective and thus eminently suitable for domiciliary care. The risk of the emergence of dapsone resistant strains of M. leprae can be reduced by (a) using the drug in full dosage and (b) ensuring regular daily treatment without any interruption.

Treatment of multibacillary leprosy with Dapsone

Adults:	DDS 100 mg daily self administered.
Children (6-14 yrs.)	DDS 50 mg daily
(below 6 yrs.)	DDS 25 mg daily
Duration:	Till the patient becomes clinically inactive and bacteriologically negative, assessment being done every year.

Multidrug Treatment for Multibacillary leprosy

Intensive Phase

Adults:	daily supervised treatment should be given during initial intensive phase or 14 days with following drugs. Rifampicin — 600 mg Clofazimine — 100 mg Dapsone — 100 mg
Children (6-9 yrs.)	Rifampicin 300 mg daily Clofazimine 50 mg daily Dapsone 25 mg daily
Children (10-14 yrs.)	Rifampicin 450 mg daily Clofazimine 50 mg daily Dapsone 50 mg daily

Continuation Phase

Treatment is given at least for a period of 24 months, or until smear negativity, whichever is later.

Adults: **24 doses should be completed within 36 months.**	Rifampicin 600 mg once montly supervised. Clofazimine 300 mg once monthly supervised and 50 mg daily self administered. Dapsone 100 mg daily self-administered.

Treatment of Paucibacillary leprosy with Dapsone

Adults:	Dapsone 100 mg daily self-administered.
Children (0-5 yrs.)	Dapsone 25 mg daily
(6-14 yrs.)	Dapsone 50 mg daily

Multidrug Treatment for Paucibacillary leprosy

Adults:	Rifampicin 600 mg once daily supervised. Dapsone 100 mg daily self-administered
Children (0-5 yrs.)	Dapsone 25 mg daily Rifampicin 300 mg monthly
(6-14 yrs.)	Dapsone 50 mg daily Rifampicin 450 mg monthly
Duration	The treatment should be continued till six months doses have been administered. If reatment is interrupted, the regimen, should be recommenced where it was left off to complete the full course provided six monthly doses are given within a period of nine months.

(Source: *Leprosy: Guidelines on case detection, treatment follow-up & reporting, published by DGHS, New Delhi 1985*)

VI DRUG RESISTANCE

When to suspect

A patient suffering from lepromatous or borderline leprosy who has been taking sulphone for a variable period and with good clinical and bacteriological result develops new lesion for no obvious reason. He is usually still taking his drug.

The new skin lesions resemble the old ones, or may be in the nature of rapidly developing papules of maculo-erythematous eruption reminiscent of drug rash. These lesions are persistent, they are not tender to touch, they increase in size and number and they are not accompanied by signs of acute exacerbation.

How to Prevent

In a leprosy treatment control programme where patients are seen regularly by competent auxiliaries or doctors, dapsone may be given at full dose from the beginning of treatment but nerve pain must be recognised and treated at once.

How to treat

In the case of multibacillary leprosy due to dapsone resistant bacilli, if possible give rifampicin for three weeks together with clofazimine 100 mg every other day and continue indefinitely with this dose of clofazimine. If rifampicin is not available, then give clofazimine alone.

Practical recommendations

1. Be on the look out for relapse, especially in patients with lepromatous or borderline-lepromatous leprosy.
2. When suspicious, proceed to clinical confirmation ofthe presence of sulphone-resistant bacilli.
3. Be on the look-out forpatients presenting themselves with any form of leprosy that does not respond as rapidly as it should to standard treatment regimens.
4. Bacteriological evidence of resistance frequently precedes the clinical. Therefore regular and frequent examination of skin smears should be performed on all patients whose multibacillary leprosy is considered to be quiescent after adequate periods of treatment.

(Drug Resistance in Leprosy by Dr. S.G. Browne Published by The Leprosy Mission London Jan. 79)

VII. BACTERIOLOGY READING

Ridley's method

One plus : 1 to 10 bacilli seen in 100 fields.
Two plus : 1 to 10 bacilli seen in 10 fields.
Three plus : 1 to 10 bacilli seen in one average field.
Four plus : More than 10 bacilli seen in one average field.
Five plus : More than 100 bacilli seen in one average field.
Six plus : More than 1000 bacilli seen in one average field.

VIII. SIGNS OF ACTIVITY

Presence of any ONE of the following indicates that the disease is reactive.

SKIN

1. Increase or decrease in *size* and *number* or lesions 2. Increase and decrease in anaesthesia 3. Erythematous and infiltrative lesions 4. Presence of bacilli by standard method of examination.

NERVES

5. Tender (Painful on tapping)

(Neuropathic ulcers, deformities, residual lesions anaesthetic patches, wrinkled skin, etc., do not indicate signs of activity.)

IX. CRITERIA FOR DISCHARGE

When all signs of activity are absent for a continuous period of 1½ years in non-lepromatous patients and for 3 years in lepromatous patients, review

being taken every three to six months, the patients are called *disease arrested* or cured. During the intervening period, the patients are called *inactive* cases of leprosy.

Treatment should be stopped in non-lepromatous cases when disease is cured. In lepromatous and borderline cases treatment should not be stopped even after declaring the case as cured, but their names should be removed from the list of active cases.

("Guide to Leprosy Control" Dr. P. Kapoor)

X. CARE AND PREVENTION OF DEFORMITIES

If a patient develops anaesthesia a few simple precautions will prevent secondary deformities and even primary deformities to a great extent.

CARE OF HANDS

(i) Examine both hands every morning in good day light for any injuries. If there is any he should immediately get it dressed and/or consult a doctor.
(ii) Not to touch any hot object. Women to preferably use tongs.
(iii) Be careful about holding sharp or rough gadgets or instruments etc.
(iv) Should use gloves or small towels formed into a pad, or the implements they use should have soft rubber or thick cloth cover at the part which is held in the hand.
(v) Regular exercises of hands and feet with any vegetable oil as advised by the medical officer or physiotherapist or leprosy tachnician.

2. CARE OF FEET

(i) Use any type of foot-wear without nails.
MCR foot-wear is better.
(ii) Not to walk long distance at a time.
(iii) Walk slowly, steps should be short.
(iv) Not to stand at one particular place for a long time.
(v) If any cracks or fissures in the sole, the feet should be kept in ordinary water for half an hour every morning and after drying a thin layer of any oil should be applied.
(vi) Examine feet every morning in good day light for any injuries. If any, get it dressed and/or consult a doctor.

3. CARE OF NOSE

(i) The inside of the nose should be washed with ordinary water. Take handful of water in the cupped palm of your hand, or in a small basin and then dip your nose into that. Repeat it 10-15 times at a sitting. Do this 3-4 times a day.
(ii) A few minutes after washing of the nose, an antiseptic ointment or cream should be applied particularly to the area where there is an ulcer.
(iii) Any crust in the nose should be gently removed and an ointment or vaseline applied to the area.
(iv) Flies should not be allowed to sit on the nostrils.

4. CARE OF EYES

(i) Exercise (closing and opening) of eyes in case eyes are becoming weak.
(ii) Check yourself in a mirror, or someone to check your eye in case eye-ball is losing sensation.
(iii) Contact doctor immediately on getting pain or ulcer in eyes or sudden decrease/difficulty/loss of vision.

XI HEALTH EDUCATION

Definition:— "Health education is the process and result of providing experience to the people for influencing their knowledge, attitudes and practices in order to promote and maintain health and prevent illness-through their own active efforts".

Principles of Health Education

1. It is not enough that a teacher teaches; more important is that the student learns.
2. All people irrespective of class, sex, caste, age, creed literacy or rural/urban background, are capable of learning. One cannot teach unless he himself believes that the student is capable of learning.
3. Though all people are capable of learning, everyone will not learn his lesson the same way.
4. Though all people are capable of learning, some will take longer than others to learn.
5. Learning is more effective when learner is motivated and feels the need of learning.
6. Learner learns not merely because a teacher teaches but only if the learning is reinforced with earlier experiences or subsequently acquired varied experiences relating to the content-matter.
7. Learning only by one sense can be reinforced by learning by another sense.

Method & Media

1. **Individual approach:—** through personal interviews for bringing about action. Useful in enlisting cooperation of departments,

municipal officers, MLAs, MPs, social workers etc.; useful in solving social problems of leprosy patients; useful for rihabilitation.

2. **Group approach:**— through group discussions, group meetings, panel discussions, movie forum, dialogue forum, seminar, symposium, workshops etc. for creating awareness, or creating motivation for enlisting active cooperation and for gaining social approval.
3. **Mass approach:**— through films, drama exhibition, slides, newspaper, radio, television, folders, pamphlets etc. for creating mass awareness about the problem and reaching minimum message to a larger number.

Material

1. Guide-line schedule 2. Slides & slide-projector 3. Film/film-strip with projector 4. Photographs-coloured and black & white 5. Booklets, folders, pamphlets 6. Models, panels for exhibition etc.

Groups to be covered

1. **Homogenous groups:**— Such as nurses, teachers, medical students, doctors, municipal or ZP councillors etc.
2. **Heterogenous groups:**— such as housewives, mahila mandals social service clubs (Lions, Rotarians), people from neighbouring houses, gossip groups, etc.
3. **Readymade groups:**— Such as schools, colleges factories etc.

Evaluation

Short term evaluation helps to modify the approach and methodology. Terminal evaluation helps, the extent of objectives achieved.

Evaluation can be done by applying following tools:

1. The guide-line schedule
2. The questionnaire
3. Observation of indices
4. Pre-stage and post-stage data
5. Baseline data
6. Survey & re-surveys
7. Interviews
8. Experiences enlisted by workers.

Indices for evaluation

1. Increase in voluntary reporting of cases;
2. Prepareness to get lesions diagnosed voluntarily;
3. Preparedness to keep the patient in home;
4. Increasing cooperation in rehabilitation;
5. Increase in the number of private physicians treating leprosy;
6. Increase in the number of patients being treated in private; dispensaries;
7. Increase in percentage of attendance of patients at clinics;
8. Reduction in severity of problem and difficulties faced by leprosy patients.

XII RECORDS

A. FOR PATIENTS

1. Running list of patients both for project area cases and outside project area cases separately arranged chronologically with monthly, quarterly and annual abstracts.
2. Villagewise list of—
   (a) Patients (b) Suspected Cases (c) Cured persons (d) Absentee patients showing the efforts made to make them regular.
3. Treatment record of patients showing signs, symptoms, treatment and progress of patients.
4. Clinic Register.
5. Bacteriological Work Register.

B. FOR SURVEY

1. Villagewise survey chart showing the month in which the previous surveys have been done and the probable dates for future surveys.
2. Villagewise familywise survey records.
3. Villagewise abstract of survey showing new patients detected, the prevalence rate etc.
4. Villagewise School Survey Register with abstract of surveys.
5. Villagewise Contact Survey Register.

C. HEALTH EDUCATION

1. Villagewise list of elected, political, social and other important persons.
2. Health education diary with advance programme and summary.

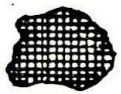
D. ADMINISTRATIVE RECORDS

1. Monthly progress records.
2. Quarterly progress records.
3. Annual progress records.

("Guide to Leprosy & leprosy Control" Dr. P. Kapoor)

Notations used for charting leprosy patients

Hypopigmented flat patch with clear-cut margin.



Hypopigmented flat patch with clear-cut margin and anaesthesia.

Hypopigmented, uniformly raised, patch with anaesthesia and clear-cut margin. If the rising is confined to the margin alone the dots should be placed around the margin.

Hypopigmented uniformly raised patch with anaesthesia, clear-cut margin and central healing.

Hypopigmented, uniformly raised patch with anesthesia, clear-cut margin and central ulceration.

Hypopigmented, flat, ill-defined patch without anaesthesia.

Hypopigmented, uniformly raised ill-defined patch with anaesthesia.

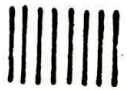
Erythematous raised patch with anaesthesia.

Dense infiltration

Diffuse infiltration

Nodules

Nodules with ulceration



Anesthesia

Flexion of fingers

Contracture of fingers

Loss of digits
(Vertical line to be longer than the horizontal line)

Ulcer

Nerve thickening (represented by a thick line drawn at the site where nerve is thickened)

Depressed nose

Gradation of thickening of nerves

Nerve not thickened	N I
Nerve thickened but not likely to cause deformities	N II
Nerve thickened and likely to cause deformities	N III
Nerve thickening with deformities	N IV

CLASSIFICATION OF DEFORMITY

I. HANDS

Grade— 1-Anaesthesia to pain
2-Mobile claw hand. Useful thumb.
3-Intrinsic paralysis involving fingers and thumb or fingers only but with contractures (include wrist drop)
4-Partial absorption of fingers but with useful length remaining.
5-Gross absorption. Stumps only left.

II. FEET

Grade— 1-Anaesthesia
2-Trophic Ulceration (present and past)
3-Paralysis (foot-drop and claw toes)
4-Partial absorption of the foot (upto 1/3rd of surface area of the sole of the foot.)
5-Gross absorption (More than 1/3rd feet lost)

III. FACE

Type— 1-A pu[illegible]rk of stigma of leprosy not amounting to ugliness, loss of eye brows, deformity of ears).
2-Colapse of nose.
3-Paralysis of eyelids, including lagopthalmos or paralysis of the facial nerve.
4-Loss of vision in one eye or dimness of both eyes (cannot see fingers.)

IV. MISCELLANEOUS

Type— 1-Gynaecomastia (in case of males)
2-Involvement of the larynx.

(WHO Technical Report Series No. 189)

PREVALENCE OF LEPROSY IN THE WORLD

Names of countries	Prevalence Rate Per 1000
Canada, Panama, USA, Japan Israel, Greece, Spain, USSR	0.0 to 0.5
Mexico, Jamaicas, Afghanistan, Ceylon, Iran, Iraq, Maldivi Islands, Turkey	0.5 to 0.9
France, South Africa, South West Africa, UAR Argentina, Cuba China, Korea, Pakistan, Phillippines Fiji, Tonga	1.0 to 4.9
Ethiopia, Kenya, Mauritania Bhutan, Cambobia, India, Nepal, Vietnam	5.0 to 9.9
Angola, Nigeria, Uganda, Surinam	10.0 to 19.0
Senegal, Burma	20.0 to 29.0
Chad, Congo, Mali	30.0 to 39.0
Gaban, Zambia, Spanish Equatorial Region	40.0 to 49.9
Central African Republic, French Guiana	above 50.0

NATIONAL LEPROSY ERADICATION PROGRAMME
(Figures in thousands)

State/Union Territory	Estimated Cases of leprosy (1981 Census)	Leprosy Cases on record by 31.3.1986	Leprosy Cases under treatment by 31.3.1985
Andhra Pradesh	651	475	475
Assam	15	18	18
Bihar	380	295	263
Gujarat	100	87	79
Himachal Pradesh	7	5	5
Jammu & Kashmir	5	6	5
Karnataka	222	165	160
Kerala	75	88	74
Madhya Pradesh	120	152	152
Maharashtra	400	396	396
Manipur	6	6	4
Meghalaya	6	6	3
Nagaland	5	2	2
Orissa	320	234	232
Rajasthan	10	15	14
Tamil Nadu	733	547	483
Tripura	10	6	3
Uttar Pradesh	410	464	435
West Bengal	430	306	229
Goa Daman & Diu	5	5	2
Pondicherry	10	8	6
Rest of India	27	18	20
	3947	3305	3060

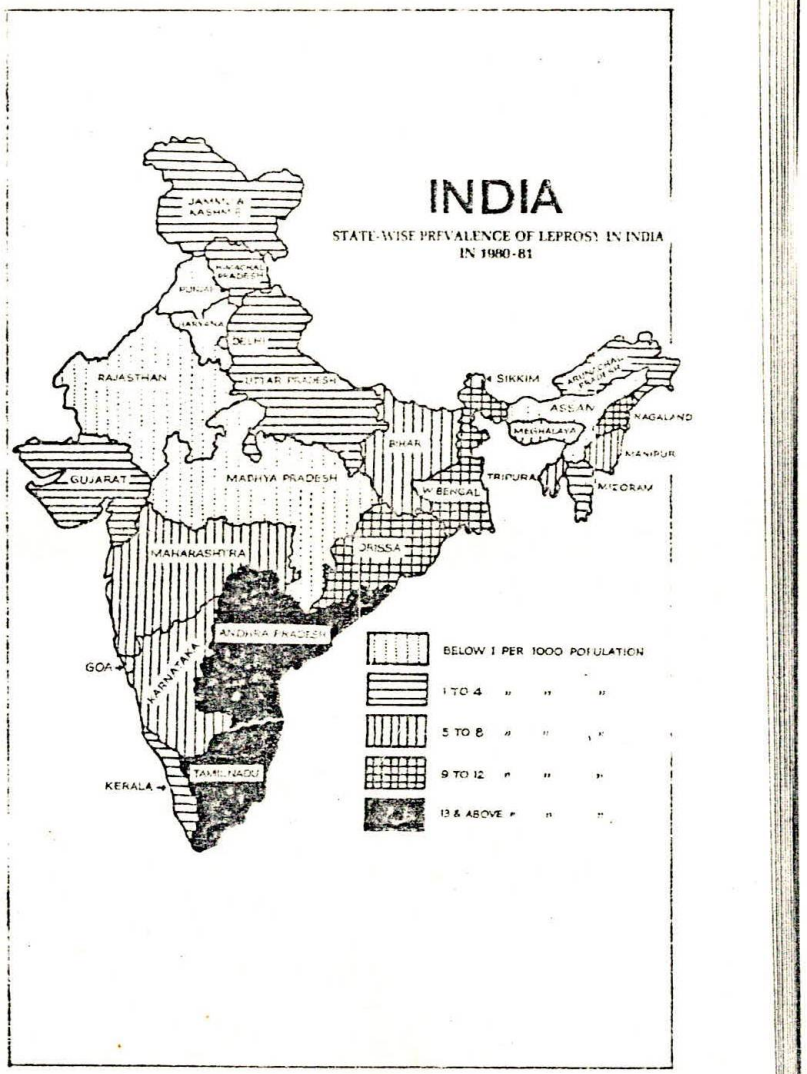
Source: DGHS, New Delhi

ENGAGEMENTS

DIS 8a-5

Report of work done during December 1987

	No. of persons examined	No. of cases detected L	No. of cases detected N	total
I. Total population by end of previous month				
II. Surveys				
1. Upto the end of previous month				
2. During the month				
3. Total upto the end of month				
III. Cases Detected				
1. Upto the end of previous month				
2. During the month				
3. Total upto the end of month				
4. Cases died and left				
IV. Cases registered				
1. By end of previous month				
2. During the month				
3. Cases died and left				
4. (a) No. registered and living at the end of the month				
(b) No. actually took treatment during the month				
V. Extra-zonal patients Registered				
1. During the month				
2. No. Previously registered				
3. Total till end of month				
4. No. actually attended for treatment				



Source: Mini Leprosy Guide 1987 (Diary)
Report - National leprosy Organisations India.

Centres	Target	Achievements	Cumulative Coverage	Plan Allocation
Fourth Plan 1969-74				
1. Lep. Con. Units	80	70	251	
2. Upgradation of LCUs	40	53	53	Rs. 291.25
3. SET Centres	460	363	1500	Lakhs
4. Leprosy Training Centres	—	—	21	Expenditure
5. Population covered	—	56.70 m	120.8 m	295.62
6. Cases recorded for treatment	—	4.56 Lakhs	18.34 Lakhs	Lakhs
Fifth Plan (Upto 31-3-1978)				
1. Lep. Con. Units	128	121	372	Rs. 1709.40
2. Upgradation of LCUs	108	94	147	Lakhs
3. SET Centres	4584	4270	5770	Expenditure
4. Urban Leprosy Centres	506	406	406	(Upto May 1978)
5. Leprosy Training Centres	19	19	40	
6. Population covered	—	155.2 m	276 m	Rs. 1385.30
7. Cases recorded for treatment	—	4.98 Lakhs	23.3 Lakhs	Lakhs

PHYSICAL ACHIEVEMENTS OF FIVE YEAR PLANS

	Target	Achievements	Cumulative Coverage	Plan Allocation
First Plan 1951-56				
1. Lep. con. Units	40	31	31	
2. Study-cum-Treatment Centre	4	4	4	Rs. 35
3. Population covered	—	20 m	30 m	Lakhs
4. Cases recorded for treatment	—	0.17 Lakhs	0.17 Lakhs	
Second Plan 1956-61				
1. Lep. Con. Units	100	103	134	
2. S.E.T. Centres	44	44	194	
3. Population covered	—	12.51 m	14.51 m	Rs. 529
4. Cases recorded for treatment	—	0.95 Lakhs	1.12 Lakhs	Lakhs
Third Plan 1961-66				
1. Lep. Con. Units	50	46	180	
2. S.E.T. Centres	786	564	758	
3. Lep. Trg. Centres	10	10	20	Rs. 424.40
4. Population Covered	—	40.69 m	55.20 m	Lakhs
5. Cases recorded for treatment	—	4.59 Lakhs	5.68 Lakhs	
Annual Plans 1966-69				
1. Lep. Con. Units	26	1	181	
2. S.E.T. Centres	659	379	1137	
3. Lep. Trg. Centres	4	1	21	Rs. 62.77
4. Population covered	—	18.90 m	64.10 m	Lakhs
5. Cases recorded for treatment	—	2.10 Lakhs	7.78 Lakhs	

NATIONAL LEPROSY ERADICATION PROGRAMME

Physical Targets for 1986-87

Leprosy Control Units	90
Urban Leprosy Centres	190
SET Centres	70
Modified Control Units	42
District Leprosy Officers Unit	4
Regional Leprosy Training & Research Institute	2
Temporary Hospitalisation wards	26
Sample Survey cum Assessment Unit	17

Objectives Targets

Case detection	4,20,000
Case Treatment	4,20,000
Case discharge due to cure / arrest	4,30,000

Centres	Cumulative	Coverage		Cumulative	Coverage	Plan	Allocation
Sixth Plan (till 31-3-1986)							
1. Leprosy Control Units		429	12. Non Medical Supervisors				1266
2. Upgradation of LCUS		165	13. Cases on record				33.05 Lakhs
3. SET Centres		6746	14. Cases discharged during (85-86)				4.36 Lakhs
4. Urban Leprosy Centres		772	15. Cases under tratment				30.60 Lakhs
5. Upgradation of ULCs		52	16. Expenditure (1985-86)				
6. Leprosy Training Centres		43	Cash—				1804.83 Lakhs
7. Reconstructive Surgery Units		73	Kind—				519.13 "
8. Temporary Hospitalisation Wards		266	Total—				2323.96 "
9. Dist. Zonal Leprosy Officers		209	17. Budget Allocation (1986-87)				
10. Upgradation of DLO		80	Cash—				932.44 Lakhs
11. Upgradation of LTCs		21	Kind—				467.56 "
						Total	1400.00 "

NATIONAL LEPROSY ERADICATION PROGAMME

Performance of Voluntary Sector under NLEP

Activity	Voluntary sector 53 VOs	Government sector as on July 86	Total
Leprosy cases on record	732669 (22.06)	2588883 (77.94)	33215 [illegible]2
Leprosy cases under treatment	628909 (20.55)	2431436 (79.45)	3060345
Leprosy cases discharged after cure	110357 (4.66)	2255834 (95.34)	2366191
Population covered (lakhs)	489.26 (12.23)	3510.74 (87.77)	4000.00
Annual budget Rs. in lakhs	1354.5 (49.17)	1400.00 (50.83)	2754.5
Expenditure per leprosy case (Rs)	184.80	54.10	
Number of leprosy beds	18607 (57.68)	13649 (42.32)	32256
Rehabilitation of leprosy cases			
(i) Medical	19014 (92.69)	1500 (7.31)	20514
(ii) Vocational	21518 (75.45)	7000 (24.55)	28518
Leprosy training activities			
(i) No of training centres	12 (27.91)	31 (72.09)	43
(ii) Intake capacity per annum			
(a) Medical	121 (50.42)	119 (49.58)	240
(b) Paramedical	575 (24.57)	1765 (75.43)	2340
(iii) No. trained so far			
(a) Medical	2537 (50.08)	2529 (49.92)	5066
(b) Paramedical	5623 (20.12)	22326 (79.88)	27949

Grant in aid released, by Central Govt. to V.Os

	No.of V.Os supported	Amount (Rs. in lakhs)
(i) 1983-84	44	35.92
(ii) 1984-85	49	51.71
(iii) 1985-86	51	62.00
(iv) 1986-87		55.00 (Provisional)

Grant-in-aid Schemes of Government of India for Voluntary Leprosy Institutions

	Quantum of Annual Grant	
	Recurring	Non-Recurring
1. Voluntary SET Centres		
(a) with two lakh population	— Rs. 2,58,200/-	Rs. 1, 08,200/-
(b) with one lakh population	— Rs. 1,75,700/-	Rs. 1,08,200/-
(c) with 75,000 population	— Rs. 1,05,000/-	Rs. 1,08,200/-
(d) with 50,000 population	— Rs. 73,800/-	Rs. 1,08,200/-
(e) with 25,000 population	— Rs. 49,000/-	Rs. 1,08,200/-
2. Training Centre	— Rs. 76,200/-	Rs. 1,20,500/-

For further particulars and form of application, please contact NLO or the Deputy Secretary to Government of India, Ministry of Health & Family Welfare, NirmanBhawan, New Delhi, 110 011

SCHIEFFELIN LEPROSY RESEARCH & TRAINING CENTRE, KARIGIRI

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Dist. North Arcot

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3. Healing while walking by Dr. E.P. Fritschi	45	Rs.850/-
4. Keep blinking by Dr. N.S. Suryawanshi	20	Rs.750/-
5. Trackingdown the mysterious agent by Dr. C.J.C. Chacko	33	Rs.845/-
6. Temporalis Muscle transfer by Dr. E.P. Fritschi	28	Rs.680/-
7. The red eye by Dr. N. Suryawanshi	20	Rs.700/-
Slide-Audio Casette Programme		
8. Leprosy : the great imitator by Dr. S. Arunthathi	42	Rs.950/-
9.An introduction to leprosy control by Dr. K. Jesudasan	20	Rs.400/
10. Five faces of leprosy : Dr. S. Arunthathi	55	Rs.950/-

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The Director,
Schieffelin Leprosy Research & Training Centre
karigiri, Tamil Nadu, S. India, 632 106

WHO'S CONTRIBUTION TO NLEP IN 1987-88

WHO will collaborate with the Government of India in strengthening the infrastructure of the National Leprosy Eradication Programme. The major thrust will be on intensification of case finding activities, expansion of treatment facilities with multi-drug regimens and improved case holding and surveillance activities, in 36 high endemic districts in the country.

Assistance will be provided for strengthening research and training centres through the provision of equipment and the establishment of facilities for monitoring drug resistance.

Workshops, seminars and task oriented training courses based on well designed modules will be organized to improve staff skills and promote programme implementation. Fellowships will be provided for training of technical staff in the epidemiology and control of leprosy.

Increased emphasis will be given to support the strengthening of health education component of the programme in 2 or 3 States so that this can be a model for other States to follow. Community involvement will be promoted to ensure the success of the new strategy.

Programme evaluation will receive priority support in order to assess the effectiveness of the managerial process and the impact of the programme.

Research projects will continue to receive assistance through the Special Programme for Research and Training in Tropical Diseases.

Window on Leprosy

Pp 395. Rs 75 -
EDITOR– Dr. B.R. Chatterjee

The overall content and application on this valuable book is decidedly international. This book should be on the working shelves of all those seriously interested in leprosy.

– LEPROSY REVIEW
1978 49 327

——has practical value for all categories of HD workers. An authoritative and comprehensive presentation of all aspects of HD

– THE STAR
1978 38. 6. 8

——This commemorative volume is a class by itself

LEPROSY IN INDIA
1978, 51. 1. 168

Society and Leprosy

Pp 297 Rs. 30/-
R.K. MUTATKAR

Head of Department of Anthropology, University of Poona

——A study in evaluation research. Health education programmes of GMLF evaluated.

The book fills a great need in the literature on health education regarding leprosy. It can be highly recommended for use of medical and social workers in leprosy.

DHARMENDRA

For orders, please contact—

Gandhi Memorial Leprosy Foundation
Hindinagar, Wardha, 442 103, Maharashtra

BOOKS ON LEPROSY

1. **Leprosy in Theory & Practice** by Dr. R.G. Cochrane Wright and Sons Ltd. Bristol.
2. **Hand Book of Leprosy** by Dr. W.H. Jopling, Heineman Medical Books Ltd. London.
3. **Hints on Diagnosis & Treatment of Leprosy** by Dr. R.V. Wardekar, Gandhi Memorial Leprosy Foundation Hindinagar, Wardha Maharashtra 442 103 Rs. 7-00
4. **Leprosy: Guidelines on case detection, treatment, follow-up & reporting;** DGHS New Delhi.
5. **Leprosy: A text book** by Dr. Dharmendra Vol. I, 1979 The Kothari Book Depot, Acharya Donde Marg, Parel Bombay-400 012. Rs 250/-
6. **Window on Leprosy**, Ed. Dr. B.R. Chatterjee, Gandhi Memorial Leprosy Foundation, Wardha, 442 103 Rs. 75-00
7. **Epidemiology for Leprosy Workers** by Dr. V. Kkambaram, (2nd edition) National Lepropsy Organisation, Hindinagar, Wardha, Maharashtra 442 103. Rs. 6/-
8. **Bacteriology of Leprosy**, by V. Periaswami, National Leprosy Organisation, Hindinagar, Wardha, 442 103 Rs. 5/-
9. **The Diagnosis & Management of Early Leprosy** by Dr. Stanley G. Browne, The Leprosy Mission, 7 Bloomsbury Square London, W.C.I.
10. **Guide to Leprosy & Leprosy Control** by Dr. P. Kapoor: Poona Dist. Leprosy Committee, 16-B1 Dr. Ambedkar Road Poona 411 001
11. **Modern Concept** by Dr. Harry L. Arnold, Charles C. Thomas, Bannerstone House 301, 327 East Lawrence Avenue Springfield, Illinois, USA
12. **Some Facts about Leprosy** by Dr. Dharmendra, Hind Kusht Nivaran Sangh, I Red Cross Road, New Delhi 110 001 (English) Rs. 3/- (Hindi) Rs. 3.75
13. **Leprosy-Diagnosis & Management** by Drs. Job, Selvapandian & Kurian, HKNS, New Delhi Rs. 19/-
14. **Orientation for Doctors in Leprosy**, HKNS New Delhi 110 001 Rs 10/-
15. **Leprosy Diagnostic**, HKNS, New Delhi (paper back) Rs. 10/-, (Hard bound) Rs. 15/-
16. **Text Book of Leprosy for Students and PMWs** by Dr. R.H. Thangaraj, Philadelphia Leprosy Hospital, Salur, Dist. Srikakulam A.P. Rs. 37/-
17. **Physical Therapy in Leprosy for Paramedicals** by Ellen Davis Kelly, Ph.D.; American Leprosy Mission 1262 Broad Street, Bloom Field, New Jersey 07003 USA
18. **The book of outlines** by Shri. S. Hassan, Hind Kusht Nivaran Sangh AP Branch, 3-4-760, Barkatpura, Hyderabad, 500 027

19. **Handbook on Leprosy** by Shri M.K. Balakrishna Menon, Ernakulam District Leprosy Welfare Committee, Tripunitura 682 301 Dist. Ernakulam, Kerala, Rs. 10/-
20. **Essentials of Leprosy**, Edited by JMH Pearson & AW Wheate, All Africa Leprosy & Rehabilitation Training Centre (ALERT) Addis Ababa, Ethiopia, 3rd Edition, 1979.
21. **A Guide to Health Education in Leprosy** by P.J. Neville, ALERT 3rd Edition, 1979
22. **A Practical Guide to the Diagnosis & Treatment of Leprosy in the Basic Health unit**, by A.W. Wheate & JMH Pearson, ALERT, 1979.
23. **A Food-wear Mannual for Leprosy Control Programmes Part I**, P.J. Neville, ALERT, 1977, 1st Edition.
24. **Gandhi Looks at leprosy**: Rs. 5/- 1971; Gandhi Memorial Leprosy Foundation, Hindinagar Wardha, 442 103 Maharashtra
25. **Teaching Guide for PMWs in Leprosy Vol, I & II** by Dr. D.S. Choudhury, GRECALTES, 35/1/A, Old Ballygunje, 1st lane, Calcutta 700 019

JOURNALS IN LEPROSY

1. **Indian Journal of Dermatology Venerology & Leprology.** 7, Shahayog Opp. Dinbhai Tower, Lal Darwaja, Ahmedabad 380 001 Rs. 20/-
2. **International Journal of Leprosy,** one Broadway, Elmwood Park, N.J. 07407, USA.
3. **Leprosy Review,** Fairfax House, Causton Road, Colchester, CO1IPU, England, 10.50 Pounds.
4. **Indian Journal of Leprosy,** Hind Kusht Nivaran Sangh, 1 Red Cross Road, New Delhi 110 001 Rs. 40/-.
5. **Partner,** Leprosy Mission, Health Education Centre, Naini, Allahabad UP, 211 008.
6. **The Star,** Box 325, Carville, La, 70721 USA, 1 Dollar.
7. **NLO Bulletin,** National Leprosy Organisation, India Hindinagar, Wardha, Maharashtra; 442 103, for members Free, For institutional non-members Rs. 20/-.
8. **Kusht Vinashak,** HKNS, New Delhi, Rs. 5/-.
9. **Joint Action,** Post Box No. 7457 Bombay, 400 060, Rs. 5 for 3 yrs.
10. **Relief,** Hansen Memorial Relief Organisation, Narasarao pet, 522 601, Dist. Guntur, AP, Supplied free to members.
11. **Kusht Seva** Gujrath Raktapitta Nivaran Seva Sangh, 2nd floor, Kamaikunj, Gandhi Gate Road, Vadodara 390 017.
12. **Snehadeepthi,** The Ernakulam District Leprosy Welfare Committee, General Hospital, Tripunithura, 682 301 (Kerala) Rs. 12/-.

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Out-turn : Till July '86, Leprosy patients recorded 18,649 & cured 5,442, rehabilited 2,362 leprosy patients through Re-constructive Surgical Hospital, MADHUPUR, after surgical correction of deformities etc.

Leprosy Eradication Programme through MULTI DRUG REGIMEN PROJECT is continuing in 10 lac population since 30th Jan. 85.

2. Other Health Services:

(i) Maternity Hospital	one
(ii) T.B. Cure Centre	two
(iii) Ayurvedic Charitable Dispensary	four
(iv) Nature Cure Research Hospital	one

3. Educational

(i) Development of Santhali Language & Literature.
(ii) High School : Three & Middle School : Four
(iii) Harijan & Adivasi Hostel : four

4.Other Activities

(i) Rehabilitation Training Centre for Handicapped Children: One
(ii) Krishi Vigyan Kendra: One
(iii) Paharia Kalyan Kendra, Chandna : One
(iv) Integrated Rural Development Work: One
(v) Khadi Gramodyog Work.

Budget for the year 1986-87 : Rs. 56,05, 800/-.

General Secretary : Shri Gauri Shankar Dalmia.

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2. Window on Leprosy	Rs. 75.00 ✓
3. Society and Leprosy	Rs. 30.00 ✓
4. Gandhi Looks at Leprosy	Rs. 5.00 ✓
5. Hints on Diagnosis and Treatment of Leprosy	Rs. 7.00 ✓
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LEPROSY

HOW THEY LOOK AT IT

Mahatma Gandhi

- ☐ Leprosy work is not merely medical relief, it is transforming frustration in life into the joy of dedication, personal ambition into selfless service
- ☐ Why should there be a stigma about leprosy any more than about any other disease?
- ☐ Leper is a word of bad odour, India is perhaps a home of lepers next only to Central Africa. Yet they are as much a part of society as the tallest among us. But the tall absorb our attention though they are least in need of it. The lot of the lepers who are much in need of attention is studied neglect. I am tempted to call it heartless which it certainly is in terms of non-violence. If we were all in earnest about winning independence through quickest manner by truthful and non-violent means there would not be a leper or beggar in India uncared for.

Dr. R.V. Wardekar

- ☐ Within limits of normality, every individual loves himself. In case where he has a deformity or abnormality or developes later, his own aesthetic sense revolts and he develops a sort of disgust towards himself. Though with time, he becomes reconciled to his deformities, it is only at the conscious level. His subconscious mind which continues to bear the mark of injury brings about certain changes in his whole personality making him suspicious of society
- ☐ In changing our attitude towards leprosy patients we will not be obliging anybody—we will be doing it only to make the environment safe for us.

Indira Gandhi

- ☐ A major obstacle is the general public ignorance and superstition regarding leprosy. People tend to evade ivestigation and hesitate to admit to the disease at the early stages when a cure could be complete and easier. This sense of shame is out-dated and dangerous.

(WHO Assembly, Geneva; May 1981)

Giani Zail Singh

- ☐ We must understand that a patient of leprosy is a MAN first and a patient later... We cannot afford to have over 35 lakhs of our citizens out of the National mainstream, they are part of us and we have to accept them back in our fold.

How to celebrate

Anti-Leprosy Week

Leprosy Day in our country was being observed on 30th January every year till 1968. From 1969, the Gandhi Centenary year, the NLO made attempts for observance of a week instead of a day. The Central Government too issued instructions to States for observance of Leprosy Week, in 1974.

Leprosy workers and institutions can undertake target oriented work in the Week. Stress should be on intensive health education. Following are some of the activities suggested for Anti-Leprosy Week.

1. Intensification of health education by holding two meetings per worker per day.
2. Arranging seminars/symposia on any aspect of leprosy, separately for medical men, teachers and other groups.
3. Seminar/panel discussion for medical men only.
4. Arranging exhibition on leprosy.
5. Persuading every irregular patient to take treatment regularly.
6. Attempt to register every unregistered patient, lepromatus patients in particular.
7. Examination of school-going children.
8. Sale/distribution of literature on leprosy.
9. Film show on leprosy.
10. Sale of leprosy seals through service organisations and students.

---

f. Re-entry:

N N?L L Total

i) Total PL in the ara
ii) No. of re-entries

Age, Sex classification of the total cases:

Sex	Age Group	Type N	Type N?L	Type L	Presence of deformity: Upper Limb	Presence of deformity: Lower Limb	Presence of deformity: Face	Presence of deformity: Absent	Total	Presence of Ulcer: Present	Presence of Ulcer: Absent	Total
Male	0-15											
	16-30											
	31-45											
	46 and above											
Female	0-15											
	16-30											
	31-45											
	46 and above											

III. A) Detections:

N N?L L Total

a) P.L.
b) Dead
c) Untraceable
d) Double entry
e) Wrong diagnosis

B) Cured patients:

N N?L L Total

a) S.H.
b) LRD
c) Inactive under observation

IV. Total active cases (Total cases *minus* PL, LRD, SH, Untraceable, double entry, wrong diagnosis) from the *Project Area Only:*

N N?L L Total

V. Regularity of treatment:

N N?L L Total

i) Regular for 75% and above of total weeks
ii) Regular for 50-74% of total weeks
iii) Regular for 25-49% of total weeks
iv) Regular for below 25% of total weeks

VI. Bacteriological Examination:

N N?L L Total

1. Total No. of cases in the project area:
2. Total No. of patients for whom smear has not been taken:
3. Total No. of patients for whom smear has been taken only *once;*
4. Total No. of patients for whom smear has been taken *twice;*
5. Total No. of patients for whom smear has been taken *three times:*
6. Total No. of patients for whom smear has been taken *four times:*
7. Total No. of patients for whom smear has been taken for more than four times:
8. Total positive cases:

VII. 1. Deformity among total patients from the project area:

	N	N?L	L	Total
No. of patients with deformity				
No. of patients without deformity				
Total				

2. Deformity among patients from the outside project area:

	N	N?L	L	Total
i) with deformity				
ii) without deformity				
Total				

Signature

Appendix 'D'

OLD MDT DISTRICTS PROPOSED FOR INTEGRATION WITH GENERAL HEALTH CARE

Districts	*State*
1. Srikakulam	Andhra Pradesh
2. Vijayanagram	Andhra Pradesh
3. Baroda	Gujarat
4. Belgaum	Karnataka
5. Dharwad	Karnataka
6. Amravati	Maharashtra
7. Wardha	Maharashtra
8. Ganjam	Orissa
9. Ambedekar District	Tamil Nadu
10. T.S. District	Tamil Nadu
11. Purulia	West Bengal

Appendix 'E'

LIST OF DISTRICTS COVERED UNDER MDT SCHEME (REGULAR PATTERN)

Districts	*State*
1. Anantapur	Andhra Pradesh
2. Guntur	
3. Rangareddy	
4. Mahaboobnagar	
5. Nizamabad	
6. Khammam	
7. Vishakhapatnam	
8. Chittor	
9. East Godavari	
10. Krishna	
11. Warangal	
12. Nalgonda	
13. Cuddapah	
14. West Godavari	
15. Karimnagar	
16. Medak	
17. Nellore	
18. Kurnool	
19. Prakasam	
20. Adilabad	
21. Hyderabad	
22. Karbi-anglong (PO Diphu)	Assam
23. Deogarh	Bihar
24. Singhum	
25. Bhagalpur	
26. Rohtas	
27. Dangs	Gujarat

28. Panchmahal (Godhra)	
29. Surat	
30. Bharuch	
31. Valsad	
32. Bidar	Karnataka
33. Gulbarga	
34. Raichur	
35. Bijapur	
36. Bellary	
37. Mysore	
38. Alleppey	Kerala
39. Trichur	
40. Trivandrum	
41. Quilen	
42. Palghat	
43. Durg	Madhya Pradesh
44. Rajnandgaon	
45. Raigarh	
46. Bilaspur	
47. Bastar	
48. Raipur	
49. Bhind	
50. Gwalior	
51. Rewa	
52. Ujjain	
53. Sagar	
	Maharashtra
54. Chandrapur	
55. Nanded	
56. Usmanabad	
57. Yavatmal	
58. Latur	
59. Gadchiroli	

60.	Bhandara	
61.	Nagpur	
62.	Thane	
63.	Solapur	
64.	Satara	
65.	Parbhani	
66.	Raigad	
67.	Akola	
68.	Buldana	
69.	Beed	
70.	Bombay	
71.	Mon	Nagaland
72.	Puri	Orissa
73.	Cuttack	
74.	Dhenkanal	
75.	Mayurbhanj	
76.	Balasore	
77.	Sambalpur	
78.	Bolangir	
79.	Koraput	
80.	Chingalpattu	Tamil Nadu
81.	Salem	
82.	P.M.R. Sivaganga	
83.	Kamarajar	
84.	Ramnathapuram	
85.	Dharampuri	
86.	Thanjavur	
87.	Periyar	
88.	Q.E.M. Dindigul	
89.	Madurai	
90.	South Arcot	
91.	Puddukottai	
92.	Tirchirapalli	
93.	Nellai Kata Bomman	

94.	V.O. Chidambarnar	
95.	Coimbotore	
96.	Nilgiris	
97.	Kanyakumari	
98.	Madras	
99.	Varanasi	Uttar Pradesh
100.	Barabanki	
101.	Dehra Dun	
102.	Faizabad	
103.	Sitapur	
104.	Kheri	
105.	Kanpur (Urban)	
106.	Kanpur (Dehat)	
107.	Uttar Kashi	
108.	Pilibhit	
109.	Bahraich	
110.	Deoria	
111.	Hardoi	
112.	Raebareilly	
113.	Azamgarh	
114.	Ballia	
115.	Gazipur	
116.	Mirzapur	
117.	Bankura	West Bengal
118.	Burdwan	
119.	Midnapore	
120.	Birbhum	
121.	Lakshadweep	Lakshadweep
122.	Pondicherry	Pondicherry
123.	Karaikal	
124.	Yanam	
125.	Bishnupur	Manipur

Appendix 'F'

DISTRICTS COVERED UNDER MODIFIED MDT SCHEME

	Districts	*State*
1.	Tirap	Arunachal Pradesh
2.	West Sian	
3.	East Siang	
4.	Towang	
5.	Dhanbad	Bihar
6.	Siwan	
7.	Patna	
8.	Aurangabad	
9.	Nawadah	
10.	Bhojpur	
11.	Purnia	
12.	Katihar	
13.	Muzaffarpur	
14.	Sitamarhi	
15.	Darbhanga	
16.	West Champaran	
17.	S. Parganas	
18.	Kasargoda	Kerala
19.	Ernakulam	
20.	Cannannore	
21.	Malapuram	
22.	Kozhikode	
23.	Bhopal	Madhya Pradesh
24.	Indore	
25.	Khandwa	
26.	Satna	
27.	Datia	
28.	Tikamgarh	
29.	Chhatapur	
30.	Jabalpur	
31.	Balaghat	

32.	Shahdol	
33.	Surguja	
34.	Tamonglug	Manipur
35.	Chandel	
36.	Phulbani	Orissa
37.	Sundergarh	
38.	Kalahandi	
39.	Keonjhar	
40.	Andaman	A & N Islands
41.	East District	Sikkim
42.	South District	
43.	Gorakhpur	Uttar Pradesh
44.	Lucknow	
45.	Unnao	
46.	Rampur	
47.	Badaun	
48.	Shahjahanpur	
49.	Etawah	
50.	Fatehpur	
51.	Banda	
52.	Hamirpur	
53.	Jalaun	
54.	Basti	
55.	Gonda	
56.	Bareilly	
57.	Cooch Bihar	West Bengal
58.	Howrah	
59.	Hooghly	
60.	Jalpaiguri	
61.	Malda	
62.	24 Parganas (S)	
63.	Nadia	
64.	24 Parganas (N)	
65.	W Dinajpur	
66.	Murshidabad	

Appendix 'G'

DIRECTORATE GENERAL OF HEALTH SERVICES
LEPROSY DIVISION

NATIONAL CONFERENCE OF VOLUNTARY ORGANISATION INVOLVED IN NLEP - BOMBAY, 21-22 SEPT. 1991

MODERATELY ENDEMIC 77 DISTRICTS (PR - 2 - 5/'000)

Sl. No.	*Districts*	*State*	*Population (in lakhs) 1981*	*Estmiated PR/000 1981*
1.	Gaya	Bihar	31.38	4.8
2.	Hazari Bagh	Bihar	21.95	4.5
3.	Giridih	Bihar	17.13	4.4
4.	Ranchi	Bihar	30.59	3.1
5.	Monghyr	Bihar	33.14	3.6
6.	Begusarai	Bihar	14.56	4.7
7.	East Champaran	Bihar	24.27	3.1
8.	Madhubani	Bihar	23.24	4.8
9.	Samstipur	Bihar	21.16	4.3
10.	Nalanda	Bihar	16.38	2.9
11.	Palamu	Bihar	19.16	2.6
12.	Saharsa	Bihar	29.52	2.2
13.	Saran	Bihar	20.74	2.3
14.	Gopalganj	Bihar	13.61	2.8
15.	Daman	Daman & Diu	0.48	4.1
16.	Bangalore (U)	Karnataka	34.92	3.1
17.	Kolar	Karnataka	19.05	3.7
18.	Mandya	Karnataka	14.18	3.8
19.	D. Kannada	Karnataka	23.36	2.8
20.	Pathanammthita	Kerala	10.76	3.3

21.	Kottayam	Kerala	16.97	3.3
22.	Idukki	Kerala	9.71	3.1
23.	Wynad	Kerala	0.55	3.0
24.	Hoshangabad	Madhya Pradesh	10.03	3.6
25.	Ratlam	Madhya Pradesh	7.82	4.6
26.	Dhar	Madhya Pradesh	10.57	3.8
27.	Jhabua	Madhya Pradesh	7.95	3.2
28.	Barwani	Madhya Pradesh	16.13	4.0
29.	Guna	Madhya Pradesh	10.01	3.2
30.	Damoh	Madhya Pradesh	7.21	4.3
31.	Chhindwara	Madhya Pradesh	12.33	4.3
32.	Mandla	Madhya Pradesh	10.37	3.8
33.	Sidhi	Madhya Pradesh	9.90	4.2
34.	Betul	Madhya Pradesh	9.25	2.7
35.	Rajgarh	Madhya Pradesh	8.01	2.7
36.	Dewas	Madhya Pradesh	7.95	2.3
37.	Shajpur	Madhya Pradesh	8.40	2.3
38.	Shivpuri	Madhya Pradesh	8.65	2.7
39.	Morena	Madhya Pradesh	13.03	2.0
40.	Seoni	Madhya Pradesh	8.09	2.1
41.	Panna	Madhya Pradesh	5.39	2.9
42.	Narsingpur	Madhya Pradesh	6.50	2.1
43.	Jalna	Maharashtra	11.85	3.4
44.	Jalgaon	Maharashtra	30.04	4.1
45.	Kolhapur	Maharashtra	28.08	3.4
46.	Sangli	Maharashtra	20.59	4.0
47.	Ratnagiri	Maharashtra	14.54	2.2
48.	Dhule	Maharashtra	23.53	2.6
49.	Ahmed Nagar	Maharashtra	30.51	2.8
50.	Pune	Maharashtra	49.49	2.2
51.	Aurangabad	Maharashtra	18.23	2.8
52.	Farrukabad	Uttar Pradesh	20.02	2.8
53.	Jhansi	Uttar Pradesh	11.33	3.2
54.	Pratapgarh	Uttar Pradesh	18.07	3.3
55.	Sultanpur	Uttar Pradesh	20.38	3.6

56.	Chamoli	Uttar Pradesh	3.64	3.2
57.	Nanital	Uttar Pradesh	11.23	3.2
58.	Moradabad	Uttar Pradesh	31.51	4.2
59.	Jaunpur	Uttar Pradesh	25.27	4.1
60.	Aligarh	Uttar Pradesh	25.65	2.1
61.	Allahabad	Uttar Pradesh	37.81	2.7
62.	Lalitpur	Uttar Pradesh	5.7	2.6
63.	Tehri Garwal	Uttar Pradesh	4.99	2.9
64.	Pithoragarh	Uttar Pradesh	4.80	2.7
65.	Calcutta	West Bengal	42.56	4.0
66.	Darjeeling	West Bengal	11.49	4.0
67.	Chamba	Himachal Pradesh	3.11	2.7
68.	Shimla	Himachal Pradesh	5.10	2.0
69.	Sirmur	Himachal Pradesh	3.06	2.6
70.	Ajmer	Rajasthan	14.40	2.5
71.	Bharatpur	Rajasthan	12.99	2.6
72.	Ganga Nagar	Rajasthan	20.29	2.5
73.	Jaipur	Rajasthan	34.20	2.0
74.	Jodhpur	Rajasthan	16.67	2.0
75.	S. Madhopur	Rajasthan	15.35	2.7
76.	Sirohi	Rajasthan	5.42	2.2
77.	Udaipur	Rajasthan	3.56	2.4

Appendix 'H'

NATIONAL COMMISSION FOR ERADICATION OF LEPROSY

1. **Chairman** — Prime Minister
2. **Vice-Chairman** — Union Minister of Health and Family Welfare

Members:

3. Union Minister of Finance
4. Union Minister of Planning
5. Union Minister of Education & Social Welfare
6. Five Chief Ministers of States in rotation
7. Eight Eminent leprologists, social workers and others engaged in leprosy control and "Health for All" programmes
8. Chairman of the proposed National Consortium of voluntary organisations engaged in leprosy control work

Appendix 'I'

NATIONAL LEPROSY ERADICATION BOARD

1. Expenditure Secretary
2. Director General of Health Services
3. Director General, Indian Council of Medical Research
4. Secretary, Social Welfare Department
5. Secretary, Information & Broadcasting Ministry
6. Adviser (Health), Planning Commission
7. Member of Research & Development (whole-time)
8. Member for Implementation, Monitoring and Evaluation (whole-time)
9. Member for Public Participation, Mass Media Mobilisation and Health Education (whole-time).

AN HISTORICAL REVIEW OF ANTI LEPROSY WORK IN INDIA

Early 19th Century	..	First Leprosy Asylum in (a) Calcutta (b) Varanasi
1873	..	Hansen discovered Mycobacterium leprae at Bergen, in Norway
1874	..	The Leprosy Mission founded by a dedicated Irishman, Mr. W.C. Bailey
1875	..	Mission to Lepers at Chamba (Punjab)
1919	..	Mitsuda introduced the lepromin test
1925	..	British Empire Leprosy Relief Association
1941	..	First official commitee for assessing the leprosy problem in India appointed by Central Board of Health

1946	..	Cochrane first used dapsone in oily suspension intramuscularly for the treatment of leprosy in India
1947	..	The above renamed as Hindu Kusht Nivaran Sangh
1951	..	Organised efforts of Leprosy control in NGO sector by GMLF The Gandhi Memorial Leprosy Foundation started at Wardha, in India
1951-52	..	Dapsone introduced in Leprosy Control
1954-55	..	Leprosy Control Programme started
1955-61	..	Leprosy Subsidiary Centres
1960	..	Shepard first reported that Leprosy bacillus may multiply to a limited extent in the mouse footpad
1963	..	Review by Director NLCP; Reorganisation of programme into LCU and SET
1964	..	Pettit and Rees first reported on secondary dapsone resistance in Malaysia, proven by the mouse footpad method.
1968	..	Rimactane (firampicin) introduced by CIBA Limited, Basle, Switzerland
1969	..	Lamprene introduced by J.R. Geigy Limited, Basle, Switzerland NLCP - 100% Centrally sponsored
1970	..	Assessment of NLCP by ICMR
1971	..	Krichheimer and Storrs reported a disseminated experimental M. Leprae infection int he ninebanded armadillo
1974	..	Waters et al. first reported that drug-sensitive M. Leprae is capable

		of persisting in spite of continuous dapsone therapy ULCs, THWs, RSU, DLO, Regional Leprosy Training Centres
1980	..	Rehabilitative Promotion Units, SSAUs, Epidemiological Survey Units
1981	..	Call by Mrs. Gandhi for eradication of
(May-June)		Leprosy from India by 2000 AD at World Health Assembly and Jt. Conference of Central Councils of Health and Family Welfare
(Nov.)	..	Mrs. Gandhi's call to Leprologists and Social Workers
1982	..	Warndorff-van diepen reported the first case of possible clofazimine - resistant Leprosy Revised Twenty-point programme of Mrs. Indira Gandhi. Swaminathan Committee
1981-83	..	Relaunching of the programme as NLEP
1983	..	MDT Programme started
1986	..	First Independent Joint Evaluation by government of India and WHO
1987	..	Second Independent Joint Evaluation by government of India and WHO
1989	..	Third Independent Joint Evaluation by government of India and WHO
1990	..	Critical Review by DGH

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Chapter 13

SUMMARY

National Leprosy Control Programme is in the form of a complex system. This system consists of a large number of components which are in complex interaction with one another. The epidemiological characteristics of the disease, the social, cultural, economic and geographic background of the population, the nature of technology adopted for diagnosis and treatment of leprosy patients within the population, the organisational structure and the various logistical considerations are examples of some of the major components which give shape to the complex interacting system of the National Leprosy Control Programme. An effort has been made to study the programme in its complex multi-disciplinary dimensions. These interactions have been studied simultaneously. This approach has been termed as systems approach. This approach has provided insights into the working of the National Leprosy Control Programme for enabling development of an alternative programme which is viable, nationally applicable, socially acceptable and epidemiologically effective.

Leprosy Control Programme in the rural populations in Chingleput district was studied in its multi-faceted dimensions. This district has a high prevalence of leprosy. Compared to other districts this district has much better organisational, personnel and equipment inputs for dealing with leprosy problem. The district also has the above average inputs since a considerable time.

Data on epidemiological component, organisational and management component, and components formed by the patients and the community were required to be collected for studying the functioning of the programme. These

components were studied in depth by adopting different techniques like interviewing the key personnel at the different levels in the programme, obtaining data from the all possible secondary sources including perusal of official records, documents and by participation in various meetings and conferences. Additional epidemiological information from the district as a whole was obtained directly by the investigator from the various sub-centres through a circulated proforma. Some data regarding the epidemiological characteristics were obtained directly by the investigator from the patients and from the records maintained by the workers. The information about the organisation and functioning of the programme was obtained by informal interview of the different categories of functionaries and by a perusal of the records and registers maintained by them as well as scrutiny of the reports and diaries submitted by them to their higher authorities. The information furnished by various categories of workers were cross-checked with their supervisors and vice-versa.

For the more detailed data collection, Tambaram leprosy control unit was purposely selected because it had better performance figures than others. As it was not possible to study all the twenty sub-centres of this unit, the sub-centres at Kelambakkam and Tirupporur were purposely selected because these sub-centres were away from urban areas. The SET centre at Ponneri was selected because it happened to be the only government run SET centre. The SET centre at Madarpakkam run by Christian missionaries was selected purposely because it covered rural populations. For each of the two sub-centres of Tambaram control unit and the SET centres, at Ponneri and Madarpakkam, the headquarters village, two villages within 2 to 5 kms. from the headquarters and two villages within 7 to 10 kms. from the headquarters were included for the study of the patients. Thus in all, patients in 20 villages were studied. One of the two villages in either category belonged to the epidemiological survey areas.

While the other two belonged to the non-epidemiological survey areas. In all, 590 patients were studied in the 20 selected villages with the help of a schedule. The data collected included the nature and duration of the disease, patients' response to the organisation, and the social interaction of the community. Clinical and laboratory data were obtained through a check list.

The community perception of and the attitudes towards the disease were studied in 6 villages by administering a schedule to 20 percent systematic random sample of the households in those villages. The headquarters villages of the Kelambakkam sub-centre, and Ponneri and Madarpakkam SET centres and one most distant village in each of the three areas comprised the six villages for the community study.

The main findings of this study have been summarised in the previous chapter where they have been used to formulate an alternative perspective for dealing with leprosy as a community health problem in India.

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Chapter 12

AN OVER VIEW OF THE IMPACT OF TEN YEARS OF LEPROSY ERADICATION WORK IN INDIA

Reduction of prevalence

As has already been commented upon, the prevalence has been reduced by large scale removal of erstwhile leprosy 'cases'. No authentic data is available regarding the relapses rate in the programme. to my knowledge the claim of the success of MDT programme appears superficial and unwarranted at this stage. It is worth reiteration that most of the existing cases have been on various stages of treatment with Dapsone mono-therapy and most of them have been removed from the rolls. Moreover the impact of self healing processes which have been estimated at 75% to 85% of the total pauci-bacillary problem have not been given credit to. Attributing the reduction of prevalence to a mere combination of drugs does not appear to have a scientific base. Any effectivity of the particular strategy can only be measured by new case detections which is a positive index of a break in the chain of transmission. It can be argued that same or better results could have been achieved if the Dapsone monotherapy was followed up with same vigour in monitoring.

The next important question is about the drug regimen itself. When a more easily amenable bacillus immersed in hyperaemic conditions in the lung (M. tuberculosis) requires a continuous daily dose of Rifampicin for six months, a bacillus more chronic in nature difficult to culture and which is supposed to be travelling along peri-neural lymphatics (which areas are least vascular) cannot be expected to be killed with an exposure of "potent bactericidal" drugs once a

month i.e. a total of 3600 mg. of Rifampicin in P. bacillary cases over a six months period (in 6 once monthly pulses) and 14.400 mg. for M. bacillary cases (in 24 once monthly pulses) is rediculous and catastrophic indeed - as we may soon land up with rifampicin resistant M. Leprae.

Even this truncated methodology is not being constantly pursued. For MB cases in higher endemic areas an initial intensive phase of 14 days daily Rifampicin administration has been advocated. This strategy has not been followed for (a) P.B. cases (b) in modified MDT districts (66) where endemicity is estimated to be high but no adequate infrastructure is available. (c) in low endemic districts (77). How can anybody presume that Leprosy can be treated with different strategies at different places, due to the whims and fancies of the Leprologists. The decision on this truncated regimen and inadequate exposure to the high 'potency' drugs seems to be 'economical' rather than technical or organisational. Where is the scientific basis, tested in field conditions, which will justify the efficacy of a particular regimen with special reference to the dissolution of the lesions and the arrest of the further progress of the disease?

The next important question is the reliability of the surveys themselves. Most of the field surveys tend to be inadequate both in the matter of quantity and quality. Qualitatively speaking the inadequacy of the para medical workers/leprosy inspections in examining the different parts of the body is well known. In a tradition bound society there are limitations to the exposure of the body, especially among the females, even if the workers tend to be sincere in their work. Quantitatively more often than not the data is provided without actually conducting the work consequent to the target oriented time bound approaches.

Epidemiological issues

There are several epidemiological issues in leprosy eradi-

cation work. Knowledge regarding the size, extent and distribution of the leprosy problems in the country is still inadequate. Apart from the prevalence rates being unreliable there is no authentic data regarding incidence rate. In chronic diseases like leprosy the incidence is difficult to calculate especially when the time of the origin of the patch cannot be reliably estimated. In a milieu where the portals of entry and exit of the bacilli are not known and in a scenario where the multiplication of bacillus is slow, incubation period not very well known, claims of success of the leprosy eradication strategy certainly tends to be unscientific. The immunological deficits in the host contributing to the occurrence of different types of leprosy have still not been explained scientifically. Moreover the phenomena of over-diagnosis of leprosy and the processes of self-healing raise very vital questions regarding the epidemiology of the disease.

There are a number of technical areas apart from the already mentioned bacteriological and immunological issues. The production of anti-leprotic drugs still is brimming with problems of procurement and supply.

There is no reliable data on the quality control of drugs periodically. The phenomenon of resistance in PB and MB cases to the drugs exposed has also to be studied systematically.

As regards research, the following paragraphs from the NLEP document[11] highlight the state of research in leprosy in India. There is an urgent need for conducting research into various epidemiological issues concerning leprosy and leprosy control leave alone eradication claims of pre-mature success of the programme and attributing the same to the MDT regimen will not take us anywhere.

"For over a hundred years Mycobacterium leprae has defied the attempts by scientists in making conclusive breakthroughs our knowledge base in many areas is inadequate and major break-throughs are yet to be made.

The natural-history of myco-bacterium leprae infection and the epidemiology of leprosy is still not clearly understood. Till recently there were no tests that could help monitor sub-clinical infection and thus the spread of M. leprae infection in the community. Recently available tests are opening up new horizons our understanding of sub-clinical infection.

Emphasis is being put on tests that are simple to execute and easy to standardise. The government of India has been introducing these tests in selected research institutions in the country for evaluation.

Leprosy is the only bacterial disease that causes peripheral nerve damage. The exact mechanism of nerve damage has not been properly worked out. Since deformity secondary to neuropathy is a major problem in 20-25% of patients with leprosy, efforts are being made to pursue studies which provide insight to the patho-physiology of neuropathy in leprosy.

Vaccine trials have been started in India and throughout the world. The outcome of these carefully planned, epidemiologically well characterised field vaccine trials, over the next five years, will enable us to decide on a strategy for eradication of leprosy based on vaccination. There is cause for optimism that an effective vaccine will be available soon.

The government of India recognises the lacunae in this country in leprosy research. It is identifying institutions and encouraging Indian scientists abroad to come forward to meet the challenges of research in leprosy. The Central Leprosy Teaching and Research Institute, Chengalpattu (Tamil Nadu), Central JALMA Institute for Leprosy, Agra and the Regional Leprosy Training Institute (RLTI), Aska in Orissa are the central government institutes for leprosy training and research, set-up at the beginning of the 6th plan. The 6th plan proposals, included the establishment of six regional institutes for research services and field studies. Two such institutes have already been established at Raipur in Madhya

Pradesh and at Gauripur (West Bengal). There are proposals with the Ministry of Health and Family Welfare for establishing institutes at Tetulmari (Bihar) and Magadi Road (Karnakata) where leprosy hospitals with field units are functioning under the concerned state governments. Much of leprosy research is virgin territory and the potential for research is immense.

Administrative

As already stated there are a number of man-power, training, supervisory, management and evaluation issues apart from financing with require urgent attention to make any appreciable dent in the leprosy problem.

Legal consideration in leprosy

The Lepers Act, 1898 has been repealed by the Government of India in respect of U.Ts. without legislatures. All states excepting Bihar and Punjab have repealed the Act.

Legal Aspects of Leprosy

The various marriage acts need to be amended suitably in the light of modern concepts of leprosy.

(a) Indian Christian Marriage Act of 1872, Sec. 13 (IV)
(b) Muslims Marriage Act of 1939 Sec. 2 (VI)
(c) Hindu Special Marriage Act of 1954, Sec. 27.
(d) Hindu Marriage Act of 1956, Sec. 10 and Sec. 13.

Under these acts, divorce is granted on the grounds of leprosy.

According to Dr. V.V. Dongre,[112]

"Surprisingly the Parsi Marriage Act of 1936 does not allow divorce on the grounds of leprosy.

— The Motor vehicle Act of 1939 second schedule, sec. (7) 5 needs rectification as only 25% of leprosy patients have sensory loss of the limbs. Hence the majority of the leprosy patients, nearly 75% should be considered as fit to get driving licences if they so want.
— Often we read in the Press that leprosy patients are not allowed to contest in elections like the imbeciles and idiots. This discrimination strengthens social stigma. The election rules should be appropriately changed in the light of modern concepts of leprosy.
— The Life Insurance premium rates were higher for leprosy patients. Recently the rules are modified but not quite satisfactorily. There is still a scope for the modifications of LIC rules for leprosy patients.
— The existing rules about certification of leprosy patients for fitness to continue in jobs must be modified as per the recommendations made by the expert groups from central Jalma Institute for leprosy. This issue is pending for a long time.
— All travel restrictions on leprosy patients by any mode of public transport should be totally removed.
— A person detained under the prevention of begging act of 1959, if found to be a leprosy patient is not discharged after the completion of term of detention.
— Under the various local accommodation acts, leprosy patients are thrown out by owners from their places of residence. Such acts are derogatory and must be suitably rescinded.
— It is also found that the children having leprosy or healthy children of leprosy patients do not get easy admission to the schools. They therefore, are likely to become outcasts of the society. If they attend a school run by a Leprosy Institution, they face a problem in training for a vacation

because of the address given on the School Leaving Certificate.

— If there are no separate acts for typhoid or for tuberculosis, why should there by a separate act for leprosy.

— Therefore it is urged that all the leprosy institutions should make concerted efforts to do away with the outdated legislation pertaining to leprosy patients."

Independent WHO/GOI Evaluation of NLEP

So far three independent evaluations were conducted jointly by and independent team consisting of WHO/government of India officials in the years 1986, 1989 and 1990.

The following is the summary of all the three evaluations:

Survey

The quality of survey is poor in the urban areas. The school survey was uniformly poor in most of the states. The evaluation also noted gross under-estimation of cases in some States like Madhya Pradesh and Uttar Pradesh.

Sample Survey and Assessment Units (SSAU)

The evaluations noted uniformly poor quality in the functioning of SSAU.

TABLE 137
STAFF STATUS OF SSAU[112]

Location of Unit	*Staff sanctioned*	*Positions vacant*	*Persons trained*
Pune	8	Nil	8(100%)
Hyderabad	8	1 (12.5%)	2 (28.5%)
Dharwar	18	4 (26.6%)	7 (63.6%)
Gandhi Nagar	18	5 (27.7%)	7 (53.8%)
Madras	16	Nil	16(100%)

Table 137 gives the staff status of SSAUs brought out by evaluation team at Pune, Hyderabad, Dharwar, Gandhinagar and Madras. The vacancy position excepting at Madras and Pune is bad.

Laboratory Services

The laboratory services have been uniformly poor. The needed equipment is either absent or in short supply. There is no mechanism of checking the findings of laboratory technicians - with the result quality of samear examination leaves much to be desired. 34.2% of the laboratory technician posts were vacant.

Temporary hospitalisation wards, rehabilitation promotion units, reconstructive surgery units

There is a gross under utilisation of facilities at these units with the result most of these are diverted to general surgical purposes. There is also another administrative bottleneck in that the temporary hospitalisation wards and urban leprosy centres are not directly under the control of district leprosy officers.

The vacancy position of physiotherapy technicians is alarming. Only 50% of the posts are filled up. Even among them only 88% are trained for leprosy work.

Staff matters

TABLE 138
VACANCY AND TRAINING STATUS BY CATEGORY OF STAFF[113]

Posts	*Sanctioned*	*Vacant* No.	%	*Trained* No.	%
Zonal/District Leprosy Officer	238	35	(14.7%)	162	(79.8%)
Medical Officer	1076	157	(14.6)	580	(63.3)
Non-Medical Supervisor	3654	628	(17.1)	2018	(64.5)
Paramedical Worker	17683	3345	(18.9)	12138	(84.6)
Lab Technician	1036	355	(34.2)	611	(88.4)
Physiotherapist	616	308	(50.0)	271	(87.9)
Total	24303	4828	(19.9)	15780	(81.0)

The vacancies in staff positions as indicated in table 138 seem to be the result of non-availability of trained man-power and the ban imposed by certain states on staff recruitment.

The status of the District Leprosy Officers and the State Leprosy Officers in some states still continues to be poor.

Training

TABLE 139
THE AVAILABILITY OF TRAINED MANPOWER IN TWENTYFOUR MDT DISTRICT[112]

Post	*Number sanctioned*	*Number vacant*	*In position*	*Number trained*
Medical Officer	115	16 (13.9%)	99	78 (86.6%)
Non-Medical Supervisor	454	36 (7.9%)	418	284 (68.0%)
Health Educator	66	4 (6.0%)	62	2 (3.2%)
Lab. Technician	130	30 (23.0%)	100	83 (83.0%)
Physiotherapist	8	2 (25.0%)	6	6 (100.0%)
Paramedical Workers	2011	252 (12.5%)	1759	1456 (82.7%)

The training status of key programme staff are indicated in table 139. A perusal of this table reveals lack of training of important personnel.

TABLE 140
TRAINING STATUS OF MEDICAL OFFICERS AT DIFFERENT LEVELS OF NLEP[112]

Level		*Trained*	*Not trained*
State	(16)	6	10 (62.5%)
District	(39)	20	19 (48.7%)
ULC	(21)	12	9 (42.8%)
LCU	(76)	50	26 (34.2%)
SETs	(17)	13	4 (23.5%)
Total	169	101	68 (40.2%)

Table 140 gives the training status of medical officers at different levels of NLEP. The training status of medical officers who are to play a key role in case confirmation, monitoring, removals from treatment and control etc. is alarming indeed. Roughly one third of medical staff only are trained at leprosy control unit and SET levels.

It is understood that in some states staff are recruited in anticipation of training.

It is also disturbing to note that the training capacity of Institutes are also not utilised adequately.

TABLE 141
UTILISATION OF TRAINING CAPACITY OF SEVENTEN[112] TRAINING CENTRES

Name of the course	*Annual training capacity*	*Staff trained in the year*	*percent utilisation*
Medical Officer	181	65	35.9%
NMS	325	127	39.0%
PMW	529	378	71.4%

Table 141 gives the details at seventeen training centres.

At most of the training institutes there is a general lack of education materials. There is a poor disbursement of stipends to traineees. There is no organised programme for re-orientation of staff. The programme presumes that staff once trained are fit enough permanently.

Topping the above inadequacies on the training front is the transfer of trained programme staff to do non-leprosy work.

49 Leprosy Training Centres (LTC) established during successive five year plan periods are functioning throughout the country. 14 of these are with voluntary orgtanisations.

The on going training programme and physical facilities available at LTCs have been reviewed by two consultants

during 1986-87. The major recommendations include:

(a) A training Cell should be created at Directorate General of Health Services under Leprosy Division which will be instrumental in specific requisite planning, implementation and follow-up of staffing and thier training needs. The Cell will also have an increasing role in matters of coordination and follow-up action between central, states and non-governmental agencies on various issues pertaining to manpower development.
(b) Orientation training of short duration for the general health care staff should be considered necessary.

Supervision and Monitoring

The quality of supervision and monitoring are very poor. The vehicles meant for leprosy work are diverted by others for different purposes. The available vehicles are in a very bad shape due to poor maintenance.

Treatment

In a massive treatment programme with MDT regimen, there is a poor retrieval of treatment defaulters.

TABLE 142
MONITORING OF DRUG INTAKE BY TABLET COUNT[112]

No. of patients contacted in past three months	*Respondents*	*No. of NMS contacting*
No patient contacted	113	38 (33.6%)
Less than 10	113	8 (7.0%)
10-50	113	33 (29.2%)
50-100	113	15 (13.2%)
More than 100	113	19 (16.8%)

The non-medical supervisors are expected to monitor the regularity of intake of medicines by independent checks. Table 142 gives the details of such checks made by Non-medical supervisors.

Consequent to poor quality of work, no importance is being given in the programme towards identification of relapses and for watching out the development of drug resistance. The whole organisation is geared to reducing the prevalence of the disease by large scale discharge of cases who have completed the prescribed treatment.

Voluntary Organisations

Several voluntary organisations are being given "S.E.T. grants". A number of organisations have eternal complaints regarding non release or irregular and untimely release of grants. Most of the organisations also complain of non-receipt of drugs of specified quantity and specified dosage of the tablets.

Chapter 13

SUMMARY

National Leprosy Control Programme is in the form of a complex system. This system consists of a large number of components which are in complex interaction with one another. The epidemiological characteristics of the disease, the social, cultural, economic and geographic background of the population, the nature of technology adopted for diagnosis and treatment of leprosy patients within the population, the organisational structure and the various logistical considerations are examples of some of the major components which give shape to the complex interacting system of the National Leprosy Control Programme. An effort has been made to study the programme in its complex multi-disciplinary dimensions. These interactions have been studied simultaneously. This approach has been termed as systems approach. This approach has provided insights into the working of the National Leprosy Control Programme for enabling development of an alternative programme which is viable, nationally applicable, socially acceptable and epidemiologically effective.

Leprosy Control Programme in the rural populations in Chingleput district was studied in its multi-faceted dimensions. This district has a high prevalence of leprosy. Compared to other districts this district has much better organisational, personnel and equipment inputs for dealing with leprosy problem. The district also has the above average inputs since a considerable time.

Data on epidemiological component, organisational and management component, and components formed by the patients and the community were required to be collected for studying the functioning of the programme. These

components were studied in depth by adopting different techniques like interviewing the key personnel at the different levels in the programme, obtaining data from the all possible secondary sources including perusal of official records, documents and by participation in various meetings and conferences. Additional epidemiological information from the district as a whole was obtained directly by the investigator from the various sub-centres through a circulated proforma. Some data regarding the epidemiological characteristics were obtained directly by the investigator from the patients and from the records maintained by the workers. The information about the organisation and functioning of the programme was obtained by informal interview of the different categories of functionaries and by a perusal of the records and registers maintained by them as well as scrutiny of the reports and diaries submitted by them to their higher authorities. The information furnished by various categories of workers were cross-checked with their supervisors and vice-versa.

For the more detailed data collection, Tambaram leprosy control unit was purposely selected because it had better performance figures than others. As it was not possible to study all the twenty sub-centres of this unit, the sub-centres at Kelambakkam and Tirupporur were purposely selected because these sub-centres were away from urban areas. The SET centre at Ponneri was selected because it happened to be the only government run SET centre. The SET centre at Madarpakkam run by Christian missionaries was selected purposely because it covered rural populations. For each of the two sub-centres of Tambaram control unit and the SET centres, at Ponneri and Madarpakkam, the headquarters village, two villages within 2 to 5 kms. from the headquarters and two villages within 7 to 10 kms. from the headquarters were included for the study of the patients. Thus in all, patients in 20 villages were studied. One of the two villages in either category belonged to the epidemiological survey areas.

While the other two belonged to the non-epidemiological survey areas. In all, 590 patients were studied in the 20 selected villages with the help of a schedule. The data collected included the nature and duration of the disease, patients' response to the organisation, and the social interaction of the community. Clinical and laboratory data were obtained through a check list.

The community perception of and the attitudes towards the disease were studied in 6 villages by administering a schedule to 20 percent systematic random sample of the households in those villages. The headquarters villages of the Kelambakkam sub-centre, and Ponneri and Madarpakkam SET centres and one most distant village in each of the three areas comprised the six villages for the community study.

The main findings of this study have been summarised in the previous chapter where they have been used to formulate an alternative perspective for dealing with leprosy as a community health problem in India.

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LEPROSY

IN

RURAL INDIA

K.VENKATESWARA RAO

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FOREWORD I

The very ancient scourge of leprosy still remains a major public health problem in India. This is despite the fact that the extensive Leprosy Control Programme (LCP) was started way back in 1954. Indeed, apart from a specific interest of Christian Missionaries in this field, Mahatma Gandhi was also deeply concerned about the problem while he was involved in constructive work in the country as a part of the National Movement. While declining to open a leprosy hospital set up by volunteers, he made the very perceptive comment that he would be very glad to perform the closing ceremony of the hospital after leprosy ceased to be a public health problem. Much later, in 1981 the then Prime Minister Indira Gandhi took a major initiative to mobilise the bureaucracy, leprosy experts and her own Science Advisory Committee and the WHO to draw up a programme for action to "eradicate" leprosy by 2000 AD. While it is understandable that a political leader should have coined such a catchy slogan, identification of some of the foremost leprologists and scientists of the country and of WHO with this slogan is most astonishing. Those even with most elementary understanding of the epidemiology of leprosy in India could have realised that such an expectation is utterly untenable. Unfortunately, such obviously unrealistic claims are also being made by WHO and UNICEF in relation to some other communicable diseases. Tall claims were made by these organisations about the impact of the Universal Child Immunization Programme in 1984, but when the programme ended in 1990, they did not make any epidemiological impact on the problem and, instead, made totally untenable of "success" of UIP on the basis of data obtained from the notoriously unreliable government sources. The WHO programme for global eradication of poliomyelitis follows the same trend (UNICEF 1992).

The prestigious Swaminathan Committee headed by the then Chairman of the Prime Minister's Science Advisory Committee set up in 1982 to draw up a programme for leprosy eradication in India

by 2000 AD also failed to provide leadership. First and foremost, there was so little data base to make any semblance of scientific analysis of the problem. Over and above was the pronounced bend in favour of technocentric issues — immunomodulators to develop a vaccine for leprosy eradication and multi-drug therapy. At the same time it virtually ignored the epidemiological requirement for making an impact on the problem, leaving aside the utopian goal of eradication by 2000 AD. There were also huge gaps in the analysis of the Administrative and social science issues. Only a pronounced lack of understanding of the administrative issues can explain why they asserted "Essentiality of verticality".

Not unexpectedly, the quality of decision making and their data base has been uniform poor since the inception of NLCP. Dr. Rao his repeatedly draw attention to the very substandard quality of the data used in assessing the programme and in formulating the changes. Unfortunately, the same group of leprologists have played a leading role for long intervals in the dicision - making process. This points to a much more serious "stigma" in leprosy work. Leprosy workers have been so preoccupied with the undoubtedly deep - seated stigma against it in the general population that they have forgotten to note that they (i.e. leprosy workers) are stigmatised among health workers and leprosy programmes occupy a "low" position in the choice heirarchy of public health programmes. That perhaps explains why the contributions from leprologists in India have been so disappointing. If for nothing else, Dr. Rao should be commended in bringing a whiff of fresh air in the otherwise stagnant and stereotyped atmosphere in leprosy work in India.

A distinctive feature of Dr. Rao's work is that he has conceptuatised the programme as a complex, interacting system, requiring interdisciplinary inputs. He has examined it as a managerial and a technological process with epidemiological and sociological perspectives. He has developed the methodology for this study on such a broad based conceptual foundation. The research design includes analysis of the managerial process, from the apical level right down to the village level. Technological issues are studied in terms of various diagnostic criteria, therapeutic approaches, deformity prevention and management of deformity, social support and rehabilitation. Predictably, epidemiological analysis has been the sheet-anchor of his study. This has brought out many perspectives which

has hitherto been neglected. Dr. Rao had also recognised that, quite apart from the well publicised issue of stigma against the disease, there are other important sociological and anthropological parameters that are critical to the development of the programme. In the course of data collection for his research Dr. Rao has collected first hand information concerning the nature of interaction among the key elements of the four categories mentioned above. Over and above, using secondary data, he has also attempted to present a picture of the dynamics of the programme as a "system" over a time dimension. He has also updated his research by getting together information concerning the developments that have taken place since he conducted his field work. The observations he has made on these developments fall in one with those that emerge from his primary data and their interpretation and analysis.

By applying system thinking in developing the concepts and the methodology for his research, Dr. Rao has been able to draw attention to a number of facets of the NLCP. He has gone on to use a systems framework to make accurate forecasts concerning advantages and disadvantages of implementing the report of the Swaminathan Committee. The systems approach has also been used by him to call into question some of the key assumption in the strategy for "eradication" of leprosy. Dr. Rao's contention gets strong support from the findings of the Danish Assisted Leprosy Project (DANLEP, 1988) in Rajanandgaon district of Madhya Pradesh. They reported that by actively involving the communities, without even carrying out house-to-house search, it is possible to "discover" a large number of additional cases (as much as 50-150 percent) which were apparently missed by the workers who carried out the surveys in NLEP.

An outstanding finding from Dr. Rao's research, which got strong endorsement from DANLEP, was that there has been considerable flaws and distortions in social science studies of "stigma" against leprosy in the population at large. Dr. Rao's study of the village population, of the families of the victims, and the victims themselves gives a different perspective to the "problem" of stigma. This got strong support from the findings of the studies of DANLEP. Through this research work, Dr. Rao has made a substantial contribution to the development of systems thinking at the Centre of Social Medicine and Community Health of Jawaharlal Nehru University for analysis and development of public health practice in India.

PROF. D. BANERJI

FOREWORD II

I have great pleasure in writing the foreword to this extensive analysis of the Leprosy problem in India. People should realise that Leprosy is curable and should be taken on hand at an early stage. Dr. Rao has provided an extensive data both official and non-official sources. I am not aware of any other book so extensive and complete on Leprosy. I commend this book to everyone interested in the problem of Leprosy and its control which is urgent. It is obvious Dr. Rao has taken enormous efforts to obtain data and to think about the problem.

From the above it is obvious that Dr. R ao has taken very pain to cover all the aspects of the problem of Leprosy in India particularly in the rural areas. He has put in his publication all the materials possible on the subject. Although Dr. Rao has not referred to Dr. Veeraraghavan's culture of Lepra bacillus quicker and has been acknowledge from many Scientists in India and abroad. I commend this book to everyone whether a Leprosy worker or an administrator or a policy maker.

DR. K.S. SANJIVI

PREFACE

Leprosy is a major community health problem in India. It is a devastating disease. It is devastating not only in terms of the degree of damage it causes to an individual, but is also devastating in the sense that the person has to live for decades together with a physically and mentally deplorable life. It also has got a deleterious influence on the family life as well as life within the community.

The estimated case load in the country is 3.2 millions, out of which 20 to 25 per cent are having deformities. This case load forms about one-fifth of the total leprosy problem in the world. Even though the government launched a National Leprosy Control Programme in the year 1954-55, there has been no sociological and epidemiological impact on the problem. The conceptualisation of the programme was not based on any sound scientific methodology applicable and epidemiologically effective solution. The programme did not envisage an inter-disciplinary effort.

The Centre of Social Medicine and Community Health, Jawaharlal Nehru University, under the able and dynamic leadership of Professor Debabar Banerji, has been striving since its inception in 1972 to evolve and implement an inter-disciplinary approach for solving the various community health problems in India. Various scholars of this Centre have accepted the suggestive motivation of Professor Banerji and worked in various fields of community health. when Professor Banerji initiated the discussion on the community health problem posed by leprosy, I took up the challenge to study the problem in its entirety. The systems approach evolved for the study of community health problems by Professor Banerji formed the main frame of the present study.

The Voluntary Health Services, Medical Centre, Madras, under the able leadership of Professor K.S. Sanjivi, gave additional

support to me for accepting the challenge. The M.A. Chidambaram Charities generously came forward with financial assistance for the study. The M.A. Chidambaram Institute of Community Health, located in the Campus of the Voluntary Health Services, Adyar, Madras, under the leadership of Brig. M.A. Ramaswamy provided the encouragement needed all through the study.

Consequent to his perseverance and zeal for solving community health problems in spite of heavy odds, Professor Banerji, amongst his multifarious commitments, gave his valuable time and guidance to me in each and every phase of the study. His interest in the study was so deep that he visited some of the field areas along with me to get a first hand information about the problem of leprosy at the grass-root level. I am greatly indebted to him and to his commitment.

To Professor Sanjivi, I am deeply indebted for the encouragement he has been giving all along my career, which began at the Voluntary Health Services, founded by him.

The members of the faculty of Centre of Social Medicine and Community Health, Jawaharlal Nehru University, Dr.(Mrs) Prabha Ramalingaswami, Dr. Imrana Qadeer, Dr. Santosh Kumar Sahu and Dr. Dipankar Gupta, have all encouraged me throughout my study. I am extremely grateful to them. Dr. Santosh Kumar Sahu, and Dr. Lakhan Singh stood by me in various stages of preparation of this work, without which this work could not have seen the light of the day.

Miss L. Lalitha, stenotypist, Voluntary Health Services and other staff working at that Institute gave considerable secretarial help in the data processing, analysis and in preparation of the draft. I am also extremely grateful to Mr. P.S. Rajagopal and Mr. J.S. Baweja for the final typing work.

I owe a special debt of gratitude to Dr. C.S. Gangadhar Sharma, the State Leprosy Officer, Tamil Nadu, for the uninhibited support given to me during various stages of a data collection. He has been most generous in responding to my numerous requests for information and comments. My thanks are also due

to Dr. K.C. Das, Assistant Director General of Health Services (Leprosy), Government of India, and Dr. S. Natesan, District Leprosy Officer, Chingleput. Dr. Sharma and Dr. Natesan instructed all the workers to extend to me their full co-operation.

To all the leprosy workers whom I contacted for the study, I wish to express my sincere thanks. To the various respondents in the community and to the patients suffering from leprosy in the different study villages, I am extremely grateful to the time they spent in spite of their avocations and sufferings.

But for my mother, my wife and children, who tolerated my long absence from home and for the uninhibited support they have been giving me, including enabling me to catch the early morning bus to the field areas, this research work could not have taken shape at all. I am thankful to them.

To all those who have been to help to me in one way or the other. I owe a word of thanks and crave their indulgence for not acknowledging their help individually.

September 4, 1992 K. VENKATESWARA RAO

REHABILITATION IN LEPROSY WORK —Role and Experiences of NGOs

S. P. TARE

Voluntary agencies have played the pioneering role in leprosy as well as rehabilitation of patients. Indeed, it is the voluntary agencies who are implementing, through trial and error, the concept of community-based rehabilitation which seems to be the only sensible way to fully solve the complex problem of rehabilitation.

THERE is probably no other disease which gives rise to so much physical mutilation (with the exception of yaws) as leprosy. This characteristic along with a few others, has wrapped leprosy into myth and mystery, and has made it a most abhorred disease. For centuries, a patient of leprosy is recognised only when he has obviously visible deformities, and it is at that stage that he has been shunned and hounded, over centuries, from job, home and society. Being a chronic disease, and not a killer, the person afflicted with leprosy has to carry the cross till he dies, years later, either due to some other reason or oldage.

Leprosy is as much a medical problem as a social one. And of the variety of problems which have to be faced, the most formidable one is that of rehabilitation of leprosy patients. It arises that the patient is de-habilitated from society.

It is thus no wonder that it came to the lot of voluntary agencies to try to alleviate the social sufferings of leprosy patients.

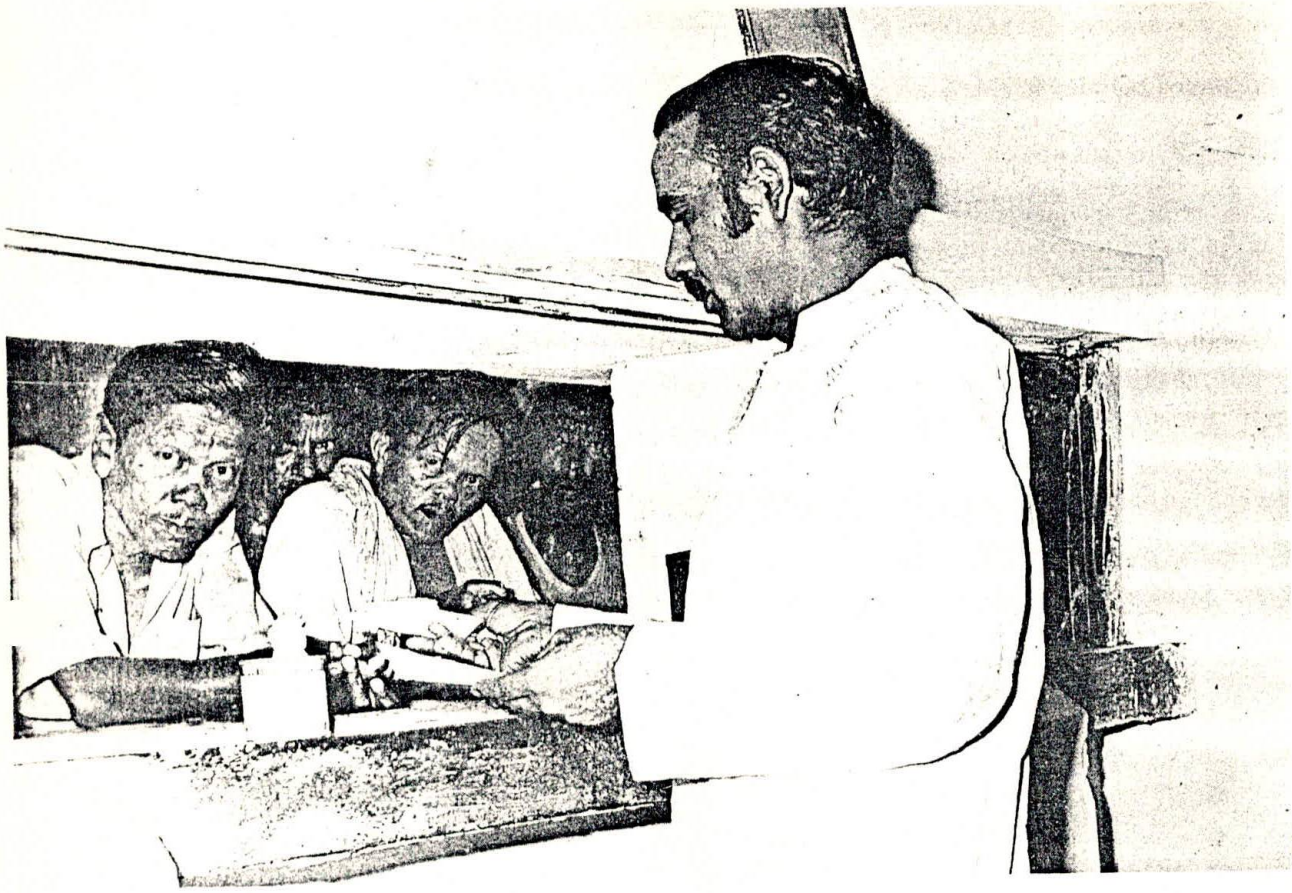
Rehabilitation made popular

Rehabilitation—a term borrowed from social welfare field—was given a very restricted meaning in leprosy field in the period soon after Independence. What they were actually doing was providing vocational engagement to their inmates within the confines of their premises. It was the Gandhi Memorial Leprosy Foundation, which spear-headed the movement to make an entirely difficult concept of rehabilitation popular. It was stressed that rehabilitation is essentially a decentralising process through which patients are helped, by training them in some skill or craft, and to go back to their original environment and win back respectful place in their original milieu. Any effort which falls short of "sending the patient back" is not rehabilitation in the real sense of the term; it is an alternative arrangement made out of failure to rehabilitate a leprosy patient to his former environment.

There was almost total lack of any follow-up of the patients so discharged, and consequently the patients found themselves lost after discharge. The only alternatives available were either to become a beggar or a landless labourer.

It was again the efforts of some pioneering voluntary agencies to explore other avenues of employment for their patients. They tried to help the patient to do whatever job/work he was doing earlier, and in some instances, through avenues of self-employment. The patients were helped in obtaining funds through loans or advances to take up poultry, or dairy or to take up vending of things of daily requirement. The capital necessary for such activity was small and could be had from numerous Government schemes for poverty-alleviation, employment generation etc. Such efforts were very cost-effective as compared to institutional-based rehabilitation where the cost was found to be too heavy.

The National Leprosy Eradication Programme as it was originally



We now have the spectacle of 25 lakhs of the leprosy patients staying in their homes and in their villages while taking medicines through out-patient clinics.

conceptualised had an in-built programme for preventing dehabilitation which in fact, should be the major thrust to solve the problem of rehabilitation in the long run. SET programme brought about slow but definite changes in the societal attitude of intolerance and we now have the spectacle of over 25 lakhs of the leprosy patients staying in their homes and in their villages while taking medicine through out-patient clinics. Even a deformed leprosy patient (whose number has dwindled to less than 10%) is able to remain in society and home.

Community-based Rehabilitation

The efforts as mentioned above made by the voluntary agencies in getting the patients gainfully engaged in society is very similar to what is now being technically termed as "Community-based rehabilitation (CBR)". The patients have the support of the entire society in whatever they do to assure their independence, and get assimilated in the society fully. This is very satisfying to the patient himself because his integration with society is complete. It is very cost-effective as compared to "institution-based rehabilitation" (IBR) which is very expensive and has very dubious results.

There is however no doubt that the concept of CBR is not yet fully understood even by the workers engaged in rehabilitation and there is still reluctance to involve the community fully by leaving all initiative to them. It will take some more time for the workers and agencies to get correctly oriented to the concept of CBR and accept for themselves the role more of a facilitator rather than that of the initiator or the service-provider.

To sum up, the voluntary agencies have played the pioneering role not only in the field of leprosy but also in the field of rehabilitation of patient and have been the only agency to take care of that aspect. The Governments have only recently become aware of the importance and urgency of rehabilitation and may make monetary provision to help the voluntary agencies. It is also evident that the voluntary agencies have tried and experimented with different models of rehabilitation and

in this process saved lakhs of leprosy patients not only from getting dehabilitated but also in gaining a place in their original society. Finally, it is the voluntary agencies who are implementing, through trial and error, the concept of CBR which, in the context of our present knowledge, and means available to us, seems to be the only sensible way to fully solve the complex problem of rehabilitation. Δ

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Towards Leprosy Eradication

Leprosy continues to be a major public health as well as a social problem in the country. Social prejudices, fears and superstitions still continue to a large extent to obstruct early case-detection and regular treatment activities.

In India, more than 430 million people live in 196 leprosy endemic districts with a prevalence rate that vary between one and five cases for 1000 people. A substantial population thus remains exposed to a greater level of risk of leprosy infection.

To combat the disease, the Govt. of India launched the National Leprosy Control Programme in 1955. It was redesignated as the National Leprosy Eradication Programme (NLEP) in 1982 with the ultimate aim of arresting the disease activity in all the known cases by the year 2000 A.D.

There are hopeful signs as the present decade has witnessed a major expansion of the leprosy control work in India both quantitatively and qualitatively with the help of the new strategy: Multi-drug Treatment. Under this strategy, rapid cure is being brought to patients by providing continuous treatment. Starting with two endemic leprosy districts in 1982 as many as 112 of the 196 leprosy endemic districts have been brought under the multidrug treatment (MDT). Rest of the districts will be brought under MDT in a phased manner by 1992. The Govt. of India is doing all it can to control leprosy and ultimately eradicate it.

However, the MDT can be a complete success only with the participation of the people. The need therefore is redoubling of efforts towards health education among patients, their families and the community.

On Mahatma Gandhi's martyrdom day—30 January—which is also observed as the Anti-Leprosy Day in India let us emulate the example set by him and rededicate "ourselves to work for the cause of leprosy-relief and thereby bring succour to this section of suffering humanity". It is with this spirit *Swasth Hind* devotes this issue to

Anti-Leprosy Day.

SWASTH HIND WISHES ITS READERS A VERY HAPPY NEW YEAR

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In this issue

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MULTIDRUG THERAPY IN LEPROSY

DR S. K. NOORDEEN

It is well recognized that leprosy combines several problems which have serious implications on the individual, the family and the community. The challenges posed by the disease include its communicability, its potential for causing physical deformities, its chronicity, and its propensity to generate intense negative social reaction.

It is estimated that there are about 10 to 12 million cases of leprosy in the world. However, the number of registered cases has varied over the years: 2.8 million in 1966, 3.6 million in 1976 and 5.4 million in 1985. Since then, there has been a distinct change in the trend with a significant reduction in the number of registered cases to 3.9 million cases by 1988, a reduction of about 28%. This is attributed to Multidrug Therapy (MDT) implementation and the resulting release from treatment of a significant number of patients.

By the early 1980s it was clear that dapsone was steadily losing its usefulness, due to drug resistance, and that there was a general lack of enthusiasm for leprosy control in many countries because of the poor results being achieved. Although more potent anti-leprosy drugs were available then, the information and guidelines available on how to apply them in a practical way was insufficient. It was under these circumstances that WHO constituted the Study Group on Chemotherapy of Leprosy for Control Programmes in 1981.

The recommendations of the Study Group, which are now recognized as a milestone in the history of leprosy, are not always fully understood, particularly its rationale. With the problem of dapsone resistance increasing in its dimensions, and with the availability of better bactericidal drugs against *M. leprae* such as rifampicin in the 1960s, the application of leprosy treatment through combinations of drugs became a clear possibility. It was realised that with leprosy patients harbouring very large bacillary populations similar to those with tuberculosis, successful chemotherapy should be one which is capable of preventing the selection of drug-resistant mutants as well as killing of all, or nearly all drug-sensitive organisms. With the prevention of selection of drug-resistant mutants and the killing of nearly all drug-sensitive organisms it was expected that relapse after stopping chemotherapy could be virtually eliminated.

Acceptance of the recommendations on MDT

The recommendations on the MDT regimens made by WHO received enthusiastic support from most of the leprosy-endemic countries, WHO Regional Committees, international and national non-governmental organizations, donor agencies, and professional bodies. Some countries had introduced modifications to the WHO recommended regimens, but these were generally minor and within the essential requirements for MDT. In several countries, MDT provided the opportunity to increase the priority for leprosy control and strengthen their political commitments.

Progress with implementation of MDT

The coverage of leprosy patients with MDT has rapidly increased over the past few years to reach, by October 1989, 45.3% of the total registered cases in the world. The increasing acceptability of MDT among national health services and leprosy patients themselves is due to: (a) the fixed, and relatively short duration of MDT treatment; (b) the

low-level of toxicity and treatment related side-effects; (c) the very low relapse rates following completion of treatment (0.1% per year for PB and 0.06% per year for MB based on information based on 85,125 PB cases and 22,087 MB cases); (d) the high level of acceptance of clofazimine discolouration (over 98%; (e) significant reduction in frequency and severity of ENL reactions. One more advantage of the WHO/MDT regimens is the considerable increase in the proportion of self-reporting cases at an early stage of the disease. Consequently, this has led to a reduction in the number and degree of deformities among new cases; an increased acceptance and compliance of patients to the treatment; and better community support to patients.

Table 1 shows the global progress of MDT implementation from 1985 to 1988. For the first time, and in spite of the considerable increase in the number of newly detected cases during MDT implementation, there are indications of a decline in the total number of registered patients in the world. This decline supports the efficacy of the WHO MDT regimens for leprosy control and opens the possibility of major reductions. However, the world coverage with MDT for leprosy is very uneven with some countries having a high coverage and others lagging behind.

Of the 109 leprosy endemic countries only 47 countries (or 43% have at least 50% MDT coverage of their patients.

TABLE 1.—PROGRESS OF MDT COVERAGE

	Oct. 1985	Oct. 1986	Oct. 1987	Oct. 1988	Oct. 1989
(a) Registered cases (X 1000)	5,368	5,341	5,813	4,908	3,866
(b) No. of cases on MDT	78,752	4,68,222	6,99,589	16,04,927	17,51,903
(c) % of total cases on MDT	1.47	8.77	14.54	32.70	45.32
(d) of cases WHO completed MDT (cumulative total)	9,425	93,216	5,10,593	6,27,919	8,53,706

Operational problems in implementing MDT

In spite of the tremendous progress made with MDT, several problems, particularly at the operational level are faced by leprosy control programmes. These include:—(a) the inability to increase the priority for leprosy in some countries as a result of other pressing health needs; (b) poor health infrastructure to cope with MDT; (c) inadequate resources particularly for drugs; (d) absence of a proper plan of action to implement MDT; (e) inadequate training of health workers; (f) lack of laboratory facilities for skin smear examinations; (g) poor referral facilities to deal with complications; (h) insufficient patient education about what to expect from MDT so that when the time comes for stopping treatment, the decision would be acceptable to the patients.

Future prospects

With the increasing political commitment in many countries to deal with leprosy effectively, with the increasing appreciation of the value of multidrug therapy as a very potent technology, and with the increasing international cooperation, both from the bilateral and multilateral sectors enabling additional inputs, **it is not unrealistic to expect a reduction of leprosy case-load by as much as 80% in the next five to seven years, at least in countries with effective programmes.** However, notwithstanding anticipated major reductions in prevalence, it should be recognized that other problems will remain for quite some time to come such as disabilities among old cured patients and a continued, albeit reduced, incidence of new disease arising from infections caught several years earlier. Hence, apart from investing heavily on efforts to reduce leprosy prevalence through MDT, there is a need to plan for the future so that leprosy control becomes part and parcel of primary health care encompassing early detection, treatment, as well as disability prevention and management. In addition, on-going research in leprosy vaccines, if found successful, offer great promise to interrupt transmission completely and attain eradication.

There is no doubt that MDT has brought about a major change in technology for leprosy control. It has also resulted in a new outlook towards the disease, and raised hopes among patients, health workers, and programme managers alike. Where the implementation of MDT is vigorous and sustained, the results are extremely gratifying. Problems, both technical and operational, need to be constantly reviewed and solutions found. The opportunities to markedly reduce leprosy in the next decade are immense. It remains to be seen whether or not we make use of them, and whether or not leprosy will ultimately be eliminated as a public health problem as part of the overall goal of Health for All by the Year 2000. △

Swasth Hind

IS ANTI-LEPROSY VACCINE IN SIGHT?

DR M.D. GUPTE

The need for vaccine against leprosy control cannot be over emphasised. Remarkable progress has been made with respect to identifying various components of *Mycobacterium Leprae* in their micro-structure. There are immense possibilities for developing a genetically engineered vaccine as well. However, it is not possible to predict when such a kind of second generation or third generation vaccine can be developed. It is, therefore, essential to undertake comparative studies with the presently available and promising anti-leprosy vaccines. Thus, answer to a question like, is anti-leprosy vaccine in sight, should be given with guarded optimism, feels the author.

"IF leprosy can be cured, then even salted fish can swim", goes an old Chinese saying. Decades have passed since we knew that effective treatment for leprosy is available. The prospects for curing leprosy are no longer bleak and it is known that leprosy is like any other communicable disease. However, the fear associated with leprosy and the stigma due to disabilities, deformities and disfigurement happen to be very deep routed cultural characteristics. Therefore, the proposition of leprosy prevention gets accepted enthusiastically and also creates lot of expectations in all the echelons of the society. Difficulties in growing *Mycobacterium leprae*, the leprosy germ, in artificial culture medium happens to be the main obstacle in developing an anti-leprosy vaccine. Efforts were, therefore, directed to organisms similar to the leprosy germ that can be used for preparation of anti-leprosy vaccine. We are now in a fortunate situation where it is possible to consider a vaccine based on the leprosy germ derived from armadillos as well as anti-leprosy vaccines based on organisms similar to the leprosy germ.

Difficulties in the treatment of leprosy, particularly lepromatous leprosy also led to the belief, "a patient of leprosy remains always a leprosy patient". A leprosy vaccine usually can be considered as preventive vaccine or a prophylaxis against leprosy disease. A very unique possibility is being explored with some of the anti-leprosy candidate vaccines about their capacity to treat a patient of leprosy. Thus in addition to the immunoprophylactic uses, the anti-leprosy vaccine can be used as an immunotherapeutic agent.

Patients of lepromatous leprosy are negative to a lepromin skin test. There is a strong belief, and some good evidence, that persons who are lepromin negative even after exposure to *Mycobacterium leprae*, are susceptible to lepromatous leprosy. Therefore, when in 1939, Fernandez demonstrated that BCG could convert the lepromin negative individuals to lepromin positive individuals, lot of enthusiasm was generated regarding the possible use of BCG as a leprosy prophylactic agent. Several studies were undertaken with BCG in different parts of the world and the results obtained were quite variable (Table-1).

TABLE 1

RESULTS OF MAJOR FIELD TRIALS AGAINST LEPROSY WITH BCG

Country	Control		BCG		protection (%)
	Person years	Incidence % o per year	Person years	Incidence % o per year	
Burma	1,51,060	5.5	1,51,415	4.4	20.4
New Guinea	27,100	6.3	29,300	3.4	46.0
Uganda	42,800	4.5	43,300	0.9	80.9
India	2,40,000	9.6	4,88,000	7.4	23.0

Evidence available from the African countries, for example, Uganda, from Table-1, indicate that there is already a vaccine available for leprosy. In fact, studies based on BCG scars and historical data as well as prevalence studies in Malawi in Southern Africa indicated that BCG would be effective at least to the tune of about 60 per cent in preventing leprosy. However, findings from other parts of the world do not support this view. For instance, in Burma, protective efficacy of BCG was 20 per cent and in India also it was similar.

Parameters

The limited success of BCG in preventing leprosy was not adequate to justify the use of BCG for leprosy prophylaxis. The search for newer vaccines continued. Several parameters were being identified to judge the possible anti-leprosy efficacy of a vaccine. Few of the parameters are mentioned in Table-2.

TABLE 2

PARAMETERS TO JUDGE APPARENT ANTI-LEPROSY EFFICACY OF A CANDIDATE VACCINE

(1) Lepromin conversion in animals
(2) Lepromin conversion in initially lepromin negative healthy individuals and in patients of lepromatous leprosy.
(3) Animal protection—Mouse foot pad studies
(4) Immunotherapy in patients of leprosy

Pioneering Research work

Dr. Jocinto Convit from Venezuela has done pioneering research work in this direction. He used killed *Mycobacterium leprae*, derived from armadillo in combination with BCG in some patients of leprosy and their contacts. He found that it was possible to achieve lepromin conversion by using this combination in contacts as well as in patients of lepromatous leprosy. He convincingly demonstrated the immunotherapeutic efficacy of this combination in patients of lepromatous leprosy. Studies of Dr. Convit led to development of a candidate leprosy vaccine, *viz.*, BCG in combination with armadillo derived killed *Mycobacterium leprae*. This vaccine is presently being tested in Venezuela by Dr. Convit himself and in Southern Africa in Malawi by Dr. P. E. M. Fine and his colleagues for the prophylactic efficacy. Both these trials are supported by the IMMLEP Programme of the World Health Organization.

Developments in India

We should be proud of the developments in this field in India. Drs. Bapat, Ranadive and Khanolkar, reported, way back in 1958, cultivation of a mycobacterium from patients of lepromatous leprosy. This mycobacterium is called ICRC bacillus (Indian Cancer Research Centre bacillus). It was observed that the ICRC bacillus was similar to the leprosy organism. Drs. Deo and Bapat continued research on ICRC bacillus and were able to develop an anti-leprosy vaccine. They demonstrated the ability of this vaccine in lepromin conversion as well as its immunotherapeutic potentials. This vaccine is presently being tested for its prophylactic value in Sholapur district in Maharashtra by Dr. Deo and his colleagues.

There is one more cultivable bacillus, somewhat similar to the leprosy germ, called *M.w.* Dr. Talwar and his colleagues have developed a vaccine based on the *M.w.* bacillus. This vaccine also shows the abilities for lepromin conversion as well as immunotherapy in patients of lepromatous leprosy. At present, immunotherapeutic trials with the *M.w.* vaccine are being conducted in Delhi by Dr. Talwar and his colleagues. It is expected that Dr. Talwar would be undertaking a prophylactic vaccine trial in Kanpur district in Uttar Pradesh.

A third candidate vaccine from India is being developed in Central Drug Research Institute, Lucknow. This vaccine is based on a mycobacterium called *Mycobacterium habana*. Interestingly, this vaccine is expected to be effective against both tuberculosis and leprosy. Developments with respect to this vaccine are being watched with expectations.

Promising Results

Availability of several candidate vaccines is thus very promising. All these candidates fulfil the requirements of a candidate leprosy vaccine to varying extents. It is not possible, nor advisable, to use any of these vaccines as prophylactic vaccines at the present stage of development. It is essential to prove their prophylactic efficacy in well planned and conducted studies. It will be extremely useful and absolutely essential to compare these candidate vaccines in similar situations.

(*Contd. on page 8*)

INVOLVEMENT OF FEMALE HEALTH WORKERS IN NATIONAL LEPROSY ERADICATION PROGRAMME

DR D. K. MAHABALARAJU

Adult females are major victims of leprosy. Pregnant women and lactating mothers are more susceptible to leprosy. So it is opined that female paramedical workers can achieve better coverage among females, particularly adult females. Hence, inclusion of Female Health Workers in leprosy case detection activities is recommended for achieving better coverage among females.

Leprosy is a major Public health and grave socio-economic problem in the developing countries: more so in India. India accounts for four million leprosy cases. The problem is far more serious than is indicated by the number of cases alone. The economic loss, physical-social handicaps, psychological problems, mental agony, and social stigma attached with the disease further compounds the problem.

The WHO from its very inception has given priority to Leprosy Control. In India National Leprosy Eradication Programme (NLEP) was launched in 1983 with the hope of eradicating Leprosy by 2000 A.D.

Now, there are many recent advances in the field of Leprosy. More potent anti-leprosy drugs are available. Multi-drug regimen is practiced to combat drug resistance. There is progress towards anti-leprosy vaccine. Facilities for early diagnosis, treatment, rehabilitation, overall support by Government and non-Government agencies at National and International levels are available. Using existing and new knowledge, pooling the resources and emphasizing health education, now it is possible to cure leprosy at any stage. Thereby we can prevent transmission of infection and protect healthy population. Prevention of deformities and complete rehabilitation is also possible. These developments suggest that Leprosy eradication is achievable in foreseeable future.

Social stigma

Social Stigma makes the patient to conceal his disease. Female patients refuse examination because of social taboos against the examination of women by male health worker. Hence, infectious patients are undetected and hidden in all sectors of societies. They are maintaining the spread of infection, and acts as a major barrier in the successful implementation of Leprosy Eradication Programme.

Paramedical workers (Leprosy) play a very important role in case detection activities. Early case detection needs complete examination of individuals with minimal clothing. Our paramedical workers are mostly males. Because of this, adult females usually refuse examination by male workers. The following study supports the above statement and suggests that involvement of female health workers is crucial for the success of the National Leprosy Eradication Programme.

Epidemiological study

An epidemiological study of Leprosy was undertaken by the Author in one rural paramedical worker sector, (Lokikere). This area is situated in Chitradurga district of Karnataka State. The study area consist of 13 villages with a population of 34,838 living in 5,317

families. All the individuals residing in the study area were contacted by house-to-house visit and examined for the evidence of leprosy. Survey was started in the early parts of the day (January 1987 to December, 1988). So that the villagers could be examined before they left for the work.

Early case detection in leprosy needs complete examination of individuals with minimal clothing. Our paramedical workers are mostly males. Because of this, adult females usually refuse examination by male workers.

Females—major victims

Observations of the study reveals that out of 34,838 population residing in the study area, only 31,367 (90.04%) population could be examined for the evidence of leprosy. Coverage was better among males (91.25%). Examination of females was less (99.77%). Only 77% of females of 25-34 years of age group could be examined for the evidence of Leprosy. The less coverage of adult females in this study was mainly due to refusal of adult females for examination. The studies conducted by Ganapati in 1976, Ramu *et al* in 1973 and Bechelli *et al* during 1973 have shown that site of prediliction of Leprosy lesions was gluteal region and thighs. Hence complete examination of body is essential in case finding activities. Females, particularly adult females, refuse examination of these covered parts by male workers. Females constitute nearly 50% of the population and they are equally susceptible for leprosy as males. Adult females are major victims of leprosy. Pregnant women and lactating mothers are more susceptible to leprosy. So it is opined that female paramedical workers can achieve better coverage among females particularly adult females. Hence, inclusion of Female Health Workers in Leprosy Case detection activities is recommended for achieving better coverage among females.

KUSHT VINASHAK.
SEP-DEC. 1989.

WORLD AIDS DAY 1990 TO FOCUS ON WOMEN

Dr Hiroshi Nakajima, Director-General of the World Health Organization (WHO) announced formally 22 January, 1990 that the theme for World AIDS Day 1990 will be Women and AIDS, while addressing the Eighty-fifth session of the Executive Board during the debate on the global strategy for the prevention and control of AIDS.

WHO announced that World AIDS Day 1990 will:

*Heighten awareness about the risk of HIV infection and AIDS especially in women;

*Expand and strengthen the worldwide effort to stop AIDS by highlighting the impact of HIV/AIDS on women around the world ——not only as a medical problem, but as HIV/AIDS affects women as care providers, health-workers, educators, and mothers;

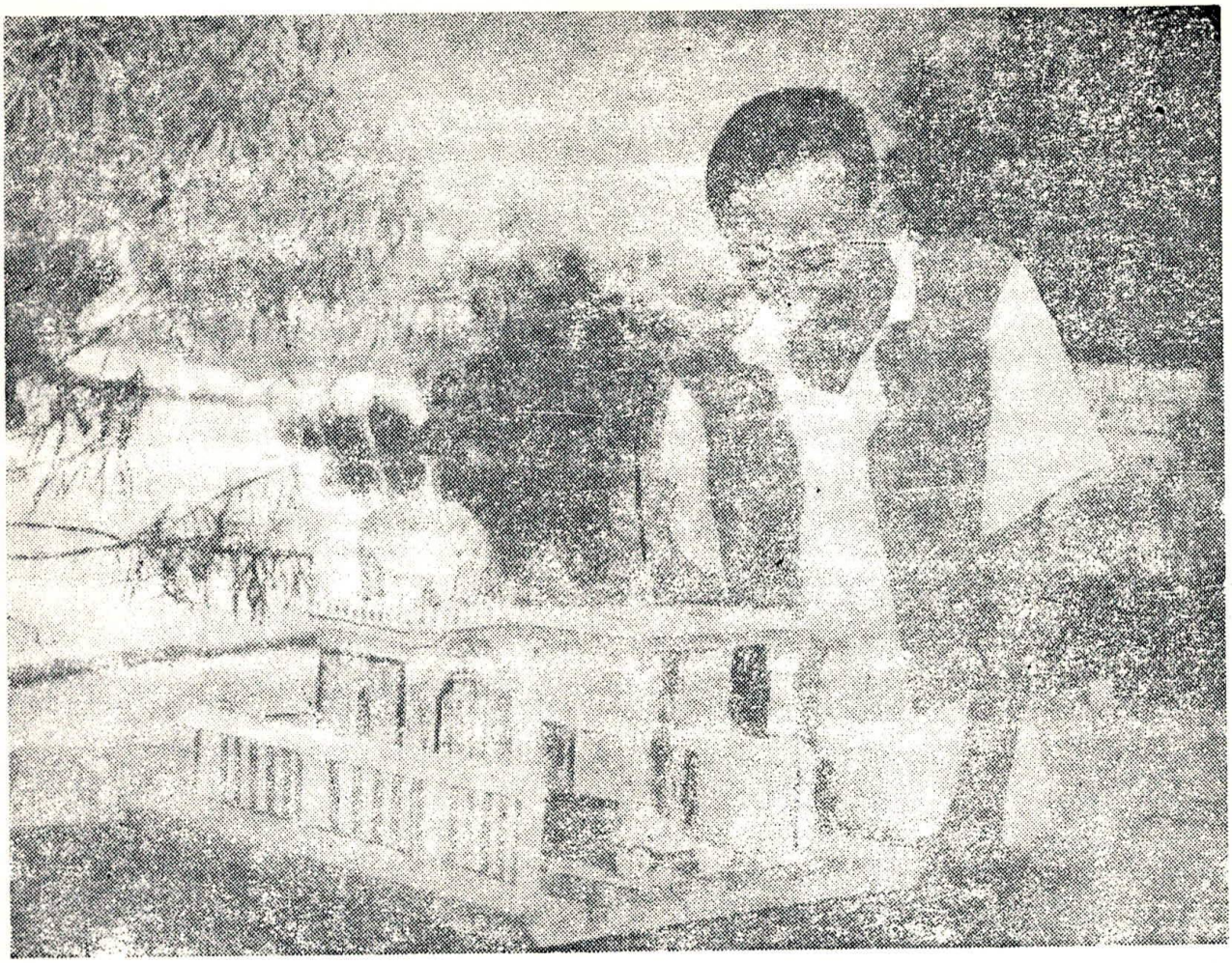
*Strengthen AIDS prevention activities and programmes at all levels of society, especially as they pertain to women;

*Promote respect and care for all HIV-infected people and people with AIDS; and

*Contribute to lasting dialogue, sustained activity and long-term commitment among all people in countries around the world.

World AIDS Day 1990 will also highlight the link between the status of women within the family and society, and their vulnerability to infection and its consequences. It will also draw attention to the special concerns related to HIV/AIDS and pregnancy, childbirth and raising children.

AIDS is a serious health problem which affects women, men and children in countries around the world. Worldwide, WHO estimates that at least six million people are now infected with HIV, and that approximately two million — or one third — are women. It is expected that by the end of 1992, a cumulative total of over 350,000 cases of AIDS will have occurred among women, or three times as many as had occurred by the end of the 1980s. WHO projects that by the year 2000, an estimated six million cases of AIDS will have occurred among men, women and children, or 10 times the current estimated number of cases. ○



ROLE OF REHABILITATION IN LEPROSY

DR SAUDAN SINGH

DR SANJIV KUMAR BHASIN

The leprosy patients and their family members are to suffer from various traumatic experience due to disruption of their social relationship. Exclusion from religious functions, social ceremonies, community gatherings and denial from participation in educational institutions and employment leaves these leprosy patients as social out-casts. The voluntary organisations have a significant role to play in the creation of a social environment by removing ignorance, superstition and prejudice against the disease. Rehabilitation is of utmost importance both for the patient and the community as the rehabilitated patients while being drawn in the social mainstream will contribute towards the national developmental efforts rather than being a burden on the society.

REHABILITATION may be defined as "The diagnosis, treatment and prevention of dehabilitation". In the context of leprosy, dehabilitation chiefly affects three areas of life; the disease can cause a patient to lose his family and place in society, his work and his means of livelihood or his self-respect. It is cited that on an average 15-20 per cent of leprosy patients develop physical disabilities, e.g., drop foot, claw toe, hammer toes, planter ulcers, depressed nose, arthritis, multiple sinuses, etc. Thus, rehabilitation of leprosy patients must fulfil the triple objectives of their physical, economic and social rehabilitation.

Rehabilitation is 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 measures that are taken in this direction are known as "preventive rehabilitation". The approach to rehabilitation should, therefore, begin with dehabilitation. We should never allow dehabilitation to take place and afterwards take up the uphill task of rehabilitation.

Physical rehabilitation

The deformities caused directly by the disease and secondarily due to factors operating on insensitive parts, constitute the two most important elements in physical rehabilitation of leprosy patients. Deformities affecting the hands and feet seriously impair the working ability of patients and require surgical correction in specialised institutions. The existing facilities for physical rehabilitation including Leprosy Rehabilitation Promotion Units, Units for Reconstructive Surgery and Regional Leprosy Training and Research Institutes (RLTRIs) functioning under the NLEP are totally inadequate to meet the need.

Economic Rehabilitation

Leprosy in India is largely a disease of the poor. The financial hardship acquires almost tragic proportions if the sole bread winner in the family contracts the disease. The patient loses employment and new jobs are difficult to come by. The disease often causes incapacitating effects. Faced with poverty, antipathy from the family members and scorn from the community, these patients often fall victim to mental depression, they shun society and neglect treatment.

There are a large number of patients suffering from leprosy, specially in rural areas, who continue with their original work. However, their efficiency generally becomes considerably low. Such persons do not need actual rehabilitation but also require some financial assistance to take up a subsidiary occupation in order to supplement their income. Thus the three kinds of activities required for vocational training are:—

— Selection of a suitable craft or vocation.
— Re-education and training in new vocations, and
— Placement of the trained persons.

Social Rehabilitation

The social dimensions of leprosy are often tragic and frequently hinder the successful implementation of leprosy control programmes. The leprosy patients and their family members are subject to various traumatic experiences due to disruption of their social relationship Exclusion from religious functions, social ceremonies, community gatherings and denial from participation in educational institutions and employment leaves these patients virtually as social out-casts. In the creation of a social environment the voluntary organizations have a significant part to play by removing ignorance, superstition and prejudice against the disease.

Thus rehabilitation which is tertiary level of prevention in National Leprosy Eradication Programme is of utmost importance both for the patient and the community as the rehabilitated patients while being drawn in the social mainstream will contribute towards the national developmental efforts rather than being a burden on the society.

Contd. from page No. 4

CJIL Field Unit, Avadi, Madras, situated in a leprosy endemic area in Chingleput district is planning for such a comparative study. Prophylactic studies against leprosy are expected to take long time—a decade, if not more. Results of the ongoing vaccine trials in India, as well as in other countries, and the proposed comparative vaccine trial are thus expected in about 10 years from now.

Remarkable progress has been made with respect to identifying various components of *Mycobacterium leprae* in their micro-structure. There are immense possibilities for developing a genetically engineered vaccine as well. However, it is not possible to predict when such a kind of second generation or third generation vaccine can be developed. It is therefore essential to undertake comparative studies with the presently available and promising anti-leprosy vaccines.

The need for a vaccine against leprosy cannot be overemphasized. It is not possible to predict that such a vaccine will definitely emerge from the presently available candidate vaccines. Thus, answer to a quetion like, is anti-leprosy vaccine in sight, should be given with guarded optimism.

NATIONAL LEPROSY ERADICATION PROGRAMME

ROLE OF CENTRAL LEPROSY TEACHING AND RESEARCH INSTITUTE, CHENGALPATTU

DR P.N. NEELAN

The Central Leprosy Teaching and Research Institute, situated about 60 kms. south of Madras City, was established in 1955 by the Government of India. It is functioning as a peripheral office of the Directorate General of Health Services, Ministry of Health and Family Welfare since April 1974 and has been providing strong research and man-power training support to the National Leprosy Eradication Programme (NLEP).

THE original objective of the Institute was to develop it as a National Centre for Training and Research in Leprosy, (a) to undertake research into the basic problems relating to the inception and spread of leprosy, (b) to promote applied research in the field which would be of use in the control of leporsy, (c) to train leprosy workers of various categories, (d) to function as a nodal centre to provide technical guidance for the promotion of anti-leprosy work on sound lines, and (e) to participate actively in the organization and development of State leprosy institutions when such are established, and make available its services for the investigation of special problems in all parts of the country.

Organization

The Institute has a Clinical division with a 124 bed hospital and an out-patients block; a Surgical division with Physiotherapy unit, a Microcellular Rubber Manufacturing unit and Orthotic and Footwear unit; a Laboratory division with clinical pathology, biochemistry, pathology, microbiology and immunology laboratories and a standard animal house; and an Epidemiology division with a field unit, Central Monitoring and Evaluation unit, Statistics unit, and Training section with a good library facility. In addition, there is an Administrative section headed by an Administrative Officer with ministerial staff to look after accounts, stores and administrative matters.

Other facilities available are a well-equipped library, a medical illustration section, a microcellular rubber unit which produces sheets of required strength for use in the footwear manufactured by the Institute and other centres, ophthalmic facilities for in-patients and out-patients care, and computer facility in the monitoring and evaluation unit of the Epidemiology Division.

Achievements in recent years

1. With the help of animal house facility, the Institute has contributed to a better understanding of the problem of dapsone resistance in leprosy through studies in the hospital as well as in three different well-defined control unit areas in Tamil Nadu. An offshoot of this was to create awareness and need for introducing multidrug therapy (MDT) in the NLEP in India.

2. Controlled clinical trials funded by WHO THELEP, using Rifampicin, Clofazimine and Dapsone in different combination regimens, have shown that the problem of drug resistance is eliminated by using multidrug therapy. Monthly administration of Rifampicin was found to be as effective as daily administration. These studies helped in evolving appropriate therapeutic regimens in

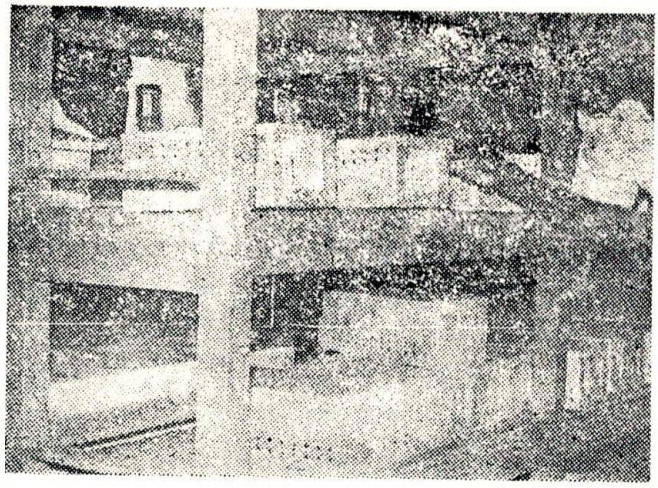
the treatment and management of multibacillary leprosy which were incorporated in the MDT programme of NLEP. Therapeutic studies in the field area of the Institute has shown that six months MDT is adequate in the treatment of pauci-bacillary leprosy.

3. Co-ordinated work in the clinical, surgical, laboratory and field divisions has resulted in a clearer understanding of the clinical manifestations of leprosy, complications like reactions and neuritis, and also the evolution and natural history of the disease process and progress in the affected individuals including borderline leprosy.

4. The Institute has devised a simple laboratory test that could be carried out in the field by peripheral level workers to monitor dapsone compliance among patients. It has also taken up the responsibility of procuring and distributing the Kits and reagents for doing the test to the various State units in India as a part of NLEP activity.

5. One of the objectives of the Programme is to reduce the incidence of disabilities in leprosy through early detection and effective treatment. Basic studies in nerve involvement and consequent development of disabilities, and management and prevention of neuritis in leprosy are areas of interest in the Surgical Division of the Institute. Studies on the structure and functions of the foot and its disorganisation in leprosy through use of barograph, EMG and other equipments have thrown light on the understanding of the genesis of plantar ulceration. The surgeons of the Institute have tested and devised short duration satisfactory treatment procedures for healing of plantar ulcers using collagen sheets, zinc tapes and *Debrisan*. They have also devised original and modified techniques in surgical correction of deformities of hands and feet in the leprosy patients.

6. The Institute has carried out longitudinal follow-up of the population (through detailed surveys) in the field area of the Institute over a period of 20 years, and used several intervention procedures like MDT and chemoprophylaxis. This resulted in the collection of information about epidemiology (distribution, transmission etc.) of leprosy in these parts of the country.



Animal House—mice cages

7. Laboratory division has standardized the smear taking procedures for the Programme and for monitoring cross-checking of smears.

8. With the help and guidance from the WHO Consultant in Statistics, officers in the Monitoring Unit have brought out a Guideline for Sample Survey and Assessment Units (SSAU) in the States. The document has been distributed to all States and Union Territories. The Unit is also training personnel of SSAU teams from the States.

9. The Monitoring and Evaluation Unit has developed a Management Information System that has been field tested and is being used for in-depth monitoring of NLEP activities in Namakkal Control Unit of Salem District. The work is being continued.

10. One of the major and continuing activities in the Institute is the training of various categories of personnel working in NLEP in the states. The Institute has also organized workshops and meetings on behalf of the DGHS to devise means to strengthen the existing leprosy training centres in the states and also to re-orient the training to meet the needs of the Programme. In addition, the Institute collaborates with JIPMER, Pondicherry in training for four months the candidates of the postgraduate Diploma course in Leprosy. A four week exposure to surgery in leprosy is given to orthopaedic and general surgeons. Fellows sponsored by WHO come every year for short training in leprosy control.

During the 7th Plan period, the Institute has further developed to take up additional responsibilities in support of a successful implementation of the NLEP. We are confident that the continued support from the Ministry and the Directorate and the future expectations based on the assessment of our present performance, will be fully reflected in our activities in the coming years.

Some of the areas in which the Institute is continuing its research activities are (a) Developing a culture medium for M. *leprae*. Effort in this direction has already been started; (b) developing simple serological test(s) that could be used in the field as a screening test, (c) operational research in cost effectiveness of alternative approaches in MDT implementation; (d) epidemiological studies in incidence of deformity and its impact on the programme; and (e) operational research in cost effectiveness of alternative strategies in disability prevention, limitation, and rehabilitation.

The Monitoring and Evaluation Unit is expected to take up in stages the work of monitoring the Programme in various districts in the country and also in carrying out operational research studies relevant to the effective implementation of the Programme.

Monitoring And Evaluation Under National Leprosy Eradication Programme

DR N. S. DHARMSHAKTU

The National Leprosy Eradication Commission has been constituted consisting of the following for the guidance and surveillance of the National Leprosy Eradication activities:

This commission is headed by Union Minister of Health & Family Welfare as a Chairman. The members of the Commission are: Union Minister of Finance, Planning Commission, Chemicals & Fertilisers, Education & Social Welfare and five Chief Ministers of the states in rotation. Eight eminent leprologists and social workers and others engaged in leprosy work are also taken as members. The Secretary, Health & Family Welfare is ex-officio Secretary of the Commission. The commission is a policy making body.

National Leprosy Eradication Board: It has been set up under the Chairmanship of Union Secretary, Health & Family Welfare. The board functions in the areas allotted under rules of business to the Ministry of Health and Family Welfare, Ministry of Social Welfare and Ministry of Information and Broadcasting in so far as the activities relating to eradication of leprosy and rehabilitation of leprosy patients are concerned. The Board has the powers of Ministry/Deptt. of Government of India. The Board serves as the executive body responsible for implementation of the plans and policies of the National Leprosy Eradication Commission. The members of the board are Secretaries of Welfare, Planning, Rural Development, Information & Broadcasting, Finance and the Secretary, Health who is the Chairman of the Board. Other members of the board are Director General of Health Services, Director-General of ICMR, Senior Deputy Director General, ICMR (ECD), and Assistant Director General (Lep.) who is the Member-Secretary.

At the state level where leprosy problem is high, similar policy and implementation bodies have been set up. Programme runs vertical in endemic areas and in low endemic areas where prevalence rate is less than five per thousand population. It is being run through general health care staff. In the vertical set up of the programme in-built system of monitoring and evaluation consists of regular reporting from:

PMW → NMS → MO → DLO/ZLO → SLO → Centre
← ←(LCU/ULC)← ←(State Dept.) ← (Leprosy Division)

In the low endemic area the in-built monitoring and evaluation consists of regular reporting from:

MPW → HA → MO → CMO → DJD → State Dept. → Centre
← ←(PHC)← ← ← ←

To strengthen the monitoring and evaluation activities, the following steps are being taken up in the Seventh Plan:

(i) Creation of Sample Survey-Cum-Assessment units for more states.

(ii) Provision of a full time consultant for major state and one for small two/three states/UTs. Currently 9 such consultants are functioning.

(iii) Provision of part-time leprologists to provide technical supervision and guidance for the high endemic MDT districts.

(iv) Annual independent evaluation of leprosy programme was done in 1986, 1987 and 1989.

(v) Annual Conference of SLOs and DLOs of MDT districts.

(vi) Annual Conference of Voluntary Organisations.

(vii) Special study of some component of programme through short-term consultants e.g. Training and Manpower Development have been studied.

(viii) Biennial Conference of Heads of Leprosy Training Centres.

(ix) Establishment of Voluntary Organisation Grant Committee.

(x) Monthly, Quartely and Annual review of the programme at all level.

(xi) Establishment of a "Consultants Coordination Cell" at the national level.

Important components of Monitoring and Evaluation:

I Central level

(a) Physical target achievement

(b) Objective target achievement: case detection, treatment and discharge.

(c) Expenditure report.

(d) Health education activities and fund utilisation.

(e) Manpower development: staff sanctioned in position and trained.

(f) Leprosy Training Centres—number of courses and seats

in the year, number of workers trained in the year and number of workers given orientation training in the year.

(g) Drug position.

(h) Monthly progress of MDT districts.

II State level

It is being done on the similar pattern as in the central level. Following aspects are also monitored through SSAUs:

(a) Quality of data generated.

(b) Effectiveness of treatment including MDT at periodic interval.

(c) Estimate magnitude of leprosy problem in the area where infrastructure is not geared to provide such information.

III District and Peripheral Unit level

All the components of Central/ State level are monitored and evaluated in much more detail. Some of the important activities monitored are case-detection by various methods, treatment, treatment regularity, defaulters, bacteriological examination, cross checking of smears, cases discharged as cured, cases died and left area, patients motivation, health-education activities conducted, relapse, vehicle position, availability of equipment/material and training status, etc.

The full-ime consultants visit peripheral units and villages for monitoring and providing guidance.

To ensure the accuracy of reported data and to improve the quality of activities under the programme, independent evaluation of programme has been undertaken jointly by the Government of India and WHO thrice. Twenty-seven experts in leprosy/health programme including nine members from outside the country were members in each of the two evaluation teams. Nine teams were constituted in April 1987, who visited 15 states, 28 districts, 150 villages and interviewed 300 patients, 600 community members and 60 para-medical workers. Several other categories of personnel were also contacted in the districts visited. Previous two evaluations have brought out that the reported data in terms of case-detection, treatment and cases cured were valid. It was also found that over 90% of patients live with their families. There are problems in respect of completeness of infrastructure, filling up of sanctioned posts, training of NLEP staff and laboratory services in the states of Bihar, M.P., Assam and Karnataka. The 1987 evaluation was also given to undertake an indepth examination of MDT activities in districts which have completed intensive phase of MDT. In all these five districts visited, reported reduction in prevalence rate by more than 75% has been validated.

Monitoring and evaluation of multi-drug treatment

Monitoring has to be carried out in the mobilisation and preparatory phases initially and subsequently in the intensive and maintenance phases. In the earlier two phases, monitoring of operational parameters is of greater importance whereas in the later phases the clinical and epidemiological parameters assume more importance.

1. *Methods to be adopted*:

(i) Monitoring is done mainly by holding monthly review meeting at district level for all Medical Officers of Leprosy Control Units and at the unit level for all paramedical workers. In these meetings the monthly reports will be scrutinised and the achievements against target reviewed.

(ii) Even more important than monthly meetings are the field visits by the District Leprosy Officer, Medical Officers, Non-medical Supervisors and Para-medical workers. During these visits the quality of work also must be monitored. The Para-medical workers will monitor the regular intake of drug by the 'Pill Count Method'. This will be supplemented by the Medical Officers.

(iii) Periodical assessment by SSAU.

(*Contd. on page 20.*)

ROLE OF VOLUNTARY ORGANISATIONS IN LEPROSY ERADICATION

Voluntary Organisations have played a pioneering role all through the history of the leprosy control activities in the country. Presently over 275 voluntary organisations are actively engaged in the leprosy relief services. Voluntary organisations are predominantly engaged in the health education and rehabilitation services under NLEP. Many of them are also providing survey, education and treatment services. Some of them are imparting training to various categories of staff in Leprosy. One of the voluntary organisations namely Santhal Pahadia Sewa Mandal has also taken up MDT in a district.

In recognition of the great potential of voluntary institutions in leprosy control, the Ministry of Health, Government of India, holds annual meeting with them with a view to establish communication and close rapport to exchange information to understand the nature of their work and to support and recognise their contributions. The last annual meeting was held in December 1988 at New Delhi where 127 voluntary organisations participated.

As per the information received from the voluntary organisations, nearly 8 lakh leprosy cases are on their records. Voluntary Organisations operate under the guidelines of the National Leprosy Eradication Programme are subject to the same type of monitoring and evaluation system. Government of India have also been supporting some of the voluntary organisations by providing grants-in-aid for setting up of SET Centres, LRPUs, Training Centres as well as health education activities. —**KUSHT VINASHAK, SEPT-DEC. 1989**

OUR NEW MINISTER OF HEALTH AND FAMILY WELFARE

Shri Nilamani Routray

On installation of the National Front Government at the Centre and induction of New Cabinet on 5 December 1989, Shri Nilamani Routray has taken over as the Minister of Health and Family Welfare. Shri Routray (born in 1920 at Mukundapur in Balasore district of Orissa) comes from a middle-class family. The early part of his life was dedicated to freedom movement and hectic political activity against the British Rule. He had to face great obstacles even in completing his college education.

At the age of 12, while in school he was first arrested in 1932 for shouting slogans along with elderly leaders picketing in front of an Opium shop. As a student of Bhadrak High School, he participated in anti-Government meetings and was arrested to have the first taste of his jail life. Once involved in the freedom movement he started organising the students and the public, and carrying on the struggle.

He joined Ravenshaw College, Cuttack, in 1937. As a student leader and the Secretary of All Utkal Students Federation, he was in the forefront of of students' activities in the freedom struggle. In 1940, his final year of graduation, he was expelled from the College and the Patna University for his involvement in political activities. Subsequently, he joined Calcutta University and completed his graduation. After graduation, he joined Banaras Hindu University and registered himself both for LL. B and Master in Political Science. In his final year, there was the call of 1942 movement. For his active participation in Quit India Movement, he was externed from Banaras Division.

Thereupon he came back to his native place to mobilize public opinion against Second World War. He was arrested and imprisoned for one year in Balasore jail. Once out of the jail, he was shaken by the devastating cyclone that hit the entire northern Orissa in 1943. For several months he was busy in relief operations in this area.

Then he went to Calcutta University with the hope of completing his Law. There he met Dr Shyama Prasad Mukherjee who helped him in completing his LL. B in 1946. During his stay in Calcutta he was actively associated with the Calcutta based Utkal Samaj and worked extensively in riot-torn Calcutta in 1946. He was also the Editor and Managing Director of 'Prajatantra', a leading Oriya daily, in 1947-48.

In 1948, he was elected unopposed for the first time to the Orissa Legislative Assembly. In 1952 he joined the Council of Ministers as a Deputy Minister. From 1948 to 1951 he was the President of the Orissa Branch of Indian National Trade Union Congress. In 1963, when he was the Labour Minister of Orissa, he was nominated to lead the Indian delegation to International Labour Organisation in Geneva.

In later years he continued as a Minister and in 1965 he was made the Deputy Chief minister of Orissa. He was elected as the President of Utkal Pradesh Congress Committee in 1967 and continued in that position till 1970, He left Congress in 1970 and subsequently became President of the Utkal Congress which was formed after break-up of the Congress Party in Orissa. From 1971 to 1973, he was again the Deputy Chief Minister of the State. In 1974, he became the President of Bharatiya Lok Dal. In 1976, he was elected to Rajya Sabha. He resigned his Rajya Sabha seat in 1977 after he was elected to State Legislative Assembly on Janata Party Ticket and became the Chief Minister. He continued as the Chief Minister of Orissa till 1980.

Shri Routray is one of the most respected surviving freedom fighters and political leaders in Orissa. He is known for his amiable personality and political maturity. In 1986, he published his autobiographical volume "Smruti O Anubhuti" in Oriya.

SYMPOSIUM

How Far the Goal of Leprosy Eradication by 2000 A.D. is Achievable?

(a) If **yes,** what is the Progress?

(b) If **not,** what are the Impediments? and How can they be overcome?

Can leprosy be erdicated by 2000 A.D.? Or controlled? Is it worthwhile to have an eradication programme when the medical opinion worldwide is that disease can only be controlled and not fully eradicated? Will the multidrug therapy prove effective? These are some of the questions that come to one's mind. SWASTH HIND, in this Symposium, had invited the opinion of three distinguished experts on leprosy who have done a yeoman service in the field.

T.N. Jagadisan has this to say : "Even with an all-out effort on a war-footing to bring MDT to the door of every patient, we may have to work at the programme for another ten years beyond 2000 A. D. frrtting out new cases and observing the cured ones".

"We need not worry too much about eradication of leprosy if we succeed in creating such an atmosphere (where leprosy patient is assured that he will not be discriminated against either by medical profession or society) eradication will come later when we have better immunological tools", says S.P. Tare.

The noted Anthropologist, R.K. Mutatkar, asks : Are our programmers willing to change the orientation of the programme from eradication of infection to control or prevention of deformities? If Yes, the disease will be controlled by the year 2000".

We reproduce here the views of these experts.

S. P. TARE

DIRECTOR, GANDHI MEMORIAL LEPROSY FOUNDATION, WARDHA

THE Government of India has pledged itself to eradicate leprosy by 2000 A.D. This decision was taken in 1983 by the Union Cabinet under inspiration of Smt. Indira Gandhi, the then Prime Minister. A Study Group was appointed by the Union Cabinet to chalk out the strategy for eradication of leprosy by 2000 A.D.

The background for this optimistic objective was that we had a very promising technology in the form of multi-drug therapy (MDT) and it was believed that if this is made available quickly to all patients in the country, it may be possible to eradicate leprosy. This was one of the important recommendations of the above Study Group to achieve the objective.

Majority of leprologists and leprosy workers, however, had their apprehensions about the time-table, though they agreed on the imperative to achieve the objective of Zero-leprosy. A period of seven years has passed and there is more sober realisation based

on the performance of MDT projects so far about the problems in achieving the desired objective within the time frame.

Progress so Far

There are 196 endemic districts in India to be covered under MDT of which over 100 have been covered. The first district in India to be covered was Wardha in 1982. Since then, six districts have completed over six years and 14 districts over five years. The rest of the districts have functioned for less than five years. The Government proposes to cover all endemic districts by the end of the Seventh Plan. Over 17.77 lakh patients have been brought under treatment in 65 districts till March 1989. Of these, 10.18 lakh patients were discharged from treatment and 7.59 lakhs are under treatment. The reduction in prevalence is over 75% in nine districts, and between 50% in 16 districts.

It will not be out of place to refer to the experience of MDT in GMLF's (Gandhi Memorial Leprosy Foundation) Leprosy Control Unit at Sewagram. The Unit had a prevalence of 23.30 in 1951-52 when control work was started and monotherapy of DDS was introduced. By 1977, the prevalence came down to 8.15/'000. It was at this stage, that multidrug therapy was introduced in the Unit. The new case detection rate was 2.7/'000. Multidrug therapy was extended to pauci-bacillary patients from 1984. The prevalence in October 1989 is 1.0/'000 and new case detection rate is 0.51/'000; the reduction being 88% and 72% respectively.

The experience of over six years on large scale is considered inadequate for having an effect on interruption in transmission of leprosy. There is no evidence of reduction in incidence of leprosy in MDT districts so far. But in all MDT districts there is a universal experience that voluntary reporting has increased and new cases tend to come on their own without fear or hesitation. The intense activity of workers moving from village to village in a jeep and giving supervised treatment on the roadside, impresses the patients. The pauci-bacillary patients need treatment for six months; they are regular for this small duration and are "removed from treatment". As they form over 85% of the total patients, there is a remarkable reduction in load of active cases.

Another indirect result of the intense and hectic movements of leprosy workers to cover their circuits is that people in villages have become more conscious of the leprosy problems in their midst, and more appreciative of the anti-leprosy campaign. This has a definite impact on the social stigma against leprosy with evidence of its gradual reversal.

What are the Impediments?

There are two types of impediments in the campaign to eradicate leprosy by MDT. Some are related to scientific aspects of leprosy and some are of an operational nature.

Among the scientific aspects, there are a few problems:

1. There is no evidence, in medical history that any disease has been eradicated by medication alone. Hence, it is doubtful whether in absence of any immunological tools, leprosy can be eradicated by multidrug therapy.

2. Due to the imminent danger of dapsone-resistance, there was no adequate time to try out experiments to standardise the drug regimen for multi-drugs. The regimen presently in force is thus not decided on the basis of any scientific controlled trials.

3. We have lacunae in the knowledge about transmission of leprosy and in the absence of that knowledge, the entire strategy is based on detecting EVERY patient of leprosy and treating him till he is cured. But firstly, detecting every case of leprosy is an impossible proposition on national scale, and secondly, the detection of a multibacillary patients is always late in the sense that he may have done the damage before being detected as a case.

4. There are very few drugs which are useful for cure in 100% cases. That is true about multidrug therapy as well. Secondly, the drugs may kill very very large number of bacilli but not *all* bacilli. The presumably very small percentage of surviving bacilli may keep the disease lingering and these lingering/surviving germs may not respond to the available drugs.

The problems relating to operational aspects are still more formidable:

1. The necessary preparation before introducing MDT in a district is many times not done due to the haste to increase geographical coverage.

2. There are number of lapses in monitoring with the result that in places, drugs are not available in enough quantity, vehicles are supplied late and there is no adequate provision for oil; vehicles are not on road and repairs are not made in time for shortage of funds/orders; bacteriological work is the weakest link in the MDT programme; disinterested medical officers and workers hurriedly hand over the drugs to road-side patients without verifying spot intake; patients are not examined properly before being put on MDT; etc. The list can be long one.

3. There is an unnecessary haste to fulfil the targets of case-detection and stoppage of treatment with the results that patients are removed at the completion of the standard duration of treatment without getting satisfied about both clinical and bacteriological inactivity.

4. The case-detection activity (survey of total population) has been relegated to a back place,

and only patients noticed casually and those who voluntarily come forward are recorded as new cases.

5. The actual attendance of patients in MDT has gone down to 50% or less in MDT districts which are functioning for three years or more. Moreover, the supervised part of drug-intake is for one drug only but that drug is also handed over to patient.

6. Another important function which is not receiving the desired attention is about surveillance. Once a patient is removed from the treatment register, he is as good as forgotten and not subsequently contacted.

The indirect effect of the great importance given to MDT programme has been on the Leprosy Control Programme in the districts where monotherapy is in progress is completely forgotten, and out of mind of the administrators. There is is no supervision and guidance in these districts where lakhs of leprosy patients are living. One can understand that due to many constraints, MDT could not be introduced in all endemic districts, but there can be no justification for neglecting them as grossly as it was occurred.

How to Improve?

MDT is a very valuable tool and can be helpful in reducing the patient-load and taking us nearer to our ultimate objective. What is actually happening however is that in the enthusiasm for the new technology, it is equated with total leprosy control programme and all other aspects and activities are neglected, as also work in those areas which are as yet uncovered under this technology. Active case-detection programme, individual attention to patients and their problems and the closer interaction between the patient and the doctor, health education in a systematic manner, surveillance of patients need to be paid more attention.

It is also necessary that efforts are earnestly made to involve general health workers in leprosy. The varticle leprosy programme cannot, and need not, be continued so, it has to be horizontalised with general health services in not too distant a future. Very little efforts have been made in the last three decades to involve them, train them, and motivate them.

As a part of the above horizontalisation, it is necessary that involvement of entire medical profession (either in services or in practice) is achieved. An experience of a leprosy patient being welcome in a general hospital, PHC clinics and private dispensaries/clinics will convince society that leprosy is a disease like any other. Once this is achieved, there will be no reason for an early patient of leprosy to conceal his disease, and the quicker he comes forward to take treatment, the safer will it be for the rest of the society.

The problem of a leprosy patient is not the 'disease' as such which gives him no physical discomfort in early stage, but the fear of societal attitude towards him. Once he is assured that he will not be discriminated either by medical profession or the society, he will take treatment, get cured and will not hesitate to tell others that he had leprosy. We need not worry too much about eradication of leprosy if we succeed in creating such an atmosphere: eradication will come later when we have better immunological tools.

T.N. JAGADISAN
HONORARY SECRETARY
KASTURBA KUSHTA
NIVARAN NILAYAM

COMMUNICABLE diseases are eradicated by vaccination if vaccines are available for the particular disease. In the case of smallpox, eradication on a global scale has been achieved through successful vaccination. In the case of leprosy, vaccines have been produced and are reported to be effective. But, the administration of vaccines on a wide scale can be attempted only on further investigations on a global scale in differing epidemiological and social conditions Hope of eradication has therefore been fixed on early detection and treatment of leprosy patients with effective drugs which have a bacteriocidal effect. Today, there is a general agreement among experts that multidrug therapy (MDT) is the key to leprosy eradication.

"Is it possible to achieve through MDT leprosy eradication by 2000 AD?".

Before answering this questition, let us take a brief backward glance at the previous history of leprosy treatent.

Search for a drug: The search for a drug for leprosy was a tortuous quest and a long story. First chaulmoogra or hydnncarpus (the best of the drugs of the presulphone era), then methylene blue, then trypan blue—short-lived wonders—then diphtheria toxoid treatment and back again to Chaulmoogra externally, internally and eternally', as the wag said. →

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Sulphone therapy: The outlook on leprosy treatment brightened with the coming of the revolutionary sulphone therapy. For the first time cheerfulness and positive hope entered the treatment of lepromatous leprosy and its remoreseless multiplication of leprosy bacilli could be arrested. An entirely new situation now arose for the leprosy patient. He could get treatment as near to his home as possible. He could look forward to cure if only he took the right number of the right tablets under medical Supervision over the prescribed length of time. The dread of isolation and separation from family and work was gone. The leprosy patient could be a man like other men, living in society and looking after his family. The administrator was quick to seize the opportunity of the new method of leprosy control. Widespread treatment with Dapsone through out-patient clinics became the new strategy. The Report of the WHO Expert Committee on Leprosy (1953) declared: 'Modern treatment which effectively reduced the infection in leprosy patients, and therefore their infectiveness, is regarded as the most potent generally applicable weapon now available in the control of the disease".

Undoubtedly, sulphone therapy has maintained its place as effective for the vast majority of patients since it can be reached out to a large number of patients at a low cost. Over the years, we have come to know the merits and limitations of sulphone therapy. Treatment with sulphones was prolonged and patients tended to be irregular and they even dropped out. New cases cropped up in sufficiently large numbers and relapses occurred not infrequently.

The great enthusiast of leprosy eradication through extensive administration of sulphones, the late Dr. James A. Doull wrote a sad confession towards the end of his life. "The eradication of leprosy promises to be a long and difficult task; sulphone therapy is of great benefit to the patients, but its value as a preventive is problematic". Moreover, by about the middle of the last decade, the leprosy bacilli had learnt the trick of resisting the effects of Dapsone and the phenomenon of drug resistance not unknown in other diseases like tuberculosis, became a subject of world-wide concern. At this juncture, experts began to think of combining more than one drug for the treatment of leprosy.

Dr Enno Freerksen, Director of the Institute for Experimental Biology and Medicine at Borstel, West Germany, conducted a well-conceived and well-executed eradication programme in the Isle of Malta in close co-operation with the German Leprosy Relief Association. This programme, which was continued for a period of ten years, was highly successful. A follow-up investigation of the Malta Project by Dr. W. H. Jopling and other experts of the WHO confirmed the success of the project in eradicating leprosy in the island. They were specially impressed by the fact that no side-effects had been encountered during the treatment. The WHO Expert Group had already come forward with their recommendations in the Technical Report Series No. 675, 1982, that three drugs, Rifampicin, Clofazimine and Dapsone, be used in multi-drug therapy.

Potency of multidrug therapy

The potency of multidrug therapy has come to be recognised. The patients, their relations and the public have been impressed by the results. The regularity of attendance has improved. The great advantage of MDT is that it is bacteriocidal and not merely bacteriostatic. The period of treatment under MDT is relatively short. It is, however, costly. Happily, International Organisations like the members of the ILEP have come forward to collaborate with Governments in MDT programmes and also to assist voluntary organisations to carry out multidrug therapy work. Wherever MDT programmes have been carefully administered and monitored, the prevalence and the incidence of the disease have come down and new deformity is a rare occurrence. **So, leprosy eradication by 2000 AD through MDT is achievable and the progress so far made is encouraging**

The progress

The progress is noteworthy. However, large endemic areas in endemic countries have not still come under MDT. There should be a rapid extension of MDT work without sacrifice of quality. Pilot projects like that of Malta have given a positive answer. But even if the cost of the treatment is overcome by increased Governmental allotments and the philanthropy of International and National Organisations,

(*Contd. from page 12.*)

(iv) NLEP consultants/Consultant Leprologists have been appointed by the WHO at the request of the Government of India and are assigned one or more States/Districts to be the eyes and ears of the Government of India/State Government to monitor the programme activities in the State including the progress of MDT districts.

2. *Parameters/Indicators*:

The selection of parameters/indicators for monitoring has to be correctly done. Selection of a large number of parameters may be good in a way out it will entail collection of information in a detailed manner involving more desk work by field staff. Hence it is essential to include only, the important, parameters/indicators so that it will be possible to monitor regularly. The indicators in multidrug treatment can be classified as (i) Operational, (ii) Clinical and (iii) Epidemiological.

3. *Operational Monitoring*:

This includes:

(i) Sanctioning of posts, positioning of personnel and ensuring that they are trained as per time schedule prescribed.

(ii) Supply of drugs, vehicles and other logistic facilities and their utilisation.

(iii) Screening of all existing cases by medical officers in the stipulated period before the implementation phase starts and maintenance of prescribed case cards.

(iv) Updating of records at various levels.

(v) Drawing of the time schedules for various phases of the project including preparation of calendar.

(vi) Promt release of advances by GOI/its approved agencies.

(vii) Formation of District Leprosy society and convening meetings periodically.

(viii) Preparation of health education action plan and its implementation and

(ix) Validity of reported data to be ascertained by periodical checks by the assessment team.

4. *Clinical Monitoring*:

The important indicators to be monitored are:—

(i) Proportion of multibacillary cases who have regular and adequate treatment.

(ii) Proportion of paucibacillary cases who have regular and adequate treatment.

(iii) Proportion of cases with complications who are on adquate and regular treatment.

(iv) Proportion of cases released from treatment (RFT).

(v) Clinical surveillance rate for multibacillary cases.

(vi) Clinical surveillance rate for paucibacillary cases.

(vii) Bacteriological surveillance rate for multibacillary cases.

(viii) Relapse rate.

The indicators (i) to (viii) are to be calculated from the data furnished in the monthly report.

5. *Epidemiological monitoring*:

(i) Proportion of cases registered as against estimated cases (estimated by survey team).

(ii) Prevalence rate.

(iii) Incidence rate/new case detection rate.

(iv) Proportion of multibacillary cases to total new cases.

(v) Proportion of cases with deformities to total new cases.

(vi) Proportion of cases among children to total cases.

(vii) Proportion of cases among contacts.

(viii) Proportion of new cases voluntarily reported.

It is essential to have the figures for all these indicators before starting multidrug treatment so that its progress can be assessed. △

WORLD HEALTH DAY—1990

THEME IS "OUR PLANET OUR HEALTH—THINK GLOBALLY ACT LOCALLY"

This double slogan, with the echo of the words of the late French ecologist Rene Dubos, has been chosen by WHO to epitomise World Health Day 1990. The choice reflects the growing awareness of environmental problems, and WHO's conviction that they will be a major topic of worldwide concern during the next decade—and indeed well into the 21st century.

In choosing the broad theme of environment and health for World Health Day this year, WHO intends to spotlight the measures that individuals, communities and countries can and must take to check any further deterioration in the overall health of the planet; because it is on the health of the Earth that depends the health of all its human passengers. △

INTERNATIONAL GANDHI AWARD ON LEPROSY-1990

IT is, indeed, fitting that medical scientists who have devoted their entire career to combat the dreaded disease—leprosy—are honoured not only in recognition of their pioneering work but also to kindle among the young medical scientists the spirit to enter this field. This is because leprosy is the least attractive discipline among medical research.

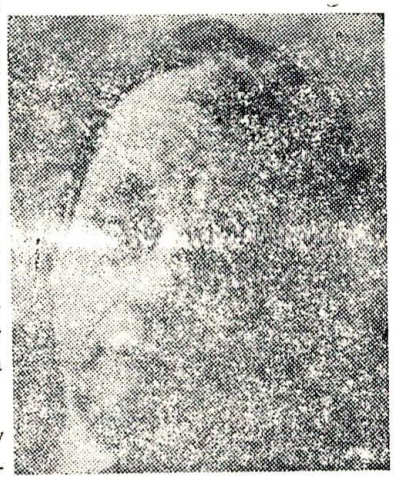
It was towards this end that the wardha-based Gandhi Memorial Leprosy Foundation instituted the International Gandhi Award for presentation once in two years to one Indian and one foreign leprologist in 1986. And if, within four years of its inception the Rs. 1 lakh award has already acquired a prestige, it is reflected in the choice of the recipients.

The first set of recipients in 1986 included Dr (Mrs.) Turkan Sylen of Turkey and Dr Dharmendra of India and the second set in 1988 included Dr Ma Hai De of China and Dr T. N. Jagadisan of India—all renowned for their valuable contribution to the understanding and treatment of the disease on the one hand and rehabilitation of the cured patients on the other.

The third set—Dr Michael F. Lechat of Belgium and Dr Ramachandra Vishwanath Wardekar—recipients for the 1990 award, belongs to this galaxy of leprologists.

Dr Lechat

AT 62, Dr Lechat has established himself as a leading epidemiologist who has contributed greatly to the epidemiological understanding of the leprosy problem. A specialist in tropical medicine and a doctorate from the Johns Hopkins School of Public Health in Baltimore (U.S.), Dr Lechat's involvement with leprosy work dates back to 1953 when he took over as Medical Director of Lyonda Leprosy Hospital in Mbandaka (Belgian Congo).



Dr. Michel F. Lechat

The following years saw him in a variety of assignments round the world as consultant to the World Health Organization, the World Bank and the Swedish International Development Agency. This brought him to India also where he worked as WHO consultant in 1986. His contribution to the understanding of the disease led him to associate himself actively with various national and international organisations engaged in this field. He was President of the International Leprosy Association for a decade from 1978, President of the Medical Commission of International Federation of Anti-Leprosy Association (1974-78), the Associate Editor of International Journal of Epidemiology, Member of the WHO panel of experts on leprosy, and Honorary Chairman of International Leprosy Union.

Dr Wardekar
—father of leprosy control work in India

THE Indian recipient, Dr Wardekar can rightly claim to be the father of leprosy control work in India, which accounts for one-third of the estimated 12 million leprosy cases in the world. Way back in 1955, when the Nationa Leprosy Control Programme was launched, the Government of India accepted the methodology for leprosy control work evolved by Dr Wardekar who was also nstrumental in the drafting of the first four five-year plans for leprosy.

Dr. R. V. Wardekar

The goal was subsequently changed from control to eradication and towards this and a scheme of covering endemic districts with Multi Drug Treatment has been introduced. A perceptible decline in the prevalence rate has been noticed in the 112 endemic districts covered by the MDT programme. But there is still a long way to go to reach the target by the turn of the century.

There can, however, be no two opinions that the strong foundation for this work was laid by the septuagenarian

(Contd. on page 24)

HEALTH SECTOR
—PRIORITIES IDENTIFIED

NILAMANI ROUTRAY

In our efforts to achieve Health for All by 2000 A.D., steps have been taken to carry health education to the common man. The Government is close to achieve the target for health delivery infrastructure in the rural areas. Voluntary Organisations and opinion leaders are being encouraged to spread the health and hygiene awareness among the masses. With collective efforts of all, a cent r cent healthy nation is not a distant dream, says Shri Nilamani Routray, Minist of Health and Family Welfare.

HEALTH for all by 2000 AD as envisaged in the National Health Policy is a worthy aim indeed. However, it will continue to evade the country unless we redefine priorities and policies. There has to be a shift in the accent and on priorities considering the fact that health services are concentrated in urban areas and rural India continues to remain backward. Any action plan on health for all has to incorporate ways and means of not only increasing the number of Primary Health Centres and Sub-Centres, but has also to ensure that the necessary manpower is deployed to man them. Medical Profession continues to be urban-oriented in our country despite all our efforts in the past to persuade qualified medical and para-medical personnel to fan out in rural India, settle down there and cater to the health needs of the common people. In fact, our efforts should be to take 'Health' to the doorsteps of our villagers. There is a need for establishing well equipped medical centres of education and research in the rural areas.

India has made significant achievements in various health programmes since Independence. The investment on Health which was Rs. 65.2 crores in the First Five Year Plan has gone upto the level of Rs. 3392 crores during the Seventh Plan. The significant progress made in the control-cum-eradication of major communicable diseases has resulted in the decline of death rate from 27.4 in 1941-50 to 10.9 in 1988. This has contributed appreciably to the rise of expectation of life from 32 years in 1941-50 to 58 years in 1985-91. The infant mortality rate considered to be an index of health status has shown a steep fall from 183 per thousand live births in 1941-50 to

44 in 1988. The birth rate has also declined from 39.9 per cent in 1988.

TREMENDOUS SUCCESS

A number of National Health Programmes launched for the control and eradication of major communicable diseases have recorded tremendous success. Smallpox has been completely eradicated due to intensive campaigns undertaken in collaboration with the World Health Organisation (W.H.O.) and the State Governments. The country attained Smallpox free-status in July 1975. The cholera control programme started in 1970 has brought down the number of cholera cases and deaths from 86,835 and 42,070 in 1951 to 5,813 and 154 in 1985.

Leprosy Eradication

For Leprosy, a National Leprosy Eradication Programme was launched in 1982 with the specific goal of arresting disease activity by 2000 A.D. The programme has rapidly expanded having a wide infrastructure consisting of 708 Leprosy Control Units, and 7400 Survey and Treatment Centres as on March 31, 1988. For the first time in 1987-88 the number of cases cured were higher by 10 per cent than the number of cases detected. This trend continues. The Multidrug Treatment introduced in 1982 has proved very successful in treatment of Leprosy cases.

Tuberculosis Control

Deaths due to Tuberculosis, a major killer, have also declined considerably with the launching of National TB Control Programme. Under the programme detection of new TB cases averaged at approximately 16 lakhs in a year registering an increase of about 26 per cent over 1985 figures. To reduce the duration of treatment of TB patients from 18-24 months to 6-8 months, short course chemotherapy drug regimen with very potent anti-TB drugs was-introduced and so far 176 districts have been covered during the last four years (1984-88). This is being extended to another 75 districts this year.

Blindness Control

Under the National Programme for Control of Blindness, each year on average, a target of 12 lakh cataract operations are fixed for the country as a whole. The achievement rate which has been more than 85.1 per cent since 1985 is close to 99 per cent during the current year. Important initiatives taken have been on training of Ophthalmic Assistants, greater involvement of voluntary organisations and setting up of Opthalmic Cells in 18 major States.

FIGHTING AIDS AND DRUG ABUSE

To meet the emerging threat of AIDS, a new Programme for control of AIDS with its three major components, namely, surveillance, education and information and screening of blood donors was launched in 1985. We now have 40 surveillance centres for screening persons in the high risk groups. In addition, 28 zonal blood testing centres have been established in Metropolitan cities for screening blood donors. Blood donor screening facility is being expanded to cover all cities with a population exceeding 0.5 lakhs. On the one hand, research and training of doctors in the proper treatment of the disease have been started and on the other, **health education to increase general awareness regarding AIDS in schools, colleges and in the public at large is also being undertaken.** Allied to this, a new scheme for development and modernisation of blood banking and transfusion services has also been launched, which aims at testing of blood from donors, its safe storage and supply to the needy patients.

To fight the overgrowing problem of drug abuse/addiction, a drug de-addiction programme has been launched which provides for setting up of Drug De-addiction Centres in major hospitals in big cities. Establishment of 30 bedded Drug De-addiction Centres in seven hospitals at Delhi, Chandigarh and Pondicherry has already been sanctioned. Besides, efforts are being made to set up OPD facilities in major private hospitals at Delhi, Vellore Ludhiana, Bombay, Madras and Calcutta.

Health Education

Above all, these years have seen a shift in the emphasis from the earlier curative approach to the preventive and promotive approach providing for more and more Health Education to the common people with the aim of obtaining 'Health for All by the year 2000 A.D.' in accordance with the objective of 'National Health Policy'. Several new health programmes for the control of diabetes, for dental health care etc. have also been launched in the current Plan.

POPULATION STABILIZATION PROGRAMMES

Family Planning Programmes have formed the core of development planning in India. Allocation

for the same under the Plans increased from 6.5 million in the First Five Year Plan to Rs. 32,560 million in the 7th Five Year Plan. About 106.2 million births are estimated to have been averted upto March 1989 as a result of the work done since inception. However, the annual rate of population growth continues to be still alarmingly high (over two per cent). This is due to a relatively slow lowering of birth rate accompanied by a rapidly declining death rate and hence this forms the base of the present demographic problems.

The total number of family planning acceptors enrolled under the programme has gone up from 16.44 million in 1984-85 to 24.11 million in 1988-89—a record since the inception of the programme. The National Health Policy 1983 has enunciated the long-term demographic goal of the country to reach a net reproduction rate of one by the year 2000 A.D. at the lowest feasible levels of birth rate at 21 per thousand and death rate at 9 per thousand.

UNIVERSAL IMMUNIZATION PROGRAMME

Provisions of services for safe motherhood and for ensuring child survival form the major planks of the family welfare programmes. Prophylaxis against nutritional anaemia for both the mother and the child continues to be provided free by giving them iron and folic acid tablets and solutions. The children between 1-5 years are also given Vitamin 'A' doses twice-a-year to prevent Vitamin 'A' deficiency.

With a view to protect children against six common childhood diseases, an 'Universal Immunization Programme' was started in the year 1985. It is stipulated to immunize 100 per cent pregnant women against Tetanus and at least 85 per cent of the infants against Diptheria, Pertussia, Tetanus, Tuberculosis, Poliomyelitis and Measles by 1990. Uptake of all the immunization services both to the expectant mothers and infants has received a significant increase since 1985. The coverage level under immunization programme has steadily risen from 51 per cent to 75 per cent in case of DPT vaccines, 40 to 72 per cent in case of DPV, 30 to 79 per cent in case of BCG vaccine and from 40 to 63 per cent in case of TT (PW) by 1986-89. Oral Rehydration Therapy is also being promoted to save children from deaths caused by dehydration due to diarrhoea. Ready-to-use Oral Rehydration Salt (ORS) packets are being distributed free through our health services outlets.

CATERING TO RURAL NEEDS

In our efforts to achieve Health For All by 2000 A.D., steps have been taken to carry health education to the common man. The government is close to achieve the target for health delivery infrastructure in the rural areas. Against a target of establishing 1,30,000 sub-centres, 21,666 primary health centres and 2,708 community health centres throughout the country by March, 1990, 1,21,776 sub-centres, 19,173 primary health centres and 1,665 community health centres were functioning upto 30 June, 1989.

Efforts are afoot to attain the goal of 'Health for all by 2000 A.D.' by making it a people's movement. Voluntary Organisations and opinion leaders are being encouraged to spread the Health and Hygiene awareness among the masses. With collective efforts, of all, a cent per cent healthy nation is not a distant dream.

(*Contd. from page 21*)

leprologist whose main contribution lay in changing the conventional method of leprosy work and bringing anti-leprosy work out of the four walls of colonies. He was instrumental in bringing about governmental lead and participation in leprosy work.

Dr Wardekar was largely responsible for laying down the patterns of leprosy control units, SET (screening, evaluation and treatment) centres, training centres, urban leprosy centres and referral hospitals. He won laurels for this and these included the Padmashri and the Dr P. N. Raju Oration Award of the ICMR, both in 1973.

Dr Wardekar has many publications to his credit covering various facets of protection against the disease, its control and rehabilitation of leprosy patients. He was President of the Indian Association of Leprologists in 1965-67, Secretary of the Leprosy Expert Group of the ICMR, Member of the WHO expert advisory panel on leprosy and a Member of the second leprosy expert committee.

NEWS

WHO LAUNCHES 'INTER-HEALTH'

—A Programme Against Diseases of Lifestyles

The World Health Organization (WHO) has announced the launch of "Inter-Health", a programme which sounds a warning against the threat to health of noncommunicable diseases—the diseases of lifestyles—and urges nations to act against them.

According to WHO, noncommunicable diseases are the cause of 70 to 80 per cent of deaths in developed countries and of 40 to 50 per cent in developing countries.

A mosquito transmits malaria; a black fly, onchocerciasis or river blindness; a bug, Chagas' disease; a worm, dracunculiasis; a flea, plague; a bacterium, cholera; and a virus, polio. These diseases are communicable in the age-old manner through a single vector: a parasite, bacterium or virus.

Such is not the case with noncommunicable diseases. They are "man-induced", caused by choice of lifestyles—notably by too much fatty foods, salt, and alcohol; by tobacco; by a lack of exercise; and by polluted air.

One bad habit carries multiple risks to ill-health, as for instance:

—Improper diet carries the risk of stroke, heart disease, hypertension, colorectal, and stomach cancers, diabetes, osteoporosis (a bone disease), malnutrition, obesity and gastric ulcers.

—Tobacco holds the risk of heart ailments, lung and mouth cancers as well as of respiratory diseases.

The aim of WHO's Inter-Health programme is to promote healthy living, as well as to advance the cause of tobacco—free societies.

Cardiovascular diseases and cancer already figure among the three leading causes of deaths, after the teenage years, in both the developed and developing world, WHO statistics show. Moreover, in absolute numbers, there are more cancer cases and deaths in developing countries than in industrialized countries.

Lifestyles are no longer purely conditioned by climate or by culture, he stated, but "are influenced by newspapers, magazines, radio, films and television. Lifestyle are imitated as fast as the written and electronic media transmit ideas from country to country".

The developing countries, therefore, bear a "double burden of age-old, communicable diseases—such as malaria, schistosomiasis, and other tropical diseases —and of man-induced, noncommunicable diseases."

—W.H.O. Release

ADALAT FOR CGHS BENEFICIARIES AND HOSPITAL PATIENTS

The Ministry of Health and Family Welfare has set up a *Shikayat Adalat* to look into the grievances of Central Government Health Scheme (CGHS) beneficiaries and the public receiving treatment at government hospitals. This Adalat will have a four-member bench chaired by a Deputy Director General of Health Services. The Adalat will take up complaints relating to CGHS and hospitals services and will be held once in three months.

All complaints may be addressed to Director (*EMR*), *Directorate General of Health Services, Nirman Bhavan, New Delhi*-110011. Δ

—Civil Services News, Oct. 1989

YOUR EYES

GLAUCOMA (KALA MOTIA)-A BLINDING DISEASE

* **Glaucoma (Kala or Neela motia) is a blinding disease.**
* **In India one in seven eyes of glaucoma patients had lost vision before going to the hospital.**
* **One in 80 patients had lost sight in both eyes and was not aware that loss of sight was due to glaucoma.**
* **Glaucoma and cataract occur in the same age group - above 35 years.**
* **Blindness due to cataract can be corrected by simple operation but blindness due to glaucoma cannot be cured.**
* **Dull pain in the eyes, difficulty in seeing in dim light, seeing rainbow colour ring around the bulb, frequent change in reading glasses (often in a year) are some warning signals of glaucoma.**
* **Whenever you go for eye examination, get your eye pressure checked to rule out glaucoma.**

National Society for the Prevention of Blindness - India,
Dr. R.P. Centre,
AIIMS, New Delhi - 110 029.

Authors of the Month
and

Dr S. K. Noordeen
Chief Medical Officer
Leprosy Division of Communicable Diseases
World Health Organization
Geneva, Switzerland

Dr M. D. Gupte
Officer In-charge
CJIL Field Unit,
Indian Council
of Medical Research,
271, Nehru Bazar,
Avadi, Madras-600 054

Dr D. K. Mahabalaraju
Lecturer in Community Medicine
JJM Medical College
Davangere-577 004

Dr Saudan Singh
Asstt. Professor

Dr Sanjiv Kumar Bhasin
Senior Resident
Deptt. of Preventive and Social Medicine
Maulana Azad Medical College
New Delhi-110 002

Dr P. N. Neelan
Director
Central Leprosy Teaching & Research Institute
Ministry of Health and Family Welfare
Chengalpattu-603 001

Dr N. S. Dharmshaktu
Dy. Assistant Director General
Leprosy Division
Dte. General of Health Services
Nirman Bhawan
New Delhi-110 011

S. P. Tare
Director
Gandhi Memorial Leprosy Foundation
Hindi Nagar, Wardha-442 103

T. N. Jagadisan
Honorary Secretary
Kasturba Kushta Nivaran Nilayam
Malayanthangal Post
(Via) Kandachipuram-605 701, SO
South Arcot District

R. K. Mutatkar
Deptt. of Anthropology
University of Poona
Pune-411 007

Smt. Krishna Basra
Librarian 'Grade—I'.
National Medical Library
Ring Road, Ansari Nagar,
New Delhi-110 029

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SWASTH HIND

SPECIAL NUMBERS 1989

January	Anti-Leprosy Day
March-April	World Health Day (Theme : Let's Talk Health)
June	Eye Health Care—I
July	Eye Health Care—II
August	Nehru Centenary Special
September	Drug Addiction
December	World Day on AIDS

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Central Health Education Bureau,
Kotla Marg, New Delhi-110 002

BOOK REVIEW

FULFILMENT THROUGH LEPROSY

'FULFILMENT THROUGH LEPROSY' is a well-brought out 436 pages hard-bound book (size 6"×10") written by Mr. T. N. Jagadisan, a selfless and ardent social worker moulded in Gandhian tradition, and published by Kasturba Kushta Nivaran Nilayam, Malavanthangal P. O., South Arcot District, Tamil-Nadu-(605 701), India.

This is an autobiography. Mr. T. N. Jagadisan, who was awarded Padmashri in 1957 and International Gandhi Award for Leprosy in 1988 and who had been described by the President of India, Mr. R. Venkataraman, as "the nearest approximation that I know of to Gandhi's concept of a constructive worker, cardinal Newman's definition of gentleman and *Bhagavad Gita's* ideal of a *sthitha-Pragna*", is it's author. He is a man of letters *par excellence* and at the age of eighty he has written in 'fulfilment through Leprosy' the story of his life with utter candour and humility.

It is an autobiography where the cause is more than the man. It is a record of the history of leprosy—from ostracism to care, from care to cure to rehabilitation. He has been a witness to the various phases of treating the disease, from chaulmoogra oil to dapsone and multidrugs, always insisting on avoiding euphoria, and the supreme necessity of supporting treatment with education and the raising of standards of living.

He was born on 2nd October 1909 in the village Thachakkadu, near Chidambaram in Tamilnadu. His father was a Revenue Inspector, who passed away in 1918 hit by the terrible epidemic of influenza. Thus, Jagadisan lost his father at the age of nine. Though he was still a boy, he had to bear the burdens of a man. When he was a boy of 14, he was married to his elder maternal uncle's daughter Asanambal. What Jagadisan has written about child-marriage in his book is worth-noting: "Early marriage even with one whom you liked, with the prospect of your liking ripening into love, has its great disadvantages. Alas! That in certain sections of our society, early marriage is still the custom. Marriage before one reaches physical, mental and emotional growth, inflicts a psychological trauma and deprives the couple of the real joy of a wedding which is their due, and cripples from the start the growth of their matrimonial life."

He developed non-infectious type of leprosy when he was 10 years old. He had heard the people say most fearful things about leprosy and panic seized him. Those were the days (1926) when the general practioners knew very little about leprosy. He had gone to Karachi for treatment of his cracked and ulcered heel. The doctors at Cuddalore explained him facts about leprosy and assured him that he had a non-serious and non-infectious form of leprosy. But he has experienced wild fear and prejudice of people towards leprosy and the social injustice to which the innocent sufferers are subjected.

The person who made the most profound influence on Jagadisan's life was Right Honourable V. S. Srinivasa Sastri, who was then Vice-Chancellor of the Annamalai University. He gave Jagadisan deepest understanding when he learnt that Jagadisan was suffering from a slight touch of non-infective leprosy. With the support of his master Srinivasa Sastri, Jagadisan took to his heart the vow of educating the people on simple facts about leprosy and make them view leprosy as a disease and not dread it as a social disgrace. He met eminent Leprologists, Dr Robert G. Cochrane, Paul Brand and many others. He was convinced that the greatest harm is done by the patient's fear of ostracism and his painful efforts at concealment till he can no longer conceal.

Leprosy work brought Jagadisan through Thakkar Bapa and Dr Sushila Nayar to Mahatma Gandhi. He visited Sewagram Ashram in February 1945 along with Dr Cochrane, his friend. He stayed thereafter with Gandhiji ever since, spiritually, intellectually and in the realm of constructive work. What Thakkar Bapa was destined to do for Harijans and Girijans, Vaikunthbhai Mehta for Khadi, Sushila Nayar for Prohibition, Soundaram Ramachandran for women's uplift and rural industries, Jagadisan was destined to do for leprosy.

He is the Honorary Secretary of the Kasturba Kusht Nivaran Nilayam, Malavanthangal, South Arcot District, Tamil Nadu, from its inception in 1945 till now. Because of his sustained efforts, it has been possible to bring down the prevalence of leprosy in and around Malavanthangal from 48 per 1000 at inception to 3 per 1000 in 1980s. He was actively associated in organizing the All India Leprosy Workers Conference since its inception till his retirement. He was the General Secretary of Akhil Bharat Kushta Samita.

Mr. Jagadisan's autobiography "FULFILMENT THROUGH LEPROSY" is a useful record of development of strategies for leprosy control during the last 50 years, from segregation to the recent and effective multi-drug treatment through chaulmoogra oil and dapsone, and from ostracism to rehabilitation through care and cure. It is a neatly printed and calico bound book that everybody interested in leprosy should procure and study.

—DR P. V. PRAKASA RAO

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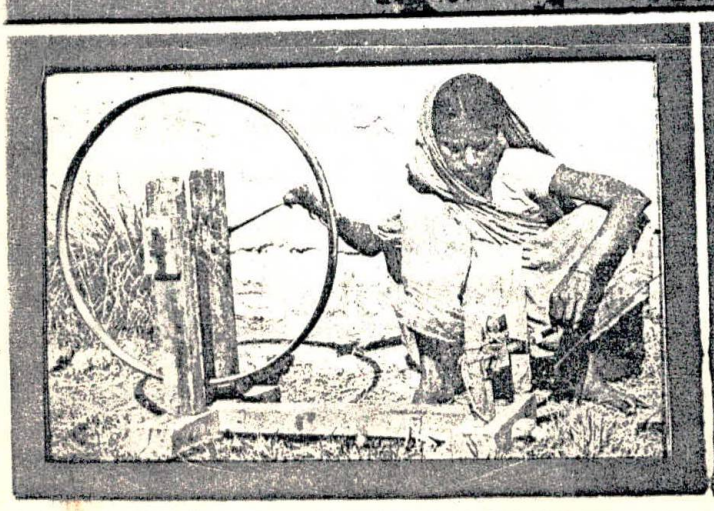

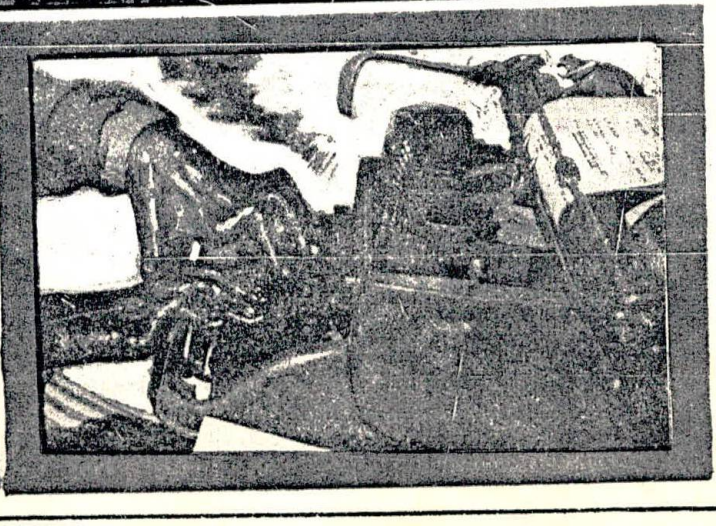

ANTI-LEPROSY DAY NUMBER

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LEPROSY ERADICATION

Mahatma Gandhi's martyrdom day — 30 January — is also observed as the Anti-Leprosy Day in India. For, India ranks foremost among the countries saddled with the burden of leprosy sufferers. It accounts for 2.5 million cases of the world load of Leprosy patients. The Government of India had launched the National Leprosy Eradication Programme in 1983 with the objective to arrest the transmission of the disease by the year 2000 A.D. It is a 100 per cent Centrally-Sponsored Programme.

Keeping this in view this issue of *Swasth Hind* is devoted to the

Anti-Leprosy Day—1993

OBJECTIVES

Swasth Hind (Healthy India) is a monthly journal published by the Central Health Education Bureau, Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India, New Delhi. Some of its important objectives and aims are to:

REPORT and interpret the policies, plans, programmes and achievements of the Union Ministry of Health and Family Welfare.

ACT as a medium of exchange of information on health activities of the Central and State Health Organisations.

FOCUS attention on the major public health problems in India and to report on the latest trends in public health.

KEEP in touch with health and welfare workers and agencies in India and abroad.

REPORT on important seminars, conferences, discussions, etc. on health topics.

In this issue

SWASTH HIND WISHES ITS READERS A VERY HAPPY NEW YEAR

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M. S. Dhillon

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State Health Directorates are requested to send in reports of their activities for publication.

The opinions expressed by the contributors are not necessarily those of the Government of India.

SWASTH HIND reserves the right to edit the articles sent for publications.

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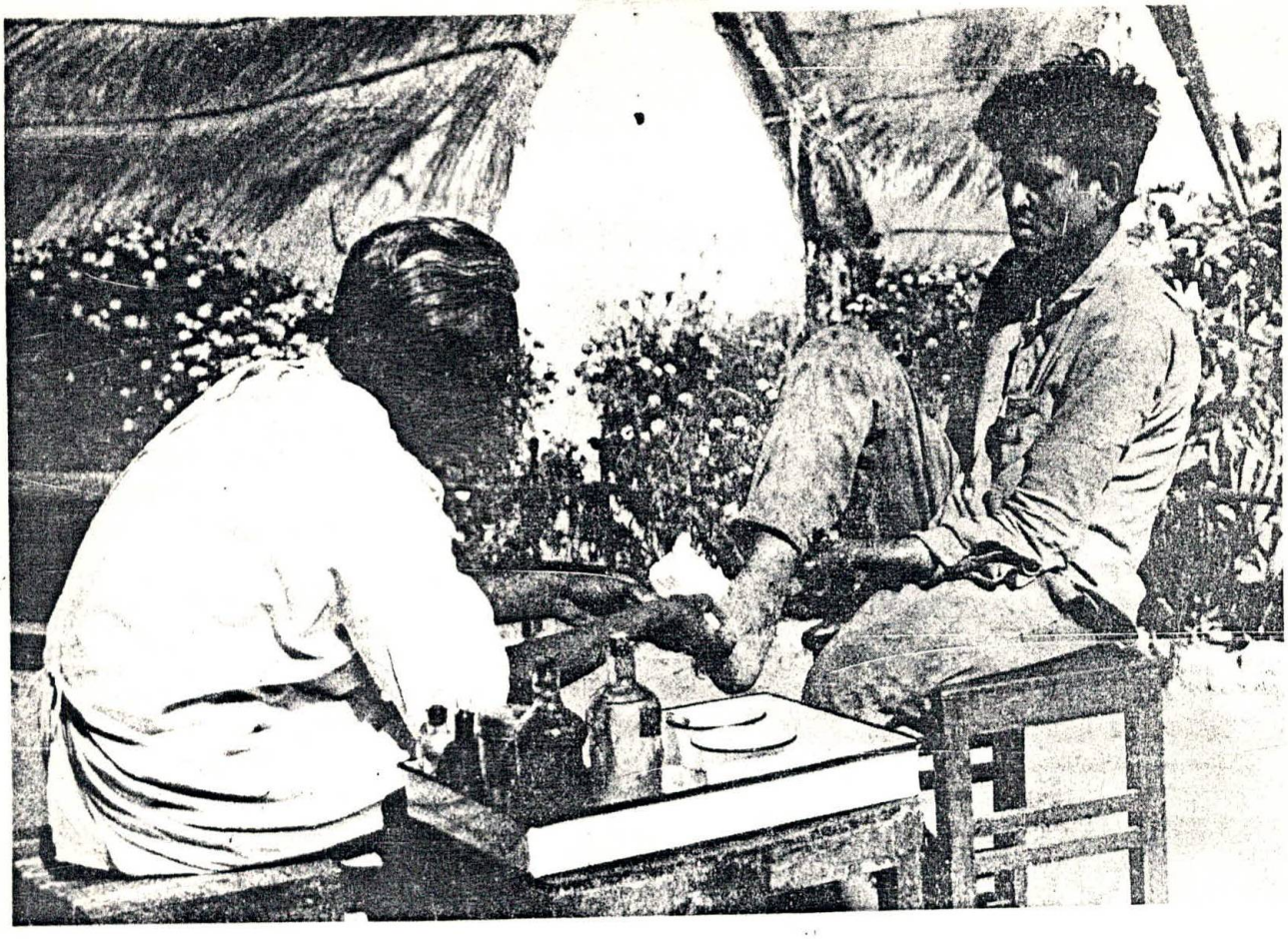


NATIONAL LEPROSY ERADICATION PROGRAMME

T. K. Das

INDIA ranks foremost among the countries saddled with the burden of leprosy sufferers. As many as 2.5 million cases of leprosy are estimated to be found in India. The disease is widely spread all over the country. The prevalence rate of leprosy exists above 5 per 1000 population in 201 districts out of 468 districts of the country. About 15% of the leprosy sufferers are children below 14 years of age. The proportion of infectious cases varies from 15 to 20% and equal number of patients suffer from deformities. At the time of launching of the National Leprosy Eradication Programme in 1983 the disease was highly prevalent in the States/UTs of Tamilnadu, Andhra Pradesh, Lakshdweep, Pondicherry, West Bengal, Maharashtra, Karnataka, Bihar, Nagaland, Sikkim, Andaman & Nicobar. Now the problem of leprosy has been reduced in many of these States.

Programme objectives

The Government of India launched the National Leprosy Eradication Programme in 1983 with the objective to arrest the transmission of the disease by 2000 A.D. It is a 100% Centrally-sponsored programme.

Strategies

The adopted strategy under the Programme involves: (a) Provision of domiciliary multi-drug treatment coverage in 135 districts, having problem of 5 or more cases per 1000 population, by specially trained staff in leprosy, (b) Introduction of modified MDT scheme in the ramaining 66 endemic districts through existing health care staff, (c) Introduction of MDT services through existing general health care services in the low endemic districts, (d) Multi-drug therapy to Dapsone refractory cases in other districts. Treatment with combination of drugs includes treatment with three drugs, *viz.* Rifampicin, Clofazimine and Dapsone. Education of the patients and the community about the curability of the disease and their socio-economic rehabilitation are other two key components of the control strategy.

Infrastructure

Over the years, a wast infrastructure of leprosy workers has been developed in the country, specially trained for providing leprosy services. In the endemic rural areas these services fan out from Leprosy Control Units (one for 0.4 to 0.5 million population) while its urban counterpart called the Urban Leprosy Centre caters to a population of about 30 to 40 thousand. Temporary hospitalization ward having 20-bed capacity has been established, at least one in each endemic district to render hospitalization services. Under the programme 49 Leprosy training Centres are engaged in providing training to various categories of health workers in leprosy. Following infrastructure exists at the end of March, 1992: Leprosy Control Units—758, Urban Leprosy Centres—900, Survey Education and Treatment Centres—6097, Temporary Hospitalization Wards—291, District Leprosy Units—285, Leprosy Training Centres—49, Reconstructive Surgery Units—75, Leprosy Rehabilitation and Promotion Units—13, Sample Survey-cum-Assessment Units—39.

Infrastructure thus created has been predominantly established by the States in the endemic districts. In districts with endemicity of less than 5 per 1000 population, the general health care staff provide the services. However, there are still gaps in the 66 endemic districts due to financial constraints. To extend the benefit of MDT to over 0.7 million patients living in these 66 districts, the Government of India sanctioned a modified MDT approach in these districts from January, 1991. This modified approach includes the involvement of PHCs in the delivery of services to leprosy patients.

Achievements

Currently, about 70% of leprosy patients are getting the benefit of multi-drug therapy in the country. Available information indicates that MDT is well accepted by the patients, the tolerance is good and side-effects are minimum. There is marked reduction of over 90% in the prevalence rate in the 40 districts which have completed MDT of 5 years or more. All the 201 endemic districts and 41 low endemic districts have been covered under multi-drug therapy. Regular training in leprosy has been provided to about 20,000 technical staff. As many as 6.39 million cases have been discharged as cured by March 1992.

Target and achievements in 1991-92

During the year 1991-92 against the target of 3,35,200 for new case detection and treatment, a total of 5,03,390 new cases have been detected out of which 5,00,242 cases have been put under treatment.

The target for case discharge was 6,12,500 during 1991-92 against which 8,16,538 cases have been discharged.

The physical target allocated for 1992-93 consists of 2,89,600 cases for detection and treatment and 5,73,900 for case discharge. The budget estimate for 1991-92 was Rs. 2280 lakhs and for 1992-93 also same amount has been allocated.

8th Plan

During 8th Plan it is proposed to provide MDT coverage to all the districts with endemicity of 2 or more per 1000 population and MDT services will also be extended through Primary health care in other districts. During the seventh plan a total of Rs. 85.82 crore has been spent and a provision of Rs. 150 crore has been kept during the eighth plan. The financial assistance proposed from World Bank will be in addition to this allocation.

World Bank assistance

To spread the MDT coverage to uncovered areas and to further intensify the efforts, the Government have sent a comprehensive proposal to World Bank for financial assistance of Rs. 300 crores. In the proposed World Bank Project, it is envisaged to provide the leprosy services with separate workers in the 66 endemic districts currently under the modified MDT Programme, and additional 77 districts would be taken up for introducing the Modified MDT Programme. The monitoring information would be strengthened and a foundation laid to embark on a rehabilitation programme. Δ

MULTIDRUG THERAPY IN LEPROSY —Progress and Prospects

DR S. K. NOORDEEN

Multi-drug therapy is extremely effective for individual treatment. Because MDT programme calls for well-organised case-detection and because the high patient acceptability of the treatment tends to encourage self-reporting, MDT is usually associated with increased early detection rates and a consequent fall in the frequency of new cases presenting with deformity.

LEPROSY is a major disabling condition in the world with an estimated load of 5.5 million patients of whom about 3.1 million are registered in over 85 countries of Asia, Africa and Latin America. Over 82% of all registered cases in the world are accounted for by only five countries (India, Brazil, Nigeria, Myanmar and Indonesia, in descending order of magnitude) and nearly three quarters of the world's known leprosy patients are in South-East Asia. Yet despite its relatively low prevalence and low ranking as a cause of morbidity and direct mortality, leprosy is for many countries an intolerable relic from the past, one that takes a disproportionately heavy toll on the social, economic and psychological wellbeing of whole families and communities. It is in recognition of its insidious repercussions on a community's overall health and of the difficulty that many countries with leprosy face in allocating resources to intensive leprosy control activities, that the World Health Organization now considers leprosy at a prevalence rate of at least one case per 10,000 population within a country or area to constitute a public health problem.

Dramatic change

Nevertheless over the past three decades there has been a dramatic change in the global picture of leprosy. In 1966, for example, when reporting of leprosy cases had become reasonably efficient in many, if not most, countries, there was a total of 2.8 million known cases. Twenty years later, the total had risen to 5.4 million. This increase was probably due partly to intensified detection of new cases, particularly in South-East Asia. A significant proportion of the increase, particularly in the 1970s and early 1980s, however, can be attributed to failure of leprosy control programmes, many of them unable to cope with rising rates of resistance to dapsone. Between 1985 and the end of 1992 the number of registered patients in the world declined—for the first time—from 5.3 million to 3.1 million, a fall of over 41%. By 1992 MDT was being administered to 1.3 million patients and had released 2.9 million patients from treatment.

Implementation of MDT tends to produce a bell-shaped curve of leprosy statistics. Since organized case detection is an integral part of any well-run MDT programme and since the short duration and low toxicity of MDT tend to encourage self-reporting, the institution of an MDT programme is generally followed by a rise in numbers of registered cases. Indeed, much of the increase in numbers of registered cases worldwide in the 1980s can be reasonably attributed to the

advent of multidrug therapy. After a few years of MDT implementation, discharge of patients completing therapy produces a dramatic decline in numbers of registered cases. This trend is more clearly seen in district or country leprosy figures, and the unprecedented 41% fall in global leprosy prevalence between 1985 and 1992 to a large extent is attributed to successful MDT campaigns, particularly in countries, like India, with large numbers of patients.

On the positive side, multidrug therapy is extremely effective for individual treatment. Early lesions in many instances resolve within a few months of starting treatment and infectivity is generally lost within a few days of starting MDT. Most paucibacillary patients can be discharged within six to nine months and most multibacillary patients within two to three years of starting treatment. Relapse rates have been extremely low, averaging, globally, 0.1% a year for paucibacillary leprosy and 0.06% for multibacillary leprosy (vs. 1-2% a year for dapsone monotherapy).

Patient acceptability

Because it is effective, finite, of short duration and association with fewer type 2 (erythema nodosum leprosum) reactions than any other treatment regimens, MDT, despite the skin discoloration linked to its clofazimine component, enjoys a high degree of patient acceptability: compliance rates average between 80 and 90% in most areas, vs. a maximum of 50% for dapsone monotherapy. As a result, MDT offers a rapid solution to a country's leprosy problem and thus a rapid return on capital invested in an MDT campaign. Backed by strong national commitment and the provision of adequate resources, a well-run MDT programme can reduce a national leprosy caseload by 70—80% within five years, thereby releasing funds for other, possibly longer-term, needs.

Because an MDT programme calls for well-organized case-detection and because the high patient acceptability of the treatment tends to encourage self-reporting, MDT is usually associated with increased early detection rates and a consequent fall in the frequency of new cases presenting with deformity.

WHO's contribution to its newly proclaimed target of elimination of the disease as a public health problem by the year 2000 is mainly one of coordinating and supporting the many institutions, agencies and organizations that have joined in the effort to achieve this aim. WHO receives invaluable support from many participants in this effort, including the Japan Shipbuilding Industry Foundation, the International Leprosy Association, the International Leprosy Union and the International Federation of Anti-Leprosy Associations.

Working group of leprosy experts

In recognition of the critical stage that the world leprosy situation has reached as a result of the steady progress made over the past five years in control activities, WHO has set up a working group of leprosy experts to oversee world efforts to increase the momentum created by recent progress. This leprosy control working group meets periodically to advise on ways of stimulating countries to intensify their leprosy control efforts and of ensuring greater support from and coordination of the different agencies working in leprosy control. It also seeks ways of improving control strategies and sets priorities related to changing epidemiological and socio-economic conditions. Part of the working group's mandate is also to evaluate scientific progress and assess the applicability of research findings to leprosy control. Overall, the working group provides the stimulus and direction to the "race" towards leprosy elimination by the year 2000.

Examples of WHO's programme development functions include: helping individual countries to plan and implement leprosy control activities, particularly through general health service facilities; helping countries to organize the technical backup needed for efficient leprosy control activities, including epidemiological evaluation and treatment monitoring; providing, at all levels of leprosy control, updated technical guidelines on diagnosis, treatment and prevention of leprosy; setting leprosy control policy on all major aspects of leprosy control, including diagnosis, treatment, follow-up, and prevention and management of disability; training of health personnel at all levels and for all aspects of leprosy control; in particular, WHO is organizing national training courses in leprosy control for managers.

Under its research promotion activities, WHO supports field tests of shorter, more effective and operationally more readily implemented multidrug regiments and new antileprosy drugs; supports and coordinates health systems research on (a) the most cost-effective leprosy control policies, especially those that provide for the integration of leprosy control with the general health services with programmes set up for the control of other diseases; (b) the organization of rehabilitation services and their integration within existing rehabilitation programmes; (c) improving case-detection and management; (d) social and economic factors, including educational activities, related to community involvement in leprosy work; and organizes, supports and coordinates the field-testing of leprosy vaccines for prevention. Δ

NATIONAL LEPROSY ERADICATION PROGRAMME : RETROSPECTS AND PROSPECTS

DR B. N. MITTAL
DR N. S. DHARMSHAKTU

Target has been fixed that by the year 1995 all the districts of the country will be brought under the coverage of multi-drug therapy which is likely to be achieved much before. The additional 77 districts with prevalence rate between 2 to 4.9 cases per 1000 population are likely to be covered on MDT during the next year with World Bank assistance. Endemic pockets in remaining low endemic districts are to be identified and such endemic pockets will be supervised by 20 zonal officers for operation of MDT.

LEPROSY has been known for many centuries and reference to it is found in the ancient Hindu Scriptures. Until a few decades ago the disease was one of neglect. Leprosy control work was started by the Government in 1941 for the first time though the voluntary organisations and philanthropists had started the same earlier. After independence a committee was established in 1954 to suggest the leprosy control measures. In 1955 the Government of India started the National Leprosy Control Programme with the objective to control leprosy through domiciliary sulphone treatment. It started as a centrally-aided scheme with its focus on rural areas of high and moderate endemicity. In the low endemic areas expectation was to provide the services through the existing infrastructure. The scheme was converted into a centrally-sponsored scheme in 1969-70 to give impetus to control work. The programme suffered because of various reasons:

(a) Non-availability of potent drugs for quick and complete cure.

(b) The duration of treatment with dapsone monotherapy was long.

(c) Population was not fully cooperative due to social stigma attached to the disease.

(d) Detection of all the estimated cases was not possible due to inadequate coverage, ignorance and stigma.

As a result of such various reasons many patients started developing resistance to dapsone.

NLEP in Retrospect

WHO recommended multi-drug therapy for treatment of leprosy patients in 1981 based on its experience in many countries. Trial with multi-drug therapy began in India in 1981 and in the year 1983 the Government of India re-designated the National Leprosy Control Programme as the National Leprosy Eradication Programme. The programme is operated as 100% centrally-sponsored scheme and has since been included in the 20-Point programme. The objective of NLEP is to arrest the disease activity in all the known cases of leprosy by the year 2000. The World Health Organisation has also set the goal of elimination of leprosy by the year 2000 which is defined as achievement of reduction in prevalence below one case per 10,000 population by the year 2000 A.D. Leprosy being a least communicable disease, its transmission in the community is broken if the above level of reduction is achieved in the prevalence rate.

Multi-drug therapy services have been meticulously planned in endemic districts on vertical pattern. In such districts MDT has been launched after creation of complete infrastructure required on vertical pattern, filling up of the posts and training of the staff, detection of most of the estimated cases and commitment of the State Government. Before launching of MDT, a District MDT Society is formed and the funds are directly released to the Society. MDT Services are made available nearest to the homes of the leprosy patients so that no patient will have to travel more than 2 kms for availing of the same.

The vertical MDT Scheme has been made operative in 135 endemic districts and in the remaining 66 endemic districts Modified MDT Scheme has been sanctioned as complete vertical staff could not be created in these districts. Since the progress of MDT is slow in 66 endemic districts on modified pattern and the case-load is also high, they are proposed to be converted into vertical pattern with World Bank Assistance.

Available information with Leprosy Division indicates that till March 1992, a total of 6.34 million leprosy patients have been discharged, out of which about 50% have been discharged as a result of MDT. Out of 1.69 million patients on record till March 1992, 70% were receiving multi-drug therapy. There has been marked reduction in prevalence rate by over 90% in the districts which are on multi-drug therapy for over five years. MDT has been accepted well and its side-effect has been minimal.

The pattern has been developed for extension of MDT to low endemic districts. So far, 41 low endemic districts have been covered under multi-drug therapy scheme.

NLEP in Prospects

The target has been fixed that by the year 1995, all the districts of the country will be brought under the coverage of multi-drug therapy which is likely to be achieved much before. The additional 77 districts with prevalence rate between 2 to 4.9 cases per 1000 population are likely to be covered on MDT during the next year with World Bank assistance. Endemic pockets in remaining low endemic districts are to be identified and such endemic pockets will be supervised by 20 zonal offices for operation of MDT. The above 20 zones will implement the MDT in the pockets identified and the same is likely to be started by 1993 with World Bank assistance. Community awareness activities will be strengthened and training of general health care staff will be carried out for all the districts. The facility for ulcer care and correction of deformity including provision of footwear will also be expanded. Monitoring system is planned to be strengthened. A comprehensive proposal has been submitted to World Bank for assistance of about Rs. 300 crores for strengthening of leprosy programme on the aspects indicated above.

Attempts are being made to further reduce the duration of treatment with still much more potent drugs. Anti-leprosy vaccines are also under field trial.

In the light of the above it can be said that the target elimination of leprosy by 2000 A.D., can be achieved. Δ

WORLD AIDS DAY MARKED AT UN HEADQUARTERS

Secretary-General Boutros Boutros-Ghali on 1 December told a meeting of the General Assembly marking World AIDS Day that he had created a single interagency advisory group within the United Nations system, with strengthened terms of reference. The Group, which had held its first meeting last month, would meet regularly and was committed to create a 'coordinated and effective response' to the AIDS endemic Mr. Boutros-Ghali said.

Noting that AIDS demanded a multi-sectoral, integrated approach from the United Nations, he recalled his report to the Economic and Social Council earlier this year in which he stressed that 'the need for the United Nations to mount a comprehensive and coordinated response' was clear. There were now 135 national AIDS programmes in operation, which have been planned, set up and assisted through the collaboration of United Nations bodies and agencies, governments and the private and voluntary sector, the Secretary-General said.

The World Health Organization (WHO) estimates that the HIV Virus has infected about 11 to 13 million people worldwide. More than two million people have developed AIDS and most of them have died.

—UN Newsletter
5 Dec. 1992.

SOCIO-ECONOMIC ASPECTS OF LEPROSY CONTROL

PROF. A.R.K. PILLAI

People's participation in leprosy eradication is of utmost importance and the existing pattern of collaborative work between Government and voluntary agencies may be further strengthened so that net working possibilities can cover almost every corner of our vast country. It is time that we open our eyes to ground realities and create long-term vision of a progressive, healthy India, says the author.

LEPROSY is a major public health problem in our country and the national goal is to eradicate leprosy by 2000 A.D. There is political will in the country to attain this goal and the series of steps taken by the Union Government and State Governments bear ample testimony to this fact. We must bear in mind the huge size of our country and massive population. According to the 1991 census figures, our population was 843.9 million with a density of 267 persons per sq. km. The national literacy level stood at 52.11% with female literacy as low as 39.42%.

Background

It will be appropriate to look at certain statistical data available to us. The growth rate in population is as high as 2.11% despite focus on family planning measures over several years. The population below the poverty line was estimated at 37% during 1984. In the backdrop of these data, number of leprosy patients in the world was estimated at 12 million with India's total of about 4 million. However, the estimated number of leprosy patients has come down in India to 2.8—3.00 million, thanks to the vigorous efforts put in by the Government and Voluntary Agencies.

Leprosy has two major dimensions—medical and social. There has been substantial improvements in the medical area concerning leprosy. Today leprosy is completely curable with modern drugs. Multi-Drug Therapy (MDT) offers complete cure for leprosy at any stage of the disease with treatment span ranging from six months to two years. The prevalence rate has come down drastically where MDT had been introduced and deformity rates too have registered a steep fall.

Social Dimensions

However, leprosy has social stigma attached to it over the generations. Reasons are many. For centuries, there was no definite cure for the disease. It is a disfiguring and crippling disease with the patient landing up in deformities. It is a visible disease. All these factors made the patients of leprosy subject to the additional burden of social boycott because of stigma. They are rejected by the society and patients suffer loneliness, poverty and allied areas of social rejection. In view of this anyone having symptoms tend to hide the disease as long as they can, rather than face rejection.

The number of leprosy afflicted persons till about five years ago was estimated to number about four million. Of these about eight lakhs constituted children below the age of fourteen. The patients and their families face social ostracism and they are normally prevented from participation in the national stream of life. The patients are thrown out of their jobs and places of residences. Consequently they go about wandering as beggars while most of them could have pursued their vocations, contributed to gross national income and earned their livelihood with respect. The loss of production and national income of four million population is a colossal waste occasioned by biased be-

haviour of an ignorant society. Social stigma carried down from generation to generation has remained far too long and the society in general has not updated in the knowledge on leprosy and its ramifications from a public health angle. We as a people are far too slow in correcting our attitudes and approaches towards leprosy and its sufferers. While contributory reasons are many, there has been appreciable change in the scenario. This welcome change has to be taken further to help elimination of leprosy from the Indian soil.

Main Factors

There are three main factors in leprosy control and eradication, *viz.*, drastic reduction/elimination of reservoirs of infection in the community, clipping all possible channels of transmission of the disease and improving the immunity levels of the population at risk. While we proceed in the matter, we have to bear in mind rapid urbanisation and large mobility of villagers into towns and cities causing near collapse of civic facilities in urban areas like lack of adequate housing, transport and the like. Poverty, illiteracy, superstitious beliefs and a host of allied factors play important contributory roles in leprosy control effort.

We have 66 hyperendemic (pre valence 10 plus) and 135 endemic (between 5 and 10 prevalence rate) districts in India and the prevalence is not uniform in various districts. MDT had been introduced in several districts with great advantage and good results are coming up. The National Leprosy Eradication Programme (NLEP) aims at elimination of the disease by bringing the prevalence rate to 1 per 10,000 population by the year 2000.

The leprosy patients and their families face social ostracism and they are normally prevented from participation in the national stream of life.

Major Constraints

What are our major constraints and how can we overcome them? If the average citizen knows the simple facts about leprosy and goes to a medical centre for check-up on seeing symptoms, the major battle is won. For this two factors must be established. *First* systematic and continuous campaign to educate the public on facts about leprosy. In a country like ours where literacy is too low, audio-visual communications may be taken advantage of. Education through TV, Cinema and Radio should be given adequate emphasis. *Secondly* conditions must be brought about in the community not to despise leprosy patients. Treating leprosy like any other disease and lending societal support for the sufferers will help those with symptoms to come forward and take treatment. Testimonial cases must be given wide publicity with appropriate media targeting to get the desired results. Leprosy treatment at Government and voluntary agencies is completely free throughout India and this should be made available through primary health centres as is being done progressively.

Women's Status

Women's status in Society is a pivotal factor in a nation's development. The declining sex ratio of

929 females to 1000 male population revealed by 1991 census is noteworthy.

Investments in educating the girls can yield the highest returns to the society at large and the family as well. Major initiatives to increase female education have potential to transform society over a period of time. Educated mothers and daughters are an asset to any society. They choose to have fewer children, whom they can care well.

Though educating boys and girls may be similar in its cost impact, girls' education is a safer long-term investment towards generating rich social benefits.

With higher female literacy levels, greater autonomy for women and higher avenues for self-reliance, better health and higher quality of life will certainly result. The States must lay adequate stress on this area. Kerala is a standing example before us to show how female literacy and self-reliance have brought out excellent results.

Conclusion

Complete MDT coverage where needed, with concurrent training of primary health workers, continuous education of the people through mass media channels, updating awareness levels in the community and simultaneously improving the living standards of the people can bring about lasting results in leprosy control and eradication efforts. People's participation is a must and the existing pattern of collaborative work between Government and voluntary agencies may be further strengthened so that net working possibilities can cover almost every corner of our vast country. We have made rapid strides in elimination and by increasing the tempo, wonderful results can follow!

It is time that we open our eyes to ground realities and create long-term vision of a progressive, healthy India. Δ

SCREENING FOR GASTRIC CANCER

A SIMPLE blood test may soon be all that is needed to detect patients at high risk of stomach or colonic cancer.

This advance is in prospect as a result of investigations carried out in North Staffordshire in the English Midlands to discover why the area has the country's highest incidence of gastric cancer and lowest survival rate among female colonic cancer sufferers.

Three members of the Keele University's school of postgraduate medicine in Staffordshire, surgeon Prof James Elder, biochemist Dr Richard Strange and epidemiologist Dr Terri Knight, applied their different disciplines to the subject and came up with what have been described as "exciting discoveries".

Dr Strange explained: "Our preliminary findings in the laboratory show an exciting link between a susceptibility to gastric and colorectal cancers, and an inability to make an enzyme called glutathione S-transferase.

"This enzyme appears to be necessary for the proper detoxification of a number of recognised carcinogens. Some people appear unable to make the enzyme, which puts them at an increased risk of cancer." Modern technology is now allowing the study of an individual's DNA using molecular biological techniques by means of a small blood test. The new approach would allow simple screening of the relatives of individuals with cancer, with monitoring carried out in hospital pathology labs.

Professor Elder said the eventual aim would be for patients with a family history of gastric or colonic carcinoma, to be able to go to their GP and be given information on their chances of contracting the disease. Δ

—SPECTRUM
Sept.-Oct. 1992

RESEARCH ACTIVITIES IN LEPROSY

DR SUSHMA GUPTA

Even though clinical trials for the available leprosy vaccines are under way, research is continuing to develop yet another vaccine for leprosy.....Studies are in progress to elucidate mechanisms of deformities developing in leprosy patients, and steps for their prevention, and effective surgical techniques for their correction.

THE Indian Council of Medical Research carries out the major parts of its Research activities in leprosy through its permanent institute, Central Jalma Institute for Leprosy, Agra. The Council also provides grant-in-aid for open ended projects and fellowships in various Medical Science Colleges.

The overall goals of the research programme of the council have been (i) to assess current methods of diagnosis, treatment etc., and improve upon them, (ii) to develop newer methods and tools which will serve these purposes better, (iii) to improve our understanding of the disease process and the complications that add to the morbidity of the disease, (iv) to increase our knowledge about the causative organism so that we may develop better methods to destroy it, (v) to improve our understanding of the disease dynamics in the community and (vi) to carry out a comparative trial of candidate vaccine preparations.

The Central Jalma Institute for Leprosy, Agra, mainly continues to investigate leprosy and related problems through various clinical, immunological, epidemiological, microbiological and molecular biological studies so as to help the Government in successful implementation of the National Leprosy Eradication Programme.

Though clinical diagnosis of an obvious case of leprosy is easy, there are enormous problems in the classification of early lesions. Molecular biological methods e.g., probes, gene application techniques like Polymerase Chain Reaction (PCR), immuno-histology and histology are used to classify early lesions of leprosy.

Leprosy, known to be a disease of nerves, macrophages and skin is also a disease of altered lipid metabolism. In a recently concluded study, it was observed that there was a significant increase in the circulating high density lipoproteins and lipoproteins-a levels in lepromatous leprosy as compared to control and the tuberculoid leprosy patients. It appears that these lipoproteins have a role in immunological aspects of nerve injury in leprosy.

Leprosy in the majority of the cases can be diagnosed on the basis of a proper examination of the case alone. Therefore a set pattern should be followed for examination e.g. clinical and bacteriological examination, histamine test, biopsy and immunological test. However, the diagnosis of early leprosy has always been a challenge. Newer *in vitro* tests such as lymphocyte transformation test (LTT) and leucocyte migration inhibition test (LMIT) have been developed and they are used to detect the level of immunodeficiency. The recent advance in study of the epidemiology of leprosy is the development of serological tests which gives hope for a better surveillance. The fluorescent leprosy antibody absorption test is now widely used for identification of subclinical infection.

Till date there is no immunodiagnostic test available for leprosy diagnosis in the National Leprosy Eradication Programme. A serological assay standardised at CJIL, using peroxidase labelled MLO4 (SACT-ELISA) was compared in terms of their sensitivity and specificity with two other currently

3—15/DGHS/92

available serological tests developed by other laboratories (PGL-ELISA and PGL-AGGLU). SACT-ELISA was found to be more specific and sensitive than the other two assays.

In lepromatous leprosy there is a poor immunological response to *M. leprae*. In a recently concluded study to find out whether this is related to interleukin-1 and/or 2 production, it was observed that there was some immunological defect with respect to production of IL-1 in all forms of leprosy. Lepromatous Leprosy(LL)/ Border line (BL) patients do not show defective IL-2 production and after 6 months of multidrug treatment (MDT), its production rises significantly.

Various viability assays for rapid determination of *M.leprae* are being developed. These viability assays could be applied to paucibacillary leprosy which remain therapeutically and prognostically important in this country. Three gene amplification techniques alongwith highly sensitive ATP bioluminescent assay system are being applied for viability assessment.

New methods

Several new methods based on analysis of lipids, isoenzymes, immunological relatedness of enzymes have been developed. Evaluation of *protein electrophoregrams and zymodemes in several mycobacteria* including *M. leprae* had shown that combination of different zymodemes and protein electrophoregrams can be used for rapid identification & characterization of various pathogenic mycobacteria. Further the detailed analysis of *Restriction Fragment Length Polymorphism (RFLP)* of rRNA gene region has shown that this technique & probes are useful to characterise various mycobacteria including *M. tuberculosis, M. avium and M. leprae* at species, subspecies and even strain level.

Cloning and sequencing of 16S genes and flanking sequences of 12 species of mycobacteria had led to identification of 9 variable regions within rRNA gene & flanking region of ribosomal genes of *M.leprae* and other mycobacteria. In addition to 17 mer probe, some more probes and primers have been designed against these variable regions and synthesized. Initial evaluation of the observation results show that a few of these probes could be useful at species/ genus level. Methodological studies for the clinical application are in progress.

Gene amplification techniques like PCR using primer based on 18Kd and 36Kd antigen genes and an reverse PCR is being standardised. Based on initial results which suggest the need to further optimise technique(s) for extraction of nucleic acids from biopsies, alter assay techniques, further studies are being carried out. An *enzymatic technique for isolating the mycobacetrial nucleic acids* from biopsies has been developed and is being evaluated.

Duration of anti-leprosy therapy

The optimal duration of antileprosy therapy has been an issue of debate. Studies are in progress to determine the minimal length of antileprosy therapy. The preliminary results indicate that in lepromatous patients, it takes up to 12 months by DDS and clofazimine combined to kill rifampicin resistant mutants suggesting that minimum duration of treatment should not be less than one year. With the aim to further reduce the duration of treatment, a regimen comprising of Dapson, Rifampicin and Prothionamide is also being tried.

India is playing a crucial role in developing and testing immunotherapeutic and immunoprophylactic agents for leprosy.

Anti-leprosy vaccine

In order to identify the best of the available vaccines for Indian situations, a randomised double blind controlled five arm prophylactic vaccine trial against leprosy involving two indigenously developed vaccines e.g., ICRC, M.w. and Killed M.leprae + BCG, BCG and normal saline has been launched in Chingleput district of Tamil Nadu.. By July 1993, the intake phase is expected to be completed. This will be followed by resurvey of vaccines.

Another clinical trial with ICRC vaccine for Immunoprophylaxis against leprosy is in progress. The study is being conducted by Canc Research Institute, Bombay, in Osmanabad, Latur and Solapur districts of Maharashtra. The objective of the trial is to assess the immunoprophylactic efficacy of two vaccines containing (i) ICRC bacillus (ii) BCG by measuring the incidence of both multibacillary and paucibacillary forms of Leprosy in ICRC vaccinated as compared to BCG groups. The intake of about 34,000 households contacts has been completed and the resurvey of vaccines has started.

Even though clinical trials for the available leprosy vaccines are under way, research is continuing to develop yet another vaccine for Leprosy. At Foundation f Medical Research, Bombay, study is being supported in which a 1.6 Kb M. Leprae DNA protein has been identified as a potential immunodominant protein. Insert of this DNA fragment in *E.Coli* holds promise of getting a recombinant *M.leprae* protein as a possible vaccine against leprosy.

Studies are in progress to elucidate machanisms of deformities developing in leprosy patients, steps for prevention of deformities and effective surgical techniques for the correction of deformities. Δ

LEPROSY VACCINES —An Update

DR M. D. GUPTE

It is not impossible to conceive emergence of effective anti-leprosy vaccines some time in future. It would be essential to understand the possible roles of these vaccines in different situations. Alternative approaches and priorities for disease control will have to be taken into account. Leprosy vaccine is a distinct research goal and an area of high research priority.

IN 1990, the subject of anti-leprosy vaccine was reviewed for the readers of the *Swasth Hind*. Available information on several candidate vaccines was summarized and the subject of second generation vaccines was also reviewed. Three years is a rather short period for getting useful information on potentials of anti-leprosy vaccines in preventing leprosy. A prophylactic vaccine trial against leprosy usually takes a decade before reaching any valid conclusions. However, preliminary results from one field study in Venezuela and progress of the ongoing vaccine studies should be of interest to the readers.

Venezuela vaccine trial

An immunoprophylactic trial against leprosy using armadillo-derived killed *Mycobacterium leprae* and BCG vaccine was launched in Venezuela during 1983. The Venezuela trial is the first of the three different vaccine trials in the world where killed *M. leprae* is being used, the other two being in Malawi and India. The first report of the results of the Venezuela trial, covering the period up to July 1991, has been published recently in *The Lancet* (Convit *et al* 1992). Zuniga, a colleague of Convit and an eminent epidemiologist, observed a sustained downward tendency of new case-detection rate from 16 per 100,000 inhabitants in 1951 to 2.5 in 1981 in Venezuela. He has drawn attention to the important demographic changes towards increased urbanization and changes in the epidemiological profile of leprosy. According to him, increase in the proportion of multibacillary cases, increase in the average age of new cases by ten years and increased proportion of leprosy in males indicated a rapid natural decline of leprosy in Venezuela. In Venezuela, the vaccine trial is being conducted in the three most highly endemic States, *viz.*, Apure, Tachira and Merida (prevalence 6.9, 2.9 and 1.9 per thousand population and incidence 10.9, 4.3 and 3.9 per 100,000 respectively) in the household and extradomicillary contacts. As many as 29,113 contacts were included for the study. The vaccine trial in Venezuela is a large-scale, randomized, controlled, double-blind trial employing BCG + killed *M. leprae* and BCG alone. The dose of BCG was decided by the tuberculin status of the individual, tuberculin negatives receiving 0.2 mg and tuberculin positives 0.04 mg.

The dose of *M.leprae* was 6×10^8 bacilli. The contacts were initially screened for leprosy and were given the *M. leprae* Soluble Antigen (MLSA) and tuberculin tests. The group of interest for the trial was that of MLSA negatives.

The participants were carefully examined for leprosy annually by doctors specialised in leprosy. Skin smears and biopsies for histopathological examination were routinely obtained. The resurveys generated 150,026 person years of observation and 59 confirmed cases of leprosy. After deleting 29 cases for reasons like pre-vaccination history of leprosy, occurrence of disease within one year, etc., the remaining 30 cases were considered for the final analysis. Fifteen each of these belonged to BCG and BCG+killed *M. leprae*, irrespective of initial MLSA status. Twenty of these 30

patients belonged to MLSA negatives at intake, and in this group of interest 11 belonged to the BCG arm and 9 to the BCG + killed *M. leprae*. The other interesting observations were, about 60 per cent protective efficacy of BCG and strong persistent MLSA positivity following BCG + killed *M. leprae* in the initial MLSA negative group. Results from the Venezuela trial remained inconclusive regarding protective efficacy of the combination vaccine over and above that of BCG alone. Whether that is on account of previous BCG vaccinations and lepromin testing, high efficacy of BCG in preventing leprosy, adoption of annual case-detection procedures or epidemiological profile is difficult to say.

BCG Story

BCG was considered as a potential tool for leprosy control following the observations on lepromin conversion. Encouraging results with respect to its protective efficacy are available from Uganda, New Guinea, Malawi and Venezuela. A prophylactic efficacy to the tune of 50% to 80% was observed in these places. Results from Burma have shown an efficacy of about only 20%. Similar moderate level of protective efficacy was observed from the recently analyzed data from the South Indian BCG trial. BCG does not appear to be a vaccine which could be globally considered for prevention of leprosy, although it might be effective in some regions.

ICRC Vaccine

ICRC bacilli were first isolated in 1958 by Bapat, Ranadive and Khanolkar. ICRC vaccine was produced in 1979. Bapat and Deo registered a patent for ICRC vaccine (C-44 strain) in 1981. The initial hospital based studies were conducted at Acworth Leprosy Hospital, Bombay, from 1979. A prophylaxis study is in progress in Maharashtra State since February 1987.

M.w vaccine

Talwar's group in Delhi was looking for a mycobacterium having desirable cross-reactive antigens with *M.leprae* with respect to the immune reactivity of TT patients, and at the same time to have antigens evoking responsiveness in LL patients. *M.w* was selected as a candidate for vaccine production. Encouraging results from hospital-based Phase-II immunotherapeutic clinical trials have been obtained in New Delhi. A prophylaxis study in Kanpur is in progress.

Comparative leprosy vaccine trial in South India

On 30th January 1991, a comparative leprosy vaccine trial involving BCG plus armadillo derived killed *M.leprae,* ICRC and *M.w* was launched by the Indian Council of Medical Research in Chingleput district of Tamilnadu. Information on the three candidate vaccines had been discussed extensively in the Indian Council of Medical Research, by the Indian Association of Leprologists, as well as at the last Pre-Congress Workshop on leprosy vaccine trials, in The Haugue in 1988. It was uniformly agreed that all these vaccines deserve to be tested for their prophylactic efficacy. The recently launched trial in South India is providing an unique opportunity to compare them together. It will take 8 years to get the first results on the prophylactic efficacy of these vaccines.

Possible second generation vaccines

A number of mycobacterial antigens have been identified. Natural or recombinant forms of these proteins are now available. Choosing antigens with possible prophylactic efficacy could prove to be a very deceptive exercise. Defining "protective antigens", and "protective and pathologic immunity" are some of the questions that are being investigated. Promising approaches for inserting different DNA sequences in BCG have been developed. However, the work on second generation vaccines is still very much in the exploratory stage.

Relevance of a vaccine

The available parameters of animal studies, sensitization to *M.leprae* antigens following vaccination and immunotherapy are only indirect measures of probable prophylactic efficacy of the candidate vaccines. Vaccines trials with different candidate vaccines against leprosy are presently in progress. Several recombinant and native antigens as well as mycobacterial components are being investigated for their role in immuno-modualtion. It is not impossible to conceive emergence of effective anti-leprosy vaccines some time in future. It woul : essential to understand the possible roles of these vaccines in different situations. Alternative approaches and priorities for disease control will have to be taken into account. Efficacy of case-detection and case-holding in controlling disease transmission, costs of case-detection and case-holding and the cost of preventing leprosy cases will need consideration in an overall context. Clearly leprosy vaccine is a distinct research goal and an area of high research priority. Δ

A Project Model for attempting Integration of Leprosy Services with General Health Care Services after the Prevalence of the Disease is reduced in the Endemic Districts on Multidrug Therapy for over Five Years

Dr N. S. Dharmshaktu

Multidrug therapy has been introduced in India for the treatment of leprosy cases on a large scale, in high endemic districts with prevalence of 5 or more per 1000 population, through a separate vertical infrastructure parallel to the general health care system (DGHS 1989). After the introduction of multidrug therapy in a district the prevalence rate is expected to be brought down to a very low level by 5 years and, after that leprosy care is planned to be integrated with the general health care system. Starting from 1982-83 multidrug therapy (MDT) has now been sanctioned for all the 201 endemic districts of the country, including the 66 districts for which Modified MDT Scheme has been sanctioned. Recently, it has been proposed to change the Modified MDT Scheme into a regular vertical approach. The endemic districts where the prevalence has been reduced to 1.5 or less per 1000 population, because of MDT intervention for 5 years or more, have now been issued with Government orders for integrating leprosy services with general health care with effect from 1-4-1991 (DGHS 1991).

Integration of leprosy services with general health care is being practised in many countries (WHO SEARO 1988), but this has not always been based on any definite evidence showing that the integrated approach is better than vertical approach. Since one third of world leprosy patients is estimated to be present in India, it is time for the Government and other interested agencies and persons to plan and study the feasibility of Integrating leprosy services with general health care services through well-conducted projects and gather adequate experience in the methodology of integration before introducing integration on a wider scale. Integration done without prior feasibility study may undo all the success that has been achieved under the National Leprosy Eradication Programme. However, we must also realize that we can ill afford the financial burden of maintaining the vertical structure for an indefinite period.

Here I present a project model for studying the effects of integration of leprosy with general health care based on utilisation of existing health care infrastructure.

The Case for Integration

The case for integration is well-known and is summarized below.

The general health care staff have better access to the community. For every 5,000 population one male and one female health worker are working full time under the general health care system whereas, under the vertical leprosy services system one worker covers 25,000 population.

The general health care system has one female worker for every 5,000 population and also has the support of trained *dais* and Anganwadi workers at village level whereas, the number of female workers employed is very small under the vertical system of leprosy services. Examination of female subjects aged above 14 years is therefore likely to be better if leprosy services are provided by the general health care services in low endemic areas.

During the surveillance period, when the case-load in the community is quite low, many patients do not feel it necessary to visit the leprosy clinic as they feel they have been cured. The number of patient-health worker contact is likely to be frequent with the general health care system since patients will be approaching the general health care staff for their other health problems and this will lead to better coverage during surveillance.

Given adequate training about early diagnosis, patient follow-up

for the treatment, referral and community education about leprosy, the general health care workers will be able to give better coverage in view of their easy access to the population.

THE PROPOSED MODEL

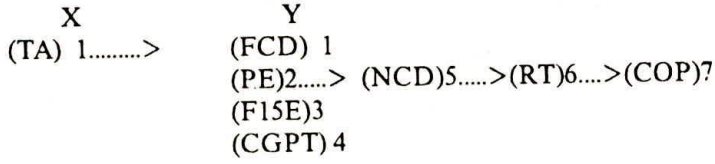
The proposed model of integration of leprosy services with general health care services envisages : (i) Development of training curriculum in leprosy for general health care staff; (ii) Job identification for each category of staff; (iii) Short training of all general health care staff including community health workers; and (iv) Integration of information system and monitoring system with the general health care system at various levels.

The proposed model will test the hypothesis that the type of approach (TA), vertical or integrated, directly or indirectly determines : the percentage of follow-up of cases discharged as cured (%FCD), the number of persons examined for leprosy (# PE), the number of females aged 15 years and above examined for leprosy (# F 15E), the number of new cases detected (# NCD), the percentage of patients put on regular treatment (%RT), the choice of patient for the type of approach (COP) and the choice of the general public for the type of approach (CGPT). Symbolically the hypothesis may be expressed as :

% FCD; # PE; # F15E; # NCD; % RT; COP; CGPT = f(TA)
in which f is 'function of'.

Definitions of the terms used : (i) Choice of patients for the type of approach (COP): In view of the large number of patients in the study districts it may be difficult to contact each and every patient and obtain her/his choice of the system. Therefore, all the patients registered during the study period (3 years) including those cured during this period will be considered for the study of their choice of the system. (ii) Regular treatment (RT) : Patients having a minimum of 75% attendance for treatment will be considered 'regular' and treatment regularity will be estimated in terms of completed months. Any continuous break of two months or more in treatment will be considered as 'irregular'. (iii) Choice of general public for the type of approach (CGPT) : Opinions of the village heads (usually male) and heads village Mahila Mandals (women's groups) regarding which approach is better and should be adopted for treatment of leprosy patients will be ascertained. The reply will be graded as vertical/integrated/not certain. The reason for the preference will also be elicited and studied. In urban areas, choices of heads of wards (usually male) and the Mahila Mandals (women's groups) will be ascertained and recorded. (iv) Persons examined (PE) : This refers to the total number of persons examined for leprosy, and '# F15E' refers to the total number of females, aged 15 years and above, examined for leprosy during the study period. (v) Follow-up of cases discharged as cured (FCD) : Treatment is terminated in cured cases and they are required to be followed-up once in a year for 2 years and 5 years, in paucibacillary and multibacillary cases respectively, for detection of instances of relapse. '%FCD' refers to the percentage of discharged (cured) cases thus followed-up during the study period. (vi) integrated General Health Care System is one in which every health worker deals with all types of disease and health problems in the area allotted to him/her, including leprosy. (vii) 'Vertical leprosy services' refers to the system in which the worker posted under the leprosy programme deals with health problems of le rosy patients only, in the population alloted to him/her. (viii) Multidrug therapy refers to treatment of leprosy with a combintion of dapsone, clofazimine and rifampicin in the dosage schedule recommended by the National Leprosy Eradication Programme.

It follows from our hypothesis that type of approach (TA) may be looked upon as the independent variable (X1) and the other parameters (% FCD, #PE...) as dependent variables ($Y_1, Y_2 ... Y_7$). The following path diagram shows the relation between these parametres.



It can be seen that
$Y_1, Y_2, Y_3, Y_4 = f(X_1)$;
$Y_5 = f(Y_2)$; $Y_6 = f(Y_5)$ and $Y_7 = f(Y_6)$.

Choice of patient (COP) in favour of integrated services will be positively influenced by care for other diseases and negatively influenced by the levels of social stigma, stigma by the worker and self-stigma. It may also be influenced by educational status, occupation, rural/urban status etc.

Choice of general public in favour of integrated services will be negatively influenced by the social and educational status of the individual.

Project Description

Two districts, 'A' and 'B', in which the prevalence of leprosy has been reduced to a very low level (preferably, less than 2/1000 population) as the result of five or more years of multidrug therapy should be selected, preferably from the same state.

A team of 4 leprosy experts should validate the alleged low prevalence rate of leprosy in the two districts.

The present vertical approach will be continued in district 'A'; but, in district 'B' the integrated approach will be adopted. The incentive salaries of vertical staff will be discontinued in district 'A' and no incentive salaries will be paid to general health care staff of district 'B'. If these two districts are selected from the ones already identified by the Government of India as ready for integration and for which orders have already been issued for stopping payment of incentives with effect from 1-4-91, there will be least administrative problems, as incentives will not be available for the control district as well.

The vertical leprosy staff of district 'B' (integrated) will be utilized for training general health care staff of the district in leprosy. After that, they may be transferred to an adjoining district where vertical approach is still being followed, or, they may be sent for training in the integrated system in an institution nearby, depending upon the needs of the State Government.

The period of training for the general health care staff in leprosy will be 5 days for medical officers and all the staff of PHCs and sub centres and, it will be 2 days for the village level workers like *dais* and village health guides.

Male health assistants and male multipurpose workers will be involved in public awareness activities, population surveys, detection of new/suspected cases, follow-up of cases on treatment and cases under surveillance, referral of cases, defaulter action, etc. The female health assistants and female multipurpose workers will be involved in referring the detected suspected cases, bringing defaulter cases for treatment to the PHC doctor, or, to the male workers of the particular area for recording and reporting. They will also be involved in the public awareness activities about leprosy.

Immediately after training, the general health care staff (of district 'B') will be introduced to the patients and their records in that area by the vertical (leprosy) staff. This should take about five working days for each male multipurpose worker covering 5,000 population. This introduction will be done by the leprosy worker of that area under the supervision of the Non-Medical Supervisor or the Medical Officer. Each vertical worker looks after 25,000 population. Therefore each vertical worker will need 25 working days for the complete handing over of records and introduction of all the cases to the five general health care workers of that area. Incentive salaries of the vertical worker will be stopped from then on, if the worker opts to remain in the same district and become a general health care worker for which he will be sent for training in the general health care system.

In both districts, the opinion of male and female patients, general public and the workers will be ascertained at the start of the project and at the end of the study period (3 years). The same individuals will be examined on both occasions. A selfstructured questionnaire will be used for comparison. Therefore, standardization of the questionnaire will not be required.

The level of basic knowledge of general health care workers will also be assessed initially and after three years of integration. The responses to the questionnaire will be graded as correct/partly correct/ wrong.

The supervision mechanism in district 'B' will be as under: (i) The 'integrated' district will continue to have a District Leprosy Unit, which will be responsible for providing supervision, technical guidance, quality check of skin smears and survey work. The staff of the District Loprosy Unit will also deliver talks on leprosy in the monthly meetings at PHC level, on rotation. The District Leprosy Officer (DLO) will work under the overall guidance of and in close coordination with the Chief Medical Officer/District Medical Officer. The Medical Officers of Leprosy Control Units in the district will be shifted to fill vacant NLEP posts, or, given duties in the primary health care set-up. The non-medical supervisors, health educators, physiotherapy technicians, laboratory technicians and other categories of workers under the NLEP set-up will be redistributed against vacant NLEP posts, or, will be reallocated appropriate duties under the

general health care set-up. (ii) Multidrug therapy in the integrated pattern will be made available at sub-centres, primary health centres, community health centres, dispensaries and hospitals. The Medical Officer of the primary health centre will be responsible for NLEP activities (including treatment delivery, case holding, follow-up and reporting etc.,) in his area as a part of his/her normal duties.

The management information system will be simplified in the district on integrated set-up and the information collected will be restricted to population examined for case detection, cases detected and treated, treatment regularity, discharges and relapse.

Coverage of leprosy services will be measured after 3 years of implementation. Following data from these two districts will be compared : coverage of discharged cases under surveillance, population surveyed, new cases detected, treatment regularity of old and newly detected cases, choice of male/female patients and opinions of general public and health workers about their preference (of integrated or vertical system).

Data source and data collection : The district 'A' (vertical set-up) data will be collected from the records with the DLO, leprosy control units, urban leprosy centres and survey-education-treatment centres in the district. In district 'B' (integrated), the source of data will be the records at district, primary health centre, sub-centre level.

Assessment of efficiency of integrated approach : As indicated below, for each parameter (FCD, PE, F15E....) the values obtained for districts 'B' and 'A' are worked out and the efficiency of integrated approach is assessed by the ratio

$$\frac{\text{Value of parameter for 'B'}}{\text{Value of same parameter for 'A'}}$$

which should be considerably greater than 1.0 to indicate a higher efficiency of integrated approach. Thus the indicator index for each parameter will be :

1. Surveillance : $\frac{\%\ FCD\ (B)}{\%\ FCD\ (A)}$
2. Survey : $\frac{\#\ PE\ (B)}{\#\ PE(A)}$; $\frac{\#\ PE\ males\ (B)}{\#\ PE\ males\ (A)}$; $\frac{\#\ PE\ females\ (B)}{\#\ PE\ females\ (A)}$
3. Survey of adult females : $\frac{\#\ F15E\ (B)}{\#\ F15E\ (A)}$
4. New case : $\frac{\#\ NCD\ (B)}{\#\ NCD\ (A)}$; $\frac{\#\ NCD\ males\ (B)}{\#\ NCD\ males\ (A)}$; $\frac{\#\ NCD\ females\ (B)}{\#\ NCD\ females\ (A)}$
5. Treatment regularity : $\frac{\%\ RT\ (B)}{\%\ RT\ (A)}$ This may be separately calculated for old and new (registered during study period) cases.

Finer details (like data on MB, PB cases) can be incorporated as desired.

The preference of patients and different categories of general public (rural, urban; males, females) is assessed by comparing the proportion of subjects favouring vertical and integrated approaches initially and at the end of the study period in each district.

Similarly the effect of integration on the knowledge status of general health workers is assessed by comparing the initial and final scores of these workers in each district.

Time schedule : The time scale of the various processes involved in this study is as follows :

1.	Appraisal of state and district authority	½ month
2.	Preparation of plan of study, training curiculum and preliminary study	1 month
3.	Training of staff	2 months
4.	Handing over of record and introduction of integrated approach to patients in the districts	2 months
5.	Study period	36 months
6.	Data collection	4 months
7.	Data processing	2 months
8.	Analysis	2 months
9.	Report writing	1 month

Additional financial and other inputs : Any additional staff and monetary input will be restricted to only those items facilitating the study. Financial support would be required for the following items :

(i) TA/DA for field visits of the main investigator who will b the key person for planning, monitoring and evaluation of the study.
(ii) Support for three statistical assistants; one each will be required for the two districts and one to help the main investigator.
(iii) Part-time secretarial support to the main investigator.
(iv) TA/DA for statistical assistants for visits to leprosy units/general health care centres.
(v) Support for initial and final appraisals by a team of four experts to evaluate the prevalence of the disease.

(vi) Financial support for short training of general health care staff in district 'B'.

(vii) Provision of transport/fuel, etc., for field visits. If it is not possible to use a local vehicle, a jeep may need to be provided.

Concluding Remarks

Such a study as described above may be expected to inform us how this model of integration of leprosy services with the general health care system affects the coverage and provision of leprosy services after the prevalence has been reduced to a very low level consequent to multidrug therapy for 5 or more years. If such a study is also carried out in other districts with different levels of low prevalence of leprosy it might also help in deciding the optimum timing and prevalence level for successful integration of leprosy services with general health care services.

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Courtesy: **Indian Journal of Leprosy Vol. 64 (3) 1992.** Δ

CLOSING IN ON ASTHMA

Results of a new trial have provided further evidence that asthma is the result of cells in the immune system mistakingly becoming overactive. It has also given a pointer to the type of drugs that could block these cells.

Doctors at the UK National Heart and Lung Institute, and London Chest Hospital, have found that cyclosporin A, a drug used to suppress organ rejection after transplant surgery, produced a marked improvement in chronic asthma sufferers. At the moment, most asthmatics need high doses of steroids to control their attacks, but these can produce serious side-effects.

It has been suspected for sometime that "T helper" cells of the immune system play a central role in asthma because their activation leads to the constriction of the airways. Cyclosporin, which is thought to work by preventing the process that activates T helper cells, was used in a double-blind trial and among the 26 people who completed it there was a clear benefit from cyclosporin. The drug is reported to have both improved the patients' breathing and reduced the number of episodes of severe asthma requiring extra steroid treatment.

Although, Dr Barry Kay, one of the leaders of the research team, believes the answer to chronic asthma is to block the T helper cells, he believes new drugs with less potential side-effects may be needed instead of cyclosporin. Δ

—Medical News from Britain

(Contd. from page 28)

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BRIEF REPORT

Beneficiary Study of Leprosy Services among Tribal and Non-Tribal Population in the selected Endemic Districts of Madhya Pradesh and Andhra Pradesh

DR N.S. DHARMSHAKTU, DR B. KAMESHWARA RAO, DR M.A. ARIF, DR S.L. GUPTA, DR V.K. MASHI, DR G.P. MISHRA, DR G.R.K. RAJU AND DR SRINIVASA RAO

THE Government of India launched National Leprosy Eradication Programme in the year 1983 with the objective to arrest the disease activities in all the known cases of leprosy by the year 2000. Under the programme MDT is being provided to the patients in a phased manner taking district as a unit. All 201 endemic districts have been sanctioned MDT project which include 135 districts on vertical pattern for implementation and 66 districts for modified pattern of implementation. In the rural and tribal areas of the districts there are often many obstacles which may prevent masses to make best use of services available such as inadequate motorable roads, inadequate communication, inadequate public transport, scattered villages, inadequate infrastructure, inadequacy of staff and non-availability of services nearest to the houses of the patients, illiteracy, pressure for earning of daily livelihood, ignorance about the cause and curability of the disease, stigma, etc.

In order to overcome the obstacles in the endemic rural and tribal areas in providing MDT services following provisions have been made under MDT scheme on vertical pattern:

(a) The funds for the project are directly released to the District MDT Society which functions under the Chairmanship of District Collector.

(b) The services are provided to all the segments of the population in the district by proper organisation of available infrastructure. In all endemic districts a District Leprosy Unit is established under District Leprosy Officer. Under the vertical pattern of MDT implementation rural areas are covered by the Leprosy Control Units and its clinics. Each leprosy control unit covers a population of 4 to 5 lakh with its headquarters and 20 clinics in the field where one para-medical worker is posted for each clinic. While the worker population ratio is one for 25000 in rural areas in general, the same is reduced to 1 for 15000 in tribal and difficult hilly areas. Each of the urban leprosy control unit provides services for 30000 to 40000 population.

(c) In the vertical pattern of MDT scheme the District Leprosy Unit and Leprosy Control Units are provided a vehicle and fund for POL. MDT allowance is given to the Medical Officers and Para-Medical Workers. Funds are also provided for short orientation trair of all categories of staii, for making community awareness and for developing records and patient cards. From the leprosy control unit and its clinics the services are carried down to the patients by dividing the area into circuits and under each circuit many drug delivery points are identified in such a way that no leprosy patient will have to travel more than 2 KMs for collection of MDT on fixed days.

(d) Each DLO Unit and leprosy control unit mostly have a post of Health Educator. The assistance of District Media Unit, Block Extension Educator and other health workers are also taken in health education campaign for creating community awareness. A provision of Rs. 24,000 per year per district is provided for community awareness activities.

The present study was conducted in tribal and non-tribal areas of Durg, Raipur and Rajnandgaon districts of Madhya Pradesh and in tribal areas of Vishakhapatnam and Vizianagram districts of Andhra Pradesh with following objectives:

(i) Conduct demographic analysis showing geographical distribution of tribal people in the districts studied.

(ii) Conduct analysis of service statistics in tribal and non-tribal people to determine the use of services and occurrence of new cases for each group.

(iii) To carry out follow up interviews with male, female patients to identify their knowledge and beliefs regarding leprosy augmented by group discussions with men and women regarding the disease and control programme in the selected villages of selected districts.

Methodology : District level information was gathered by checking records available with the District Leprosy Office on a predesigned proformae. The villages were selected randomly from tribal and non-tribal blocks respectively. In the selected villages group discussions were held based on pre-designed format with adult males and adult females respectively. Wherever school was available in the village the students of 9th and 10th standard were covered under group discussion. The response against cause of the disease, its curability, availability of treatment, programme activities and choice of treatment were graded in terms of % as correct, wrong and uncertain categories. Patients and community members were interviewed by questionnaire method and their response was graded under correct, wrong and uncertain categories. The village data verification was also done in the selected tribal and non-tribal villages separately and information was gathered on a pre-designed proformae.

Summary of the Results : The percentage of tribal population to the total population of the district is 18.5% in Raipur, 12.6% in Durg, 25.3% in Rajnandgaon, 13.7% in Vishakhapatnam and 8.5% in Vizianagram. The % of rural population is higher among tribals as compared to non-tribal population in all these districts.

The prevalence rate of leprosy and annual new case detection rate are less among tribal community compared to non-tribal community in all the five districts under MDT project for a period of three to nine years. The awareness of both tribal and non-tribal community is good in general about curability of the disease, availability of treatment at the nearest place, visit of leprosy workers to villages and their activities and people's choice of treatment. 90% of both tribal and non-tribal patients are satisfied by improvement in their disease condition as a result of MDT and 80 to 100% patients are taking MDT regularly. 96 to 98% of patients are found living with their families. While the level of leprosy awareness in general is less among tribals in comparison to non-tribals in the district of Raipur, the same did not differ much in Durg and Rajnandgaon districts among tribals and non-tribals. This may be due to intensive health education campaign conducted in Durg and Rajnandgaon by DANIDA assistance in both tribal and non-tribal areas. Community members and patients had adequate knowledge and awareness about cause of the disease in both tribal and non-tribal areas. The feeling that leprosy deformity is not preventable and that the child born to woman with leprosy will also have leprosy still exists both among tribal and non-tribal communities with slightly higher side among tribals. The majority of tribal and non-tribal community members stated that allopathy is the best treatment available for leprosy (75 to 100%) and small percentage of tribal community members in Raipur district still feel Ayurveda and Homoeopathy as better remedy for leprosy.

Recommendations

1. Additional funds should be provided to the District MDT Society for carrying out intensive community awareness campaigns about leprosy along with new case detection drives. A calendar of the cultural/religious events celebrated by the local people be prepared for each community block separately particularly for the tribal areas so that special group awareness and case detection drive can be launched on those days with vigour. Health education messages about cause of leprosy, its communicability and removal of stigma should be used with caution in tribal areas which may otherwise have negative effect.

2. New case detection in the tribal areas should be done by group campaigns preferably on Sundays by house visits. This will provide better coverage of the population for case detection and at the same time community awareness would increase.

3. Available local Government/Non-Government staff and the volunteers must be involved for creating public awareness, referral of cases and retrieval of defaulter patients. Identification and involvement of such categories of persons should be done by DLO and his staff as

(Contd. on page 12)

THE STATE OF THE WORLD'S CHILDREN 1992

THE United Nations Children's Fund has made an impassioned plea for a renewed international commitment to the task of ending mass malnutrition, disease, and illiteracy in the poor world. Governments of developing countries are indicated for spending, on average, only about 12% of their budgets on basic health and education services for the poor; rich countries are criticized for allocating only about 10% of international aid to health, education, and family planning.

At a time when a new world order is struggling to be born, says the 1992 State of the World's Children report, the voice of the poorest quarter of humanity must be heard. One billion people still lack adequate food, safe water, primary health care, and basic education. "For almost half a century, war and ideological division have distracted attention and diverted resources from this task", says UNICEF. "Those threats are now receding. And the time has come for the world to recommit itself to meeting basic human needs and building a new world order which will reflect mankind's brightest hopes rather than its darkest fear."

Ending the worst of world poverty is far from being a lost cause, says the report. "We have already travelled three quarters of the way towards a world in which every man, woman, and child has adequate food, safe water, basic health care, and at least a primary education. There is no financial or technological barrier to prevent the completion of that journey in our times."

Children

The ones who are being most shamefully failed by the present world order, says UNICEF's Executive Director James Grant, are the quarter of a million children who are dying every week and the millions more who survive into half-life of malnutrition and almost permanent ill health.

"This is not a threatened tragedy or an impending crisis", says Grant. "It happened today. And it will happen again tomorrow. It is a problem which should rank in importance with any on the human agenda. But in practice, it has been given a low priority because it is primarily a problem of the poor and the powerless."

There are some signs that this may be changing. "The needs of children are beginning to feature on the political agenda in a way that is unprecedented in UNICEF's forty year history", says Grant.

The most obvious sign of that new priority was the convening of the World Summit for Children in September 1990. It was the largest gathering of Presidents and Prime Ministers in history, and it met specifically to discuss the problems of the world's children. The outcome was an agreed programme for, among other things, preventing 4 million child deaths a year, ending mass malnutrition, eradicating polio, and ensuring clean water, family planning services, and basic education for all.

"The emergence of such an agreement, at a time when the existing world order is rapidly changing", says Grant "means that there is today a better chance than ever before of finding a place on the world's political agenda for the rights of children and for meeting the minimum needs of all families."

Immunization

The setting of such ambitious targets was prompted by the growing realization that the world now has both the low-cost means and the outreach capacity to achieve dramatic gains in children's well-being. The most convincing demonstration of that potential has been the successful attempt to reach 80% immunization coverage by the end of 1990. When that target was set in the late 1970s, vaccines were reaching barely 10% of the developing world's children. Today, immunization is saving the lives of over 3 million children a year and protecting many millions more against infection and malnutrition.

"Such programmes also help to slow population growth", says UNICEF, "because parental confidence in the health and survival of children is vital to family planning efforts."

Skewed spending

It is still too early to tell whether the new commitments made at the World Summit for Children are real or rhetorical. The 159 nations represented agreed to draw up, within one year, national plans for achieving the new goals by the year 2000. So far, over 60 nations have completed such plans and that number is expected to rise to over 100 by early 1992. Some, like Mexico, have already begun to move; President Carlos Salinas de Gortari has instituted a six-monthly cabinet meeting to review progress towards the goals and approved a 40% increase in the budget of PRONASOL, the government programme which aims to provide basic services to the poorest fifth of Mexico's people and which has received $1.7 billion in 1991 — over 8% of the government's total social expenditure.

As agreed at the Summit, some industrialized nations have also been reviewing aid programmes to see how they can promote progress towards the new goals. "The public in the industrialized world has long believed that the great majority of the aid it gives to the developing world is spent on directly meeting the basic needs of the poor", says Grant, "whereas in fact only a tiny percentage is used for that purpose". Only about 1% of aid goes to the primary health care systems which could prevent or treat 80% of the disease and malnutrition in the developing world. Only about 1% goes to family planning services. And less than 1% goes to primary education.

The same distortion can be seen in spending patterns within the developing world itself. UNICEF estimates, for example, that three quarters of all health budgets go to urban hospitals, usually serving only a small minority of the population. According to some estimates, 80% of the $12 billion allocated each year to water-supply systems is spent on putting private taps in the homes of the not-so-poor and only 20% is going to the wells and stand-pipes which, with today's technology, could bring clean water to the very poorest communities at low cost. Spending on education is similarly skewed in favour of the few rather than the many. Δ

—UN Newsletter

Role of Health Education in Leprosy Control Programme

DR MANJIT SINGH

HEALTH Education aims at healthy individuals, a healthy community and a healthy nation. Health Education is more important in Leprosy Control Programme because of long incubation period of the disease; social stigma it carries; misconceptions, wrong beliefs and long duration for which a patient has to take treatment, thereby leading to more dropout rate. Mycobacterium Leprae is the causative organism.

It takes 3—5 years to manifest as disease (incubation period). Gandhiji had given most of his time in the service of leprosy patients to show that it does no harm to those coming in contact with the patients, thus encouraging people to come forward in their service. People are ignorant and do not have the scientific knowledge about the cause of the disease. They believe that they get this disease becuase of their old sins. There still exists a misconception that those who come in contact with them or their near and dear ones only shall contract the disease.

The Government of India is committed towards eradication of the disease. It is providing services through following infrastructure in the country:

* 758 Leprosy Control Units
* 900 Leprosy Centres
* 6097 Survey and Treatment Centres
* 291 Hospital Wards
* 285 Distt. Leprosy Units
* 75 Reconstructive Units
* 39 Sample Survey and Assessment Units

Leprosy Rehabilitation and Promotion Units

Early detection of the case and proper treatment prevents disability. Depigmented patch on skin with loss of sensation should cause suspicion and the patient should get him/herself investigated further for leprosy.

A. **In positive/confirmed cases,**

(i) Chemotherapy with DAPSONE (D.D.S.), M.D.T. should be continued for the period advised by the doctor. He/she should not blow nose or spit (secretions) to avoid formation of neclei which act as a source of infection.

(ii) Patient should be made self-responsible for continuing treatment through motivation and health education.

(iii) Patient should continue working along with continuing treatment. His co-workers and employers need intensive health education to cast away their apprehensions.

(iv) Patient should live and lead normal life with treatment (Drugs).

(v) There is no sensory loss if drugs are continued for specified period.

(vi) With proper care and treatment there is no need for rehabilitation if treatment is begun early.

B. **Contacts of the case** should be kept under surveillance to avoid any chance of having a new case.

C. **Relatives/friends/family members** should be involved in Health Education Campaign so that they do not carry misconceptions/wrong beliefs regarding the disease.

Leprosy organism produces sensory loss, as a result of which deformity, trauma, burns, etc. can occur. Health education aims at prevention of deformities by making patients aware of the consequences of sensory loss due to disease and the precautions a patient should observe so as to avoid burns and injuries etc.

D. **Rehabilitation**

If any one's body part is lost due to burn/injury, constructive surgery can help him to lead near normal life.

Drop-foot, claw-toes, planter ulcers, depressed nose, and multiple sinuses shall not be seen in leprosy patients if (1) detected early, (2) proper and adequate treatment is taken by patient.

Health education about possible risks due to disease should be made known to the community at large and patients in particular. Let there be no lepers. Help fight leprosy. Δ

WORLD BREASTFEEDING WEEK—1-7 AUGUST

In an effort to re-establish and sustain global breast-feeding culture, the World Alliance for Breastfeeding Action (WABA), with the support of the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF), had proclaimed 1-7 August World Breastfeeding Week. This date marked the anniversary of the Innocenti Declaration of July 1990, a landmark statement which identified a set of goals for adoption in all countries to protect, promote and support breastfeeding.

World Breastfeeding Week was intended to focus attention on a variety of breastfeeding issues. The theme for 1992 complemented the Baby-Friendly Hospital Initiative recently launched by UNICEF and WHO to support and encourage breastfeeding.

Recognizing that breast milk provides the best possible start in life for all children, WHO and UNICEF paid tribute to the many dedicated members of nongovernmental organizations that are promoting sound infant and young child feeding practices.

For many babies, breastfeeding can be a matter of life or death. In the words of UNICEF Executive Director James P. Grant, " every day, 3000 to 4000 babies die from diarrhoeal dehydration and acute respiratory infections because they are not breastfed. Thousands more succumb to other illness and malnutrition. And yet, the more science discovers about breastfeeding, the more the benefits are confirmed.

"Only a global effort, involving both North and South, can remove barriers to breastfeeding and permit mothers to offer the healthy start in life their babies deserve". Δ

—UN Newsletter

LEPROSY

—A Select Bibliography—1990-1992

K. C. SINGH AND H. KAUR

We publish below a select bibliography on Leprosy compiled by the National Medical Library (DGHS) as part of its activities aimed at providing Documentation Services to the Health Science Community in the country. It covers selected contributions on Leprosy during 1990-1992. Entries follow a classified arrangement using subject headings. Photocopies of these articles can be ordered from the National Medical Library (DGHS), Ansari Nagar, Ring Road, New Delhi-110029.

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BOOK REVIEW

Maternal Mortality
A global factbook

Maternal Mortality: A Global Factbook—Compiled by *C. AbouZahr* and *E. Royston*
1991, 608 pages (English only);
ISBN 92 4 159001 7
Sw. fr. 50-/US $45.00;
In developing countries: Sw. fr. 35.
Order No. 1930024

This book sets out the facts and figures needed to understand why so many women continue to die as a result of pregnancy and childbirth despite the fact that technical means to prevent such deaths have long been available. Drawing upon a vast data base of some 3,000 reports and studies, the fact-book shows, in the form of country profiles, where women are dying, what they are dying of and what other aspects of their lives contribute to their deaths. Noting that maternal death is most often the tragic end to a life-long chain of events and disadvantages, the book tracks down the underlying factors, often rooted in sex discrimination present since infancy, as well as the more immediate factors, such as lack of access to life-saving care, that reveal the true complexity of the forces at work. Information such as that contained in this factbook provides the key for effective action, making the best use of limited resources despite the often difficult circumstances.

The main body of the factbook, which runs to some 600 pages, consists of country profiles which, for the first time ever, bring together and analyse the results of all available surveys and studies on maternal mortality, women's reproductive health and allied subjects, as well as indicators of the coverage of maternity care, family planning and other back-ground factors. Profiles are given for each of 117 developing countries in Africa, Latin America, Asia and Oceania. Data on developed countries are also tabulated for comparison. In compiling the profiles the authors have drawn upon the unique WHO women's health data base which, in addition to the more readily available government reports and articles from scientific journals, contains information from a large variety of disparate sources, including unpublished articles, doctoral theses and consultant briefings.

To make it easier to compare countries, each profile follows a common format, starting with a section containing demographic and socioeconomic indicators that shed light on women's lives in each country: their chances of going to school, eating well, and receiving health care, the age at which they are likely to marry, their chances of planning their families, and the number of children they are likely to bear. These data provide a backdrop for the detailed statistics on coverage of care and maternal mortality which follow, and which detail the numbers of deaths, the mortality rates and ratios, the causes and circumstances surrounding each case, the groups of women most at risk of dying, and the kinds of preventive and curative actions that might have averted death.

The interpretation of this vast amount of information is facilitated through the inclusion of four background chapters. The first provides an overview of the dimensions and causes of maternal mortality and morbidity in the world today as well as of the extent of the coverage of care. The different ways of measuring maternal mortality are described in the second chapter, which discusses and strengths and weaknesses of each method. The third explains how the results of surveys should be interpreted and analyses the information that can, or cannot, be obtained from hospital studies, community surveys or registration data. The book also features a comprehensive listing of general resource materials for readers who wish to expand their knowledge on this complex issue. Δ

Authors of the Month

T.K. Das
Joint Secretary
Ministry of Health & F.W.
Nirman Bhawan,
New Delhi-110 011

Dr S.K. Noordeen
Chief,
Leprosy Unit,
World Health Organization
(WHO)
Geneva.

Dr B.N. Mittal
Deputy Director General
(Leprosy)
and
Dr N.S. Dharmshaktu
Asstt. Director General (Leprosy)
Dte. General of Health Services,
Nirman Bhawan,
New Delhi-110 011

Prof. A.R.K. Pillai
President,
Indian Leprosy Foundation,
PB. 7477, 11 Hardeni Society
Bombay-400 060.

S.P. Tare
Director,
Gandhi Memorial Leprosy
Foundation,
Hindinagar, Wardha-442 103.

Dr Sushma Gupta
Asstt. Director General,
Division of Epidemiology &
Communicable Diseases,
Indian Council of Medical
Research,
Ansari Nagar,
New Delhi-110 029.

Dr M.D. Gupte
Officer Incharge/Deputy Director
CJIL Field Unit (ICMR),
Nehru Bazaar, Avadi,
Madras-600 054

Dr Manjit Singh
Chief Medical Officer (Training)
Central Health Education Bureau
Kotla Road
New Delhi-110 002.

K.C. Singh
and
H. Kaur
National Medical Library
Dte. General of Health Services
Ansari Nagar, Ring Road,
New Delhi-110 029.

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Editorial

LEPROSY CONTROL AND THE IMPLEMENTATION OF MULTIPLE DRUG THERAPY: TO WHAT EXTENT CAN THE OPERATIONAL STRATEGY BE SIMPLIFIED FOR PRIMARY HEALTH CARE?

Since the publication of the recommendations of the World Health Organisation (WHO) on the use of regimens of multiple drug therapy (MDT) of relatively short duration for all cases of leprosy,[1] remarkable progress has been made, not only in the implementation of such regimens, but also in the development of leprosy control programmes in many parts of the world. In the first few years, the implementation of MDT was slow, reaching a coverage of only 8·8% in 1986, but thereafter increasing rapidly to 55·7% in 1990. From a total of 5·4 million registered cases in 1985, the figure dropped to 3·7 in 1990 (a reduction of about 31%), attributable mainly to the implementation of MDT and the release from treatment (and eventually from surveillance) of very large numbers of patients. Disability and child rates have come down, relapse rates are remarkably low, and the incidence of toxic (drug) reactions or immunological reactions based on either cell-mediated or humoral mechanisms, has been no greater (and possibly less) than with dapsone monotherapy. Given time, it is expected that some early reports of reduction in incidence rates following MDT will be confirmed. By 1987, speaking at a meeting in New Delhi on the evaluation of MDT through Primary Health Care (PHC), Dr SK Noordeen, Chief, Leprosy, Division of Control of Tropical Diseases, WHO, drew attention to the major changes in technology brought about by MDT, the improved outlook, virtually worldwide, towards the disease, and the immense opportunities to reduce leprosy in the next decade.[2] In 1988, a widely circulated WHO publication bore the title *Multidrug therapy for leprosy: an end in sight*,[3] and this was followed by a second in 1991, entitled *Towards elimination of leprosy*,[4] drawing attention to the progress being made in many endemic countries and to the possibility of reducing prevalence to an elimination level of less than 1 case per 10,000 of the population by the year 2000. New estimates by WHO for the number of cases worldwide have recently been published, revising the previously quoted figure of 10–12 million cases to 5·5 million.[5]

The overall pace and extent of MDT implementation worldwide

Despite these encouraging results, concern has been expressed in recent years about the

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overall pace and extent of MDT coverage worldwide. A recent WHO report[6] draws attention to considerable regional variations with regard to prevalence and MDT implementation between 1986 and 1990; the South-East Asia Region (SEARO) and the Western Pacific Region (WPRO) have achieved satisfactory levels, but elsewhere this is not the case. Progress in the development of control programmes and the implementation of MDT has been distinctly weak in Brasil, Nigeria, Myanmar and Indonesia. In Africa (AFRO Region), the overall rate at the end of 1990 was only 18·4% (compared, for example, with 66·2% for South-East Asia), with some notably low figures in Burkina Faso, Cape Verde, Chad, Congo, Côte d'Ivoire, Guinea, Madagascar, Mali, Mozambique, Niger, Reunion, Rwanda, São Tomé, Senegal, Swaziland, Togo and Uganda. Figures for the Americas are also unsatisfactory. The reasons which lie behind this situation vary greatly from one country to another, or even in different regions of the same country, but they include—(1) lack of political commitment and motivation, (2) constant, even increasing pressure to allocate time, money and personnel to health problems other than leprosy (for example, AIDS/HIV infection, tuberculosis, malaria, immunization, population control), (3) poorly developed infrastructure and lack of trained personnel, (4) absence of a proper plan of action, (5) shortage of money, (6) lack of laboratory facilities, notably for slit-skin smears, (7) poor referral facilities for complications and (8) inadequate resources, including regular supplies of dapsone, clofazimine and rifampicin for MDT.

We are now well into 1992 and the goal, whether in terms of 'control', 'elimination', 'eradication' or 'MDT for all' is almost universally directed at the year 2000. Despite the progress described above, it is clearly disconcerting that many leprosy endemic countries, especially in Africa, have barely started to implement MDT, or have achieved only single figure percentage results in their cases on treatment.

Integration with primary health care and the district health programme

Various proposals have been made through the years[7,8,9] to overcome these problems, for the most part based on the wider use of PHC, including the District Health Programme (DHP), the latter being defined as '. . . a geographical area that is small enough for its health and related social and economic problems to be properly understood and for appropriate action to be taken in response, but large enough to permit the deployment of essential technical and managerial skills for planning and management of the health programme.' Writing in 1978, before the development of MDT as we now know it, Buchmann reviewed the entire subject of PHC in relation to leprosy control in great detail,[10] concluding that it was not only advisable, but clearly the most obvious strategy for the full development of leprosy control programmes, including treatment delivery. Since the publication of the Declaration of Alma Ata on PHC in 1978,[11] all Who documents and publications on leprosy (and tuberculosis[12]) have accepted the principle of integrating leprosy control into the general health services wherever possible, whilst at the same time underlining the importance of maintaining a vertical, specialized element at various levels of the programme, for supervision, referral facilities, drug supply and financing. *The International Federation of Anti-Leprosy Associations* (ILEP), representing over 20 independent, voluntary organizations working in the field of leprosy, has also strongly affirmed its commitment to the use of the general health services based on PHC,

whilst at the same time describing the basic, rather than optimal, requirements for implementation[13]—a most valuable step in the direction of simplification. The principle of using PHC/DHP in leprosy control seems to have been accepted by most agencies working in leprosy as the only operational technology likely to have a progressive epidemiological impact, but in practice, its application continues to present problems. These are basically similar to those which have been described for tuberculosis[12]—planning, training, provision of supplies and supervision.

The possibility that the pace and extent of MDT implementation are unsatisfactory and unlikely to improve in the foreseeable future, unless new strategies are introduced, has recently been reviewed in depth by Yuasa in the *International Journal of Leprosy*.[14] He outlines the main problems which have so far been encountered and makes a plea for the involvement of *all* members of the health services, in *all* leprosy-endemic countries, to bring the benefits of MDT to *all* patients in need, without delay. He emphasizes that '. . . the MDT program must be simple, so that any leprosy-endemic country, with whatever the current state of health services, can adopt it'. His approach gives great emphasis to the use of PHC and DHP personnel in detecting, diagnosing and treating leprosy cases (but without any expectation that they will routinely participate in the prevention and management of disability or deformity—a somewhat unconventional view, which is discussed in more detail below). The strategy described seems to have worked well in the Philippines, where it has to a large extent been carried out by 'barangay' midwives, with facilities for supervision and the referral of problem cases, and including the provision of MDT for both pauci- and multi-bacillary cases in blister calendar packs. This account of a successful programme is by no means unique. In 1982 an entire number of this *Journal* was devoted to the subject of leprosy and PHC,[15] with accounts of experiences from Tanzania, the Sudan, Kenya, Indonesia, Sri Lanka and India. Some reservations were expressed, particularly about the timing of integration in relation to the treatment of all known cases, but in general the views recorded were positive and encouraging. In 1986, an important report from WHO[16] described a consultation on leprosy control and PHC, with contributions from the Gambia, Malawi, Vietnam, Malaysia, Ethiopia, Brasil and Thailand. Some failures and a number of problems were reported, but in general it was agreed by participants that the approach had great advantages over the continued use of vertical, specialized systems.

PHC and leprosy control in India

Despite encouraging progress in the implementation of MDT in the National Leprosy Eradication Programme in India, the Leprosy Division recently identified an area of difficulty in extending MDT services to 66 of their endemic districts. The problem had been accentuated by the large numbers of patients in need and the lack of trained personnel, coupled with the impossibility of training them in the foreseeable future. A decision of potentially great interest and importance, not only for India, but for control programmes elsewhere, was therefore taken by the Leprosy Division late in 1990, when *Guidelines for Modified MDT Scheme in Selected Districts* were drawn up and circulated to appropriate regions, accompanied by training manuals for various grades of health staff. This 66-page document is reviewed in greater detail elsewhere in this *Journal*;[17] it describes the administrative and technical steps which must be taken in order to

implement MDT through the general health services, using PHC and DHP (as opposed to using the specialized staff of the NLEP). The 14-day period of intensive therapy at the outset, used hitherto by the NLEP, will be discontinued; the WHO regimen will be used instead. Health education activities are to be intensified and the bacteriological examination of skin smears will be limited to multi-bacillary cases, or suspected multi-bacillary cases. This initiative should clearly be monitored with great care; it represents, at least in concept, a significant simplification of the existing operational strategy in India (estimated to have 3 million cases), thus affording an opportunity for the collection of date and an assessment of feasibility, presumably within a relatively short period of time. Inherent in the modified approach is the continued use of NLEP staff wherever possible and it bears repetition that this is in keeping with the advice which has been given by WHO and other agencies advocating this approach, to the effect that integration with PHC does *not* imply that all specialized elements should disappear from the scene; on the contrary, a specialized element, wherever it is available, should be retained at various levels.

Further simplification

In recent years, either from WHO or ILEP, several modifications which undoubtedly simplify the approach needed at PHC level, have been made. They include the following—(1) for the treatment of multi-bacillary patients, 24 months' treatment (rather than extending, wherever possible, until skin smears are negative, as in the original recommendations of 1982) is acceptable, particularly if there are resource constraints, (2) the supervision of monthly doses of rifampicin (pauci-bacillary cases) or rifampicin and clofazimine (multi-bacillary cases) should ideally be carried out by a health worker, but if this is difficult or impossible, responsibility may be delegated to other members of the community (teacher, village leader, family member, etc.), (3) provided they are reliable, skin smears are valuable and should be made available, but they are no longer regarded as an absolute prerequisite for initiating MDT, since in most cases it is possible to diagnose leprosy and distinguish between multi- and pauci-bacillary cases on clinical grounds. Two further aspects of the subject call for more serious investigation in the context of simplifying MDT at PHC level. The *first* concerns the use of systems which take note of the number of skin, or skin and nerve lesions, or of the number of 'body areas' affected, in order to allocate patients to either pauci- or multi-bacillary groups for treatment. A number of publications recording experience from different parts of the world[18,19,20,21] suggest that this approach may be preferable in certain circumstances to reliance on skin-smear results. The *second* relates to the use of blister-calendar packs for MDT drugs[22] and to the need for an objective assessment of their value, particularly in programmes using the PHC DHP approach. If found useful and potentially cost-effective, efforts should be made to set up local production thus avoiding the main impediment to their wider use at the present time, which centres on the additional cost of packs manfactured by drug companies. Finally, the proposal by Yuasa, in the editorial referred to above,[14] that disability management should realistically be separated from the public health activities of staff who are engaged in case detection and chemotherapy, giving responsibility to a separate agency, or to non-government organizations, calls for serious consideration. This is partly because current (and past) efforts to combine case detection and chemotherapy with disability prevention and management have been, in general, unsuccessful and partly because the proposed separation could, if properly planned and executed, very considerably simplify the work of PHC/DHP personnel.

Conclusion

The principle of using PHC/DHP in leprosy control appears to have been widely accepted by WHO and other agencies. Some progress has been made in its application, but in many countries where control programmes and MDT are particularly weak no systematic attempt has so far been made to develop its potential. The success of MDT under a wide range of circumstances, including some which, at least at the outset, had sub-optimal personnel and other resources, suggests that PHC/DHP should be considered more widely. Some important simplifications for this purpose have already been made; others could be developed quite quickly. Particularly for those who have identified the year 2000 for elimination, time may be short, unless new strategies are used. Is this perhaps the moment to look more closely at what is needed and what is possible, and to use PHC/DHP to close the gap, thus bringing the benefits of MDT to a much wider segment of patients?

Department of Dermatology
The Slade Hospital
Headington
Oxford OX3 7JH
England

A C McDougall*

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Evaluation of four semi-synthetic *Mycobacterium leprae* antigens with sera from healthy populations in endemic and non-endemic areas

J T DOUGLAS*, L M STEVEN*[1], D. S. HIRSCH†, T FUJIWARA‡, K E NELSON§, M G MADARANG¶[2] & R V CELLONA¶

**University of Hawaii, Department of Microbiology, 2538 The Mall, Snyder Hall 111, Honolulu, Hawaii 96822; †Hawaii Department of Health, Communicable Disease Division, P.O. Box 3378, Honolulu, Hawaii 96801; ‡Nara University, Institute for Natural Science, Horai-cho 1230, Nara 631, Japan; §Johns Hopkins University, School of Hygiene and Public Health, Department of Epidemiology, Baltimore, MD 21205; ¶Leonard Wood Memorial Center for Leprosy Research, P.O. Box 727, Cebu City, Philippines*

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Summary In order to determine the frequency of occurrence of antibodies to semisynthetic antigens of *Mycobacterium leprae* in clinically healthy nonpatient populations and to establish a 'baseline' for comparison with antibody frequencies in both patients with a history of leprosy and their contacts, ELISAs were conducted using representative sera from two areas: a leprosy endemic area, Cebu City, Philippines and a nonendemic area for leprosy Chicago, Illinois, USA. These sera were tested, by an indirect IgM ELISA, for the presence of antibodies reacting with four semisynthetic antigens based on the phenolic glycolipid I antigen of *M. leprae*: ND-O-BSA (natural disaccharide with octyl linkage to bovine serum albumin), NT-O-BSA (natural trisaccharide with octyl linkage to BSA), ND-P-BSA (natural disaccharide with phenolic ring linkage to BSA) and NT-P-BSA (natural trisaccharide with phenolic ring linkage to BSA). Using an OD reading $\geq 0{\cdot}16$ as positive, the antigen with the lowest background seroreactivity was ND-O-BSA, which reacted with 5/398 (1·3%) sera from Cebu, and 3/426 (0·7%) sera from Chicago. A total of 10 (2·5%) of 398 sera from the endemic area reacted with at least one antigen and 5 (1·3%) sera reacted with all four semisynthetic antigens. Of the 426 sera from Chicago, 12 (2·8%) were reactive with at least one antigen and 3 (0·7%) were reactive with all four semisynthetic antigens. Mean ELISA values for the 22 positive sera for each antigen ranged from 0·17 to 0·3 OD units, while the mean values for all sera in

[1]Deceased 30 January 1990
[2]Deceased 8 January 1988

La evaluacion de cuatro antigenos *Mycobacterium leprae* semi-sinteticos con sueros de populaciones sanas en zonas endemicas y no endemicas

J T Douglas, L M Steven, D S Hirsch, T Fujiwara, K E Nelson, M G Madarang y R V Cellona

Resumen Para poder determinar la frecuencia de ocurrencia de los anticuerpos en los antígenos semi-sintéticos de *Mycobacterium lepræ* en populaciones clinicamente sanas que no son pacientes, y para establecer una 'linea de base' para comparar las frecuencias de anticuerpos en los pacientes con antecedentes de lepra y sus contactos, se realizaron ELISAs usando sueros representativos de dos zonas: una de lepra endémica, Cebu City, Islas Filipinas, y una zona no endémica, Chicago, Illinois, EE.UU. Se probaron estos sueros por medio de ELISA IgM indirecta, para la presencia de anticuerpos que reaccionan con cuatro antígenos semisintéticos basados en el antígeno fenólico glicolípido I de *Mycobacterium lepræ*: ND-O-BSA (disacárido natural con enlace octílico con albumina sérica bovina), NT-O-BSA (trisacarido natural con enlace octílico con albumina sérica bovina), ND-P-BSA (disacarido natural con enlace fenólico con albumina sérica bovina), y NT-P-BSA (trisacarido natural con enlace fenólico con albumina sérica bovina). Usando una lectura OD ≥0,16 como positiva, el antígeno con la seroactividad de fondo más bajo fue ND-O-BSA que reaccionó con 5/398 (1,3%) de los sueros de Cebu, y 3/426 (0,7%) de los sueros de Chicago. Un total de 10 (2,5%) de los 398 sueros de la zona endémica reaccionó con al menos un antígeno y 5 (1,3%) de los sueros reaccionaron con los cuatro antígenos semi-sintéticos. De los 426 sueros de Chicago, 12 (2,8%) eran reactivos con al menos un antigeno y 3 (0,7%) reaccionaban con los cuatro antígenos semi-sintéticos. Los valores medios ELISA para los 22 sueros positivos de cada antigeno variaban entre 0,17 y 0,3 unidades OD, y los promedios para todos los sueros en cada zona variaban entre 0,01 y 0,04 unidades OD para todos los antígenos. La reactividad de 14 de los sueros positivos con algunos de los antígenos, pero no todos los antígenos semi-sintéticos, indica que el portador y los enlaces pueden ser asociados con esta reactividad de fondo. Se justifica la investigación de otros portadores y enlaces. Concluimos que la reactividad de fondo no específica con los antígenos semi-sintéticos que representa la molécula PG-I de *Mycobacterium lepræ* es 0,7 a 1,3%, valor basado en un valor de corte de ≥0,16 OD. Estos datos nos permiten concluir que la reactividad de individuos libres de lepra fue suficientemente bajo para justificar el uso de estos antígenos en un ambiente diagnóstico, por ejemplo el control de contactos familiales y en populaciones muy endémicas. Cuando la incidencia y frecuencia de la lepra son bajas, pruebas que usan estos antígenos no serían rentables, al menos que se les aplicará a individuos muy expuestos a riesgo. El control serológico por medio de estos antigenos podría ser útil en la detección y diferenciación de los relapsos bacteriológicos, las reacciones de tipo 1 o 2, la detección temprana de la lepra y para controlar el tratamiento en zonas endémicas.

Leprosy in French Polynesia. Epidemiological trends between 1946 and 1987

J-L CARTEL,* J-P BOUTIN,* A SPIEGEL,* Ph GLAZIOU,* R PLICHART,* R CARDINES† & J-H GROSSET‡

**Institut Territorial de Recherches Medicales Louis Malarde BP 30 Papeete, Tahiti, Polynesie Francaise; †Public Health Services, BP 611 Tahiti, Polynesie Francaise, ‡CHU Pitié Salpetrière, 91 Bd de l'Hôpital, 75634 Paris Cedex 13, France*

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Summary The analysis of computerized data (OMSLEP system) on patients from French Polynesia followed since 1940 has shown a decrease in the mean annual detection rates for leprosy, all forms combined, from 24.73 per 100,000 inhabitants in 1946 to 8·1 per 100,000 in 1987 ($y = -0.49\,x + 45.83$; $p < 0.05$). In fact, the decrease was significant ($y = -1{\cdot}18\,x + 83{\cdot}54$; $p < 0{\cdot}05$) during the first half of the study period (1946–66), but not during the second half (1967–87). Similarly, a significant decrease in all of the specific mean annual detection rates (according to the form of leprosy and to the sex and age of patients), in the proportion of multibacillary patients among the total of newly detected cases, and in the proportion of all patients with disabilities at the onset of leprosy was observed only during the first half of the study period (1946–66). Nevertheless, when comparing age-specific cumulative detection rates, calculated by 10-year age groups over the period 1946–66, to those of the period 1967–87, an ageing of the leprosy population was noted. Finally, the decrease of mean annual detection rates was greater in the smaller populations of remote islands than in the population of Tahiti, the main island, where 70% of the total population were living during the study period. This decline was shown to correspond to an effective improvement of the leprosy situation which could be attributed, among other factors (such as economic development and systematic BCG vaccination), to the implementation of a control programme for leprosy in 1950. The introduction in 1982 of multidrug therapy for all patients suffering active leprosy has raised the hope of a subsequent decline of leprosy in French Polynesia in the near future.

Introduction

Up to now, leprosy control has been based on the adequate treatment of patients detected as early as possible. The knowledge and understanding of the evolution of epidemi-

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ological indicators for leprosy are essential for evaluating and monitoring control strategy. Therefore, the collection and analysis of epidemiological data is a most important part of leprosy control programmes. However, reliable epidemiological data on leprosy are difficult to collect in most countries, especially for operational reasons. In French Polynesia, an area where the population is of a relatively small size and where medical infrastructures are considerable, a control programme for leprosy was implemented by the end of the 1940s. In 1986–7, computerization of data on leprosy patients registered from 1940 onwards was initiated according to the OMSLEP[1] system and reliable information on leprosy for the past 40 years has now become available. This enabled us to analyse the evolution of the main epidemiological indicators for leprosy in French Polynesia for the period 1946–87.

Background

French Polynesia is made up of about 130 islands (88 usually inhabited), with a land surface of only 4000 km^2, scattered over an oceanic area of 4 million km^2. The 130 islands are divided into 5 archipelagoes (Society, Australes, Tuamotus, Gambiers and Marquesas); Papeete, the main town, where administrative authorities are concentrated, is located on Tahiti, the main island of the Society archipelago (Figure 1). The population increased dramatically between 1946 and 1987; according to the IT Stat.[2] records, there were 56,601 inhabitants in 1947 (18,462 < 15 years of age and 38,139 > 15 years of age), and 181,862 in 1986 (69,077 < 15 years of age and 112,785 > 15 years of age). For each year of the study period, the population was calculated from the results of 8 censuses (1946, 1951, 1957, 1962, 1967, 1971, 1977 and 1983) assuming a linear increase between two censuses. It is important to note that, between 1946 and 1987, about 75% of the total population of French Polynesia were living in Tahiti while only 50% were born on that island.

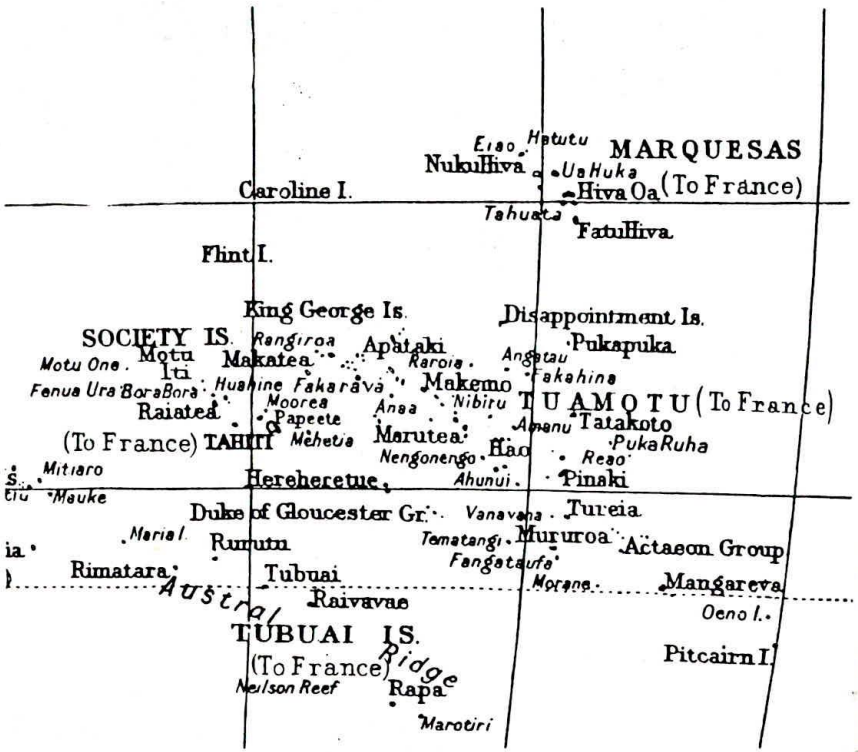

Figure 1. Archipelagoes of French Polynesia.

As in many countries, the leprosy control programme started with the construction of leprosariums, the first two in Tahiti and in a remote valley of the Southern Marquesas (1500 km north of Tahiti) in 1914; a third one was opened in 1934 in Reao, one of the easternmost islands of the Tuamotu archipelago. Since 1902, notification of all cases of leprosy to the Health Authority by the diagnosing physician has been compulsory. For each new case of leprosy, a patient form is filled out indicating name, sex, date and place of birth, date and place of detection, as well as the results of clinical, microbiological and pathological examinations, and the nature and duration of treatment. Each month assessment of drug intake and of clinical evolution is performed and the form updated. All data on leprosy patients living in the 3 leprosariums are centralized in Tahiti where a central leprosy register is kept. In 1950, the 'Louis Malardé' Institute was created and was given direction of the leprosy control unit. This unit organizes active case-finding among household contacts of known leprosy patients, and passive case-finding; it is responsible for the prescription, distribution, supervision and evaluation of chemotherapy. Today the Institute is still in charge of the leprosy control programme and keeps the territorial leprosy register.

Materials and methods

The data analysed in this study comes partly from the territorial register and partly from the medical files of patients followed from 1946 to 1987. The diagnosis of leprosy was based on the clinical examination of patients (including examination of the skin and the large nerve trunks) supplemented by biological tests: the lepromin intradermal reaction, the search for acid-fast bacilli in nasal mucosa and skin (earlobes and skin lesions) and biopsy for pathological examination. Clinical examination and biological tests also permitted the assignment of cases retrospectively into paucibacillary and multibacillary categories.

Between 1951 and 1982 the basis of treatment for leprosy was dapsone monotherapy, which was prescribed lifelong for multibacillary patients and for an average of 10 years for paucibacillary patients. Rifampicin (RMP) was prescribed occasionally and over short periods of time from 1973 to 1982. After January 1982, multidrug therapy, including daily administration of 10 mg/kg RMP, has been implemented in French Polynesia. All drugs are distributed free of charge every month to patients, either at the Institute, or in non-specialized public health clinics (in this latter case the drugs are provided by the leprosy control unit).

The annual prevalence rates for leprosy were calculated according to the definition

given by Lechat and Vanderveken,[3] i.e. taking into account all known leprosy cases (on treatment as well as under surveillance after treatment). Because important variations in the number of newly detected leprosy cases were observed from year to year, the following indicators were calculated for 3-year periods: crude, type-specific, sex-specific, and age-specific (< 15 years, > 15 years) detection rates; proportion of multibacillary patients among the total number of cases, and with disabilities[4] of grade > 2. Also, cumulative detection rates, specific for 10-year age groups, and mean annual detection rates according to the place of birth were calculated for the two consecutive 21-year periods, 1946–66 and 1967–87.

All data from the medical files of the patients were anonymously entered on the OMSLEP record card and analysed by computer. For statistical analysis, Pearson's χ^2 test and the Student's t test were used.[5] Regression curves were established using a computer statistical package (Chart 3 Microsoft).

Results

PREVALENCE RATE

In 1946, 133 leprosy patients, all on treatment, were recorded in the territorial register, giving a prevalence rate of 2·4/1000; in 1987, the number of registered patients was 291 (88 on treatment and 203 under surveillance after treatment) and the prevalence rate was 1·57/1000, not significantly different ($p > 0{\cdot}05$) from that of 1946. If taking into account only the patients requiring treatment for the calculation of the prevalence rate, as recommended by WHO in 1988,[6] then the prevalence rate in 1987 was 0·48/1000, significantly lower ($p < 0{\cdot}01$) than that of 1946.

CRUDE DETECTION RATES

Between 1946 and 1987, 520 new leprosy cases were detected, 233 (45%) were multibacillary and 287 paucibacillary cases; 306 (59%) were males and 214 were females (Table 1).

During the first 3-year period of the study (1946–48), the number of newly-detected patients was 42 and the mean annual detection rate for leprosy (all forms combined) was 24·73/100,000 (Table 1). The corresponding figure was 44 during the last 3-year period (1985–87) but, given the dramatic increase of the population to 181,862 inhabitants, the mean annual detection rate for leprosy was 8·1/100,000, significantly lower than that for the period 1946–48. The regression curve, plotted on the basis of mean annual detection rates for all 3-year periods (Figure 2) indicates a significant decrease ($y = -0{\cdot}49\,x + 45{\cdot}83$; $r = -0{\cdot}80$; $p < 0{\cdot}05$). In fact, the regression was not constant between 1946 and 1987; the detection rate fell dramatically from 24·73 in 1946–48 to 8·6/100,000 in 1964–66 ($y = -1{\cdot}18\,x + 83{\cdot}54$; $r = -0{\cdot}89$; $p < 0{\cdot}05$); conversely, between 1967 and 1987, no significant decrease ($p > 0{\cdot}05$) was observed in the detection rates of the 7 3-year periods.

SPECIFIC DETECTION RATES

With respect to the type of leprosy (Table 1), during the first 3-year period of the study, 25 of the 42 newly-detected cases were multibacillary (14·7/100,000 mean annual detection

Table 1. Mean annual detection rates for leprosy according to (a) type, (b) sex and (c) age by 3-year periods between 1946 and 1987

3-year periods	(a) Type: Total No.	(a) Type: Total Rates*	(a) Type: Paucibacillary No.	(a) Type: Paucibacillary Rates*	(a) Type: Multibacillary No.	(a) Type: Multibacillary Rates*	(b) Sex: Males No.	(b) Sex: Males Rates*	(b) Sex: Females No.	(b) Sex: Females Rates*	(c) Age: <15 Years No.	(c) Age: <15 Years Rates*	(c) Age: >15 Years No.	(c) Age: >15 Years Rates*
1946–48	42	24·73	17	10·01	25	14·72	25	28·04	17	21·07	10	18·05	32	27·96
1949–51	60	33·19	27	14·93	33	18·25	31	32·08	29	33·06	12	16·97	48	43·60
1952–54	43	21·44	19	9·47	24	11·96	25	24	18	18·07	19	22·45	24	20·70
1955–57	33	14·75	19	8·49	14	6·25	23	20	10	9·22	8	8·23	25	19·75
1958–60	35	14·63	17	7·10	18	7·52	21	17·01	14	12·04	5	4·80	30	22·18
1961–63	28	10·98	17	6·67	11	4·31	16	12·02	12	9·07	6	5·42	22	15·24
1964–66	24	8·61	14	5·02	10	3·59	15	10·32	9	6·75	3	2·49	21	13·27
1967–69	24	7·75	15	4·84	9	2·90	15	9·18	9	6·15	3	2·22	21	12·00
1970–72	30	8·53	15	4·26	15	4·26	16	8·58	14	8·48	5	3·21	25	12·77
1973–75	37	9·67	22	5·75	15	3·92	21	10·04	16	8·85	8	4·83	29	13·34
1976–78	37	8·94	21	5·07	16	3·86	16	7·36	21	10·07	4	2·30	33	13·72
1979–81	37	8·11	22	4·82	15	3·28	28	11·73	9	4·13	1	0·55	36	13·10
1982–84	46	9·19	29	5·79	17	3·39	28	10·74	18	7·52	6	3·14	40	12·92
1985–87	44	8·06	33	6·04	11	2·01	26	9·15	18	6·88	14	6·75	30	8·86
Total	520	—	287	—	233	—	306	—	214	—	104	—	416	—

* Per 100,000 inhabitants.

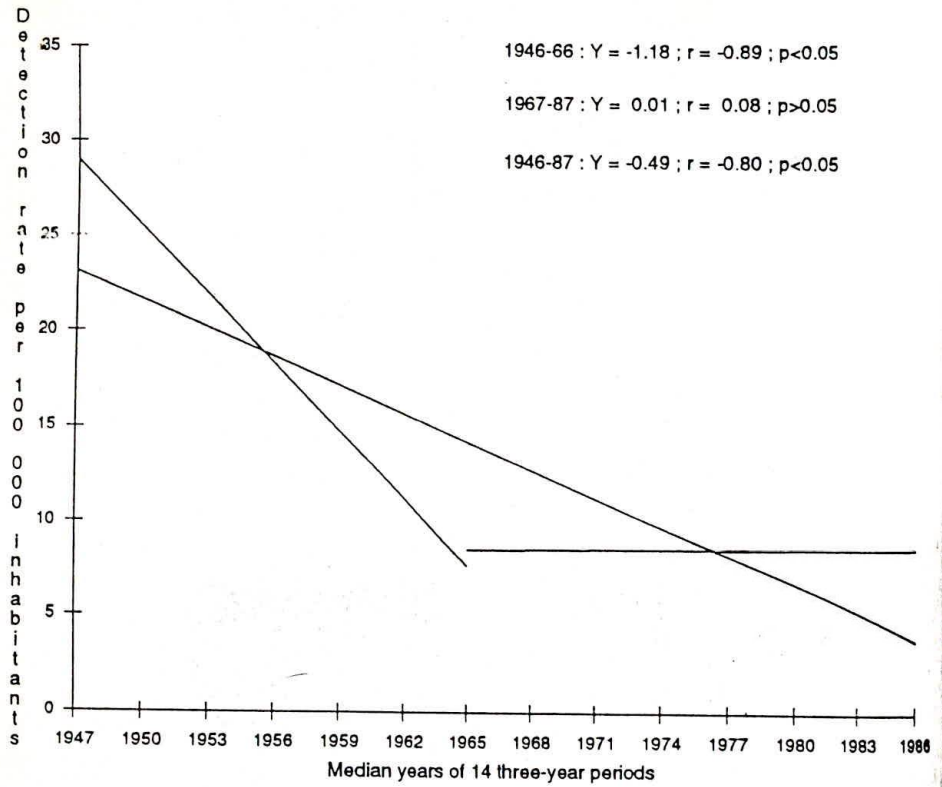

Figure 2. Evolution of mean annual detection rates for leprosy (all forms) by 3-year periods between 1946 and 1987.

rate) and 17 were paucibacillary patients (10/100,000) whereas, during the last one, of the 44 newly detected patients, 11 were multibacillary (2·01/100,000) and 33 were paucibacillary (6·04/100,000). The regression curve plotted on the basis of the 14 specific 3-year detection rates showed a significant ($p<0·05$) decline for both multibacillary and paucibacillary detection rates. The decline was significant for multibacillary as well as for paucibacillary detection rates between 1946 and 1966 ($p<0·05$), but not between 1967 and 1987 ($p>0·05$).

With respect to sex of the patients (Table 1), a significant decrease ($p<0·01$) of the detection rate was observed between 1946 and 1987, from 28·04 to 9·15/100,000 in males and from 21·07 to 6·88 in females. Again, the regression was significant in males ($p<0·01$) as well as in females ($p<0·05$) between 1946 and 1966, but not between 1967 and 1987 ($p>0·05$).

With respect to age (Table 1), of the 42 newly detected patients during the first 3-year period of the study (1946–48), 10 were less than 15 years of age (mean annual detection rate: 18·05/100,000) and 32 were 15 years of age or more (27·96/100,000). The regression curves plotted on the basis of all 14 age-specific detection rates showed a significant

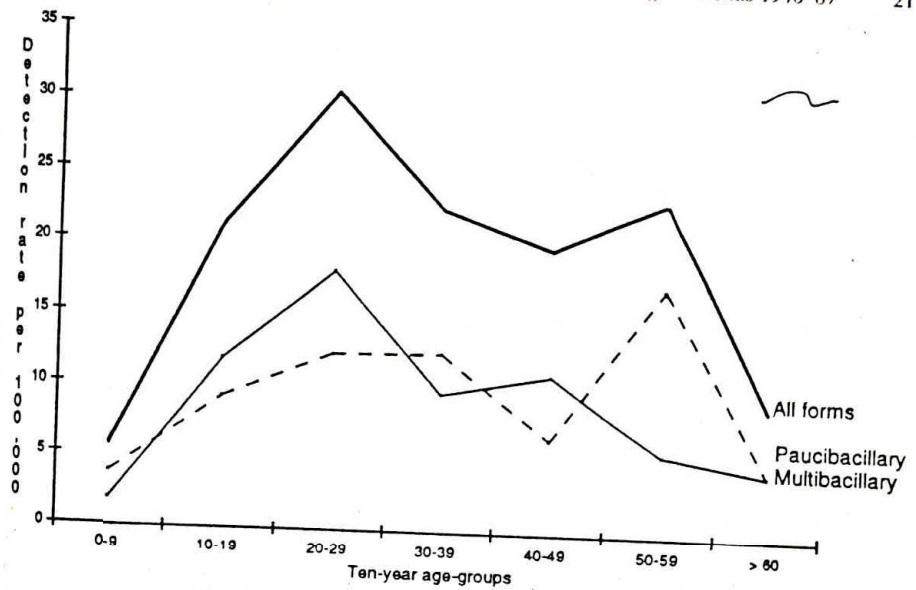

Figure 3. Age-specific detection rates of leprosy between 1946 and 1966.

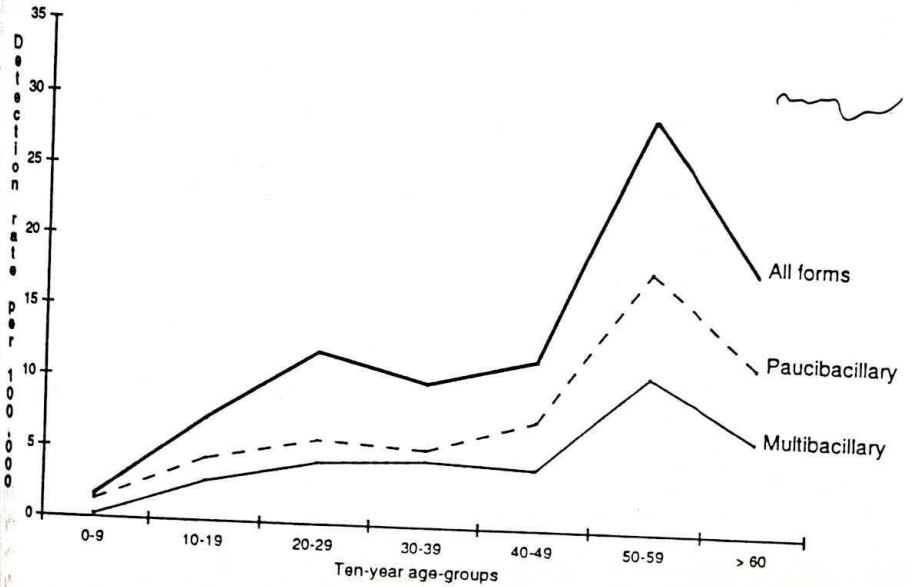

Figure 4. Age-specific detection rates of leprosy between 1967 and 1987.

decrease ($p < 0.05$) for both < 15 years of age and > 15 years of age detection rates; as observed for previously reported epidemiological indicators, the regression was effective ($p < 0.05$) during the period 1946–66, but not during the period 1967–87 ($p > 0.05$).

This led us to consider two study periods, 1946–66 and 1967–87, for analysing our results concerning detection rates as well as other epidemiological indicators.

When considering age-specific, 21-year cumulative detection rates, calculated by 10-year age groups, more pertinent data became available for analysis of results. Between 1946 and 1966, 265 new cases of leprosy (130 paucibacillary and 135 multibacillary) were detected; as shown in Figure 3 the highest detection rates were observed in the 20–29 years age groups for leprosy, all forms combined (30·5/100,000), as well as for multibacillary cases (18·1/100,000); whereas, for paucibacillary patients, detection rates were not significantly different in the 7 10-year age groups ($p > 0.05$). During the period 1967–87 (Figure 4), 255 new cases (157 paucibacillary and 98 multibacillary) were detected, with the highest detection rates being observed in the 50–59 years age groups for leprosy (all forms combined, 29·2/100,000), as well as for paucibacillary (10·9/100,000) and for multibacillary patients (18·3/100,000).

With respect to place of birth, during the period 1946–66, the highest mean annual detection rates were observed in remote islands, especially in the Gambier islands, and in the Northern and Southern Marquesas islands, where they were 198, 72 and 49 per 100,000, respectively (Table 2); during the same period, the detection rate was 9·2/100,000 in the Society archipelago (where 70% of the population were living). During the 1967–87 period, the mean annual detection rates decreased dramatically to 54 and 12/100,000 in the Gambier and Northern Marquesas islands, respectively, while they remained stable in the Southern Marquesas (49/100,000) as well as in the Society archipelago (7/100,000).

PROPORTION OF MULTIBACILLARY PATIENTS AMONG NEWLY-DETECTED CASES

The proportion of multibacillary patients among newly-detected patients was 59·5% during the first 3-year period (1946–48) of the study and 25% during the last one (1985–7);

Table 2. Mean annual detection rates for leprosy according to place of birth in French Polynesia by 21-year periods between 1946 and 1987

	1946–66 period			1967–87 period		
Place of Place of birth	Mean* population	Mean* No. of cases	Mean* rate	Mean population	Mean No. of cases	Mean rate
Society islands	58,388	5·4	9·2	97,405	7	7·2
Marquesas islands						
Northern	2505	1·8	72·2	4600	0·6	12·4
Southern	1356	0·8	49·6	2824	1·4	49
Australes islands	4206	0·9	22·1	7036	0·7	9·5
Tuamotu islands	6530	2·2	34·3	9655	1·4	14·3
Gambier islands	552	1·1	198·4	870	0·5	54·7
Outside of FP†	9708	0·42	4·4	18,239	0·7	3·6

* Annual mean population, number of cases and detection rates (per 100,000 inhabitants).

† Patients born outside of French Polynesia, but detected in French Polynesia.

the regression curve plotted on the basis of the 14 3-year proportions ($y = -109·8 x + 114$) indicates a significant decrease ($p < 0.05$). As was noted for other indicators previously reported, the decrease was significant between 1946 and 1966 but not significant between 1967 and 1987.

PROPORTION OF PATIENTS WITH DISABILITIES OF GRADE > 2 AT DETECTION

In 1946–8, among the 42 newly-detected patients, 22 (52%) presented disabilities of grade > 2 at the moment of detection; this percentage fell dramatically to reach 6·8% in 1985–7; for the whole study period, the regression curve ($y = -0·51 x + 79·5$) indicates a significant decrease ($p < 0.05$). Again, the decrease was significant ($p < 0.05$) during the first period of the study (1946–66), but not during the second one (1967–87).

Discussion

As mentioned above, the number of newly-detected patients differed greatly from year to year during the whole study-period. Such a phenomenon may be due either to the small number of cases and random fluctuations, or to a lack of continuity in the active case finding performed in the islands. Therefore, to validate detection rates as estimates of incidence, we examined the evolution of 2 indicators: the proportion of newly-detected patients with deformities of grade > 2 and the proportion of multibacillary patients among the total number of newly-detected patients (though the use of the latter indicator may be controversial). The proportion of patients with deformities among the newly-detected cases should tend towards zero if detection rates approach incidence rates and the proportion of multibacillary patients (who are usually detected first when control schemes are initiated) should decrease steadily some years after the implementation of a leprosy control programme.[3] In fact, we observed a reduction of these 2 proportions, along with the decrease of the detection rates. This suggests that, 20 years after the implementation of the control programme, the 3-year detection rates reported in our study closely approximated the true incidence of leprosy.

The next point to emerge from our data is the consistant decrease in the leprosy detection rates. The fact that it is limited to the period 1946–66, that is, during the period following the introduction of dapsone, must be considered very carefully. The evolution of the epidemiological situation may not always be attributed to the efficacy of a control programme,[7] and the declining incidence of leprosy coincident with the implementation of a leprosy control programme is difficult to interpret because of other possible influencing factors, such as a change in control programme efforts, economic development of the country and the natural decline of the disease.[8] After 1946 the main change in leprosy control in French Polynesia was the closure of leprosariums in the remote islands of the Marquesas and Tuamotu archipelagoes, and, in 1950, the centralization at the Louis Malardé Institute of the activities of the leprosy control unit. In fact, this operational change resulted in the strengthening and the standardizing of the activities of the control unit and treatment measures. Thus, the reduction of detection rates is likely to reflect an improvement in the epidemiological situation rather than a failure of the control strategy, and it may be assumed that an actual decline in leprosy has occurred since 1946. A period of important economic development occurred in French Polynesia but, because

this only commenced after 1962,[9] it is unlikely to be the only cause of the improvement in the leprosy situation between 1946 and 1966. Moreover, this economic improvement affected remote islands much less and much later than Tahiti; thus, it is not likely to be responsible for the decrease of the detection rates for leprosy in the remote archipelagoes. Though several reports have suggested that control programmes only resulted in improvement of the leprosy situation in a few areas,[10] some of our findings suggest that improvement in the leprosy situation noted in French Polynesia could be attributed, among other factors, to the efficacy of the control programme implemented in 1950. The most important is the decline in the proportion of newly-detected patients with disabilities, which has been demonstrated in other countries[11] to be the main effect of a control strategy. Another point is that the most important decrease in detection rates was observed in remote islands. This suggests that control programmes, including not only standardized treatment and the follow-up of patients, but also active case-finding among household contacts, are easier to manage, and, thus, are more effective in small size populations. That such a decrease was not observed in the South Marquesan population, which is also of a small size, remains difficult to explain.

Regarding the second study period of 1967–87, the stability in detection rates might suggest, as reported in a previous study,[12] that no change occurred in the leprosy situation. It must be emphasized that, during that period, the highest detection rates were observed in the oldest age groups (in terms of age at detection) whereas, during the first period (1946–66), they were observed, at least for multibacillary leprosy, in the 20–9 year age group. In fact, the difference between age at onset and age at detection was probably longer during the first period than during the second, due to the delay in case finding. Thus, the difference in age at onset between the two periods was most likely greater than what we have reported. However, the ageing of the leprosy population may have several explanations, among them the introduction in French Polynesia by the mid-1960s of systematic BCG vaccination for all new-born children. As reported by Bagshawe, BCG should afford protection against leprosy, more particularly in vaccinated children under 15 years of age.[13] Also, it is known that the efficacy of a leprosy control programme should result in a more marked decrease in children,[14] and that increase in the mean age of patients at the onset of leprosy reflects a decrease in the risk of infection in a community. However, it should be kept in mind that increasing mean age of patients has been considered as an indicator of long-term decreasing trends irrespective of any control strategy.[8] Why detection rates for leprosy remained stable during the period 1967–87 is difficult to explain. It is assumed that, theoretically, effective treatment of all patients with overt disease (known prevalence) together with the reduction to zero of the reservoir of undetected cases (unknown prevalence) should interrupt transmission, and that after a period of latency, no new cases should appear.[15] In that assumption, a most important point is that treatment should be effective: in French Polynesia, nearly half of the multibacillary patients on dapsone monotherapy have relapsed and have become additional sources of transmission.[16] Therefore, it might be speculated that an additional reservoir of infection, consisting of all relapsing multibacillary patients since 1946, has contributed to the emergence of new cases of leprosy and to a slowing down of the decrease in detection rates which was observed during the previous period. Whatever the explanation and despite the stability in detection rates for leprosy during the period 1967–87, our results suggest that the leprosy situation also improved during the last 21 years of the study. Finally, it should be noted that, ever since multidrug therapy was implemented

in French Polynesia in 1982, no relapses have been detected;[17] whereas, as mentioned above, during the time of dapsone monotherapy, cumulative relapse rates of 30–50% were observed in multibacillary patients.[16] It seems reasonable to hope that, by suppressing or greatly reducing the occurrence of relapse, the implementation of MDT in French Polynesia will reduce the risk of transmission of the disease, and that a subsequent fall in detection rates should be observed in the near future.

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Lèpre en Polynésie Française. Tendances épidémiologiques entre 1946 et 1987

J-L Cartel, J-P Boutin, A Spiegel, Ph Glaziou, R Plichart, R Cardines et J-H Grosset

Résumé L'analyse des données informatiques (système OMSLEP) sur des patients de Polynésie française suivis depuis 1940 a révélé une diminution des taux annuels moyens de détection de toutes les formes de lèpre, de 24,73 pour 100 000 habitants en 1946 jusqu'a 8,1 pour 100 000 en 1987 ($y = -0,49\,x + 45,43$; $p < 0,05$). En réalité, la diminution était significative ($y = -1,18\,x + 83,54$; $p < 0,05$) pendant la première moitié de la période d'étude (1946–66), mais ne l'était pas pendant la seconde (1967–87). De même, on a observé seulement au cours de cette même première moitié (1946–66) de la période d'étude une diminution significative dans tous les taux de détection annuels moyens spécifiques (selon la forme de lèpre, le sexe et l'age des patients), dans la proportion des patients multibacillaires sur le total des nouveaux cas détectés, et dans la proportion de tous les patients souffrant d'infirmités au début de leur lèpre. Pourtant, lorsque les taux de détection cumulatifs par age, calculés par groupe d'age de 10 ans, au cours de la période 1946–66, ont été comparés à ceux de la période 1967–87, on a noté un vieillissement de la population lépreuse. Enfin, la diminution des taux de détection annuels moyens était plus importante dans les plus petites populations des iles isolées que dans la population de Tahiti, l'ile principale, où 70% de la population totale vivait pendant la période de l'étude. On a montré que ce déclin correspondait à une amélioration réelle de la situation quant à la lèpre, que l'on pourrait attribuer, entre autres facteurs, (tels que le développement économique et la vaccination BCG systématique), au programme de contrôle de la lèpre exécuté en 1950. L'introduction en 1982 d'une thérapeutique multidrogue pour tous les patients atteint de lèpre évolutive a fait naître l'espoir d'un nouveau déclin de la lèpre en Polynésie française dans un avenir prochain.

La lepra en la Polinesia Francesa. Las tendencias epidemiologicas entre 1946 y 1987

J-L Cartel, J-P Boutin, A Spiegel, Ph Glaziou, R Plichart, R Cardines y J-H Grosset

Resumen El análisis de datos informatizados (sistema OMSLEP) sobre pacientes de la Polinesia Francesa desde 1940 ha indicado una reducción del promedio anual de detección de la lepra, en una combinación de todas sus formas, de 24,73 por 100 000 habitantes en 1946 a 8,1 por 100 000 en 1987 ($y = -0,49\,x + 45,83$); $p < 0,05$). En efecto, la reducción durante la primera mitad del periodo del estudio (1946–66) fue significativa ($y = -1,18\,x + 83,54$; $p < 0,05$), pero no durante la segunda mitad (1967–87). Igualmente, se observó una reducción significativa de todos los promedios anuales específicos de frecuencia de detección (según la forma de la lepra y el sexo y edad de los pacientes), en la proporción de pacientes multibacilares en el total de casos recién detectados, y en la proporción de todos los pacientes con incapacidades al inicio de la lepra, durante el la primera mitad del periodo de estudio (1946–66). No obstante, cuando se compara la frecuencia de detección cumulativa para edades específicas, calculada en grupos de 10 años durante el periodo 1946–66, con la frecuencia para 1967–87, se notó un aumento de la población leprosa. Finalmente, la reducción del promedio anual de frecuencias de detección fue más grande en las poblaciones más pequeñas de las islas remotos que en la población de Tahiti, la isla principal, donde vivía 70% de la población total durante el periodo del estudio. Se mostró que la disminución correspondía a una mejora efectiva de la situación leprosa que se podía atribuir a, entre otros factores (como el desarrollo económico y la vacunación antituberculosa sistemática), debida a la implementación de un programa de control de la lepra en 1950. La introducción en 1982 de una terapia multi-droga para todos los pacientes que sufrían de lepra activa ha creado la esperanza de una reducción posterior de la lepra en la Polinesia Francesa en un futuro próximo.

Leprosy in French Polynesia. The possible impact of multidrug therapy on epidemiological trends

J-L CARTEL,* A SPIEGEL,† L NGUYEN NGOC,† J-P MOULIA-PELAT,† P M V MARTIN† & J-H GROSSET‡

**Institut Territorial de Recherches Medicales Louis Malarde BP 30 Papeete, Tahiti, Polynesie Française; †Institut Louis Malarde; ‡CHU Pitié Salpetrière, 91 Bd de l'Hôpital, 75634 Paris Cedex 13, France*

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Summary In 1982, following the recommendations of a WHO study group, multidrug therapy (MDT) was introduced into French Polynesia to treat all patients suffering from active leprosy, and—only on request—those still on dapsone monotherapy. After 5 years, a clear-cut decrease of prevalence and mean annual detection rates for leprosy (except for detection rates among children aged less than 15 years, many of such cases being detected early by increased household contact training) has been observed. There was also a decrease in the proportion of newly detected cases with disabilities. During the 21-year period preceding the introduction of MDT into the control programme, mean annual detection rates for leprosy had remained stable, and this led to the consideration that such a decrease was due neither to the natural decline of the disease nor to the economic improvement of the country. Our results, together with the fact that, to date, the relapse rate was nil in the Polynesian patients put on MDT, strongly suggest that the implementation of MDT has resulted in a decrease of detection rates for leprosy which may be a consequence of a decrease in the transmission of the disease.

Introduction

From the early 1950s, dapsone monotherapy was the basis of the treatment for leprosy in French Polynesia, prescribed to paucibacillary patients for an average of 10 years and for life to multibacillary patients. In November 1982, following the recommendation of the WHO study group,[1] multidrug therapy (MDT) was introduced to treat all patients suffering from active leprosy. These included newly-detected patients as well as those detected before 1982 and suffering a relapse; patients detected before 1982 and still on dapsone monotherapy without signs of active leprosy were put on MDT only on request. The aim of this study is to discuss if changes in the epidemiological trends of leprosy have

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been observed after MDT was introduced and to determine if this could be attributed to the introduction of MDT into the control programme. Because the results of a previous study have indicated that detection rates for leprosy remained stable between 1967 and 1983,[2] the epidemiological indicators were analysed over the period 1967–83 (pre MDT) and 1983–90 (post MDT).

Patients and methods

As shown in Table 1, the population increased dramatically in French Polynesia between 1967 and 1990; according to I.T.Stat.[3] records, there were 98,378 inhabitants in 1967 and 197,061 in 1990. For each year of the study period, the population was calculated from the results of 5 censuses (1967, 1971, 1977, 1983 and 1988) assuming a linear increase between 2 censuses. During the entire period 1967–90 about 75% of the total population were living in Tahiti although only 50% were born on that island.

The data analysed in the study came partly from the territorial register and partly from the medical files of patients followed from 1967 to 1990. The diagnosis of leprosy was

Table 1. Annual population and prevalence rates* for leprosy in French Polynesia between 1967 and 1990

Year	Population	Prevalence Rates*	No. of patients on treatment			
			Total	DDS	MDT	Other†
1967	98,378	3·21	315	315	0	0
1968	103,199	3·09	319	319	0	0
1969	108,020	2·94	318	318	0	0
1970	112,842	2·57	290	287	0	3
1971	117,663	2·47	291	285	0	6
1972	120,949	2·36	286	272	0	14
1973	124,236	2·28	283	271	0	12
1974	127,522	2·26	288	276	0	12
1975	130,808	2·21	289	277	0	12
1976	134,095	2·13	286	283	0	3
1977	137,381	2·1	288	282	0	6
1978	142,276	1·98	281	269	0	12
1979	147,172	1·95	287	266	0	21
1980	152,067	1·76	267	251	0	16
1981	156,962	1·66	260	234	0	16
1982	161,858	1·45	234	181	1	52
1983	166,753	1·25	209	141	14	54
1984	169,778	1·1	186	98	60	28
1985	174,141	0·96	141	55	67	19
1986	178,619	0·59	105	51	44	10
1987	183,232	0·48	88	35	43	10
1988	187,841	0·25	46	19	21	6
1989	192,451	0·18	35	19	14	2
1990	197,061	0·14	28	17	11	0

* Per 1,000 inhabitants.

† Rifampicin added to dapsone monotherapy (patients diagnosed before 1983).

based on the clinical examination of the patients (including examination of the skin and the large nerve trunks) supplemented by biological tests: the lepromin intradermal reaction, the search for acid-fast bacilli in the nasal mucosa and the skin (earlobes and skin lesions) and biopsy for pathological examination. Clinical examinations and biological tests permitted the diagnosis of leprosy and, retrospectively, the assignment into paucibacillary and multibacillary categories.

From 1951, dapsone monotherapy has been the basis of treatment for leprosy; from 1970 to 1984, rifampicin (RMP) was prescribed occasionally and over short periods to patients on dapsone monotherapy. After November 1982, the multidrug therapy for paucibacillary patients has consisted of the daily administration for 6 months of 100 mg of dapsone (DDS) and 10 mg per kg of RMP. For multibacillary patients MDT has consisted of the daily administration for 24 months of DDS and RMP in the same doses as for paucibacillary with a daily supplement of 100 mg of clofazimine (CLO) during the first 12 months and of 5 mg per kg ethionamide (ETH) for the first 2 months. All the drugs are distributed free of charge every month to the patients, either in the Leprosy Control Unit or in non-specialized Public Health Clinics.

Annual prevalence rates for leprosy were calculated according to the definition given by the WHO Expert Committee in 1988,[4] i.e. taking into account only leprosy patients on treatment. Because of the annual variations in the number of newly-detected leprosy patients, the following epidemiological indicators were calculated on 3-year periods: mean annual detection rates, proportion of multibacillary patients among the total number of cases and the proportion of patients with disabilities[5] of grade $\geqslant 2$.

All data from the medical files of the patients were anonymously entered on the OMSLEP record card and analysed by computer. For statistical analysis, Pearson's χ^2 test and the Spearman test were used.[6] Regression curves were established using a computer statistical package (Chart 3 Microsoft).

Results

PATIENTS ON MDT

Between November 1982 and December 1990, 141 leprosy patients were given multidrug therapy—86 were newly-detected cases and 55 were patients diagnosed before November 1982 and still on dapsone monotherapy (including 2 multibacillary patients who relapsed while on dapsone monotherapy).

PREVALENCE RATE

The number of patients on treatment decreased steadily from 315 in 1967 (prevalence rate 3·20/1,000) to 209 in 1983 (prevalence rate 1·25/1,000)—that is a 61% reduction over 17 years (Table 1). The regression curve plotted on the basis of the 17 annual prevalence rates indicates a significant decrease ($y = -0{\cdot}10\ \chi + 208{\cdot}43$; $r = -0{\cdot}97$; $p < 0{\cdot}001$). After the introduction of MDT into the control programme, the number of patients on treatment decreased from 209 in 1983 to 28 in 1990 (prevalence rate 0·14/1,000)—that is a reduction of more than 89% over 7 years. The regression curve plotted on the basis of the 7 annual prevalence rates indicates a significance decrease ($y = -0{\cdot}17\ \chi + 346{\cdot}12$; $r = -0{\cdot}97$; $p < 0{\cdot}001$).

DETECTION RATES

Between 1967 and 1990, 276 leprosy patients were detected in French Polynesia of whom 107 (38·8%) were multibacillary and 169 paucibacillary; 44 (16%) were less than 15 years old and 232 were 15 years old or more (Table 2 and 3).

As shown in Table 2, the mean annual detection rate for all forms of leprosy was 7·75/100,000 during the 1st 3-year period of the study (1967–1969) and remained roughly stable up to the 7th 3-year period (1985–1987); no significant difference ($r = 0·10$, $p > 0·05$) could be demonstrated between the 7 detection rates. During the 8th 3-year period of the study (1988–1990), the mean annual detection rate fell to 3·46/100,000 and was significantly lower ($p < 0·01$) than those of the previous period.

According to the type of leprosy, the mean annual detection rate for multibacillary leprosy remained roughly stable between the 1st and 6th 3-year period of the study, and

Table 2. Mean annual detection rates for leprosy according to type by 3-year periods between 1967 and 1990

	Total		Paucibacillary		Multibacillary	
3-year periods	No.	Rates*	No.	Rates*	No.	Rates*
1967–69	24	7·75	15	4·84	9	2·90
1970–72	30	8·53	15	4·26	15	4·26
1973–75	37	9·67	22	5·75	15	3·92
1976–78	37	8·94	21	5·07	16	3·86
1979–81	37	8·11	22	4·82	15	3·28
1982–84	46	9·19	29	5·79	17	3·39
1985–87	44	8·06	33	6·04	11	2·01
1988–90	21	3·63	12	1·9	9	1·39
Total	276	—	169	—	107	—

* Per 100,000 inhabitants.

Table 3. Mean annual detection rates for leprosy according to age by 3-year periods between 1967 and 1990

	Total		< 15 Years old		≥ 15 Years old	
3-year periods	No.	Rates*	No.	Rates*	No.	Rates*
1967–69	24	7·75	3	2·22	21	12·00
1970–72	30	8·53	5	3·21	25	12·77
1973–75	37	9·67	8	4·83	29	13·34
1976–78	37	8·94	4	2·30	33	13·72
1979–81	37	8·11	1	0·55	36	13·10
1982–84	46	9·19	6	3·14	40	12·92
1985–87	44	8·06	14	6·75	30	8·86
1988–90	21	3·63	3	1·45	18	4·80
Total	276	—	44	—	232	—

* Per 100,000 inhabitants.

subsequently decreased to 2·01 in 1985–87, and reached 1·39/100,000 in 1988–90 (Table 2). No significant difference could be demonstrated between the first 7 mean annual detection rates ($r = -0·10$, $p > 0·05$); conversely, the 1·39 mean annual detection rate during the 3-year period 1988–90 was significantly lower ($p < 0·05$) than the mean detection rate over the previous 7 3-year periods (3·32/100,000). Similarly, annual mean detection rates for paucibacillary leprosy remained roughly stable during the first 7 3-year periods of the study ($p > 0·05$) and decreased suddenly during the last period to reach 1·9/100,000, significantly lower ($p < 0·001$) than the mean detecton rate over the previous 7 3-year periods (5·32/100,000).

According to age, the mean annual detection rates for leprosy patients 15 years old or more remained stable during the first 6 3-year periods of the study ($r = 0·49$, $p > 0·05$) then decreased to 8·86/100,000 in 1985–87 to reach 4·80/100,000 in 1988–90 (Table 3). Both these last 2 mean annual detection rates (8·86 and 4·80/100,000) were significantly lower ($p < 0·05$ and $p < 0·001$) than the mean annual detection rate (13·03/100,000) over the previous 6 3-year periods. Conversely, no significant difference could be evidenced ($p > 0·05$) between the 8 mean annual detection rates for leprosy patients less than 15 years.

PROPORTION OF MULTIBACILLARY PATIENTS AMONG NEWLY DETECTED CASES

During the 8 3-year periods of the study, the proportion of multibacillary patients among the newly detected patients ranged from 25 to 50%. No significant decrease ($p > 0·05$) of that proportion occurred between the 1st and 8th 3-year periods (Table 4).

PROPORTION OF PATIENTS WITH DISABILITIES OF GRADE ≥ 2 AT DETECTION

During the first 5 3-year periods of the study (1967–81), the proportion of patients with disabilities of grade ≥ 2 among newly detected patients remained stable, ranging from 29·2% to 22·6% (Table 5), average value 31·5%. By contrast, it was on average 11·7% during the last 3-year periods of the study (1982–90), significantly lower ($p < 0·01$) than during the preceding period.

Table 4. Proportion of multibacillary patients among newly-detected cases by 3-year periods between 1967 and 1990

	Total		Paucibacillary		Multibacillary	
3-year periods	No.	%	No.	%	No.	%
1967–69	24	100	15	62·5	9	37·5
1970–72	30	100	15	50	15	50
1973–75	37	100	22	59·5	15	40·5
1976–78	37	100	21	56·7	16	43·3
1979–81	37	100	22	59·5	15	40·5
1982–84	46	100	29	63	17	37
1985–87	44	100	33	75	11	25
1988–90	21	100	12	55	9	45
Total	276	100	169	61·2	107	38·8

Table 5. Proportion of patients with disabilities at detection by 3-year periods between 1967 and 1990

3-year periods	Total newly detected	Newly detected cases with disabilities	
		No	%
1967–69	24	7	29·27
1970–72	30	10	33·33
1973–75	37	11	29·72
1976–78	37	12	32·43
1979–81	37	12	32·43
1982–84	46	7	15·21
1985–87	44	3	6·81
1988–90	21	3	14·3
Total	276	65	23·6

Discussion

The main finding of this study is that, in French Polynesia, a clear-cut decrease of leprosy prevalence and mean annual detection rates has been observed in the 3-year period 1988–90. There was also a decrease in the proportion of newly-detected cases with disabilities. However no significant decrease occurred in the detection rate among children less than 15 years old. The crucial question is to determine if such findings are related to the implementation of MDT from 1982.

A gradual decline in the prevalence rate was observed between 1967 and 1983, before the implementation of MDT into the control programme, but this decline was much more marked in the years after this, obviously because of the increasing number of patients who were released from the active file on completion of treatment. More important, from the epidemiological point of view, is the reduction in the detection rates. Following the introduction of MDT into any control programme, a decline in new-case detection is only expected after 5 years;[7] this was effectively observed in the current study. The fact that such a decline was observed in all specific detection rates except in that for leprosy in children less than 15 years old is not surprising. Active case-finding, which is only performed in household contacts in French Polynesia, has been more intensive in the years following the introduction of MDT, which has resulted in an increase in the number of new cases among children. As a matter of fact, this number was 14 (of which 11 were detected among household contacts) over the period 1985–87, approximately twice as high during this period as during the 6 preceding 3-year periods. Similarly, intensive active case-finding should permit the detection of new cases at an earlier stage of the disease, thus resulting in a decrease of the proportion of patients with disabilities at detection; this was also noted in the present study.

When assessing the decrease in detection rates for leprosy, it might be questioned if it reflects an improvement of the leprosy situation due to the implementation of MDT or whether it is caused by other possible influencing factors, such as a change in the control programme efforts, the economic improvement of the country and the natural decline of

the disease. Since detection rates remained stable during the period 1967–87, that is over 21 years, one is led to assume that the subsequent decrease observed after 1987 is more likely to be due to other causes than natural evolution. Moreover, even in the case of natural decline, it is known that the decrease in detection rates, which has effectively been observed in some countries before MDT was introduced, has been very gradual.[8] With respect to the organization of the Leprosy Control Unit, no change occurred during the past 24 years except for the implementation of MDT, which has resulted in intensifying active case-finding and in improving the management and follow-up of patients, newly-detected as well as 'old' ones still on dapsone monotherapy and who were put on multidrug therapy on request. The only other factor which could have possibly influenced the evolution of the disease might be the economic improvement which started in the early 1960s in French Polynesia.[9] Nevertheless, if such a factor has to be taken into account, again, one would expect a faster improvement in the leprosy situation: in the present study the improvement began to be noted only after 25 years. Also, the rapid decrease in detection rates observed between 1988 and 1990 does not fit well with the possible long-term effect of economic improvement; such a result is much more consistent with the conclusions of theoretical calculations on what is expected from the implementation of MDT.[7] Finally, the small number of cases detected over the whole study-period might be considered to represent a possible limitation in the intepretation of our findings. In fact, precisely because detection rates for leprosy were already low before MDT was implemented, it may be assumed that any significant decrease should be more difficult to prove and, if proved, that decrease should be considered even more significant.

From the results reported here it may be suggested that, together with the improvement of the economic situation of the country, the implementation of MDT has resulted in French Polynesia in a decrease of detection rates for leprosy, which may be a consequence of a decrease in transmission of the disease. This finding, and the fact that, to date, the relapse rate was nil in the Polynesian patients put on MDT,[10] strengthens the hope that total control of leprosy might be obtained through MDT in the next decade(s).

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Seroepidemiological Study of Leprosy in a Highly Endemic Population of South India Based on an ELISA Using Synthetic PGL-I[1]

Padebettu Krishnamurthy, Potluri S. Rao, Bapura N. Reddy, Murugan Subramanian, Subramanian Dhandayudapani, Vivekanad Bhatia, Phillapakkam N. Neelan, and Arabinda Dutta[2]

Leprosy is an enigmatic disease. Persistent efforts to unravel the various facets of the disease have met with limited success. The phase of infection still remains unrecognized. A reasonably valid marker, serological or otherwise, of past or current infection with *Mycobacterium leprae* would certainly help in understanding the natural history of the disease and would answer many epidemiological questions, such as the probable major course of transmission, the incubation period, the risk factors for infection and disease, etc., answers that remain elusive to this day ([9]). The recognition of infection, which is one of the principal goals of leprosy research ([17]), will also provide us with credible support for the control of the disease.

Several serological tests have been developed over the past 80 years to detect leprosy infection ([15]). The results, however, are not gratifying. Interest in the past few years in serodiagnosis has been heightened by the development of serological tests based on supposedly *M. leprae*-specific antigenic determinants ([4, 7, 13, 18, 19]). The enzyme-linked immunosorbent assay (ELISA) based on phenolic glycolipid-I (PGL-I)([12]) is now widely used in seroepidemiological studies. The availability of the synthetic disaccharide portion of PGL-I as an antigen in ELISA, its relative specificity to leprosy, and the fact that it is the only assay thus far standardized among laboratories, may be the reasons for its widespread acceptance.

The majority of the serological studies that have been carried out so far have been confined to small, selected, nonrandom populations of cases and controls. These studies have reported widely varying results, e.g., from 6% to 92% ([1-3, 5, 16]) seropositivity among contacts of leprosy cases. There have been only a few large-scale seroepidemiological investigations using an ELISA based on PGL-I reported to date ([6, 10]).

This paper presents the results of a seroepidemiological study conducted in a highly endemic area of leprosy in South India using a synthetic ND-O-BSA ELISA.

MATERIALS AND METHODS

The 54 villages in the field area of the Central Leprosy Teaching and Research Institute (CLTRI) located about 10 kms from Madras, with a total population of about 100,000, were divided into 135 population clusters varying in size from 400 to 1000. Each cluster, which was formed keeping in mind the natural or administrative boundary, was weighted. Cluster weighting was done using the criteria of relative risk derived from available data of the study area to obtain the incremental gain(s) in prospective case detection. Each household in a cluster was given a risk factor depending on the presence or absence of a leprosy case (paucibacillary or multibacillary) in the household. If there was one or more paucibacillary (PB) cases in a household, a risk factor of 2 was given and was multiplied by the number of household members minus the case to arrive at the weightage score for the household. For instance, a PB case in a household of five constitutes a weightage of 8 = [2 × (5 − 1)]. A single multibacillary (MB) case in a household would get a score of 5, and multiple MB cases, a score of 8.

It is hypothesized that a case in a household would contribute to a neighborhood effect in terms of transmission of infection, especially since the households and houses in a rural setting are closely crowded. Risk factor scoring ranging from 1.5 to 2.5 was therefore resorted to for neighboring houses and households, and for one house all around the house in which the case was located, keeping in mind the proximity of the inhabited structures. A house was defined as a structure, tent, shelter, etc., used for residential or nonresidential purposes, or both. A household was defined as a group of persons, who may or may not be related to one another by blood, living together and taking food from a common kitchen.

All of the 135 clusters were weighted and a random sample of 20 clusters was selected after stratification for size and weightage. The population sampled was 14,633, with a ratio of cases to household contacts, neighborhood contacts, and noncontacts of 1:5:10:30, respectively.

Examination of the population for leprosy was done by research officers, and confirmation of the diagnosis of leprosy was based on clinical examination alone.

Finger-prick blood samples were collected from individuals in the study area on Whatman no. 2 chromatography paper. Four spots (each at least 15 mm in diameter) were collected from each person; two spots each on a single 2.0 × 7.5-cm sheet of paper on which the identification particulars were written. The papers were air dried, placed in zip-seal plastic bags, brought immediately to the laboratory at CLTRI and stored at −20°C until tested.

At the time of testing, the blood specimens were taken from the freezer and eluted in phosphate-buffered saline (PBS) containing 1% bovine serum albumin (BSA) and 0.05% Tween-20 (PBST). A 7-mm-diameter disc (containing approximately 7 μl of blood) was punched out from each dried blood spot and treated with 140 μl of PBST separately in plastic vials for 2 hr. The eluates were considered equivalent to a 1:40 dilution of the sera.

Synthetic glycoconjugate antigen (ND-O-BSA), supplied by IMMLEP, World Health Organization (WHO), was coated on one half of flat-bottom, microtiter plates (Dynatech, Germany). The other half was coated with BSA alone in order to measure the nonspecific binding of the eluates. The coated plates were incubated overnight at 37°C and then washed with PBST. The eluates of the blood specimens were then applied in duplicate antigen and control wells. After incubation and washing, peroxidase-conjugated, antihuman IgM (Dakko, Denmark) was added, and the plates were incubated and washed again. Following washing, chromogenic substrate *O*-phenylene diamine and hydrogen peroxide in citrate buffer, pH 5.0, were added to develop color. The color was then read as absorbance at 490 nm using a Dynatech ELISA reader.

The serological data were linked to information in the household schedules and analyzed by computer at CLTRI. The standardized seropositivity ratio for contacts and noncontacts was calculated using the indirect standardization method.

A contact was defined as a person who had stayed for more than 6 months with and was found in the same household as the case at the time of blood collection.

RESULTS

Sera from 4243 individuals (including 132 leprosy cases) from seven clusters have been analyzed. The demographic particulars of this population are given in Table 1. Out of the 132 cases examined, there were 10 MB cases and 122 PB cases. The disease prevalence rate among females was 24.15 per 1000 and it was 38.19 per 1000 among males; 36% of the PB cases and 63.6% of the MB cases were females. Seropositivity (defined as OD > 0.200) was 12.7% in PB and 28.6% in MB cases (Fig. 1). All of the MB cases were under treatment for varying periods (3 months to more than 1 year).

Figure 2 shows that nearly 80%–90% of the population in the different age groups had low antibody levels. Seropositivity in the general (noncase = contact + noncon-

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[2] P. Krishnamurthy, M.D. (PSM), Assistant Director (Epid.); P. S. Rao, D.P.H., D.T.M.&H., Deputy Director (Epid.); B. N. Reddy, M.D. (PSM), Assistant Director (Epid.); M. Subramanian, M.Sc. (Stat.), Statistical Assistant; S. Dhandayudapani, M.Sc., Ph.D., Senior Research Officer; V. N. Bhatia, M.D. (Micro.), Former Director (Micro.); P. N. Neelan, D.P.H., M.P.H., Former Director; A. Dutta, D.P.H., D.E.C.D., Director, Central Leprosy Teaching & Research Institute, Chengalpattu 603001, India.

Reprint requests to Dr. Krishnamurthy.

Present address for Dr. Bhatia: Serologist and Chemical Examiner, Calcutta, India.

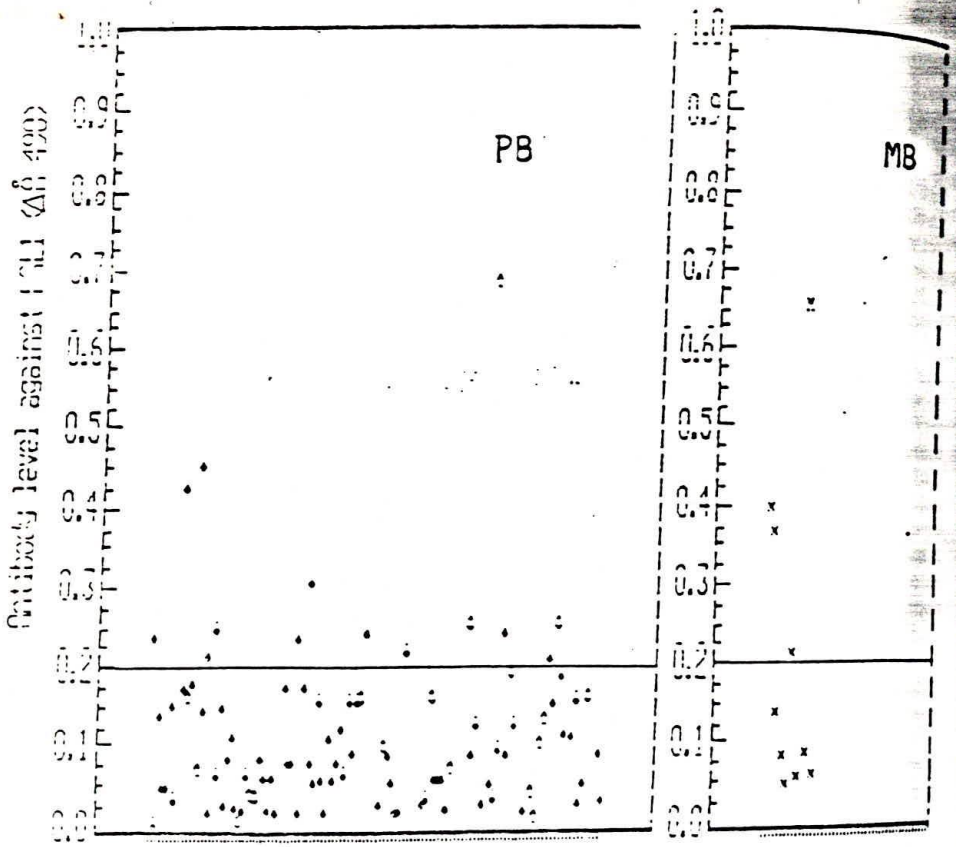

FIG. 1. Antibody level against PGL-I (Absorbance 490) among paucibacillary and multibacillary leprosy cases.

tact) population was 10.5%. Although the peak of seropositivity is seen at 10 years, it is sustained until the age of 30 years and then shows a gradual decline (Fig. 3). Among contacts the seropositivity was 14.5%; in noncontacts it was 13%. It was higher among female contacts than male contacts (Table 2). The marginally higher rates are borne out by the standardized rates for the two groups of both sexes. (Standardization was

TABLE 1. *Distribution of study population by contact status case, sex and age.*

Age group (yr)	Contact population		Noncontact population		Leprosy cases	
	Male	Female	Male	Female	Male	Female
0–4	30	18	228	239	0	0
5–9	43	32	302	284	2	1
10–14	34	22	251	260	15	8
15–24	54	54	438	468	22	11
25–34	35	32	377	312	15	5
35–44	18	22	234	263	13	8
45+	26	29	339	325	25	24
Total	240 (215)[a]	209 (187)	2169 (1843)	2151 (1866)	92 (86)	57 (46)

[a] Figures in parentheses = number of individuals examined.

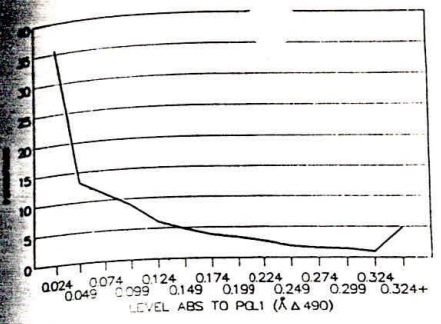

FIG. 2. Distribution of IgM against PGL-I in the general population.

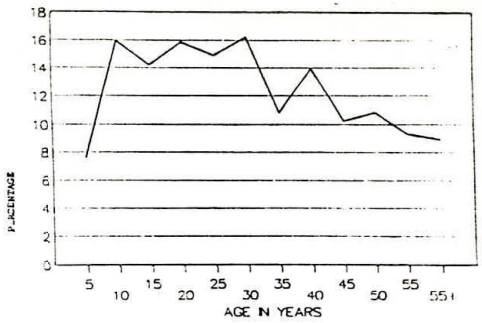

FIG. 3. Seropositivity among the general population.

done in order to even out the differences in the age structure between the contact group and the noncontact group.) This difference, however, was not significant.

BCG scar status as a variable was not studied because the BCG scar rate in this population was less than 10%.

DISCUSSION

This study is part of a longitudinal immunoepidemiological study being carried out in a highly endemic district (prevalence of > 10 per 1000) of South India. One of the objectives of the study was to see if ELISA using PGL-I could be used as a specific marker of leprosy infection in endemic populations. The determinate criterion for appreciating the difference between infected and noninfected populations should be based on disease endemicity. In an endemic area the criterion value is set at a decidedly high level to achieve reasonably unequivocal specificity. Positivity criterion of OD > 0.200 was adapted in the study because the area is highly endemic, and the value was found to represent three standard deviations above the mean (+ 3 S.D.) of a sample of sera from healthy persons in this area. The finger-prick spots on Whatman paper withstood the rigors of the field conditions, and the results obtained were comparable with those of venipuncture sera [8].

Even though a higher positivity is seen in MB cases, which could be explained on the basis of a higher antigen load seen in these cases, overall it appears surprising that in both MB and PB cases the seropositivity is low. The very low seropositivity (11%) among cases could be due to the fact that a majority of the cases were PB and most of the cases were under treatment. The prevalence of seropositivity of 14.5% among contacts compares well with the 14.4% obtained in an earlier study [4] carried out among contacts in the same area using the FLA-ABS test. The manifest default of distinction between contacts and noncontacts by this test appears disappointing. This possibly could be due to the fact that in an endemic area the intensity of exposure to

TABLE 2. *Seropositivity rate among cases, contacts and noncontacts by age.*

	0–4	5–9	10–14	15–24	25–34	35–44	45+	Total	SSPR[a]
				Males					
Cases	0	0	20	10	20	8.3	18.18	15.1	1.21
Contacts	12.5	6.98	10.64	13.04	12.90	11.76	8.70	11.68	0.953
Noncontacts	5.14	15.19	16.74	13.44	12.11	10.78	8.97	12.26	0.995
				Females					
Cases	0	0	25	10	20	12.5	7.14	13.04	0.905
Contacts	7.69	28.13	23.81	8.16	26.66	21.05	13.04	18.18	1.229
Noncontacts	7.14	13.79	14.11	17.27	17.25	14.04	9.48	13.93	0.977

[a] Standardized seropositivity ratio using the indirect standardization method.

M. leprae is likely to be high and, at the same time, the risk of exposure may be uniform in the population.

The reason for a marginally higher seropositivity among females is not clear. Higher seroprevalence rates among females were reported in other studies as well ([6, 10]). Case rates among the female population in this region are not higher than in males. An attempt has been made to explain this phenomenon on the basis of relative IgM globulinemia reported among females ([11, 15]) and/or to a higher probability of seroconversion among males ([10]).

The reason for the higher positivity rates among adolescents and young adults, when compared to other age groups, is not clear. Seropositivity may be a transient phenomenon and is perhaps reversible. What is really interesting is that it parallels the case prevalence pattern observed in the area.

It now appears that the excitement generated a few years back by the introduction of various serological tests, especially ELISA using PGL-I, is waning because of the disappointing results that have been obtained in several studies. PGL-I based on an ELISA does not appear to be effective as a seroepidemiological tool for diagnosing preclinical infection or of prognostic value for clinical disease, at least in high-endemic populations.

SUMMARY

As part of a continuing longitudinal immunoepidemiological study, blood samples were collected by finger prick from 4243 individuals living in a highly endemic area for leprosy in South India. The samples were tested for IgM antibodies against phenolic glycolipid-I using an ELISA. Seropositivity defined as optical density ≥ 0.2000 was marginally higher in the age group 10–30 years and in females. There was no evidence for a higher level in contacts than in non-contacts. The future prospect for the large scale use of this ELISA in high-endemic populations in special epidemiological investigations or routine control programs as a serological tool to detect leprosy infection appears questionable.

RESUMEN

Como parte de un estudio inmunoepidemiológico, se colectaron muestras de sangre por punción digital de 4243 indi[illegible]s habitantes de un área altamente endémica del [illegible]e la India. Las muestras se probaron para la búsqueda de anticuerpos IgM in contra del glicolípido fenólico-I usando un ELISA. La seropositividad, definida como una densidad óptica igual o mayor a 0.2000, fue marginalmente mayor en el grupo de edad entre 10 y 30 años y en mujeres. No hubieron evidencias de que los niveles de anticuerpos fueran mayores en los contactos que en los no contactos. Por lo tanto, la utilidad de este tipo de ELISA como herramienta para detectar la infección leprosa en los estudios a gran escala en poblaciones altamente endémicas, parece ser muy cuestionable.

RÉSUMÉ

Dans le cadre d'une étude immunoépidémiologique longitudinale, des échantillons sanguins ont été prélevés par piqûre au doigt chez 4243 personnes vivant dans une région à forte endémicité de lèpre dans le Sud de l'Inde. Les échantillons ont été testés par un ELISA pour rechercher la présence d'anticorps IgM vis-à-vis du glycolipide phénolique-I. La séropositivité définie comme une densité optique ≥ 0.2000, était légèrement supérieure pour le groupe d'âge 10-30 ans et pour les femmes. Il n'y avait pas d'évidence de taux plus élevés pour les contacts que pour les non-contacts. La perspective d'une utilisation à grande échelle de cet ELISA comme un outil sérologique pour détecter l'infection lépreuse dans les populations à haute endémicité pour des recherches épidémiologiques particulières ou pour des programmes de routine de lutte contre la lèpre, apparait discutable.

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Added in proof: Since submission of this paper two other recent investigations on HIV and leprosy have been brought to our attention. Neither found any evidence for an association between the two conditions.

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Effect of BCG on the Risk of Leprosy in an Endemic Area: A Case Control Study[1]

Jayaprakash Muliyil, Kenrad E. Nelson, and Earl L. Diamond[2]

There has been considerable uncertainty regarding the effect of BCG vaccination on the risk of developing leprosy. Even though there is experimental evidence to suggest a protective effect ([10, 21–23]), major field trials have failed to produce consistent results. The study from Uganda ([25]) showed 80% protection, while studies from Papua New Guinea ([18–20]) and Burma ([1]) showed 46% and 20% protection, respectively. A study from India showed 23% protection (Tripathy, S. P. Chingleput trial of the protective effect of BCG against leprosy. Paper presented at the Sixth IMMLEP SWG Meeting, Geneva, June, 1982). More recently, a case-control study from Malawi showed 50% protection ([12]). The variation in the protective efficacy of BCG in these studies has been postulated to be related, in part, to variations in the intensity of exposure, prevalence of other mycobacteria providing some protection, differing strains of *Mycobacterium leprae*, and genetic susceptibility of the populations in these studies ([15]).

At present, several field trials are being planned or are in progress in different parts of the world to measure the protective effect of various mycobacterial vaccines against leprosy ([12]). A fresh look at the effect of BCG may help in planning these studies and in interpreting the results. Using a case-control design, we have evaluated the efficacy of BCG in leprosy prevention since it was introduced, primarily as an antituberculosis vaccine, in a high incidence area for leprosy in the state of Tamil Nadu, India. Our study raises interesting methodologic questions concerning the efficacy of BCG and suggests that the vaccine may have differential efficacy in different types of leprosy.

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[2] Muliyil, M.D., Dr.P.H.(Epid.), Associate Professor, Community Health Department, Christian Medical College, Vellore 632 002, South India. K. E. Nelson, M.D., Professor of Epidemiology, E. L. Diamond, Ph.D., Professor of Epidemiology, School of Hygiene and Public Health, The Johns Hopkins University, Baltimore, Maryland 21205, U.S.A.
Reprint requests to Prof. Nelson.

METHODS

Study area. The state of Tamil Nadu in India is known to be highly endemic for leprosy. The prevalence of leprosy in the Indian states of Tamil Nadu and Andhra Pradesh has been reported to be about 20 per 1000 ([5]). BCG vaccination against tuberculosis has been done in Tamil Nadu since 1960. Therefore, this area offers an ideal setting for measuring the protective effect of BCG vaccination against leprosy using a case-control design ([24]).

The study was carried out in the leprosy control project area of the Department of Community Health, Christian Medical College, Vellore. The project has responsibility for a rural population of about 200,000 persons. The annual case detection rate is about 2.5/1000. Leprosy surveillance and diagnosis is done in accordance with the guidelines established by the National Leprosy Eradication Programme of India. Case detection occurs through various surveys and voluntary reporting. By 1983 the entire population had been covered by a general survey at least once. The information pertaining to the members of each household was recorded sequentially on separate pages in the general survey register during the house-to-house survey. These registers, with 200 pages each, played a key role in the design and conduct of our study.

Initially, BCG vaccination (1331 Copenhagen strain) was offered to all Mantoux-negative individuals younger than 20 years of age as part of the National Tuberculosis

Control Programme. Pretesting with Mantoux was subsequently discontinued. During the early 1970s school children formed the main target population of the BCG team. By 1980 the vaccine was being offered mainly to newborns at the hospitals and to the infants at the under-five clinics. The rate of vaccination in the control population was 42%; rates varied from 26% for those 5–9 years of age to 56% in those 20–24 years old.

Study population. All newly detected cases of leprosy, aged 5–24 years, from among the resident population of the project area during July 1986 to June 1988 were included in the study. All individuals whose names appeared in the general survey register by 1983 were considered residents of the area. The cases were subjected to a skin-smear examination and classified by trained physicians using the Ridley and Jopling classification into tuberculoid (TT), borderline tuberculoid (BT), borderline (BB), borderline lepromatous (BL), and lepromatous (LL) leprosy ([17]). Macular lesions with equivocal loss of sensation were classified as indeterminate leprosy. Histopathological examination was carried out only in doubtful cases. Cases were identified by general survey (86 cases), school survey (141), contact exam (22), voluntary referral (76), and other means (72).

Controls were chosen from among the resident population and they were matched with a case for age (± 1 year), sex, and locality. Matching for locality was achieved by selecting the controls from the same general survey register to which the cases belonged. A table of random numbers up to 200 was used to identify the page number in the register from which the search for each control was to start. Two controls were chosen for each case younger than 15 and one control for each older case.

Cases and controls were visited at their homes by a team consisting of the investigator, a nonmedical supervisor, and the leprosy paramedical worker. The following information was obtained regarding the cases and controls: a) presence of BCG scar; b) presence of a known case of leprosy in the household; c) presence of previously unknown case in the household; d) presence of a case among the extra household relatives; e) socioeconomic characteristics: i) type of house, ii) occupation, iii) land ownership, iv) number of years spent in school, and v) level of education of the highest educated individual in the family.

Exposure to BCG was ascertained by the nonmedical supervisor by looking for the typical scar over the deltoid region. The information was recorded as positive, negative, or equivocal. Individuals with equivocal BCG scars were excluded from the analysis. Every effort was made to mask the BCG reader regarding the clinical status of the subjects by presenting them as a mixed group and exposing only their deltoid regions to the reader. Controls were examined to rule out any clinical evidence of leprosy. Similarly, all other members of the household were also examined. Information on the presence of an extra-household family member with leprosy and the socioeconomic characteristics of the household were obtained by interviewing the subjects and the adult members of the family.

The data were analyzed on an IBM computer (Model 4381) using the Statistical Analysis System (SAS) package. Unmatched logistic regression was carried out with the Logiest program prepared by Frank E. Harrel, Jr. Matched set logistic regression ([2]) was done with the McStrat program prepared by James N. Naessins, *et al.* (SAS Inc., 1986). These procedures indirectly measure the odds ratio (OR), which is the ratio of the odds for the disease among the exposed to that among the unexposed. In a relatively rare disease, such as leprosy, the odds ratio gives a good estimate of the relative risk (1-odds ratio) % gives the protective effect of the vaccine.

RESULTS

During the study period, 421 eligible cases were detected; 405 cases and 694 controls were followed up. BCG was recorded as equivocal for eight cases and 25 controls, and these have been excluded from the following analysis. Thus, there were 397 cases and 669 controls available for unmatched analysis and 380 cases and 625 controls available for matched set analysis.

The distribution of cases according to age and sex is shown in Table 1. The distribution of cases according to the type of leprosy and nerve involvement is shown in Table 2. Three of the six BL cases were studied by slit-skin smear and were bacteriologically positive.

TABLE 1. *Distribution of cases according to age and sex.*

Age groups (yr.)	Males (%)	Females (%)	Totals (%)
5–9	49 (20.0)	47 (30.9)	96 (24.2)
10–14	105 (42.9)	58 (38.2)	163 (41.1)
15–19	60 (24.5)	31 (20.4)	91 (22.9)
20–24	31 (12.7)	16 (10.5)	47 (11.8)
Total	245 (100.0)	152 (100.0)	397 (100.0)

Several socioeconomic and demographic characteristics in the control population were significantly associated with the presence of a BCG scar. Among these were age and sex; 47.2% of males and 33.5% of females had BCG scars. The number of years of education of the individual and the duration of education of the highest educated member of the household were both associated with BCG vaccination. Also, the type of housing and land ownership were surrogates for the socioeconomic level of the family; both correlated with BCG vaccine status. Housing type was classified as "pucca" if it was of brick construction with a tiled or cement roof, hut (or "katcha") if it had mud walls and had a thatched roof, or "semipucca" if it was between the above two in construction.

Analysis of the distribution of these characteristics among the cases and controls showed they were well matched by age, education, years of schooling of the most educated in the family, and family size (Table 3). Also, cases and controls were well matched by occupation (Table 4) and by housing type (Table 5).

TABLE 2. *Frequency of nerve involvement by leprosy type.*

Leprosy type	Total	Nerve involvement	
		No.	%
Ind.	25	0	0
TT	303	11	3.6
BT	61	24	39.3
BB	2	1	50.0
BL	6	4	66.7
Total	397	40	10.1

TABLE 3. *Comparison of cases and controls by age, education, and family size.*

	Cases (mean ± S.D.)	Controls (mean ± S.D.)
Age	13.13 ± 4.88	12.30 ± 4.43
No. years in school	5.34 ± 3.11	5.32 ± 3.06
No. years in school of highest educated in household	8.18 ± 2.84	8.34 ± 2.94
Size of family	6.74 ± 1.85	6.93 ± 1.81

The unmatched analysis showed that BCG was not significantly associated with the risk of leprosy (Table 6). The presence of a known case in the family appeared to increase the risk of the disease considerably (odds ratio = 4.75, $\chi^2 = 89.7$, $p < 0.001$).

Exposure to noninfectious (I, TT, BT) and infectious (BB, BL, LL) leprosy cases within the family increased the risk for the disease 2.7 times and 11.7 times, respectively, when compared to those having no familial cases in the household (Table 7). Similarly, there was a significant association between having an extra familial case in the household and the risk of leprosy (OR = 1.7). Age and sex did not appear to significantly modify the effect of BCG on the risk for leprosy (Table 8).

When the effect of BCG on the risk of developing the different types of leprosy was studied, an interesting pattern emerged.

TABLE 4. *Distribution of cases and controls by type of work of head of household.*

Occupation	Cases		Controls	
	No.	%	No.	%
Laborer	179	45.1	267	39.9
Small farmer	50	12.6	80	12.0
Self-employed	65	16.4	89	13.3
Medium farmer	26	6.5	59	8.8
Artisans	16	4.0	28	4.2
Clerk/Teacher	49	12.3	105	15.7
High income	9	2.3	17	2.5
None	1	0.3	5	0.7
Not known	2	0.5	19	2.8
Total	397	100.0	669	100.0

TABLE 5. *Distribution of cases and controls by type of housing.*

Housing type	Cases		Controls	
	No.	%	No.	%
Pucca[a]	100	26%	182	28%
Semipucca[b]	103	27%	182	28%
Hut[c]	180	47%	286	44%
Total	383	100%	650	100%

[a] Brick construction with tiled or cement roof.
[b] Between pucca and hut.
[c] Mud walls and thatched roof.

BCG appeared to increase the risk of developing indeterminate leprosy (OR = 2.7), but when one went down the spectrum from tuberculoid to borderline diseases, there was a gradual increase in the degree of protection associated with BCG (Table 9). BCG was found to offer 61% protection against Borderline forms of leprosy after adjusting for significant confounders in a matched set analysis using multiple logistic regression (Table 10). Variables adjusted for this analysis included the following: a) having a known case in the family, b) having an infectious or noninfectious case in the household, c) having an extra-household relative with leprosy, d) being a laborer.

DISCUSSION

Matching the cases and controls for the general locality of the household appears to have created a good balance between cases and controls with respect to many of the socioeconomic factors which could have had a bearing on the chance for receiving BCG, on the one hand, or the risk of disease detection on the other. The magnitude of the association between infectious and noninfectious intra-familial cases and risk of disease is similar to that reported by the other workers ([8, 9, 16]).

BCG was found to increase the risk of indeterminate leprosy while offering protection against the borderline forms. The point estimates of the odds ratio suggest increasing protection as one goes down the spectrum from the indeterminate to pau-

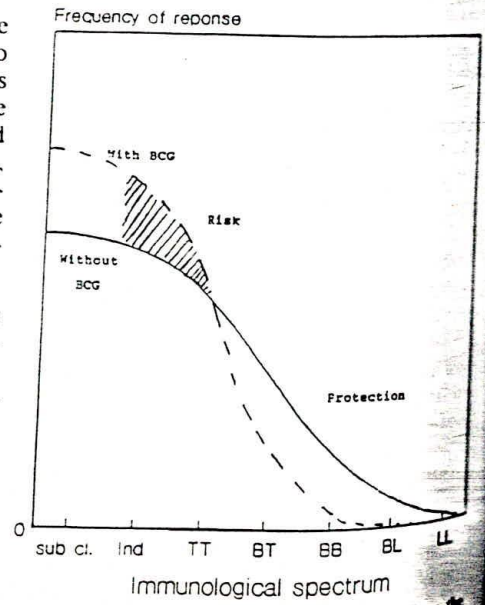
TABLE 6. *Effect of selected risk factors on risk of leprosy; unmatched analysis (univariate).*

Risk factor	Odds ratio ± S.E.M.	p
BCG	0.82 ± 0.13	0.12
Known case in family	4.75 ± 0.17	< 0.001
Own land	0.99 ± 0.13	0.925
In school >5 years	0.98 ± 0.13	0.875
Living in a hut	1.02 ± 0.13	0.844
Having anyone in house with >8 years in school	1.00 ± 0.13	0.928

TABLE 7. *Association between selected risk factors a eprosy; matched set analysis using multiple logistic regression.*

Risk factor[a]	Odds ratio	95% Confidence interval	p
BCG	0.80	0.59–1.10	0.172
Infectious case in family	11.74	3.97–34.71	< 0.00
Noninfectious case in family	2.73	1.90–3.92	< 0.00
Extra household family case	1.74	1.09–2.80	0.021
Landless laborer	1.26	0.94–1.68	0.127

[a] All of the above risk factors were simultaneously entered into the model so that the independent contribution of each factor to the outcome of a leprosy infection could be assessed.



THE FIGURE. Hypothesized effect of BCG on the immunological spectrum of leprosy.

TABLE 8. *Effect of BCG on leprosy by age and sex; matched set analysis using logistic regression.*

Age group (yr.)	No. sets[a]	Odds ratio	95% Confidence interval	p
		Males		
5–14	151 (288)	0.84	0.54–1.30	0.434
15–24	88 (99)	0.65	0.35–1.22	0.179
All males	239 (387)	0.77	0.54–1.10	0.155
		Females		
5–14	102 (192)	0.63	0.34–1.16	0.136
15–24	39 (46)	0.71	0.30–1.70	0.422
All females	141 (238)	0.65	0.40–1.00	0.422

[a] Figures in parentheses are number of controls.

cibacillary to multibacillary leprosy. There was 61% protection against borderline types. Although the finding appears to be paradoxical at first glance, this may offer a new insight into the manner in which BCG affects the natural history of the disease. *M. leprae* infections elicit a highly variable response in the host, ranging from subclinical infection to polar lepromatous leprosy. A majority of the indeterminate and some of the tuberculoid cases may heal spontaneously, and may not contribute substantially to the public health importance of the disease ([4, 13, 14]). Following vaccination with BCG, the host immune response may be shifted to the left (The Figure), resulting in a greater proportion of individuals responding to infection with subclinical disease and indeterminate leprosy and a smaller proportion manifesting borderline forms of the disease. This would explain the variability in the protection offered by BCG with respect to the different types of leprosy.

The results of the BCG trial in New Guinea had some similarities to our findings ([20]), namely, the protective efficacy against indeterminate, tuberculoid, and borderline tuberculoid forms in the New Guinea trial were 20%, 27% and 69%, respectively. However, the protective efficacy against what probably was BB/BL and LL disease was 39% and 40%, respectively. The Uganda trial found 80% protection; all cases but one in this study were tuberculoid.

The findings of this study also offer a possible new explanation for the variation in the protective effect of BCG reported by the major field trials. The study from Uganda, which reported the greatest protective efficacy of BCG, was designed in such a way that the duration between examinations was about 3 years ([25]). This implies that the investigators would have missed many of the self-healing forms, and were dealing with a higher proportion of persistent cases. In the Burmese study, on the other hand, the subjects were examined annually and a greater proportion of earlier and transient forms would have been detected ([1]). If BCG causes a shift in the immune response, it is conceivable that the vaccinated population may manifest a higher risk for these transient

TABLE 9. *Effect of BCG according to type of leprosy; matched set analysis using logistic regression (univariate).*

Leprosy type	No. sets[a]	Odds ratio	95% Confidence interval	p
Ind.	23 (41)	2.76	0.85–8.97	0.092
TT	291 (489)	0.78	0.56–1.09	0.150
BT	59 (85)	0.32	0.14–0.73	0.006
BB/BL	7 (10)	0.25	0.03–2.22	0.250
BT/BB/BL	66 (95)	0.31	0.14–0.67	0.003

[a] Figures in parentheses are number of controls.

Table 10. *Effect of BCG by type of leprosy[a]; matched set analysis using multiple logistic regression.*

Leprosy type	No. sets[b]	Odds ratio	95% Confidence interval	p
Ind.	23 (41)	2.74	0.84–8.95	0.095
TT	291 (489)	0.85	0.59–1.22	0.378
BT/BB/BL	66 (95)	0.39	0.17–0.83	0.033

[a] Adjusted for: a) belonging to a family with known case; b) having an infectious or noninfectious case in the household; c) having an extra-household relative with leprosy; d) being a laborer.

[b] Figures in parentheses are number of controls.

forms of leprosy ([4, 11, 13, 14]). This hypothesis is also consistent with the reports on "BCG-induced Leprosy" ([26]).

From a public health point of view, leprosy cannot be considered to be simply a dichotomous phenomenon. A vaccine that protects against the more serious forms of leprosy might be recommended even if it increased the risk for milder transient forms of the disease. This study also highlights an important issue related to designing field trials of vaccines against leprosy. The emphasis should be on type-specific protection, rather than on overall protection. Since classification of early lesions may be difficult and since one is ethically obliged to treat all detected cases promptly, too frequent a follow up of subjects may provide misleading information on the true impact of the vaccine ([14]). Another issue in vaccine trials relates to the duration of follow up required to reliably estimate vaccine efficacy. Since multibacillary leprosy may have generally longer incubation periods than indeterminate or paucibacillary types ([11]), a study that is not continued for a sufficient length of time may underestimate vaccine efficacy.

Since there were no cases of lepromatous leprosy in this series among patients aged 5–24 years, we cannot draw any conclusions on the effect of BCG with respect to this type of disease. The age at vaccination of the subjects in our study was not known. It is extremely unlikely that any of our cases were vaccinated after the onset of leprosy, since by 1980 BCG was used exclusively among newborns and in the under-five clinics. Unfortunately, since they were not available we could not verify the time of BCG vaccination with medical records. The effect of the temporal relationship between vaccination and exposure to *M. leprae* to the degree of protection offered by the vaccine needs to be studied further. Convit's experiments with the immunotherapy of cases appear to suggest that immunization with some *M. leprae*-derived vaccines may be useful even after exposure to *M. leprae* ([6, 7]).

A case-control study of the type we performed is more easily done in developing countries with limited resources than is a placebo-controlled vaccine trial. Of course, there are several sources of bias that need to be considered in interpreting case-control studies of this type. Most importantly, the controls should be selected from a population having a similar risk of exposure to *M. leprae*, of diagnosis of leprosy, and access to vaccination. In order to obtain unbiased estimates, it is important that the probability of selection on the basis of outcome is independent of the probability of selection by vaccination status.

We attempted to minimize bias by selecting controls from the same population as the cases. When we examined the controls and cases stratified by various socioeconomic variables, namely, occupation, education, education of household head, type of house, and land ownership, the two groups were similar in distribution. As we expected, many of these socioeconomic variables were correlated with BCG vaccination status. Controls and cases were matched by age, sex, and geographic area of residence. The matched analysis reduced or eliminated bias related to several demographic and socioeconomic characteristics. Residual bias, such as the presence of a case in the household, was adjusted for a multivariate analysis (Table 10).

Random misclassification could have occurred in exposure ascertainment and in selection of cases and controls. This, however, would have the effect of moving the odds ratios closer to unity ([13]), thus providing a conservative estimate of risk for determinate leprosy and protection against borderline forms. Finally, had there been self-selection bias with respect to vaccination, the association would have been unidirectional for the entire spectrum.

In conclusion, our study found that BCG offers about 60% protection against borderline forms of leprosy probably by bringing about a shift in the immune response to a higher level of cell-mediated immunity. This shift appeared to cause an increase in the risk for milder forms of the disease. From a public health point of view, BCG should be recommended for the prevention of leprosy until a better vaccine is available. In designing field trials to measure the protective effects of other mycobacterial vaccines against leprosy, efforts need to be made to demonstrate type-specific protection against the various types of leprosy in addition to overall protection.

SUMMARY

The effect of BCG on the risk of leprosy was measured using a case-control design in an area endemic for the disease. In this study, 397 newly diagnosed cases and 669 controls matched for age, sex and locality were selected from a defined population. Information on exposure to BCG, contact with another case of leprosy, and relevant socioeconomic variables were obtained from the subjects. Having infectious (multibacillary) and noninfectious (paucibacillary) contacts in the household increased the risk of disease 11.7 times ($p < 0.001$) and 2.7 times ($p < 0.001$), respectively. Overall, the protection offered by BCG was not significant (odds ratio = 0.8; $p = 0.17$). However, BCG appeared to increase the risk for indeterminate leprosy (adjusted odds ratio = 2.7; $p = 0.09$) while protecting against borderline disease (adjusted odds ratio = 0.39; $p = 0.03$). It is possible that BCG causes a shift in the overall cell-mediated immune response, thus increasing the risk for milder and transient forms of leprosy while protecting against more serious forms. These findings may have important implications for the design and interpretation of vaccine trials. Namely, trials should be designed to measure the protective efficacy of vaccines against the more serious forms of leprosy, which have the greatest public health significance.

RESUMEN

Usando un programa diseñado para el control de casos en un área endémica de lepra, se midió el efecto del BCG sobre el riesgo de desarrollar la enfermedad. Para el estudio, se seleccionaron 397 casos recién diagnosticados y 669 individuos control similares en cuanto a edad, sexo y localidad. De los participantes se obtuvo información sobre exposición al BCG, contacto con otros casos de lepra, y aspectos socioeconómicos relevantes. Los resultados señalaron que el tener contactos infecciosos (multibacilares) y no infecciosos (paucibacilares) dentro de los convivientes, aumentó el riesgo de la enfermedad 11.7 veces ($p = 0.001$) y 2.7 veces ($p = 0.001$), respectivamente. Aunque en lo general, la protección conferida por el BCG no fue significativa (relación entre grupos = 0.8; $p = 0.17$), el BCG pareció incrementar el riesgo para lepra indeterminada (relación = 2.7; $p = 0.09$) al mismo tiempo que pareció proteger contra formas intermedias de la enfermedad (relación = 0.39; $p = 0.03$). Es posible que el BCG cause un cambio en la respuesta inmune celular general, aumentando el riesgo para las formas leves y transitorias de la lepra y protegiendo contra las formas más severas. Estos hallazgos pueden tener importantes implicaciones en el diseño y en la interpretación de los resultados de los programas de vacunación; esto es, los ensayos de campo deben diseñarse para medir la eficacia protectora de las vacunas contra las formas severas de la lepra, las de mayor importancia en salud pública.

RÉSUMÉ

L'influence du BCG sur le risque de lèpre a été mesuré par une étude de type cas-témoin dans une région endémique pour la maladie. Dans cette étude, 397 cas nouvellement diagnostiqués et 669 témoins appariés pour l'âge, le sexe et la localité ont été sélectionnés à partir d'une population définie. Des informations sur l'exposition au BCG, un contact avec un autre cas de lèpre, et des variables socio-économiques pertinentes ont été récoltées chez ces personnes. Le contact domiciliaire avec un malade infectieux (multibacillaire) ou non-infectieux (paucibacillaire) augmentait le risque de maladie respectivement de 11.7 fois ($p < 0.001$) et 2.7 fois ($p < 0.001$). Dans l'ensemble, la protection offerte par le BCG n'était pas significative (odds ratio = 0.8; $p = 0.17$). Cependant, le BCG semblait accroître le risque pour la lèpre indéterminée (odds ratio ajusté = 2.7; $p = 0.09$), mais protégeait contre la forme borderline de la maladie (odds ratio ajusté = 0.39; $p = 0.03$). Il est possible que le BCG provoque une modification dans la réponse immunitaire de type cellulaire, augmentant donc le risque pour une forme plus bénigne et transitoire de lèpre, mais protégeant contre les formes plus sévères. Ces observations peuvent avoir

des implications importantes pour la conception et l'interprétation de'essais de vaccination. Plus précisément, des essais devraient être conçus pour mesurer l'efficacité protectrice des vaccins contre les formes plus sévères de la lèpre, qui ont la plus grande signification du point de vue de la santé publique.

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Fixed D ation MDT in Paucibacillary Leprosy[1]

Rachel Mathai, Soshamma George, and Mary Jacob[2]

This study was initiated at the Christian Medical College Hospital, Vellore, India, in 1984, about 2 years after the World Health Organization (WHO)-recommended multidrug therapy (MDT) became the standard for treating leprosy patients in India. The objective of the study was to determine the efficacy of MDT as recommended by WHO for paucibacillary leprosy as compared with that of conventional dapsone monotherapy.

MATERIALS AND METHODS

All consecutive new patients with a single leprosy patch who attended the dermatology clinic were screened. The following were the exclusion criteria: a) children younger than 5 years; b) facial lesions; c) patches less than 2.5 cm in size; d) patients who were unable to come for periodic follow-up for 2½ years; and e) patients who had already received any form of antileprosy treatment. Fifty-four patients were included in the study. At the initial visit, the clinical classification was recorded and skin smears for acid-fast bacilli (AFB) were taken from the edge of the patch. A skin biopsy was taken from the margin of the lesion, and a lepromin test was done using the Mitsuda antigen. The patients were then randomly allotted to one of two therapeutic regimens.

The clinical classification was based on the morphology of the lesion and the perception of light touch over it. The color and size of the lesion were recorded. An ill-defined hypopigmented, hypoesthetic or nonanesthetic patch was classified as indeterminate leprosy. A well-defined, hypopigmented anesthetic patch or a well-defined erythematous anesthetic plaque was classified as tuberculoid leprosy. An ill-defined hypoesthetic or anesthetic patch or a plaque with satellite extension was classified as borderline tuberculoid leprosy.

The histological classification was based on the character and intensity of the dermal infiltrate (7) and the number of AFB, if present. Lesions showing perineurial or intraneural lymphocytic infiltration were classified as indeterminate leprosy. Lesions with well-defined tuberculoid granulomas with many lymphocytes in the dermis and dermal nerve twigs were classified as tuberculoid leprosy. Lesions showing ill-defined, small tuberculoid granulomas with many epithelioid cells and a sparse lymphocytic infiltrate in the dermis and dermal nerves were classified as borderline tuberculoid leprosy.

The lepromin responses were assessed clinically on the 21st day after inoculation of the antigen by measuring the resultant induration at the test site. The test site was biopsied and examined histologically, irrespective of the presence or absence of induration. An absence of induration or a 1–3 mm area of induration at the test site was recorded as a negative response (−); a 3–5 mm area of induration, as a doubtful response (±); and induration over 5 mm, as a positive response (+). Histologically, a nonspecific cellular reaction at the biopsy site was considered as a negative response, while a positive response was characterized by a tuberculoid granuloma in the dermis.

Two therapeutic regimens were adopted. Regimen I was the WHO-recommended multidrug (WHO/MDT) treatment for paucibacillary leprosy (8) consisting of rifampin 600 mg administered once a month under supervision for 6 months along with dapsone (DDS) 100 mg daily for the same period. Children were given appropriately smaller doses. Regimen II consisted of dapsone monotherapy with daily doses of 50 mg for 5 years. Patients on Regimen I were seen once a month for the initial 6 months and then at intervals of 6 months up to 2½ years from the time of initiation of treatment. Patients on Regimen II were seen at intervals of 6 months.

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[2] R. Mathai, M.B.B.S., D.D., F.R.C.P.(G); S. George, M.B.B.S., M.D., M.N.A.M.S.; M. Jacob, M.B.B.S., M.N.A.M.S., Professor and Head, Department of Dermatology, Christian Medical College & Hospital, Vellore 632 004, South India.
Reprint requests to Dr. George.

match and healed better. The results were satisfying to the patients, improving their appearance. Bone grafting was not done because the disease was active and there was risk of graft absorption.

To prevent nasal myiasis patients need to be educated about routine nasal care and hygiene. Instillation of oily nasal drops (liquid paraffin with eucalyptus oil) prevents crust formation and nasal obstruction. Partial closure of nostrils using local mucosal flaps (Young's procedure)[8] has been tried by us successfully in a few cases to prevent recurrence.

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Myiase de la muqueuse nasale chez les lépreux

S Husain, G N Malaviya, A Girdhar, Sreevatsa et B K Girdhar

Résumé Les larves de certaines mouches peuvent être la cause d'une infestation des muqueuses nasales chez les lépreux qui résultent en des douleurs graves et intenses et peut causer d'importantes lésions tissulaires. Les facteurs de prédisposition, le tableau clinique et le traitement sont décrits.

Miasis nasal en la lepra

S Husain, G N Malaviya, A Girdhar, Sreevatsa y B K Girdhar

Resumen La infestación de la nariz con larvas de ciertas moscas puede ser observada en pacientes con lepra. Esto resulta en gran dolor y agonía y puede causar un extenso daño al tejido. Se describen los factores de predisposición, la presentación clínica y el tratamiento.

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An educational approach to leprosy control: an evaluation of knowledge, attitudes and practice in two poor localities in Bombay, India

N CROOK,* R RAMASUBBAN,† A SAMY‡ & B SINGH†

**School of Oriental and African Studies, University of London, Thornhaugh Street, Russell Square, London WC1H 0XG, England; †Centre for Social and Technological Change, 10 Zeba Corner, Sherly Rajan Road, Bandra, Bombay 400 050, India; and ‡Alert-India, 6/B Mukhyadhyapak Bhavan, Sion (West), Bombay 400 022, India*

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Summary Based on the hypothesis that a systematic, carefully planned educational approach to leprosy would yield results in terms of knowledge, attitudes and case presentation superior to those of the established and traditional mass survey method, ALERT-India launched a programme in S ward of Bombay in February 1985, to compare the two. An intensive programme of health education, using trained teams, was carried out in one zone of this ward over a period of 12 months. Eight months later, mass survey work (as used routinely in previous years and on a country-wide basis) was carried out in an adjacent zone. In 1987, the Centre for Social and Technological Change in Bombay, in association with the School of Oriental and African Studies, University of London, was requested to evaluate the effect of the above educational approach in terms of knowledge, attitudes and practice in both the trial and control zones. Other aspects of this experimental approach, including its cost and effectiveness in identifying cases of leprosy, will be published separately. The design of the 'KAP' evaluation and the social and environmental controls introduced in the statistical analysis are described. The results pointed to a considerable degree of ignorance about leprosy as a disease (and its treatment) in both the study and the control zones. Knowledge about early symptoms was particularly weak and on all aspects scores for women were invariably lower than men. General education enhanced the absorption of specific knowledge, and the education of children compensated adequately for lack of parental education in this respect. Overall the evaluation indicated that the intensive educational approach was superior to the survey approach in terms of improving knowledge, attitudes and practice.

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Introduction

ALERT-India is a voluntary organization committed to the control of leprosy in the eastern suburbs of Bombay, by identifying and treating early cases of leprosy, and by enlightening the public on various aspects of the disease.[1] The prevalence rate for leprosy in Bombay is believed to be between 10 and 15 cases per 1000 population,[2 4] and the city is listed as a hyperendemic district by the National Leprosy Eradication Programme.[5] The neighbourhoods covered by ALERT consist mainly of slum settlements, with an aggregate population of some 400,000. For case detection the main tool has been the door-to-door survey, during which some educational material is disseminated, mainly in the form of leaflets. The educational component is backed up by slide or film shows at local schools, factories, and community meeting places.

A major drawback of the mass survey method is that it is time consuming. Further, as the approach is one of 'seeking out' the patient, and following him or her up to ensure completion of the required treatment, patient conviction and motivation are sometimes lacking. Finally, as an educational tool, the method has disadvantages. Whatever education is imparted mainly reaches the patients as a result of treatment and follow-up. Non-patients receive only perfunctory information at the time of the initial door-to-door examination, and the community-level programmes are spread too thinly over the population, whose attendance at these events is sometimes meagre.

Methodology

In 1985 ALERT launched an experimental approach designed to eliminate these drawbacks. Over a 12-month period a well-defined slum community (referred to as L zone) was visited by a health education team, which held a film or slide show at the end of every road or lane. Leaflets were distributed door-to-door. Posters and stickers were widely displayed and talks and exhibitions held at the community level. In short, the approach was one of intensive education, rather than mass survey and more peripheral education.

This paper reports the results of a subsequent evaluation of knowledge, attitudes and practice carried out in 1987 in L zone by the Centre for Social and Technological Change.[6] A questionnaire was presented to 200 residents; they were selected so that there should be 100 patients and 100 nonpatients. Similarly, in another community (referred to as M zone), where a mass survey had been conducted in 1985 8 months after the experiment in L zone, a further sample of 200, similarly selected, was used as a control. The questionnaire was designed to test the public's basic knowledge about, attitudes towards, and behavioural practice of relevance to the disease. Items for the test of knowledge consisted of a range of symptoms, the bacteriological origin of the disease, the transmission mechanism, and the curability and methods involved. Knowledge of symptoms was graded from basic knowledge (the existence of a skin patch), through an intermediate level (for example, absence of sensation on the patch) to a higher level (for example absence of hair or sweating on the patch). Use of a questionnaire to elicit responses on questions such as these may not be fully reliable in a semi-literate population. However, in Bombay the illiterate are more familiar with the ways of the modern world than they would be in a remote rural village, and in our experience are unusually articulate. Furthermore, the investigators were paramedics working for ALERT, who would have some familiarity with testing opinions and knowledge in this population.

Results

In both zones the amount of knowledge absorbed was distressingly low: only 30% of respondents could recall the symptom classified as basic, roughly the same proportion recalled symptoms at the intermediate level, and 17% at the higher level. However, the difference between the experimental and control zones was brought out fairly clearly, with the experimental zone yielding a higher proportion of respondents with pertinent knowledge at all levels (a statistically significant difference at the two higher levels, as illustrated for the medium level in Table 1).

As the sample design was not stratified by social factors it would seem desirable to control for these statistically. Doing so reveals that, for example, in households where fewer than half of the adult members have achieved the middle school level of education, basic knowledge of symptoms is still further enhanced by the intensive education programme (though the effect in the better-educated households is unclear); medium level knowledge is also better in the experimental zone after general education controls are made. Similar findings are made regarding the knowledge that leprosy is caused by a 'germ': the differences between the zones are large, and statistically significant in the case of the less educated households (Table 2). This pattern of the superiority of the experimental zone over the control tends to repeat itself for most items of knowledge and is robust against the effect of general education differentials.

Respondents were canvassed on their attitude to different aspects of the disease: here responses from the patients proved most conclusive, with their willingness to accept the diagnosis and their confidence in the cure both being significantly enhanced by the intensive educational programme in comparison with the survey method (Table 3). This is a clear indicator of the better motivation achieved when patients have been identified by themselves (or their peers) rather than by visiting paramedics. Again the observation remains valid when controls for general educational attainment are introduced. However, some care in interpretation is needed here, in that a small proportion of patients will have

Table 1. Medium-level perception of symptoms by zone

	Zone		
	M	L	Total
Knowledge	46 (23·0)	77 (38·5)	123 (30·7)
Rest	154 (77·0)	123 (61·5)	277 (69·3)
Total	200 (100·0)	200 (100·0)	400 (100·0)

Difference between zones is significant at 5% level.

Table 2. Knowledge of germ according to educational composition of household

	Zone		
	M	L	Total
Less than 50% of educated adults in household			
Knowledge of germ	14 (11·2)	15 (22·7)	29 (15·2)
No knowledge	111 (88·8)	51 (77·3)	162 (84·8)
Total	125 (100)	66 (100)	191 (100)
More than 50% of educated adults in household			
Knowledge of germ	18 (25·0)	47 (36·4)	65 (32·3)
No knowledge	54 (75·0)	82 (63·6)	136 (67·7)
Total	72 (100)	129 (100)	201 (100)

Difference between zones is significant at 5% level in the lesser educated group. Difference between educational levels is also significant at 5% level.

already suffered some deformity, so that the concept of cure will have had some ambiguity for them since chemotherapy cannot repair the damage already done.

As far as practice is concerned, our questions were confined to eliciting information on how far people looked for symptoms in each other and motivated clinic attendance in suspected patients. Here the superiority of the experimental zone failed to emerge. However, 30% of patients in that zone claimed to have been motivated in that way

Table 3. Confidence of patients in cure

	Zone		
	M	L	Total
Confident of cure	71 (72·4)	84 (88·4)	155 (80·3)
Not confident	27 (27·6)	11 (11·6)	38 (19·7)
Total	98 (100·0)	95 (100·0)	193 (100·0)

Difference between zones is significant at 5% level.

(against only 11% in the control zone). It is possible that those motivating, though no greater in number, were more active and successful in L zone.

In some cases the superiority of the intensive education method was enhanced or diminished by other characteristics of the individuals surveyed (besides zonal residence). For example, overall educational attainment by adult members of the household nearly always strengthened the effect of the experimental method in imparting knowledge and in improving attitudes (see, for example, Table 2). More strikingly, relevant knowledge was increased by the presence of school-attendant children in the household, often compensating for the effect of lack of parental education. The sex of the respondent was another important differentiating characteristic. Women were in possession of less of the relevant knowledge than were men, even in the experimental zone.

Discussion

It should be stressed that this evaluation was not intended to test the superiority of case-detection in the experimental zone. Its purpose was purely to see whether the same levels of public awareness would be achieved by the cost-saving experiment of an intensive community-level educational approach in place of the laborious door-to-door survey technique. In fact both patients and non-patients who were subjected to the educational experiment showed superior awareness of important facts relevant to the prevention, cure and social understanding of the nature of the disease. This should constitute a step on the road towards the ultimate removal of stigma. Furthermore, since a higher proportion of those in the experimental zone claimed they were convinced that treatment would be effective, there is some reason to expect that non-compliance would be reduced. Some of the recent literature has linked compliance to the quality of information that is provided to the patient.[7] The outcome of our study has prompted ALERT-India to enhance the educational component in its existing survey programme.

The question may be raised, however, as to whether appropriate personnel would be readily available to replace the survey technique comprehensively with an intensive educational programme. The ALERT experiment drew on the existing skills of its health educators, and simply used more intensively the educational materials they already possessed. Our view (which in essence is shared by others)[8] is that at least the more experienced members of the existing paramedical corps could be adopted as health educators in the programme; they would need to be equipped with additional educational materials which would add to the resource cost, but only as a one-off expenditure. This would create a two-tier structure of paramedics, which would have the added advantage of offering promotional prospects as an incentive for the greater involvement of new recruits in the wider aims of the organization: by developing their understanding of and ability to interact with the community, rather than simply acquiring skills in case detection and delivery of curative services, they would be securing a career for themselves as a valuable cadre of health educators. At the same time, this awareness would ensure some much needed variety in the activities and career structure of paramedics, for whom the repeated combing of vast urban slums for new and recalcitrant patients is a tedious chore, as detrimental to the motivation of paramedics as to the compliance of their patients.[9]

Finally our study brings out the importance of seeking to involve specifically both

women and children in any health education programme. The less informed responses of women in both our zones underlines how any programme of information that relies upon the spontaneous attendance of women is likely in most cultures effectively to discriminate against women: special programmes for women's groups and appropriate timings for women to attend would seem to be the solution. At the same time, the fact that better informed respondents came from households where school-attending children were present suggests the value of carrying out leprosy education work in schools, especially in urban settings where attendance is high.

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Le contrôle de la lèpre grâce à l'éducation: une évaluation des connaissances, des attitudes et des habitudes dans deux localités pauvres de Bombay en Inde

N. Crook, R Ramasubban, A Samy et B Singh

Résumé Estimant qu'un programme éducatif bien conçu sur la lèpre donnerait des meilleures informations en matière de connaissances, d'attitudes et de dépistage des cas de lèpre que celles obtenues par les enquêtes traditionnelles à grande échelle, ALERT-India a lancé en février 1985 un programme de comparaison des deux méthodes dans le quartier S de Bombay. Un programme intensif de 12 mois d'éducation sanitaire faisant appel à des équipes entraînées fut organisé dans une zone du quartier. Huit mois plus tard, une étude à grande échelle (faite régulièrement dans tout le pays les années précédentes) fut menée dans une zone voisine. En 1987, le Centre pour le Changement social et technologique à Bombay en association avec la faculté des études orientales et africaines de l'Université de Londres fut prié d'évaluer l'effet du programme éducatif en matière de connaissances, d'attitudes et d'habitudes dans les zones d'essai et de contrôle. Les autres aspects de cette expérience y compris son coût et son efficacité en matière de dépistage des cas de lèpre, seront publiés séparément. Le rapport décrit la méthode d'évaluation des connaissances, des attitudes et habitudes ainsi que les contrôles sociaux et environnementaux inclus dans l'analyse statistique. Les résultats révèlent une ignorance profonde de la lèpre et de son traitement dans les zones faisant l'objet de l'étude et dans les zones de contrôle. La connaissance des premiers symptômes était particulièrement faible et à tout égard, les scores des femmes étaient constamment inférieurs à ceux des hommes. L'éducation générale favorisait l'assimilation de connaissances spécifiques et l'éducation des enfants compensait le manque d'éducation des parents dans ce domaine. Dans l'ensemble, l'évaluation indiquait que les résultats du programme intensif d'éducation étaient supérieurs à ceux de l'étude à grande échelle en matière d'élargissement des connaissances, d'attitudes et d'habitudes.

Un enfoque educacional del control de la lepra; una evaluación del conocimiento, actitudes y práctica en dos localidades pobres de Bombay, India

N Crook, R Ramasubban, A Samy y B Singh

Resumen Basándose en la hipótesis de que un enfoque educacional sistemático y cuidadosamente planeado de la lepra podría producir resultados superiores, en términos de conocimiento, actitudes y presentación de casos, a aquellos de los métodos de estudios en masa tradicionales y ya establecidos, ALERT-India lanzó un programa en el distrito S de Bombay en febrero de 1985, para comparar los dos métodos. Se llevó a cabo un programa intensivo de educación en la salud, usando grupos entrenados en una zona de este distrito durante un periodo de 12 meses. Ocho meses más tarde, se llevó a cabo un estudio en masa en una zona adyacente (como se usó en forma rutinaria en los años previos y basado en todo el país). En 1987, se le solicitó al Centro para Cambio Social y Tecnológico de Bombay, en conjunto con la Escuela de Estudios Africanos y Orientales, Universidad de Londres, que evaluaran el efecto del enfoque educacional mencionado arriba en términos de conocimiento, actitudes y práctica en las dos zonas, en la de control y en la en estudio. Otros aspectos de este enfoque experimental, incluyendo su costo y eficacia en identificar casos de lepra será publicado separadamente. Se describe el diseño de la evaluación 'KAP' y los controles sociales y medio ambientales introducidos en el análisis estadístico. Los resultados indican un considerable grado de ignorancia acerca de la lepra como una enfermedad (y su tratamiento) en ambas zonas, en la en estudio y en la control. El conocimiento acerca de los primeros síntomas fue particularmente pobre y en todos los aspectos las mujeres consiguieron invariablemente menos puntos que los hombres. La educación general mejoró la absorción de conocimiento específico, y la educación de los niños compensó en forma adecuada por la falta de educación de los padres en este aspecto. La evaluación, en forma completa, indicó que el enfoque educacional intensivo fue superior al enfoque de estudio en masa en términos de un conocimiento, actitudes y práctica mejoradas.

La coloration au diacetate de fluorescéine et bromure d'éthidium pour determiner la viabilité de *Mycobacterium smegmatis* et d'*Escherischia coli*

V Jayapal, K M Sharmila, G Selvibai, S P Thyagarajan, S Shanmugasundaram et S Subramanian

Sommaire La capacité de la méthode de coloration au diacetate de fluorescéine et bromure d'éthidium pour estimer le pourcentage de céllules bactériennes viables en suspension a été comparée avec la méthode de compte des colonies sur plaque. Des suspensions de céllules de *Mycobacterium smegmatis* et d'*Escherischia coli* ont été incubées à 60 C. Aux différents intervalles de temps des échantillons ont été pris et le pourcentage de céllules viables estimé sur chaque échantillon par la méthode de coloration fluorescente. Le résultat obtenu a été comparé à la compte des colonies sur plaque. La méthode de coloration fluorescente a montré une corrélation positive avec la méthode de compte sur plaque. Néanmoins, la valeur obtenue pour la recompte des colonies viables sur plaque a été moins élevée que chez la méthode de coloration après incubation à 60 C, ce qui indique un décalage entre la morte des bactéries et la détérioration des enzymes. D'ou la méthode de coloration fluorescente peut être utilisée pour estimer les tendances dans le dépérissement des bactéries plutôt que pour le calcul exacte du nombre de bacilles viables.

Coloración a base de diacetato de fluoresceíne y bromuro de etidio para determinar la viabilidad de *Mycobacterium smegmatis* y de *Escherichia coli*

V Jayapal, K M Sharmila, G Selvibai, S P Thyagarajan, S Shanmugasundaram y S Subramanian

Resumen Se comparó el método de coloración a base de diacetato de fluoresceína y bromuro de etidio para calcular el porcentaje de células bacterianas viables en suspensión con el método de cuenta de colonias sobre placas. Se incubaron a 60 C suspensiones de células bacterianas de *Mycobacterium smegmatis* y de *Escherichia coli*. Se tomaron muestras a intervalos de tiempo distintos, se calculó el porcentaje de células viables en cada muestra por el método de colorantes fluorescentes y se comparó el resultado al obtenido por el método de cuenta de colonias sobre placas. Se halló una correlación positiva entre los resultados obtenidos por ambos métados. No obstante, la cuenta de células viables por el método de cuenta de colonias sobre places resultó inferior a la cuenta obtenida por medio del método de colorantes (llevándose la incubación a cabo a 60 C). Esto sugiere que existe un periodo de retraso tras la muerte de las bacterias hasta iniciarse el deterioro de las enzimas. Por lo tanto, el método de coloración fluorescente puede utilizarse más bien para evaluar las tendencias del decaimiento de las bacterias que para calcular el número exacto de bacilos viables.

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SPECIAL ARTICLE

ALERT-India 1981–89: nine years' experience of leprosy control in the slums of Bombay

A A SAMY, J MANCHERIL, K P MANEK & A C McDOUGALL*

*Alert-India; Association for Leprosy Education, Rehabilitation and Treatment—India, 6-B Mukhyadhyapak Bhavan, 3rd Floor, Sion (West), Bombay 400 022, India; and *Department of Dermatology, The Slade Hospital, Headington, Oxford, OX3 7JH, England*

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Summary Bombay has a population of about 8 million people, one-half of whom live in slums. In 1981, ALERT-India started its first leprosy control project in N, S and T Wards of Greater Bombay Municipal Corporation covering an area of 122 sq km in the north-eastern suburbs of Vidhyavihar, Ghatkopar, Vikhroli, Kanjurmarg, Bhandup and Mulund, with a total population of 1,100,000 according to the 1981 census. In the 9 years of operation, over 12,000 patients have been registered and treated and of these 7425 have been released from treatment, having satisfactorily completed courses of chemotherapy. However, over 1000 cases are still identified every year by house-to-house or school surveys, or by self-reporting, including a considerable percentage in children. The origin, development, staff structure, operational procedure, administration and recording system of ALERT-India are described in detail, with emphasis on what has been accompolished with purely outpatient facilities, using paramedical workers, all of whom have received inservice training from Government recognized training centres for their specific tasks. The account includes a brief description of an expansion of the organization's work into townships in New Bombay, where preliminary surveys in 1988 confirmed the presence of leprosy cases and the need for treatment facilities. The discussion addresses: 1, the better use of the large volume of statistical information which has been collected by ALERT-India during the past 9 years, with emphasis on its value in assessing the impact on the control programme and modifying future policy; 2, the need to radically examine the present policy of survey, *versus* an 'education campaign approach' with regard to increasing early case-detection and self-reporting; 3, the establishment of a central coordinating body for leprosy control in Bombay to exchange information, coordinate efforts and formulate a future plan of action, the latter in association with the National Leprosy Eradication Programme; and 4, the development of a health education resource centre in association with the Bombay Municipal Corporation.

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Introduction

ALERT-India was founded in October 1978. The letters stand for 'Association for Leprosy Education, Rehabilitation and Treatment' and this organization in India should not be confused with the All-Africa Leprosy and Rehabilitation Training Centre, also called ALERT, in Addis Ababa, Ethiopia. ALERT-India is registered under Acts of 1860 and 1950; it is a registered charity with audited accounts and donations are exempt from tax. The main financial support up to 1984 was from OXFAM (UK); from 1985 onwards it came from the Damien Foundation (Belgium) and other ILEP agencies such as the Associazione Italiana Amici de Raoul Follereau (Italy), Institute Fame Pereo (Canada) and the Association Francaise Raoul Follereau (France). The Damien Foundation is the ILEP Coordinator in India for finance and technical supervision. Its main objective is the eradication of leprosy, but the full list of subsidiary objectives as formulated and adopted by the Founder Members in October 1978 is as follows:

1 To detect early and infectious cases of leprosy in the community and reach the goal of total case detection through intensive surveys.
2 To treat every person diagnosed as suffering from active leprosy with adequate case-holding.
3 To create leprosy consciousness among the sections of the community through intensive health education programmes.
4 To work ardently towards total prevention of dehabilitation and promote sociopsychological and economic rehabilitation of leprosy patients in the milieu of the community.
5 To undertake and promote study and research in leprosy and related sciences.

To reach these objectives, three phases were envisaged.

Phase One

1 The establishment of a control programme and personnel to implement it; and
2 Bringing the maximum area under the Urban Leprosy Control Programme of the Association.

These would entail undertaking the following activities:

(a) conducting on-going surveys (house-to-house) in the project areas;
(b) progressively establishing treatment centres in surveyed areas;
(c) carry out a widespread programme of education particularly towards removal of existing deep-rooted prejudice and bias against the disease and its victims;
(d) setting up the office and records system (data collection, tabulation, analysis and control);
(e) establishment of a laboratory and a physiotherapy centre;
(f) publicising ALERT's aims, objectives and involvement, gaining community goodwill and cooperation at large, and the mobilization of local resources.

Phase Two

1 Establishment of a mini-hospital for special cases together with a full-fledged physiotherapy (physical rehabilitation centre); and

2 Health education Centre;
3 Undertake and promote study and research.

Phase Three

1 Implementing the economic, occupational, rehabilitation programmes;
2 Promotion of an Urban Training Centre (woefully lacking) and the establishment of a social research wing to promote the cause of eradication. Depending upon the progress made, funds available and the situation then prevailing, it will quite likely be possible to dovetail the phases into each other and thereby implement the programme more expeditiously and effectively.

Board of management

ALERT-India has a Board of Management of 9 members, most of whom have been on the Board since at least 1983; some were in fact founders of the Association. Some are medically qualified and experienced in leprosy, others have backgrounds in community or social work, education, nursing or administration. The Board is the legal body responsible for the Association and the overall policy decisions/directives and sanctions. The Chief Executive is an Ex-officio member of the Board of Management. Project planning, implementation and day-to-day administration are delegated to the Chief Executive, who carries out tasks through his team of officers and field staff. He also acts as Project Holder for the sponsoring agencies on behalf of the Association and as the 'Reporting Trustee' to the Governments and their departments.

Buildings, offices, clinics

The main administrative office is convenient to the centre of Bombay and is used by the Chief Executive and office staff. For field work and administration, two large rooms were acquired in 1985 in an industrial block in the heart of the control area, Vikhroli. This 'Project Office' includes a laboratory for slit-skin smears, storeroom, office accommodation, a teaching or meeting area and space for the reception and treatment of patients at a weekly clinic.

The project area

The area allocated is that of the three wards N, S and T as shown in Figure 1. These wards include the areas known as Vidyavihar, Ghatkopar, Kanjurmarg, Bhandup and Mulund. The estimated population of the three wards is 1,500,000. For administrative purposes the whole target area has been divided into 18 zones, each of which has one paramedical worker in charge, who carries out a full range of control activities, including surveys, case-detection, follow-up and health education, he also assists the medical officer during weekly visits to each zone. A field supervisor is responsible for the performance of 4 to 5 paramedical workers, and he in turn is supervised by the Project Officer, who is also

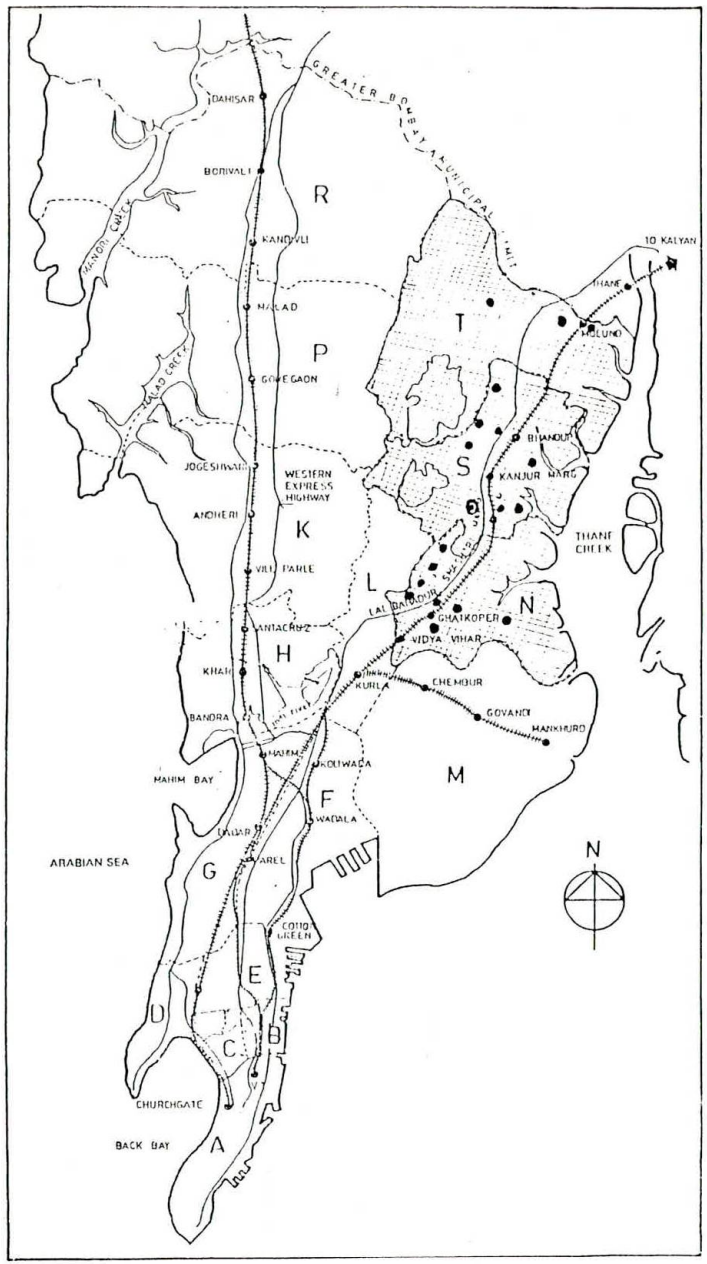

Figure 1. Map of Greater Bombay; total population 8 million. The letters A H, K N, P, S and T refer to 'wards' of Greater Bombay, of which N, S and T (shaded ara) are the control areas for ALERT-India. The area of the 'New Bombay Townships', in which programmes will be set up by ALERT-India in 1990, are to the right of Thane Creek, i.e. inland, towards the East.

responsible for the planning and execution of the control programme as a whole. The medical officers are ultimately accountable for the proper implementation of all technical and professional aspects of the programme and are directly responsible for the diagnosis and treatment of all patients. Every 3 months there is a general meeting of the entire staff, including health educators and the social worker to discuss problems and to review progress. Once yearly a general self-evaluation is carried out by field workers and officers, using a questionnaire, and the outcome discussed at a meeting, chaired by the Chief Executive.

Staffing

This includes: 1, the Chief Executive (with qualification in social welfare administration); 2, two full-time medical officers (one of them functioning as the Project Officer); 3, four field supervisors (trained paramedical workers); 4, twenty paramedical workers, all of whom have had inservice training with ALERT-India and in Government recognized training centres; 5, one smear technician; 6, one physiotherapist; and 7, one social worker (female; with a degree in social work), one driver and one typist. One paramedical worker is responsible on average, for about 50,000 people, with four field supervisors for 20 paramedical workers. Fifteen out of the 20 paramedical workers are already trained as health educators and the rest will complete their training in health education in 1991.

Control policy and field activities

These follow essentially conventional lines, as laid down (and used widely in India) by the National Leprosy Control (now Eradication) Programme in 1954.[1] This is based to a large extent on the principle of 'survey education and treatment'. Surveys have been carried out in this project in: 1, the general population; 2, contacts of known cases and 3, schools. In addition, a considerable number of cases are referred from private practitioners and others are apparently entirely self-reporting. Through the 9 years of operation, the approximate percentages of cases found in the above categories are: 1, 37%; 2, 16% and 3, 12%. From the 18 zones referred to above in the three wards of this project, one is still to be surveyed, but in the others surveys have been completed on a door-to-door basis, identifying slum colonies, one room tenements and lower middle-class housing societies in each zone of the project area. These teams examine 80% of the population in every cluster. Anyone familiar with conditions in the slums of Bombay will readily agree that this is neither complete nor satisfactory as a basis for 'survey' and it is likely that the teams fail to contact some members of the community, including those who leave the house early to go to work, even if visits are repeated. It has also to be appreciated (see Discussion) that the population is to some extent 'shifting' due to employment opportunities in the City or in villages which defy monitoring. All survey activity has been accompanied, from the early years of the work of ALERT-India, by intensive health education, using verbal communication, leaflets and pictures of early leprosy, and the attempts which have been made to assess its value will be discussed below.

Treatment

Nineteen clinics are scattered throughout the project area and they are held weekly, each patient receiving medication for 4 weeks at a time, on the occasion of attendance for supervised drugs. The regimens followed are those advised by the World Health Organization (WHO) in 1982[2] (not those of the National Leprosy Eradication Programme) and the criteria for the grouping of patients for pauci or multibacillary regimens are also those of WHO, with the following modifications: 1, All patients with less than 4 lesions are treated as pauci-bacillary; 2, all patients with 10 or more lesions are treated as multi-bacillary, regardless of bacteriological findings (i.e. even if negative); 3, all cases with between 4 and 9 lesions, and less than 3 nerves involved, are treated as paucibacillary; and 4, all cases with more than 4 lesions and more than 3 nerves involved are treated as multibacillary. Pure neuritic cases with only 1 or 2 nerves involved are treated as paucibacillary and those with multiple nerves involved as multibacillary, but only after thorough examination and assessment by a medical officer. The periods of treatment are also essentially those advised by WHO, with the following modifications:

1 All paucibacillary cases are allowed a maximum of 9 months to complete the course of 6 supervised doses.
2 If a medical officer confirms that there is clinical activity on completion of the 6 months course, treatment may be continued for a further 6 months.
3 Triple drug therapy for multibacillary cases should be completed within 36 months, or continued until smears are negative and or clinical inactivity, whichever is the longer.
4 In certain cases, however, at the discretion of the medical officer, treatment for multibacillary cases has been stopped after 40 supervised doses, regardless of bacteriological positivity.

It is important to note that multiple drug therapy is given only to patients who are able to give an address or contact point; who understand what is needed by way of monthly attendances and daily, unsupervised treatment; and who agree to keep in touch with the programme for the necessary period of time. Unless these criteria are met ALERT-India, in common with other agencies doing leprosy work in Bombay, has not used multiple drug therapy. These patients are either given a supply of dapsone 100 mg to take daily, with a prescription or a letter introducing them to the health services in another part of India, if they intend to leave Bombay. This policy, developed because of the danger of issuing expensive and potentially toxic drugs to patients who might never appear again, is judged now to be increasingly unacceptable, and alternative strategies to ensure that all patients presenting with active leprosy, especially if multibacillary, receive multiple drug therapy, are under discussion (see Research).

Drug supplies and distribution

Dapsone, clofazimine and rifampicin are supplied loose in stock bottles or plastic containers and made up into 1-month supplies (in the case of dapsone and clofazimine) for dispensing to patients. Blister packs, already widely used in some other parts of India, have not been used in this project, nor to our knowledge, in other parts of Bombay. Their use in the future, especially if advantages in compliance are demonstrated by trials, has not however, been ruled out. Based on personal interviews with patients, pill counts, occasional checks of the urine for dapsone and assessment of the clinical and bacteriological results, our impression is that compliance to prescribed medication is satisfactory.

Planning, monitoring and evaluation

From the earliest stages of work, attention has constantly been given to the yearly development of a 'plan of work', identifying priority areas for attention, writing specific objectives and drawing up a monthly timetable of work for all members of the team. Monthly progress and work reports have been in use throughout, including specific suggestions for the improvement of work performance. Quarterly reviews and reports are made by the Project Officer, including an analysis of achievements (or failures) in priority areas. Half yearly and yearly evaluations are made by the Chief Executive, including an analysis of the overall achievements of the Association, based on the set objectives. Of particular importance are the operational assessments which have been carried out every 3 years by an external team (usually 3 or 4 experts in the field of leprosy control), to assess the quality of work, achievements and overall plan of action, whilst at the same time making proposals for changes, corrections and improvements for the future.

Referral of reactions, complications, cases requiring hospitalization

It is of interest that the need to refer patients for any of these reasons has been remarkably low. It has in fact been necessary to refer patients for severe reactions or other serious complications on less than 100 occasions, during the 9 years of the programme. We have been fortunate to have excellent contact with the staff and facilities of the Vimala Dermatological Centre, to whose physicians we are extremely grateful. Patients stay in hospital for a minimum of time needed and then return to our care. The entire element of 'removal' to an isolated leprosarium has thus been avoided by an almost totally outpatient approach and this may have contributed to the high level of interest and cooperation by patients and the community.

Laboratory services for slit-skin smears

Facilities for taking smears are available in all 19 clinics of the project area. Sites are selected either by a medical officer or by the next most highly experienced paramedical worker available. Smears are taken and fixed by a laboratory technician or a paramedical worker trained in this procedure. Until the end of 1985, patients with less than 4 lesions were not routinely smeared, unless requested for some special reason. The present policy is that all cases are smeared prior to starting treatment, the only exception being children with a single lesion on the face. Appropriate instructions have been issued to Medical Officers concerning the possibility that multibacillary patients, who are partially (and perhaps inadequately) treated, or relapsing, may present with less than 4 lesions. Once

fixed, labelled and dated, smears are sent to the 'Project Office' in Vikhroli, where one laboratory has been maintained through the years for the staining, examination and reporting of all smears, in accordance with advice given in a recent publication on the subject,[3] to the effect that selection and taking may be peripheral, but the staining and interpretation should be centralized and constantly under supervision. The bacteriological index (BI) only is recorded, not the morphological index (MI) or any other index. One technician has been trained at the Schieffelin Leprosy Research and Training Centre in Vellore, South India. It has been possible only during the last 2 years to organize reliability or comparability checks with other centres in India, but medical officers check approximately 5% of smears on a random basis. Particularly in view of the recent recommendations by WHO[4] that the finding of a positive BI at any site means that the patient should receive the multibacillary regimen (3 drugs for a minimum of 2 years), all slides with a BI of 1 will be double checked by a medical officer from now on.

Records, registers and reports

In recent years, following recommendations made by independent consultants, the number of registers and reports has been considerably reduced, but it is still necessary to supply them for three different agencies: 1, ALERT-India itself; 2, the Government of Maharashtra; and 3, the International Federation of Anti-Leprosy Associations (ILEP) in London. (The OMSLEP recording system has not been used.) The forms in use for ALERT-India for clinical details, smear reports, survey findings, contact examinations, etc., are entirely conventional and relatively easy to complete, but the monthly progress report for the Government is a lengthy and somewhat complicated document of 24 pages, which is time consuming for the health staff concerned, but nevertheless obligatory for administrative purposes. The ILEP Questionnaire or Form BG called for over 150 separate items of information, and although these are for the most part readily available from other sources and the form is required only once a year, it is clear that health staff are generally being asked to allocate an unreasonable amount of working time to the completion of these and other forms. Our belief is that the most important items which require recording are: 1, the total number of patients registered; 2, the number on multiple drug therapy; 3, the number who have satisfactorily completed it and been released from treatment; and 4, the proportion of new and currently registered cases with significant disability.

Healthy contact survey examination

As far as possible all contacts of index cases are examined once yearly, except contacts of multibacillary cases, who are examined every 6 months. The total number of contacts examined between 1981 and the end of 1989 was 48,060 from which 1189 cases (2·4%) have been diagnosed as having leprosy and treated.

School surveys

To date 249,122 school children have been examined, all between the ages of 5 and 15

Table 1. ALERT-India 1981–89: population covered, new cases detected and prevalance rate per thousand

	Population covered	New cases detected	%	PR/1000
1 Door to door survey among slums, chawls and housing colonies	461,628	4150	37	8·9
2 School survey among municipal, private, primary and secondary school	249,122	1348	12	5·4
3 Contact examination of known cases	48,060	1189	11	24·7
4 Health contact examinations	—	586	5	—
5 Voluntary referals and others	—	3946	35	—
Total		11,219	100	

years. The case detection rates per thousand in recent years have been as follows: 1, 1984—4·16; 2, 1985—4·66; 3, 1986—9·79; 4, 1987—6·4; 5, 1988—4·2; and 6, 1989—5·7. The overall prevalence of new cases among school children was 5·4 per 1000.

Rehabilitation

This term appears in the title of ALERT and in the 'Plan of Action' of 1978, but in the sense of mental and physical rehabilitation of disabled patients to enable them to find gainful occupation, it has not been possible to develop this activity with much effect. Although this has been largely due to lack of trained staff, premises and equipment, it became clear after only a few years of experiences that it is extremely difficult, probably unrealistic, to rehabilitate patients in a community where there is already unemployment amongst healthy people, or to train them for useful work in remote villages, if they intend to return home. In the more general sense, we continue to teach disability prevention and self-care by patients, but incline increasingly to the view that the treatment of seriously disabled patients and their rehabilitation should be undertaken by agencies which have the staff, expertise and premises, and who are prepared to integrate leprosy patients with those disabled from other causes.

Public reactions to house-to-house and other forms of survey

We had anticipated opposition and refusal to allow health staff to enter houses and examine occupants, but this occurred on only a very small number of occasions. A second visit, once confidence has been established, usually meets with complete success. We attribute such good relations to: 1, the careful orientation of staff before they embark on this kind of work, to ensure that they proceed diplomatically and with respect for the privacy and convenience of others; and 2, the fact that the slum populations of Bombay are now more than used to visitors, students and health or social workers of various kinds;

Table 2. ALERT-India 1981–89: yearly case detection, child and disability rates, smear positive cases

	1981	1982	1983	1984	1985	1986	1987	1988	1989	Total
1 Total cases detected in each year (Annual) (new & old cases)	847	1416	1615	1019	1921	2038	1018	1094	1088	12,056
2 New cases among the above	847	1313	1517	964	1875	1831	896	988	988	11,219
3 Percentage of new cases	100	92	94	94·6	97·6	89·8	88	90·3	90·8	93
4 Child cases among the new cases	213	402	627	266	349	586	285	440	326	3494
5 Percentage of child cases (new cases)	25	30·6	41·3	27·5	18·6	32	31·8	44·5	33	31
6 Deformed (Grade 2 & 3) cases among new cases	45	47	76	42	76	85	35	40	47	493
7 Percentage of deformed cases (new cases)	5·3	3·5	5	4·3	4	4·6	3·9	4	4·7	4·4
8 Smear positive cases among new cases	28	76	97	54	132	165	94	78	74	798
9 Percentage of smear positive cases (new cases)	3·3	5·7	6·3	5·6	7	9	10	7·8	7·4	7

Table 3. ALERT-India 1981–89: total of registered cases, chemotherapy, cases released from treatment or lost to control

	1981	1982	1983	1984	1985	1986	1987	1988	1989	Total*
1 Total cases registered (new & old) (Annual)	847	1416	1615	1019	1921	2038	1018	1094	1088	12,056
2 Total cases put on MDT	1	55	149	132	1126	1434	1052	1022	1019	5990
%	0·12	3·8	9·2	13	58·6	70	103	93	94	49·6
3 Total cases put on dapsone monotherapy	846	1361	1466	887	795	604	—	72	69	6066
%	99·8	96·2	90·8	87	41·4	30	—	7	6	50·4
4 Total cases on MDT released from treatment (RFT)	—	2	53	58	180	1270	1006	727	882	4178
5 Total cases released from control (RFC) including some on dapsone monotherapy	—	1	13	44	139	394	1611	723	322	3247
6 Total cases lost to control (deletions)	8	164	198	172	423	573	620	313	355	2826†

* The figures in this column have to be interpreted in the light of the fact that 15% of all cases are still on MDT or monotherapy at the time of writing this report.

† Anecdotally, information from social workers in ALERT-India and other agencies working in leprosy control in Bombay, indicates that many of these patients have transferred to other parts of the City and re-registered for treatment.

once assured that the enquiry has nothing to do with legal matters, they are in general highly cooperative. Female staff work in pairs and appear to be able to carry out their duties with complete safety.

The personal health record of staff in ALERT-India

In the 9 years of operation in the slum areas described, often under conditions of great heat and without facilities for washing, etc. it is notable that we have had a low incidence of viral or other illnesses in doctors or paramedical workers. This is despite frequent contact with people suffering from measles, typhoid, dysentery, hepatitis, influenza, respiratory infections of various kinds, including active tuberculosis. During the 9 year period only one case of leprosy (pauci bacillary) has been diagnosed in an employee. Part-time or voluntary workers have included male and female students in their teens, none of whom has contracted a significant illness to our knowledge.

Research

ALERT-India has always been open to liaison with medical schools, universities and scientists, but with priority for operational and 'field-based' research on urban leprosy control and the extraordinary sociological conditions which prevail in the slum conditions of the project area. Pressure of work and lack of time have to a considerable extent precluded adequate attention to such research but we have had many visitors from different parts of the world and in 1987–88 data was collected by Dr Atul Vadher (Department of Experimental Psychology, Oxford University) which will contribute to a thesis on social and psychological aspects of leprosy in relation to compliance to prescribed medication.[5] More recently, Dr Nigel Crook (Department of Economic and Political Studies, School of Oriental and African Studies, The University of London) has completed a final assessment of a study of the 'educational campaign method' which started in Maharashtra Nagar in early 1986, which is due for publication in the near future.[6] Another study of sociological and population data in the New Townships of Vashi and Turbhe, with a preliminary estimate of the number of leprosy cases in those areas, has been submitted for publication.[7]

At least two other subjects calling for operational research remain and they are both of potentially great importance to the immediate plan of action. The first concerns the disconcertingly large number of patients who present, or are discovered to have leprosy in ALERT-India, but who are unable to give an undertaking that they will be in the area long enough to take a course of multiple drug therapy. Some of these are transient or visiting: others intend to return to their villages in the near future; others are unable to give an address or point of contact for supervision and follow-up, or are judged for a variety of reasons to be unlikely to pursue daily self-medication and monthly attendances for a reasonable period of time. To deny these patients any form of treatment or to give them dapsone monotherapy is an unacceptable policy which is now under intensive review in this organization. There are, however, good reasons for concluding that this problem (which occurs in slum programmes in several other parts of India) cannot be solved without consultation between ALERT-India, all other agencies working in leprosy

control in Bombay, the Ministry of Health of Maharashtra and probably also the national Leprosy Eradication Programme of India. Meanwhile, we have outlined a pilot research programme to: 1, identify the patients concerned in greater detail; 2, define the sociological and other reasons which impede safe implementation of multiple drug therapy; and 3, propose solutions.

The second subject concerns the remarkably large number of private practitioners in the N, S and T wards of this project and the likelihood that many more will settle in the New Townships in the coming years. The potential of private practitioners in Bombay in cae-detection and referral for treatment has already been shown to be considerable and it is now our intention to compile a comprehensive list of all practitioners in the area and to invite their cooperation, whilst at the same time carefully respecting their right to receive and treat patients as they see fit, and any element of professional confidence which may be involved. This enquiry will include information on the controversial question: 'Does the acceptance and treatment of leprosy patients in private practice enhance, or damage, the reputation of the doctor and the numbers of patients who come for consultation?'

Discussion and future plans

The registration of over 12,056 cases in a period of 9 years, followed by the release from control of over 7425, after completion of satisfactory courses of treatment, would appear to be a significant contribution towards the control of leprosy in the urban slums of this project. The disease has obviously been arrested in a large number of individuals; nerve damage has been prevented; relapse rates are low and there is at least a possibility that we have reduced the pool of infectious/contagious cases. There remain, however, a number of disconcerting aspects to this work, including the fact that we continue to register about 1000 new cases each year, but have little knowledge of their source of infection, whether within the project area or from some other part of Bombay (or India). We are also uncertain about the cost-effectiveness of our approach to case-detection and treatment. Survey can be laborious, time-consuming and expensive and it is notorious for the 'discovery' of cases who are unlikely to accept the diagnosis of leprosy and attend well for treatment. Broadly based educational campaigns, using all kinds of media, have been found by Ganapati[8] and others to have advantages over routine survey and it is to be hoped that the study already referred to in Maharashtra Nagar will contribute further information in this area.

Under **Treatment** it has already been pointed out that a considerable number of patients with active leprosy do not, for a variety of reasons, receive multiple drug therapy and this is a matter of considerable concern which points to the need for some kind of central or coordinating body amongst the agencies working in leprosy control in Bombay. It should not be impossible to analyse and overcome the operational and other obstacles which give rise to this situation, whilst at the same time reviewing working methods, report forms, records and other matters of mutual interest to the 10 agencies concerned.

As already indicated, ALERT-India is now entering a new phase of work in the Townships of New Bombay and this may point to the urgency of making sure that baseline data are properly assembled and that data from the main project areas is analysed to greater advantage. We aim to educate the public and prevent disability through early case detection and chemotherapy. To do this effectively, we have to constantly keep in mind the need to study not only the disease and the drugs available for treatment, but also the complex and challenging pattern of society in the slums where we work.

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ALERT-India 1981–89: Une expérience de 9 ans du contrôle de la lèpre dans les taudis de Bombay

AA Samy, J Mancheril, K P Manek et A C McDougall

Résumé Bombay a une population d'environ 8 millions d'habitants dont la moitié vit dans des taudis. En 1981, ALERT-India commença son premier projet de contrôle de la lèpre dans les quartiers N, S et T de la municipalité du grand Bombay d'une surface de 122 km carré dans les faubourgs nord-est de Vidhyavihar, Ghatkopar, Vikhroli, Kanjurmarg, Bhandup et Mulund dont la population totale s'élève à 1.100.000 habitants d'après le recensement effectué en 1981. Au cours des neuf années d'activités, plus de 12.000 patients ont été enregistrés et soignés dont 7425 chez qui le traitement a été arrêté ayant terminé avec succes un traitement complet de chimiothérapie. Toutefois, plus de 1000 cas sont encore identifiés chaque année par des enquêtes à domicile ou dans les écoles ou par notification volontaire et comprennent un grand nombre d'enfants. La création, le développement, le personnel, les méthodes de travail, l'administration et la méthode d'enregistrement utilisée par ALERT-India sont décrits en détail. L'accent est mis sur les résultats obtenus uniquement en consultations hospitalières externes avec l'aide des paramédicaux qui ont tous reçu une formation spécifique en cours d'emploi dans des centres de formation reconnus par le gouvernement. Le rapport inclut une brève description de l'essor des activités de l'organisation dans les banlieues de New Bombay où les enquêtes préliminaires effectuées en 1988 confirmaient l'existence de lépreux et la nécessité de dispensaires. Les questions abordées sont les suivantes: 1, l'emploi plus judicieux des données statistiques recueillies par ALERT-India au cours des 9 dernières années soulignant leur importance sur l'évaluation de l'impact du programme de contrôle et sur l'évolution des politiques futures; 2, la nécessité de comparer en détail le programme actuel d'enquêtes au système de campagnes éducatives afin de promouvoir le dépistage des cas précoces et les notifications

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Community-Based Rehabilitation for the Leprosy Cured

S.P. Tare

Director, Gandhi Memorial Leprosy Foundation, Hindinagar, Wardha 442 103 (Maharashtra) India.

Being primarily a medical problem with very serious social overtone, persons suffering from leprosy have to face numerous problems. But the rehabilitation of the leprosy cured is a very major problem and at the same time, a very complex one. It calls for efforts not only of the leprosy workers, but requires multi-pronged efforts involving people from influential groups in society, social leaders as well as the entire community in general. Rehabilitation of a leprosy patient cannot be achieved unless the community in general is willing to accept persons having leprosy or cured of leprosy in their fold.

The problem of rehabilitation arises primarily because of the deformities which are associated with leprosy so much so that people generally equate leprosy work with that of rehabilitation of leprosy patients. The presence of physical deformities results in: (a) making out the person with deformity as a patient of leprosy; (2) incapacitating him from doing normal work, and (3) creating a strong societal reaction in the community leading first to loss of job by the patients and subsequently losing family support and finally displacement from society.

The Indian Model

The model that was followed in India about three decades ago before a nation-wide leprosy control programme was launched was providing life-long shelter to rehabilitated patients in an institutional set-up. These institutions not only provided shelter and food for life but also kept the patients vocationally engaged in one or the other departments. The patients thus lived in a separate world of their own, permanently cut-off from their family and society.

After the launching of the national programme to control leprosy the concept of rehabilitation also underwent a change and it was realised that the life-long institutional shelter provided to patients of leprosy was no rehabilitation in the real sense of the term. It was also recognised that the existing institutions could play a role in short-term training of leprosy patients in some skill, vocation or craft so that the patient could be sent back to society, after training. Many institutions gradually accepted this modified concept and started discharging leprosy patients after training them in some trade/skill. Unfortunately, there was no mechanism of follow-up of the discharged patients with the result that very little informa-

tion was available with the institutions as to how the trained pat were faring after their discharge. Two studies conducted in respect of patients discharged from two supposedly-ideal rehabilitation centres brought out a sad revealation that majority of trained-and-discharged patients were not continuing the trade-craft in which the training was provided and had become either beggars or agricultural labourers. A further probe in the reasons for this failure brought out the following:

1. These patients were trained in something other than what they were doing earlier.
2. They were trained in something other than what they would have liked to do; the institutions chose the skill/job in which to train them without taking into account their performance or liking.
3. There was no follow-up of patients discharged from the institutions.
4. There was hardly any support extended to the discharged patients to gainfully establish themselves in the field of their training; either by providing them with necessary tools, or by helping them in obtaining raw material or in marketing of the things they produced.

In view of the limitations noticed in institution-based training programmes and consequent loss of considerable time; energy and money spent on the training, an effort was made to explore avenues of placement of leprosy patients in already existing/available jobs. A study of 23 public sector industries was conducted by the Gandhi Memorial Leprosy Foundation (GMLF) and thousands of job specifications were studied to identify those where patients with varying degrees of infectivity and deformity could safely be placed. This study brought out a list of thousands of jobs where even an active patient of leprosy could be employed without any risk of spread of infection to other co-workers, without any likelihood of further damage to his limbs and without need for any special training acquiring skills. The findings of this study brought out the great potential of likelihood of vocational placement of a large number of even illiterate and unskilled patients for various jobs.

In GMLF, greater emphasis was given to "prevention of dehabilitation" rather than to "rehabilitation of dehabilitated patients" because it was felt that the final solution of the problem of rehabilitation will come out only if the process of dehabilitation of patients from society could be totally halted. There is no doubt that those who are already dehabilitated have to be taken care of, but that alone will not solve the problem as long as problem continues to be aggravated in numbers by addition of newly dehabilitated patients year after year.

The methodology followed for preventing dehabilitation was two-fold:

a) Early detection of every patient of leprosy.
b) Immediate and full treatment of every patient of leprosy in as early a stage of the disease as possible.

In every field centre of GMLF, a population of 2 to 3 hundred thousand is covered and entire population is physically examined, once a year to detect any new case of leprosy.

Every case of leprosy is trea freely in a clinic locally close to his village. The therapy earlier was monotherapy with DDS and for a decade now multi-drug therapy. It may be noted that these field centres were located in rural areas and hence the experience is based on work with rural population.

Simultaneously, with detection of every new patient and his treatment, special efforts were made to take interest in the social life of every patient and to help him to stay with family and stand on his own. Some of the efforts, for example, are as follows:

1. Help the patient to continue whatever work he is doing and intervene in instances where he is on brink of dehabilitation (e.g. helping teachers with deformity to carry on as teacher by convincing/persuading his employers; co-teachers and guardians of pupils of the school in which he is teaching. Similarly, an employee in a Bank by convincing/persuading his officers, co-workers, Trade Union of the Banking Staff and clients of the Bank.
2. Help a patient to regain the job which he was doing earlier but has lost it (e.g. helping a school-teacher who was dismissed on the ground of leprosy to be re-instated in his post with all back-benefits paid to him)
3. Wherever it is necessary to provide a new job to a patient, to help him in one of the avenues of self-employment in his village (e.g. as a vegetable-vendor, or taking up smithy or dairy or poultry or tailoring or spinning, etc.). This prevents, on the one hand, any likelihood of getting displaced and on the other hand, enables him to continue with the family as an earning member and with acceptance from society.
4. Help a patient to obtain benefits of numerous schemes of the Government as a part of their employment, poverty-eradication or welfare programmes and old-age/disability schemes (e.g. to obtain land, to obtain loan for building a house, to receive pension for old and crippled patients, to receive loans extended to start self-employment project, etc.).

The above efforts have been conducted for nearly four decades now in the field of GMLF, and the results achieved can briefly be summarised as follows:

1. There is no deformed patient among the newly-detected cases for last four years.
2. There is no active patient having an ulcer (the credit entirely goes to the patients who have understood the importance of taking self-care of their affected limbs, and developing it into a daily habit of check-up.
3. There is no instance, in over twenty years, of any single leprosy patient being compelled to leave family or home.
4. There is no instance, in over a decade, of any employed leprosy patient being removed from job on account of leprosy.

5. There is no instance, in over a decade, of a patient-w eing divorced (through GMLF's doctor appearing in the court as an expert witness in defence of the patient-wife and testimony being accepted by the Court to reject the petition for divorce) or being rejected by the husband (through direct persuation of the husband and/or taking help of local support to convince the husband to accept the patient-wife back).

6. There are numerous instances of young patients being helped to get married to a healthy spouse; even young girl-patients with visible deformity could get married to a healthy groom with his and his family's full knowledge.

What is explained above is what is being presently termed as "Community-based rehabilitation". The GMLF had based the entire strategy in respect of its approach to deal with rehabilitation in helping the patient to remain in his natural environment, and getting gainful employment in his own surroundings with full support of the community in which he lives. This strategy entirely does away with the costly model of institution-based rehabilitation which need workshops, machinery, craft-teachers and whole range of production and marketing mechanisms, and fails if there is no follow-up support for considerable length of time to see that the patient is not only carrying on gainfully in what he was trained for, but also that he is accepted by the community to which he has gone back.

To summarise, it can be stated that:-

1. It is very important to carry on case-detection at as early a stage as possible and introduce therapeutic intervention as quickly as possible so that no patient develops physical deformity and is exposed to the threat of vocational and social displacement.

2 Active efforts should be made to take interest in social problems faced by every patient and effective intervention be made in case of those identified as being on the brink of dehabilitation, so that the patient is not dehabilitated. In other words, prevention of dehabilitation is the final and ultimate strategy to get rid of the problem of rehabilitation.

3. As far as vocational rehabilitation is concerned, the strategy of "Community-based rehabilitation" is far more effective compared to the model of institution-based rehabilitation programmes. This implies in helping the patient to continue to do what he has been earlier doing, but do it in a better way and/or to help him through some avenues of self-employment. This strategy is preferable because 1) it is very cost effective, 2) it is very satisfying to the patient concerned because this enables him to stay in his own environment and do what he likes to do, 3) moreover, it ensures his integration in his own community in a very smooth way, 4) finally, it has an educational value for the rest of the society to see that leprosy is curable and not such a fearful disease, and that a person having leprosy is as much a part of the society as any other person.

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TRENDS AND OPINIONS

Planning for the Disabled Child

D.J.K. Cornelius
Navajyothi Trust, Madras

ABSTRACT

Childhood is the most dynamic period of development, consequently "untreated" childhood disabilities will result in profoundly handicapping conditions. Specially developed schooling programmes are essential for "exceptional" children. Most disabling conditions can be managed with the exception of Mental Retardation, which will respond largely to special educational and training exposures. It is necessary to determine the aetiology of the condition to plan appropriate intervention systems. Services initiated early are most benificial. While services are targetted to the disabled child, appropriate services need to be planned for the care giver. Educational facilities need to be upgraded and the aspect of intergrated education carefully evaluated. The challenges of service delivery in developing countries with a large proportion of its population in the villages are stupendous and have to be most carefully planned, to make them relevant. Perhaps the greatest input to successful habilitation and rehabilitation will be the introduction of environmental restructure to meet the specific needs of the disabled child. A recommendation for a CBR programme has been made.

Planning for the Disabled Child

Childhood is a period extending, classically over twelve years (from the age of two years, or as generally understood, upto eighteen years, when the period of adolescence concludes). When services are understood as a system organised to provide for needs; the enormity of the challenge of meeting them, over the continuosly changing requirements throughout this relatively long developmental process in childhood, is not difficult to concieve.

Recalling the need for a clear understanding of the concepts; for this purpose, the following definitions have been adopted:- That

SCREENING OF REGISTERED LEPROSY CASES AND ITS EFFECTS ON PREVALENCE RATE

P. SIVARAMAKRISHNA RAO[1] AND P. SIRUMBAN[2]

Prevalence rates of leprosy in 6 endemic districts in Andhra Pradesh, India with a population of 168.71 lakhs (1981 census) were studied before and after screening of registered cases. The screening was carried out as part of multidrug treatment project implementation. After such screening a sharp fall in the registered prevalence rate, by 26.2% on the average, was observed in all the districts. About 34.8% of the total cases were declared as Released from control. The implication of these findings regarding registered cases fit for such release and the overall registered prevalence rates in the country must be kept in mind.

INTRODUCTION

The prevalence pool of leprosy in a population in general is in a constant flux resulting from inflow of cases (new cases, relapses and immigration) and outflow of cases (cure or inactivation, emigration and death).

Where leprosy treatment facilities exist, inactivation or cure due to specific treatment is an important mode of elimination of cases from the prevalence pool (Noordeen 1985). However, information on registered leprosy cases is often not updated and inactive cases often remain in the registers, either because patients have been lost to follow-up or because of the inability to assess the patients' clinical and bacteriological condition (W.H.O., 1988). To what extent inactive cases remain in the registers is not known.

Multidrug teatment (MDT) projects divided into 4 phases (Mobilisation, Planning and Preparatory, Intensive and Maintenance) are being implemented in several endemic districts in India since 1983. Rapid survey of the community (to detect hidden cases) and screening of registered cases medically (to declare cured cases as released from control (R.F.C.) and to identify cases for multidrug regimens) are the two important activities undertaken during the planning and preparatory phase (NLEP, 1987).

1. Dr. P. Sivaramakrishna Rao, MBBS, DTM & H, DPH., Deputy Director (Epidemiology) and Head of Division of Epidemiology and Statistics,

2. Mr. P. Sirumban, M.Sc., Senior Statistical Assistant,

Central Leprosy Teaching and Research Institute, Tirumani Chengalpattu, Tamilnadu 603 001.

MATERIAL AND METHOD

Data on screening of registered cases and detection of new cases by rapid survey were collected from 6 endemic districts in Andhra Pradesh where multidrug treatment projects were under implementation, through the courtesy of the NLEP Consultant and concerned District Leprosy Officers. Rapid survey and screening of cases was completed in one year on an average in these districts (except in Visakhapatnam District where it took two years) between 1985-87. Prevalence rates of registered cases before commencement of screening and after completion of screening were calculated, based on the estimated population for each of the districts and the percentage fall in prevalence rates were worked out.

From 4 of the 6 districts information was collected on case detections, discharges annually and the number of cases in the registers at the beginning and at the end of the year, for 4 years prior to the screening year. Point prevalence rates at the beginning and end of the year, percentage fall or rise in prevalence rates, new case detection rates and proportions of cases made R.F.C. were calculated year-wise.

RESULTS AND DISCUSSION

As may be seen from Table I, the coverage of screening of registered leprosy cases ranged from 70.4% in Visakhapatnam to 97.4% in Chitoor District with an average of 88.1% for the 6 districts. The registered fall in prevalence rates varied from 9.75% in Krishna District to 43.65% in Visakhapatnam District, the over all average being 26.2% for the 6 districts, in the year when the rapid survey and screening of registered cases was undertaken. As compared to this, the fall or rise in prevalence rates in each year for 4 years prior to screening in 4 of the districts ranged from a fall of 6.16% in West Godavari District during 1985 to a rise of 9.30% in Cuddapah District during 1982 (Table II). As such, the percentage fall in prevalence rates in the year when rapid survey and screening was conducted, was considerably high. The new case detection rate (per 1000 population) in the rapid survey year ranged from 1.33 in West Godavari District to 4.09 in Cudappah District, the average being 1.92 for the 6 districts. The annual new case detection rate in 4 of the districts for the 4 years immediately prior to screening and rapid survey ranged from 1.12 in West Godavari District during 1984 to 2.29 in Cuddapah District during 1982 (Table II). The sharp fall in prevalence rate during screening year occurred despite an appreciable increase in new case detection rate during that year.

TABLE I. Data on Popul[illegible], Leprosy Case Detections, Screening Cases Etc., in 6 Dis[illegible]s of Andhra Pradesh.

PARTICULARS	DISTRICTS						
	VISHAKA-PATNAM	E. GODA-VARI	W. GODA-VARI	KRISHNA	CUDDA-PAH	CHITOOR	TOTAL
1. Population (1981 census—in lakhs)	25.76	37.01	28.74	30.5	19.33	27.37	168.71
2. Cases detected during rapid survey and screening	4651	8826	4283	4915	8923	5040	36638
3. Total cases for screening	22105	38386	16722	25048	31728	33010	166999
4. Cases screened	70.4%	96.7%	95.7%	73.8%	94.7%	97.4%	81.1%
5. Cases deleted during screening	12065	16543	6627	6585	12867	14472	69159
6. Cases deleted as RFC	6639	10028	4192	4122	8293	11290	45364
7. *Prevalence rates (per 1000) before screening	5.98	7.18	3.92	5.95	10.62	9.3	6.95
8. Prevalence rates(per 1000) after screening	3.37	5.22	3.13	5.37	8.64	6.07	5.13
9. Fall in prevalence rates	43.65%	28.34%	20.15%	9.75%	18.64%	34.73%	26.19%
10. R.F.C. case proportion to total Regd. cases	38.04	33.92	40.13	20.47	36.37	40.36	34.80
11. New case detection rate (per 1000)	1.56	2.11	1.33	1.43	4.09	1.65	1.92

Cases detected during rapid survey and screening were excluded for calculating Item 10.

* (Item 3 — Item 2) × 1000/ Estimated population.

The percentages of cases deleted from among the total number of cases during the rapid survey and screening year ranged from 32.71 to 69.11 as against 9.58 to 14.15 in 4 of these districts 4 years immediately prior to the screening year. Of these deletions, majority (65.59%) were due to R.F.C. The percentages of cases released from control (R.F.C. rate) from among the total number of cases on registers during the rapid survey and screening year ranged from 20.47 to 40.36, with an average of 34.80, for 6 districts as against 1.13 to 9.65 with an average of 4.96 in 4 of the districts during the 4 years prior to screening. The percentages of cases deleted and declared RFC under Dapsone Monotherapy have also been reported high, 52.39 and 37.53 respectively in North Arcot District of Tamil Nadu where MDT project has been under implementation since 1983 (Ekambaram and Rao, 1989). From the above data it is clear that the marked fall in prevalence rates during the rapid survey and screening year was mainly due to large number of deletions and that too due to cases released from control.

The question is why so many cases fit for R.F.C. were kept undeleted from the registers. It appears that screening of cases for declaring them as RFC was not taking place regularly resulting in accumulation of inactive cases on registers. Another reason may be a change in the criteria for declaring cases as R.F.C. since in all the 6 districts a vertical leprosy control programme was being run with dapsone monotherapy for the last several years. It seems likely that if we can organize medical screening of all registered cases in the country, in one year, we may be able to declare about 35% of them as fit for R.F.C. with resultant savings of manpower and finances. Similarly, the registered prevalence rate could be brought down by about 26% in a year if screening and rapid survey could be completed in a year. This will also give more reliable prevalence statistics for monitoring and evaluation of the Programme. It should be noted that the above fall in prevalence was mostly due to increase in RFC rate and was independent of MDT. Perhaps to a large extent it was due to dapsone monotherapy that had gone on for a considerable period.

The second independent evaluation of NLEP Report (1987) observed a sharp fall of over 80% in prevalence rates in the districts under M.D.T. for about 5 years. It is not clear whether this fall was inclusive of the fall arising out of screening and rapid survey or exclusive of it. However, it may be concluded that prevalence rate is not a very satisfactory indicator for evaluating leprosy control activities since it is liable to be affected by many variables.

TABLE II. Data on Total Leprosy Cases, New Cases Detected, Cases Deleted, etc., in 4 Districts of Andhra Pradesh, (1982-85).

PARTICULARS	DISTRICTS															
	E. GODAVARI				W. GODAVARI				KRISHNA				CUDDAPAH			
	1982	1983	1984	1985	1982	1983	1984	1985	1982	1983	1984	1985	1982	1983	1984	1985
1. No. of cases at the beginning of the year	41944	43446	42997	41692	22834	23845	24440	24295	22648	24288	25779	25443	21522	23720	25255	26608
2. New cases detected	5310	5300	5338	5362	3722	3374	3421	3720	4400	4252	4206	4116	4554	3303	3418	4177
3. Cases deleted	3808	5749	6643	7619	2711	2779	3561	4442	2759	2762	4541	3782	2346	1778	2065	3110
4. Cases deleted as released from control	474	627	3942	3726	941	1444	1811	2345	1252	1471	2171	1483	181	318	276	516
5. R.F.C. case proportion to total Regd. cases	1.13	1.44	9.17	8.91	4.12	3.99	7.45	9.65	5.52	6.06	8.42	5.83	3.97	1.31	1.09	1.94
6. Percentage fall/rise in prevalence rates	+2.64	—1.85	—3.79	—6.16	+3.59	+1.62	—1.36	—3.67	+6.31	+5.21	—2.12	0.00	+9.30	+5.49	+4.44	+1.64
7. N.C.D.R.	1.40	1.37	1.36	1.35	1.26	1.13	1.12	1.20	1.40	1.33	1.30	1.25	2.29	1.63	1.65	2.00

Note : Cases detected during the year were excluded for calculation of Item 5.
— : fall, + : rise, N.C.D.R. : Annual new cases detection rate per 1000 population.

CONCLUSIONS

1. Systematic medical screening of all registered leprosy cases, irrespective of whether MDT project is sanctioned to an area or not, if carried out on priority basis can save considerable manpower and finances and also make registered prevalence rates more realistic.

2. While evaluating the MDT programme with reference to fall in prevalence rates, one should remember and take into account the likely fall in prevalence rate arising out of screening and rapid survey. This is independent of the effects of MDT.

3. Wherever MDT projects are being implemented or planned to be implemented, the programme managers should expect to find a large number of registered cases waiting for deletion and R.F.C. and also a good number of new cases in the community awaiting detection. during the planning and preparatory phase.

ACKNOWLEDGEMENTS

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EDITORIAL

(The editorials are written by the Members of the Editorial Board or by guest writers. The editorials express the personal views of the writers).

LEPROSY CONTROL WITHIN URBAN PRIMARY HEALTH CARE

R. GANAPATI*

Leprosy is the same whether it is encountered in the rural or urban area. But the approach towards control of the disease in these two different situations warrants some differentiation. An urban area is a highly artificial situation where a large number of human beings have learnt to live together in close proximity to meet their needs. Urbanization brings together, among others, patients suffering from leprosy and it is noticed that the health services needed to combat leprosy are inadequate unlike some of the other facilities. Studies in the field of leprosy and field research for its control have in the past been confined to those carried out under rural set-ups. It is only since the early 1970s that urban ecology and living patterns in relation to the spread of leprosy have received serious attention.

The earliest references one gets from the literature on the subject of urban leprosy are the recommendations of the WHO Fifth Expert Committee on Leprosy (1976) as well as the panel on leprosy control at the Tenth International Leprosy Congress, Bergen, (1973) which stated that research studies should be undertaken regarding the methodology to be applied in urban leprosy control. Since then considerable amount of leprosy control work has been carried out in many major cities located in endemic areas, but reports of systematic field studies have been scarce in the scientific literature with a few exceptions such as those from the city of Bombay.

More recently, "Leprosy control in urban community" was the special topic for the Fifth International Workshop on Leprosy Control in Asia arranged in Singapore in 1983 by the Sasakawa Memorial Health Foundation together with the Ministry of Health of Singapore and the Singapore Leprosy Relief Association in collaboration with the WHO. The Report of the WHO Expert Committee on Leprosy (1988) has made a more detailed reference to the problem of urban leprosy and it is gratifying to note that the recent WHO Guide to Leprosy Control (1988) has devoted a chapter to this important subject. A review of the subject in relation to the Indian context was made by Dharmendra and Ganapati

* Dr. R. Ganapati, Director, Bombay Leprosy Project, Vidnyan Bhavan, 11 V.N. Purav Marg, Sion-Chunabatti, Bombay - 400 022.

in 1983 and since then more and more information is becoming available on the extent of the problem in cities like Delhi, Bombay, Calcutta, Madras, Bangalore, etc. From Africa and South America, reports on urban leprosy are available for Dakar (Senegal), Bamako (Mali), Freetown (Sierra Leone), Georgetown (Guyana) and Sao Paulo and Rio de Janeiro (Brazil).

Transmission factors of special significance to urban environments

Certain special features of the transmission of leprosy need to be borne in mind in relation to the planning of urban control programmes and these have been summarized earlier (Ganapati, 1983). The enormous bacillary dissemination from nasal discharges, ulcerated nodules and even saliva of patients under conditions of overcrowding, with the possibility of survival of *M. leprae* in the environment, provide excellent opportunities for transmisstion of the disease. However, this may not be true for the risk associated with paucibacllary leprosy. The large number of multibacillary cases, particularly thosei not exposed to adequate chemotherapy, together with their distribution in urban communities calls for special studies in the various cities. While several rural programmes seem to be better off in this respect, information on urban reservoirs of infection, by and large, are still unclear. Still, some conclusions are available through limited studies made in this respect (Ganapati & Girija 1979; Revankar *et al.*, 1982; Ganapati *et al*, 1985), and it is hoped that further field investigations on reservoirs of infections in urban locations in various parts of the world will provide sufficient information to enable better global understanding of the problem.

Immunological studies have shown that infection with *M. leprae* is far more common than overt disease and that transmission takes place within a short time after initial exposure to the bacillus (WHO, 1988). There is also some evidence (Ganapati *et al*, 1986) that the urban pool of infection emanating from hyperendemic slums may lead to the spread of disease to far off places through migration. In view of the prolonged incubation period and chronicity of leprosy it is not easy to identify the sources of infection and exposure factors in such instances. It is worthwhile to recall the observation of Davey (1978) who stated "Considering the clinical and bacteriological data of a known untreated patient with early lepromatous leprosy in the setting of personal habits, social behaviour, insect transmsision and modern transport, it becomes possible to envisage an ordinary day in the life of this patient in which he becomes the source from which 100 people are infected with *M. leprae* up to a distance of 50 miles from his home. In one month this total becomes 3000 and if only 1% of them develop clinical leprosy, 30 cases of leprosy would result, of whom possibly three could be potentially lepromatous in type". This may be an overstatement of the case but it clearly brings out the nature of the problem. If such statements and experiences are really significant, there is a great need to study rural-urban migration patterns in different cities and for urban leprosy programmes to have better coordination with their rural counterparts.

The importance of bringing down the bacillary load resting in adult infectious cases living in urban communities as against the unjustified emphasis on repeated school surveys has also been brought out by well-planned field investigations (Ganapati *et al.*, 1977, Ganapati and Revankar, 1978). The exact place of repeated school surveys resorted to as an easy recourse to case detection in hyperendemic urban foci needs to be reviewed.

Case detection

Cost-effective methods of case detection, not based on whole population surveys, and specifically suitable for metropolitan areas have to be considered for urban programmes in the light of urban primary health care. There is enough evidence in the literature on the effectiveness of using health education and surveys of captive adult populations such as those in general hospitals and industries as techniques for case detection. Massive campaigns organized in collaboration with public services like city railway or bus service systems in populous cities like Bombay and Madras have registered a spurt in the voluntary registration of new cases. Novel methods of attracting suspicious cases for examination in crowded cities by using mobile exhibitions, have been tried (Ganapati *et al.*, 1987). Techniques using medical students for unearthing new cases in the community have also been reported by Bombay Leprosy Project (1988).

A method referred to as "passive surveillance" consisting of encouraging referrals of suspected cases by medical personnel working in out-patient departments of general hospitals is in vogue in some parts of India. Community health volunteers consisting of women from slum areas who receive small incentives have also been employed with advantage for case-detection in some situations. This procedure is believed to be more cost-effective than using salaried paramedical workers.

While the urban context is particularly suitable for adopting several such innovative techniques, it is very important to analyse how many of these techniques are actually employed in various cities for case detection. It would also be interesting to know from the concerned people about the problems met with in employing them in special urban locations.

Case holding and treatment delivery

Difficulties encountered in case holding are mainly related to the prolonged nature of treatment and patient mobility leading to a high proportion not completing the prescribed course of treatment. Lack of coordination among the different agencies leading to multiple registrations and the desire of patients, at least in some cities, to remain unknown are also real problems.

There has been no occasion to discuss case holding with Multi Drug Therapy (MDT) in an urban environment based on the experience so far gained. Since the advent of MDT, some of the problems met with during dapsone monotherapy era and in the early stages of introduction of MDT, have been overcome. As we are gaining more knowledge about the scientific basis and practice of short-term fixed-duration chemotherapy, the nature of case holding problems have changed and methods to overcome them are also likely to change. Therefore, those practising management of leprosy in urban locations should be quick to keep abreast of these changes. In fact, it is the experience of some that if treatment facilities are offered in an integrated manner in a general medical set-up instead of in a special centre for leprosy and if that is coupled with suitable motivational techniques at the time of initiation of MDT, case holding became easier. It is different during surveillance phase without chemotherapy when a proportion of patients have persisting clinical symptoms as well as sequelae and when patient motivation is not strong. This calls for a degree of coordination among leprosy control projects, whether rural or urban, and also among private practitioners who are involved in the treatment of leprosy in cities. It is in this context that running leprosy programmes in a vertical and isolated manner is harmful to leprosy control. Those responsible for leprosy control, particularly in urban areas, have a special responsibility to incorporate leprosy treatment into the structures offering general health services. Difficulties in achieving such integration in various cities need to be discussed at length.

The actual motivational techniques to ensure completion of treatment of supervised MDT administration are by now quite well-known. Logistic difficulties to trace residences of multibacillary patients living in slums pose a problem. It has been suggested that a spot map indicating the location of each patient be attached to case records as soon as a patient is registered so that by using these maps anyone can locate the patient's home.

The concept of "care after cure", gaining currency with the increasing number of patients completing MDT, could also be practised in an integrated manner, though admittedly it is relatively more difficult. While it may be difficult to offer ulcer dressing facilities in the surgical department of a general hospital or physiotherapy to a disabled leprosy patient in a hospital out-patients section, attempts could be made in these directions to adopt innovative methods most suitable to overcome local problems. Whenever such an approach is followed, case-holding of even deformed subjects appears to be possible in an integrated way.

If urban programmes are lucky to function in the vicinity of hospitals with trained surgeons, they should attempt to get the reconstructive surgery for leprosy patients done in such centres, instead of referring patients to far off rural leprosy hospitals. This, however, may be possible only in some cities at present.

While treatment delivery of patients living in slums may be effected in small dispensaries offering primary health care services as part of municipal health services, it is more challenging to offer such help to inmates of self-settled leprosy colonies commonly found in some metropolitan areas. Some degree of successful case holding is possible even in such situations through the use of motivated volunteers like university students (Ganapati *et al.*, 1984). Whether such field experiences are replicable under different situations is not very clear. Unless more urban programmes offer scientifically planned integrated services, urban leprosy work will be confined to just sympathy and charity from some motivated social workers, philanthropists or service clubs. The very existence of self-settled leprosy colonies located in proximity to some cities, and exclusive leprosy services propagated by well-meaning citizens, are serious deterrents for educating the patients and the public on the positive aspects of integrated leprosy work.

Health education

The advantages of health education at the community level as well as through mass campaigns in augmenting both case detection and case holding have been referred to earlier. It must be reiterated that the very magnitude, complexity and stratification of urban society offers enormous scope for the application of a variety of health education tools, to lead to total acceptance of leprosy patients in the not too distant future. The enlightenment of urban folk on health aspects may also have an overflow effect on rural populations. This function of an urban leprosy programme cannot be overstressed.

The phenomenon of non-acceptance of leprosy patients in general medical facilities has been commented upon in almost every forum discussing leprosy. As medical institutions and universities are often found in clusters in metropolitan areas, leprosy programmes functioning in such situations have the added responsibility of establishing rapport with this sector which consists of nurses, medical students, postgraduates and teachers. With necessary resources made available, it should be possible to provide guidance to medical students, arrange for competitive examinations, provide relevant literature and encourage students to participate in leprosy surveys, etc. Competent personnel should participate in the teaching of leprosy in medical schools and should interact with other teaching staff of medical institutions. In such instances, audio-visual aids are likely to be of great use. Fortunately, in the field of leprosy such material is available, and leprosy programmes in the neighbourhood of such institutions could use this to their advantage.

Training

The recent report of the Expert Committee on the involvement of primary health care in leprosy in India has laid great stress on the need for preparatory "job oriented brief training of all categories of primary health centre staff" before assigning them the tasks pertaining to leprosy. While this Committee had essentially a rural scenario in view, the situation regarding training of personnel engaged in urban primary health care, such as those manning city dispensaries and hospitals, is the same. Leprosy programmes functioning in such locations should equip themselves suitably to offer such training. Training does not necessarily imply elaborate classrooms or fancy equipment or even highly qualified staff. Simple field techniques such as case detection through surveys, skin smear examination, supervised administration of MDT, health education, and elementary disability care can be demonstrated by experienced leprosy paramedical workers. As medical colleges are gradually showing an inclination to get involved in community health strategies to overcome health problems, a medical student of today, at least in some situations, is not averse to learning about leprosy from health auxilliaries.

Co-ordination

In many large cities multiple voluntary agencies, international as well as national, are operating field programmes adopting well-defined areas for their leprosy control work. Local government or city corporation units may also be functioning in the same areas. It is essential that the

various units should co-ordinate their activities periodically in order to avoid duplication of work. Occasionally an attitude of ego on the part of some programme managers is noticeable which will need to be subdued in the larger interest of patient services. Coordination meetings should help to resolve any conflicting issues among units.

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CULTIVATION IN VITRO OF ACID-FAST NOCARDIOFORM CHEMOAUTOTROPHIC BACTERIA FROM MOUSE FOOT-PADS INFECTED WITH HUMAN STRAINS OF LEPROSY BACILLUS

A.N. CHAKRABARTY[1], S. G. DASTIDAR[2], S. DAS[3] AND A.K. CHANDRA[4]

Four acid-fast nocardioform bacteria could be isolated and cultivated as pure cultures in vitro *from mouse foot-pads (MFP), which were infected with serially passaged strains of human leprosy bacillus; the liquid mineral medium, such as paraffin urea minimal (PUM), paraffin gelatin minimal (PGM), gelatin minimal (GM), and GM agar (GMA) slants containing only simple sources of C and N were used, just like the human and the armadillo isolates of these organisms reported earlier. Morphologically, metabolically and enzymologically, these were closely related to the previous ones and were also chemoautotrophic in nature. Serologically there appears to be a heterogenicity in these isolates, i.e., some of them showing higher affinity to nocardio forms while others showing significant binding to several mycobacteria. Normal (uninfected) mouse foot-pad harvests were not found to harbour such organisms.*

INTRODUCTION

We had reported previously on the *in vitro* cultivation of a cluster of chemoautotrophic, nocardioform bacteria from human multibacillary cases of leprosy which could not be grown on any conventional media and that such organisms could not be recovered from non-leprosy cases (Chakrabarty *et al.*, 1986 a, 1986 b; 1987). Dastidar *et al.* (1987) reported further on the isolation in pure culture of a similar bacterium from the spleen tissue of an armadillo, experimentally infected with *M. leprae* (Kirchheimer

1. Dr. A.N. Chakrabarty, M.D., D.C.P., D. Bact. Professor, Deptt. of Medical Microbiology and Parasitology, Calcutta University College of Medicine, 244 B, Acharya J.C. Bose Road, Calcutta 700 020.

2. Dr. Sujata G. Dastidar, M.Sc., Ph.D., Professor, Division of Microbiology, Deptt. of Pharmacy, Jadavpur University, Calcutta 700 020.

3. Dr. S. Das, M.D., D.C.P., Research Associate (ICMR), Deptt. of Medical Microbiology and Parasitology, Calcutta University College of Medicine, 244 B, Acharya J.C. Bose Road, Calcutta 700 020.

4. Dr. A.K. Chandra, M.Sc., Ph.D., Research Associate (ICMR), Deptt. of Medical Microbiology and Parasitology, Calcutta University College of Medicine, 244 B, Acharya J.C. Bose Road, Calcutta 700 020.

Conclusions

The success of decision models as an aid in leprosy control cannot be guaranteed beforehand. But applied modelling could be important when addressing questions in prediction, planning, monitoring and evaluation. There are excellent control programmes with longitudinal data which could form the backbone for constructing validated simulation models. Those in charge of leprosy control programmes should seriously consider a collaboration with scientists and decision makers for jointly developing practical decision aids.[9,10,11]

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Figure 1. Model development (1) and application (2).

Lepr Rev (19--), **63**, Supplement, 53s–60s

Major issues involved in the evaluation of leprosy control programmes through MDT

C K RAO

Introduction

In the past 4–5 years countries where leprosy is endemic have increasingly adopted multidrug therapy (MDT) in the treatment of leprosy. The broad aim of MDT is to interrupt the transmission of infection through early case detection and regular and complete treatment, and also to prevent disabilities and deformities. Reports on effectiveness, safety and patient acceptability from countries implementing MDT have continued to be positive, and also show that MDT has increased community confidence in the curability of the disease, which promotes voluntary self-reporting of patients.

Planning and evaluation are managerial tools that contribute to the success of leprosy control programmes. Evaluation helps further prospective planning to be effective by identifying achievements or shortcomings and highlighting the points that could improve programme performance.

The implementation of MDT for leprosy cases demands a highly sensitive monitoring and evaluation system to ensure the programme's smooth and coordinated progress. The use of expensive and effective drugs under supervision for relatively long periods makes treatment monitoring a crucial component of the programme. The correct time of programme inputs, including drugs and educational material, is ensured through programme monitoring. Monitoring also helps in reshuffling priorities, dropping unproductive efforts and in indicating neglected areas.

In this paper evaluation has been taken to include both monitoring (day-to-day follow-up of activities) and evaluation. Monitoring is also referred to by some programme designers as internal evaluation and is often in-built in leprosy control programmes. Unlike monitoring, external evaluation is periodic and independent of the programme personnel, which ensures greater individuality and greater reliability of data reported.

My experience in planning and participating in the independent evaluation of leprosy programmes in India and Myanmar in recent years is the basis for delineating important issues involved in the evaluation exercise.

Issues

OBJECTIVES OF EVALUATION

The objectives of the programme may vary from country to country, depending upon the

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aims, strategies, infrastructure, and duration of the MDT operations, and may include some or all of the following:

—Assessment of case detection progress, case treatment, drug delivery and reasons for patient default.
—Validation of reported data through examination of records and field visits.
—Assessment of the ongoing information system in terms of its promptness and completeness.
—Ascertainment of the technical competence and devotion of the staff involved.
—Determination of the impact of health education, if any, in dispelling ignorance/prejudices in the community, in promoting regularity of treatment and in retrieving the defaulters.
—Examination of the impact of the measures on the disease.

KEY COMPONENTS IN MDT DELIVERY

Treatment delivery

MDT is delivered once a month by the health personnel at predetermined points near the patient's home or in health centres/dispensaries/out-patient departments of hospitals, either to all eligible patients or only to selected patients, as decided in a country's programme.

Case detection

This is achieved through the promotion of voluntary self-reporting of patients, through active surveys, or by both methods, envisaged under the programme chosen.

Patient card maintenance

This should indicate the clinical/bacteriological status before, during and after MDT.

Case treatment

It should be specified which MDT regimes are followed for multibacillary (MB) and paucibacillary (PB) cases, and the regularity of MDT and monitoring drug intake by patients under the programme.

Record maintenance

Data recording and reporting systems should be maintained at different levels and there should be officers responsible for this, and feedback should be given to the senior officers clarifying the strong and weak points in the reports.

Health education

This occupies a high priority in the success of MDT—though it is the responsibility of every health worker involved in the programme to educate the patients, their families and

the community, this may receive very little attention from most of them, especially in integrated programmes. Voluntary self-reporting of cases, a high compliance rate and a high rate of treatment completion reflect how effective the education component is in the community, considering patient awareness, patient participation and community acceptance.

Leprosy profile

General information on leprosy prevalence and other epidemiological indices in the area before and during MDT should be available.

Infrastructure

Enumerating general health services personnel and/or special leprosy workers involved/available for a leprosy programme and designating their job training status.

Voluntary organizations

These have to be active participants in monitoring and evaluation from the programme planning stage when working for leprosy control in a country

Monitoring methodology

The existing information recording and reporting procedures followed to monitor a leprosy control programme may vary from country to country. Most programmes that originated as strong vertical programmes continue to have a comprehensive reporting system compatible with/adopted from OMSLEP. Appropriately most integrated programmes have a simple and practical reporting system that include the core activities of case detection and case treatment as a part of health care reporting. The aim of leprosy information systems is to give timely though roughly correct figures rather than unduly precise but delayed data.

Sources of information

These should be leprosy patient cards and registers, leprosy survey data, surveillance information and supervisors' reports.

Training of monitoring personnel

All health workers responsible for monitoring data collection and for supervision should obtain their skills during job training for leprosy control.

Selection of indicators for monitoring leprosy programmes

These may vary from country to country based upon the programme aims, strategies and the infrastructure implementing it. The broad goals of MDT in leprosy control programmes should be to provide in full the course of MDT to leprosy cases, therefore

certain minimum indicators must be monitored. The following five indicators suggested to be 'required' at the WHO Consultation on Technical and Operational aspects of leprosy in Male, Maldives, in June 1990, are considered appropriate as minimum indicators: (i) prevalence; (ii) case detection; (iii) the proportion of patients with disability grade II among newly detected cases; (iv) MDT coverage, i.e. the proportion on MDT against all registered cases for chemotherapy; and (v) MDT completion, i.e. the proportion who have completed MDT among those put on MDT. Advanced programmes could develop additional indicators that were suggested in the report of the WHO Study Group on the Epidemiology of Leprosy in Relation to Control (TRS716). Operational criteria for definition of an active case for computing prevalence suggested by the Sixth Expert Committee on Leprosy (TRS768) would be appropriate to ensure uniformity, to define the targets for MDT and to determine the disease trends following MDT programmes.

Supervision

This is central to monitoring. Supervision ranges from validation of disease diagnosis, classification, activity, treatment delivery, treatment intake, detection and the management of reactions, skin-smear results and also logistics—delivery of drugs and transport. Part-time or full-time supervisors at different levels are identified and trained in the supervisory skills and techniques of leprosy control programmes.

Feedback on reports

Regular feedback from supervisors on their observations concerning both strong and weak points of the programme and comments on reports to lower reporting echelons, though not involved in decision-making, improves the programme performance.

STRENGTHENING MONITORING SYSTEM

An in-built monitoring system is often subjected to decay, and becomes less effective with time. However, the decay could be minimized and delayed by the periodic training of workers in skills to review critically the data and initiate corrective actions, maintenance of patient cards, encourage effective supervision, a periodic programme review of different levels by the highest administrative authority, listing priority indicators for monitoring, issuing a periodic news letter, maintenance and storage of records, etc.

The Indian programme appears to be unique in having a system of internal evaluation of leprosy programmes by creating regular assessment teams supported by the central programme at the state level and hiring full-time/part-time consultants supported by the WHO at national level. Though a formal review of their contributions has not been done, it is considered that they help to improve the quality of reported data, as well as tackling the operational/administrative problems in time. The programme is considering ways and means of keeping internal evaluators on a continuous basis.

EXTERNAL EVALUATION

The existence of a leprosy information system is basic to evaluation and monitoring. As

mentioned earlier, an evaluation undertaken by an expert who is independent of the programme planning and implementation, ensures lesser individual bias and a greater reliability of data.

Objectives

The objectives of evaluation listed above are perhaps relevant for external evaluation as well as with varying priorities. Broad objectives of evaluation are two-fold: one is determination of operational efficiency, i.e. to examine if what was planned or expected was in fact carried out, and the other is the determination of the impact of the control measures on the selected indices, i.e. whether what was expected in terms of selected indices did actually happen.

Collateral benefits

An element of healthy competition among the staff, especially middle-level managers, raises the morale of the peripheral staff, motivating health administrators, health planners and politicians for their increased support. Through their active participation it educates the administrative medical officers at state/division level on the strengths and weaknesses of the programme in their area *vis-à-vis* at the national level.

Sources of data

Records and reports maintained at all (peripheral to national) levels on the programme activities to delineate the leprosy profile.

Annual reports of the programme for the last 2–3 years.

Monthly/quarterly reports, if any, for the current year and previous year.

Leprosy patient data/cards maintained at villages/health centres.

Data obtained from discussions with programme managers – national, provincial, divisional, township/regency/district levels.

Interviews with health workers, supervisors, leprosy patients and community members.

Questionnaires for data collection

Appropriate questionnaires are constructed and pretested by the country programme manager taking account of the terms of reference for independent evaluation and the time available for evaluation. The questionnaires are used for interviewing programme managers, medical officers, supervisors and health workers involved in leprosy control at different levels to determine their competence and contribution. Questionnaires are also used for interrogation of leprosy patients and community members to determine the level of their awareness, participation in the programme activities, perception on social aspects of leprosy, etc. Questionnaires are also developed to collect appropriate data on leprosy control programmes at different levels. About 14 or 15 questionnaires were used in the three Indian programme evaluations and 7 in the Myanmar programme evaluation. Questionnaires to ascertain the leprosy profile from the states in India and divisions in Myanmar were sent to all concerned with the central programme 2 weeks before the

proposed field visits with a request to place the data at the disposal of the evaluators, should they visit that particular state/division. This ensured a timely submission of data and self-review of the data in the states/divisions irrespective of the actual visit of evaluators.

Sample selection

Effective evaluation, unlike monitoring, can only be carried out in a small sample because of time and funding constraints. Samples for field visits were selected by a WHO consultant independent of the programme managers both in India and Myanmar. Random samples of states and then districts were selected in India to ensure wide coverage of the country after stratification by levels of leprosy endemicity, varying organizational infrastructure and duration of MDT activities in force. A total of 10 multibacillary (MB) and 10 paucibacillary (PB) patients and 20 community members in 2 villages selected by the evaluators were interrogated in each of the districts assigned for evaluation in India.

In Myanmar 5 MB and 5 PB patients were chosen to be interviewed in 2 villages in each township selected for evaluation. Voluntary organizations involved in leprosy control efforts in the districts selected for evaluation were also included for evaluation of the Indian programme. No voluntary organization was involved in leprosy control work in the townships selected for evaluation in Myanmar.

Selection of evaluators

In India teams of 3 experts each have helped to improve competent evaluation of programme management (by a health administrator), impact assessment (by an epidemiologist), and validation of reported data (by a leprologist) besides giving other administrative and operational advantages of a team approach. In India 9–12 teams were formed for the three evaluations of the programme in 1986, 1987 and 1989. As mentioned above, each team had the services of a leprologist/leprosy control expert provided by the WHO from outside India. National evaluators were drawn from directors of health services of states or the equivalent, professors of community health or the equivalent and similar experts working with voluntary organizations whose involvement motivated them to support the programme.

In Myanmar, regional leprosy officers from outside their divisions were involved as evaluators along with a WHO consultant, the latter having selected the divisions and townships on a random sampling basis, and 2 teams of 3 experts were formed.

Should in-depth evaluation of some areas or some component of the programme be considered necessary, suitable experts as evaluators have to be recruited.

It is necessary to ensure that the evaluators are adequately briefed at the start of the evaluation so that they are able to fill the questionnaires and collect the requisite data correctly and uniformly. Briefing was given for 2 days both in the Indian and the Myanmar evaluations.

Duration of evaluation

It is convenient to complete the evaluation—travel, briefing and report—in 10–15 days.

With appropriate planning and preparation this period was found to be satisfactory. Disruption of routine programme activities are marginal in brief evaluations. When a smaller number of evaluators/teams are available, evaluation has to be prolonged over a relatively longer period. The Indian and Myanmar programme evaluations were all completed within 15 days. Funds for these evaluations were available from their respective WHO country budgets.

Collection of data

Appropriate data are collected by the evaluators from the reports using the assigned terms of reference. Information on the infrastructure availability against the sanctioned strength, training status of personnel, leprosy prevalence, case detection, case treatment, MDT coverage, MDT completion, health educational activities and their impact, quality of laboratory services, quality of supervision, supply of drugs, mobility, etc. are collected by the evaluators on a sample basis. Evaluators also validate a small sample of reported data on diagnosis, classification, treatment schedules, regularity of drug delivery and drug intake, disease activity, skin-smear results, etc. and record the data on the appropriate questionnaires.

Analysis and interpretation of data

Evaluators are expected to present orally their findings to the senior health officer of the state/division at the end of the visit. Hence data collected will have to be analysed before leaving the assigned states/divisions. It is a good strategy first to highlight the strengths of the programme, if any, before indicating the areas that need strengthening by the state/division health administration. On return to the central programme headquarters to report and deliver the duly completed questionnaires the points of view of the state/division, if any, have to be considered to see if it is necessary to relay them to national level. During oral presentation and debriefing the strengths found are to be projected while also suggesting areas that require urgent corrective action at all levels of the programme, including the central level.

Report and recommendations

Each evaluator team has to give a narrative report with the completed questionnaires using the terms of reference assigned for evaluation. Brief, lucid and timely reports including positive features of the programme are helpful to improve strengthen the programme performance. The evaluation reports have provided valuable support to the Indian programme—strengthening laboratory services; making possible the rapid extension of MDT to a large number of districts; the timely release of funds for health educational activities; giving priority to the filling of vacant posts; the training of personnel; and increasing the budget.

Actions taken on the report

The major aim of leprosy programme evaluation is to improve its performance. Evaluation guides in decision making. This purpose will not be achieved if the report is

unduly delayed or timely corrective actions are not initiated. Hence it is necessary to review the actions taken on the recommendations of earlier evaluation, if undertaken.

Conclusion

It may be stated that leprosy evaluation procedures followed in one country could be adopted in another country with only minor modifications, where warranted, to suit the local conditions.

Lepr Rev (19..)3, Supplement, 61s–65s

Defining a case of leprosy

V K PANNIKAR

Introduction

In leprosy, as in many other diseases, there are situations where the definition of a 'case' is uncertain. Some diseases can be diagnosed with certainty at autopsy only, such as Alzheimer's disease, and hyaline membrane disease. For some other conditions, such as cervical dysplasia and the adult onset of diabetes, there is a continuum from normal to abnormal with no clear demarcation line between them.

A Dictionary of Epidemiology[1] defines a case as 'a person in the population or study group identified as having a particular disease, health disorder, or condition under investigation'.

There have been attempts to provide an operational definition by assigning levels of certainty to the diagnosis of a number of different diseases. The Expanded Programme for Immunization (EPI) has produced guidelines to grade various EPI diseases as 'suspect', 'probable' or 'certain'.[2] To formulate a definition of a 'case' that would cover all aspects of a disease would be difficult, since it would be voluminous and academic, and probably of very little practical value. The usefulness of a definition that is meant to serve as a basis for action—an operational definition—may be determined by its practical applicability, not by the degree of its completeness. An operational definition must be judged in the light of its stated purpose, and what is relevant is whether it contributes to meeting the agreed purpose, which is control of leprosy in the community. It is widely recognized that the diagnosis of leprosy is often difficult. It has even been said that the absence of a clearly-stated 'case' definition calls into question much of the leprosy literature in so far as it renders results incomparable and unreproducible. Newell[3] remarked that 'there is no definite, finite or absolute test, sign or finding which can be said to divide a person with leprosy infection or leprosy illness from the rest of the population'.

The disease

Leprosy is often defined as 'a chronic disease of man resulting from infection with *Mycobacterium leprae* and affecting primarily nerves, skin and mucosa of the upper respiratory tract'. In the absence of any reliable tools for detecting the subclinical stages of the infection process, the emphasis for diagnosis of the disease is on clinical manifestations. The most remarkable thing about leprosy is the enormously wide variation in the

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on the control measures (number of patients cured with MDT). The information generated by the system has to be carefully analysed for decision-making, and feedback information should be given to the users.

The quality of the surveillance system should be regularly assessed to ensure that it is based on a good understanding of the epidemiology of leprosy. The surveillance system should facilitate rapid action which in turn leads to a reduction in the prevalence and incidence of the disease.

Information collected routinely at the periphery is usually considered to be of poor quality and inadequate. However, this is often a misconception. Most leprosy control managers are aware of the fact that health workers in the field are faithfully collecting, recording and reporting the data. Unfortunately, this vast amount of painstakingly collected data is neither compiled nor analysed at the intermediate or central level. Moreover, whenever information is required, there is an attempt to conduct fresh surveys or demand the completion of new sets of forms. This has often resulted in an increase in the workload without any potential benefit to the programme. If we study carefully the available data, we can see that it is more than adequate and of a reasonably good quality. If the data are compiled properly and analysed they provide a very powerful tool for decision-making. Cohort analysis will be able to do this efficiently for the various needs of leprosy control, without overburdening the routine activities.

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Indicators for use in leprosy control programmes

MYO THET HTOON

The leprosy control measures currently being undertaken in almost all the control programmes in the world are based on the two main strategies of case-finding and treatment. These two measures have been the cornerstone of leprosy control activities since the era of chemotherapy with dapsone. Unless a major breakthrough occurs in the development of a vaccine, these two measures will be the main strategy used in the elimination of leprosy as a public health problem by the year 2000.

Most of the leprosy control programmes operating in endemic countries are to be monitored and evaluated using these two activities. Depending on the type of the health care delivery system and availability of resources, each country or even each region in a country have developed their own unique case-finding and treatment activities. Indicators to be used for either monitoring or evaluation are going to differ from programme to programme, depending upon the type of control programme (specialized vertical or integrated), nature of activities undertaken and the availability of resources.

Generally it is felt that as leprosy control measures are integrated into the primary health care services (which means that less specialized persons are to be used) the amount of data routinely to be collected needs to be reduced as well as simplified. Certain information that was routinely available during the years when leprosy control was a specialized service activity will no longer be routinely available. A trade-off between information that is thought to be essential and that which is not essential must be made. The operational and epidemiologic indicators to be used for the monitoring or evaluation of a leprosy control programme will also differ between that of a central or intermediate level programme manager and a peripheral programme manager. Some of the indicators intended for use by the peripheral programme managers may not be of use for the central planners.

Since the programme managers at the peripheral levels are the ones who are mainly involved in the day to day implementation of the case-finding and treatment activities it is important that a set of minimum indicators be identified which could be routinely collected and used by the personnel at the peripheral level. Indicators are to be divided into two categories. One set of indicators are intended for the peripheral programme managers and the second set for the central or intermediate level programme managers. Each set of indicators is then to be subdivided into operational and epidemiologic indicators.

The formula for the calculation of each indicator is as shown in the OMSLEP,

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Recording and Reporting Systems for Leprosy Patients, edition 3.[1] The list of indicators recommended for use in integrated leprosy control programmes is as follows.

REGISTERED PREVALENCE

The registered prevalence is a very useful indicator and has been used by almost all control programmes. It is also easy to calculate since almost all control programmes have the total number of registered cases. Usually the registered prevalence is calculated as a point prevalence. Since the treatment duration for paucibacillary (PB) patients is now much shorter under the MDT regimen, in programmes where MDT treatment activity is efficient the registered number of cases may be comprised of only multibacillary (MB) cases. If the true magnitude of the problem of leprosy in an area is to be estimated, the period prevalence may be more appropriate.

With the introduction of MDT in most control programmes the registered prevalence has drastically declined in a very short period and it may no longer reflect the true situation in areas where the detection rates do not approximate the incidence rate.

PROPORTION OF REGISTERED CASES AMONG ESTIMATED CASES

This is a very useful indicator for central or intermediate level programme managers, especially if one aims at cutting the transmission through MDT. As pointed out in the OMSLEP, the problem is finding the denominator for this indicator which is the total number of estimated leprosy cases. If future leprosy control programmes are to have a specific time frame target, this indicator will highlight the success of the control measures in an area. It is possible that an area may report a very low registered prevalence but the present registered caseload could be only a small fraction of the total estimated cases as a result of poor case-finding activities.

TOTAL NUMBER OF SCHOOLCHILDREN SCREENED FOR LEPROSY, SCHOOL DETECTION RATE, TOTAL CONTACTS EXAMINED, CONTACT DETECTION RATE, TOTAL POPULATION MASS SURVEYED, MASS SURVEY DETECTION RATE AND ACTIVE CASE-FINDING PROPORTION

The indicators concerned with the operational aspect of the active case-finding activity are the total numbers of schoolchildren screened for leprosy, the school detection rate, total contacts examined, the contact detection rate, the total population mass surveyed, the mass survey detection rate and the active case-finding proportion. In programmes where the registered cases are almost equal to the number of estimated cases or if the incidence of leprosy is too low the active case-finding measures may be very inefficient and costly. In such programmes these indicators need not be used on a routine basis. In programmes where the proportion of registered cases is still low compared to the estimated number of cases, these indicators are helpful in monitoring the operational aspect of the case-finding activities with the aim to increase them.

PROPORTION OF REGISTERED CASES ON MDT

This indicator is useful in monitoring the MDT coverage of an area. The proportion of registered cases on MDT will become obsolete as the MDT coverage expands in an area and reaches 100%. This indicator is useful during the transition period from dapsone monotherapy to MDT in assessing the operational coverage of MDT, especially in programmes introducing MDT on a phase-by-phase basis.

The numerator for this indicator is the total number of cases obtaining treatment during a given period. The denominator is the total number of cases registered for treatment in that specific area during the same period. This is a kind of period prevalence, where the total number of prevalence cases at the start of the period of reporting is added to the total number of cases that are newly treated during the same reporting period.

PROPORTION OF CASES ON REGULAR MDT

This indicator could be calculated for all cases on MDT or separately for PB and MB cases. Regularity of treatment is to be taken as those who receive at least two-thirds of the recommended number of MDT doses during the year as defined in OMSLEP. Though this information is important for assessing whether patients are receiving sufficient treatment, this information could not be collected routinely through monthly reports and should only be calculated on a yearly basis.

NEW CASE MB PROPORTION AND NEW CASE UNDER 14 YEARS PROPORTION

These two indicators are useful in assessing the transmission of the disease when incidence could not be calculated easily. As stated in OMSLEP, when the MB proportion stabilizes the detection rate approaches the incidence rates.

These two indicators could be influenced by the mode of case-finding activities conducted in a specific area. A programme which stresses school surveys will have a high proportion of new cases under 14 years of age. Programmes with only passive case-finding activity may be picking up relatively more MBs than PBs and so in such areas the new case MB proportion will be high.

Assuming that no drastic change in the mode of case-finding has occurred in the past, these two indicators are useful in assessing the transmission of the disease.

PROPORTION OF GRADE II DISABILITY AMONG NEW CASES

This indicator reflects the effectiveness of the case-finding activity. It is a good operational indicator, especially when used together with other case-finding indicators. Since the numerator of this indicator includes only visible disability (grade II) this indicator will approach zero as cases are being detected at an early stage as a result of a good case-finding programme.

TOTAL CASES COMPLETING MDT DURING THE YEAR

The total number of cases completing MDT during the year is to be used as a crude indicator to measure the efficiency of the MDT activity. This figure is easy to obtain and though it reflects MDT activities carried out in the past it nevertheless gives a rough estimate of the outcome of the MDT activity in an area. Assuming that the regularity of

Table 1. Indicators for use in control programmes

Indicators	Peripheral programme managers		Central/ intermediate programme managers	
	Op:	Epi:	Op:	Epi:
1 Registered leprosy prevalence	++	++	++	++
2 Proportion of registered cases among estimated cases	+		++	+
3 Total schoolchildren screened for leprosy	++		+	
4 School detection rate	++		+	
5 Total contacts screened	++		+	
6 Contact detection rate	++		+	
7 Total population mass surveyed	++		+	
8 Mass survey detection rate	++		+	
9 Active case-finding proportion among new cases	+		++	
10 Proportion of registered cases on MDT	+		+	
11 Proportion of cases on regular MDT during the calendar year	+		+	
12 New case MB (proportion)	+	+	+	++
13 New case under 14 years (proportion)	+	+	+	++
14 Proportion of grade II disability among new cases		+		++
15 Total cases completing MDT during the year	+		+	
16 Relapse rate (MDT)	+		+	

treatment has not changed during the period under study, it could be assumed that this indicator reflects the MDT activity carried out in the past.

RELAPSE RATE

The relapse rate to be estimated is based on the clinical relapses detected. As pointed out in the OMSLEP, the problem with this indicator lies in the validity of the denominator. The total accumulated discharged cases are difficult to review during a given year, especially in programmes where the on-going MDT caseload is still high. The majority of the relapses will be self-reported and the denominator will be made of all discharged cases. This makes the interpretation of the relapse rate a little difficult since a cohort analysis of the discharged cases will be impossible to calculate from routine data collection forms, especially in an integrated leprosy control programme. The programme managers will have to use this as a rough measure to assess the effectiveness of the MDT in an area.

Reference

[1] OMSLEP, *Recording and Reporting Systems for Leprosy Patients*, edition 3.

Lepr Rev (1992) Supplement, 77s–83s

OMSLEP as an evaluation tool

E DECLERCQ

If leprosy is to be controlled, those in charge of the programmes at the local, regional or global levels should be able:

—to check whether the control measures, that is the strategies and targets that have been planned, are effectively and efficiently implemented. This is the operational evaluation; and

—to evaluate whether the programme has reached its medium- or long-term objectives, that is the reduction of the problem in terms of the numbers of patients in need of the health services. That is the epidemiological evaluation.

The evaluation process should be based on the use of objective indicators. These indicators need also to be simple to allow health workers at all levels, even the most peripheral, to collect the data necessary to calculate them.

The need to use standardized indicators is evident at the national level. It is also advantageous at the regional or global level. For instance it would allow the epidemiological trend to be analysed in relation to the control strategies used locally.

From the start this has been the objective of the OMSLEP system in the recording and reporting of leprosy patients: to propose not only a set of standard indicators for the operational and epidemiological evaluation, but also a system for collecting the data necessary to calculate them.

When it was decided to create the system in 1976, the first step was to make a review of the information systems used in 78 leprosy control projects from 45 countries. This enabled a list to be drawn up of indicators whose value had been thoroughly reviewed by a group of experts. Then the data that needed to be collected were listed, and an individual patient form and two annual statistical forms designed. A booklet was published, explaining how to fill in the form, how to calculate the indicators, and how to interpret them.

From the start, the OMSLEP system was also designed to facilitate the transfer of data onto microcomputers.

In the years following its conception, a second edition of the booklet was published, with some minor modifications. In 1987 the third edition was published in order to adapt the system to evaluate MDT programmes, based on the list of 25 indicators recommended by a WHO Study Group in 1985. The design of the system remained basically unchanged, with an individual patient form, and two annual statistical forms:

—the individual patient form is a summary of the patient's clinical chart, which only takes into account the data necessary to calculate the indicators (Appendix 1);

—the detection form, which is a summary of the status at detection of all the patients

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disability still need to be developed and the approach adopted by the new International Classification of Impairments, Disability and Handicaps needs to be given consideration by those in the leprosy field. Measures of disability are important for evaluation of programmes, evaluation of treatments, to identify needs for patient education and for rehabilitation. Approaches to disability prevention need to be evaluated in terms of cost-effectiveness which take into account the natural progression of disability and must be based on controlled trials. Disability is the measure of progress in leprosy control which is relevant to the general public.

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Epidemiometric modelling in leprosy based on Indian data

M F LECHAT

Introduction

Today, I suppose, any moderately bright child who has had a minimal exposure to computers could programme an epidemiometric model on a rainy Sunday afternoon using existing softwares and a technologically basic machine, but the situation was quite different in the early 1970s when the leprosy epidemiometric model was first designed.

The problem addressed was clearly circumscribed. After 20 years of large scale, mass control campaigns based on dapsone monotherapy, leprosy had not been eradicated, and even worse, it was not known whether the disease was or was not on the decrease. International funding agencies such as UNICEF, nongovernmental organizations, as well as governments, all were getting tired of emphatic promises and overdue delays. There were talks of a vaccine which could revolutionize the control strategy.

The concerns at that time were: (1) was it reasonable to expect a decline of the leprosy problem in the next 20 years, using current control methods? How much of a decline? How long would this take? (2) Could some improvements in the implementation of control, such as earlier detection or better compliance, speed up the decline? (3) Could some radical changes in the strategy, such as old-fashioned isolation or futuristic vaccination, modify the prediction? In what direction, and by how much?

The model aimed at predicting the trends in incidence over 20 years by using the control methods of that day. It also attempted to simulate the trends which resulted from changes in the control parameters. The indicator used was incidence, i.e. the number of new cases per year in the population.

Structure

As a first step, the development of the model required the definition of a structure and the identification of the various population subgroups (stages) as well as the permitted transitions and their directions (Figure 1). The stages were:

healthy susceptible;
latent;
multibacillary patients, nontreated, treated for less than 1 year, treated for 1 year or more, dropped from treatment, discharged;
paucibacillary patients, with the same categorization as the multibacillary patients.

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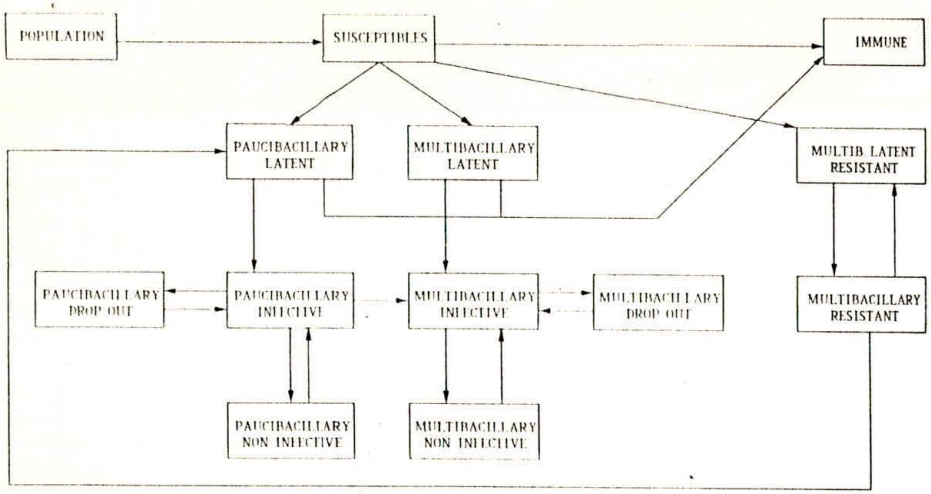

Figure 1. Model structure. Reproducted by kind permission of the *Bulletin de l'Organisation mondiale de la Santé*.[2]

For the sake of keeping it simple, the structure of the model is based on a number of epidemiological assumptions, such as no discharge without treatment, no reversal reaction, no extra-human reservoir, a constant age distribution of the population, and no migration out of or into the area.

The model is macroscopic and deterministic. It is macroscopic since it intends to describe the evolution of incidence and prevalence of the disease in the entire population, or in subpopulations, rather than in foci or at the individual level. It is deterministic because it only considers the prevalences and incidences as averages, and does not take their variability into account.

Estimation of parameters

The equation of the model was based on actual data. We were quite fortunate to have access to the files that had been assembled for nearly 16 years (1955–70) at the Leprosy Centre, Polambakkam, South India. They were allocated first by Dr F Hemerijckx, then by Dr C Vellut and their respective staffs, on 35,262 patients, representing 320,000 person-years of observation. These data had distinct characteristics.

1 They were population based, i.e. the whole population of 500 villages in a circumscribed area was regularly surveyed during the period.
2 No individuals from outside the area were included.
3 Detection was carried out in a standard way by personnel trained in the same manner over the whole period.
4 Treatment remained unchanged, based on dapsone monotherapy at a weekly dose.

It is possible that some occasional divergences from this ideal pattern occurred during the period. The consensus was that such divergences, which could not be controlled a

posteriori, were minimal. Data validation for various types of internal inconsistencies caused the rejection of less than 0·5%.

There were 28 parameters calculated from the observed data or estimated by a statistical approach. Those parameters calculated from observations were the annual population in each stage, the transition rates, the birth and death rates, and the respective proportion of multi- and paucibacillary patients.

To represent the transition from one stage to the next, 2 types of equation were used.

Equations of the first type were based on a negative exponential probability function of staying in the initial stage. They were in the form of a negative exponential. They were used to calculate the transitions from undetected cases to detected, treated to drop-out, drop-out to retreated. The second type included conditional probabilities of transition from 1 stage to another but no special function of duration in the initial stage was used.

A negative exponential function was also used to model the delay at detection. It was set up in such a way that 75% of the new patients could be detected after 1 year from the onset of the disease. To the best of the knowledge of the field staff this estimation was reasonable.

Two major parameters could not have been directly derived from actual observations and had to be estimated by a least-square method. They were (1) the latency period between infection and onset of disease for both multibacillary and paucibacillary patients, and (2) the specific infective power of these 2 patient types. The latency period was estimated to be shorter for multibacillary than for paucibacillary patients (respectively 2·4 and 4·0 years). These values are in clear contradiction to the periods calculated from a few actual observations in Louisiana and among US War Veterans. Estimation of the infective capacity by considering the type of leprosy yielded more consistent estimates. The risk of a person developing leprosy through contact with a multibacillary case is higher than through contact with a paucibacillary one. This agrees with the epidemiological studies of Doull.[1] However, due to the high proportion of paucibacillary patients among the diseased population, those patients constitute a nonnegligible source of infection.

Simulations

A number of simulations were carried out, either at the initial stage of the model, or later by changing some of the basic epidemiological assumptions.

Incidence depending on multibacillary or paucibacillary types of leprosy was predicted over a period of 20 years with ongoing control methods. The results indicated that with dapsone monotherapy a reduction of 50% incidence could be expected after 12 years (Figure 2). We believe this conclusion was important as it showed that control of leprosy requires perseverance, firm financial commitments, and unyielding efforts. Eradication cannot be achieved overnight.

Earlier detection, resulting in an increase to 90% from 75% of the annual input of new patients detected within 1 year of onset (assuming a negative exponential detection rate over time) does not significantly change the incidence in the long run (Figure 3). Intensifying case detection, a costly and fastidious method, had been repeatedly advocated as one of the more efficient ways to improve control. Long-term incidence is slightly more sensitive to the rate of compliance to treatment. After decreasing by 50% the

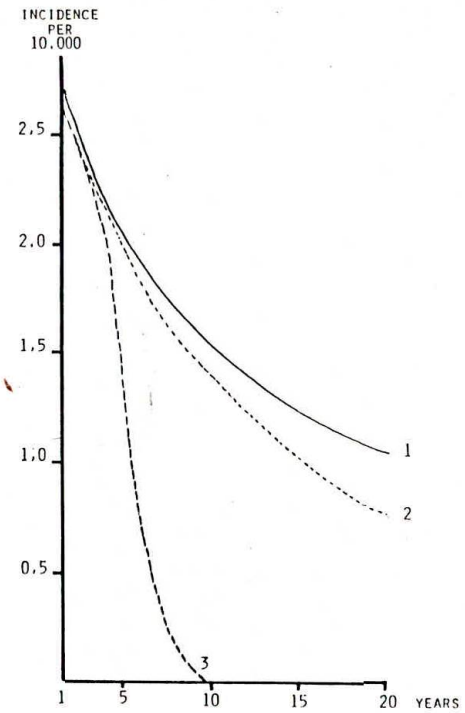

Figure 2. The incidence of 20 years:

(1) present control methods;
(2) reduction to 50% drop out; and
(3) vaccination of 100% of the population with immunoprophylactic vaccine.

annual proportion of patients who abandon treatment, incidence is reduced by 50% after 20 years (Figure 2). A cost-benefit analysis has shown that the latter method is much more advantageous than increased efforts to achieve earlier detection.

The effects of isolation were also simulated. This confirmed the largely held belief that the isolation method is futile in reducing long-term incidence (Figure 3).

The initial simulations suggested that vaccination was by far the most promising method (Figure 2). This conclusion is one of the major drawbacks of the exercise. It could have encouraged investing resources in a long-term research programme on the basis of a much too simplified model. Subsequent simulations draw a distinction between a prophylactic and a therapeutic vaccine and show that the effect of a vaccine preventing infection is delayed for several years. In the long run it is quite effective though slow for decreasing incidence (Figures 4 and 5). On the other hand, a vaccine active in preventing the appearance of leprosy in those individuals already infected has an immediate effect. It must be repeated at periodic intervals to catch those recently infected, which reduces its long-term effectiveness. In addition, the respective efficacy of using either one of these types of vaccines depends on the prevalence of infection in the population.

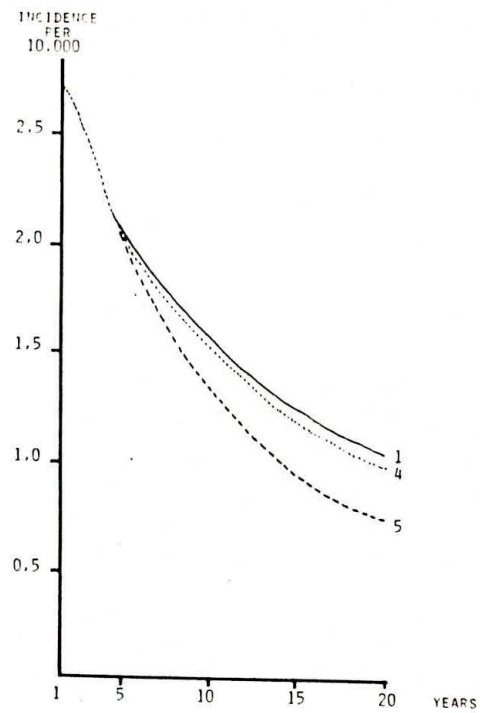

Figure 3. The incidence of 20 years:

(1) present control methods;
(4) 90% detection within one year of onset; and
(5) isolation of multibacillary cases at detection.

Simulation of various treatment regimens—dapsone monotherapy for all patients, multiple drug therapy (MDT) for all patients, MDT for multibacillary cases and dapsone therapy for the paucibacillary ones—showed that because of the ratio of multi- to paucibacillary patients which prevails in South India (about 13% of multibacillary cases), MDT treatment for all patients, including paucibacillary, is imperative (Figure 6). Restricting MDT to the multibacillary patients is of little or no avail (for the paucibacillary patients, in spite of their low infectivity, constitute a significant source of infection because of their large numbers). This introduces the paradox that if MDT is restricted to only one type of leprosy, in this model it is most effective when only applied to paucibacillary patients.

An obvious conclusion is that it would be incorrect to restrict treatment to the paucibacillary patients even when resources are scarce. This demonstrates the paradox of individual risk vs population risk.

Simulation of various *relapse rates* (10–100%) in multibacillary cases with various treatment regimens indicate that relapse with MDT is not a major problem (Figure 7). The declining trend of incidence slows down (with a 20% relapse rate) or is slightly

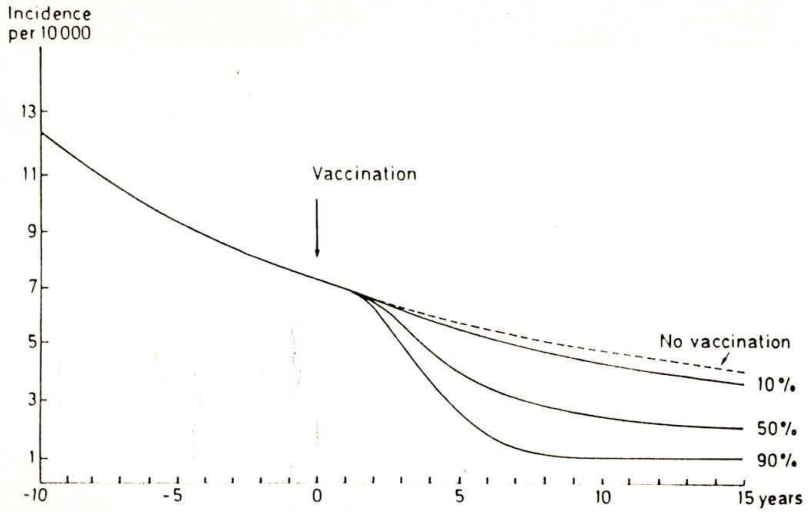

Figure 4. Prediction of incidence for both types of leprosy with an immunoprophylactic vaccine covering 10—50—90% of the population. Reproduced by kind permission of the *International Journal of Leprosy*.[3]

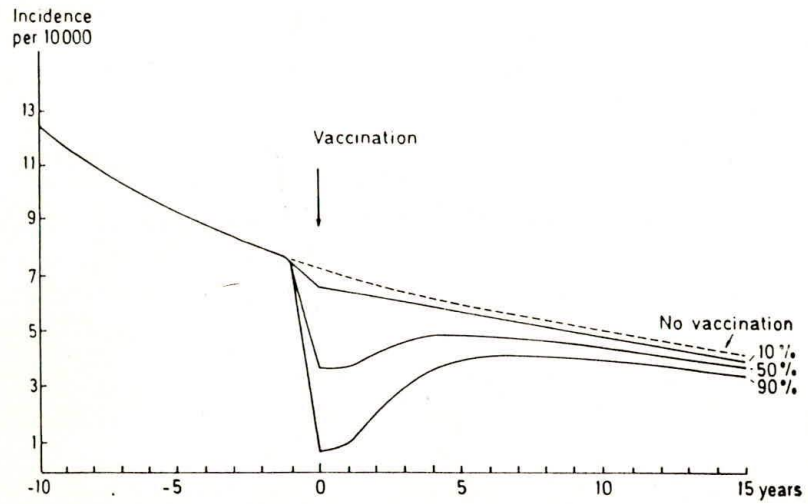

Figure 5. Prediction of incidence for both types of leprosy with an immunotherapeutic vaccine covering 10—50—90% of the population. Reproduced by kind permission of the *International Journal of Leprosy*.[3]

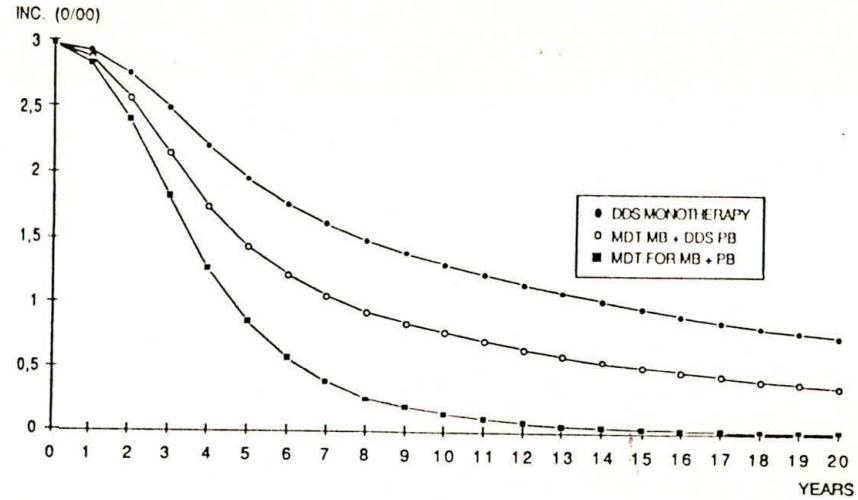

Figure 6. Computer simulation of incidence of leprosy with three different therapeutic regimens. Reproduced by kind permission of the *International Journal of Leprosy*.[4]

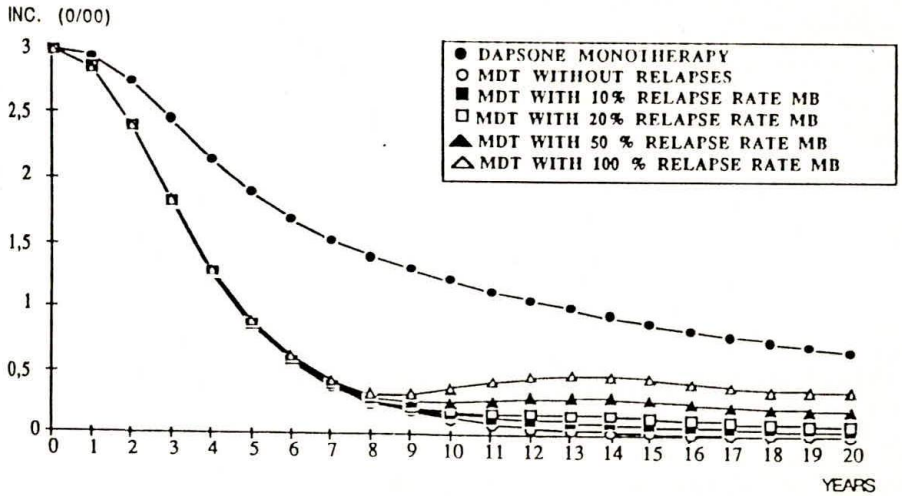

Figure 7. Computer simulation of incidence with dapsone and MDT with different relapse rates.

reversed for a period (with a 50–100% relapse rate) only after 8 years. These results are important in view of a popular claim that multibacillary patients under MDT should continue treatment after 2 years even when they become bacillary negative. Some say they should even be treated for life. As for control, relapses are not significant as long as they are detected early; in other terms, all treatment requires a close surveillance system.

Simulation of resistance required the introduction of new compartments in the model and an extension of 50 years (which probably has little justification due to the long-term

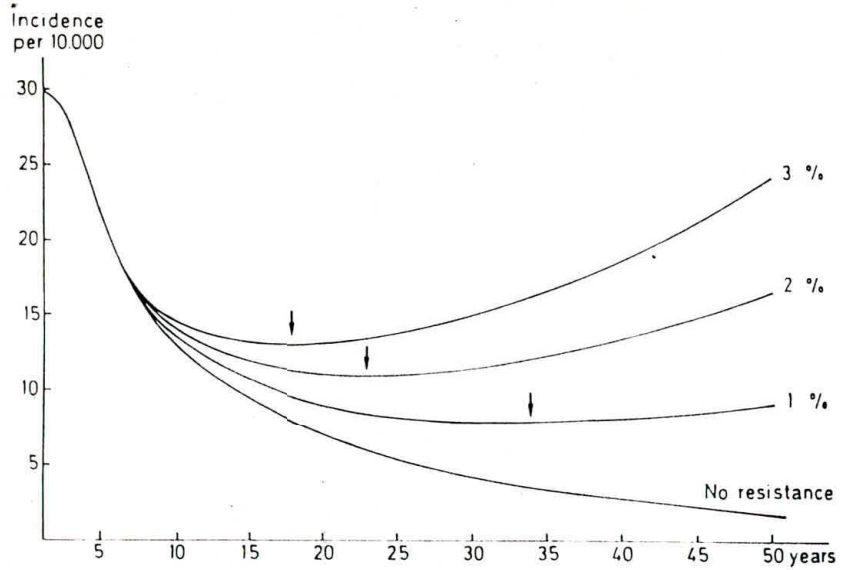

Figure 8. Prediction of incidence for both types of leprosy with 1—2—3% secondary drug resistance. Reproduced by kind permission of the *International Journal of Leprosy*.[3]

unpredictability) (Figure 8). In the observed conditions, secondary resistance constitutes a major problem. With a 3% annual incidence of secondary resistance, the declining trends in incidence slow down after 6 or 7 years and then begin rising at increasing speed after 15 years. These results are more forboding because no provision was made in the very simplified model for the contribution of subsequent cases with primary resistance to incidence in subsequent years.

Cost-benefit analysis can also be simulated by introducing various cost-parameters. Such econometric analysis should be subject to caution, for it is often difficult to calculate the various components of different control strategies. This approach is interesting to compare annual cost with long-term cumulative cost. Highly effective strategies are costly at the beginning, but may prove to achieve good long-term saving.

Conclusion

Overall, we must consider the possible uses and drawbacks of the model. It was developed in a specific area, South India, which presents its own special epidemiological contexts. Therefore it has clear limitations.

The resulting figures should be viewed with caution. The results are highly sensitive to a number of parameters, either directly observed or derived through statistical estimation. The model is based on a number of assumptions, not all verifiable and possibly too simplified. The quantitative results should not be generalized for use in other areas which might have different conditions of prevalence, incidence, multi/paucibacillary ratios,

birth and death rates. It is not certain that epidemiological data with an equal value to those collected in South India could be found in many places.

The model serves its own purpose and might not be best used when repeating the exercise exactly in different places. It acts as a type of grammar or structure. The model helps to clarify epidemiological concepts as exemplified by the existing differences between immunoprophylactic and immunotherapeutic vaccines or the epidemiological similarity of noncompliance and treatment-sensitive relapse albeit on different time scales. The model's most important purpose is to list the problems it tackles in the order of importance and make various comparisons. It could consider whether every patient should receive MDT, or only multibacillary patients; it could compare the relative insensitivity of incidence to early detection (despite the complete and early detection in the study area); or it could stress the importance of resistance in the long term as compared to nondrug resistant relapses.

Due to the present success of MDT-based control, this modelling approach in leprosy is no longer a part of basic research. The future belongs to microscale modelling for disappearing diseases. What can be expected in terms of limited foci, clusters, and erratic time fluctuations? This could be called, to use a fashionable new avenue of research, fractal epidemiology.

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[3] Lechat MF *et al.* Simulation of vaccination and resistance in leprosy using an epidemiometric model, *Int J Lepr*, 1985; **53:** 461–7.
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Chapter 1

INTRODUCTION

Magnitude of the leprosy problem in the world

It has been estimated that the number of leprosy cases in the world at 1965 was 10,786,000, of whom 3,872,000 had some disability (including anaesthesia). Sixty eight per cent of the registered cases and 18 per cent of the estimated cases were being treated.[1]

The number of estimated cases by continents was as follows: Africa 3,868,000, America 358,000, Asia 6,475,000, Europe 52,000 and Oceania 33,000. About 2,097 million people were estimated to be living in areas with prevalence rates of 0.5 per thousand or higher.[2]

Revised estimates from a number of larger countries indicate that the total cases throughout the world may well exceed 12 million.[3]

Problem in India

Leprosy is a major public health problem in India. It is estimated that there are 3.2 million leprosy cases in India. About 372 million population (1971 census) in 250 districts of 29 States/Union Territories live in the high and moderate endemic areas of leprosy.[4] Out of the 3.2 million estimated leprosy cases in India, about 25 per cent of the patients are of infectious nature and about 25 to 30 per cent suffer from deformities. About 4,00,000 patients are socio-economically dislocated and about 200,000 patients have become floating beggars. About 25 per cent of the leprosy cases are children

up to 14 years of age.[4] 2.4 million out of 3.2 million estimated cases were detected and 2.2 million cases were brought under treatment.

The state-wise distribution of cases according to the latest (1978)[5] estimates is indicated in Table 1. This shows that the Union Territories of Lakshadweep and Pondicherry are having the highest degree of leprosy. They have a prevalence rate of 31.3 and 40.3 per 1,000 respectively.

Among the states, Tamil Nadu has the highest prevalence rate of 19.0 per 1,000, followed by Andhra Pradesh and Orissa with a prevalence rate of 14.5 and 10.8 per 1,000 respectively.

Bihar, Karnataka, Maharashtra, Manipur, Meghalaya, Nagaland, Sikkim, Tripura, West Bengal, Andaman and Nicobar islands, Goa, Daman and Diu have a prevalence between 5 and 9.9 per 1,000.

Gujarat, Himachal Pradesh, Jammu and Kashmir, Kerala, Uttar Pradesh, Arunachal Pradesh, Dadra and Nagar Haveli and Mizoram have a prevalence rate ranging between 1 and 4.9 per 1,000.

Assam, Rajasthan, Delhi, Haryana, Madhya Pradesh, and Punjab have a prevalence rate of less than 1 per 1,000.

The state-wise prevalence is indicated in Map 1.

Problem in the State of Tamil Nadu

There are about 8,50,000 living cases of leprosy in Tamil Nadu out of which about 99,513 cases have been released from control. After taking away 85,864 cases having inactive disease, there are 665,000 cases in Tamil Nadu of which 557,000 are under treatment.[6] The district-wise prevalence of the disease in Tamil Nadu is indicated in Table 9. Of the 665,000 active cases, 17.9 per cent have got deformity. There are 7,500 beggars suffering from leprosy.

Problem in the Chingleput District

There are 80,528 known cases of leprosy in Chingleput

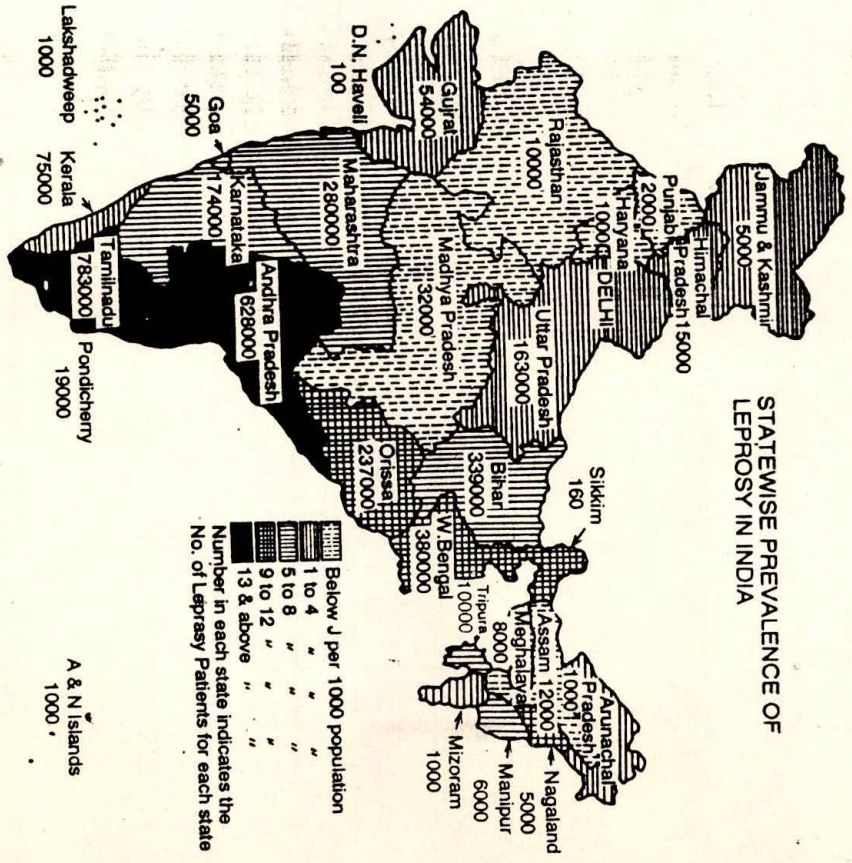
TABLE 1

PREVALENCE OF LEPROSY IN DIFFERENT STATES AND UNION TERRITORIES OF INDIA DURING 1978

State/Union Territory	*Population as per 1971 census (in lacs)*	*Estimated caseload projected on 1971 census (in lacs)*	*Prevalence rate of Leprosy per thousand*
1. Andhra Pradesh	435.0	6.3	14.5
2. Assam.	146.3	0.1	0.8
3. Bihar	563.5	3.4	6.0
4. Gujarat	267.0	0.5	2.0
5. Haryana	100.4	0.0	0.1
6. Himachal Pradesh	34.6	0.2	4.3
7. Jammu & Kashmir	46.2	0.7	1.1
8. Karnataka	293.0	1.7	5.9
9. Kerala	313.5	0.8	3.5
10. Madhya Pradesh	416.5	0.3	0.8
11. Maharashtra	504.1	2.8	5.6
12. Manipur	10.7	0.1	5.6
13. Meghalaya	10.1	0.1	5.9
14. Nagaland	5.2	0.1	9.7

15. Orissa	219.5	2.4	10.8
16. Punjab	135.5	0.0	0.2
17. Rajasthan	257.7	0.1	0.4
18. Sikkim	2.1	0.0	7.7
19. Tamil Nadu	412.0	7.8	19.0
20. Tripura	15.6	0.1	6.4
21. Uttar Pradesh	883.4	1.6	1.9
22. West Bengal	443.1	3.8	8.6
23. A & N Islands	1.2	0.0	8.7
24. Arunachal Pradesh	4.7	0.0	2.1
25. Chandigarh	2.6	-	-
26. D & N Haveli	0.7	0.0	1.4
27. Delhi	40.7	0.0	0.3
28. Goa Daman & Diu	8.6	0.1	5.8
29. Lakshadweep	0.3	0.0	31.3
30. Mizoram	3.3	0.0	3.0
31. Pondicherry	4.7	0.2	40.3
India	5481.6	32.5	5.9

Source: National Leprosy Control Programme - Annual Report 1978 Lep. section - DGHS (Mins. of H & F.W.) Govt. of India, Nirman Bhavan - pp. 1-44.



Map-1

STATEWISE PREVALENCE OF LEPROSY IN INDIA

district, of which 56,180 cases are active. Among these, 47,273 are under treatment. Of these 14.4 per cent have got visible deformities.[7] The magnitude of the problem in Chingleput district is indicated in Table 15.

Anti-Leprosy Work in India

In India, most ancient references to this disease are found in the medical works of Charaka, Sushruta and Vagbhatta.[8]

In the late Eighteenth and early Nineteenth century some beds were provided in contagious disease hospitals for cases of leprosy. Poor homes were established throughout the country. The establishment of the Indian Council of the British Empire Leprosy Relief Association in 1925 provided a fresh impetus to organised anti-leprosy work in India. As a result of the working of this Association, the knowledge regarding problem of leprosy in the country increased. By 1937, 32 institutions of mission to lepers were established having 8,000 inmates.

The attainment of independence in 1947 resulted in a fresh upsurge in national interests in the disease. This upsurge fortunately coincided with the introduction of new and potent drugs against the disease. The first official committee for assessing the leprosy problem was appointed in 1941 by the Central Board of Health.[9] The report submitted by them put the leprosy cases in India at 100,000.

LEPROSY CONTROL WORK DURING PLAN PERIODS

First and Second Five Year Plan Periods

During the First Five Year Plan a committee for the control of leprosy was formed by the Health Ministry of Government of India at the recommendation of the Central Council of Health.[10] That committee, based on limited sample surveys, estimated the total cases at 1,500,000. Prevalence of disease

was found to be high in Assam, Bihar, Madhya Pradesh, Madras (Tamil Nadu), Orissa, West Bengal, Travancore-Cochin, Hyderabad and pockets of Uttar Pradesh. The endemicity was moderate and low in other areas of the country. At that time in the whole country there were 152 leprosy homes and hospitals with about 19,600 beds and about 1,203 out-door clinics. About 100,000 to 200,000 cases (about 10 per cent of estimated cases) were taking treatment.[11] On this basis, on the recommendations of the committee, the Government of India launched what is now called the National Leprosy Control Programme (NLCP) in 1954-55. According to NLCP, cases were detected through house to house survey of population by physical examination. The treatment of the cases was in the form of oral administration of Dapsone.[11] These services were provided through a network of leprosy subsidiary centres. Each subsidiary centre covered a population of 60,000 to 80,000. Each subsidiary centre had two medical officers and four para-medical workers in addition to ancillary staff.[12] For the country as a whole, four Leprosy Treatment Study Centres were established to provide training for the staff of the NLCP and supervision to subsidiary centres. This strategy was continued during the Second Five Year Plan.

Third Five Year Plan Period

In 1963, a review by the Director, National Leprosy Control Programme revealed that 300 million out of 439 million (1961 census) population of the country were exposed to risk of infection with leprosy and that there were 2.5 million leprosy cases. The states in the country were grouped depending upon the estimated endemicity into high, moderate and low endemic zones. During this plan period, for population with endemicity of 10 or more per thousand, the leprosy subsidiary centres were reorganised and redesignated as

Leprosy Control Units and their coverage was increased to 1,50,000. Each unit was manned by one doctor and 11 para-medical workers and other ancillary staff. For a population with an endemicity between 5 and 10 per thousand, the concept of Survey Education and Treatment Centres (SET Centres) was introduced, to integrate leprosy work with various institutions providing general health services, like a Primary Health Centre or a dispensary or a hospital. An SET centre provides leprosy services to 20,000 to 25,000 population through a trained para-medical worker. For every 5 para-medical workers, one non-medical supervisor was appointed for supervision and guidance. One hundred and eighty one Leprosy Control Units, 774 SET Units, and 10 training centres were established during the Third Plan. There were 28,100 indoor beds for leprosy. There were 29 voluntary organisations doing leprosy control work.[12]

Fourth Five Year Plan Period

In the Fourth Plan Period the magnitude of the problem was reassessed. The population living in endemic districts was 372 million as per 1971 census. The estimated case load was 3.2 million.[13]

During this Plan, the National Leprosy Control Programme was categorised as a centrally sponsored scheme with 100 per cent grant-in-aid to the states for the expansion and implementation of the programme.

The population coverage by each control unit was increased to 300,000,with one medical officer, one non medical supervisor,15 para-medical workers and other ancillary staff.

The endemic population coverage up to the end of the Fourth Plan period was 131 million out of the estimated 372 million. The total number of control units by the end of Fourth Plan was 251 and the number of SET centres was 1,500. There were 13 training centres. There were 30 voluntary organisations doing leprosy work. The total indoor beds for leprosy were 28,300.[14]

Fifth Five Year Plan Period

Several new components were added to the scheme in addition to the control units, SET centres and Training centres. These were urban leprosy centres, temporary hospitalisation wards, reconstructive surgery units, district leprosy units and regional leprosy training-cum-referal institutions. At the end of Fifth Plan, the programme achieved a coverage of 320 million out of the estimated 370 million endemic population. 2.4 million out of 3.2 million estimated cases were detected. 2.2 million cases were brought under treatment. During this Plan about 0.6 million cases were discharged from the list as disease arrested and cured.[11]

382 control units, 6,595 SET centres, 430 urban leprosy centres, 71 reconstructive surgery units, 190 temporary hospitalisation wards, 106 district leprosy units and 41 training centres were functioning in the country by the end of Fifth Five Year Plan.[11]

During 1979-80 and 1980-81 some SET centres and leprosy control units with their workers merged into the Multipurpose Scheme. As a result, there was a setback to the programme and the tempo generated during the first three years of the Fifth Plan was lost.[11]

The number of institutions engaged in leprosy control work up to the end of Fifth Five Year Plan are indicated in Table 1(A).

Sixth Five Year Plan Period

The following targets have been laid down to be achieved by the end of Sixth Five Year Plan i.e., March 1985.[4]

TABLE 1A

Number of Leprosy Units and Institutions of any kind Established or Functioning upto the end of V Plan

Leprosy Homes and Hospitals	300
Leprosy Control Units	382
S E T Centre	6595
Urban Leprosy Centres	430
Reconstructive Surgery Units	71
District Leprosy Units	106
Leprosy Training Centres	42
Temporary Hospitalisation Wards	190 (20 beds each)
Regional Leprosy Institutes	2
Central Institutes for Research and Training	2
Voluntary Leprosy Organisations	35
International Agencies Engaged in Leprosy Work	8

Source: Report of the Working Group on the Eradication of Leprosy - Ministry of Health and Family Welfare - Government of India, New Delhi (1982).

(a) reduction of active prevalence rate by 50 per cent;
(b) reduction of infectious case-rate by 50 per cent (present rate 20 to 25 per cent);
(c) reduction of deformity rate of active cases by 50 per cent (present rate 20 to 25 per cent);
(d) correction of 50 per cent of correctible deformities;
(e) preparation for rehabilitation of 50 per cent of the socio-economically dislocated patients.

The following lines of action were prescribed to achieve the above objectives:

(1) early detection of cases;
(2) all detected patients to be brought under treatment;

(3) multi-drug therapy for all infectious cases, following pilot study in 15 hyper-endemic districts;
(4) establishment of regional training centres;
(5) establishment of 15 rehabilitation promotion units to act as epidemiological centres for rehabilitation to meet the minimum rehabilitation needs of the patients;
(6) special emphasis on research to produce a vaccine against leprosy;
(7) establishment of sample survey cum assessment units to define the magnitude of leprosy problem in uncovered areas and for assessment of the work of leprosy institutions;
(8) creation of epidemiological surveillance units for consolidation and intensification of work in hyper-endemic districts;
(9) creation of more leprosy beds both in governmental and voluntary sectors;
(10) emphasis on health education through pamphlets, posters, booklets, slides and short films and publicity of leprosy work;
(11) gradual integration of leprosy work in general health services starting with low-endemic areas;
(12) the Union Government to take responsibility for running regional leprosy training cum referal institutes, pilot projects for intensification of leprosy control work, epidemiological surveillance teams, leprosy rehabilitation promotion units and sample survey cum assessment units.

The physical targets laid down for the Sixth Five Year Plan are indicated in Table 1(B).

Funding: In the first three Five Year Plan periods the leprosy control programme was only centrally aided (partially centrally sponsored). From the Fourth Five Year Plan,

the programme is entirely centrally sponsored.

More Recent Developments

The Prime Minister while opening a three day joint conference of Central Council of Health and Family Welfare on 15th June, 1981, gave a call for eradication of leprosy by 2000 A.D. She had also made a reference to the programme of eradication of leprosy from India by the end of the century in her address to the World Health Assembly in May, 1981.[14] Following this directive, the Ministry of Health and Family Welfare, Government of India, constituted a working group for formulating an appropriate strategy for undertaking an eradication programme for leprosy control in the next twenty years with Dr. M.S. Swaminathan, Member, Planning Commission as Chairman. The committee has been requested to make a time-bound programme.[13]

TABLE 1B
Physical Targets for the Sixth Five Year Plan

Leprosy Control Units	15
S E T Centres	200
Urban Leprosy Centres	50
Reconstructive Surgery Units	10
Leprosy Training Centres	3
Leprosy Wards	50
District Leprosy Units	50
Regional Leprosy Institutes	6
Leprosy Survey Units	12
Leprosy Epidemiological Surveillance Teams	15
Leprosy Rehabilitation Promotion Units	15
District-wise Leprosy Pilot Projects for Intensification of Leprosy Control Programme	8

Source: Report of the Working Group on the Eradication of Leprosy - Ministry of Health and Family Welfare - Government of India, New Delhi (1982).

Again a sense of urgency for leprosy control was indicated by the Prime Minister when she received a group of eminent leprologists, social workers, administrators in the voluntary sector on 20th November, 1981. Leprosy has also been included as a part of the new 20-point programme announced by the Prime Minister on 14th January, 1982.[15]

Leprosy Control Work in Tamil Nadu

Prior to independence, leprosy control work in Tamil Nadu was mainly in the hands of voluntary organisations in places like Tirumani, Pollambakkam, Thirukoilur etc. Soon after independence the State Government created a state leprosy survey unit with one health officer, one health inspector and one health visitor (both of them trained in leprosy). The headquarters of this unit was at Vellore. One district unit was created at Thirukoilur. These units collected some particulars regarding the prevalence of the disease.[16]

During the First Five Year Plan one Leprosy Treatment and Study Unit was started as a pilot scheme for field study of leprosy control through chemotherapy, at Thirukoilur in South Arcot district which is one of the endemic districts in Tamil Nadu.[17]

During later phase of First Plan and Second Plan units subsidiary to the pilot project at Thirukoilur were started in some places and they were designated as Leprosy Subsidiary Centres. Thirteen such centres were started up to the end of Second Five Year Plan. A training centre was established at the Treatment and Study Centre in Thirukoilur. It gave training to 80 para medical workers (now called Leprosy Inspectors in Tamil Nadu) and the duration of training was 9 months.

In the Third Plan eight control units were established each with 11 para medical workers (Leprosy Inspectors). Six of the subsidiary centres were upgraded as control units to cover

wider area and larger population and each had 11 para medical workers (Leprosy Inspectors). Each upgraded subsidiary centre covered a population of 1,50,000. Seventy eight SET centres were established.

In the Fourth Plan, the number of para medical workers was increased to 15 and the population coverage was increased to 3,00,000. Each para medical worker was in charge of a sub-centre and covered a population of 20,000 to 25,000.

Forty four SET centres and 10 control units were added. In addition, 7 subsidiary centres established during Second Plan were upgraded as control units.

During the Fifth Plan, there were 20 para medical workers for a control unit and it covered a population of 4,00,000. Each para medical worker (Leprosy Inspector) was in-charge of a sub-centre. Each sub-centre served a population of 20,000 to 25,000. Twenty seven control units were added during this period. The area of each sub-centre of the control unit, which is under the charge of a Leprosy Inspector, has been divided into epidemiological survey areas and non-epidemiological survey areas. A group of villages yielding approximately 5,000 population has been demarcated as Epidemiological Survey areas, and the rest of the villages have been designated as non-epidemiological survey areas. In the epidemiological survey areas, a total population survey is done every year. In the non-epidemiological survey areas, a general population survey is conducted once in 3 or 4 years.

Urban leprosy centres were established with one Leprosy Inspector to cover an area of 80,000 population. In order to supervise the larger number of units created and also to intensify the health education programme posts of district leprosy officer and health educator were created. thirteen district leprosy officers wee sanctioned.

The growth of National Leprosy Control Programme in Tamil Nadu is shown in Table 2. Present position of number of centres for leprosy control work in Tamil Nadu is indicated in Table 34.

TABLE 2

LEPROSY CONTROL PROGRAMME DURING DIFFERENT PLAN PERIODS IN TAMIL NADU

Plan Period	Training Centres	Leprosy Subsidiary Centres	Leprosy Control Units	Upgraded Leprosy Control Units	SET Centres	Urban Leprosy Centres	Temporary Hospitalisation Wards	Reconstructive Surgery	Distt. Leprosy Officer
		-							
			11 15 20	11 15 11-20					
			LIS LIS LIS	LIS LIS LIS					
I	1	2	- - -	- - -	-	-	-	-	-
II	..	11	- - -	- - -	-	-	-	-	-
III	-	-	8 - -	6 - -	78	-	-	-	-
IV	-	-	- 10 -	- 7 -	44	-	-	-	-
V	-	-	- - 27	- - 12	10	48	25	9	12

Source: Office of the State Leprosy Officer - Directorate of Medical Services and Family Welfare, Tamil Nadu.

REVIEW OF LITERATURE

One of the significant features of the relevant literature is that there are virtually no studies available which give reasonably reliable dat on epidemiological, sociological, clinical and organisational aspects which can be used to formulate a nationally applicable, socially acceptable and epidemiologically effective leprosy programme for the country. This review has therefore to be confined only to studies which can at best be called adhoc studies because of their many methodological limitations.

EPIDEMIOLOGICAL STUDIES

Prevalence

Dharmendra (1945)[18] observed a variation in prevalence rate of 1.7 to 66 per 1000 in the different parts of India. He also (1963)[19] observed regional variations in both epidemiological and clinical manifestations. He described variations in type distributions, the prevalence rates, sex ratio and in age distribution in the different regions and in the same region for different races.

Mohammed Ali (1963)[20] gave a prevalence rate of 30.9 per 1,000 in Madras State based only on findings of leprosy control centres. In the same year Kapoor (1963)[21] worked out a prevalence rate of 8 per 1,000 for some areas in Maharashtra.

Specially for Chingleput district, Mohammed Ali (1963)[22] reported on a study of 213,721 population in 381 villages, a prevalence rate of 21 per 1,000.

Sharma (1969)[23] compared figures in 1937 and 1956 in a 10,000 population of Bengal and found almost no difference in the child prevalence, male and female prevalence between those two surveys.

In the North Arcot district, Karat *et al* (1967)[24] in a survey of 197,756 persons in Gudiyattam taluk observed a gross prevalence rate of 29 per 1,000. Ekambaram *et al* (1969)[25] described a fall in prevalence from 5.9 per cent to 4.5 per cent in a decade within a population of 6,000 in Thirukoilur taluk of South Arcot district. Wardekar R.V. (1969)[26] observed a reduction of 61.9 per cent in the 'incidence' of the disease. Noordeen (1972)[27] in a long term population study of 8,000 population in Chingleput district (population not precisely defined) worked out a mean prevalence rate of 60.3 per 1,000.

Age Distribution

In Mohammed Ali's study[22] of 1963, 68 per cent of all the patients were above 25 years. Eighteen per cent were below 15 years and 14 per cent were in 16 to 25 year age group.

Christian *et al* (1963)[28] in a study at Zaheerabad found 14.2 per cent being below 14 years, 4.6 per cent in 15 to 19 years, 7.1 per cent in 20 to 24 years, 10 per cent in 25 to 29 years, 21.8 per cent in 30 to 39 years, 20 per cent in 40 to 49 years and 22.3 per cent in 50 years and above.

Dutta Chowdhury (1965)[29] working in Bankura observed 23.0 per cent of cases occurring below 15 years and 77 per cent cases occurring above 15 years.

The percentage of children among leprosy patients was 13.5 per cent in Kapoor's study (1963)[21] and 17 per cent in Mohammed Ali's[22] study.

Age at Onset

Sehgal *et al* (1977)[30] reporting on a study of 1,053 patients in Goa found the onset of disease to be between the ages 20 and 39 years. Age at onset was lowest in non-lepromatous type and highest in neuritic type and in between in the lepromatous and border-line (N?L) types. His findings do not tally with the data on prevalence of leprosy among children in general and school children in particular given later in this chapter.

Type Distribution

Kapoor (1963)[21] worked out a lepromatous rate of 25 per cent. He observed lepromatous rate to be inversely proportional to the prevalence rate.

Mohammed Ali (1963)[22] calculated a lepromatous rate of 14.3 per cent, non-lepromatous rate of 84.5 per cent and non-lepromatous positive rate of 1.2 per cent in the Chingleput district.

Karat *et al* (1967)[24] in their study at Gudiyattam observed 50 per cent having tuberculoid, 20 per cent having lepromatous type, 20 per cent having indeterminate type and 10 per cent having border-line type.

Sex Ratio

Mohammed Ali (1963)[22] worked out the male and female sex ratio as 3:2; the rate given by Karat *et al* (1967)[24] was 3.2:2.4. Noordeen (1972)[27] gave a sex ratio of 2:1.

Deformity

Mohammed Ali (1963)[22] observed that 40 per cent of lepromatous type and 14 per cent of non-lepromatous type had deformities.

Dutta Chowdhury (1965)[29] observed a deformity rate of 43.5 per cent in lepromatous and 19.7 per cent in non-lepromatous cases.

Noordeen *et al* (1966)[31] in a total population of 200,000 in 300 villages analysed male patients above 15 years of age. Physical disability was found in 15.7 per cent, social disability was found in 1.9 per cent, combined physical and social disability was found in 17.8 per cent. Harijans showed a low disability rate. The disability rate increased with the duration of the disease. 13.5 per cent of patients changed or lost their occupation because of the disease. Disability was least in skilled light occupations and in agricultural work. Disability and worsening of economic status went together.

Srienivasan *et al* (1966)[32] observed that 19.7 per cent of deformities were claw hands. Absorption was present in 8.3 per cent. 15.7 per cent had ulcers. Foot drop was present in 0.9 per cent. Blindness was in 1.3 per cent. 57.8 per cent of lepromatous cases had hand deformities and 20.4 per cent of non-lepromatous cases had hand deformities. Deformities were more common in skilled heavy workers and weavers.

Noordeen *et al* (1969)[33] in a study at Sriperumbudur taluk of Chingleput district observed a deformity rate of 19.4 per cent. The deformity rate increased as the age increased. The mean duration of leprosy for the deformed was 8.1 years and for the non-deformed 5.4 years. Males had a deformity rate of 23.9 per cent and females had a rate of 11.0 per cent. Hand deformities were more common than foot deformities. Deformities involving multiple limbs were common than those involving one limb alone.

Hasan (1977)[34] in a study of 1,000 patients in Hyderabad city worked out deformity rate of 44.3 per cent. This high rate may be because of selective migration of patients with deformities from rural areas. 66.4 per cent of lepromatous cases had deformities. 29.1 per cent of hands, 30.7 per cent of feet and 5.2 per cent of faces had deformities.

Relapse

Vellut (1969)[35] in a 10 year follow up of 1,300 lepromatous cases under sulphone treatment at Pollambakkam gave a total relapse rate of 7.4 per cent among bacteriologically negative cases and a majority of relapses occurred within the first six years of bacteriological negativity.

Studies on contacts

Kapoor (1963)[21] found the prevalence among contacts to be 28.0 per cent.

Mohammed Ali (1963)[22] gave the infection rate among contacts as 17.0 per cent.

Noordeen (1964)[36] in a study of 579 multiple case families found 15.8 per cent of families having leprosy had more than one case. He also found the family size to be large in multiple case families. The average number of cases remained at 2.2 in all multiple case families irrespective of the size of the family.

Mohammed Ali (1965)[37] in a study of conjugal leprosy among 4,384 leprosy patients found 5.5 per cent spouses living with an affected partner had the disease. They estimated that this figure might actually be very low as some of the spouses could have contracted the disease prior to their marriage. Ninety of the 106 spouses developed the disease even though their spouses were not discharging bacilli.

Christian *et al* (1966)[38] in a study of 793 families observed the occurrence of the disease in grand and great grand children. They found that all persons exposed to the disease do not get infected due to variations in susceptibility. The decrease in the lepromatous rate in the third generation is attributed to the development of resistance in the affected families which is possibly inherited from their parents by this third generation.

Prasad *et al* (1966)[39] in a study of 579 families consisting of 3,382 individuals found 38.4 per cent of the exposed population had contracted the disease. They suggested genetic studies to find out the susceptibility among individuals.

Figueredo *et al* (1967)[40] studied 1264 family members from the records of the Acworth leprosy hospital in Bombay and found that 27.8 per cent of the contacts had developed the disease. He found no difference in the risk of infection for both sexes. Risk decreased with increasing duration of contact and with rising treatment status of infector. They explained the differences as probably being due to an immune mechanism.

Noordeen (1972)[27] in a study of 8,000 population in Chingleput district, estimated that cases among contacts form 12 per cent to 15 per cent of total leprosy problem.

Rao et al (1975)[41] reporting on a study of 23,285 contacts from 5,088 families, worked out a secondary attack rate of 6.8 per 1000 person years as compared to an annual incidence rate of 0.8 per 1000 in the total population. The secondary attack rate doubled when there were multiple index cases in the family.

Govila (1980)[42] in a study of 96 families at Gwalior observed more than one secondary case in 13.6 per cent of the families.

School survey

Selvapandian et al (1980)[43] in a study of 10,163 children in 53 schools of Kaniyambadi panchayat area in North Arcot district reported a prevalence of 13.5 per 1000 among school children. The prevalence figure rose to 38.6 per 1000 in the age-group of 13 years. Study of distribution of patches did not reveal any difference from covered and uncovered parts. Mani (1976)[44] reported findings at Madras in two consecutive school surveys at 2 year interval. The average prevalence among school children was found to be 11.3 per 1000. Thirty per cent of the cases detected were among already examined children. School surveys contributed 29.9 per cent of the total cases in their project area. Ganapathy *et al* (1976)[45] summarised their experiences in greater Bombay school survey. The prevalence rate among school children varied from 3 to 10.8 per 1000. Even school children coming from richer families had a prevalence of 6 per 1000. 24.7 per cent of the children had progressive form of disease. However, Koticha (1979)[46] reporting on a study of 415,497 children in Bombay schools found a prevalence rate of 4.8 per 1000. He found the disease to be more common among male students in the age group of 10 to 19 years. Sixty-one per cent of cases were single lesion cases mostly in the covered parts of the body. Sehgal *et al* (1977)[47] in their study of 8 schools at Panaji in Goa reported a prevalence of 5.3 per 1000. Majority had a single lesion at the exposed parts of the body.

Self healing leprosy

Ekambaram *et al* (1977)[48] in a study at the ELEP leprosy control project at Dharampuri studied 432 untreated children after 6 year period. 72.9 per cent of the cases became self healed and 20.8 per cent have remained stationary. Only 6.3 per cent have become worse. Ramanujam (1979)[49] in a study of 690 untreated children at Saidapet, found 88.7 per cent of tuberculoid major cases showing spontaneous healing.

These findings are of considerable importance in dealing with the problem of leprosy in India.

Social Aspects

Social aspects of leprosy have not been studied very systematically. Different scholars like Selvapandian A.J. *et al* (1972)[50], Damle (1972)[51], Dwivedi (1974)[52], Ramu et al (1975)[53], Christine M.E. et al (1978)[54], have studied only a few social aspects. The studies have been carried out in different parts of the country and so they are not comparable. Finally the designs of the studies in terms of the study population, research tools and the process of data collection also showed not only wide variations but also considerable limitations in each of the studies.

Assessment of the Leprosy Control Programme

It has to be recognised that the National Leprosy Control Programme is in the form of a complex system. This system consists of a large number of components which are in complex interaction with one another. The epidemiological characteristics of the disease, the social, cultural, economic and geographical background of the population, the nature of technology adopted for diagnosis and treatment of leprosy patients within the population, the organisational structure and various logistical considerations are examples of some of the major components which give shape to the complex

interacting system of the National Leprosy Control Programme. The Leprosy Programme has thus to be assessed while considering all its major components in all their complex interactions. A review of the literature reveals that virtually no efforts has thus far been made to study the programme in its complex multi-disciplinary dimensions.

Indeed in 1969 the Director General of Health Services, Government of India requested the Director General of Indian Council of Medical Research to undertake the assessment of the National Leprosy Control Programme in operation in the country. A committee was appointed to advise the council to define the methodology of assessment for leprosy control centres. The deliberations of the committee were published as a report on "Methodology and measurements for assessment of leprosy control work in India" by the Indian Council of Medical Research.[55]

The scientific working group constituted by the Indian Council of Medical Research have recommended three types of assessments viz. (a) operational assessment, (b) assessment of effect on patients and (c) assessment to determine the trend of leprosy in the area (Wardekar 1979)[56].

In 1974 the Indian Council of Medical Research appointed Dr. R.V. Wardekar and Dr. M. Christian as Project Officers for assessment of the National Leprosy Control Programme, at Vairag leprosy control unit (Sholapur district, Maharashtra State) and at government leprosy treatment and study centre, Thirukoilur (South Arcot district, Tamil Nadu) respectively. Each of the officers-in-charge had a medical officer, para medical workers and some ancillary staff to assist them. The methodology pursued at both places was to peruse records maintained at the respective unit headquarters and collect statistical information. It is important to note that no field work was conducted. Obviously these data are not uniform in terms of statistical reliability and validity. Information regarding various aspects was collected at both the centres from

1955 to 1974, by dividing them into 4 or 5 cohorts. In the Vairag centre between 1955 and 1964 data was collected from 22 villages. From 1965 and 1973 it covered data from 42 villages, and for the year 1974 data of only 17 villages were included.

In the Thirukoilur study[55] an attempt has been made to study the locational facilities at the headquarters. Though passing references were made to the records maintained by the leprosy inspectors (then called para medical workers) no efforts was made to talk to individual workers and assess their performance.

Though the assessment at Thirukoilur was expected to cover operational and epidemiological aspects, excepting a mention of the inadequacy of facilities at the organisational level, the whole study was devoted to evaluating the time-differences in various epidemiological parameters based on the information culled out from the records of the centres. No attempt was made to interview the patients or the community to assess the impact of the programme.

The Summary of the Findings of the Thirukoilur Study are:

Active case finding by general survey and healthy contact survey was 67.0 per cent in 1965-74 as compared to 75.0 per cent in 1958-64. In the earlier years 80.0 per cent of the villages had 90.0 per cent population coverage by surveys, whereas in 1970-73 only 26.0 per cent of the villages had 90.0 per cent population coverage. Eighty nine per cent of all adult contacts were covered in 1957 as compared to 33.0 per cent coverage in 1974. Coverage of child contacts up to 1957 was 88.0 per cent as against 38.0 per cent in 1974. The healthy contact coverage was poor in distant villages when compared to proximal villages.

Almost every component of the organisation was in a bad shape. This included correction of deformities, facilities for dispensing of drugs and for dressing of ulcers, laboratory and

physiotherapy services, transportation, health education and case holding activities.

The following epidemiological information was obtained in the study: The prevalence in 1955-57 was 62.7. In 1967-73 it was 43.1. Prevalence of lepromatous type was 11.7 in 1955-57 as compared to 5.1 in 1967-73. Non-lepromatous type prevalence was 48.7 in 1955-57 as against 35.6 in 1967-73. Borderline type prevalence varied between 2.3 and 2.1. Male-female ratio was 1.6:1 in 1955-57 and 1.3:1 in 1970-74. Child rate was 28.0 per cent in 1955-57. This increased to 47.0 per cent in 1970-74. Lepromatous rate was 18.0 per cent in 1955-57. This decreased to 2.0 per cent in 1970-74. Lepromatous rate in survey cases was low as compared to lepromatous rate among voluntary cases. Speed of commencement of treatment was slow in females, older patients, non-lepromatous cases and in cases coming from distant villages. Seventy-one per cent of the patients collected 50.0 per cent of drugs in 1958-60 whereas in 1970-71 only 36.0 per cent of patients collected 50.0 per cent of the drugs. The regularity was dropping with each year after registration. The irregularity of drug collection was high in non-lepromatous cases, young people, females, survey cases, and in patients coming from distant villages. Nineteen per cent of lepromatous cases, 20 to 60.0 per cent of borderline cases and 3 to 5.0 per cent of non-lepromatous cases were bacteriologically positive. Bacteriological assessment was not undertaken periodically after the start of treatment, even for lepromatous cases. Initial deformities were higher for lepromatous cases, voluntary cases, males and in those aged above 45 years. Initial deformities were more in hands followed by face, feet and least in the eyes.

The following findings were reported from the Vairag study:[56]

Epidemiological Information :

Only 59.2 per cent of the total cases in 1974 were being detected by active search. Only 32.2 per cent of lepromatous

cases were detected by active search. Contacts and healthy contacts have contributed to 24.0 per cent of the total case load. Prevalence rate per 1,000 examined healthy contacts was 4.3. 7.8 per cent of the cases were detected through school surveys. Prevalence of leprosy among school children was 1.9 in 1974. There was a significant decline in the prevalence rate.

Age Distribution

1.3 per cent were in 0-4 year age group, 13.3 per cent were in 5-9 years, 24.7 per cent were in 10-14 year age group, 17.3 per cent were in 15-24 years, 30.7 per cent were in 25-44 year age group and 12.7 per cent were in 45 years and above age. Male-female ratio was 1.9:1. Lepromatous rate was 11.2 per cent in 1970-74 as compared to 21.3 per cent in 1960-64. Non-lepromatous rate was 82.0 per cent in 1970-74 as compared to 78.5 per cent in 1960-64. Borderline rate was 6.8 per cent in 1970-74 as compared to 0.2 per cent in 1960-64.

Type and Age

4.5 per cent of lepromatous cases, 91.8 per cent of non-lepromatous and 3.7 per cent of borderline cases were in 10 to 14 year age group. 9.6 per cent of lepromatous cases, 86.2 per cent of non-lepromatous and 4.2 per cent of borderline cases were in 15 to 24 year age group. 22.1 per cent of lepromatous type, 65.3 per cent of non-lepromatous type and 12.6 per cent of borderline type cases were in 25 to 44 year age group. 8.7 per cent of lepromatous cases, 82.6 per cent of non-lepromatous cases and 8.7 per cent of borderline cases were in 45 years and above age group. 11.2 per cent were lepromatous cases, 82.0 per cent were non-lepromatous cases and 6.8 per cent were borderline cases in all the age groups put together. Deformity rate has shown a decline from 33.0 per cent to 11.4 per cent. Highest deformity rate was in 25-44 year age group. Deformity rate in lepromatous type varied from 36.1 per cent to 51.2 per cent. 30.6 per cent had deformity of both hands. 9.7 per cent had deformity in both legs. 3.2 per cent had deformities in face.

Record maintenance was very poor in the centres studied. Very few bacteriological examinations were done even for lepromatous cases. There was a lot of delay in declaring disease arrested patients. Healthy contact examination was poor and varied between 55.0 to 89.0 per cent.

In addition to assessment of National Leprosy Control Programme by Indian Council of Medical Research, some eminent leprologists have also made some impressionistic remarks on the Leprosy Control Programme. While these assessments can provide some valuable insights into the working of the programme, they cannot be considered as scientific studies of the programme.

Khoshoo (1965)[57] in his review of the Leprosy Control Programme in India indicated that the states have not utilised the plan allocations. He has indicated some lacunae like improper location of control units, non-provision of full complement of trained staff, inadequate health education, non-utilisation of funds for welfare benefits and the state leprosy officers were not given the same supervisory responsibilities as others for leprosy control units.

According to Dharmendra (1969)[58] the Leprosy Control Programme has no doubt expanded but the attendance of the patients has usually been so low that with this low attendance the spread of leprosy cannot be expected to be controlled.

Ekambaram (1969)[59] identified some defects in the implementation of the programme while taking a fresh look at leprosy control work. He advocated more facilities for a control unit so that the medical officer of a control unit is not a distributor of DDS tablets, but a real doctor. He identified prolonged treatment and deplorably low living standard of patients, resulting in a mental apathy and indifference to getting treated consequent to his struggle for existence as the main reasons of absenteeism.

Tare (1974)[60] opines that all that was planned in the SET methodology has not been implemented. According to him

surveys of 80.0 per cent of the population, that too once in 7 or 8 years, have no value. Education component of SET has been attended in default than in implementation.

In another study, Tare (1975)[61] has also observed that the patients feel tired due to monotony of long term treatment. He identified some challenges in the course of leprosy control work like lack of interest in workers, falsification of diaries, improper training by untrained staff, excessive load of work on the workers, lack of security in service and social security in old age for workers in voluntary organisations, increasing governmental controls and dictation on the private leprosy institutions through the conditioning of grant-in-aid.

Kapoor (1976)[62] in his critical assessment of National Leprosy Control Programme has stated that many of the States were not doing the work according to the operational guide prescribed due to lack of proper liaison between centre and states. He also observes that there is inadequate provision for temporary hospitalisation, non-removal of self healed and patients with resolved lesions from the lists, inability of the medical officers to look after SET centres and to supervise and guide the work cf staff. Medical officers were not trained for the work; undergraduate training is very inadequate. The training facilities for non-medical supervisors were not proper and were inadequate.

Das (1976)[63] has indicated that the programme did not gain the required momentum because of the slow rate of implementation and insufficient recruitment of the staff, and purchase of material and equipment.

Noordeen (1977)[64] assessed the present level of efficiency in applying mass treatment at 30.0 per cent. In his opinion the reasons for this low level of efficiency is among other things the operational component and the methodology of the programme which have not changed since the inception of the programme. In his opinion they were not based on any well tested operational studies not only to review various components of the programme but also for development of newer

operational components.

Studies in Absentees/Defaulters

Hemerijckx (1959)[65] reported that among 13,394 patients registered at Pollambakkam, 12.7 per cent were irregular and 42.2 per cent were absentees. Associated with this redeeming feature was the higher attendance rate among lepromatous patients.

Karat *et al* (1967)[24] in a study at the Brahmapuram centre in North Arcot district, reported that 60.0 per cent of the registered cases were defaulters.

Kapoor (1969)[66] reviewing leprosy control work in Maharashtra identified reluctance of the patient to walk miles to just get a few tablets, lack of proper attention to patient, lack of accommodation, physiotherapy and ulcer dressing, lack of attention to concomitant ailments and bad personal behaviour of para medical workers as the causes of absenteeism by patients. He stressed that lack of devotion on the part of everyone as being a major hurdle to the success of the programme.

Neelan (1972)[67] in his study of 454 registered cases at Chingleput and Sriperumbudur taluks reported a 40.0 per cent defaulter rate. The relapse rate among those cases was high.

Noordeen (1972)[27] in his study of 8,000 population in Chingleput district found a defaulter rate of 90.0 per cent in non-lepromatous cases.

PREMISES OF THE PRESENT STUDY

From a perusal of the above studies it is evident that no comprehensive assessment of the problem has been made so far. Only piecemeal attempts were made to identify the different problems, by different workers at different times. The leprosy problem was not viewed as a system consisting of a number of sub-systems. There was no holistic approach for assessing the different components of the programme.

The structure and functioning of the organisation for leprosy control in a population is woven around the epidemiological issues of the disease. These again depend on the attitude of the patients and the community to the programme. Thus all the four components namely (1) the structure and the functioning of the organisation, (2) epidemiological issues related to the problem of leprosy, (3) the attitude of patients and (4) the community at large, are in complex interaction with one another and they must be studied *together:* they must be studied as a whole.

Such a holistic approach is necessary not only to study all the major facets of programme, but also to study *simultaneously* the interaction amongst them. On the basis of identification and study of the major components and interactions amongst them, it will be possible to develop insights into the working of the National Leprosy Control Programme which will provide the basis for bringing about changes within it to make it more effective.

For the purpose of this research Chingleput district of the State of Tamil Nadu was selected. Chingleput district has a high prevalence of leprosy and the district has been having inputs in terms of organisation, personnel and equipment to deal with this problem for a considerable time. Because of these considerations, the leprosy programme in Chingleput district provided a very good setting for studying all the four components of the system of leprosy control programme in a population, (organisation and management component, epidemiological component, the component formed by the patients and the community component).

Objectives of the Study

In developing an approach to study the Leprosy Control Programme in the district of Chingleput, the first objective will be to obtain data concerning the four components mentioned above, including how the functioning of the

programme at the state level influences the functioning of the programme at the district level.

The second objective will be to bring together the data concerning the four components in order to describe the functioning of the programme as a whole within the district.

The third objective will be to use the data from the study to offer suggestions for improving the functioning of the programme at various levels.

Chapter 10

LEPROSY ERADICATION EFFORTS THROUGH MULTI DRUG TREATMENT

In view of the limitations of Dapsone monotherapy viz. (1) the prolonged treatment adversely affecting case-holding and (2) evidence of development of resistance, the multi-drug treatment was introduced in higher endemic districts with prevalence rates of 5 or more for 1000 population as a national policy since 1982. The priority in the treatment is being given to multi-bacillary patients.

The programme, redesignated as National Leprosy Eradication Programme in 1982-83, is a 100% centrally centrally sponsored scheme.

Programme objectives and strategies in regular MDT districts

The ultimate aim of the eradication programme is to achieve the zero transmission of leprosy by the year 2000 A.D. To achieve this, the programme aims to bring all endemic areas in the country under MDT by the end of 1992. The adopted strategy involves provision of domiciliary multi-drug treatment (MDT) coverage in the high endemic districts in a phased manner by staff specially trained in leprosy.[102]

New classification of leprosy

Currently the Leprologists have agreed to classify leprosy as multi bacillary (MB) and Pauci Bacillary (PB).[103]

The types included in the old classification coming under the new Multi Bacillary (MB) classifications are as follows:

a) Lepromatous
b) Border line lepromatous
c) Poly-neuritic (more thane) one nerve involvement)
d) Border line Tuberculoid (more than 5 lesion) Border line borderline

The types included in the old classifications presently coming under the Pauci Bacillary (PB) group are as follows:

a) Indeterminate
b) Tuberculoid
c) Poly neuritic (one nerve)
d) Border line Tuberculoid (1-4)

Drug Regimen

I. Multi Bacillary cases

(1) Two weeks intensive treatment at the clinic with daily doses of:

	15 yrs	*10-14 yrs*	*6-9 yrs*
Rifampicin	600 mg	450 mg	300 mg
Clofazimine	100 mg	50 mg	50 mg
Dapsone	100 mg	50 mg.	25 mg

(2) Continuation phase of multibacillary treatment regimen

(a) Once monthly Doses for 24 month at the clinic

	15 yrs +	*10-14 yrs*	*6-9 yrs*
Rifampicin	600 mg	450 mg	300 mg
Clofazimine	300 mg	150 mg	100 mg
Dapsone	100 mg	50 mg	25 mg

(b) Daily Domiciliary Doses for 24 months

	15 yrs +	*10-14 yrs*	*6-9 yrs*
Clofazimine	50 mg (daily)	50 mg (alternate days)	50 mg (twice weekly)
Dapsone	100 mg	50 mg	25 mg

II. Pauci Bacillary cases

(a) once monthly Doses for 6 months at the clinic

	15 yrs +	*10-14 yrs*	*6-9 yrs*	*1-5 yrs*
Rifampicin	600 mg	450 mg	300 mg	150 mg
Dapsone	100 mg	50 mg	25 mg	10 mg

(b) Daily/Domiciliary Doses

	15 yrs +	*10-14 yrs*	*6-9 yrs*	*1-5 yrs*
Dapsone	100 mg	50 mg	25 mg	10 mg

The criteria for selection of distric under the MDT programme are as follows:[104]

i) Complete infrastructure in position in the district;
ii) Adequate training of leprosy staff in MDT operations;
iii) Rapid survey to detect the undetected cases; and
iv) Screening of all recorded cases and preparation of individual case cards.

In the beginning of 1983, two districts were extended MDT. Subsequently detailed guidelines for MDT operations

were developed, printed and distributed. In all 136 endemic districts with disease prevalence of five or more per thousand population were brought under MDT coverage. Presently these districts are under various stages for MDT implementation. Out of these 11 districts have been proposed for integration of leprosy activities with General Health Services. The names of these districts as well as the remaining 125 districts are given at Appendix 'D + E'.

At the end of March 1991 nearly 75% of the recorded leprosy cases i.e., 1.5 to 1.6 million cases are getting MDT inthe above 136 districts.[102] Over a million leprosy cases have been disharged since 1985 as disease cured due to effective MDT implementation in the above districts.

Modified MDT Programme[105]

In 66 endemic districts where 25% of the total leprosy problem still exists (mainly in the states of Madhya Pradesh, Uttar Pradesh, Bihar, Orissa, Kerala and West Bengal) a modified MDT has been planned. Most of these districts have inadequate infrastructure to implement Multi Drug Treatment as per Government of India guidelines issued for endemic districts. The names of 66 districts are indicated in Appendix 'F'.

Salient Features of Modified MDT Strategy

I. Administrative

1. Each endemic district would have a registered District Leprosy Society under the Chairmanship of District Collector. The Society would have overall responsibility for the operation of modified MDT activities, including funds and health education activities etc. as envisaged in the guidelines.
2. The salary and TA/DA of the general health care staff and/of NLEP staff wherever available in the district under the project will continue to be born on source.

However, the NLEP staff will be paid from programme funds.

3. The funds for operation, as envisaged in the modified MDT scheme would be provided to the District Leprosy Society by the Central Government. The District/ Zonal Leprosy Officer of the District will act as member secretary of the society.
4. Chief medical officer of the district or equivalent will be the vice-chairman of the District Leprosy Society.
5. Funds for this project would be operated by Member-Secretary of the Society under control of the District Leprosy Society.
6. To encourage Primary Health Care functionaries, a scheme of awards based on their performance willbe introduced. The details of the scheme would be worked out separately.
7. To improve new case detection, an incentive @ Rs. 3/- per new case detected/reported will be introduced.
8. Similarly to imporve case holding, patients will be paid Rs. 10/- for each supervised pulse administered limiting 24 pulses in MB and 6 pulses in PB. In addition, patients taking the full course in prescribed period will get Rs. 100/- in cash or kind as may be decided by the District Leprosy Officer.

II. Technical

1. 14 days intensive therapy for MB cases will be discontinued.
2. Fixed duration chemotherapy will be introduced for allMB and PB cases. However, PB with multiple lesions will be examined at the time of sixth pulse.
3. Instead of rapid survey prescribed in the government of India existing guidelines, Health Education activities will be intensified to encourage voluntary reporting. It is expected that adequate case detection can be

ensured by intensive Health Education supported by case detection through screening and patient satisfaction due to effective treatment.

4. Bacteriological examination of skin smears will be continued to MB cases and suspected MB cases. However, MDT will be started on basis of clinical examination.

III. Main objectives

The main objectives of the modified MDT programme are:

1. To render all infectious cases as non-infectious in a short period, so as to interrupt the chain of transmission of the disease in the community.
2. To give adequate and regular treatment to allthe existing and new cases and cure them in a short period.
3. To prevent the emergence of drug-resistant strains of M. leprae.
4. To ensure early detection and treatment of cases to prevent deformities.
5. To carry-out systematic health education activities, with a view to disseminate important facts about leprosy and to remove social stigma.
6. To prevent the spread of leprosy.
7. To finally eradicate leprosy.

IV. Prerequisites for starting modified MDt in a District

To ensure satisfactory introduction of modified MDt the district shall satisfy the following criteria.

1. Prevalence rate per 1000 population should be five or more.
2. The district should have a full time functioning DLO supported by minimum ancillary staff.
3. The districts have adequate coverage by Primary Health Care set-up.

4. One trained non-medical supervisor shall be available at block level and he will be attached to the community health centre. However, it shall be ensured that one non-medical supervisor is available for about 1,00,000 population.

This approach differs from the original MDT pattern in the following manner:

i) District Leprosy Unit would function in the district under overall charge of the district medical officer.
ii) Leprosy services would be delivered though primary health care set-up. Leprosy workers would be provided to the extent they are available in the district.
iii) Medical Officer of the Primary Health Centre would be overall incharge of MDT operations in the area.
iv) No cash incentives would be given to the health workers.
v) Cash assistance would be given to the leprosy cases to collect their drugs from the treatment points.
vi) Cash awards would be given to theh leprosy patients who complete the MDt treatment schedule in time.
vii) Treatment points would co-incide with Primary Health Centre, Subsidiary Health Centre, Community Health Centre and Hospitals.

Mobile central training teams are being sent to the districts to train medical officers and other health workers in these districts. Some of the districts have since started actual MDT operations. Rest are likely to follow shortly.

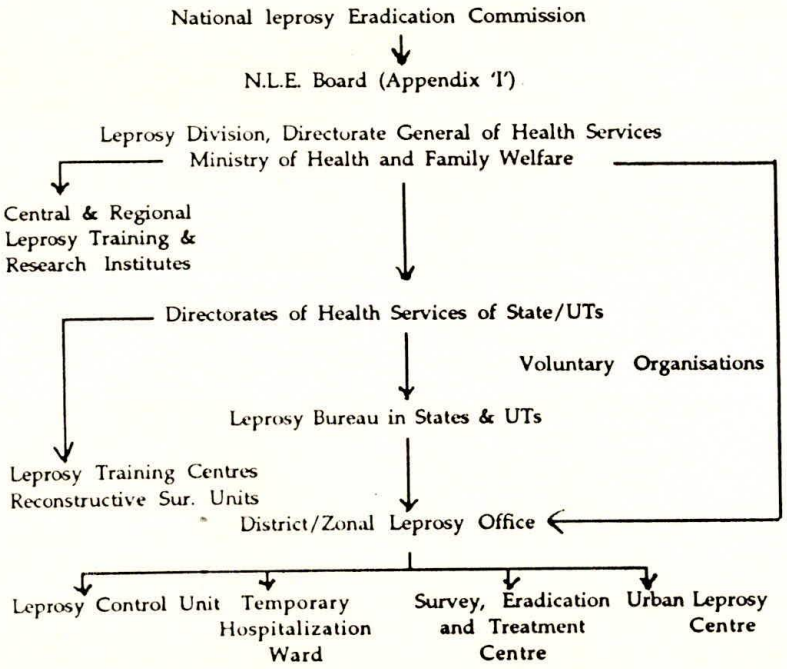
Future approach to cover the remaining cases approximating to 8% of total case[102]

Presently 90-92% of the cases residing in the endemic districts have been extended the benefit of MDT. The remaining 8% of the cases are from the 254 low endemic districts. These cases are not uniformly distributed in the districts. There are pockets here and there within the districts where

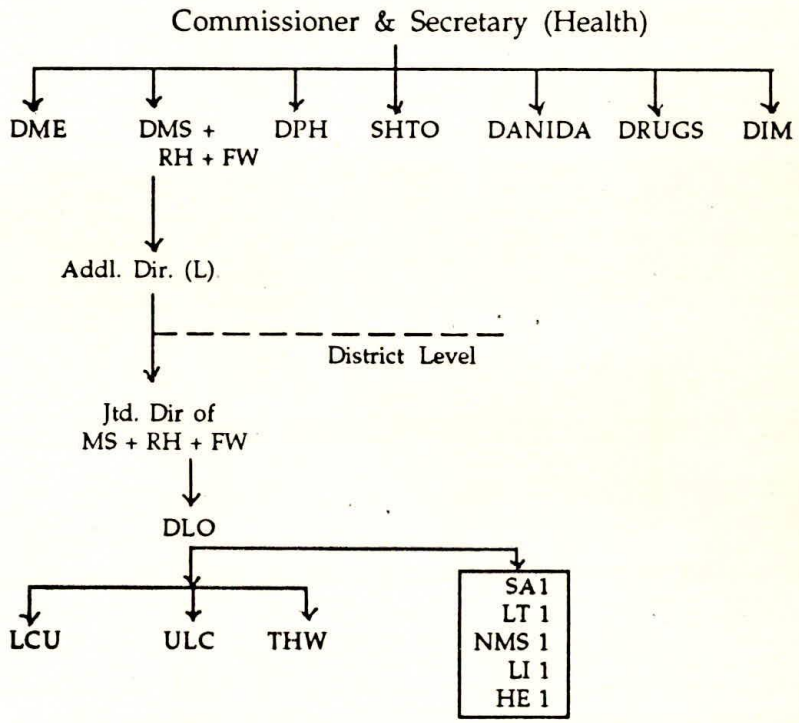
cases are actually residing. Majority of these cases roughly totalling 180,000 - 200,000 are residing in the 77 districts of the country.

To achieve an effective break in the disease transmission, it was found necessary that these cases are also brought under MDT within the near future. Modified MDT approach would be followed in these districts. There is a proposal to seek world bank assistance for implementation of MDT in these 77 districts. The names of the 77 districts are given at Appendix 'G'.

The Organisational Structure of the NLEP in India



THE ORGANOGRAM OF LEPROSY ERADICATION PROGRAMME IN TAMIL NADU



LEPROSY

07 Miss a turn to comfort your neighbour who has just discovered that he has leprosy. Tell him that Nature knows no despair. It heals itself. So will his body if he has the will to take the treatment. The future is nothing more than the will to live.

11 Talking to your clients at the beauty saloon, has helped many to know the facts of the disease and to overcome their fears and prejudices. Most people, unfortunately, think that leprosy is incurable, and that it disfigures and deforms a person. Excellent ! Advance 3 steps.

15 Don't let the patch on your arm frighten you. Miss a turn while you check to see if there is hair on the patch. Do you feel any sensation there? Does the skin sweat in that area? Only if you have no sensation, no hair, no sweat on the patch need you check with a doctor.

20 You have saved a mechanic his job by explaining to his employer that there are two kinds of leprosy : the infectious and the non-infectious; and that only 15% of the leprosy cases in India are infectious. The mechanic has the non-infectious type of leprosy. Go ahead 3 steps.

22 Your tailor does seem to have the infectious type of leprosy. He has innumerable patches all over his body. These are oily and shiny and do not seem to have any clear cut edges. He can be made non-infectious within a month if he is started on the multi-drug therapy. Miss 2 turns. Get him started on the treatment. Ask people to continue to give him their orders.

26 You did well to explain to Asha that leprosy is caused by a germ and that it is not a punishment from God. She has been crying bitterly thinking God has punished her for some misdeed.Have another turn.

30 Miss a turn. Repeat three times: Leprosy is not a dreadful disease. It is not incurable. It is not hereditary. It is not a punishment from God. It is caused by a germ. It does not require separation from others. It does not always lead to deformities and disabilities.

34 Advance 3 steps. Visit Mrs. Gupta. She is annoyed that her son has become a smuggler and has threatened him that God will punish him with leprosy.Tell her that you understand how she feels. Smuggling is bad, but her threats will promote incorrect ideas about leprosy.

38 Miss a turn. Repeat 3 times : Because leprosy affects the motor nerves, they do not send messages from the brain to the muscles. Unused muscles become wasted and weak and this leads to disabilities.

40 You broke off your engagement to Keya when you discovered one of her relatives has leprosy. Did you not know that leprosy is not hereditary? Move back tthree steps.

43 Sharad insisted that one could get leprosy when bitten by a two headed snake. You had no courage to contradict him and give him the facts about leprosy. Move back 4 steps.

48 You still doubt the curability of leprosy! Why did you refuse to employ that woman because her fingers are misshapen ? She has been cured long ago. Move back 4 steps.

51 You did not employ that woman because you were scared of the reactions of your friends and neighbours. When are we going to give the cured acceptance ? A chance to live ? Miss two turns to organize a talk on leprosy at your residence. Invite as many as you can to this talk.

54 Advance 5 steps. You did well to write to the Editor of the Times of India protesting the use of the word 'leper' and indicating that we do not talk of 'chicken-poxers', 'aidsers', 'cancerites' or poliottes'. Why do we not refer to those who suffer from leprosy as leprosy patients ?

58 With the letter Dr. Kumar gave you certifying that Kumar has leprosy, you booked him a round trip ticket to Wardha for treatment, obtaining a 75% discount. This discount is available to all leprosy patients Advance 4 steps.

61 Your efforts to convince your uncle that leprosy is both curable and not always infectious has saved your aunt from being turned out of the house. Take 2 more turns. 85% of the leprosy cases in India are non-infectious.

63 You have again said, 'leper'. Move back 6 steps. Remember to say 'leprosy patient'.

65 Leprosy patients hide their illness from everyone, including doctors. They are terrified of being rejected by society - by US , you and me ! Miss a turn and spend some time trying to imagine how they suffer in their isolation.

68 The leprosy patients who came to your talk today were struck by this comment. "Tears can never blot out the sun, but they can kill our appetite for food, work and life." You certainly did well to motivate them to continue with the treatment. Excellent ! Have another turn.

72 Do you know that a judgement was reversed in the High Court in Madras on the evidence provided by a leprosy patient ? Once upon a time, leprosy patients could not be presented as witnesses. Now they can. Move ahead 2 steps. Spread this information as you move ahead.

78 If you come from any of these states, you may move forward 3 steps as the Indian Lepers Act of 1898 has been withdrawn by their State Governments: Maharashtra, Andhra Pradesh, Karnataka, Madya Pradesh and the Union territories of Delhi and Chandigarh.

83 Are you hoping to get a divorce on the grounds that you wife has leprosy ? Remember that you live in Maharashtra where the courts have rejected such petitions. Miss a turn. Get over your hang - ups.

86 You did very well to make clear to your friends that leprosy affects the nerves. The person loses sensation when the sensory nerves are affected. We lose the capacity to move our fingers when the motor nerves are affected. Have another turn.

90 Move 4 steps ahead. Give Minoo a treat. He has followed your instructions very carefully, daily checking his hands and feet for any cuts or scratches. This is very necessary as the cuts can get infected and lead to gangrene.

96 Explain why it is so necessary to check daily for cuts or scratches. Does the person not know when she cuts himself/ herself ? If you cannot, move back 5 steps. (Answer in no:84)

96 Even though you are a temporary worker in your company, as a leprosy patient you can take special extraordinary leave of 18 months on producing a medical certificate. Stop hesitating. Go apply for leave. Have another turn.

99 As a student representative, you did well to urge your principal to join with other principals to demand that the Textbook committee include a chapter on leprosy in the Science Textbook for Std.X. Move forward 2 steps.

102 You have been collecting money and old clothes for distribution to leprosy patients at Divali. This is good, but don't you realize that they want to be treated as 'people'.They want our acceptance more than our charity. Miss 2 turns to think about ways in which you can organize something different to stress this acceptance.

105 Excellent ! You have done well to go on a door to door campaign in your village explaining away fears about leprosy so that a widow in the village can continue to use the village well. Move 4 steps ahead.

107 Weren't they surprised when you told them leprosy was curable unlike diabetes which isn't ? That was a good comparison to shake people up. Move ahead 2 steps.

111 Cheers ! The National Institute of Immunology has developed a leprosy vaccine which has been approved by the Drug Controller of India. It will be available at an affordable cost soon. Take one step forward.

114 This is an excellent idea creating a network of penpals between leprosy patients and children from your neighbourhood. Have 2 more turns. Continue to collect addresses of children who want a penpal.

118 Do you know of this contribution Gandhiji made to the nation. Pacchure Shasthri , suffering from leprosy, came to Seva Gram for assistance. Move ahead two steps telling people along the way about Gandhiji's personal care of Pacchure Shasthri, his attitude to the disease, to those suffering from it, and to those fearing it.

122 List 3 important symptoms of leprosy. If you can, move forward 4 steps. if you cannot, move back 7 steps. (The symptoms are in no: 22)

126 Advance 4 steps. You did well to explain to people that leprosy does not always disfigure and deform a person, especially if treatment is started before the motor nerves are affected.

T/IS-8A

5. Disease Control

Leprosy Patients Care

In our General Secretary, Mrs. Namgyal L. Taklha's recent visit to three Tibetan Settlements in Arunachal Pradesh (Tezu, Miao and Tenzingang) she met three leprosy patients and visited their homes. All are under treatment from local Indian authorities but Mrs. Taklha was concerned to discover that some of their family members have contracted the disease too.

Mrs. Taklha and I visited the Palampur Leprosy Hospital and Home on June 17th 1991. Of the 30 patients resident there, 10 are Tibetan. Under the supervision of Dr. Issac R. Nath (Superintendent) and his assistant Mr. Das, the home is well run and patients are treated as part of the family and seem very happy. We therefore plan to admit all Tibetan leprosy patients from the Northern Zone to Palampur, where we will also be able to give them better attention from our side. we are asking Community Health Workers (CHWs) to report all Leprosy patients in their settlements so we can establish a leprosy register and monitor their treatment and progress more efficiently.

Tsamcho Dolma (Mrs)
Project Officer
Disabled & Handicapped Unit

6. EVALUATION

Utilizatio nPattern of Tibetan Hospitals

In 1990, as part of the fulfilment of his final examination in the post-graduate diploma in Health Care Administration, Mr. Dawa undertook the study into the Utilization pattern of Tibetan Hospitals in the state of Karnataka. The following is a summary based on the paper.

There is no doubt that a hospital could play an important role in the provision of health care to a community. But one should not over look the facts that hospitals are complicated organizations, expensive to build and maintain, requires professional management of its staffs and facilities and are not always responsive to the health needs of the public. It is therefore imperative that regular surveys and audits are undertaken to maintain quality, and to initiate changes.

Three hospitals in three separate Tibetan Settlements in the state of Karnataka in India were studied. The backgrounds and findings of each are as follows.

The Doeguling Tibetan Hospital in Mundgod was built in 1969 and serves a population of 10,000. It employs 34 staffs including 1 medical officer, 2 staff nurses, 5 nursing aids and 8 CHW. It has 40 beds for general and 12 beds for T. B. patients. It provides an out patient service and has X-ray and other laboratory facilities and has launched a PHC programme and TB Control Project. It has also set up a peripheral dispensary to serve those living farther away. 25% of the hospital budget is financed by local Health care contribution and the rest through donations.

COMMUNITY HEALTH CELL
326, V Main, I Block
Koramangala
Bangalore-560034
India

In the questionnaire administered to 5 selected members of the 19 strong Management Committee, 4 felt that the hospital facilities were 75% utilised and one 25% utilised. When asked which facilities were under-utilized, one identified in-patient service but 4 identified out-patient services only.

Table No. 1

Year	Ave. out-patient attn. per working day	% inpatient bed occupancy	no. of Laboratory investigations per working day	Ave. no. of X-ray taken per Working day per technician
1987	34	26	6.5	1.4
1988	42	20	6.0	1.4
1989	35	19	3.8	2.0
1990	30	19	4.6	5.0

The second hospital studied serves the Dhondenling Tibetan Settlement in Kollegal, Mysore district, with a population of 4500. It was established in 1976 and most of its budget is now self generated. It has 35 beds, provides outpatient, TB Control, Maternal and child health and community opthalmic services. It has X-ray and laboratory facilities and has started training CHW in May, 1990. It employs a total of 12 staffs, including a medical officer, 2 staff nurses, 1 health coordinator cum X-ray technician and a lab technician.

Table No. 2*

Year	Ave. O. P. attn. per working day	% bed occupancy	no. of lab. investigations per working day	no. of X-ray taken per working day
1987		7.2	1.5	
1988		10.2	3.2	0.6
1989	26.8	8.9	1.3	
1990	26.1	9.4	1.0	

*When 5 members of the management committee were asked about utilisation rate only one replied to the figure of 25%, the others chose 50% or 75%.

The last hospital studied is the Rabgayling Tibetan Settlement in Hunsur. It was built in 1971 and serves a population of 3650. The hospital has facility for 35 inpatients but due to the lack of a full time attending physician, this is not being utilize d. A local doctor visits thrice a week. Once a month the medical

officer from Dhondenling Hospital visits to supervise the T. B. Control Project. 9 staffs are employed, including 2 CHW and 1 nurse aid.

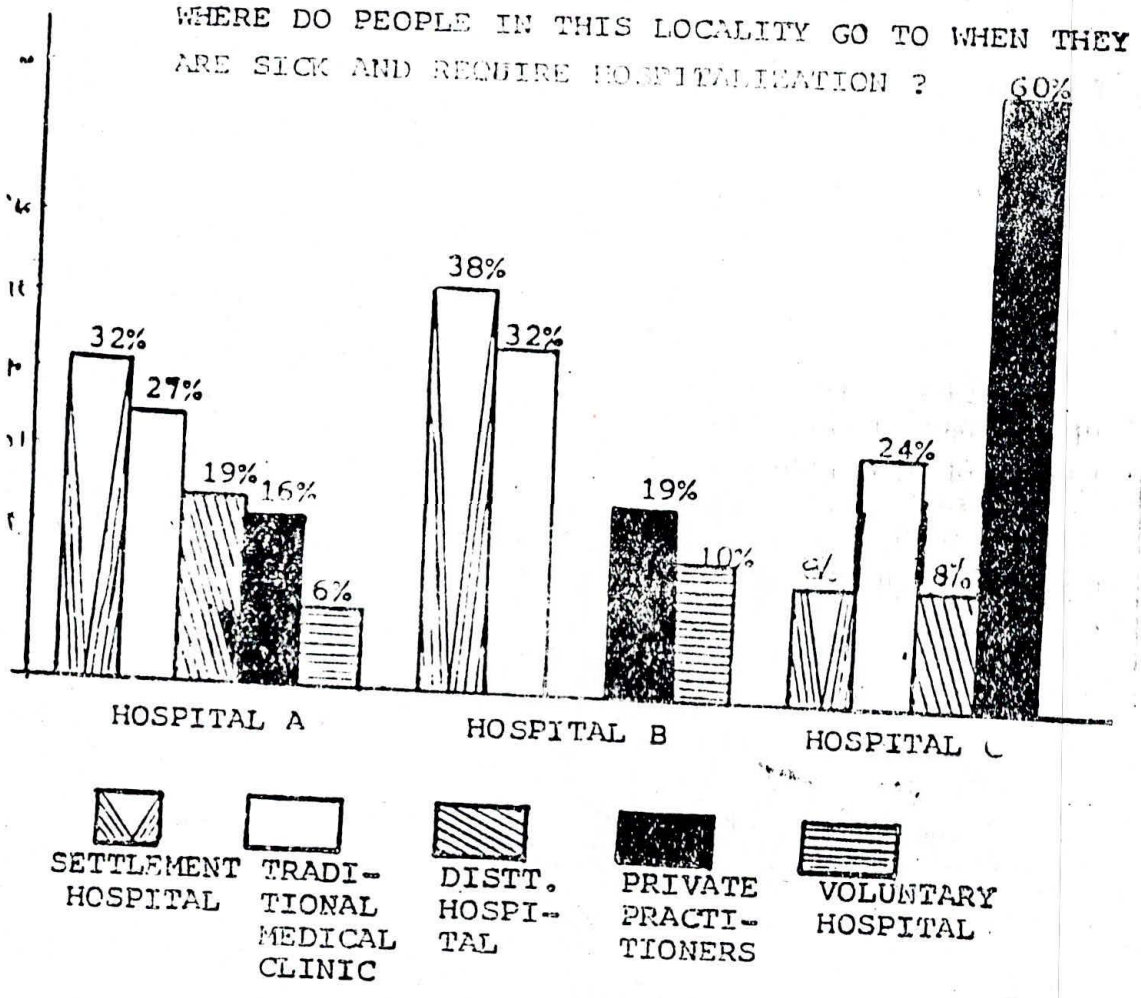
Table No. 3

Year	Ave. OPD attn per working day
1987	12.0
1988	20.4
1989	20.0
1990	19.6

All 5 elected members of the managing committee felt that facilities were only 25% utilized, and most expressed that this was especially so for in-patient and laboratory services.

When the respective camp or village leader, nearly all of whom have resided in their Settlements since establishment, were asked about where the settlers go to consult when they are sick, the following figures were returned. One should note that the responses were based on the leaders' impressions, not quantitative analysis.

Although the study was hampered by a lack of important datas, a number of observations may be made.



1. In all the three hospitals, there is possibly evidence of substantial under-utilization of a large proportion of the facilities available.

2. In Rabgayling, the difficulty with staff recruitment may have contributed towards an estimated 92% of the settlers seeking help from outside the Settlement hospital.

3. There is a lack of important datas, such as the cost to maintain one hospital bed, to be able to assess efficiency.

4. Areas of under-utilization of existing facilities may be under-estimated by members of the hospitals.

In conclusion, although the 3 hospitals studied on the whole provide a wide range of useful services to their people, some of these services seems to be substantially under-utilised. The paper suggests the following areas of study and research :

a. The study of break-even analysis of X-ray plants
b. The role of a hospital managing committee.
c. The organization climate of a hospital.
d. The educational status and age group of people who avail themselves of the hospitals.
e. Common ailments among the people.

ATTENTION :

Since 1987, "Tibetan Health" has been published twice a year to inform all our friends, donors and health workers at home and worldwide about the activities of the Department of Health.

Now we feel, it is time for us to evaluate Tibetan Health to see whether it is serving your needs. Your frank Comments will be much appreciated.

Please send us your suggestions before September 1991.

DIS-8A.

FOR DISCUSSION AT MFC MEET
by DR BR CHATTERJEE, JHALDA

We have to keep the fact in mind that Leprosy disappeared from Europe by the 16th Century at a time when we knew nothing of microbes, infections and chemotherapy. Natural history of leprosy in the individual dictates self-healing or self-limiting disease. This is reflected at the community level in a slow but steady correction of the endemicity with a decline in the rates of lepromatous types of leprosy, even as there is a rise in non-lepromatous disease. This is the result of a slow correction of the susceptibility trait (susceptibility to develop lepromatous types of the disease) at the genetic level. When we see less lepromatous leprosy, it means there are fewer people in the community to manifest lepromatous leprosy, an improvement in the genetic stock of the population.

Unless this equilibrium is attained, and this is a natural process - no amount of Chemotherapy can bring this about in leprosy as is clearly evidenced by the undiminished new case detection rates (NCIR) even in areas brought under MDT coverage for 15 years - leprosy will continue to be with us for some more time. The unseemly haste with which the WHO and the Ministry of Health is going about eliminating leprosy is doing lot of disruption to the programme. Workers under the Voluntary Organisations face a dim prospect of abolition of the Grants-in-Aid after 2001 AD. Definition of a case of leprosy is being compromised to show less number of cases.

Whatever little could be achieved by the NLEP is also negated by half-baked treatment regimens with bizarre and impractical combination of drugs. There is a great deal that could be done even within the constraints dictated by the natural history of leprosy if the drug regimens were rationalised, and an effective immunotherapy brought in. This vital dimension of Immunity has been a casualty in the din of the **"drugs that kill the bugs"**. Unless this vital dimension of immunity is appreciated as the centre-piece of leprosy, drug treatment alone to eliminate leprosy will be an unrealistic and costly exercise. One must never lose sight of the fact that persisting bacilli alive or dead, will continue to precipate reaction, and reactions are the bases of leprosy pathology and symptomatology: the pathology of leprosy is rightly called immunopathology.

Lastly, we are still ignorant about many facets of leprosy knowledge in which could help.

Dear Friend,

I am sending a copy of Sathya's review of the leprosy control program. Hope you have got the previous mail regarding tuberculosis etc.

Yogesh

LEPROSY (review of some documents, for discussion at the ID cell meet in July 1988)

History of leprosy control programe:

C. Sathyamala

1871-72 : Leprosy survey as part of the British Imperial Census

1890-91 : British Leprosy Commission

1925 : Indian Council of the British Empire Leprosy relief association later renamed as Hind Kusht Nivaran Sangh in 1947

1911 : Committee appointed by government of India to review the extent of the problem and made specific recommendations
(Till 1950 prevalence rate obtained as part of dicennial population census)

1954 : Concrete plans for the control of leprosy including legislation

1955 : In the last year of the first five year plan the National Leprosy Control Programme was launched as a centrally aided scheme, main objective to control through domicillary dapsone therapy

1969-70 : 100% centrally sponsored programme. Programme was input oriented .

1976: Programme made performance oriented. Each state was given a target of new cases to be detected and brought under treatment and number of patients to be discharged as disease arrested or cured. Performance was to be measured by the percentage of endemic population served and percentage of estimatedcases detected. Each LCU/SET was expected to undertake total population examination once in 5 years only. The NLCP was launched in rural areas because 80% of the population lived in the villages and ' leprosy being a disease of rural incidence and urban prevalence' control in rural areas would decrease migration of cases . This was found not to be completely correct because of indigenous urban foci and so was extended to urban areas as well. The programmes assumption was that by detecting all the cases and bringing at least 90% of them under continuous treatment with sulphones it would be possible to bring down load of infection by about 80%.

1981 : Indira Gandhi makes an appeal in the World Health Assembly for all developed countries to help in leprosy eradication. Working group set up under the chairperson ship of S Swaminathan, the then member, Planning Commission to evolve strategy to tackle leprosy. The changes in the programme were NLCP was to be changed into time bound programme with the specific goal of arrest of disease activity in all leprosy cases by 2000 and sulphone was to be supplemented by one or more bactericidal drugs.

1981 : WHO recommends Multi Drug Therapy (MDT) because of problem of resistant bacilli to Dapsone for treatment of all Multi Bacillary(MB) and Paucibacillary (PB) patients . GOI launches MDT with the assistance of SIDA and UNICEF.

1983 : Leprosy 'eradication' programme with the aim of achieving arrest of disease activity in all the known leprosy cases in the country by 2000AD

1991 : Aim changed to achieve elimination of leprosy by reducing case load to 1 or less/10,000 population, following the World Health Assembly resolution

1993-94 : Agreement signed with the World Bank for a total assistance of Rs 302 crores for a period of 6 years. After this agreement the whole country has been brought under MDT through 490 DLSs (?)

1997 : Mid term appraisal by World Bank in April . Following recommendations of WHO the duration of MDT reduced to 12 months for MB patients from Nov 1997. Single dose ROM treatment for single lesion introduced from Jan 1998. Modified Leprosy Elimination Programme(?)

LEPROSY SITUATION IN INDIA:

Till 1950, prevalence rate was obtained as part of the dicennial population census
In 1931, there were 160,000 cases registered (prevalence rate of 0.49/1000 population)
This was an under estimate because:

* it included cases with the advanced form of the disease only
* all cases were not reported because of stigma
* many cases not recognized
* errors in coverage of population

In 1951 - prevalence rate (PR) 3.81; in 1961 PR 5.83; in 1971 PR 5.84; in 1981 PR 5.72.
Endemicity differs from state to state:

In 1951	West Bengal	14.1
	Tamil Nadu	8.4
	Himachal Pradesh	7.8
	Orissa	7.8

In 1966, population covered was 54.724 million i.e., 14.7% of endemic population. During the IV Five Year Plan, another 16.§% population was added and in 1974-1977 another 35.99. At the end of 1985, total population covered was 439.9 million representing 64.2% of the endemic population. This coverage also differed from state to state with Bihar and West Bengal less than 50% and Tamil Nadu and Andhra Pradesh more than 70%.

In 1981 review the PR in different states were

HIGH ENDEMICITY

Pondicherry	31.67
Lakshadeep	25.00
Orissa	12.14
Tamil Nadu	15.14
Andhra Pradesh	11.58

MOD.ENDEMICITY

West Bengal	7.88
Sikkim	7.81
Nagaland	6.49
Maharashtra	6.37

Population at risk is also uneven from state to state. Most of the load is in the eastern belt. According to the 1981 census, about 400 million (58%) of the population was estimated to be at risk due to leprosy in areas with prevalence rates of > 5/1000.
The Status Report of 1985-86 states that 'the disease is on the decline'. On the bais of work done over a period of 12 years, the PR decreased in an observed area from 2.16% to 1.1% and total infectiousness (?)declined from 149 to 36 with an average reduction of 9% per year though the incidence rate did not come down appreciably (How did they measure infectiousness and incidence??)
In 1991 the country wide PR was 3.26/1000

An explanation given for the high prevalence rate of the earlier period was
* they represented the cumulated number of cases,
* the surveys were ususally carried out in endemic areas with high PR and this was extrapolated to the whole country. The trend of increase in the 'estimated' cases got arrested after 1983 when the MDT programme was introduced. Because of intensive case finding and establishment of reliable information, and because it discharged from existing registers patients who were no longer in need of treatment
* 'new case' detected increased phenomenally during the first three years before levelling off and even started a slow decline. The upsurge comprised of:
  - new cases representing recent transmission (1-3 years)
  - cases resulting from infection acquired a long time ago (10-30 years)
  - the backlog of cases that had failed to report during the earlier years.
  (??????????)

'The pattern of new case detection rates during the first three years of MDT strongly suggested that most of the backlog of the earlier undetected cases would now be on record (a trusim?) Cases registered for MDT approximated to the true load of leprosy cases needing treatment'.
Estimated case load for June 1990 was 27,64,000 cases giving a PR of 3.26/1000 population (registered cases were 23,70,687. Tamil nadu, AP,Orissa, Bihar, MP, UP, Maharashtra and WB accounted for approximately 90% of total registered case loadand an equal percentage of population at risk in the country. By 1991, MDT had reached all 201 districts which had an endemicity of 5/1000 or more. In March 1991, the infrastructure facilities extended upto 568.5 million representing 67.4% of endemic population. The introduction of MDT entailed large scale elimination of cases at initial screening and was supplemented by actual decrease in the number of cases in areas where MDT had been in operation for more than 3 years.
In March 1991, cases on record 20,43,136, brought under treatment 18,77,199 (91.9%) and discharged/
cured/ died 5.41 million cases.
(an interesting graph from page 30)

The incidence rate(?) in children varied from 1.61 to 54.5% of all new cases with an average of 23.9% ,
deformity accounted for 5.0% of the new cases. The unusually high childhood rate was seen to be due to
detection of the disease in children in large numbers at the surveys that focused primarily on schools (?
interesting but could also represent incidence of disease?)
Examination of skin smears for bacilli was essential prerequisite of MDT programme. Such examination was carried out to supplement (? not mandatory?) disease classification before starting treatment and later as a follow up measure. The document however states that

'currently bacteriological services constituted a weak link. On an average, 60.0 percent of the patients were subjected to bacteriological examination and
bacteriological cover was available to 72.5% MB and 47.6% of PB cases.
(ID cell members can find out what % of MB cases are being bacteriologically examined).

The epidemiological indices used are:
* Prevalence rate per 1000
* annual case detection rate per 1000
* proportion of MB cases among the new case per 100 (%)
* childhood leprosy rate among new cases per 100 (%)
* Deformity rate in new cases per 100(%)
* relapse rate per 1000 (cases??)
* voluntary reporting rate per 100

(Tables 24 and 25 show targeted acheivements under NLEP till 2001 Seems more of wishful thinking!)
Tentative plan for the elimination of leprosy by 2000 AD : By providing rapid universal MDT coverage in
endemic areas. Concern raised about
* will the general health services be able to maintain leprosy control in the face of competing priorities of Family Planning and other diseases?
* do the general health staff possess the necessary competence , knowledge and skills and above all the
commitment for leprosy control?

India 1996 (from WER, 2 May 1997)
New cases 44,2114
New cases classified as MB 82,251 (18.6%)
Skin smear positive 39,790 (9%)
New cases with bacterial index more than 3+ 8842 (extrapolation from reports of specilized institutions or projects)

WER 6 june 1997 (Progress towards leprosy elimination)
One of the major difficulties is to assess the proportion of the population covered by the programme.Special Leprosy Elimination Monitoring programmes have been set up.

Performance of national elimination prog is assessed by
*reduction in performance
*MDT coverage
*number of patients cured

Increasing attention is being paid to
*geographical coverage
*quality of MDT services
*timely detection of cases
*prevention of impairment of disabilities

Prevalence in the world continued to show a declining trend. Number of countries showing PR of >1/10,000 has been reduced from 122 in 1985 to 55 in 1997. But in some major endemic countries (including India), there is a slowing down of a further reduction in prevalence.

Although it is too early to judge whether or not this situation is sustainable, one can be reasonable confident that leprosy as a public health problem has been eliminated from most of these countires (Not at all sure how WHO can say this with such confidence)

* Distribution of estimated and registered prevalence by WHO region shows only a MODEST reduction in the number of registered cases between 1996 and 1997.

*The global PR is still 1.6/10,000

* In the 16 major endemic countries which represent 91% of the global leprosy problem, the prevalence rate is 4.3/10,000

* It is possible that some of the countries might need to continue and intensify activities beyond 2000 to reach their targets

South East Asia (1996-97)	Estimated number of cases		800,000 (5.7/10,000)
	No.of registered cases	(1996)	651,562 (4.72/10,000)
		(1997)	637,413 (4.5/10,000)
		% change	-2

The global detection in 1996 was approximately 566,000 (9.8/100,000). 95% of this was from the 16 major endemic countries and 73% of the newly detected cases were living in India alone. The detection rate for SE Asia was 32.36/100,000. Among the newly detected cases 16% were children below 15 years; 31% were MB; and 5.5% showed severe disabilities.

The WHO asserts that the increase in detection in endemic countries is due to increase in case finding activity and increase in geographical coverageand states (without any hard core evidence) '....it should be recognized that there is no direct relationship between detection trends and intensity of transmission of the disease and therefore detection trends should be interpreted with great caution(!)

WHO supplies MDT, the last two years, free of cost through a contribution from the Nippon Foundation for >1.7 million patients living in 35 endemic countries

Top endemic countries have the following characteristics

* Prevalence rate of >1/10,000
* number of prevalent leprosy cases > 5000
* number of newly detected cases > 2000
* Ranking countries based on number of ESTIMATED cases

High prevalence in Brazil (6.56); Nepal (5.83); Myanmar (4.08); Mozambique (6.1); Madagascar (4.3); and Guinea (5.0).

Indian situation in 1997 : PR is 5.86/10,000; Detection rate 44/100,000;cases on MDT 97%.

Operational challenges: to reach geographical areas and populations which have not yet registered for MDT; to reduce delay in detecting and diagnosing the disease; and to continue providing patients with good quality services including the supply of drugs free of cost.

WER No.24, 13 June 1997 (Global case-detection trend in leprosy)

The report states that 'although it was logical to consider monitoring of incidence as a more appropriate and theoretically more relevant measure for evaluating progress towards leprosy elimination, it was clear that this was not technically possible' because '...unfortunately dependable tools for measuring infection and for monitoring incidence trends in leprosy are still not available. Assessing incidence requires special prospective studies which involve large amount of resources and would have to be repeated using consistent procedures and several years if trends are to be assessed.'

(Actually there is nothing 'logical' , it is merely epidemiologically sound!. This is an important point for discussing at the ID cell meet)

The detection of leprosy globally has remained unchanged over the last 10 years in quantitative and to some extent qualitative terms. Acording to the WHO, what is not clear is the extent to which these changes can be attributed to the level of transmission, improved case finding, expansion of health services, changes in case definitions, increased population at risk or a combination of these factors. From 1985-96, MDT coverage increased to 97% of all registered cass which is = to 75% of estimated cases. The average duration of treatment decreased to between 2 to 4 years. Thus introduction of MDT was successful in clearing backlog of cases and the new situation is that 'for the first time prevalence and detection are converging'.

FACT is globally, and at a national level in many countries, detection has been increasing 'significantly' over the last 10 years to reach a plateau of about half a million NEW cases per year.

The WHO asks itself 'how can this increase and persistence be explained?'
* Is the incidence of leprosy really (!) increasing in many countries?
* Is it the result of the impact of elimination strategy leading to improved coverage?
* Is it just the effect of an improved information system, or changes in case-finding methods?
* Is it an after-effect of the 'clearing of registers' forcing some programmes to bring back some patients from the cleared prevalence pool to the new detection pool? (what does this mean????)
* Was the leprosy problem so much under estimated that the backlog is much higher than expected?

'In all probability, several of the factors mentioned above have contributed to the current situation. However, it is difficult to estimate the proportionate contribution attributable to any one of the above factors to the stagnation of case-detectin trends'.

Fact is between 1985-96, while a steep reduction in prevalence was observed (78%) in this group of endemic countries, the trend in new cases detected has remained stable. Because the weight of India in relation to global figures is so important that statistics have been provided with and without India.
* The prevalence trend is steeply decreasing (70% while the detection trend is significantly increasing
especially after 1991
* While the child specific detection rate was 8.0/100,000 population in 1985 and 8.9 in 1996, the peak of 15 was reached during 1991.
* the proprtion of patients disabled at the time of diagnosis decreased from 9.7% to 5.4% but excluding India, it has increased from 6.8 to 10.3%
* While the detction rate/100,000 of MB leprosy was 5.9 in 1985 and 7.1 in 1996 with a peak of 10.2 in 1992, excluding India it has increased from 1.9 to 4.7

(I will now quote from the WHO document verbatim)
'At first glance, one might think that incidence of leprosy is remaining the same or is even increasing in some part of the world, despite the considerable reservoir. This is in contradiction with information collected through some special studies which show that the incidence of leprosy is decreasing by about 10% a year. However, an increasing detection trend with a decreasing incidence trend is compatible when a significant number of backlog cases exist in the community. In one way, increasing detection trends providde reassurance since they clearly demonstrate the effectiveness of the global elimination strategy in

identifying the backlog cases for treatment with MDT. This is likely to be the scenario in countries which still have a high endemicity for leprosy and where the programmes are continually expanding their activities to previously uncovered areas, leading to improvement in their case-finding activities. However, considering that leprosy distribution is very uneven among countries and that different countries in the world started with different different levels of prevalence and incidence, and considering the variations in the intensity of operations among countries, it is useful to analyze the situation according to different country groupings and regions in the world'.

Even after doing all that, WHO is not in any position to come to a conclusion about transmission and incidence.

In India, although detection trend is declinig the current rate is still very high and the decline not as fast as one could expect. This according to the Who, is because the last 40 years efforts were mainly concentrated in AP;MS and TN and here the PR and DR have decreased. The profile of cases newly detected in these states show a high proportion of single lesions, low incidence of MB, low disability rate which indicates that the disease is being recognized very early. On the other hand states like Bihar, MP and UP which are not considered highly endemic are getting priority and here there is a backlog of cases. and that the combination of these factors could explain the overall high rates and slw progress in India which is a matter of concern. and that it would be unrealistic to expect major changes in the epidemiological trend of the disease in the near future (straight from the WHO's mouth!!!)

I will be presenting the relevant tables at the meet.

The controversial issues that become apparent reading these papers are

1. Use of PREVALENCE instead of INCIDENCE as a measure of global elimination
2. There seems to be evidence from the WHO's own data that the elimination strategy is in fact producing
information contradictory to the claim that the disease is on the wane. WHO refuses to accept that there could be an increase in transmission rate or incidence. We need to look at the data more carefully
3. A concern about the possibility of increasing disability rate has been raised. This is particulary important when and if the LEP gets integrated with general health services where the health personnel may not be trained in leprosy
4. Issue of MDT and ROM that Dr BR chatterjee raises in the two articles on leprosy in the mfcb. The GOI has reduced the duration of treatment for MDT fro 24 doses (2 years) to 12 (1 year). This is based on scanty data (I think). We need to look at their 'double blind' clinical trials.
5. What is the consequence of declaring a country leprosy eliminated if the trends are not so clear. Is there a possibility of doing computer simulation exercises to look at trends 5, 10 years from now?
6. There seems to be a disparity between recommendations and field level activity. For instance, the case
definition for a MB case (What percentage are detected through bacteriological examinations.

India alone accounts for 73% of the newly detected cases in the world so whatever strategy is being
implemented affects our country the most.