DIS-8A.

Leprosy Archives

Preserve Them!

INTERNATIONAL
LEPROSY ASSOCIATION

INTERNATIONAL
COUNCIL ON ARCHIVES

"History is our guide to the future, for there can be no vision
without a sense of history"
Kofi Annan, Secretary-General, United Nations, 1998

Donated by Dr. V Benjamin on 24/12/2004

This Project

The Global Project on the History of Leprosy exists to help ensure that the legacy of the human experience of leprosy survives.

The four project areas are:

1 To locate existing historical resources and make a database. This will create a pathway for future researchers to study and discover leprosy's rich history.

2 To collect video testimonies of people affected by leprosy. This will add a living history dimension to leprosy.

3 To give advice on the good storage of leprosy archives and historical resources.

4 To put together information on the legal and social discrimination faced by people affected by leprosy.

The purpose of this booklet is to help fulfil the third task and assist with the first.

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Why bother?

You can help to ensure that leprosy is properly documented by saving the archives in your care and ensuring that they are there for people in the future to learn from.

Leprosy is a disease with a long history connected with many countries. It has influenced kings, shaped communities and formed attitudes. It has brought out both the best and the worst in humankind: personal courage, loving care, and scientific perseverance on one side; cruelty against fellow human beings on the other.

In much of the world it is gradually being conquered, but it leaves behind it a knowledge and an experience which is of great medical, historical and sociological value.

You can help to ensure that it is properly documented by saving the archives in your care and ensuring that they are there for people in the future to learn from. Without them there will be little to document the progress of the disease as the memories of those who have experience of it, either as patients or carers, are lost. **Bear in mind that good record keeping for organisations will also save money.** If you cannot house the material safely or have concerns that it may not survive, consider offering it to another archive or library.

What?

What are archives? Technically they are the original, no longer used, records of an organisation or individual which are kept because of their continuing interest and relevance. Archives come in many forms.

In organisations (e.g. charities, hospitals, government offices etc).

- financial or legal records
- property deeds outlining ownership
- minutes of meetings
- admission/discharge records or clinical treatment records
- key policy files/correspondence
- patient records

Individuals (e.g. those who have had, or have leprosy. Also carers, medical researchers, health care workers, politicians, administrators and those involved in any way). Their archives may include any of the following:

- letters or notes which are important in that they may be about key events in a career, or contacts with significant people in the leprosy field
- papers of importance from committees attended, the groups they have been involved in, the places they have visited or the contacts they have made.
- detailed observation records or medical notes
- photographs of people and places
- recordings, films or videos, especially of personal interviews

Who cares?

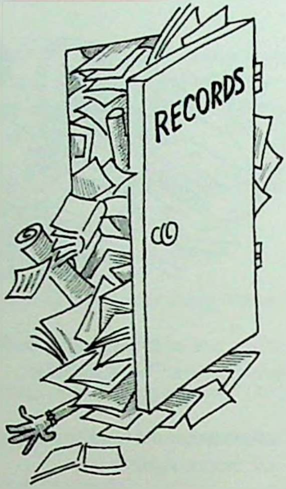
Archives are of importance to different groups of people at different times. These include:

- administrators who use records and historical material for future reference
- historians of leprosy, interested in the medical history and social, economic and other aspects
- biographers who wish to learn more about people or institutions involved in leprosy
- individuals who have been involved with the communities or who may be searching for information about members of their own families
- media researchers, both radio and television who may have an interest in the survival of communities or the disease

Keeping selected archives will

- save money for organisations in the future through reducing storage space as well as through using better day to day administration systems
- ensure the survival of important material to document the history of leprosy
- concentrate effort on essential issues
- Help with health education and training by providing sources of background materials

Sort it out!



What can be destroyed?

Everyone has records of one sort or another. Many of these do not need to be kept. You can't keep everything but here are some hints about what you should keep.

It doesn't have to be old to be kept. Consider how useful something may be in 10/20/50 years time.

For organisations

Many organisations accumulate records but don't have a system for their selection or long-term storage. Understandably, they are more interested in the treatment of leprosy today than keeping archives. This makes life much more difficult for anyone wanting to do research later.

Have a system for keeping and for throwing out records. This should involve regular sorting and storage of files by an appointed person. Ideally this should be introduced after consultation with a qualified archivist/records manager. The following guidelines give an idea of the main types

Sort it out!

of records that any organisation should consider preserving permanently. All these can be in either paper or electronic format (if regularly updated) or both.

Always keep the original if at all possible. It is authentic while a copy is not.

- minutes of boards/committees
- departmental and administrative papers
- annual reports/special reports
- financial records/annual audited accounts
- legal agreements/contracts etc.
- building works/plans
- key policy files/correspondence
- management records
- papers relating to important events
- relations with government, WHO/ILA/ILEP members, charitable, religious or other institutions
- press/media contacts including press releases
- publicity material
- newspaper clippings

Sort it out!

For personal papers

What should be kept depends on the person and the importance of their work. Often However, papers of great value to researchers are to be found in unlikely places. The following are general guidelines for the kinds of papers that may be worth preserving.

- letters to/from colleagues/organisations and possibly family (including letters of congratulation/ condolence etc)
- records kept as a member of committees/organisations (not necessarily just minutes and agenda but related documents and reports).
- legal records, ownership of property, finances etc.
- records relating to appointments, degrees, honours, awards, career in general
- diaries, especially if not simply appointments/lists
- calculations and data for published papers
- research notebooks, memoranda, research notes, project papers
- lectures, talks, speeches, broadcasts and unpublished papers including draft articles
- drawings, photographs, film, tape recordings
- list of publications/CVs

Sort it out!

What can be destroyed?

It is best to take advice from an archivist or records manager (contact either your national archives or a local archive) before throwing anything away. A few general points however, are given below. Also, remember to make a list of anything you decide to throw away; not only will it help future researchers to know what was there but it will also form the basis for knowing what to throw away in the future.

Most of the following can be thrown away but only after it has been carefully checked

- duplicate copies of reports, publications etc (but bear in mind they may be useful to another institution)

- manuscripts of published papers (keep only if the text is very different from the published work)

- multiple drafts of anything (unless the development of an idea or work is of key importance. Depending on the person/institution it may not be necessary to keep even one copy, although a list of publications is always useful)

Sort it out!

- fully published data (but in some cases samples or significant experiments may be saved)
- page and galley proofs
- routine/daily correspondence and papers e.g. arrangements for travel, cheque stubs, all the paperwork associated with attendance at one meeting
- printed matter circulated for conferences etc.
- appointment diaries (unless the person is very famous and likely to be the subject of a biography)
- agenda papers/miscellaneous committee records and circulars (unless it is the formal record of the event)
- references
- offprints of articles by others (but not if part of a group of related papers e.g. part of a research topic or included amongst correspondence with the author, or if the publication is rare or hard to obtain)

Now what?

Never update, alter or correct a document, even if it appears to be wrong. If necessary attach separate notes, signed and dated, with your views on what is correct.

Here are some guidelines on what you should do with records that you have decided to keep.

Even with limited resources your efforts to keep important records will not be wasted and the information will be available for years to come.

Care and Management

- make a list of everything to be kept
- keep all the material together (it forms a whole) and do not separate, lend, sell or destroy any part of it; separating even damaged material from its original place may destroy evidence
- keep them in the original order - it will be helpful to future researchers. For instance, don't be tempted to put all similar materials together, such as invoices, or letters of condolence, if they are not already arranged like that

Now what?

- never update, alter or correct a document, even if it appears to be wrong. If necessary attach separate notes, signed and dated, with your views on what is correct

- seek advice on the best way to catalogue the material so that it is easily accessible to the owner and to any researcher in the future. This also provides security as uncatalogued material is at risk from accidental loss or deliberate theft

- encourage good practice in creating records as well as keeping them; encourage regular records management to avoid future problems of selection and disposal

- keep computer disks and tapes. Also keep any paperwork that goes with them as this may be crucial if the disk or tape becomes technically outdated and no longer readable with current machines

- identify photographs with dates and names on the back in pencil whenever possible

Now what?

Practical care

- store all material on shelves in boxes with lids. Some of the greatest threats to archival material come from light, water, insects and dirt. The best boxes are acid free (made from rags not wood pulp) but if you cannot get these, use the strongest locally available. Maps should be stored flat or rolled round in acid free tubes.
  Acid free folders can be used to wrap individual bundles of paper. Also it may be cheaper and easier to get acid free paper to line boxes and tubes.

Acid free paper and boxes may not be easy to buy or recognise. If your stationer cannot help you, try contacting your national archives for advice. See page 17 for more details.

- use acid free paper (if possible) for important documents such as minutes etc.

- store all material at least 15cm (6 inches) off the floor to protect against flooding

Now what?

Store all material at least 15cm (6inches) off the floor to protect against flooding.

- store archival material in secure, stable, cool, dry and clean conditions. If the temperature can be kept the same, records last a lot longer (especially photographs and films) than if it changes with the time of day and the seasons. Monitor the conditions if possible with a thermometer and hygrometer. The ideal conditions for most types of material are no more than 18° C and no more than 60% relative humidity.

- when creating records of importance use a fountain pen. Avoid the use of biros, felt tip pens or magic markers, all of which fade.

- only use pencil when writing on existing documents

- don't repair materials with sellotape, scotch tape or other sticky tape

- don't store records in plastic files, or use any materials which degrade or rust such as staples, lever arch files or metal film containers

- make sure that photocopiers are well serviced for copying records (such as newspaper cuttings and other delicate records)

- handle the material with care, do not let readers use uncatalogued material and supervise them while they are using original material.

The basics

DO

- ✔ Put records in boxes with lids
- ✔ Adopt a system for regularly keeping and getting rid of stuff
- ✔ Keep the temperature as stable as possible
- ✔ Keep originals not just copies
- ✔ Keep stuff together
- ✔ Keep a list of what you keep and what you get rid of
- ✔ Use acid free paper if you can for making minutes Tell us

(ILA/ICA) about your collection so that we can let others know about it!

DON'T

- ✗ Alter records
- ✗ Write on existing records in pen
- ✗ Rearrange files
- ✗ Just keep piles of paper on shelves
- ✗ Throw it all away if you haven't enough space – find somewhere else to keep your archives
- ✗ Use biros, marker pens, etc. if you can help it for making important records – fountain/ink pens are best

For your eyes only!

There is frequently correspondence or documentation such as case notes, which is of a sensitive nature. This may be due to:

- comments on colleagues, relations or friends,
- individual sensitivity such as medical information/ relationships with others/compromising information
- semi-official business of outside organisations
- relations with government or other organisations which may contain confidential information

The first reaction may be to destroy this but it is better to discuss the problem with an archivist or records manager who will be used to dealing with this kind of material.

Bear in mind that with the passage of time even very confidential matters become less sensitive. It is preferable to plan restricted access or closure periods if necessary than to destroy evidence forever. Many public organisations operate a closure period of 25-30 years before information which has not already been in the public domain, can be seen by researchers. Information about the health of individuals may well be kept closed for a longer period. If material is to be deposited elsewhere it should be discussed with the archivist who will have responsibility for administering the access rules.

Who will give advice?

Advice should be sought as early as possible from a professional organisation or a local archival institution. Addresses can be sought from national, local and regional archives or libraries. Contract archivists can sometimes be employed for a short time for particular situations.
The international organisations listed below can also be contacted for help.

International Council on Archives (ICA);
60 rue Francs-Bourgeois, 75003 Paris, France
(e-mail; ica@ica.org) for information on regional and local archives as well as archival advice

International Federation of Library Associations (IFLA);
IFLA-PAC, Bibliotheque Nationale de France, 2, rue Vivienne, 75084 Paris cedex 02, France for information on regional and local libraries as well as archival and library advice

International Records Management Trust;
12 John Street, London WC1N 2EB,
United Kingdom
(e-mail; irmt@sas.ac.uk)

ILA – Global Project on the History of Leprosy,
Wellcome Academic Centre, Euston House,
24 Eversholt Street, London, NW1 1AD, UK.
Tel: +44 (0)20 7611 8861
Fax: +44 (0)20 7611 8562
Email: info@leprosyhistory.org
URL: http://www.leprosyhistory.org
This project will end August 2002.

Acid free paper suppliers

To find acid free paper try contacting your local, good stationer. If they cannot help contact your national archives or library for advice.
Listed below are three international suppliers.

PEL
Shelfanger, Diss
Norfolk
IP 22 2DG
UK
Tel: +44 (0)1479 651527
Fax: +44 (0) 1379 650582
Email:

Atlantis France
26 rue des Petits-Champs
7500 Paris
France

Hollinger Corporation
P.O. Box 8360
Fredricksburg
VA 22404
USA

This booklet has been printed on acid free paper

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50 YEARS: COMMEMORATIVE SERIES - 2

LEPROSY
IN THE SOUTH-EAST ASIA REGION

50 1948 1998

WORLD HEALTH ORGANIZATION

HEALTH FOR ALL- ALL FOR HEALTH

50 YEARS: COMMEMORATIVE SERIES - 2

LEPROSY

IN THE SOUTH-EAST ASIA REGION

1948
1998
WORLD HEALTH ORGANIZATION
HEALTH FOR ALL- ALL FOR HEALTH
Regional Office for South-East Asia
New Delhi
1998

Message

Leprosy has, for ages, been one of the major public health problems in several countries of the world including those in WHO's South-East Asia Region. However, as we approach the new millennium, it is encouraging to note that, for the first time ever, the magnitude of the leprosy problem appears to be declining. This has been made possible with the discovery of the multi-drug therapy (MDT) regimen in the early 1980s, the commitment of governments and the dedication of health workers in controlling the disease.

Yet, while the progress has been gratifying, there is no room for complacency. The challenge of responding to the needs of the already disabled remains an important and difficult one and needs to be addressed through an intersectoral, community-based approach with full recognition of cultural and cost considerations.

There are still many hurdles to be overcome to achieve the leprosy elimination goal of one case per 10,000 population by the year 2000. The South-East Asia Region accounts for 66% of the world's leprosy cases. The task of achieving the elimination goal will therefore require intensified efforts by countries and by all those involved in addressing the challenge. WHO affirms its commitment to support Member countries and communities in their efforts to control leprosy. What we need to do is to establish and strengthen partnerships with all concerned in order to harness the needed resources, and to reinforce the determination of Member countries to conquer leprosy. We also need the support of individuals and communities in understanding the disease, and in enabling those afflicted to sustain the required treatment.

Leprosy is no longer the concern of governments or the health community alone - it is everyone's concern requiring a multi-sectoral effort.

This information kit outlines the extent of the problem as well as the strategies to deal with it. It is hoped that the publication will help strengthen our efforts at all levels to eliminate leprosy from the Region.

Dr Uton Muchtar Rafei
Regional Director

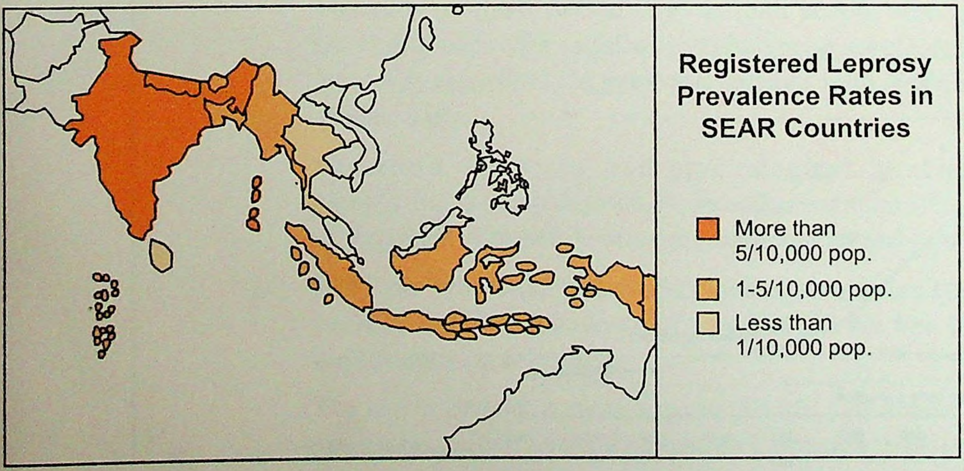
LEPROSY IS CURABLE

DO NOT FEAR IT. TREAT IT.

A major public health problem

Although a cure was found for leprosy several decades ago, it is still a major public health problem, particularly in several countries of the WHO South-East Asia Region. Out of the five countries with the largest number of leprosy cases in the world, four are in the South-East Asia Region. These are Bangladesh, India, Indonesia and Myanmar which account for an estimated 70% of the global registered cases, with India contributing nearly 55% of the total. Every year around 400,000 new cases continue to be detected. This constant increase is no doubt cause for concern. But the optimistic news is that the total numbers cured by the revolutionary multidrug regimen (MDT) increased from 1,100,000 in 1985 to 8,400,000 in 1997. And the registered cases declined from 3,800,000 in 1985 to 640,000 in 1997.

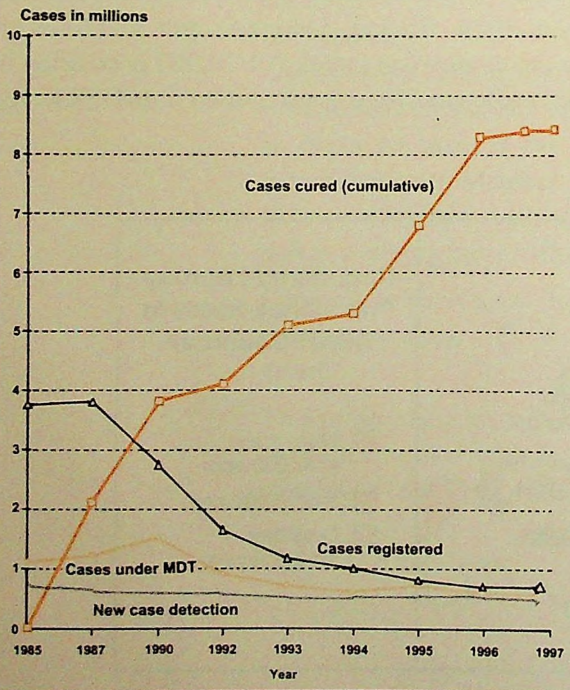
Despite the high numbers still afflicted, many countries such as Bangladesh, India, Myanmar, and Nepal hope to eliminate leprosy by the end of the millennium. Thailand and Sri Lanka have achieved the elimination targets in 1994. Bhutan, Indonesia and Maldives are expected to achieve the elimination target of 1/10,000 population by the year 1998. No cases of leprosy have been reported from DPR Korea.



Leprosy - the cause and transmission

Before we can begin to address the problem of leprosy elimination, it is important to understand what causes leprosy, how it is spread and how its transmission can be prevented.

- Leprosy or Hansen's disease, is a communicable disease caused by a microscopic germ, *mycobacterium leprae.*
- The leprosy germ is commonly transmitted through repeated and close contact with the patient.
- Leprosy is less infectious than diseases like measles or tuberculosis. What is more, all leprosy cases are not infectious - only 15-20% cases are of the infectious type.
- As in the case of other diseases, personal and environmental hygiene is very important to prevent transmission of leprosy.
- There is no effective vaccine that can provide protection against leprosy.
- Leprosy is curable through a regimen known as Multidrug Therapy (MDT) which must be taken for as long as prescribed.



Trends in multidrug therapy (MDT) and cured leprosy cases in SEAR, 1985-97

Source: *WHO/SEARO, Leprosy Unit*

The MDT Experience

Although the regional situation is still quite serious, much progress has been made since the 80's with multidrug therapy (MDT) which provided the necessary momentum to the leprosy control programmes.

WHO Region	Registered cases	Prevalence per 10,000	Cases on MDT	MDT coverage (%)	Cured with MDT (cumulative total)
Africa	95,901	1.77	87,739	91.5	443,610
Americas	336	1.64	93,004	75.3	225,450
Eastern Mediterranean	23,005	0.54	19,083	83.0	52,784
South-East Asia*	***638,296***	***4.60***	***631,913***	***99.0***	***8,373,122***
Western Pacific	32,254	0.20	31,943	99.0	206,635
Total	**926,259**	**1.67**	**842,438**	**91.0**	**7,988,404**

**Data for South-East Asia is provided as of July 1997, for the other Regions, 1996*

The overall MDT experience has been positive:

- The record of MDT in prevention of relapse and drug resistance has been outstanding. MDT has cured patients in finite periods of time. However, the duration of treatment is relatively too long for multibacillary cases. Following the WHO Expert Committee meeting in Geneva in mid 1997, the Simplified Treatment of Leprosy (STP) recommended for multibacillary cases, reduced the duration of treatment from 24 to 12 months with each dose given monthly.
- The success with MDT has brought leprosy control within the mainstream of medicine and public health. This has enabled health care to be provided within the general health services with the emphasis on primary health care.
- Although MDT, applied sufficiently early, can significantly prevent deformities, it cannot remove existing deformities. There are estimates of about two to three million people who are disabled physically and suffer socially due to past or present leprosy infection. However, since1982 the number of patients with disability declined considerably.
- Therefore, the social and psychological problems due to complications of leprosy need to be addressed even after completion of treatment with MDT, through social and mental rehabilitation.
- MDT can drastically reduce the number of registered cases, but its capacity to reduce incidence of new cases in the first five years of implementation is limited.
- The use of Special Action projects (SAPEL) in remote or difficult areas along with Leprosy Elimination Campaign (LEC) can increase community awareness and improve self-reporting of new and unreported cases, and accelerate the achievements.

Programme Management

To stimulate the leprosy elimination process, some innovative approaches have been proposed and tried according to the situation, conditions and available resources of each country:

Bangladesh

- Upgradation of combined TB-leprosy services from central, divisional, district and *thana* health levels to union-level; and of the reporting system from the *thana* health level to the Central level.
- Prompt management of leprosy patients who delayed seeking treatment, to reduce the number of new cases detected with serious deformities.

Bhutan

- Integration with general health services in leprosy hospitals.
- Detection and follow-up of leprosy patients in remote areas.
- Improved distribution and supply of MDT up to the health centres.

India

- Better coordination with NGOs, especially in case-detection, to avoid duplication in the reporting system; and MDT supply.
- Special programme in the hyperendemic and remote areas of Bihar.
- Integrated approach in Tamil Nadu with prospects of introduction to other states.
- Improvement in MDT distribution from the central to health-centre level; and a more reliable reporting system.

Indonesia

- Emphasis on better coordination with NGOs; and case-detection to avoid duplication in reporting system and MDT supply.
- Better systems of management and reporting at all levels.
- Extending target for achieving the elimination goal (prevalence rate less than 1/10,000 pop.), from national to district level.

Maldives

- Priority to management of surveillance in all health units.
- Improved case-management and reporting systems in the islands.
- Reliable MDT distribution in all remote areas (islands).

Myanmar

- Fully integrated approach at the rural and subcentre levels and fully de-centralized system up to subdistrict level (township).
- Involvement of village midwives (the Red Angels/Red Loungies) in case finding and distribution of MDT to individual patients.

- Upgradation of systems for management, reporting and supervision at central, regional and district levels.

Nepal

- Closer monitoring of MDT distribution and supply.
- Coordination with NGOs in case detection to avoid duplication in treatment, reporting system as well as MDT supply.
- Selection and appointment of experienced and committed national consultants for advising on the leprosy programme.

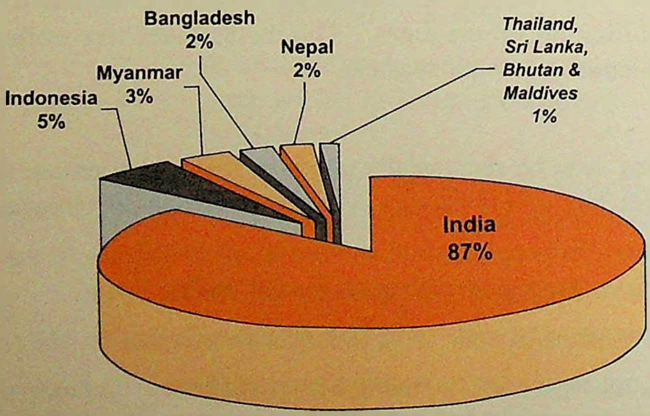
Sri Lanka

- Management of, and sustaining the social marketing endeavours.
- Partial integration of leprosy control into the PHC; prevention of disability and emphasis on community-based rehabilitation (CBR).
- Institution of improved surveillance systems in primary health centres and other health units.
- Emphasis on more reliable reporting and MDT distribution systems.

Thailand

- Prioritizing post-elimination strategies with special attention to surveillance, fixed-duration MDT, Prevention of Disability(POD), IEC in health centres and rehabilitation.
- Introduction of CBR in northern Thailand and, gradually, to other areas.

Proportion of Registered Cases in SEAR Countries (Total Registered Cases: 6,38,296)



Priorities for future action

These include:

- Intensification of monitoring and evaluation of leprosy- elimination activities in highly endemic countries and states.(> 3/10,000 pop.)
- Introduction and adoption of the post elimination strategy in the low endemicity countries, and in countries where the elimination target of 1/10,000 pop. has been achieved.
- Continuation of the Leprosy Elimination Campaign (LEC) and Special Action Projects (SAPEL) to detect hidden/undetected cases.
- Introduction of a nationwide LEC is planned in some countries like Bangladesh, Indonesia and Myanmar during 1998, along with observation of a Leprosy Week to provide focus on key issues.

The real challenge of leprosy

Leprosy has long been considered a dreadful and feared affliction. There is still a strong social stigma attached to the disease. As a result, those with leprosy hide their symptoms and diagnosis from families, friends and employers instead of seeking treatment.

The medical, social and psychological dimensions:

- The medical dimension involves early detection, proper and sustained treatment with the MDT regimen, or physiotherapy, treatment for ulcers, and physical rehabilitation.
- The social dimension involves love and support from families, society and employers to overcome humiliation and the need to hide.
- Patients undergoing treatment could develop psychological problems which may require rehabilitation through community-based rehabilitation programmes. This helps them live normal and productive lives within society.

Leprosy: the myths and reality

If leprosy is to be successfully eliminated, we must ensure that the disease is demystified through correct information dissemination:

- Contrary to popular belief leprosy is not hereditary. It can affect anyone - the rich and the poor, the old and the young.
- Leprosy is not a curse from God, or a punishment for sin.
- It is not necessary to isolate leprosy patients. Leprosy patients undergoing regular treatment must be encouraged to seek treatment and live normal and productive lives with their families.

Some important facts about leprosy

Causes and prevention of deformities:

- Deformities develop because leprosy damages some nerves - thus patients may develop claw hands, foot drop, etc.
- Deformities can be prevented through early, regular and complete treatment. Some early deformities can be remedied through physiotherapy and surgical interventions.
- Early detection with early treatment leads to early cure without disabilities or any physical signs of the disease. " An early case of leprosy is no longer a tragedy; what is a tragedy is no treatment in an early case of leprosy" - Dr.Hemmerijckx, famous leprologist from Belgium.
- Ulcers are caused when the disease affects the nerves and leads to loss of sensation so that the patient is unable to feel heat, cold or pricks from sharp intruments and can get injured without being aware of it.

Management problems in leprosy control

The progress of leprosy elimination activities in the SEAR countries has been rather slow because of several factors.

The main problems are:

- Financial constraints due to the low priority accorded to leprosy control.
- Shortage of qualified leprosy workers, coupled with frequent turnover of staff, and the complexity of the reporting system.
- Poor management of drug distribution from the national level to the health centres.
- Inability to reach those in remote areas.
- Inadequate implementation and lack of other innovative approaches such as LEC to detect hidden or unknown cases according to WHO guidelines.
- Lack of active involvement of local authorities and community leaders in control activities at the district and health centre levels.

The other problems faced by some countries are:

- Over dependence on NGO assistance for the control of leprosy.
- Lack of coordination between NGOs and the government.
- Difficulties in implementing the integration policy for leprosy

Strategies for combating leprosy:

A landmark resolution was adopted by the Fourteenth World Health Assembly on WHO's commitment to eliminate leprosy as a public health problem by the year 2000 through the use of MDT. Substantial support of NGO's and an increased priority to leprosy elimination by governments was also called for.

WHO pledged technical support and promised to mobilize and coordinate resources to achieve the elimination goals of 1 case per 10,000 population by the end of the millenium.

To attain this goal, countries need to give attention to:

- Effective surveillance systems for proper case finding and reporting, with greater vigilance in endemic areas.
- Strengthening infrastructure of health facilities for diagnosis and treatment, especially in difficult-to-reach cases and areas.
- Proper motivation and incentives for sustaining treatment.
- Monitoring and follow-up of treated cases; estimation of hidden cases.
- Securing NGO cooperation and assistance in capacity building.
- Ensuring an adequate number of trained and motivated doctors and health workers dedicated to the cause.
- Strengthening facilities for the proper rehabilitation of leprosy patients through physiotherapy and surgical interventions; and imparting of vocational training.
- Ensuring cooperation of the private sector in the regular supply and distribution of drugs.
- Designing and mounting regular information, education and communication campaigns to educate people on the basic facts about leprosy, and to generate community support.

WHO's role and contribution

- WHO works with countries to focus attention on the problems and the issues of leprosy control and to promote action on managing leprosy elimination programmes according to national targets.
- WHO provides technical support and inputs, advises on surveillance techniques and monitoring systems, assists in drawing up realistic and achievable programmes, and helps in implementation and evaluation strategies.

- WHO supports training and development of guidelines on leprosy control including innovative strategies, and also collaborates in research activities.
- WHO also highlights the need for political commitment to the programme goals, and promotes healthy policies and legislation to ensure the rights of those afflicted by leprosy.

The role of the community and the individual

While governments and NGOs can do much to control and eliminate leprosy, communities and individuals have a more critical role to play in addressing the social dimensions of the problem. This must start with a good understanding of the facts about the disease, its transmission, spread and treatment. More importantly, they must encourage the leprosy-afflicted to seek treatment early and give them the love and support to sustain it.

Here is how you can contribute:

- Educate yourself and share and discuss the correct information on leprosy with friends and relatives.
- Protect yourself against leprosy by having yearly medical check-ups.
- Be vigilant and watch out for the early signs of leprosy. If you see any signs go for an immediate medical examination.
- Educate the family and community not to reject leprosy patients.
- Accept leprosy patients and support them to lead happy, healthy and productive lives.
- Give equal opportunities for education, employment, and marriage to leprosy patients and their children.

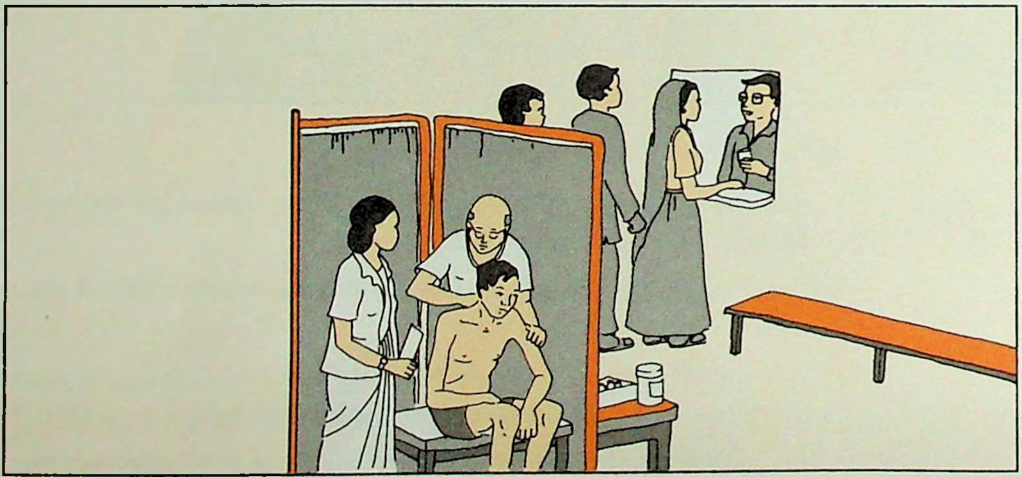
How to recognize leprosy

Leprosy is curable at most stages with sustained MDT treatment. However, MDT cannot reverse any existing deformities by the time a diagnosis is made, and treatment begun. Hence, early detection is very important for a complete recovery and for the prevention of any deformity.

Suspect leprosy when you see any one or more of the following early signs:

- A pale or red patch on the skin and a change in texture on any part of the body.
- A raised or flat patch, which may be dry, shiny or smooth.
- A well demarcated patch on the skin which is insensitive to pain.
- Loss of sensation in certain areas of the body to touch, heat or cold - either in the presence or absence of a patch.
- A lesion which does not itch.

However, all skin patches may not be leprosy. They could be due to some other skin condition. It is always better to get them examined by a doctor, or community health worker rather than to neglect them



Leprosy is curable

Leprosy can be eliminated. What is needed is early detection, early intervention, sustained treatment, and community support throughout. Leprosy can be cured. But the real healing touch must come from you.

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LEPROSY CONTROL: EVERYONE'S CONCERN

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NEW DELHI-110 003.

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स्वास्थ्य एवं परिवार कल्याण मंत्री
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नई दिल्ली-110011
**MINISTER OF
HEALTH AND FAMILY WELFARE
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FOREWORD

I am happy to learn that the UNICEF is bringing out a publication on Leprosy Control on the occasion of 12th International Leprosy Congress being held in India during February, 1984. The Congress is an appropriate occasion for all those who are engaged in the work of fighting Leprosy, to get together, pool their experiences and evolve strategies for attaining the national objective of eradicating leprosy. Leprosy is one of those fields where intensive research has resulted in the evolution of a strategy which can lead to the eradication of this disease. It is now for all of us to intensify our efforts, educate leprosy patients, advise them about the medicines and ensure that medicines are administered regularly. Rehabilitating the cured patients would be another dimension needing attention of the planners, social scientists and medical professionals.

Leprosy Eradication Programme is one of the important programmes in the Prime Minister's 20–Point Programme and additional resources have been provided to combat this disease. We have intensified our efforts to detect and cure the patients suffering from this disease. I am sure the UNICEF publication which is addressed to different categories of people like the health professionals, the voluntary agencies, the mass media, the teachers in the medical profession etc. would evoke discussion leading to action for the eradication of leprosy.

New Delhi,
February 3, 1984.

(B.SHANKARANAND)

INTRODUCTION

Leprosy is an ancient, and in many aspects incomparable, disease. A new front in the battle against it was opened by the discovery of the bacillus causing it. Yet the disease remains unyielding in many parts of the world. Despite the availability of the technological means to control it, the disease still eludes even those countries that have the needed financial resources.

The obstacles are many. Leprosy is not yet considered a public health priority by the policy makers. In consequence, anti-leprosy work fails to attract the necessary budgetary support. The available leprosy services have remained underutilised–as a result of ignorance about, and indifference to, early manifestations and unexpected complications of the disease. An unfavourable socio-psychological environment in which affliction by the disease has been associated with social stigma, has reduced the chances of early diagnosis, the effects of adequate intervention, and the prospects of sustained treatment.

Of the 15 million people the world over suffering from leprosy, nearly 4 million are estimated to be in India. And, as many as 20-25 percent of the newly detected cases are children. Leprosy in the child represents nearly all the aspects of the disease in the adult, with additional characteristics peculiar to itself. Next to poliomyelitis, leprosy is the greatest crippler in the world. Physical deformity and disability are major consequences of the disease. But early detection and adequate treatment will.diminish the damages of deformity. For a person suffering from leprosy, rehabilitation should start when the diagnosis is made. Rehabilitation implies the physical,psychological and social restoration to as near normalcy as possible, of treated patients. It is with reference to their position in the home, in society and at the workplace. To achieve this, treatment of the physical disability is obviously necessary but it must be accompained by the education of the patient, the family and the community, so that they will not only accept him but also assist in completing the restorative process.

The link between an environment of poverty, with its implications for the quality of human life, and the occurrence of leprosy is beyond doubt. Poor housing, commonly linked to overcrowding, insanitary conditions, inadequate hygienic practices, a precarious nutritional status, lack of educational opportunity and similar drawbacks are closely correlated with ill health in general, and leprosy in particular. Any effective approach to leprosy control has therefore to address these intimately inter-related factors which are but reflections of low level of socio-economic development. It is becoming increasingly clear that simple and uniform answers to leprosy are inadequate. Renewed efforts are being made to understand not only its medical ramifications, but also the social, economic, cultural and psychological factors that interfere with its control.

To control a chronic disease like leprosy, a permanent and reliable community-based health service infrastructure is of utmost importance, for detection, uninterrupted treatment,.surveillance and other essential public health measures and complementing activities. Thus, to be effective, leprosy-specific health services must be close to the people for whom they are meant. The most promising strategy to overcome constraints in the way of leprosy control seems to be a functional tie-up with the primary health centres. The primary health care approach, involving the active participation of the community, may well be appropriate for effective leprosy control. Such an approach integrates, at the community level, all the elements necessary to make an impact on the health status of the people, bringing together preventive, promotive, curative and rehabilitative health measures as well as supportive development activities in allied fields.

It is common experience that patients present themselves for examination only after they themselves are somehow convinced that they have leprosy. Consequently, the diagnosis is delayed, the patient may have infected others, and in many cases permanent nerve damage leading to disability and deformity, may have set in.

The control of leprosy is rooted in health education, early diagnosis using active methods of case detection and early treatment of all forms of the disease. An effective health care programme with a well planned health education input will encourage people to voluntarily report any newly-noticed skin patch. All sectors of the community are equally important as far as health education is concerned. Co-ordinated health education activities should be carried out by the public health services in charge of leprosy control programmes, school health officers and private organizations concerned with leprosy in the community. Medical and para-medical personnel as well as education authorities, school teachers, the media, voluntary agencies and the community as a whole must be aware of the importance of early diagnosis, regular treatment and social acceptance of leprosy patients. They key to leprosy control is the attitude of the community.

A breakthrough can come through a change in the knowledge, attitudes and practices of society, and in particular of various influential groups including of course, the health personnel. This publication is intended to promote the process of such change. It is addressed to different segments of society–the health profession, the education system, voluntary agencies, the media, the policy makers and the general public. It is hoped that the discussion that follows will stimulate the reader to make his or her own invaluable contribution to leprosy control.

TOWARDS ERADICATION

K C Das

Leprosy was prevalent in ancient India. References to the disease are found in old Indian literature like Charak and Sushrut Samhita, Bhagwat and Manusmriti dated as back as 400 B.C. Two types of the disease were described. Establishment of social relations by hiding the disease was considered to be a sin. Ayurvedic treatment was given. Some of those drugs are used even today by the practitioners of that system.

In the years before political Independence, the disease was tackled mostly by foreign missionary organizations and some local voluntary bodies supplemented by limited activities of Government, Municipal Corporations and District Boards. By 1947 when India became free, there were 152 leprosy homes and hospitals with 19,600 beds and 1,203 leprosy clinics with about 120,000 cases treated annually. The method of work was propaganda, treatment and survey (PTS method). The drug of choice was Hydnocarpus oil used by injection and occasionally by massage in addition. The period of treatment was almost throughout life. The Lepers Act 1898 was also in force. Most of the patients were then isolated in leprosy homes, hospitals or colonies. Returning to the family was rare. There was a great prejudice against the disease. Due to prolonged sickness and ineffective treatment most of the patients ultimately developed gross physical deformities. Sulphone came to be used as an antileprotic drug by about 1948.

The National Leprosy Control Programme (now named the National Leprosy Eradication Programme) was launched in 1954-55, in the latter part of India's first Five Year Plan. The modes of control chosen were the early detection of cases through house to house surveys; education through individual and mass communication for community involvement in removing the social stigma and ostracism associated with the disease and in encouraging voluntary reporting of cases; and mass treatment through a domiciliary and ambulatory pattern with oral dapsone tablets. This method of Survey, Education and Treatment, called SET in short, formed the basic pattern of leprosy control work. Leprosy control units, SET centres, training centres, temporary hospitalization wards, urban leprosy centres, voluntary SET centres, district leprosy units, leprosy training and research institutes were established in different parts of the country in subsequent plan periods. Rehabilitation is a very difficult and costly effort. The emphasis therefore is on preventive dehabilitation, reserving rehabilitation for the few who have been already dehabilitated.

The Magnitude

The first authentic estimate of the magnitude of leprosy problems in the country was made in 1954 by the Committee of the Government of India for the control of leprosy. The estimated number of cases then was 1.5 million, of which about 1,20,000 were patients receiving treatment. The problem was assessed subsequently and the estimated number of cases was 2.5 million in 1961, 3.2 million in 1971 and 3.95 million in 1981. The average proportion of infectious cases was 25 percent, the deformity rate was 25 percent and childhood rate 20 percent. Of late, the rates seem to have reduced marginally. The latest position is that out of 412 districts of the country 212 districts have a prevalence rate of 5 and above per 1000 population. About 400 million people live in those districts. Most of the 3.95 million cases belong to this population. On an average about 0.5 million additional cases are identified annually and about 0.3 million cases are dropped from the list, discharged after cure, or due to death or other reasons. About 3.1 million cases are on record now, of which, about 2.9 million are receiving treatment.

Operational Pattern

The main components of the National Programme are case detection, health education, treatment, prevention and correction of physical deformities, training, rehabilitation, research and assessment. These are done by trained medical and non-medical personnel working in various government and voluntary leprosy centres and institutes established under the programme, and also by some general health and leprosy institutes established outside the programme. Trained leprosy workers are provided at the ratio of one worker to a rural population of 20,000 to 25,000, and one worker to an urban population of 30,000 to 70,000. In leprosy endemic areas in difficult terrain, there is one worker to a population of 5,000 to 10,000. For every five to seven workers, there is a trained non-medical supervisor, and for every three to four such non-medical supervisors, a trained doctor, a laboratory technician and health educator are in position

Recently, the District Health Officer has been made responsible for supervision and administration of the entire Leprosy Eradication Programme in the district. This step has made for unified control and better results are obtained through improved supervision and proper use of available staff.

Approach

The SET approach is as follows:

Survey

This is done house to house, at schools, by family visits, and through health educational approaches, voluntary reporting, contact examinations and referral services. Diagnosis is confirmed by the doctor and sometimes, in the absence of a doctor, by the non-medical supervisor.

Education

This is imparted through individual and mass communication by utilizing coloured picture cards of patients with hints of diagnostic signs and symptoms, pamphlets, posters, and booklets on leprosy. Individual and group talks are arranged. The mass media like radio, television, newspapers, and journals are used.

Treatment

The line of treatment is indicated by the doctor or the non–medical supervisor and delivered by the leprosy paramedical worker who holds weekly or fortnightly outdoor clinics at vantage points in the area. Domiciliary treatment is also given through the network of outdoor clinics. Segregation of leprosy patients has no place in the modern leprosy control programme. Hospitalization for temporary periods to tide over the crisis in respect of a few leprosy patients who suffer from complications is necessary and facilities are made available for such patients for special care and treatment. Clinics are held at health centres and hospitals. Complicated cases are treated in leprosy hospitals or under the close supervision of the medical officer of the field unit. Monotherapy with Dapsone tablets takes a long time to attain negativity in respect of infectious cases. Multi-drug therapy (with DDS in combination with Rifampicin, Clofazimine or Prothiconamide and, when needed, INH and Thiacetazone) has been introduced to bring down infectivity expeditiously and to thwart emergence of drug resistance. The new multi-drug regimen is implemented under the close supervision of the doctor.

Policy Changes

A working group set up by the Government in 1981 made far-reaching recommendations on a package of public policies and practical approaches needed for leprosy control. In consequences a National Leprosy Control Commission with the Union Health Minister as Chairman, and a National Leprosy Eradication Board under the chairmanship of the Union Health Secretary have been established. Other changes in the direction of systematic detection campaigns, multi-drug therapy, medical education, support for voluntary work, legislative measures, mass education campaigns and research activities are underway.

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COMMUNITY ACTION

K V Desikan

As you stand in the street, waiting for a bus, a hand is thrust towards you, a hand of an annoying beggar, a hand with distorted fingers and festering sores. You loathe to look at the face. You only screw up your own and with a feeling of disgust and pity, hastily toss a coin at him and turn away.

You know the person is afflicted with leprosy, a disease which is feared and abhorred. Your act of charity might have been an impulse to help or to get rid of a wretched persosn. Your coin might help him to buy a meal, but it will not help to solve the problem that has plagued the community for generations. By turning away your face, your eyes, your attention, you cannot elude this human problem. Something has to be done. The society and the community has to accept the full share of the responsibility and every individual member of the society has his own part to play.

"What else can I do?" you will ask, since you are of the workaday world and not a saint or a sanyasi to go and serve the "lepers". It is true that great men and women have poured their compassion to relieve the sufferings of these unfortunate victims, but the contribution that could be made by the society would go to the roots of the problem and eliminate it completely.

The modest first step that everyone should take is not to use the word "leper". It is an odious term associated with indignity and degradation rather than a word used to describe a person afflicted with a disease. A "leprosy patient" is a better term. Some people prefer to avoid the word "leprosy" itself and call it "Hansen's Disease". Changing the name alone does not improve matters. The attitude must change. There is no reason for any special prejudice against leprosy or a person afflicted by it. It is a disease like any other, caused by germs. Anyone can catch the infection irrespective of his social and economic status. Fortunately it is not highly infectious and only about one in five is mildly contagious, the other four being completely non-infectious. It is not hereditary. Nobody is born with leprosy. Some essential facts about leprosy must be understood before one considers what should be done to solve the problem or help the diseased persons.

Society recognizes leprosy by the badly disfigured or deformed persons seen in public places. This category forms only about three to four percent of the total number of patients. If we focus our attention, as we do, to this visible tip of the iceberg, we are only deceiving ourselves.

There is another hard-to-believe truth about leprosy. It is a scientifically established fact that a majority of those begging in the streets with advanced deformities are not infectious, while the infectious cases are moving unnoticed, spreading the disease. Since such persons have no recognizable disfigurement, we do not recognize them as a source of the disease. In many instances, the patient does not know that he or she is suffering from leprosy since the disease does not produce any pain or discomfort. It first manifests itself as a slightly light coloured patch on the body or as a slight discolouration of the skin. These skin changes are neither painful nor itchy; so the patient ignores them. When the disease advances, the skin changes lead to disfigurement and deformities. At this stage, the patient gets noticed by others, but by this time in the course of months or even years of development of the disease, the patient has spread the infection often unknowingly.

This is how leprosy erupts, spreads and manifests. As this process is surreptitious, any attempt to stop it needs the full cooperation from the people and that is why leprosy is everybody's problem. The strategy adopted by the Government under the National Leprosy Eradication Programme is to trace every case of leprosy and treat the person so that the disease does not advance in him and does not spread to others. There are effective drugs against leprosy and disease is completely curable at any stage. However, we have to catch it early and knock it down before it produces any havoc.

It requires trained personnel to detect in early stages and cannot be recognized by the patient himself. So the task calls for systematic examination of the entire population–men, women and children. Such a mass survey could be undertaken only with the full cooperation of the entire community. Therefore one important duty of every individual is to spread this message not only to members of his own family, but to all his neighbours, friends and relatives.The Government of India has spread out a vast network of centres to cover a population of 300 million population in this "Trace and Treat" effort. This is done mainly in villages. The cooperation of the village people has been encouraging. However, in urban areas a greater effort is needed to involve the community. Educated persons, youth, student organizations, social welfare workers should come together and help in carrying out this campaign. Society has to be informed that leprosy is not a disease seen only in beggars and in slums, but in all its segments. It is no shame to get checked by a doctor or a trained worker, to exclude the disease. At the earliest suspicion, rush to the doctor as you would rush for any other ailment.

Today there are new, very effective drugs against leprosy. Detected early, there is a hundred percent cure without leaving behind any obvious marks on the body. Even in advanced cases, the disease can be cured, only it takes more time. Treating the cases helps also in reducing or removing the source of infection. So, if I or my family members should be protected against leprosy, the persons known to be having the disease must be encouraged to get regularly treated. The cooperation of the patient is therefore essential if the spread of the disease is to be stopped.

How are we get the cooperation from the patients? Not with hatred, fear and prejudice. Such hatred and prejudice will make him hide the disease, refuse treatment and thereby spread the disease. There should be a balanced approach so that he will cooperate to help himself and others. Once a person gains the confidence that he will not be ostracised and penalized for catching a disease for no fault of his, he will cooperate as much to his own advantage as to the benefit of others.

To inculcate confidence in the patient, society has to throw away the baseless prejudices. The majority of the obvious and deformed cases who are not infectious, should be accepted in society and given employment with the same compassionate consideration as to persons disabled due to accident or injury. Even those with active disease who are possibly infectious should not be shunned. They could continue in the avocation while under regular treatment and should only avoid close contact with healthy persons, particularly children including their own. Rehabilitation of disabled leprosy patients is an important duty of the society, but a more urgent work is to see that leprosy does not spread so that the need for rehabilitation is avoided.

Leprosy can be eradicated if the community works together with the health authorities. The disease is to be fought with knowledge and not with prejudice and false beliefs. It is a scientific truth that an infectious leprosy patient spreads the disease, but it is a sociological fact that society actually helps him to do so, by fear, prejudice and hatred. The fear is more dangerous than the germ.

Dr K V Desikan is the Director of the Central Jalma Institute for Leprosy, Agra, New Delhi.

THE MEDICAL ROLE

R H Thangaraj

A large majority of the four million leprosy sufferers in India are seen in the hyperendemic areas of Tamil Nadu, Andhra Pradesh, Orissa and West Bengal. The National Leprosy Control Programme has been in operation for over two decades, but it has had no appreciable effect on the overall incidence of new cases that appear. However, in some of the well-run centres, where an effective programme has been going on for 10-15 years, the incidence ofleprosy has come down - in other words,leprosy can be brought under control with the existing means and methods. But this will not prevent us from our search for more effective and economical alternatives.

What can the medical profession contribute to the 'Control of Leprosy and its Eradication by the year 2000 AD?' Leprosy is more than a medical problem but the problem is primarily medical and the disease is among the grossly neglected subjects by the medical profession.

Leprosy control is based on the principles of early detection of cases and regular treatment of patients to bring down the quantum of infection and thereby to reduce the transmission of the disease to heathy contacts. Let us consider what health professionals can do in detecting the cases, in educating the public and in effectively treating the patients. They should, first of all, be willing to treat leprosy on par with other diseases if the leprosy control programme has to be successful. The medical world should accept leprosy like any other disease and this change in attitude towards leprosy should start at source–the teaching institutions where young doctors and other paramedical personnel are trained.

It is a fact that not much time is devoted to leprosy in the medical colleges. The young medical students should be convinced that leprosy is like any other disease. They should be given adequate exposure during their clinical years, to the various manifestations of leprosy, its complications and the treatment of such complications. Short visits to leprosy centres could be arranged where they can see a variety of cases. Guest lecturers from these centres could be invited for clinical meetings, teaching sessions and discussions at the medical colleges.

Though leprosy patients are usually seen in the dermatology out-patient wards, screening patients for leprosy should be made a routine practice in the general medical examination, like looking for anaemia, clubbing, oedema etc.

It is common practice for students to devote more time on topics which are likely to come up in the examination. Leprosy cases should be included in the clinical examinations conducted at the end of the year. All possible encouragement should be given to the doctors who take up leprosy work.

A certain number of beds should be allotted in the general hospitals for admission for complications like reactions and plantar ulcers. These beds should not be used for other patients while leprosy patients wait for admission. Basic service facilities should be provided in all the centres, and these include physiotherapy (where care of anaesthetic extremities is taught so that mutilation does not occur), facilities for providing simple protective footwear and laboratory examination.

About 20-25 percent of patients have deformities which are the main cause for the stigma attached to this disease. Much of the deformity is preventable if only certain simple methods are followed. Even if deformity occurs, it can be corrected. Patients with deformities of hand or foot should be seen in the orthopaedic department, where special facilities should be available for instruction on hand and foot care, as well as for management of complicated problems like neuropathic disorder of foot which if detected early and treated promptly, will obviate much suffering. Students are to be given adequate training in prevention and management of deformities. Leprosy is one of the major causes of blindness in adults and it should be an important concern of the ophthalmology department.

The patients' waiting-rooms are usually filled with health education posters on nutrition, scabies, diarrhoea, and tuberculosis. For some reason, leprosy is not elevated to that respectable position. Adequate measures should be taken for display of information on leprosy in simple language. It is also the duty of the health profession to educate the public about leprosy so that they may help in detecting the cases early. Early detection and regular treatment would mean prevention of much deformity and disability.

It is relatively more effective when health information comes from a medical person. There are many misconceptions among the public about the nature of the disease: that the disease is hereditary, that it is incurable,that the word leprosy is synonymous with deformity and disfigurement. These wrong beliefs only help to perpetuate the problem. The medical prefession should lead the way in all attempts to remove such wrong notions. The television, radio and newspapers should be made use of to disseminate scientific information on the disease and the information should be given in simple language, avoiding the technical jargon. The medical profession, which is very much respected by the community, can also work through organisations like the Lion's Club, Rotary Club and other social-service organisations.

In the medical exhibitions that are conducted in colleges, leprosy should find a prominent place and such opportunities should be fully made use of in educating the public.

During the routine medical check-up in schools, factories and other work places, it should be made an invariable practice to look for leprosy. This again helps in early detection of cases.

Doctors in general practice should become aware of the magnitude of the problem and they should be acquainted with the common signs and symptoms of the disease and also its treatment. They are the ones to see the patient first and they also have a good contact with the rest of the family. In fact some of the leprosy patients might prefer taking treatment from their own family physician, to going to a leprosy hospital, where everybody comes to know that he has leprosy. Refresher Courses should be arranged at regular intervals to keep the doctors in general practice up-to-date: for example–on Multidrug Therapy which has recently been introduced on a mass scale. These doctors could play a big role in the control of leprosy, since they are better placed to retain the patient for treatment (case holding).

The same principles apply to doctors working in smaller hospitals at the district, taluk and primary health centre level.

When leprosy patients suffer from other ailments, doctors should not hesitate to admit them into general wards along with other patients, remembering to treat them with equal respect. The nurses and other paramedical staff should be educated first so that they will not show discriminaion against the leprosy sufferers because any such discrimination might turn them into anti-social elements.

In addition to survey and education, doctors have an important role to play in the treatment of the patients–treatment which attends to his physical, mental and social needs and not just doling out tablets. In a chronic disease like leprosy, it is very difficult to retain patients for long on treatment. However, once the patient develops trust and confidence in the doctor, he will continue treatment for as long as necessary.

Patients should also be educated on the proper care of hands and feet so that much disability can be prevented. At the village level all health personnel, inspite of the fact that people specially trained in leprosy are available, should be trained in how to recognize early leprosy. Cases for confirmation of diagnosis and treatment can be referred to bigger centres. This will increase the case detection rate.

About 25 percent of the patients have deformities. These should not have occurred but those that occur should be corrected, to improve function as well as appearance. However, the few existing centres will not be able to deal with such a big load of cases and it is not economical to start new centres for reconstructive surgery. This problem can be solved if the medical colleges could incorporate reconstructive surgery in their orthopaedic or plastic surgery units. Young doctors can also be trained in surgery so that they in turn develop their own team and also train others.

Laboratory facilities for skin smear examinations should be provided and smear examination must be made part of general laboratory-technicians' training. Or if necessary, laboratory technicians could be sent to leprosy centres for training in smear examination.

Leprosy should find its rightful place in the curriculum for nurses. They should be able to recognise the various signs of leprosy and its complications and report to the doctor where necessary for prompt treatment. Visits to leprosy centres should be arranged for orientation. In addition, they should also be trained in the care of anaesthetic hands and feet.

Individual patient care helps directly in the control of leprosy. Rehabilitation efforts start from the first exposure to diagnosis of leprosy. The diagnosis itself causes a lot of psychological trauma and every patient must be talked to and his questions answered and all attempts made to prevent his dehabilitation and displacement from society. Which other profession is better suited in counselling the patient and his family than the doctor and his team? It is time for the medical profession, which has isolated itself from the disease to come forward to shed some light on those who have been in isolation because of the disease. Though the medical profession is not trained in the various rehabilitation methods, they can guide the person and the rehabilitation experts from the medical point of view.

Workshops and seminars on leprosy conducted by the leprosy centres to which doctors from the teaching institutions are invited to take part, will not only increase the awareness among the medical profession of the problem of leprosy, but might also generate more interest in particular aspects of the disease. It is heartening to note that teaching and training sessions are included for young doctors at the XII International Leprosy Congress to be held in Delhi in February 1984.

Thus, the health profession has a very important role to play in detection of cases of leprosy, dissemination of health information to public and treatment and rehabilitation of the individual patient—all of which work towards the control of leprosy.

Dr R H Thangaraj is the Director of the Leprosy Mission for Southern Asia.

EFFECTS OF EDUCATION

M S Nilakanta Rao

Leprosy has been a disease of man, probably for more centuries than recorded history. Nobody knows the region of its origin and the methods by which it spread all over the world.

Leprosy is known to have existed in almost all known parts of the world even 2000 years ago. One computation indicates that there were 200,000 patients in India at that time. In the 15th and 16th centuries a large number of people in European countries were afflicted by leprosy.

Evolution of Misconceptions:

People had their own conceptions based on what they had heard before and what they observed. They considered their observations as facts. Their reactions were moulded by what they had known. Such impressions and reactions were passed on from one generation to the next, with some additions at each stage.

These notions may be summed up:

Leprosy was something terrible. Hence those who had the disease were "lepers".

Leprosy was "unclean", whatever that might have meant.

Leprosy was a disease which spread from such "unclean" persons to other members of the society who were probably considered as clean. Therefore the "lepers" had to be isolated and kept far away from the society. In case they would come to the areas of normal society they should announce their arrival by some means.

The concept of isolation extended to such an extent that contracting leprosy meant social death. For all practical purposes a "leper" was no more alive so far as the rest of the society was concerned.

This thought extended further and caused the immediate relatives to perform their last rites ahead of their death! In some countries the "leper" was expelled to jungles. In some others he would be buried alive.

These concepts led to some interesting procedures in some places. To give one example: once a year, the village chief and his associates would sit in a particular place, and all the villagers had to parade in front of them. The village leaders would pick out the "lepers"; and order either exile or burial.

In the minds of all the people leprosy meant gross deformity, that is complete disfigurement of the face and loss of limbs. People generally believe that man was made in the image of God. In other words, striking and chiselled features which rendered a human being attractive was considered closer to God. A "leper" with total disfigurement of face and mutilated limbs was therefore far removed from God. So he must have been positively a sinner. And his disease was the result of sins.

Leprosy was found in children of leprosy parents; or an adult "leper" had leprosy parents. Therefore leprosy was considered hereditary.

These and similar misconceptions were rampant and had taken deep root in the human psyche. Even now large sections of the people, all over the world harbour such ideas. On account of such misapprehansion and the absence of an effective drug in any system of medicine, the only methods of approch towards the sufferers were either to be compassionate or to be hateful. Those who were compassionate were few. The discovery of lepra bacillus in 1873 and of DDS as an effective drug (in 1947) were momentous. This triggered the process of development of a positive and rational attitude towards the disease. Since 1947 considerable amount of new knowledge on various aspects of leprosy has accumulated. This includes discovery of very effective drugs, physiotherapeutic measures, surgical procedures to improve appearances as well as functions, and better understanding of rehabilitation procedures. But it was realised long ago that it is far easier to treat and cure a patient than to change the opinions and beliefs of people. If a leprosy patient has to accept the diagnosis and take treatment regularly without concealing his disease, he has to be greatly supported by the society.

Evolution of Health Education

Ernest Muir was probably the first to suggest that the society should be informed the true facts about leprosy. That was in 1926. He suggested that the best way to control leprosy is by the PTS method–Propaganda, Treatment and Survey. The WHO recommended in 1960 that Health Education should be taken up "to awaken the mind to think correctly". The objectives of health education should be:

"to convince patients and the public of the curability of the disease in the early stages, especially before deformities have developed; and

"to demonstrate to the community that it will not suffer if it assumes a more liberal attitude to leprosy patients and that their reabsorption into the community, even if they have deformities, is necessary on the ground of common humanity and in the interest of the more effective prosecution of the campaign".

Based on its experience, the Gandhi Memorial Leprosy Foundation (GMLF) recommended the Survey, Education and Treatment (SET) programme to the Government of India in 1954-55. The National Leprosy Control Programme (NLCP) of India was launched in 1955 using the SET method. Under this programme, health education was to be an important component. But it did not get the necessary attention because the stress was on survey for the purpose of case detection and treatment. As a consequence the social acceptance of leprosy patients has not made much headway. Similarly the misconceptions of the community continue to remain as before.

The Gandhi Memorial Leprosy Foudation

GMLF began to give greater attention to health education from 1962 onwards. As they experimented finding out the correct words for the messages to be conveyed, the different methods of communication suited to different types of audiences, the tools of communication such as spoken word, written word (leaflets, books, etc), visuals (flash cards, photographs, films), they realised that even when the community was prepared, the need for the patients to know the places of treatment was important; and there should be someone to treat. Therefore they organised a series of refresher courses for General Medical practitioners by suitable trained personnel (non-medical men to organise and medical men to deliver the lectures). In the period 1969-78, 3, 189 medical men were given orientation in 105 batches. The organisation of such courses was very difficult and required considerable effort to be put in. The response from the trained medical men was rather disappointing, in the sense that the majority of them were not interested to enlarge their knowledge or absorb new ideas. Thus there was no appreciable change in their attitude or practice.

As a result, GMLF decided that the next best step would be to give orientation to the teacher trainees. In the period 1968 to 1978, more than 160,000 teacher trainees were given orientation. The advantages of giving such orientation was:

The school teacher always happens to be a local leader; hence he will be influencing the others in the society.

The teacher will be putting new ideas into the minds of the young who are being exposed to all aspects of the world for the first time. In other words, their minds are like clean slates. Therefore, to 'write' the new knowledge on their fresh minds is easier than on those of adults. Also the child's acceptance of the new knowledge is more total than in the case of an adult.

The teacher will be able to recognise suspicious spots amongst the children and others; and guide them for seeking medical help.

Because of his knowledge, he would protect the interests of child-patients under his care; and not allow victimisation.

The teacher is not actively concerned in the treatment of the patient. Therefore his reactions towards a patient are likely to be positive and less inhibited.

Other methods involving students and teachers

As the teacher training programme continues, it was realised that the teacher would be helped to talk about leprosy if there was a lesson on the subject in the textbook Therefore GMLF made efforts for insertion of such lessons in the books for the seventh and tenth standards. Some states like Maharashtra and Karnataka accepted this suggestion and introduced the lessons.

The survey part of SET programme includes school survey. To prepare a school for survey, the head of the institution has to be given relevant information, before his help and permission can be had. He, in turn, takes the assistance of other teachers to get all the students examined by the health staff. This process tickles the curiosity of the students. Therefore it would be worthwhile to deliver lectures to the students on the subject, at the same time.

Students (primary or collegiate) are very responsive. After such a lecture many of them contact a doctor (or even the lecturer himself) to find out whether the patches they have, are due to leprosy.

Essay competitions on leprosy arranged for students always elicit a good response, especially if the prizes are attractive. Those who would like to participate in such essay competitions will be very receptive to a lecture on the subject. In addition many of the youngsters take the initiative to gather more information from all other available sources. Therefore, the organisers of such competitions should provide such sources in an unobtrusive way.

Occasionaly one comes across school children approaching the public for donations, to a cause such as rehabilitation. They would have been directed by their teachers in the matter. Many of these students ask questions about the subject such as curability and rehabilitation. They become interested and read articles in newspapers, hear lectures and give attention to visuals, especially if their interest is maintained.

Health Education by other Agencies

All the agencies working in the field of leprosy have recognised the great importance of imparting knowledge to the student generation. Hence many of them arrange educative lectures in schools and colleges for students and teachers, as often as possible. But these programmes are not continuous and sustained. Isolated, disjounted and fragmented communication and educative activities will not yield longlasting results.

The mass media supplement the knowledge gained in schools and colleges. But the time and space they give for leprosy is totally inadequate to tackle this serious health problem.

All the same it may be said that the general level of understanding about leprosy has gone up considerably. This has helped to reduce the sufferings of patients and obtain more willing cooperation for treatment.

Conclusion

If children have correct understanding about leprosy, the stigma will melt away in the measurable future. If they get the disease, they will take treatment. If others get the disease, they will encourage them to take treatment from the first day and to get cured without deformity.

Intensive health education beamed towards today's children will make the difference to tomorrow's leprosy control work.

Dr M S Nilakanta Rao, President of the National Leprosy Organization (India) is a WHO Consultant on Leprosy to Government of India.

VOLUNTARY WORK

S P Tare

Leprosy is one of those disease which attacks only the human species. It has however evaded medical solution for centuries and till a few decades ago was incurable. Because of the absence of effective medicine and the great physical damage visibly associated with the disease, leprosy has been, at all times and in all places, abhorred and patients of leprosy hounded. There was very scanty medical knowledge about this disease due to which the medical profession remained apathetic. Till about a century ago, there was no organised anti-leprosy work to protect and give relief to those suffering from this disease.

The Christian missionaries in India, however came forward about 120 years ago to serve the patients of leprosy. Two Indian institutions are reported to have been working at Varanasi and Agra in the earlier part of the 19th century. These institutions tried their best to give asylum to leprosy patients and provide them some medicine and keep them engaged in agriculture and cottage industries.

One non-missionary voluntary institution started near Wardha in 1936 under the inspiration of Mahatma Gandhi. It was however only after the coming of Independence, that many more voluntary agencies came forward for leprosy work. Another important factor which paved the way for accelerated work was availability of DDS as a curative drug for treatment of leprosy. Today, the number of voluntary agencies in this field in India exceeds 300, but of these over 150 are actively engaged in anti-leprosy work.

The place and role of voluntary effort is appreciated in all fields of developmental activity. So it is in leprosy. Almost all leprosy work in the country was in the hands of voluntary workers before 1947. They, by their very constitution and motivation , are best suited to take up innovative and exploratory work which is so necessary in leprosy field. There are many lacunae in the medical knowledge of leprosy. The social stigma about leprosy is deep-rooted. And the drugs available have their limitations. Hence even though the Government has taken up leprosy control work on an extensive scale in all known endemic areas in the country, the need for the participation and pioneering contribution of voluntary agencies remains.

Voluntary agencies have the advantage of a band of committed and motivated workers. They usually cover a small and compact area. They have the facility of constant and close supervision with the freedom to quickly tackle instances of dishonesty and shirking of work. Their management has the necessary flexibility to alter, correct and modify their approach or method or work. They can quickly undertake studies and researches in areas wherever these are called for.

Considering the above advantages available to the voluntary sector, it can play a valuable qualitative role to strengthen and support the wider quantitative coverage by the government. In other words, the voluntary agencies should guide, complement and supplement the public health system. Their contribution can be specifically in four areas; demonstrational, exploratory, supplementary and ameliorative.

Demonstrational Role

Voluntary leprosy institutions can conduct model leprosy centres of various types (Leprosy Control Units, SET Centres, Urban Leprosy Centres, Referral Hospitals), wherever utility of such a centre is established, and necessary modifications to the plan and methods are made depending on prevailing circumstances. Centres of these types will also be run by the government in more numbers and hence those run by voluntary institutions can serve as models for the government workers and can also experiment with changes in methods and approaches. It has been noticed that the presence of a good voluntary agency in a district and the services available there for leprosy patients has a beneficial indirect effect on the quality of work of nearby governmental centres.

In order to help voluntary leprosy institutions to fulfil their role as models the government could:

__ encourage voluntary institutions to establish any type of leprosy work if they have necessary trained personnel. For this , the government should be prepared even to vacate in favour of a private institution.

__ give freedom to these voluntary institutions for making changes in the methods of work, provided they adhere to the broader objectives laid down by the government.

Exploratory Work

The second field of activity which can be left largely to the initiative of private leprosy institutions is exploratory work. This includes taking up pilot studies or projects to find answers to various facets of leprosy problems. Such studies are essential for the success of the leprosy control programme. For example though our aim is to control leprosy, we have not yet been able to achieve it in any area in the country. There are some good institutions who have given ample demonstration that the intensity and complexity of the leprosy problem can be considerably reduced with control programme but there are numerous factors which hamper and hinder achievement of total control of disease. These and other epidemiological problems need to be studied in the field. Voluntary institutions can devote themselves to this, rather than duplicating the government patterns of leprosy work carrying with it the attraction of government grant. It is urgent to find solutions to handicaps and constraints noticed in some control centres, as these would eventully be noticed in the governmental work also, thereby retarding the fulfilment of objectives of the national programme.

Supplementary effort

There are some fields of activity which can be engaged in both by the government and voluntary institutions but where the government has limitations in effective functioning, these activities can be simultaneously entrusted to voluntary leprosy institutions, wherever they exist, as supplementary to the government effforts.

Training Centres :

This is an activity whose importance for the success of the National Leprosy Control Programme has unfortunately not been given due attention. In training of any type, what is important to be imparted to the trainee is not merely knowledge of the subject but also the moral intellectual commitment to the cause. The national leprosy programme is today suffering due to the half hearted and often inadequate training given in earlier decades to the field workers. This is evident in wrong and sloppy reporting, lack of health education and absence of reliable data for evaluation. From this point of view the training imparted by a few private institutions in the country is definitely superior and the government should encourage involvement of voluntary institutions in the training of personnel.

Referral Centres :

With a wide field network of leprosy centres manned mostly by paramedical personnel and with increasing number of private practitioners taking up diagnosis and treatment of leprosy, there is greater need for centres where they can refer difficult, complicated or unresponding cases for advice in diagnosis, treatment and care. There are some well developed private institutions with competent and experienced medical staff which can be recognised as referral centres. These centres, one in two or three endemic districts, can be useful to leprosy technicians of SET centres, medical officers of leprosy control units and private practitioners treating leprosy patients.

Intensive Health Education Work

Even though health education is incorporated in the SET pattern of work since the beginning, it has hardly been emphasised all these years. No learning aids of any kind are available to most of the field workers nor were they told about health education in their training. As a result, health education which is essential for bringing new cases out and in holding old cases for treatment till their cure, has been and is being almost totally neglected.

Voluntary leprosy institutions can be helpful in organising short term training in health education techniques to government paramedical workers. These agencies can also be entrusted with the responsibility of doing health education work not merely in their own area of work but also in the surrounding area or part of the district which is covered by the government.

Participation of Medical Practitioner and other Social Bodies

It is accepted that active participation of all medical practitioners is absolutely necessary for the success of leprosy control and for removal of stigma from the society. As long as people see that doctors do not treat a patient of leprosy with the same care and courtesy as they treat patients of tuberculosis or other infectious disease, they are not going to believe that leprosy is a disease like any other. Those voluntary institutions who have experienced medical personnel with ability to influence medical groups can take up this activity in their own areas.

The Ameliorative Aspect

Leprosy is a medical problem but with very serious social repercussions due to the chronic nature of the disease and the centuries-old stigma prevalent in all societies. The National Leprosy Control Programme has restricted itself primarily to the medical and public health side of it. It cannot, however, be denied that the patient has not only the problem of having the disease but also the more serious problem of social boycott. The biggest of the social problems is that of rehabilitation of leprosy patients. The other allied problem is that of those who take to begging. There is also the married women patients who have been divorced or disowned by the husbands. These and other social problems are the inevitable aftermath of the disease. We cannot shut our eyes to the immense unjust suffering of hundreds of thousands of leprosy patients, whether they are abandoned, crippled, beggars or other dehabilitated groups. In the governmental centres the workers are not expected to help such persons nor do they have the time or inclination to do so It is the voluntary leprosy institutions which can help such leprosy patients in preventing their social dehabilitation, in providing protection; in helping them stay in job, family and community; in organising training in skills and crafts; in helping trained persons to stand on their own; in running sheltered workshops for those who are unable to get a job in society; in helping married woman patients to stay with their husbands. This type of help can be given not only to leprosy patients of the area served by these institutions but also extended to leprosy patients in nearby areas covered by governmental centres.

In summary, voluntary institutions have a major role to play in the National Leprosy Eradication Programme in areas which are vital for its success and where the government has diffifulties and limitaions. The role as elaborated above will not only be helpful to the people but also welcome to the government because that will not only strengthen the national programme but also ensure wider and deeper participation of community in fulfilment of the national pledge to eradicate leprosy provided we understand it not as "zero-leprosy but as leprosy being reduced to the status of a common disease curable by two to three years treatment – and not a curse for life".

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LEPROSY AND THE LAW

S P Tare

The law is expected to protect the rights of the people and help them to enjoy the benefits of their rights without interference. It is also supposed to be an expression of the existing social norms and public opinion.

If one reviews the laws relating to leprosy and leprosy patients and also various legal enactments concerning leprosy patients, it is evident that they are fulfilling the above two functions. They do reflect the fear and prejudices existing in the society about leprosy, and their objective, obviously, is to protect the society from infection of leprosy.

There are a number of laws and legal enactments which put numerous restrictions on the movement of a leprosy patient and severe legal impediments in his social mobility. For all practical purpose, a patient of leprosy, in the eyes of the law, is little short of a criminal who, at the slightest opportunity, should be hauled and put behind bars so that he does not pollute the social atmosphere.

The oldest enactment relating to leprosy is the Indian Lepers Act of 1898. This Act was first enacted in Bengal and was later made applicable to the whole of India. It is a federal law applicable to states, only if the State Governments agree to its application to the state territory. Most of the State Governments in earlier years have opted for its applicability to their states.

The Act was passed in 1898, and one can well imagine the ignorance prevalent then, not only among the public but also among the legislators who passed the Act. The Act makes no distinction between infectious and non-infectious types of leprosy and presumes a leprosy patient to be a patient for life. It has also used the words 'leper' and 'pauper' as synonymous, as if every patient of leprosy is necessarily a pauper. (The word 'pauper' was however deleted by the Maharashtra Government in 1955 by Act No. XXVIII). Section 9 of the Act prohibits leprosy patients from "preparing or sale of food or drinks or clothes, taking water from public wells, driving or travelling through public conveyance and any such other transactions which will affect public health". It imposes fine in cash and imprisonment for infringing any of its provisions. Section 11 holds the employer responsible for giving jobs to leprosy patients and provides for punishment to such employers. The Act provides for setting up segregation camps for those patients who are found to be in notified areas against prohibitory orders.

Another Act which puts restrictions on the mobility of leprosy patients is the Indian Railways Act of 1890. Sections 47 and 91 of this Act prohibits patients of leprosy from railway travel.

There are four laws concerning marriages which recognise leprosy as a sufficient legal ground for divorce. The Indian Christians Marriage Act of 1872, Muslim Marriage Act of 1934, Special Marriage Act of 1954 and the Hindu Marriage Act 1955 have permitted a married person to apply for divorce if his or her spouse is suffering from "virulent" or "virulent and incurable leprosy". The period for which the spouse is suffering from leprosy, however, differs under different laws–under the Indain Christian Marriage Act, it is not less than three years [Section 13(i) (iv)] under Muslim Marriage Act, it is two years [Section 2 (iv)] and under the Hindu Marriage Act, it is three years (Section 13).

There are a number of "prevention of beggars" laws under which there is a separate provision for leprosy patients. In Maharashtra, in cities like Bombay, Poona, and Nagpur, leprosy patients found begging are immediately arrested and sent to Beggar Homes run by the government.

Besides the above laws applicable to the entire country, there are many other State laws which put a variety of restrictions on leprosy patients. Some State laws have prohibited leprosy patients from inheriting property from a share in a joint family; others have debarred a woman patient from claiming alimony after divorce. Some laws have taken away the rights of tenancy from patients of leprosy. The Motor Vehicles Act in some States do not issue driving licences to a leprosy patient. In States like Karnataka, a patient of leprosy is not allowed to stand for elections.

Leprosy patients are not insured by the Life Insurance Corporation of India, and there used to be additional premium to be paid by leprosy workers. Through the efforts of National Leprosy Organisation, India, Life Insurance Corporation has stopped charging extra premium on life insurance of leprosy workers in the field. Leprosy patients are not recruited in the Defence Services either

These laws and legal provisions have been extremely harsh on leprosy patients through the years. It has been particularly hard on women leprosy patients who are married. In our male dominated society, the wife is expected to live faithfully with the husband in spite of all his faults and misdeeds, and hence there are too few instances of wives applying for divorce against their patient-husbands. But woman-patients have been and are, even now, quickly divorced by their husbands on the ground of leprosy. The provisions about inheritance, tenancy, and ineligibility for election have also been too often taken advantage of by relatives and interested parties. In the course of leprosy work, we come across cases where healthy people are certified as patients of leprosy at the instance of interested relatives or opponents and debarred from property rights or from standing for election.

Besides the inhuman suffering that leprosy patients have undergone due to these unjust laws, they have also had an unfortunate effect on public opinion, strengthen the fear and prejudices existing in the community. The laws, instead of reflecting scientific knowledge and moulding public opinion, have played a discouraging role as far as leprosy is concerned. The courts of the land, have, by and large, also been satisfied in dispensing blind justice by following the letter of the law, without exercising the right of giving a liberal interpretation to the spirit behind the law. Thus, there have been legal tangles on the meaning and interpretation of the words 'virulent' and 'incurable' despite expert medical witnesses.

Leprosy workers all over the country have waged a relentless struggle, for over two decades, against these unjust laws. This has had some effect. The Indian Leper Act 1898 has been repealed in the State of Maharashtra from 2 October 1983 and the Government of India has also repealed its application to Union Territories from January 1984. The Railway Board is now not only allowing railway travel by leprosy patients but also giving them concessions for travel by railway from their residence to the place of their treatment. An effort to get a law passed by the Parliament in 1969 providing for compulsory sterilisation of leprosy patients was defeated in the Lok Sabha as a result of the campaign made by some leading leprosy workers. The High Court of Tamil Nadu has passed strong strictures against the decision given by a lower court where the statement of a witness was not recorded on the grounds that he was a patient of leprosy. The High Court issued a circular (No. 251/1976, dated 9.12.1976) to all lower courts that patients appearing in courts as parties or witness should be treated with compassion and respect. Some courts in Maharashtra have accepted the expert medical advice in divorce cases where the wife-patient is taking regular treatment and is not in a position to spread infection, and have rejected the petition for divorce.

The Study Group appointed by the Government of India, in 1981, to draw up a Strategy Plan for the Eradication of Leprosy has made the following unambiguous recommendation:

"All such outmoded and derogatory Acts or prohibition in Acts adversely affecting the fundamental rights of a leprosy patient as a citizen of India, should be repealed or amended where needed, without any delay. It must be ensured that in any subsequent legislation, this point is not lost sight of. A patient of leprosy should be treated on par with a patient suffering from other infectious diseases. The Law Department at the Centre and in the State should be instructed to identify all derogatory and dehumanising laws concerning leprosy patients and take immediate steps to have them repealed or amended".

Even now, some of the State Governments are not yet convinced about the urgency of repealing the Indian Leprosy Act, though the Government of India has advised all the State Governments to do so. Other States are considering the modification and the amendment of the Act to tone down the obvious harsh provisions. The assumption is that a law is necessary to control leprosy.

Intelligent sections of society and politicians and legislators often think of the law as a solution to social evils and problems. This is erroneous. No law has ever succeeded in totally removing social evils. There are laws against untouchability, dowry and child marriage, which remain in statute books and are seldom enforced. A proper law is useful but what is decisive in leprosy is not a law, but enlightened public opinion.

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COMMUNICATION FOR CONTROL

R Ganapati

Dealing with a disease riddled with misconceptions, the programmes engaged in eradication of leprosy are still struggling to find out the best means to communicate with the community. There is no other way to persuade them that the only method available to break the chain of transmission of the disease is to reach chemotherapy to all, or a large enough, number of patients living amongst them. The success of the programme depends upon the conviction of the society about the facts concerning leprosy as known to the scientific community and techniques of modern methods of control.

Unlike diseases dealt with mostly by the "hospital approach", those which required "field application" like leprosy depend to a considerable extent for their success upon certain "messages" about the disease effectively reaching the community in general. In achieving this object, mass communication media are of utmost importance and these should be sufficiently exploited to generate faith, among the public as well as the patients, in modern techniques of control. Such educational approaches reaching the people cannot be expected to succeed if this process is not followed up with services found satisfactory from the point of view of patients reporting voluntarily as a result of mass communication. If effectively carried out, the mass communication effort coupled with convincing follow-up action may therefore be expected to lead to peoples' participation in the programme instead of the treatment process being "thrust" on unwilling patients.

Objects of Health Education

The broad objects of health education are two-fold:

—To augment case detection efforts by promoting voluntary reporting of symptomatic patients to leprosy clinics.

—To dispel prevailing misconceptions about disease in the society and to make leprosy sufferers accepted by the community.

By using mass media of communication the first object,namely promoting voluntary reporting of cases,can very easily be achieved. But it is exceedingly difficult to inculcate scientific facts about the disease and to change the outlook of the society to accept leprosy patients like any others. It may not be enough if knowledge about leprosy alone is imparted to the community. The attitude to leprosy patients and the behaviour towards them also should change.

Available Media

Cinema and Radio

In India with a very low literacy rate, the most powerful media of health education are easily the cinema and the radio. There are around 10,400 cinema theatres in India and the total number of seats sold annually exceeds 3,000 million. Four to five new theatres are added every week. The cinema is believed to have the "highest penetration" of 69.6 percent in the southern states of India. The broadcasting system is believed to reach about 55.5 percent in urban areas. It may be interesting to note how radio broadcasts have been used by a rural leprosy control programme for treatment purposes. In this programme which is operating in Miraj, the date of visit of leprosy teams to particular villages for offering modern drugs is announced through the radio to help patients to assemble and collect their medicines.

Television

With a vast television network covering more and more cities in India this medium can easily be exploited to reach certain target groups for education in the field of leprosy, but unfortunately no organised efforts are being made. The authorities should note that charitable organisations cannot afford to bear the commercial rates of telecasting.

Press

In India there are 15000 or more newspapers and periodicals. The percentage of urban population exposed to the press is 52.8 percent. Besides publication of articles and news items on leprosy, this medium has been used by us for giving wide publicity to treatment centres and their timings.

Exhibitions

In our experience health exhibitions portraying information about leprosy have been most rewarding as far as case detection in the community is concerned. As a result of exhibitions held especially in urban slums, the yield of new cases reported voluntarily to slum clinics has considerably increased. Even agencies not directly concerned with leprosy such as the Railways can be used as a medium of health education to innumerable commuters, as exemplified during the recent campaign of Bombay Leprosy Project in collaboration with the Western and Central Railways. Massive exhibitions put up in major railway terminal stations drew large crowds and posters were even displayed inside the railway compartments. An even larger potential awaits in the postal system and its countless users.

It has also been amply demonstrated by us that exhibitions put up in out-patient departments of general hospitals with large attendance have a special significance, in that immediate diagnostic and treatment facilities within the hospital premises can be offered to self-reported cases after being educated by the exhibits

Community Approach through group talks

The simplest method of mass communication is by "word of mouth". Personal transfer of message through "group talks" using sample visual aids has limitation in that it is time consuming reaching a smaller circle of target groups and effectiveness depends upon the personality of the communicator. However, this has a most significant impact on the audience and the results may be dramatic. The feedback from the target groups can immediately be realised.

We were impressed by the effectiveness of "non-survery technique" as a case detection device. This technique consisted of elaborate health education procedure adopted in a large slum community of about 20,000 subjects. We subjected the above community to 232 exposures of intensive group talks, exhibiting photographs. These were augmented by projection of slides on 46 occasions and nine film shows. A careful record of self-reported leprosy patients was maintained. The next phase of the programme was to subject the slum dwellers for intensive house to house survey by employing paramedical teams in the conventional manner.

The total number of patients identified during the whole period of study (i.e. two phases consisting of health education and mass survey) was 347 (33 smear positive cases). Out of this 184 (27 smear positive cases) were detected during the phase when the non-survey technique was employed. And 163 (6 smear positive cases) were added on during whole population survey. The figures within brackets indicate the epidemiologically significant infectious cases. It can be seen that most of them were identified through health education, and during the survey phase only six cases could be added to the total number.

The observations of this study indicate that in comparable urban situations, namely slums, it should be possible to identify 54 percent of the total leprosy cases, and more significantly 82 percent of cases of true public health significance namely smear positive patients by employing techniques of mass communication and these techniques may replace survey programmes which are costly, more time-consuming and taxing.

Conclusion

It is unfortunate that though the principle of mass communication through community education has been included in the SET (Survey, Education and Treatment) pattern of leprosy control work, the component of Education has received the least priority in the actual implementation of programmes. It is hoped that with the committment of the nation to eradicate leprosy by the year 2000 AD, the potential of the various media of communication in reaching this goal will soon be exploited and fully realised

This may help in unearthing leprosy cases from the community at a low cost in time and money. It may help more patients to be brought under treatment by giving publicity to places where treatment is freely available. In course of time it may also lead to the society to shed its traditional fear of the disease.

Dr R Ganapathy is the Director of the Bombay Leprosy Project, Bombay, Maharashtra.

Annex I

GANDHI ON LEPROSY

"Leprosy work is not merely medical relief; it is transforming the frustration in life into the joy of dedication, personal ambition into selfless service. If you can transform the life of a patient or change his values of life you can change the village and the country".–Mahatma Gandhi.

An abundance of words and images recalls the life of Mahatma Gandhi, each one standing as a testament to his courage and humanity. Not the least among them are the episodes that record his concern for people stricken by leprosy. Of all the examples of service that he set for those who sought to follow him, this was perhaps one of the most difficult. It showed his country the way to a National Leprosy Control Programme.

Gandhiji's attitude to leprosy was reflected in many other chapters of his life. Little things have lasting and life-long impact, while small things precede great deeds. All his life, Gandhiji moved and mixed with leprosy patients fearlessly and with complete freedom. He always gave a listening ear to a leprosy patient, visited leprosy institutions, showered his blessings on different leprosy meetings,conferences, organizations and on individuals. While in Sevagram, Wardha, he allowed a leprosy patient named Parchure Shastri to stay in his ashram and used to look after him with regular dressings and treatment and also invited him to perform religious ceremonies like marriage as a priest.

Leprosy, then was a dreaded and incurable disease. Gandhiji had great inner commitment for the cause of leprosy. The seeds of his concern for the patients were sown thus, when he was only about thirteen.

"My profession progressed satisfactorily but that was far from satisfying me. The question of further simplifying my life and of doing some concrete act of service to my fellowmen has been constantly agitating me, when a leper came to my door I had not the heart to dismiss him with a meal, so I offered him shelter, dressed his wounds and began to look after him. But I could not shelter him indefinitely. I could not afford. I 'lacked the will' to keep him always with me. So I sent him to a Government Hospital for indentured labourers".

But Gandhiji never gave up his conviction that it was wrong to turn them into social outcasts. Gandhiji's own insight into the disease had long since dispelled conventional prejudice and fear of infection from his mind. He included the leprosy victims among his chosen brothers. To the inmates of one leprosy home he wrote,"I would like you not to feel sorry over your disease. I am sure that a diseased mind is worse than a diseased body".

Gandhiji was well aware of the fear and loathing the sight of leprosy evoked in most people. He had nothing but high regard for anyone who tried to ameliorate the sufferings of leprosy patients. He also championed the right of leprosy patient to equality and often campaigned for asserting that right.

"I must own that the missionaries have founded many leper asylums and the like. I have founded none. But I stand unmoved. I am not competing with the missionaries or anybody else in such matters. I am trying humbly to serve humanity as God leads me. The founding of leprosy asylums is only one of the ways, and perhaps not the best, of serving humanity. But even such noble service loses much of its nobility when conversion is the motive behind it. That service is the noblest which is rendered for its own sake".

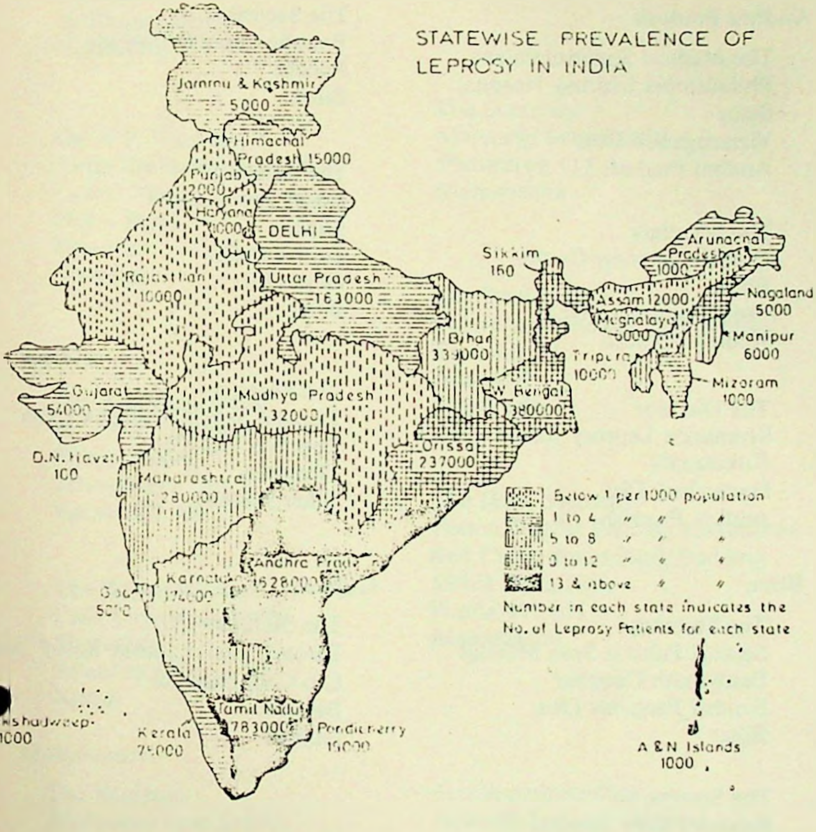
Mahatma Gandhi's Constructive Programme did not include leprosy work until 1945 when he revised its mandate. When he looked at the neglect of leprosy sufferers, he confessed,"I am tempted to call it heartless, which it certainly is in terms of non-violence". And he deliberately introduced leprosy work as a component of the Constructive Programme.

By this time, several programmes for the relief and rehabilitation of leprosy patients were under way in the country. More than once he was invited to open a new hospital. His usual response was,"Get someone else to open it; opening a hospital is not a big matter. But, I shall come to close it". Prevention, he knew, was the real challenge.

"There is another type of medical relief which is a boon. It is given by those who know the nature of the diseases, who will tell the patients why they have their particular complaints and will also tell them how to avoid them. Such servants (of the people) will rush to assist at any odd hour of the day or night. Such discriminating relief is an education in hygiene, teaching the people how to observe cleanliness and to gain health".

Very few know as to how much Mahatma Gandhi was interested in and from how many aspects he viewed the leprosy problem of this country. Commending those who had devoted themselves to leprosy work, he said: "An honour to them - but what of us?"

Annex II



STATEWISE PREVALENCE OF LEPROSY IN INDIA

Number in each state indicates the No. of Leprosy Patients for each state

VOLUNTARY ORGANIZATIONS ENGAGED IN LEPROSY CONTROl

Andhra Pradesh

The Medical Superintendent
Philadelphia Leprosy Hospital
Salur
Vizianagaram Dist.
Andhra Pradesh 532 591

The Secretary
Damien Leprosy Centre
Eluru
West Godavari Dist.
Andhra Pradesh

The Director
Sivananda Leprosy Rehab Centre
Kukutapalli
Hyderabad Dist.
Andhra Pradesh

Bihar

The Secretary
Santhal Paharia Seva Mandal
Baidyanath-Deoghar
Santhal Parganas Dist.
Bihar

The Secretary
Rajendra Seva Ashram
Anugrahnagar
Mairwa
Siwan Dist
Bihar

The Secretary
Brambe Leprosy Institute
Ranchi
Bihar

The Secretary
Kusht Seva Kendra
Kapasia
Tq. Nawadha
Gaya Dist.
Bihar

The Director
Damien Social Welfare Centre
Post Box No. 17
Dhanbad
Bihar 926 001

Gujarat

The Secretary
Baroach Dist. Leprosy Relief Assn.
C/o Civil Hospital
Baroach
Gujarat

The Secretary
Baroda District Anti-Leprosy Assn.
Baroda
Gujarat

Karnataka

The Superintendent
St. Joseph's Leprosy
Hospital
Kankanady
Mangalore
S. Kanara Dist.
Karnataka

Dr. V.P. Macaden
Swiss Emmaus Association
Laxmi Nagar
Hubli Road
Dharwar
Karnataka

Kerala

The Superintendent
St. John's Hospital
Pirappuncode
Trivandrum Dist.
Kerala 695 607

The Superintendent
Poor Leprosy Hospital
Shertallay
Alleppey Dist.
Kerala

Maharashtra

The Secretary
Maharogi Seva Samiti
Dattapur
Wardha
Maharashtra

The Director
Gandhi Memorial
Leprosy Foundation
P.O. Hindinagar
Wardha 442 103
Maharashtra

The Secretary
Maharogi Seva Samiti
Warora
Maharashtra

The President
Vidarbha Maharogi Seva Mandal
Tapovan
Amravati
Maharashtra

The Hon. Secretary
Poona District Leprosy Committee
Red Cross Blood Bank Building
593/2 Rasta Peth
Poona 411 011
Maharashtra

The Superintendent
Acworth Leprosy Hospital
Wadala
Bombay 400 031
Maharashtra

The Superintendent
Richardson Leprosy Hospital
Miraj
Sangli Dist
Maharashtra 416 410

Madhya Pradesh

The Director
Pavitara Atma Ashram
P.O. Auliya
Khandwa Dist
Madhya Pradesh

Orissa

The Secretary
Leprosy Relief Committee
Parlakimedi
Ganjam Dist.
Orissa

Tamil Nadu

The Medical Officer Incharge
Hamerijckx Leprosy Centre
P.O. Polambakkam
Madurataka Tq.
Chingleput
Tamil Nadu

The Director
ILEP Leprosy Control Project
Post Box No. 3
Dharmapuri
Tamil Nadu

The Director
S.L.R.T. Centre
Karigiri
Via Katpadi
North Arcot Dist
Tamil Nadu 632 106

The Director
Workshop for Rehabilitation &
Training of the Handicapped
Katpadi Extension
Vellore
North Arcot Dist.
Tamil Nadu 632 006

The Secretary
German Leprosy Relief Association
4, Gajapathy Naidu Street
Shenoynagar
Madras 600 030
Tamil Nadu

The Chief Medical Officer
Salvation Army
Catherine Booth Hospital
Nagercoil
Kanyakumari
Tamil Nadu

The Superintendent
Rawtakuppam Hemmerijckx Rural
Auroville P.O. Centre
Tal. Tindivanam
South Arcot Dist.
Tamil Nadu

The Medical Officer
Sagaya Matha Hospital
Pullambadi
Trichy Dist.
Tamil Nadu

The Superintendent
Sacred Heart Leprosy Hospital
Sakkottai P.O.
Kumbakonam
Thanjavur Dist.
Tamil Nadu

The Hon. Secretary
The Wallajah Taluk Leprosy
Relief & Control Scheme
Scudder Memorial Hospital
Ranipeth
North Arcot Dist.
Tamil Nadu

The Secretary
Kasturba Kusht Nivaran Nilayam
1, Malavanthangal
South Arcot Dist.
Via Kandachipuram
Tamil Nadu

The Superintendent
Holy Family Hansenorium
Fatima Nagar
Trichy Dist.
Tamil Nadu

The Superintendent
Dayapuram Leprosy Centre
Manamadurai
Ramnad Dist.
Tamil Nadu 623 606

Uttar Pradesh

The Superintendent
Kushta Seva Ashram
(Leprosy Hospital)
Gorakhpur
Uttar Pradesh

The Hon. Secretary
Kanshi Kushta Seva Sangh
P.O. Sarnath
Varanasi
Uttar Pradesh

Mr. Singh
Adm. Officer
SBD Leprosy Hospital
100 Gandhigram
Krishna Nagar
G.T. Road
Kanpur
Uttar Pradesh

The Secretary
Kusht Seva Ashram
Seorahi
Deoria
Uttar-Pradesh

Miss J.R. Tipping
Health Education Centre
Naini Leprosy Hospital
P.O. Naini
Allahabad Dist
Uttar Pradesh 211 008

West Bengal

The Superintendent
Bankura Leprosy Control Program
P.O. Box 27
Bankura
West Bengal 722 101

Dr. Margaret Owen
Health Education Training Centre
Purulia Leprosy Hospital
Purulia
West Bengal 723 101

Union Territory of Delhi

The Director for Southern Asia
The Leprosy Mission
4th Floor, Sheetla House
73-74 Nehru Place
New Delhi 110 019

The Secretary
Hind Kusht Nivaran Sangh
1, Red Cross Road
New Delhi 110 001

SPREAD THE WORD

Leprosy is like any other disease. And it is the least infectious.

Leprosy is caused by germs. It is neither hereditary nor a curse of the gods.

Eighty percent of leprosy cases in India are non-infectious.

A pale or red patch on the skin may be leprosy. Do consult a doctor.

Leprosy is completely curable with regular treatment.

Early detection and regular treatment prevent deformities and disabilities.

Help to overcome fear. Encourage early detection and sustained treatment.

Leprosy patients can continue to live at home and do normal work, while under regular treatment.

Do not isolate leprosy patients. Accept them in the family and the community.