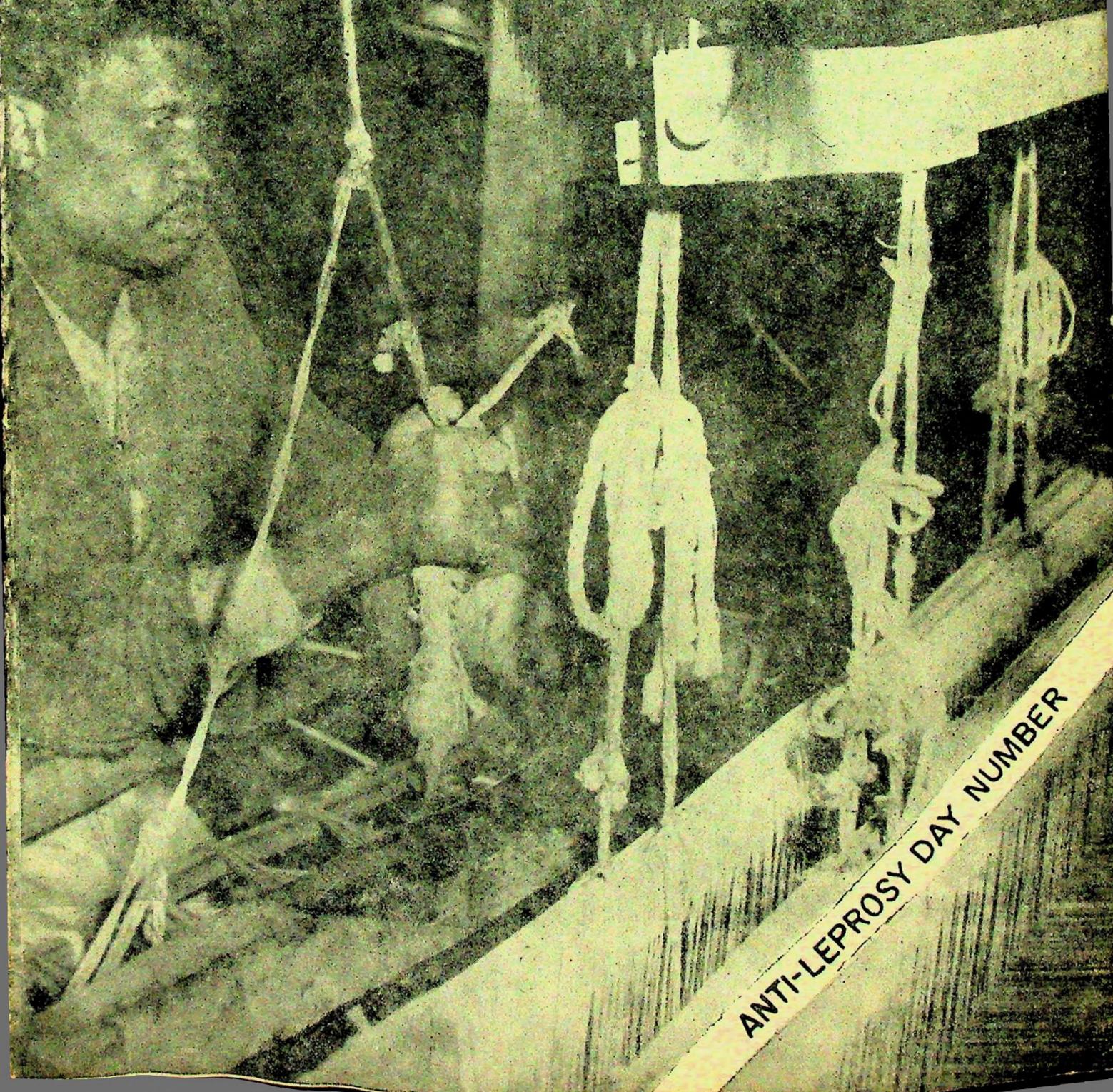


# swasth hind

january 1988



ANTI-LEPROSY DAY NUMBER

# swasth hind

Agrahayana-Pausa  
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January 1988  
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Mahatma Gandhi's Martyrdom Day—30th January—is also observed as the Anti-Leprosy Day throughout the country. Gandhi's "life was a message" and a testament to his courage and humanity. Not the least among them are the episodes that record his concern for people stricken by leprosy. It showed his Country the way to a National Leprosy Control Programme. We devote this special number of *Swasth Hind* to leprosy eradication. *Our cover* shows that leprosy patients can be gainfully employed after treatment.

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## Editorial and Business Offices

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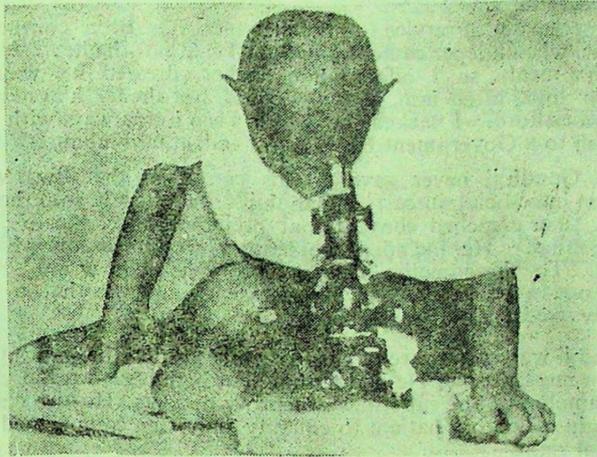
Articles on health topics are invited for publication in this Journal.

State Health Directorates are requested to send in reports of their activities for publication.

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## GANDHI ON LEPROSY

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“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

## GANDHI ON LEPROSY

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".

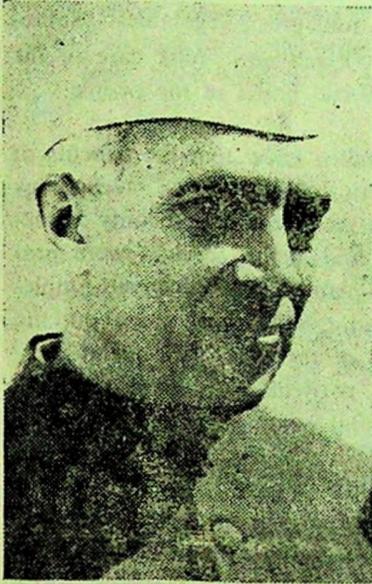
Mahatma Gandhi's Constructive programme did not include leprosy work until 1945 when he revised its mandate. When he looked at the neglect of leprosy sufferers, he confessed, "I am tempted to call it heartless, which it certainly is in terms of non-violence". And he deliberately introduced leprosy work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

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Jawaharlal Nehru Centenary Year : Feature

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# RAISING HEALTH STATUS OF INDIA

—Role of Pandit Nehru

DR SUBHASH C. KASHYAP

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**J**AWAHARLAL NEHRU was the architect of modern India. His contribution to the evolution of Constitution of India was unique. The Constitution aims at building a welfare State, developing an egalitarian society and uplifting the social and economic life of the poorest of the poor. It was Nehru who drafted the preamble to the Constitution, embodying its fundamental principles, and moved it in the Constituent Assembly on 13 December, 1946 in the form of the famous Objective Resolution. The resolution had unambiguously laid down the basic structure of the Constitution which envisages the establishment of a new social order based on equality, freedom, justice and the dignity of the individual and elimination of poverty, ignorance and ill-health.

The Constitution directs the State to regard the raising of the level of nutrition and the standard

According to Pandit Jawaharlal Nehru, the pursuit of health or the raising of health standards of the nation did not mean merely the curing of disease but much more than that—the prevention of it.....while hospitals, dispensaries, etc., were necessary, Nehru felt, what counted most was the public health approach as well as health education, says the author.

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of living of its people and the improvement of public health as among its primary duties.

If a nation has to march ahead and improve its future, it has to take special care of the health and development of its children. The Constitution, framed under the close guidance of Pandit Nehru, therefore, made several provisions against exploitation of children, prohibition of forced labour and employment of children in factories.

In accordance with the spirit of the Constitution, Jawaharlal Nehru,

as the first Prime Minister of free India, initiated the planned socio-economic development of the country with the introduction of the First Five Year Plan in 1951. Nehru had full faith in the glorious future of the country. He once said:

“Tomorrow’s India will be what we make it by today’s labours. I have no doubt that India will progress.... that our people’s standards will raise, that education will spread and that health conditions will be better.”

He was unhappy that in the pre-independence period little attention had been paid to the health status

of the country. In his scheme of things, promotion of health was basic to national progress.

Under Nehru's stewardship, the successive Five Year Plans provided the framework within which the States could develop the infrastructure of their health services, facilities for medical education, research, etc. Besides, legislations were enacted by Parliament to regulate the standards of medical education, prevention of food adulteration, maintenance of standards in the manufacture and sale of certified drugs, etc. These efforts resulted in paving the way for vastly improved medical and health facilities and services in the country. The number of doctors, nurses and hospitals multiplied. The number of medical colleges increased. In rural areas, the Government established thousands of primary health centres whereas none existed before 1951.

#### **Public health approach including health education**

According to Pandit Nehru, the pursuit of health or the raising of the health standards of the nation did not mean merely the curing of disease, but much more than that -- the prevention of it. Pandit Nehru took effective measures to make India a strong and healthy country in the comity of nations. Thus, while hospitals, dispensaries, etc., were necessary, what counted most was the public health approach as well as health education. Therefore, the Government initiated effective steps to control malaria, tuberculosis and cholera which used to take a heavy toll of life. Smallpox, a dreaded disease, was completely eradicated. Besides, the general death rate came down from 27.4 per

thousand in 1951 to 11.7 per thousand at present. The life expectancy at birth increased from 32 in 1941-51 to 54.71 in 1985-86. The infant mortality rate came down from 146 per thousand live births during the fifties to 95 in 1985. The per capita expenditure on health incurred by the country also went up considerably.

#### **War on disease and ill-health**

Nehru was aware that the large scale incidence of disease in India was mainly due to low level of resistance caused by inadequate nutrition. He, therefore, felt that it was indeed very important for the health of the individual as well as of the community that such food habits were encouraged and developed that ensured balanced diet. Nehru was conscious of the fact that poverty, too, acted as an impediment in raising the health status of the country. He always worked for the upliftment of the common man and dedicated himself to the service of India pledging all possible efforts for ending the evils of poverty, ignorance and disease. In fact, he declared a war on disease and ill-health and said, "It is essentially a war on poverty and all its evil brood."

#### **Food for health**

The Indian diet was not adequate either in quantity or in quality and led to nutritional deficiency rendering the people more prone to diseases and hence economically less productive. Therefore, in the First Five Year Plan, Nehru favoured greater accent on the production of cereals so that an adequate intake of food could be assured to the masses. In the Second Five Year Plan, however, emphasis was laid on the production of protective and nutritive

foods such as milk, eggs, fish, meat, fruits and green vegetables. Subsequent Plans also took care of the nutritional needs of the people.

Panditji knew that the benefits of modern science and technology could reach the people only if medical and health services were properly planned and effectively implemented. Nehru was sad about the plight of medical and health services, particularly, in the countryside and commented:

"While our cities and towns required to be looked after very much than they are at present, it is really the village that has been terribly neglected and cries loudly for succor."

Nehru felt that villages required special attention as about 80% population of our country lived there and they had little or no access to modern medicine and health care. Public health was, therefore, taken to the villages, and the villagers were not compelled to come to the towns in search of medical and health facilities. With a view to fulfil this objective, Nehru started the community development movement which, among other things, played a very important role in extending public health services to the rural areas.

#### **National health service for free treatment**

In order to raise the health standard of the country, Nehru's objective was a National Health Service which would provide free medical treatment and advice to all those who required it. And he tirelessly worked to achieve this aim through the development plans. He believed

in involving the State medical services much more intimately and deeply to produce the desired results. He was often distressed to find that:

"In spite of good hospitals the poor man does not always get the same treatment as the rich man does. Many of them hardly get any treatment at all, and they cannot afford the very expensive drugs that are used more and more in modern medicine. These people must get proper treatment; and they must get the drugs they need."

In order to make available essential drugs to every person, rich or poor, Nehru entrusted the manufacturing of certain drugs to the public sector enterprises.

### **Concern for rapid population growth**

From the very beginning, Jawaharlal Nehru was deeply concerned with the rapid rate of growth of population, particularly among the poorer sections of the community. In his opinion, it was imperative to ensure that the rise of population in future would not be so steep as to nullify or neutralise the increase in production that India was aiming at. Thanks to Nehru's farsightedness and efforts, a positive approach was made to contain the rapid population growth from the First Five Year Plan onwards. The policy, as enunciated in the Plan, aimed at a reduction in the rate of growth of the population and considered that family planning or spacing of children was necessary and desirable and would ensure better health to the mothers and better care for the children. The methods for attain-

ing the objective were the education of the masses in family planning, research in the efficacy of different methods of birth control, and provision of centres for rendering advice to the people on the subject. Thus, Nehru's Government became one of the few governments in the world which had undertaken the family planning programme in a scientific way.

Addressing the First Asian Population Conference in New Delhi on 10 December, 1963, Pandit Nehru emphasised the need of controlling the rapid population growth in under developed countries and said:

"It is not merely a question of providing food for a growing population, although that is primary consideration, but, generally, it is a question of providing the means for a good life, a healthy life, for all the people who live in the country. We have thus to face a kind of race between the rate of economic growth and the rate at which population grows."

### **Alarming population growth—a social problem**

Nehru termed the alarming population growth as a social problem of great magnitude and said:

"Obviously, this cannot be left to take its own course because that course would bring tremendous difficulties in its trail. We have to tackle it with some foresight and with some efforts at planning."

Nehru accorded priority to the spread of education, particularly among the girls, who, he felt, were likely to change the living habits of the people and would probably succeed in carrying the message of family planning farther than even the official workers. However, he felt that in order to achieve all round

success, family planning had to go hand in hand with the general economic and social development of the country. India had to plan in terms of food, clothing, housing, education, health, etc.

### **Alliance between ancient and modern systems of medicine**

Nehru had great appreciation for our ancient and indigenous systems of medicine like Ayurvedic and Yunani, which had a long history and a great reputation in India. He felt that this accumulation of past knowledge and experience should not be ignored. Instead, we should profit by them and not consider them as something outside the scope of modern knowledge. According to him, there was no reason why we should not bring about an alliance of old experience and knowledge, as found in Ayurvedic and Yunani systems, with the new knowledge that has been provided by modern science. It was, however, necessary that our approach should be on the basis of modern scientific methods and persons who are Ayurvedic and Yunani physicians, should be imparted a full knowledge of these methods so that the benefits of both the systems could reach the people at large.

Thus, Nehru regarded health as a fundamental necessity and the key to national development. He felt that only healthy citizens could make a strong nation. He once said:

"I want young people and old to be healthy and strong and agile, and I want them to be physically an A-1 nation. I do not think we can really make much intellectual progress unless we have a good physical background."

# INDIA'S NATIONAL LEPROSY ERADICATION PROGRAMME —Current Status

DR B. N. MITTAL DR N. S. DHARMSHAKTU

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To meet the challenge of a major public health problem—leprosy—in India, the National Leprosy Control Programme has been in operation since 1955. The control programme has been redesignated in 1983 as the National Leprosy Eradication Programme with the objective of arresting the disease in all the known cases by the turn of the century.

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**L**EPROSY is a major health as well as social problem in India. Of the estimated 12 million leprosy cases in the world four million are contributed by India. All the States and Union Territories (UTs) report the disease but the States of Tamil Nadu, Andhra Pradesh, Orissa, West Bengal, Bihar, Maharashtra, Karnataka, Meghalaya, Manipur, Sikkim, Tripura, Goa and U.Ts. of Pondicherry, Lakshadweep, Andaman & Nicobar Islands are highly endemic with a prevalence rate of five and above cases for every thousand population. Twenty per cent of cases in the country are infectious type and 15--20 per cent cases have deformities. Social prejudice and superstition still continue to obstruct the disease. The advent of more effective chemotherapy known as multi-drug treatment promises to bring about a favourable change

in reduction of morbidity and social stigma.

#### Priority and Objective

The National Leprosy Control Programme has been in operation since 1955. It is only after 1980 it has received high priority. The control programme has been redesignated in 1983 as the National Leprosy Eradication Programme (NLEP) with the objective of arresting disease in all the known cases by the turn of the century. The programme has been included in the 20-Point Programme of the Prime Minister with 100 per cent Central assistance to the States/U.Ts.

#### Strategies

The strategies laid down for achieving the objectives are (a) early detection and regular treatment, (b)

multi-drug treatment to all the patients in a phased manner, (c) education of leprosy patients, their families and communities, and (d) rehabilitation of cured leprosy patients.

#### Infrastructure

NLEP is implemented as a vertical programme in endemic areas. One leprosy control Unit for every 4.5 lakh population and one urban leprosy centre for every 50,000 population have been established in a phased manner since the inception of control programme in endemic areas. The infrastructure created under vertical structure currently cover 439 million population in areas with endemicity of more than five per thousand population. Survey, Education and Treatment (SET) Centres have been established within the framework of primary health care centres. By the end of March

1987, as many as 601 leprosy control units, 919 urban leprosy centres, 215 district leprosy units, 6239 SET centres, 45 leprosy training centres, 294 temporary hospitalisation wards, 22 sample survey *cum* assessment units and 11 leprosy rehabilitation promotion units have been established.

#### **Objective Performance**

Till March 1987, as many as 3.3 million cases have been brought under record of which 3.01 million cases have been put under treatment. A total of 2.59 million leprosy cases have been discharged as cured/migrated/dead since the inception of the programme.

#### **Multi-Drug Treatment (MDT)**

Keeping in view the prerequisites and the large quantity of drugs required for extending MDT simultaneously to the whole country, it has been planned to introduce MDT in a phased manner to all the highly endemic districts by the end of seventh Plan Period. MDT has been extended so far to 48 high endemic districts and five low endemic districts. So far, 13.50 leprosy cases have been inducted on multi-drug treatment in these districts. The dapsone refractory cases are also being covered under MDT throughout the country.

#### **Training**

There are 45 leprosy training institutes/centres in the country involved in imparting job-oriented training to medical and para-medical staff working under the programme. An operational guide-book has been prepared as a complement to the training courses for the staff working under the programme. About 13,000 para-medical workers and over 4000 medical officers have been trained in leprosy at the above centres so far.

January, 1988

## **LEPROSY ERADICATION**

### **—Part of Prime Minister's 20-Point Programme**

The National Leprosy Eradication Programme is of major public health and social importance to the Govt. of India, for which reason it finds a place in Prime Minister's 20-Point Programme.

It is estimated that about 400 million people in our country reside in moderate and high endemic areas of this disease. As many as 250 districts are affected. In view of this great magnitude of leprosy problem, it has claimed complete political commitment at all levels for its eradication.

The present programme had its beginning in 1954 but it has rapidly expanded both in infrastructure and its content following the adoption of a revised strategy for disease control. An important qualitative change introduced in the programme is to provide multidrug treatment (MDT) coverage in all the districts where the disease prevalence is 10 or more per 1000 population in a phased manner. At present, MDT extends to 41 districts in the country and it is proposed to cover another 40 districts by 1990.

The programme operates both in the rural and urban areas through Leprosy Control Units, Urban Leprosy Centres and Survey, Education and Treatment Centres. Leprosy Training Centres exist for preparing trained manpower for the programme. In view of the time-bound nature of the programme and also because of proposed expansion of MDT activities, it became necessary to assess the programme and the first independent programme evaluation was made in 1986. Even as it attempted to cover all facets of NLEP, the financial constraints and the time available did not permit the exercise to go in-depth of various NLEP activities. However, it did produce a baseline data for future reference and brought certain weaknesses affecting eradication activities besides providing valuable experience to the programme personnel for maintaining performance data.

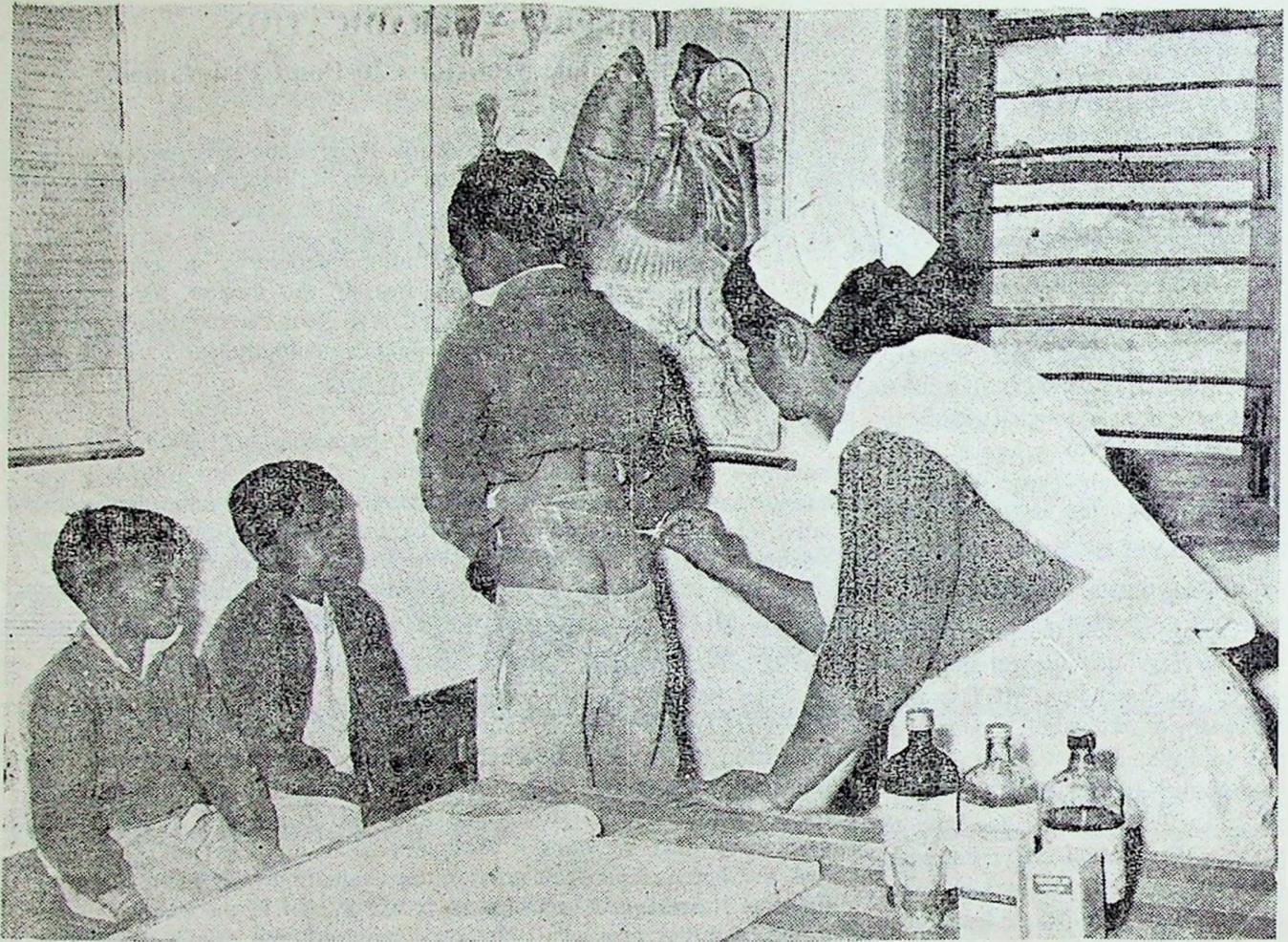
The second evaluation meant to be an indepth exercise, particularly of MDT—related activities. In the meantime, a number of new activities have been introduced. MDT coverage is also being extended to all those patients who have failed to respond in five years to continuous dapsone monotherapy.

— Dr G. K. Vishwakarma

#### **Voluntary organisation**

Over 100 voluntary organizations are pioneers in the field of leprosy control efforts. They continue to be involved in detection and treatment of cases in providing training facili-

ties for the staff and in helping to develop health educational methodologies besides providing vocational and social rehabilitation of cured leprosy patients. Their activities are dovetailed with the activities under the programme to avoid duplication



Early detection and regular treatment prevent deformities and disabilities.

of efforts. About a quarter of participating voluntary organizations are provided with enhanced financial assistance as grants-in-aid under the programme towards activities related to survey, education and treatment of cases, maintenance of leprosy cases and stipends to trainees besides providing free supply of drugs. One of the districts taken up under MDT is operated under the overall supervision of a voluntary agency.

#### **Budget**

An amount of Rs. 14.4 crores has been provided to the programme for 1985-86 out of an outlay of

Rs. 70 crores for the Seventh Plan period. The target of achieving arrest of the disease in 60 per cent of the leprosy cases by 1990 is likely to be held up due to inadequate outlays. During the sixth plan period, the expenditure under the programme was to the tune of Rs. 39 crores. The outlays for the last three years of the sixth Plan have been enhanced substantially due to high priority accorded to the programme since 1982.

#### **Research**

World-known leprosy research institutes like the Central Leprosy

Training and Research Institute (CLTRI), Chengalpattu, Schefflin Leprosy Research Centre (SLRC), Karigiri in Tamil Nadu and the Central JALMA Institute for Leprosy, Agra, are functioning in India. The thrust areas for research include operational research for effective treatment schedules and drug delivery system, development of an clinical trials with vaccine against leprosy, and development of immunodiagnostic tests for detection of leprosy infection before the disease is recognised clinically/bacteriologically. The Multi-Drug Treatment

regimen followed under the programme has been adopted based on results of operational studies under the auspices of the C.L.T.R.I., Chengalpattu and SLRC, Karigiri in Tamil Nadu. A vaccine has been developed by the Indian Cancer Research Centre, Bombay and is under field trials under the aegis of the Indian Council of Medical Research to determine its effectiveness.

### Monitoring

The programme is monitored through periodic reports. Steps have been initiated to strengthen the monitoring and evaluation activities to ensure rapid compilation, analysis and interpretation data. It is proposed to organise effective central monitoring of the programme by creating necessary set-up at the CLTRI, Chengalpattu during 1985-86.

### Problems

The programme faces the following problems in its implementation:

1. Inadequate priorities to this programme by the States resulting in a slow creation of infrastructure and operation of the programme.
2. Several sanctioned posts are vacant in some States.
3. 10—30 per cent of the staff are working without training in some States.
4. Most of the States have yet to repeal the outdated Lepers Act 1898.

### Health education

High priority is accorded to health education during the seventh plan period. During 1985-86, an amount of Rs. 48 lakhs was provided for development of health education materials and purchase of films on

the subject to educate the patients, their relatives and the community on the causation and control of leprosy. The efforts are being stepped up. The Central Health Education Bureau, New Delhi plays a major role in helping the programme to develop suitable health education material.

### Rehabilitation

Prevention and control of leprosy has been receiving priority under NLEP; but the socio-economic aspects of the disease have been receiving the similar attention by the voluntary organisations involved in leprosy control activities. Greater and closer cooperation between voluntary organisations and NLEP is being aimed in the area of vocation

and social rehabilitation of cured leprosy patients. Under the programme, facilities for medical and surgical rehabilitation of patients have been created in the form of 72 reconstructive surgery units. The latest addition to this activity is the sanction of seven leprosy rehabilitation promotion units in highly endemic areas to provide surgical rehabilitation and also to act as nodal point for establishment of vocational training and production centres by social welfare or labour departments or by voluntary organizations. It is planned to involve the Ministry of Social Welfare in providing massive support in provision of vocational training facilities to cured leprosy patients through voluntary organisations.

## 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 per cent 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.

# REHABILITATION OF LEPROSY PATIENTS

AJIT BHOWMICK

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There is no short-cut to rehabilitation of leprosy sufferers. Rehabilitation can be effected in a number of ways depending on the type of disability, availability of funds and specialised personnel. There could be no hard and fast rule in starting rehabilitation projects. The whole effort should be directed towards helping the debilitated patients to return to self-sufficiency, so that they can lead a normal life in the society.

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LEPROSY is a chronic infectious disease resulting in disabilities and crippling deformities. Next to Poliomyelitis, leprosy is known to be the greatestcrippler. According to the Status Report of the Government of India, on an average 15 to 20% of the leprosy patients suffer from disabilities.

The disabilities and crippling deformities are partly due to the disease, but are largely because of certain other factors like burns, injuries etc. due to loss of sensation. To the public, however, leprosy means a disease causing inevitable mutilation, disfigurement and progressive deformity though much of the deformities and disabilities can be prevented if timely treatment is given and adequate precautions are taken. The most agonising part in the life of leprosy sufferers is that even after cure, the patient's problems do not end. Whereas in other diseases the patient as also his relatives are happy to see the patient well on his feet, away from the hospital, the reverse is the case with leprosy patients. Even his own near and dear

ones refuse to accept him in the family in any spontaneous manner. The disabilities rather than the abilities of the patients draw the attention of the public, and the victim of deformities is subjected to such a severe social reaction that he finds himself stared in society. Thus, because of the deep rooted public prejudice against the disease, the leprosy sufferers are virtually ostracised in their own homes and society as well. Often deprived of their hearths and homes, and having no proper means to sustain their livelihood, many of the patients ultimately take to begging. It is, therefore, necessary that Rehabilitation in leprosy should be comprehensive encompassing physical and social aspects. The WHO Expert Committee on Leprosy in its Second Report defined Rehabilitation (*WHO Technical Report Series*, 1960, 189, page 20) as follows:

“By Rehabilitation is meant the physical and mental restoration, as far as possible, of all treated patients to normal activity, so that they may be able to resume their

place in the home, society, and industry. To achieve this, treatment of the physical disability is obviously necessary, but it must be accompanied by the education of the patient, his family and the public, so that not only can he take his normal place, but society will also be willing to accept him and assist in his complete rehabilitation.”

Dr. Paul Brand, the well known Reconstructive Surgeon, has aptly said that in leprosy, rehabilitation must be an integral part of the programme of prevention and treatment and of final restoration of normal social relation. He has held the view that without effective rehabilitation, leprosy control programmes would be a total failure.

In many diseases, rehabilitation is an after thought, i.e. it is assumed that rehabilitation should begin only after the cure of the disease. In some diseases this sequence may be logical. However, in leprosy, rehabilitation begins as soon as the

disease is diagnosed, because the surer and more economical method of rehabilitation is to prevent physical disability and social and vocational disruption by early diagnosis and treatment. So long as a minor deformity does not impose any functional restraint on the individual in pursuing his avocation and so long as it does not divulge him to the society as a patient of leprosy, that individual does not face the prospect of displacement or dehabilitation. When a person afflicted with leprosy loses the means of livelihood, it is not he alone who suffers, but his entire family. Therefore, it is very essential to prevent socio-economic dislocation. The measures that are taken towards this direction are known as "Preventive Rehabilitation." If from the beginning leprosy patients are taken care of, they may not be displaced from their normal environment. By early treatment, even patients with minimal deformities recover normal appearance and function. They have thus a good chance to return to normal life. The approach to rehabilitation should therefore begin with prevention of dehabilitation. We should never allow dehabilitation to take place and afterwards take up the uphill task of rehabilitation.

#### Rehabilitation of the cured cases

With the introduction of multi-drug therapy in leprosy, it is expected that the patients will become non-infective within a short span of treatment. This increased hope bestows greater responsibility on the part of Physicians, the Government and the Voluntary Organisations to rehabilitate the cured leprosy patients.

### UNDP approves project for treatment and prevention of leprosy

The United Nations Development Programme (UNDP) has approved a project for treatment and prevention of leprosy in India. With a UNDP input of \$341,000, the project will be for a duration of four years.

While the executing agency will be the World Health Organization (WHO), the government implementing agency will be the Department of Science and Technology through the Bose Institute in Calcutta. The Government of India will make an input of Rs. 3,150,000 in kind.

Leprosy is a serious health problem of the tropical and subtropical countries, of which India is one of the worst victims with about four million people suffering from the disease.

It is estimated that India has the largest number of leprosy patients numbering about four million, which is nearly 40 per cent of the global estimate of 11 million patients.

Technical skill and expertise generated by this programme will also

It is not enough to declare that the patient is bacteriologically negative i.e. he is no longer infectious and that he may return to his family and to his work. When he is discharged from the hospital, he will have to face the loneliness of an outcast and the poverty of the beggar. His family may not take him in and his employer may refuse to take him back. All this means that we have to help the patient to prepare for his entry into the world again by giving training in some crafts or trades so that he could earn his livelihood and lead a normal life.

be shared by other developing countries like Bangladesh, Pakistan and South East Asian countries and, ultimately, the information gathered will be shared and transmitted to concerned authorities like the Department of Health, Government of India, World Health Organization and UNDP.

The present project will act as complementary to other research Programmes of UNDP, World Bank and WHO in their special programmes for research and training in tropical diseases.

The Bose Institute is an eminent basic science institute and is expected to give the country "leads" on which other institutions can build up their further developments.—*UN Newsletter*, 12 Sept. 1987.

Leprosy is not a disease of beggars. It is a disease which results in beggars. Nobody ever becomes a beggar by preference. The leprosy patients are forced to take to begging because the community rejects the patients after he is afflicted with the disease and even after his complete cure. Hence, Rehabilitation aims at making the patient a useful and productive member of his family and thus avoid the danger of displacement both from his home and from the society.

The cured leprosy patients who need to be rehabilitated may be

categorised under four main groups. These are:—

- (1) Patients with no obvious physical deformity and whose hands and feet are not anaesthetic.
- (2) Patients with moderate deformity.
- (3) Patients with severe deformities, but not crippling deformities.
- (4) Patients with advanced and crippling deformities.

The first category of patients who do not suffer from any deformity or loss of sensation may not need any special care. Some of them may already be employed and may not have been displaced. Only those who are displaced will need help and encouragement in finding a job. In persons with loss of sensation in the extremities i.e. the hands and feet, the patients should be educated about taking proper precautions for protecting their insensitive parts as they are prone to get injuries.

In case of persons with deformities, the patients may need physiotherapy and surgical correction before they can be actually rehabilitated. Having had physiotherapy and reconstructive surgery, these patients can be channelled into ordinary outside employment. Ideally, they should return to the work they were doing before they developed leprosy. If this work is harmful or closed to them, the patients need to be advised about choosing a suitable trade and actually need to be helped in finding a job. If the patients are unskilled, they should be trained in some suitable craft or trade according to their aptitude and capability. Whatever arrangement is made for their rehabilitation, they should be taught specially about how to make correct use of their reconstructed parts, how to avoid injury and recurrence of ulcers and deformity.

The third category of patients having severe deformities need special attention. After surgical correction, many of these patients will still have a residue of deformity such as missing fingers or uncorrectable contractures. Many of them are well able to work; however, it is difficult for such patients to find acceptance in industries outside. For such patients, Leprologists advocate setting up of Sheltered Industries. In many centres, these industries are run on business lines. The patients are trained in some trades and are employed. The only difference between this and the other industries is that in Sheltered industries preference is given in recruitment to patients with deformities, and the conditions of work are studied with special care to prevent further deformity.

The only way of rehabilitating the fourth category i.e. the crippled, severely deformed or blind leprosy patients who are not able to engage themselves in competitive work is to keep them in infirmaries or leprosy homes. They are not infective and thus not a danger to the healthy population from the health point of view. However, if they are not cared for, they often display their deformities in public places in order to arouse the pity of passers-by and make begging a gainful profession. Some Leprologists advocate starting of pilot projects for their rehabilitation to demonstrate that even deformed and crippled patients can be gainfully employed.

Dr. Dharmendra, the renowned Leprologist, has said that "Rehabilitation work is not a work of charity or compassion. Neither it is a work wholly for the good of the handicapped persons, though they obviously

stand to gain by it. It should be looked at in its over-all perspective, as a corrective measure in the interest of economic structure of the whole society; instead of the handicapped persons remaining a load and economic drag on the society, they can become earning members of the society, and thus contribute to its economic progress." ("Leprosy", Volume 2, by Dr. Dharmendra Samant and Company, Bombay-400 028. Page 1386).

Rehabilitation can be effected in a number of ways depending on the type of disability, availability of funds and specialised personnel. There could be no hard and fast rule in starting rehabilitation projects. The whole effort should be directed towards helping the debilitated patients to return to self sufficiency, so that they could stand on their own feet and lead a normal life in the society.

In a country like India, where large scale unemployment of the able bodied men persists, it is not so easy to rehabilitate leprosy patients in suitable jobs unless they are trained in some crafts or trades. Vocational training is, therefore, the next step in rehabilitation. The training has to be in such an area as to give the trainee a fair chance of getting employment which will support not only him but also his family. In choosing a trade for the trainee, the degree, type and extent of disability or deformity of the patients must be taken into account. Besides, the patient's own aptitude and choice must be ascertained. The patients with no deformities and whose hands and feet are not anaesthetic can be taught any trade or craft that suits their intellect. The patients with minimal deformities can be taught only such trades or crafts where handling of sharp and

not objects or standing of walking for long periods is not involved. For patients with considerable but not crippling deformities, the training in some trades or crafts will largely depend on the extent and severity of the deformities and the ability of the person to do a particular type of work. In general, some of the avenues open to them are: Agriculture, Horticulture, Small Scale Industries, Textile Industry, Leather Industry, Light Machine Tool and Engineering Industry, Printing and Book binding Industries, Cottage Industries like Candle making, Mat weaving, Toy making, Cardboard box making etc, Tailoring, Carpentry, Dairy farm, Poultry rearing etc.

It has been found that model farms maintained by leprosy patients are admirable. Despite handicaps, leprosy patients after a short course of training become better and more successful farmers than their healthier fellow villagers. Soil preparation, composting, fertilisers, grafting, seed selection, contour ploughing etc can all be taught to the great advantage and profit of the patients. The breeding of chickens, rabbits, goats, pigs etc. may also provide them a good return for living.

Leprosy patients are prone to get ulcers in their feet due to injuries from outside and stresses from inside. In order to protect their feet, they are required to wear protective footwears specially made from microcellular rubber without any nails. In addition, different kinds of prosthetic appliances are required for crippled patients or whose limbs are amputated due to malignant growth of ulcers. For them, there is a great demand for microcellular rubber footwears and other prosthetic appliances. At present such demands

are being met in a limited way by some of the leprosy centres which have facilities for manufacturing these products. A centrally located "Footwear and Artificial Limb Manufacturing Centre", if established in technical collaboration with those already engaged in manufacturing these products, would not only help the leprosy patients in rehabilitating them in a useful manner, but also cater to the footwear and prosthetic needs of leprosy patients all over India.

Another area where cured leprosy patients could be successfully rehabilitated is to set an example by employing them in our own offices, centres and hospitals. This will not only boost the morale of the leprosy patients but will also give us strength to persuade others to employ cured and trained leprosy patients in their establishments.

Realising the need for considering the Rehabilitation Services as an essential and integral component of eradication programme, the Working Group on Eradication of Leprosy in its report submitted to the Ministry of Health and Family Welfare, Government of India, in 1982 had made the following recommendations:—

"Vocational training cum shelter work centres available for physically handicapped should also open their doors to leprosy patients. In addition, big leprosy homes, hospitals or colonies should have their own unit for vocational training and production. The leprosy rehabilitation promotion unit and the regional leprosy training and research institutes can act as a nodal point for establishment of such vocational training and production

centres by the social welfare or labour department or by a voluntary organisation, to supplement the effort of rehabilitation at these medico surgical centres". Report of the Working Group on the Eradication of Leprosy, February 1982. Page 39.

In pursuance of these recommendations, the Government of India, under its National Leprosy Eradication Programme established eight Leprosy Rehabilitation and Promotion Units till the end of March 1985. However, considering the magnitude of the problem, many more centres need to be established. In this task, in addition to the Government of India taking effective steps, the voluntary organisation such as the Hind Kusht Nivaran Sangh (Indian Leprosy Association) have also a big role to play.

#### **Some successful Rehabilitation ventures of Voluntary Organisations**

In the beginning, long before the Government of India launched its National Leprosy Control Programme in 1955, leprosy work was carried out in India only by the Missionaries and Voluntary Organisation. Even now, though the Government of India is doing a lot to control and eradicate leprosy in our country, the Voluntary Organisations (both national and international) are also doing commendable work in all spheres of anti leprosy work, specially in health education and in vocational and social rehabilitation of cured leprosy patients. To mention a few examples of voluntary organisations which are running Training-cum-Production Centres for leprosy cured as well as for persons handicapped by other diseases, the following centres may be quoted.

**“Leprosy work is not merely medical relief, it is transforming frustration of life into joy of dedication, personal ambition into selfless service...”**

—Gandhiji

(1) **The WORTH Trust, Katpadi** (formerly known as the Swedish Red Cross Rehabilitation Centre for the Handicapped). The WORTH Trust (WORTH stands for Workshop for Rehabilitation and Training of the Handicapped), now being a self-supporting enterprise, provides employment for nearly 450 handicapped people of which nearly 100 persons are leprosy cured. It has five production centres, the area covered being foundry, light engineering fabrication, production of wind mill pumps, tractor trailers, agriculture dairying etc.

(2) **The Salvation Army Catherine Booth Hospital Training Centre for the Physically Handicapped, Aramboly, Tamil Nadu.** This Centre caters for 50 trainees at a time. The training, food, accommodation are provided free for the trainees who stay for 2 to 3 years and develop knowledge and skill according to their aptitude and ability. The training is given in light engineering skills—fitting, turning, drilling, milling, shaping, electric gas welding, sheet metal work and spray painting. Poultry rearing is also done in a small way. All instructors and workers in the centre are ex-leprosy or physically handicapped people.

(3) **The Maharogi Seva Samiti, Dattapur, Wardha.** This Centre

under its Rehabilitation programme gives training in agriculture, dairy, khadi and village industries. It is a model centre which has successfully experimented in rehabilitation of leprosy patients through agriculture.

(4) **The Schieffelin Leprosy Research and Training Centre, Kari-giri, near Katpadi (Tamil Nadu).** This centre, besides imparting training in several trades, is also experimenting on domiciliary rehabilitation of leprosy patients.

(5) **The Vidarbha Maharogi Sewa Mandal, Tapovan, Amravati (Maharashtra).** The Mandal has a huge rehabilitation centre in which leprosy patients are given training in Carpentry, Printing, Poultry, Handlooms and Power looms weaving, Carpet making, Iron smithy etc. If the patients, after training, cannot be rehabilitated at home, they are eventually rehabilitated in the centre itself.

(6) **The Maharogi Sewa Samiti, Warora, Anandwan (near Wardha).** This Samiti which made a modest start in 1950, has now expanded into a major institution with centres at five places. There are over 2000 leprosy patients under its institutional care. Some trades in which the patients are trained are: Tincan Project (recycling old tins), Carpentry, Iron Smithy, Water management training in Electric works,

Printing and Book-binding (including composing and exercise book making), Tailoring, Spinning and Weaving (power-looms, handlooms, Ambar Charkhas), Carpet manufacturing, Leather craft (Chappals, Shoes, Leather hand bags, Fancy goods), Automobile engineering, Coal briquette manufacturing, Brick manufacturing, Handicraft, Painting, Cane work, hand made Greeting Cards etc. It has a land of 300 acres where intensive modern farming is being done. Besides manufacturing of conventional agricultural implements and modified tools and gadgets for handicapped, the centre is also maintaining dairy farms, poultry, and goat and sheep rearing.

These are but a few examples of the fact that given the initial financial support and encouragement, the Voluntary Organisations with their dedicated workers can do substantial work for the training and rehabilitation of the cured leprosy sufferers. Besides a host of other Voluntary Organisations, the Hind Kusht Nivaran Sangh (Indian Leprosy Association), being the premier voluntary Organisation in India and having branches in almost all the States and Union Territories, is striving hard to supplement the efforts of the Government.

There is no short cut to rehabilitation of leprosy sufferers; there is no other alternative than to give them vocational training in some suitable trades or crafts. Provision for Vocational Training and Rehabilitation, on a more urgent and wider basis, is both an obligation and a responsibility of those others who are not victims of leprosy. The question to be asked is “Have we performed it well and enough?” If not, there is still some time before it becomes too late to act. ○

# SOCIAL PROBLEMS OF LEPROSY

## —A Doctor's Experience

DR KUNAL SAHA AND DR N. M. CHAWLA

During the 13 years' experience of numerous contacts with leprosy patients, the authors feel, their problem can be classified into three categories—(a) doctor's problems, (b) social problems of patients and their families, and (c) leprosy beggars and social problems.

THERE are 32 million estimated cases of leprosy in India, of these about 25% suffer from deformities. About four lakhs have become socio-economically dislocated and two lakhs are floating beggars. Out of them 20% are infectious and they form a rich reservoir for spread.

### Social Stigma

Ignorance about scientific facts is the breeding ground for superstition and misunderstanding. In case of leprosy, wrong notions and misunderstandings are deep rooted in every society of the world. As a result leprosy is feared and it becomes a dangerous disease in the eyes of the common man.

### Social Problems

During our 13 years' contact with numerous leprosy patients as research workers on this disease, we had experienced several social problems, which can be classified in three categories.

(1) *Doctors' Problem:* Doctors treating leprosy patients in an urban general hospital face several pressing social problems. Most importantly, a majority of doctors, specialist or generalists, as well as nurses

and technicians are extremely apathetic towards these patients. Only 5% doctors may touch them.

To illustrate these, we mention our experience. A lepomatous full-term pregnant woman with labour pain went from hospital to hospital to be delivered in a obstetrical ward at midnight, she was refused admission in all hospitals, finally she went back to the leprosy home, where she used to live, and died of severe uterine bleeding due to some manouvre by an unexperienced local woman inmate. Another patient with severe erythema nodosum, who needed immediate hospitalization, could not be admitted in our hospital, since she had obvious signs of lepomatous leprosy. Further no ambulance could be available to take this severely sick man back to his dwelling place. What is lamentable is that even nurses were indifferent to these patients. One ward sister refused to give drinking water in a drinking pot to a blind lepomatous woman, but instead gave water in a toilet mug to her, whom I admitted in a medical ward several years ago.

This unkind action of the sister was so painful to this elderly blind woman, that next morning, when I enquired about her physical condition, tears welled up in her white blind eyes with a vague look towards me. Often these patients, when admitted in a general ward were not given any bed and were put on the floor of the wards, infested with rats and cockroaches. These vermin took the flesh out from the ulcerated feet of these patients when they were asleep at night, who had no pain sensation and thus could not feel any pain.

The administration of the hospital is also shamelessly apathetic to these unfortunate patients. While we had been treating these severely ill patients in our hospital by a new method developed by us (passive immunotherapy) all these years, most technicians were antagonizing our activities except a few. They made official representation about their safety to their union leader though the Medical Superintendent. Surprisingly, the hospital administration also asked for our explanations about the safety of the hospital staff.

[Contd. on Page 18]

# OPERATION HEALTH CARE AT

Kum. Saroj Khaparde, Union Minister of State for Health and Family Welfare, visited the worst drought affected areas in the States of Rajasthan and Gujarat with a view to assessing the medical care facilities for drought-affected areas.

In Rajasthan, the Minister travelled extensively and saw at the first-hand the realities of extreme natural conditions and calamities which the people have been facing for years. She discussed with men and women who were engaged in drought relief work at various sites. It was brought to her notice that diseases like nightblindness, diarrhoea, malnutrition and skin diseases were the burning examples of consequences of severe drought. The Minister also visited the hospitals, primary health care units and had meetings with the higher officials.

A new Scheme, Operation Health Care at Drought Relief Sites, emerged. This new concept envisages the idea of providing a temporary shelter, necessary health care which includes supplementary nutritional programmes and the health education component with an emphasis to gear up utilisation of the existing health care personnel starting from the grassroot level up to the medical college professionals. This new concept can also give a bonus by way of involvement of health personnel in the realities of life—an opportunity by which the drought conditions that have been forced on people by nature can best be utilised. This Scheme was launched in the States of Rajasthan and Gujarat in the worst drought-affected areas on the 19 November, 1987, the birthday of the late Prime Minister, Smt. Indira Gandhi.

## Salient features

The salient features of the Scheme are:

In the Scheme, Rs. 1.05 lakhs would be provided to three medical colleges each of Rajasthan and Gujarat. These medical colleges are Dr. S. N. Medical College, Jodhpur, R.N.T. Medical College, Udaipur, S.P. Medical College, Bikaner in the State of Rajasthan and Medical Colleges at Baroda, Ahmedabad and Jamnagar in the State of Gujarat. This financial assistance would be spent on three Primary Health Centres (PHC) attached to each medical college. Thus Rs. 35,000 have been earmarked per PHC. The total expenditure on this pilot Scheme would be Rs. 6.30 lakhs for both the States. This amount would be in the form of grant-in-aid to the State Governments. Requisite orders have been issued to the State Governments.

The salient features of the Scheme are expansion of medical and relief activity at PHCs and sub-centres in the form of:

(a) *Manpower*:—Doctors and students deputed in the department of preventive and social medicine of the medical colleges would be mobilised to provide preventive and curative medical facilities at PHC and sub-centre and at the worksite. These personnel would provide treatment, cent per cent immunization in the entire PHC, extra-supplement of Vitamin A tablets to prevent nightblindness health education in *Anganwadis* and *Balwadis*, special care to children, expectant mothers and older people and to conduct health and nutrition survey.

(b) *Other services*:—The other services to be provided at the worksite are:

(i) Health Education at the worksite will be organised once-a-week.

## DROUGHT RELIEF SITES

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(ii) A first-aid box and clean drinking water would be made available at the worksite.

(iii) Feasibility of creche services for children of the workers at the worksite is also being explored.

(iv) The Government of India would supply free vaccine for coverage of the entire population at the worksite.

(v) Extra supplement of Vitamin A tablets would be given to the State Government on request.

The entire programme would be monitored regularly.

### Details of the Scheme

The parameters of this Scheme would be:

(1) In the State of Gujarat, the medical colleges of Baroda, Ahmedabad and Jamnagar and in the State of Rajasthan, the medical colleges of Jodhpur, Udaipur and Bikaner would be involved in this Scheme.

(2) Medical relief would be provided primarily in the PHCs and Sub-centres covered under the ROME Scheme.

(3) The students would visit the worksites once-a-week for treating those who are obviously ill and for Health Education purpose.

(4) A First-Aid Box and clean drinking water would be supplied at the worksites and, if possible, creches for keeping the unattend-

ed children of the workers would also be provided.

(5) Health and Nutritional Survey of the drought-affected people would be carried out by the students to judge the impact of drought conditions on the health status of these victims.

(6) Immunization coverage would be provided in the entire area of the primary health centres on cent per cent basis. In case there is any demand for vaccines from the State Governments, the Government of India would supply free vaccines. The rest of the Cold Chain arrangements for immunization would be dependent on the EPI Programme already existing in these States.

(7) Extra supplement of Vitamin 'A' tablets to prevent nightblindness would be given by the Central Government to the State Governments on demand and on payment by them.

(8) Advice would be given on nutritional supplement to the ICDS Blocks, *Anganwadis* and Rural Development Agencies working in these PHCs by the medical students. Special care will be given to children, expectant mothers and older people.

(9) The work of the voluntary organisations like the Indian Red Cross Society and other agencies who are interested in medical relief will be coordinated under this Scheme as far as their area of operation is concerned.

(10) Health Care Monitoring in these primary health centres would also be done according to the Health Contingency Plan circulated to the State Government in these PHCs under the ROME Scheme. ○

## SOCIAL PROBLEMS OF LEPROSY—A DOCTOR'S EXPERIENCE (Contd. From Page 15)

All these disturbances created by the medical personnel, from doctors to technicians, we believe, were due to their ignorance about scientific facts of transmission of leprosy. This ignorance created misunderstanding even among the family members of the doctors and technicians. Several years ago we became sad to know that a marriage engagement of a woman technician was broken, when the bridegroom came to know that the girl worked as a technician on leprosy.

### (2) Social problems of the patients and their family members:

A small unnoticed patch on the body, once medically diagnosed as leprosy, envelops the patients with feeling of helplessness, shame and dependency. He starts considering himself as a potential outcast. Because of this, his initial response is to hide the disease and thus he is not willing to attend the clinic for treatment, with the result that the disease progressively takes the downhill course. This affects the patient's personality and behaviour pattern adversely. Thus as the disease progresses, the patient may spread the disease to his neighbours in the community.

We knew a young borderline tuberculoid patient, who had been a cook in a very rich family for several years. He had few anesthetic patches on his body for a couple of years. He used to cover these patches by his uniform. Once detected by his employer, who herself was physician he became mentally very much upset. Thereafter he was not allowed by his employer to enter into the kitchen and was put in the out house as a chowkidar where his friend,

who were once very intimate with him, began to avoid him. This was a great shock to this patient, which totally disturbed his mental equilibrium and finally, he ran away.

Often some patients with advanced infective leprosy, who outwardly were not disfigured could not be recognized by the general public as leprosy patient. We know at least two such women patients. One lepromatous leprosy case had plus four bacillary index and another lepromatous case had plus four bacterial load and pulmonary tuberculosis. Both had infectious form of leprosy and were working as maid servants in well-to-do families residing in good localities of Delhi. On the other hand, one such lepromatous man with plus three bacillary load and foot ulcer was a panwala, selling pan to the public on the roadside.

### Social and economic persecution of the patients

As soon as the society knows that an individual is suffering from leprosy, he is socially uprooted. The patient is not invited to any religious or social function. He is refused admission to an educational institution and public transport. More importantly he loses his job and accommodation. Thus he becomes isolated and dependent entirely on charity. These factors drastically alter the personality of the individual. What really hurts them most is that children, though perfectly healthy, are refused admission to schools and if some of them are lucky enough to complete

schooling, they do not get even the humblest of jobs. Thus the family of the patient is left destitute.

Recently a young muslim childless poor woman with multibacillary lepromatous leprosy, though not disfigured, was under our treatment. She was very much mentally disturbed not from her illness, but for the constant fear of separation. Her husband, being instigated by the neighbours and mullah used to threaten of divorcing her and remarrying.

In muslim families, it is an usual practice that husbands and wives take food from same plate. This woman's husband being afraid of getting leprosy from her did not take any food from the same plate and so much so did not have conjugal sex life. This caused tremendous impact on her mind. She often bursted into tears before us. On enquiry, the husband admitted to us that he had no masculine power and refused to give his semen sample for pathological examinations. We had known another lepromatous woman with severe uncontrolled lepra reaction. She had several children and belonged to the low socioeconomic status. She used to come to our hospital for getting treatment, accompanied by her husband or occasionally her brother. Initially her husband seemed to be devoted to her, but at last became disgusted with her illness due to terrible social, economic and family pressure. Being depressed she committed suicide. On the other hand, we have also very devoted wife helping her sick multibacillary lepromatous husband who was a rich business man.

### **Varying degree of social stigma.**

This socio-economic stigma on leprosy tends to vary in intensity with type of society, country and community. Thus the tribals, who do not know much about leprosy are less fearful of it. On the contrary, the educated urban society is highly prejudiced against leprosy. We have already mentioned how medical doctors, nurses and hospital technicians often refuse to render treatment to the leprosy patients requiring even emergency operations and maternity care.

It is interesting to note the socio-psychological behaviour patterns of educated middle class patients. Most of them fear to go to leprosy hospitals and to reveal their identities, so they roam in front of the outdoors of the leprosy clinics of big urban hospitals. The agents easily recognize them and send them to the private clinics of the doctors of the leprosy hospitals.

In this connection we may mention about the severe mental and social pressures on lepromatous patients holding high position in the society. This was once confessed by one middle aged highly educated bacilliferous lepromatous patient with foot drop. He was a professor in a college, was a bachelor and held a good political position. He was always haunted with the idea that he might be exposed as a leprosy patient by his opponents in the society and thus he might lose all the high social status that he was enjoying all these years.

### **Social problems of institutional patients.**

Patients approach leprosy institution with different motives which make an impact on their medical needs. Some patients regard the institution as their permanent residence and have no desire to go out and thus they are likely to neglect their treatment. Others go to the institutions as a last resort and feel a keen desire to return to their family and community. They are likely careful about their treatment. Those who are completely disabled, crippled or blind (terminal cases) cannot return to their society and

require long-term attention, which is not always feasible within the institution. Thus they have to depend physically as well as economically on those who are relatively fit enough to work, or conversely, the relatively physically less handicapped leprosy patients exploit physically more handicapped ones by taking them out for begging. Finally there are patients, who after treatment become non-contagious or 'burnt-out' cases. But regrettably, most of them have no contact with their families, have no home to get to, are not accepted in their societies. Therefore they need rehabilitation badly. In most of these colonies, there are hardly any governmental help worth mentioning. The authorities may provide only two days of physical work in a week and that too not round the year. The official agencies provide some food rations (worth Rs. 80/- a month) and clothing in these colonies. However, the ration provided is highly inadequate. In these circumstances, the patients have no other way but to go out begging. Often quite a large number of these patients sell their ration and clothings donated by voluntary organizations. Finally they become addicted to country liquor, ganja, charas and bhang and indulge in other anti-social activities.

### **Marriage of leprosy patients and its social and psychological problems:**

Leprosy patients are also human beings. They often live a long life and thus they cannot be deprived of their biological functions and necessities. A young patient, when medically certified safe to others, i.e., he or she ceases to be an active leprosy transmitter, may marry and produce children. Unfortunately, social stigma may adversely affect his or her conjugal life and even their off springs. Society has no right to deprive these individuals of their fundamental biological necessities. In the light of modern knowledge, there is no need for special legislation on leprosy. Any legal measure dealing with leprosy patients and family planning should form a part of the general public health organizations. Infective patients, on the other hand, should not marry and should be discour-

aged to produce children till they are clinically and bacteriologically cured. This is specially true for infective woman patients, because the strain of child bearing and lactation may have severe adverse effect on their disease course and may spread infection to their off springs through contact and by breast milk containing millions of leprosy germs.

Children born of such infective patients are cause of real social and psychological problems. Segregation of these children in separate children home may cause psychological trauma on these children because they are deprived of parental affection and care. On the other hand, if they stay with their parents with infectious form of leprosy, they may contract the disease. Delhi Administration has a boys' and a girls' home for these apparently healthy children of leprosy patients, where such children from four years of age are kept, brought up, sent to schools, given vocational training and rehabilitated in the society. Some girls have become trained nurses in government hospitals and start earning Rs. 800/- per month; others are married and settled in happy life while boys have become motor drivers, fitters and technicians. Thus these children, though their number may be insignificant with respect to their total Indian figure, have been rescued from this dreadful disease.

### **(3) Leprosy beggars and social problems.**

It is now agreed that begging is primarily a social problem, and not a medical one. Because the leprosy affected beggar suffers from two stigmatisations, both as beggar and as leprosy patients, he gets isolated for fear that he might spread the diseases. He may be arrested by the police while begging in the public places, detained in the beggars' home for one year and then released. He again becomes a beggar due to hunger, again arrested and the cycle is repeated. Therefore the question of rehabilitating leprosy beggars should primarily be a subject of administration and not of public health. ○

# VITILIGO—PHULBEHRI

DR SARDARI LAL

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Patients must be told that Vitiligo—the commonest cause of leucoderma—should not be confused with leprosy. This can be treated like any other parasitic infestation and deficiency state.

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**V**ITILIGO is the commonest cause of Leucoderma (white skin). It is an acquired depigmentation of skin and occurs without preceding skin disease or skin damage.

### Actiology

The cause of the disease is not known. Most accepted view is that it is a genetic disease with dominant mode of inheritance. Family history of the disease is available in 7.5 to 40% patients in different reports. Another view is that it is an autoimmune disease.

### Clinical picture

The disease occurs equally in both sexes. It can start at any age after infancy. The skin lesions are depigmented macules without any change in texture of skin and with normal superficial sensations. The skin at the periphery of the macules may be hyperpigmented. Some lesions may show depigmentation of hair, *i.e.*, leucotrichia. The most commonly affected sites are exposed parts like face, neck, hands, forearms, feet and legs. The disease may start at one site or at multiple sites. It may remain localized or become generalised. After certain degree of progress, the disease may become stationary. In about 25% cases the disease may regress spontaneously.

### Differential diagnosis

Vitiligo may have to be differentiated from a number of skin diseases which show hypo/depigmentation. *Partial albinism* is a congenital

disease showing depigmented macules. *Pityriasis alba* is a disease characterized by recurrent hypopigmented macules occurring on face of children. *Pityriasis versicolor* is a fungal disease characterized by hypopigmented scaly macules in which the fungus can be easily demonstrated. *Naevus anaemicus* is characterized by a hypopigmented macule which fails to show whealing in contrast to surrounding skin. *Tuberculoid (macule) Leprosy* is characterized by hypopigmented macules with impaired/lost superficial sensations and thickening of peripheral nerves. *Secondary depigmentation* due to skin damage or skin diseases usually shows change in texture of skin.

### Management

Patient must be told clearly that his skin lesions are not due to leprosy and he is not suffering from a contagious disease. The disease being only a cosmetic problem, treatment is not essential. General measures to treat vitiligo are the same that are applicable to any parasitic infestation and deficiency state. Watch for spontaneous recovery before starting any treatment.

Most popular treatment is photochemotherapy. Psoralens are used topically in localized disease. Systemic therapy is carried out in widespread disease. Following topical application of psoralen solution, the lesion is exposed to sunlight for half to

two minutes. For systemic use there are two preparations—trimethyl psoralen and 8-methoxypsoralen, the former is preferred for treatment of vitiligo. The dose is 0.6 mg/kg body weight, *i.e.*, 20 to 40 mg daily or on alternate days. One to two hours after ingestion of the drug, the lesions are exposed to sunlight for five minutes and period of exposure to sunlight is slowly increased till erythema is produced. Because of possible eye damage following this treatment, the patient is advised to wear sunglasses while going outdoors. Pigmentation occurs around hair follicles and at the periphery of the macules initially.

Corticosteroids/ACTH is another drug which is used by some dermatologists and claimed to be beneficial. The author has rarely used this drug for the treatment of vitiligo. Based on interviewing many patients of vitiligo treated with this drug by others and the author is not in favour of using this drug because of unconvincing benefit and side-effects of the drug.

Placental extract has been reported to be beneficial in some patients.

In resistant cases or for temporary coverup, a pint of 0.3 mg of potassium permanganate in 30 ml of water can be used for the macules on exposed parts.

Some workers have reported beneficial results by skin grafts in resistant cases. ○



# LEPROSY:

## Some Facts you should know

### 1. What is Leprosy?

Leprosy is a communicable disease like any other disease. The germ which causes leprosy was identified by Hansen and so leprosy is also known as "Hansen's Disease".

### 2. What causes Leprosy?

Leprosy is caused by a germ. The germ is so small that you need a special instrument (microscope) to see it. Leprosy is not a curse from God nor a result of sin, as many people believe.

### 3. Is Leprosy infectious?

All leprosy cases are not infectious. Most of the cases are non-infectious types and only 15-20% of cases are infectious. Leprosy is least infectious when compared to measles, tuberculosis etc.

### 4. Is Leprosy hereditary?

Leprosy is not hereditary. Many leprosy patients have children who are healthy. Leprosy patients can marry and lead a happy life.

### 5. Does Leprosy affect everyone?

Leprosy can affect anyone; rich or poor, old or young, man or woman, educated or uneducated, low caste or high caste.

### 6. How does the disease spread?

All leprosy patients do not spread the germ. Only 15-20% of leprosy cases are infectious. The germ cannot live outside the human body. Repeated close contact with infectious leprosy patients may cause the disease. Like many other diseases, leprosy germs also spread through coughing, sneezing, sputum etc.

### 7. Does environment have a role in spreading Leprosy?

In general, germs which cause diseases grow in unclean surroundings. People who are undernourished are more susceptible to these germs. So, leprosy patients should avoid spitting everywhere and coughing without covering their mouths. As in the case of other diseases, personal and environmental hygiene is very important in the prevention of leprosy.



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

**8. What are the signs of Leprosy?**

One can suspect leprosy when he sees any one or more of the following early signs:

- \* a pale or red patch on the skin and change in texture on any part of the body
- \* a raised or flat patch—dry, shiny or smooth
- \* a well demarcated patch on the skin which does not burn or pain
- \* inability of certain areas of the body to appreciate touch, heat or cold. In other words, loss of sensation with or without a patch

However, all skin patches may not be leprosy. It can be due to some other skin diseases. Very often people ignore patches. It is always better to get yourself examined by a doctor if there is a pale patch on your body.

**9. Is Leprosy curable?**

YES, leprosy is curable. Effective drugs are now available which can cure leprosy completely. If one takes early and continuous treatment, patients will not only be cured completely but can also be protected from deformities.

**10. Why do Leprosy patients develop deformities?**

Leprosy damages some nerves and some patients develop claw hands (bent fingers), foot drop (difficulty in lifting the foot upwards or dragging the feet while walking) and difficulty in closing the eye. The deformities develop when they do not report early for treatment.

**11. Can treatment prevent deformities?**

Deformities can be prevented by early detection and regular and complete treatment. Early deformities can be prevented by regular physiotherapy which includes massage, special exercises and use of splints etc. Some of the deformities can be corrected by surgery. The best way to prevent deformities is to ensure early, regular and complete treatment.

**12. What causes the ulcers?**

The ulcers are not caused directly by the leprosy germ. Since the germ affects the nerves and leads to loss of sensation in certain parts of the body, the patient is unable to feel heat, cold or pain and can get injured without being aware of it.

Leprosy is caused by a germ. It is neither hereditary nor a curse.



For e.g.: While cooking, the steam can cause blisters on the hand, form an ulcer which gets infected and leads to loss of the finger. The patient can damage his feet if he/she walks around without footwear. It is actually the injuries from heat, cold, sharp equipment etc that leads to ulcers.

**13. Is it necessary to isolate Leprosy patients?**

Leprosy patients should not be isolated from the family and the community. The leprosy patient under regular treatment, can stay with the family, lead a normal happy family life and continue his/her vocation.

**14. How can we encourage rehabilitation of Leprosy Patients?**

Family and community support is necessary to rehabilitate the leprosy patients. Family members and community need to be educated and motivated to promote family rehabilitation—accept them in the family and community. If we reject the patients, they are then forced to resort to beggary.

**15. Are there any welfare programmes that can support Leprosy patients and their families?**

The rehabilitation of leprosy patients, at the family and community level, is extremely important. Children of leprosy patients often have trouble regarding schooling, in getting a job or getting married. There are several welfare schemes which help the leprosy patients to get equal opportunities for education, employment and marriage. Several agencies help and support leprosy patients, including the physically disabled, in getting vocational training.

**16. Is there a vaccine which can protect us from Leprosy?**

At present, there is no effective vaccine which can protect us from leprosy. We hope that the research being carried out now will be successful in developing an effective vaccine in the future.

**17. How many Leprosy patients are there in our country?**

There are nearly 15 million leprosy patients in the world, of which 4 million cases (40 lakhs) are in India. The incidence of leprosy is high in



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



There is no need to isolate leprosy patients. Accept them in the family and the community.

states like Andhra Pradesh, Tamil Nadu, Orissa, West Bengal etc.

**18. What are the programmes being planned to eradicate Leprosy in India?**

The National Leprosy Eradication Programme is being implemented throughout the country with special emphasis in endemic states. Government and voluntary agencies are actively involved in early detection and treatment of leprosy as well as educating the community to accept the leprosy patients in the family and community. A wide network of leprosy control units, in both urban and rural areas, offer free treatment to patients. Recently the emphasis has been shifted from monotherapy to multidrug therapy. MDT is being introduced in 15-18 endemic districts, in the country and will be introduced in the remaining endemic districts in phased manner. The Government of India plans to eradicate leprosy from the country by 2000 A.D.

**19. What are the laws regarding Leprosy?**

Since leprosy is not only a medical problem but is also a major social problem, the government and voluntary agencies, involved in leprosy work, are concerned about the laws and regulations which prevent leprosy patients from enjoying their normal human rights.

Listed below are some of the laws:

The 'Prevention of Beggars Act' has a special provision for arresting and sending to beggar homes, leprosy patients found begging.

Some States have laws preventing leprosy patients inheriting property.

The Hindu Marriage Act of 1955 allows people to divorce spouses who have leprosy.

Leprosy patients are not allowed to rent a house to live in.

The Motor Vehicles Act in some states do not allow leprosy patients to have a driver's licence.

The Life Insurance Corporation did not give insurance coverage to leprosy patients but now it is not so. They have also stopped demanding a high premium from leprosy workers.

Some of the State Governments have challenged and repealed the 'Indian Lepers Act'.

The Railway Board allows the leprosy patients to travel on trains and also gives concessions to travel from home to the place of treatment.

**20. What can you do about Leprosy?**

- \* Educate yourself and share and discuss the correct information with friends and relatives.
- \* Protect yourself against leprosy by having yearly medical check-ups.
- \* If you see the early signs of leprosy in anyone, encourage them to go for an immediate check-up.
- \* Educate the family and others not to reject leprosy patients.
- \* Accept leprosy patients in the family and community and help them to lead happy, healthy lives.
- \* Give equal opportunities for education, employment and marriage to leprosy patients and their children.

—Courtesy: UNICEF

## WHAT ARE THE MISCONCEPTIONS/PREJUDICES AND CORRECT FACTS ABOUT LEPROSY

### MISCONCEPTIONS & PREJUDICES

1. Some people still believe that leprosy occurs due to
  - Heredity (from parents to children)
  - Immoral behaviour
  - Impure blood
  - Faulty eating habits such as dried fish
  - Past sins etc.
2. People think that leprosy spreads in some families only. It can be contacted by mere touch.
3. Leprosy is often associated with deformity. Leprosy can be diagnosed only after deformity.
4. Leprosy is highly infectious and infectivity is associated with deformity.
5. Leprosy is incurable and children in families having a leprosy patient always develop leprosy.
6. The attitude of the society is very unfavourable; a strong negative attitude towards disease results in non-acceptance of the disease and the patient. The stigma may lead to 'rejection' and hatred of afflicted.
7. Following type of practices are seen in the society :
  - Shunning away from leprosy patient;
  - Social boycotting or keeping a social distance from a family having a leprosy patient;
  - Social harassment of the patient and members of his family;
  - Refusal to help a patient of leprosy in retaining his job or place in family and society;
  - Disinclination to know about the disease and lack of cooperation with leprosy workers.
8. Lepers Act 1898 forbids a leprosy patient from having a bath or washing clothes at a public tap or travelling in public vehicle.
9. All begger leprosy cases spread the disease.

### CORRECT FACTS

1. Leprosy is caused by a germ. It is a communicable disease like tuberculosis, poliomyelitis, diphtheria, etc. but spreads rather slowly compared to these diseases.
2. Only 20% cases of leprosy are infectious and may help in the spread of the leprosy infection to healthy people. Mere touch with an infectious patient does not spread leprosy. Prolonged contact with an untreated infectious case can spread leprosy. Not more than 2 to 3 per cent of the population develop leprosy in any endemic community.
3. Early sign of leprosy could be skin patch with or without loss of sensation over the patch.
4. Deformity is often not related to infectivity of a patient.
5. Leprosy is completely curable. If infectious cases live within their family and do not take treatment then only they can spread the infection to the family members.
6. The disease must be accepted like any other communicable disease. The social stigma is unjustified.
7. People with suspected leprosy should come forward for confirmation of diagnosis and treatment.
8. The Leprosy Act must be repealed by all the States in view of the scientific facts about Leprosy. States of Maharashtra, Orissa, West Bengal, Tripura and M.P. have repealed the Leprosy Act. The Act was never in force in Goa, Pondicherry, Rajasthan, Sikkim and Haryana. Parliament has repealed the Act in 1983 in respect of UTs without legislatures.
9. Begger leprosy cases often do not spread the disease.

# Welfare of Leprosy Patients of Delhi

THE role of voluntary organisations in leprosy welfare cannot be overemphasised. In Delhi, Hind Kusht Nivaran Sangh, Kusht Rog Seva Samiti, Leprosy Rehabilitation Society, The Leprosy Mission, Missionaries of Charity, Lotts Carey Baptist Mission and Rama Krishna Mission have been working for the welfare of leprosy patients for over 30 years.

Although Delhi is not an endemic area for leprosy, but the continuous influx of these patients from the endemic belts into the city in search of job has resulted in a great increase in their number. Many of these patients are squatting on the roadside working in Dhabas, and as maid servants, driving cycle-rickshaws and live in unhygienic environment. Since leprosy is a socio-economic and medical problem, it was felt that a joint action of the above voluntary organisations and conscientious citizens of Delhi including medical personnel, scientists, National Service Scheme (NSS) Volunteers, industrialists and businessmen is needed to strengthen the national leprosy control programme in the capital on a warfooting.

A co-ordination committee was, hence, formed under the Chairmanship of the Chairman of the Metropolitan Council of Delhi in 1985.

## Activities of the Committee

**Identification of leprosy cases:** Since there is no report of any field survey of the prevalence of leprosy in Delhi, the Committee has trained NSS volunteers and medical personnel of the School Health Scheme of Delhi Administration to detect leprosy cases. Seven health check-up camps were organized in Delhi with

the help of TB control officer of Municipal Corporation of Delhi, ophthalmologists of Dr. Rajendra Prasad Centre for Ophthalmic Sciences, dermatologists of the All-India Institute of Medical Sciences, research staff of the immunology department of Vallabhbhai Patel Chest Institute and paediatricians of the Maulana Azad Medical College, New Delhi.

The Committee has undertaken a pilot survey of 4,000 school children of Delhi with the help of the staff of the school health scheme, Delhi Administration. For this purpose, training-orientation programmes for detection of early leprosy cases were organized.

The Health Checkup Camps were organized in different parts of Delhi including Red-Fort, Karol Bagh, Azadpur, Bal Greh, (Khyber-pass), Remand Home (Delhi Gate) and Leprosy Home Shahdara. Generous donations were made by the Kusht Rogi Seva Samiti and Lotts Carey Baptist Mission, Delhi, for these camps. Three cases of childhood leprosy cases were detected.

**Rehabilitation:** Raw materials such as thread yarn and dye-stuffs were provided to arrested leprosy cases for establishing handloom work at Shahdara leprosy complex. Three looms and four *charkhas* were operation and 40 members were said to have been benefitted on cooperative basis. To encourage the rehabilitation further, two cycle rickshaws, one cyclecart, five sweing machines were also provided to these patients. The Committee also arranged wedding receptions to three couples, who are healthy children of

leprosy patients at the Delhi School of Social work.

The Committee had also arranged sports materials and vitamins, tonics to children of leprosy patients.

Due to unprecedented drought this year, the Committee has provided handpumps to seven leprosy colonies in Shahdara and two hand pumps at Patel Nagar Leprosy Colony. The Committee helped the leprosy patients of Shalimar Bagh in getting built-up quarters of DDA at Raghuvir Nagar.

**Education of Healthy Children of leprosy patients:** Although the Social Welfare Department of Delhi Administration provided free boarding and educational facilities to institutionalized children, however, in view of those children, who lived in leprosy colonies and were deprived of school education, a primary school named Dr. Mohan Lila Soni School for children of leprosy patients at Shahdara was opened recently, at a cost of Rs. 15,000. Another primary school is also run at Raghuvir Nagar leprosy settlement colony.

During 1986, a Padayatra of leprosy patients and workers of the Co-ordination Committee, and N.S.S. Volunteers started from Gandhi Samadhi at Rajghat and ended at the India Gate. It was arranged on the eve of the World Anti-Leprosy day to focus the attention of the public on the problem of the leprosy patients. The slogan of the day was *Hamare Haath Apke Saath* (we are with you).

—DR. LILA SONI, SUNIL PRAKASH, DR. M.M. CHAWLA, DR. K.N. RAO AND DR. KUNAL SAHA.

# MAKING LEPROSY PATIENTS SOCIALY USEFUL

G. RAVINDRAN NAIR

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*Leprosy is not only a medical and public health problem today but it is also a major socio-economic conundrum with serious psychological overtones: the reason being primarily our lack of proper understanding of the disease. In this article the author pleads for a better understanding and a humane and rational attitude towards the leprosy patients so that their social ostracism ends and they become a useful partner of the society.*

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IN the village Mettugudisai, nine kilometres from Karigiri, North Arcot District, Tamil Nadu, a little boy, twelve years old Subramoni, was found to have a few patches on his body. The doctor's diagnosis traumatised the entire family. The poor boy was having the first symptoms of leprosy. The parents took him, to the Schieffelin Leprosy Research & Training Centre in Karigiri, and since the disease was detected early, he was treated systematically and completely cured of leprosy. But, unfortunately, Subramoni could not resume his studies since he lost his father when the family had not yet recovered

from its traumatic ordeal. While the family sold their property bit by bit to meet their basic needs, the poor boy tried his hand at various jobs, ending up as a helper in a tailoring shop with a rented machine. His earnings approximated a paltry Rs. 5 a day. Tragedy again struck him when he lost both his brother and brother-in-law, resulting in the added responsibility of looking after two families besides his own. It was then that the Domiciliary Rehabilitation Project of the Schieffelin Leprosy Research & Training Centre at Karigiri came to his rescue by lending him a new machine. This made a big difference in Subramoni's life. His monthly income rose to Rs. 350.

Not everyone is so lucky (if we dare call him so) as Subramoni, for the prejudices against leprosy and those affected by it are so deep-rooted that rehabilitation of leprosy sufferers has been a problem through the centuries. Both the family and society slam the door tight on even the cured leprosy patients. There are stray instances where matrimonial alliances between educated families flounder on the rocks when the news is broken that the bridegroom had once leprosy, but has now been completely cured and has in his possession a medical certificate to the effect. The dreadful truth is that bulk of the people—even the educated—hug the wrong notion

that leprosy cannot be cured. All this has made leprosy not only a medical and public health problem, but a major socio-economic conundrum with serious psychological overtones. The soul-searing social stigma that sent several leprosy sufferers into virtual exile in the island of Molokai in the Hawaiian Islands a century or more and for whom Father Damien died a martyr, himself contracting leprosy while nursing their wounds of the flesh. Spirit haunt millions of leprosy sufferers even today, with all our pretensions to the high-vaunted advances in science and technology notwithstanding. The social ostracism and the crippling deformities leave the hapless sufferers a lonely brethren, smitten by abysmal agony and driven to a kind of socio-economic vacuum. Few dare employ them even after they are completely rid of the scourge. Even non-infective and able-bodied patients have to bear the cross, and may be deprived of the means of livelihood. Begging is the only profession open to them. Where the victim happens to be a head of the family, the future is bleak for the entire family. An entire family becomes rudderless all of a sudden.

Who is to be blamed?

Can't we prevent the tragic drama of this suffering and stigmatised humanity increasing in their number

and migrating to distant places to escape social stigma and earn a meagre living? Can't we help them from developing those loathsome deformities? We can if we care. That the problems of leprosy patients have reached alarming proportions over decades as of the widespread apathy of the general public, more particularly of the educated public and the medical profession, and on top of all, of the mass media to the plight of four million leprosy-affected in our country. Deformity occurs when, on the first signs of the disease, the patient runs out of the family and society into hiding out of fear till the disease runs its course and he gets the deformities. Either he is afraid that people should not know that he has contracted leprosy or he is not aware that systematic treatment by monotherapy or multi-drug therapy can cure him of the disease.

#### **Control and cure possible**

Control of leprosy and the resettlement of the patients is possible only when the public is enlightened sufficiently about the disease and on the need for developing a humane and rational attitude towards the afflicted. Let it be known that all patients with leprosy are of infective, and that in our country only less than 20 per cent of the patients are infective. It should be made known that all persons infected with leprosy bacillus do not get the disease, and that over ninety per cent of the infected persons destroy the bacilli that enter their bodies, and thus do not get the disease. In a nutshell, the virulence or pathogenicity of the leprosy bacilli is very low. The public has yet to know that leprosy is curable and that leprosy beggars we find in the big cities and pilgrim centres are those who can no longer

infect the public, the disease having run its full course, what with their deformities due to lack of care and timely treatment.

Early detection and treatment makes cure easy, and prevents development of deformities. In Tamil Nadu which has the largest number of leprosy patients in the country, school health surveys are doing a good job in detecting potential cases in highly endemic areas, helping them get early treatment and cure. It is necessary to take the treatment regularly and for as long as the doctor advises. The patients should be treated in or near their homes as far as possible so that they are not dislocated and the problem of their rejection by the family after return from a leprosy hospital does not arise. The treatment should include simple methods of physiotherapy such as oil massage and exercises that can easily be carried out in the home, though treatment should be the responsibility of the local leprosy centre. But the basic question remains that with medical facilities in the rudimentary stage, not to speak of the facilities for the treatment of leprosy, domiciliary treatment has yet to become a reality for the largest number of the affected people.

Of course, under the National Leprosy Control Programme in India introduced as early as 1955 we have been performing the tasks of intensive case finding and arranging for domiciliary treatment; we have also provided for temporary hospitalisation of patients suffering from acute complications caused by leprosy. Late in 1982 we formed a well-planned strategy in eradicating leprosy by constituting high-level bodies at the Centre with top minis-

ters and officials from different Departments and even from the States.

#### **Rehabilitation process**

In the process of rehabilitation the education of the patients is as much necessary as the education of the public. Much of the deformity is preventable if the patients are taught the right use of their hands and feet by protecting them against injury, pressure and burns, if necessary, by the use of simple devices; and where the deformities have occurred, they can be corrected by physiotherapy and surgery. Few can forget the pioneering role played in this direction by Dr. Paul Brand and the Vellore Hospital in Tamil Nadu.

Rehabilitation is thus a long drawn-out process requiring the co-ordinated activities of a number of disciplines; the physician, surgeon, physiotherapist, occupational therapist, social worker, craft instructor, industrialist and the like. It becomes all the more complicated when the patient is forced to leave his home and, is not received back even after cure. Better not to speak of those with disfigurement forced by circumstances many take to alms and tend to live in segregation alongwith other sufferers welded by the spirit of the bond of suffering. One would wish that segregation were not there to facilitate rehabilitation, but that remains a mere desideratum.

#### **The Gandhi Kusht Ashram**

Beyond the eastern gate of the Taj Mahal in Agra is another wonder about which people know very little: the site of a leprosy patients' settlement, the Gandhi Kusht Ashram, which has become an ideal centre of self-rehabilitation. For

long the migrating leprosy sufferers from different parts of the country to the tourist city of Agra lived on begging, pitching their tents on the banks of Yamuna. On 2nd October, 1969, a new day dawned for those who lived on the doles of tourists : the foundation of an Ashram was laid on the land belonging to the forest department and the Jalma Institute. The strength of the families at this time was 25 and they took the pledge that they would henceforth never take to begging. What with the help of a retired dermatologist, the Jalma (the Japanese Leprosy Mission for Asia) and a few nationalised banks, the patients have been running a flourishing goatery unit in the Ashram area. The 150 goats they proudly possess can be seen grazing around the shrubbery in their new habitat.

To meet the needs for a proper footwear which would prevent injuries to their insensive feet, the patients have started making slippers themselves. They were joined by two patients who were trained in the Purulia Leprosy Centre in shoe-making. The shoe-makers produce five pairs of micro-cellular rubber sandals per day. These sandals are purchased by Jalma and other leprosy control units. A vegetable garden has also been started with the help of irrigation from a tubewell provided by the Lion's Club. Low-cost tenements have been built with the help of Rotary Club and other voluntary organisations. The residents are provided with potable water, electricity, a workshop for making candies, a meeting hall and a congregation room.

A panchayat comprising elected office bearers looks after the day-to-day administration of the patients'

## 7 April 1988: No-Smoking Day around the world

**T**HE Fortieth World Health Assembly at the conclusion of its deliberations in Geneva has called on all the member states to celebrate 7 April 1988, which will mark the World Health Organization's 40th anniversary, as a worldwide No-Smoking Day. In a strongly worded resolution, the WHA delegates, representing 166 nations, also call on all manufacturers to observe a sales and promotion "truce" on that day.

Welcoming the WHA initiative in interviews in Geneva, WHO officials drew attention in particular to the call for a voluntary "cease fire" by manufacturers and sales outlets next World Health Day.

**"If we can generate sufficient pressure at all levels, this proposal for a one-day truce could prove to be a powerful way of jolting people out of their inertia on smoking", said Dr Roberto Masironi, who is the coordinator of the WHO Smoking and Health Programme.**

The event could also be used by governmental and nongovernmental organizations to launch, or strengthen existing anti-smoking drives and health promoting initiatives, noted Dr Masironi.

Each of the WHO Regions would be working with the Geneva headquarters to develop campaigns. The Regional Offices in Alexandria, Brazzaville, Copenhagen, New Delhi, Manila and Washington would act as focal points for the participating groups.—Tobacco Alert April-June 1987.

settlement. Elections are held every year. For the 45 families living in the Ashram, life is far better than it used to be when they whined day after day for alms for a living. Today they have their own bank accounts and their children attend residential schools. A few are undergoing college and technical education. There is a code of conduct enforcing self-discipline for all the inmates : no drinking and no more begging, no children beyond two and work hard to the best of one's ability to earn one's livelihood.

Gandhi Kusht Ashram could be an ideal to others, but the basic question is should the leprosy sufferers live as isolated communities? Will they ever become part of society? We are waiting in the corridors for the vaccine that could deal the death knell to leprosy the same way we eradicated smallpox with the vaccine perfected by Edward Jenner. Till then..... what do we do ?

—Courtesy: Yojana, December 16-31,

1987

# TEN YEARS WITHOUT SMALLPOX

ZDENEK JEZEK

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Victory over smallpox has implications that go far beyond one disease. It provides an outstanding example of what can be achieved when countries throughout the world join together in a common cause. It reasserts human ability to change the world for the better and creates a new, strong impetus towards Health for All by the Year 2000.

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ON 26 October 1987, the world will have been 100 per cent free from smallpox for ten years. This tenth anniversary is therefore one of the most important health milestones achieved in the 20th century.

These ten years have proved incontrovertibly that:

- small pox *has* been eradicated;
- *no* other poxvirus has replaced it;
- millions of deaths, cases of blindness and disfigurement per year have been prevented;
- some US \$1,000-2,000 million, urgently needed for other health purposes, have been saved each year as a result of eradication.

Smallpox was a common disease in most countries of the world until the early 20th century. It claimed countless victims and severely handicapped or blinded many of those who survived. As long as it remained endemic in any country, there was a continuing threat of it being introduced into other countries anywhere in the world. From this threat stemmed the idea of an intensified, coordinated global effort leading gradually from control of the disease to its world-wide eradication.

The ravages of smallpox have been one of the preoccupations of the World Health Organization (WHO) since its first session in 1948 when the World Health Assembly singled it out as an important disease, and put great emphasis on its control. In 1958 the Soviet

delegation proposed a resolution calling for a global smallpox eradication programme, and this was adopted by the Health Assembly a year later. Although progress was made in a number of countries in the years that followed, the disease was still endemic in 31 countries with a total population of 1079 million in 1967, the year that WHO launched its Intensified Smallpox Eradication Programme.

Step by step the disease was pushed back. The last known case in West and Central Africa occurred in June 1970, in Brazil in April, 1971, and in Indonesia in January 1972. South-East Asia posed many difficult problems, but as a result of extensive educational and vaccination campaigns and with increasing emphasis on surveillance and containment, the disease slowly retreat-

ed. One of the largest programmes was carried out in India, with its population of 600 million and a long history of smallpox. Nevertheless, it was in Bangladesh that variola major, the most severe form of the disease made its last stand. Control activities were hampered by disasters that included war, floods and mass population movements. Yet the last case there was reported in October 1975.

### Final victory

From Asia the focus of attention shifted to East Africa. Since 1976, the endemic foci were confined to the Horn of Africa. In the Ethiopian Ogaden desert, variola minor—the milder variant of smallpox—proved to be remarkably tenacious; nevertheless, the last case there occurred in August 1976. In Kenya the last case occurred at the beginning of 1977 and was due to an importation.

In the spring of 1977, smallpox spread widely through southern Somalia, which became the last fortress of the disease. Large-scale emergency efforts quickly succeeded and the thousand-year-old chain of transmission was interrupted in the town of Merka, in southern Somalia, where the last case was detected in October 1977. Ali Maow Maalin, a 23-year-old hospital cook, had the dubious distinction of being the last-known case of endemic smallpox in the world.

Ten years, nine months and 26 days had elapsed from the beginning of the Intensified Smallpox Eradication Programme until this last case in Somalia. But the programme staff kept up the hunt for any possible further cases.

Then the disease made a totally unexpected reappearance, in August 1978. As the result of a laboratory accident in Birmingham, England, two further cases of smallpox occurred, one of which proved fatal. Since then even though WHO announced a reward of US \$1,000 for the report of any new case which could be confirmed as smallpox, no reward has ever had to be paid.

As watchdogs, WHO had earlier set up 21 international commissions and the Global Commission for the Certification of Smallpox Eradication. These have one by one verified and certified as being free from smallpox all countries reporting cases between 1967 and 1977 or at special risk of importations.

In December 1979, the Global Commission solemnly declared:

- smallpox eradication has been achieved throughout the world;
- there is no evidence that smallpox will return as an endemic disease.

This was certified at an epoch-making session of the Thirty-third World Health Assembly on 8 May 1980. It put the official stamp of approval on the most outstanding achievement in international public health: the eradication, for the first time in history, of a major disease.

Even then the job was not quite finished. It was necessary to convince the world community that the disease had gone for ever, and to ensure that every advantage was taken of the benefits of this achievement. The Organization mapped out its

“insurance” policy focusing on the main goal: safeguarding public health by maintaining the world permanently free from smallpox. Every report of suspected cases of smallpox was treated as a public health emergency and properly investigated. No one has proved to be smallpox.

Since 1984, variola virus has been confined to glass vials kept under high security in two WHO Collaborating Centres. Both centres are inspected periodically by WHO experts in microbiological safety. Culture of variola virus has ceased at both laboratories and neither has plans to resume such experiments.

In order to free the world from the need for vaccination regulations, the national health authorities demanded that a smallpox vaccine reserve be kept in case of unexpected emergencies. Such a reserve stock has been maintained by WHO since 1980 and would be sufficient to vaccinate about 200 million persons.

By 1985, all Member States had discontinued routine vaccination against smallpox. No country in the world now officially requires a certificate from international travellers, and most countries no longer vaccinate even their military personnel against smallpox. WHO hopes that the remaining countries may elect to do likewise, since vaccination of military personnel involves risk for both the vaccinees and their contacts.

Because of its close clinical resemblance to smallpox, human monkeypox became an important disease for surveillance. Since 1970, more than 400 patients suffering from monkeypox have been recognized

in seven African countries, mostly occurring in small, remote villages in the tropical rain forest. Despite intensified surveillance human monkeypox is viewed as an infrequent and sporadic zoonosis that poses neither significant health problems nor a challenge to the achieved eradication of smallpox.

#### **Benefits of eradication**

The first and most important achievement of eradication is the prevention of human tragedies and suffering. Back in 1967, an estimated two million people died from smallpox and each year 10 to 15 million more were affected. The suffering, disfigurement, blindness and bereavement that the world has been spared since the disease was stamped out are incalculable.

During the 13-year eradication campaign (1967-1979), the international contribution is estimated to have been about US \$ 98 million.

The endemic countries probably spent twice this amount—about US \$ 200 million. So it is safe to suppose that globally, US \$ 300 million were spent on eradication activities, an average of US \$ 23 million a year.

Smallpox had cost the world every year between US \$ 1,000 and US \$ 1,500 million, when we add together the production of vaccine, the maintenance of routine vaccination, care and treatment of patients, loss of productivity, maintenance of surveillance and quarantine services, handling emergencies and so forth. Since eradication that annual burden represents a net saving. So economic terms, the smallpox eradication programme is likely to be one of the best investments ever made by national and international public health.

The release of funds which were previously tied up for smallpox could have a massive impact on

public health, provided they had been diverted to health development programmes. National programmes of eradication were terminated, but the strengthened capacity for national surveillance remained. Voluntary workers and members of the public were sensitized to offer their services for further cooperation with public health services. Perhaps the best dividends are the hundreds of thousands of experienced, imaginative, tireless and dedicated health workers who remain in the countries and who serve as a solid base for implementing other important public health programmes.

Victory over smallpox has implications that go far beyond one disease. It provides an outstanding example of what can be achieved when countries throughout the world join together in a common cause. It reasserts human ability to change the world for the better and creates a new, strong impetus towards Health for All by the Year 2000.—*Courtesy* : WHO.

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# BOOKS

**Management training modules for Medical Officer. Primary Health Centre.** Somnath Roy *et al.* Published by National Institute of Health and Family Welfare (NIHFW), New Mehrauli Road, New Delhi 110067, 1987. Price not indicated.

**M**ANAGERIAL skills in varying degrees are essential for the organisation and development of the health care delivery system. All health personnel, even those at the grassroot level, require a certain minimum level of managerial skills in order to ensure the delivery of comprehensive and effective primary health care services. Evolving of suitable training programmes from a rationalised role reallocation of health personnel poses a challenge for trainers and health administrators. Modules encouraging problem solving are important for developing competence. The book under review is the first of series of managerial training modules for the different categories of health personnel at Primary Health Centre (PHC) level and below, *viz.* medical officers, health guides (male & female), health workers (M & F), health assistants (male & female) and trained *dais*. These have resulted from a project co-ordinated by N.I.H.F.W. involving Indian Institutes, of Management at Ahmedabad and Bangalore and the Gandhigram Institute of Rural Health and Family Welfare Trust and supported by a grant from the World Health Organisation, Geneva.

Four approaches, *viz.* job analysis, interviews, participatory observation and workshop have been utilised for identifying the managerial requirements and problems at P.H.C. level and below. The problems amenable to change through management training, have been addressed to in the modules under review.

Seventeen modules which together cover 81 hours and can be taught comfortably in 14 working days, have been presented in this volume. The topics covered include Planning, implementation, co-ordination, monitoring and evaluation of PHC services, supervision, teamwork, leadership and motivation, communication, community participation and personnel, financial material and patient referral system.

Emphasis has been placed on development of management skills and not on theory, 80% of the training time being devoted to practical exercises and field work which involve active participation of the trainee.

Provision has also been made for evaluation of the course by the trainees and the trainers. An attempt has been in structuring these modules as independent blocks which could be arranged in any sequence which a trainer considers appropriate for the given situation. A possible training schedule has also been suggested.

The modules, as presented, could be put to use in one of several ways—as a basis for short-term management courses, as a part of Continuing Education, for self-learning or as an integral part of the basic pre-service training curriculum. The modules which have

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been scientifically developed will help in the development/improvement of managerial skills among medical officers of P.H.C. and contribute towards achieving the targets India has set for itself in the field of health and family welfare. The modules will benefit not only the medical officers but also all those interested in primary health care and health management.

**Dr. S. Venkatesh**

