A Collaborative effort of MOHFW & NGOs **Issue-4**

Women's Health Towards Empowerment...

Dear Readers,

We hope you enjoyed reading the previous newsletter and found the information on 'Wiser Old Women's Health' to be useful as well as interesting.

The present issue focuses on Leprosy. Even though leprosy continues to afflict a number of people, it is no longer a major public health problem. As a result of the very encouraging results from the intensive use of treatment based on a combination of antileprosy drugs, known as multidrug therapy (MDT), the World Health Assembly in 1991 resolved to eliminate leprosy as a public health problem by the year 2000.

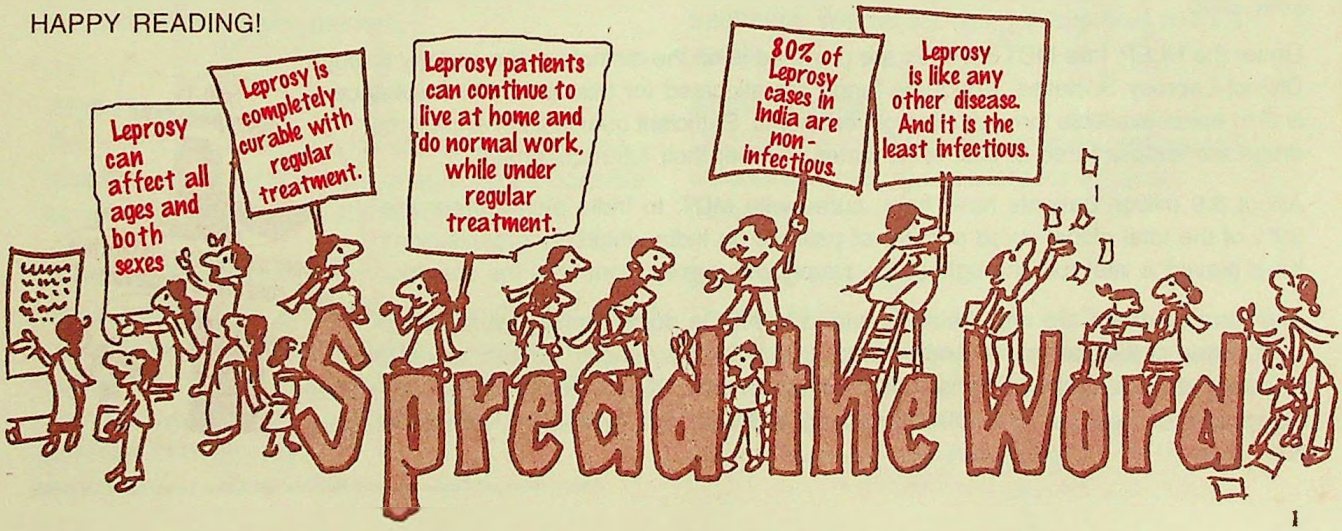
The key to leprosy control is the attitude of the community. A breakthrough can be made through a change in knowledge, attitudes and practices of society, and in particular of various influential groups, such as health practitioners and policy makers. This newsletter is intended to promote such a change. It is hoped that the information that is included in the newsletter will stimulate readers to make their own contribution to leprosy elimination.

The National Leprosy Elimination Programme (NLEP) is a Central Government sponsored programme and is gradually being integrated within the Primary Health Care System. This programme is playing a key role in fighting and eliminating leprosy all over the country.

A module on 'Leprosy and Women's Health' at the State, District and Village level is available in English, Gujarati and Hindi Languages at CHETNA. If you are interested in receiving it, please write to us. As mentioned earlier, you will only be charged the cost of photocopying the material.

Please note that this is the last issue of the newsletter, ***"Women's Health towards Empowerment..."***

HAPPY READING!



WHAT IS LEPROSY ?

Leprosy is a chronic infectious disease caused by Mycobacterium Leprae, an acid-fast, rod shaped bacillus. The disease mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract and the eyes, apart from some structures. It has afflicted humanity from time immemorial. It is one of the diseases feared over the centuries because of its potential to cause progressive disfigurement, disabilities and mutilations. The stigma attached to leprosy had often led to ostracisation to the people afflicted, and their families, by society.

EPIDEMIOLOGY: Some Facts

Leprosy is transmitted from one untreated person to another via the respiratory tract or skin.

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

Early detection and regular treatment prevents deformities and disabilities.

Leprosy can affect all ages and both sexes. The incubation period can spread over several years but is usually 3-5 years. It is transmitted directly from person to person through the respiratory tract or skin. However, it is acquired through prolonged exposure and only a small proportion of the population is affected. Untreated persons, in particular those who are smear positive, are the principal source of infection.

Although Hansen identified the disease - causing organism M. Leprae in 1873, the treatment for leprosy emerged only in the late 1940's with the introduction of Dapsone. This dramatically changed the treatment policy of leprosy, from one of isolation of leprosy sufferers to treating the disease as an outpatient basis. The life long treatment and development of resistant stains of bacilli led to further research and introduction of the Multi Drug Therapy (MDT) in 1981. Current regimen of fixed duration multi drug therapy of 6 months for Paucibacillary (PB) cases, 12 months for Multibacillary (MB) cases and single dose ROM therapy for single lesion cases has further made it possible to achieve the elimination of leprosy as a major public health problem.

NATIONAL LEPROSY ERADICATION PROGRAMME (NLEP)

Leprosy is one of the oldest diseases known to mankind. To combat the disease, the Government of India (GOI) launched the National Leprosy Eradication Programme (NLEP) in the year 1993, as a 100%centrally sponsored scheme. The objective was to reduce the disease prevalence to less than 1 per 10, 000 population by the end of year 2000.

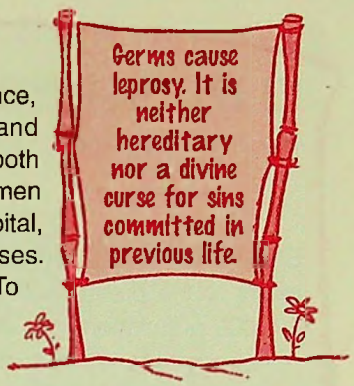
Under the NLEP, free MDT services are provided in all the districts of the country through District Leprosy Societies. Adequate funds are allocated for this and cash assistance is also made available through state governments. Sufficient quantities of anti-leprosy drugs are supplied free of cost to all states to meet their full requirement.

About 8.9 million patients have been cured with MDT. In India alone, there are 90% of the total global cured number of patients. In India, voluntary organisations have played a vital role throughout the history of Leprosy Control in the country.

Anti leprosy drugs are also being provided to NGOs doing leprosy work free of cost. If any of the patients are not availing free MDT, they should contact any of the following officials. District Leprosy Officer of the District, State Leprosy officer in the State, Directorate of Health and or DDG (Leprosy), DDGHS, Family Welfare, Nirman Bhavan, New Delhi.

Source: Asian and Pacific, Women's Resource and Action Series: HEALTH (1990)

LEPROSY AND WOMEN'S HEALTH



Women suffering from leprosy are doubly disadvantaged. Due to a culture of silence, they usually do not complain about their illnesses and hence, the diagnosis and treatment usually gets delayed. In case of leprosy, social stigma is attached to both men and women who do not come forward for treatment on time, however, women are more at a disadvantage. It is reported by several social workers that in a hospital, registered cases of women having deformities are more common than male cases. The male cases are usually registered during the earlier stages of the disease. To overcome this, more female health workers and anganwadi (crèche) workers have been trained to whom the female patients go for medical assistance.

It is common for a young unmarried woman who has undergone leprosy treatment and is cured not to find a life partner whereas, a man does not face any such major problem for marriage. Discrimination is also observed in surgical treatment. Even among families who can afford, male patients get a priority for surgical treatment, whereas women patients are neglected. There is a need to create health awareness about the disease so as to remove social stigma attached to the disease.

Laws and legal provisions have been extremely harsh on leprosy patients through centuries. It has been particularly biased where married women leprosy patients are concerned. In the Indian male dominated society, the wife is expected to be monogamous in spite of his faults and misdeeds, and hence there are few instances of wives applying for divorce against their husbands. Ironically, female patients have been and are, even now divorced by their husbands on the grounds of leprosy.

SOCIAL PREJUDICE FACED BY WOMEN IN SOCIETY

HE HAS LEPROSY

The Husband breaks the news to his wife

Wife: Leprosy is a terrible disease but you can be cured. Do not worry, I will support you.

The man breaks the news to his family

Bad luck has befallen us, but these days leprosy is curable. We will take you to the hospital and pay for your treatment. Do not worry, there will be no problem in getting you married.

At the hospital

Doctor: We will treat you for your deformities and take you for surgical treatment as soon as possible as you have come to us at the right time.

After the Treatment

The family and wife accept the man in the family and he continues with his normal life. If he was unmarried, then he easily gets a girl who is willing to marry him even though she knows that he was suffering from leprosy.

SHE HAS LEPROSY

The wife breaks the news to her husband

Husband: Stay away from me. I do not want to be infected by the terrible disease. Do not touch or go near the children. Leave the house. I want a divorce.

The woman breaks the news to her family

Bad luck has befallen us. Who will marry you now? You will be a burden to us for the rest of our lives. Where will we get the money for your treatment. We have to keep this terrible news a secret.

At the hospital

Doctor: We will try to treat your deformities but unfortunately you are too late for surgical treatment.

After the treatment

The family is not keen to take her back and mostly the husband and children refuse to also accept her. If she is unmarried, it is very difficult to find a husband for her. If she is married, then it is likely that her husband will divorce her.

ELIMINATING LEPROSY

ELIMINATING LEPROSY

ELIMINATING LEPROSY

Elimination of leprosy as a public health problem refers to the prevalence of less than one case per 10, 000 population. It is assumed that if prevalence of leprosy reaches to such a low level, it should no longer be considered a public health problem and integration of leprosy with general health services will become possible. The NLEP (National Leprosy Eradication Programme) of the Government of India has consistently guided the states of India to achieve the target of leprosy elimination. Availability of multidrug therapy has proved to be extremely beneficial in reaching nearer to the stated goal.

Elimination of Leprosy can be achieved by:

- ensuring regular health education at the community level. Disseminating the message that leprosy can be cured without deformities
- making MDT accessible to all communities and areas;
- treating all registered cases with MDT;
- diagnosing and promptly treating all new cases;
- improving the quality of patient care, including disability prevention and management;
- ensuring regularity and completion of treatment;
- enlisting community support for the programme

THE CURRENT LEPROSY SITUATION

Today, the global prevalence rate of leprosy is 1.4 cases per 10, 000 people. In 1985, there were 122 Leprosy endemic countries worldwide. In 1999, that figure reduced to 24. Ninety percent of world leprosy is now confined only to 12 countries.

Approximately 804,000 new cases were detected around the world in 1998. There were 820,000 cases on the register at the end of 1998.Bhavan, New Delhi.

It is estimated that about 2.5 million patients around the world will be detected between 2000 and 2005.

Leprosy remains a health problem in 24 countries situated mainly in the inter-tropical belt of the world. Of the 24, a total of 12 countries would have met the elimination by the year 2000, special efforts will be needed to reach elimination in 12 other countries which include India.

At present India has 61.1 of the world's recorded leprosy cases. That amounts to 4.61 lakh cases. In March 2000, India had 89% percent of the world's cured leprosy cases. That amounted to 8.9 million people out of a global total of 10.00 million cured cases.

The major leprosy elimination challenge in India is in the following states, which contributed 71% of total country caseload including higher percentage of cases of consequences. Recorded cases in March 2000 in these states is as follows: Bihar: 110664, Jharkhand: 385566 Uttar Pradesh (UP): 98225, West Bengal (WB): 42440 Madhya Pradesh (MP): 17806 Chhatisgarh: 18049 Orissa: 40717

Hidden cases are also likely to be higher in these States.

With leprosy elimination defined as less than 1 case per 10, 000, the above states recorded the following prevalence rates by March 2000:

Bihar: 15.40

Jharkhand: 14.62

Uttar Pradesh: 6.20

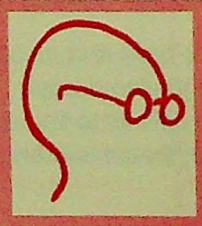
West Bengal: 5.44

Madhya Pradesh: 3.57

Chhatisgarh: 5.62

Orissa: 11.46

Total eradication means zero case in any place at any given time.



"Leprosy work is not merely medical relief, but it is transforming the frustration of life into the joy of dedication and personal ambition into selfless services."

Mahatma Gandhi

ROLE OF FAMILY AND COMMUNITY MEMBERS

The members of the family and community should encourage leprosy patients to take regular treatment. They should also aim at enabling people with disabilities to reach and maintain their optimal physical, sensory, intellectual and social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Community based rehabilitation is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities, and appropriate health education, vocational and social services.

Social stigma is the chief cause of the social and economic dislocation that people affected by leprosy experience. Addressing such stigma is an essential step towards reintegration in society. The rehabilitation process must concentrate on overcoming the ignorance and prejudice that underline the stigma. Education campaigns can achieve this. Other activities may include exhibitions, leaflets, drama, street plays, films, and TV programmes. The media has a powerful role to play in this regard. Simple messages like "Leprosy is curable - All it needs is your support', Do not fear it, Treat it" may be utilised. This goes a long way to change the community attitude.

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

Source: Asian and Pacific, Women's Resource and Action Series: HEALTH (1990)

NEED FOR A NEW APPROACH

➔Support early identification and voluntary referral through a communication campaign

➔Raise awareness about the reasons for stigma and its resulting trauma to the victim

➔Partner with local, national and international groups

➔Update legislation and vigilant enforcement to assure the rights of those affected

➔Orient action to prevent disabilities and dehabilitation

➔Strengthen family and community networks

➔Arrange meetings of people's representatives to build political will.

➔ Develop training modules and kits for front-line workers

➔ Undertake and support research evaluation and documentation

CHRONOLOGY OF SCIENTIFIC WORK AND IMPORTANT EVENTS IN INDIA REGARDING LEPROSY

1984 Repeal of the Leper's Act in Maharashtra

1984 International Leprosy Congress at New Delhi

1986 First Indian Evaluation conducted and National consultants appointed. District MDT society for every district started

1987 Lepra India started work in India

1990 3rd Independent assessment of the programme

1991 Hundred percent Centrally sponsored Programme started and elimination goal accepted

1994 Agreement with World Bank for Assistance for six years. All the districts in the country under MDT. Mobile control units for hypo - endemic districts started. 9.5 lakh Leprosy patients in India

1995 WHO/GOI 5th Independent assessment programme. 7.4 lakh Leprosy Patients in India.

1996 Second International conference on Elimination of Leprosy at New Delhi.

1998 MLEC/Tamilnadu goes for integration

2000 VRC, step towards integration of leprosy services

2000 First Asian Leprosy Congress at Agra

CASE STUDY FROM RAJASTHAN STATE

Ms. Ratni Bai Khatik is a resident of Keer Kheda village in Rajasthan State. She belongs to a backward caste and is semi-literate. She was married at the age of 13 years but stayed with her husband for only a year since she found him to be of immoral character. Inspite of repeated persuasion by her family, she refused to go back.

Since the last three years, she is associated with a grassroots organisation, the Centre for Human Development (CHD), Chittorgarh District, as a networker. Her responsibilities include participation in training programmes and information dissemination by organising awareness generation events. Her commitment, courage and perseverance in improving rural life has made a continuing impact on the community. She informs the villagers about the importance of 'educating women'. She was also instrumental in setting up the local village school and played a key role in the enrollment of schoolgirls. For this, she worked jointly with schoolteachers, parents and members of the panchayat.

The creative aspects of her approach include use of local songs about physiology and hygiene, folk stories and folk sayings. Health has been the other focal point of her activity. She regularly attends training programmes on 'Reproductive and Child Health, Sanitation, etc organised by CUTS-CHD. She disseminates the learning among her friends during informal discussions. She encourages and educates the villagers to either filter or boil their drinking water. The village women have started analysing 'the access of health services in rural areas'. Their interaction with health officials have resulted in increased frequency of visits by health personnel and timely availability of necessary drugs. They also have done some plantation work near the drainage points of their houses. Ms. Ratni Bai Khatik has been a catalyst in the formation of women's self help groups (SHG) in her village. This has had a multiple effects in the neighbouring villages too.

IMPORTANCE OF PARTICIPATION IN TRAINING

Participation is a fundamental process within a group, because many of the other processes depend upon participation of various members. Levels and degrees of participation vary. Some members are active participants - talkative, demanding, volatile; while others are more withdrawn, quiet and passive. In essence, participation means involvement, concern for the task, direct or indirect contribution to the group goal.

Participation by members is basic to the existence of a group. If members do not participate, the group ceases to exist. But participation does not mean just physical presence or that everyone speaks. Silent members could be listening very carefully. What needs to be identified and tackled are the members who are "there but not there" those who are indifferent, uninvolved or could not care less. They could be a detriment to the group.

The factors that affect member's participation are the content or the task of the group, whether it is of interest, importance and relevance, the physical atmosphere, whether it is comfortable physically, socially and psychologically, the psychological atmosphere, whether it is accepting and non-threatening. Also important are the members' personal preoccupations, whether there are any distracting thoughts on their minds, the level of interaction and discussions-is adequate information provided for everyone to understand. Familiarity among group members is also critical.

Source: Asian and Pacific, Women's Resource and Action Series: HEALTH (1990)

Experiences of Master Trainers and Village Leaders

"The women's self-help group is gaining more confidence in their strength. The project Women's Health towards Women's Empowerment has done a lot in enhancing the self-confidence of these women. Now they are ready to fight for their rights, for the safety of their family and against gender discrimination and injustice existing in society."

-Experience from the State of Kerala

"The pictures and illustrations were useful and effective. After the training, the women's negotiating ability has increased. Now they have started talking more vocally with panchayat and family members. They have even negotiated with the PHC staff."

Experience from the State of Andhra Pradesh

"The modules used were helpful. On the basis of those, we have prepared new case studies and illustrations on different subjects. We have encouraged village women to communicate with their husbands regarding the importance of health for both boys and girls. Village leaders are also motivated to go on house visits and spread messages on health".

Experience from the State of West Bengal

"After the training, we have demanded better access to health services. People have also started utilising government schemes. Women are making efforts to increase employment opportunities through the panchayat. They have started getting support from ANMs and Anganwadi workers. The women have taken up some critical issues at the District level".

-Experience from the State of Madhya Pradesh

Source: Building and Strengthening of Manila Mandal, Dept. WCD Govt. of Rajasthan

References:

Books

- A Guide to Eliminating Leprosy as a Health problem: Second Edition 1997: World Health Organisation (WHO)
- The Diagnosis and Management of early Leprosy: 1984
- Leprosy Control: Everyone's Concern: UNICEF: 1984
- A Manual for participatory Training Methodology in Development by PRIA: 2000

ARTICLES

- Newsletter: 'Hamari Chitthi Aapke Naam': 2000
- Health for the Millions: Leprosy: January - February 2001
- Leprosy Elimination Disability Care and Rehabilitation, Gujarat - Status Report and Action Plan 2000

SOME INDIAN NGOS WORKING FOR THE ELIMINATION OF LEPROSY

Andhra Pradesh

Assisi SevaSadan, Allapalli

GREVALTES, Vishakapatnam

Vimuti, Kakinada

Bihar

Bharat Sevashram Sangh, Jamshedpur

Rajendra Kushtha Ashram Research and Training Centre, Mairwar

Santhal Pahadiya, Seva Mandal, Deoghar

Gujarat

Gujarath Raktapitta Nivaran Sangh, Vadodara

Shram Mandir trust, Sindhrot

Haryana

Hind Kusht Nivaran Sangh, Chandigarh

Karnataka

Katharina Kasper Leprosy Control Scheme, Bangalore

Sumana halli, Bangalore

Maharashtra

Acworth Leprosy Hospital, Mumbai

Gandhi Memorial Leprosy foundation, Wardha

Kusht Seva Samiti, Dattapur

Maharogi Seva Samiti, Anandwan, Warora

Poona District Leprosy Committee, Pune

Vidarbha Maharogi SevaMandal, Amravati

Manipur

Leprosy Patients' Welfare Society, Chingmeirang

Orissa

Dr. Isaac Santra Institute, Sambalpur

Port Blair

Andaman and Nicobar Leprosy Eradication Society

Tamilnadu

GREMALTES, Chennai

Sacred Heart Leprosy Centre, Sakkotai

Scheffelin Leprosy Research and Training Centre, Karigiri

West Bengal

Calcutta Urban Service, Calcutta

GRECALTES, Calcutta

CHETNA Editorial Team:
Indu Capoor, Pallavi Patel & Pallavi Shah
Input provided by: Dr. G. K Trivedi, Medical Consultatnt, CHETNA

Design & Illustrations: Anil Gajjar, Nagji Prajapati, Pallavi Patel & Pallavi Shah

Concept : CHETNA
Centre for Health Education Training and Nutrition Awareness
Lilavatiben Lalbhai's Bungalow, Civil Camp Road, Shahibaug, Ahmedabad - 380 004, Gujarat, India.
Ph. :+91(79) 2868856, 2866695 Fax :+91 (79) 2866513, 2113005 E-mail:chetna@icenet.net Website:www.chetnaindia.org

PRINTED MATTER BOOK-POST
(For Private Circulation Only)