CHAPTER IV

MEDICAL, SOCIAL AND LEGAL ASPECTS OF LEPROSY AND SIGNIFICANCE OF HEALTH EDUCATION IN LEPROSY

4.0 INTRODUCTION

In this chapter in Part I an attempt has been made to unravel some of the medical aspects: Epidemiology of leprosy, Diagnosis, Immunology of leprosy, Classification of leprosy, Therapy of leprosy, Reactions in leprosy, Neuritis in leprosy, Epidemiology of Deformities and Disabilities, and Physiotherapy in leprosy. In Part II we have dealt with the Socio-cultural-economic aspects which have a bearing on the perpetuation of the disease and also the legal aspects relating to the care and rehabilitation of the leprosy afflicted. In Part III we have dealt with the significance of health education in leprosy control from the points of view of (a) interrupting the transmission (b) diagnosis (c) treatment (with different regimens) (d) preventing and controlling deformities and disabilities and (e) rehabilitation. This analysis help not only to understand the magnitude of the problem but also appreciate the need for eradication programmes on a war-footing. It is a pity that in many developing countries because of misconceptions about the disease the people do not come forward for treatment in the initial stages which makes matters worse both for the patients and the leprosy control programme. So social awakening is warranted along with eradication programmes, is the message of this chapter.
PART I

4.1 MEDICAL ASPECTS OF LEPROSY

4.1.1 Definition of Leprosy

Leprosy is a chronic infectious disease of man caused by Mycobacterium leprae. It mainly involves the peripheral nerves but also the skin, mucous membrane of upper respiratory tract, eyes, bones, muscles and testis.

4.1.2 Epidemiology of Leprosy

Epidemiology is the study of the distribution and determinants of disease frequency in man (population). The two main areas included in this definition are

i. The study of the distribution of the disease and its manifestations are essentially descriptive, dealing with characteristics such as age, sex, race and geography etc.

ii. The study of causation (determinants) of the disease is essentially analytical, dealing with the three cardinal causative factors - Infectious agent, transmission, and susceptible host.

The ultimate aim of epidemiology is to understand the disease and discover the causes of the same so as to suggest best means of preventing, controlling and finally eradicating the disease from human population, and also to provide guidance for health administration.
4.1.2.1 Descriptive Epidemiology

4.1.2.2 Magnitude of the problem

It is difficult to estimate the total number of leprosy cases in the world today, because of the following inherent constraints (WHO TRS 716 1985)

1. Incompleteness and inaccuracy of the information recorded.
2. Neither case finding nor reporting has attained the desired level of efficiency.
3. The diagnosis and definition of cases is neither clear nor consistent in all countries.
4. Many patients are retained on official statistics despite the fact that they have neither recovered, emigrated or died.
5. Several patients remain unrecognized, while others are wrongly diagnosed and included in official lists.
6. Because of the fear, shame and social stigma associated with the disease, leprosy is greatly under-reported and some countries are reluctant to reveal its true prevalence. The exact number of leprosy patients is therefore not known.

Despite these constraints which are inherent in extrapolations from reported data, it has been estimated that the total number of leprosy cases in the world today is approximately 12 million.

4.1.2.3 Geographical Distribution

The distribution of leprosy is not uniform. There are wide variations in its clinical manifestations in different countries. Major differences are seen at all levels viz., continental, national, regional, village and even at home levels.
Approximate distribution of leprosy in the world is Asia-60%, Africa-35%, America-4% and other countries-1%. Leprosy is highly prevalent in Central Africa and South East Asia, with prevalence rates 10 and above per 1000. Though the number of cases are more in Asia, the prevalence is more in Africa (i.e. often 10-40 per 1000) due to less population there, in comparison to Asia. In endemic areas the prevalence rates vary widely, ranging from 28 and above per 1000.

4.1.2.4 Age Distribution

The age distribution of leprosy is not uniform. Leprosy occurs in all age groups from infancy to old age (Newell 1966). The few cases reported are mainly in children of patients. Thangaraj and Yawalkar (1986) say that "although children may run a greater risk of acquiring leprosy, the disease occurs in all age groups". Of the estimated 4 million cases of leprosy in India, nearly a million of them are children living under the shadow of this dreadful disease. Incidence rate usually rise to a peak between 10-20 years as reported from Latin America, Philippines, Burma and South India. In hyper endemic areas it has been observed that children are more frequently affected. This is mainly because opportunities for exposure occur at an earlier age, rather than to increased susceptibility (WHO, 1985).

4.1.2.5 Sex Distribution

Both men as well as women are affected with leprosy. It appears that more males are affected than females with a male - female ratio of 2:1. The difference in prevalence between the sexes may be artificial, as men are more thoroughly examined than women due to genetic or hormonal differences between the sexes. However the differences in sex prevalence of leprosy is inconspicuous in children below the age of 15 years. It is a fact that lepromatous leprosy is more common in men than in women (WHO, 1985).
4.1.2.6 Race Distribution

Leprosy occurs in all races whether they are black, brown or white, but the type of leprosy differs from race to race, as mentioned below (Fig. 2) in countries where people belong to different races:

**Figure 2**

<table>
<thead>
<tr>
<th>Country</th>
<th>Lepromatous</th>
<th>Non-lepromatous Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>African Countries</td>
<td>5%</td>
<td>95%</td>
</tr>
<tr>
<td>India</td>
<td>15 - 20%</td>
<td>80 - 85%</td>
</tr>
<tr>
<td>Thailand &amp; Burma</td>
<td>30%</td>
<td>70%</td>
</tr>
<tr>
<td>Japan &amp; Korea</td>
<td>70%</td>
<td>30%</td>
</tr>
</tbody>
</table>

When people from different races live in the endemic area, where the environmental factors are the same for everyone, they tend to develop leprosy of the same type to which they are susceptible. It was also observed that the occurrence of maculo-anaesthetic and polyneuritic types of leprosy among Indians, Leucio leprosy among Mexicans and lepromatous leprosy among Japanese may be due to racial factors.

4.1.2.7 Environment (Secondary Factors)

A number of environment factors have been attributed to play an indirect role in occurrence and spread of leprosy.

4.1.2.7.1 Proximity of contact and duration

If heavy exposure leads to immuno-suppression and hence to lepromatous type, the incidence of lepromatous cases should be particularly high among close contacts of lepromatous patients. Closeness of contact is also
linked to over crowding in the home environment. Crowding is also confounded by several variables linked to poverty, poor personal hygiene, inadequate sanitation and malnutrition.

4.1.2.7.2 Climate

A few are of the opinion that a hot and humid climate favours transmission of leprosy as a dry and cold climate inhibits the same. But this is not proved by facts observed as there are areas with dry climate having a high prevalence of leprosy as areas with a hot and humid climate. The association of leprosy with hot and humid climate has also been referred to by Rogers (1923), Muir (1927) and Risi (1937).

4.1.2.7.3 Rural / Urban distribution

Leprosy is predominantly a rural disease. However with rapid industrialisation in many countries migration from the country side to towns and cities may facilitate the spread of leprosy.

4.1.2.7.4 Distribution according to socio-economic status

Leprosy has been found to affect more people belonging to poor socio-economic strata than higher strata of society. In our country the rich are equally affected by leprosy as are the poor. No consistent association between any occupation or caste to leprosy has been shown.

4.1.2.7.5 Distribution in Time

The rise and fall of leprosy in Europe is very fascinating to know. The disease was endemic in Europe even before Christian era but during the 14th and 15th centuries, the disease reached its peak and then rapidly declined, and by the end of 18th century the disease was almost eradicated from Europe.
So among the environmental factors, social and economic factors do have a definite role in influencing the prevalence of leprosy. The social and economic factors that influence the prevalence of the disease among the population are overcrowding, low standards of living, lack of hygiene, poverty, illiteracy, ignorance and above all apathetic attitude, prejudice, and indifference to leprosy.

4.1.3 Determinants of leprosy (Analytical) (Fig. 3)

<table>
<thead>
<tr>
<th>Source of Infection</th>
<th>Mode of Transmission</th>
<th>Susceptible Host</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Portal of bacilli exit</td>
<td>Contact</td>
<td>- Portal of bacilli entry</td>
</tr>
<tr>
<td>- Skin &amp; mucous membrane (active leprosy lesions)</td>
<td>Nasal (air)</td>
<td>- Skin &amp; mucous membrane (healthy &amp; abraded)</td>
</tr>
<tr>
<td>- Nose</td>
<td></td>
<td>- Nose &amp; Resp. system</td>
</tr>
<tr>
<td>- Breast Milk</td>
<td></td>
<td></td>
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</tbody>
</table>

4.1.3.1 Causative Agent

The mycobacterium leprae (an acid fast bacilli) was discovered to be the causative agent of leprosy in 1873 by G.A. Hansen of Norway (Vogelsang, 1978).

The long generation time of 12 - 14 days of organism explains about the long incubation period of 3 - 5 years of the disease, but it may be as short as few months and as long as 40 years. Incubation (latent) period is the time gap between the entry of germs in the body and the clinical onset of the disease (Jopling 1984).
4.1.3.2 Source of Infection

Man is the host and leprosy bacillus which habitate inside the body of leprosy patient is a parasite. With the present knowledge, man is the only source of infection to other man. Recent studies have shown that leprosy bacilli can multiply when injected into the foot pad of mice or in an Armadillo (Shepard, 1960).

Though the patients suffering with all types of active leprosy are infectious, open cases (mostly borderline and lepromatous) have been reported to be 4 - 10 times more infectious than closed cases (mostly non-lepromatous).

There are more than one portal of entry and exit. The likely routes are the nose and skin. Skin which is broken due to abrasions, injury, dermatoses and insect bites provides easy access for M. leprae. Millions of M. Leprae are found in the nasal secretions, sneezing and coughing of lepromatous leprosy patients. From an untreated lepromatous leprosy patient, especially an ulcerated nodule, 20 million bacilli per day could be shed. Few bacilli are shed from intact skin. The nasal discharge of an untreated lepromatous patients in 24 hours may contain \(2.4 \times 10^8\) AFB with a M.I. of 12.8 (Davey and Rees 1974). While speaking and coughing \(1.6 \times 10^6\) AFB may be discharged. Even during normal breathing the spread of bacilli is possible. \(1.6 \times 10^6\) M. leprae can be spread per mouth wash. Full survival of M. leprae outside the human body is possible for 7 to 9 days (Desikan and Sreevatsa 1979). Moist soil at room temperature prolongs the period of survival.

4.1.3.3 Mode of Transmission

The exact mode of transmission is not yet known, and three possible routes are under consideration, namely the skin, the gastro-intestinal tract, and the respiratory tract.
4.1.3.1 Contact transmission

Figure 4

It has been observed that prolonged intimate contact is not essential in transmission, repeated intimate contact may be sufficient, and that perhaps one contact, under ideal circumstances is sufficient. The risk of infection varies with the type of contact; the more intimate the contact the greater the risk of infections, and the risk of infection is greater with intra-familial contact. The larger the family the greater the crowding and intimacy of contact within the house is a definite factor in transmission (Rao, 1975).

The intimacy of contact is directly related to the state of civilization, or social and economic status. The greatest prevalence has been and remains, among people of low economic status, with inadequate housing, etc. which leads to crowding and intimate contact. The greater the intimacy of contact the greater the risk of becoming infected.
4.1.3.3.2 Inhalatory (Airborne) Transmission

Millions of M. lepraee are discharged while coughing, sneezing and while speaking. It can also live outside the human body in the dried up secretion for 7 to 9 days. So infection may occur through respiratory tract while inhalation.

4.1.3.3.3 Vector Transmission

There is experimental evidence that insects do mechanically carry M. lepraee. M. lepraee were found in house-bound or non-flying insects like bed bugs, lice, fleas and also in mosquitoes especially in houses of lepromatous leprosy patients. However we cannot incriminate, insects are responsible for the transmission of the disease at this stage due to insufficient evidence.

4.1.3.3.4 Ingestion

M. lepraee have been identified in the breast milk of mothers with lepromatous leprosy (Pedley 1968). It is not known whether their children develop the disease after ingesting the milk which contains M. lepraee. Most probably M. lepraee are killed by the acid present in the stomach.

4.1.3.3.5 Host factors

Whatever may be the leprosy endemicity of an area, of the total population living in that area, only a small proportion of it gets leprosy. This is because of the immunity the people possess against leprosy. Immunity process plays an important role in deciding whether a person would get leprosy, or not, if so, what form of leprosy. It has been shown that the natural and acquired cell mediated immunity (CMI) plays protective role against leprosy and the degree of immunity may vary from person to person, place to place, any one race to other. The manifestations of the disease in susceptible host depends to a great extent on the immunity of the susceptible host. The
development of immunity against leprosy may depend on 'genetic factors' and
the 'immunological background of the individual'. Hence the portal of entry
of M. leprae in the susceptible host was thought till recently to be the skin,
nose and the respiratory tract.

4.1.4 Diagnosis

Leprosy is diagnosed on the basis of its clinical signs and symptoms
and in some cases with the help of laboratory investigations. Cardinal signs for
diagnosis of leprosy are:

1. Loss of sensation (touch, thermal or pain) in skin patch / or in periphery
   of limbs.
2. Tenderness and/or thickening of the nerve trunks in the limbs (peripheral
   nerve trunks) or cutaneous nerves.

The majority of leprosy cases can be diagnosed on the basis of the
above three signs. Every case of leprosy does not show all the three signs but
a case which shows even one of the above signs is a case of leprosy.
Bacteriological examination is necessary mainly for deciding infectivity of case
and in some instances in diagnosing doubtful cases; ‘Slit’ and ‘Scrape’ method
is generally used for the demonstration of M. leprae. The skin smears are
usually stained by Ziehl Neelsen's method.

The M. leprae appears rod shaped and deep pink colour. Its length is
2.8 µ (µ means micron = \frac{1}{1000} of a mm) and width is 0.2 - 0.8 µ. They are
seen in large numbers often arranged in parallel bundles resembling a packet
of cigars. The individual organism may be straight or slightly curved.
4.1.4.1 Bacteriological Index

Bacteriological Index is calculated by adding the index from the various sites and dividing the total by the number of sites examined.

It is used (1) for diagnosis (2) to know the degree of infectivity (3) for classification (4) to know the prognosis (5) to know whether the disease is arrested (6) to decide the line of treatment.

4.1.4.2 Morphological Index

This is the percentage of solid - bacilli in the smears. Morphological Index is useful to know the prognosis quickly. (Waters and Rees 1962).

\[ M.I. = \frac{\text{Total number of intact bacilli}}{\text{Total number of bacilli counted}} \times 100 \]

4.1.5 Immunology

Immunology is the study of host's defensive response towards any foreign agent generally micro-organism. Immunity helps to kill the germs and thereby to prevent the onset of the disease. Immunity is therefore a method of defence by which the body protects itself (Roitt, 1974).

4.1.5.1 Defence methods of the body

Healthy skin does not permit the entry of germs except through cuts, injuries, and respiratory tract. Body fluids like sweat, tears and gastric juices are mildly antiseptic and can wash out or kill the bacteria. Thus there is a good 'wall' protecting the body. This forms the first line of defence. There are several types of defence cells which can swallow and kill the germs. If the germs manage to break through any weak defence cells other types of defence cells come into action. Thus there is 'fight' between the germs and the defence cells. This is called 'inflammation'. It is also the second line of defence. The germs
manage to escape all these, settle in the tissue, and multiply in the tissues in order to produce the disease.

4.1.5.2 Mechanism of Immunity

Two types of immunity operate by two different mechanisms.

1. Humoral Immunity carried out by 'B' lymphocytes.
2. Cell Mediated Immunity (CMI) carried out by T lymphocytes.

4.1.5.2.1 Humoral Immunity

Humoral immunity is manifested by the production of "antibodies" (Jha et al 1971). The antibodies are special chemical substances that react against foreign substances or germs (antigens). The presence of antigens in the body stimulates certain type of defence cells to produce antibodies. Such cells are initially 'B' lymphocytes which later become plasma cells and secrete antibodies. Therefore the germs (antigens) which enter the body start the production of antibodies which in turn acts against them to kill them. In some disease conditions antibodies are produced in large quantities, but fail to act against the antigens. This unfortunately happens in lepromatous leprosy where the germs continue to multiply despite the production of antibodies.

4.1.5.2.2 Cell Mediated Immunity

This immunity is directly expressed by certain types of defence cells against the antigens. These cells are 'T' lymphocytes, and are influenced by the 'thymus gland'. When the T lymphocytes come in contact with the antigen and begin to proliferate in large numbers. These sensitized cells secrete certain substances (lymphokines) which in turn stimulate other defence cells (macrophages) to ingest and kill the organisms. This type of defence mechanism is particularly seen in diseases like Tuberculosis and Tuberculoid
leprosy. This type of immunity which is carried out by cells is called cell mediated immunity.

In Tuberculous leprosy, CMI is well developed but no humoral immunity. In Lepromatous leprosy it is just the opposite.

4.1.5.2.3 Natural Immunity

The capacity to resist the disease without prior exposure to the infection, is called natural immunity. In most populations, even after the leprosy bacilli enter the tissues, 90 - 95% of the individuals do not get leprosy because their natural resistance, or specific immune responses kill the invading organisms.

4.1.5.2.4 Acquired Immunity

If a person develops immunity after coming into contact with infectious agents he is said to have acquired the immunity. In otherwords, this immunity is not naturally present from birth but is initiated by the introduction of the antigens in childhood or in later life. Many people have natural immunity against leprosy, but others develop immunity after sub-clinical infection, and do not suffer from leprosy. Still others do develop the disease, but only for a short while during which time, spontaneous healing occurs due to the acquired immunity they develop. Only the remaining few are likely to develop leprosy of different types depending on the level of their immunity.

As far as immunity is concerned, lepromatous (LL) and tuberculoid (TT) are called "polar types" because like the north pole and south pole, they are very distant from each other and opposite of each other. Between the two poles there is border line or Dimorphous type of leprosy which is unstable (Fig.5). The polar types of leprosy do not change their types, but in borderline type there is a considerable possibility of shifting from one end of the spectrum to the other. Such an instability is due to a delicate balance between bacillary load and immunity.
Types of leprosy and immunity (Fig. 5)

If CMI - very good - No leprosy (90 - 95%)
CMI - moderate - Tuberculoid
CMI - lacking or absent to M. leprae - Lepromatous leprosy
CMI - Mild, moderate - Borderline leprosy

4.1.6 Classification of leprosy (Fig. 6)
On the basis of the clinical and bacteriological examination leprosy can be classified into the following five types according to Indian Association of Leprologists (Fig. 6) as (i) Indeterminate; (ii) Tuberculoid; (iii) Borderline; (iv) Lepromatous; (v) Pure-neuritic.

The new approach to leprosy control involving the use of multidrug therapy has resulted in some changes in terminology in the classification of patients. It must be stressed, however, that these changes were not an attempt to formulate another system of classification but only a method of grouping patients together for the purposes of multidrug therapy.

In this context, the WHO Study Group on Chemotherapy of Leprosy for Control Programmes (WHO, 1982) classified patients as having multibacillary (MB) or paucibacillary (PB) leprosy. This is essentially an operational categorization for purposes of multidrug therapy.

4.1.7 Therapy of Leprosy

4.1.7.1 Pre-Hydnocarpus Era

Prior to the introduction of any form of therapy for leprosy, the life of the leprosy patient was one of the object misery and hopelessness. Inhuman treatment was practiced on them. The church mercifully took over the care of these people. A funeral service was conducted over them, earth sprinkled over their head, thereby signifying that they were dead in so far as the community was concerned, and they lived in seclusion. Then came the establishment of "Lazar" houses where they were segregated, waiting for merciful death to release them from their physical and mental anguish. Isolation was the only solution in those days.
4.1.7.2 Hydnocarpus Era

A Burmese prince who was himself a victim of the disease has been credited with the discovery of hydnocarpus nut. Chaulmoogra (Hydnocarpus) oil and its preparations, which till about three decades ago were the mainstay in the treatment of leprosy have now been generally discarded in favour of the new chemotherapeutic drugs, which have brought about a revolution in this field of leprosy treatment.

4.1.7.3 Chemotherapy of leprosy

Drugs used in the treatment of leprosy patients may be divided into two categories.

1. The drugs against the causative organism of the disease, and therefore required as a basic routine for all the patients, and

2. the drugs, for the treatment of special symptoms and complications, and therefore not used as a routine, but only when specially indicated.

4.1.7.3.1 Dapsone Era

The first chemotherapeutic drug which was used in treatment of leprosy is D.D.S. (Diamino Diphenyl Sulphone) in short (Lowe 1952) which has minimum toxic effects. The drug is bacteriostatic. This means that the drug does not kill leprosy bacilli directly but prevents its growth and multiplication in the body by causing an unfavourable environment. It is cheap also. Dapsone is still given in monotherapy in places where multidrug cannot be given.

4.1.7.3.2 Dapsone Resistance

Sometimes leprosy germs multiply inspite of the fact that the patient is taking and absorbing dapsone in order to stop the bacteria multiplying. In such a case germs are said to be resistant to dapsone. The infective agent
will develop strains on which a drug is not acting. As long as the drug is acting, the organisms are drug sensitive.

Dapsone resistance occurs in any places where dapsone (monotherapy) has been given for a long time. Clinical evidence of DDS resistant leprosy was available even as early as 1953 (Wolcott and Ross 1953). DDS resistance has also been reported from India (Chaudhury and Desikan 1975).

Studies from South India have shown prevalence of dapsone resistance of the order of 95 per 1000 in North Arcot District and 86 per 1000 in Chengleput. These reports together with results from other parts of the world indicate that dapsone resistance is already a significant problem. The main factors now attributed to this ever increasing problem are monotherapy, the drug having been given alone, irregular intake and suboptimal dosage as discussed earlier. Evidence from studies carried out in various parts of Africa, India, Malaysia & Burma have demonstrated that dapsone compliance is often very poor, in some studies no more than 40% drug intake has been reported (Ellard 1981).

4.1.7.3.3 Primary dapsone resistance: is suspected when there is no improvement within six months in a case for which treatment is given at the maximum dose and take regularly. This occur in any type due to lack of response to therapy from the start of the treatment.

Cases of primary sulphone resistance have been reported from Ethiopia (Pearson et al 1977), Columbia (Londone 1977), and Malaysia (Waters et al 1978b), and many other countries. The other main problem faced in therapy of leprosy is the persistence of drug sensitive organisms despite long years of continued therapy. This has been considered in the past to be
responsible for continued smear positivity after several years of treatment and for relapse after discontinuation of therapy. Vellut (1978) came across 17 cases who were positive despite 10 years of treatment. Ramu and Desikan (1979) found persisting bacilli in scrotal skin after 2 to 10 years treatment. Waters et al (1974) came across a relapse to the tune of 0.96 per 100 over 9 year observation period.

4.1.7.3.4 Secondary dapsone resistance: is suspected in patients who had improved under DDS therapy and whose condition suddenly deteriorate. This occurs in MB cases only, because the number of bacilli is very high and the chances of developing resistant strains are good.

4.1.7.3.5 Causes of dapsone resistance: is the development of strains of bacilli which are resistant to dapsone, due to mono-therapy. The precipitating factors for this resistance are

1. Use of low doses of DDS
2. Irregularity of intake of DDS
3. Interruption of treatment during other complications.

The most important way to prevent dapsone resistance is by giving MDT, and taking some precautions of regularity and continuity in treatment. Otherwise multibacillary resistance can establish itself.

4.1.7.4 Multi Drug Therapy

The recommendation by the WHO Expert Committee on Leprosy in its fifth report in 1977 (WHO, 1977), that all active cases of multibacillary leprosy be treated with at least two effective anti leprosy drugs, was not followed for several reasons, including financial considerations. It was in this context that
a WHO Study Group on Chemotherapy of Leprosy Control Programmes met in Geneva in October 1981 to define drug regimens that would be both effective and applicable under field conditions (WHO, 1982). This group devised a treatment schedule involving the combined use of dapsone plus rifampicin for six months in paucibacillary cases and dapsone plus rifampicin and clofazimine for a minimum of 24 months in multibacillary cases. Thus multidrug therapy (MDT) for leprosy was born.

The more recent additions to the therapy of leprosy are

1. Rifampicin and 2. Clofazimine

4.1.7.4.1 Rifampicin: Rifampicin is a potent antibiotic drug and has bactericidal effect on M.leprae, i.e. it kills the M.leprae directly. It should never be given in monotherapy.


This drug, which is very effective in tuberculosis and leprosy, is not without serious side effect. These side- effects are particularly marked, if the drug is given with substantial intermissions, particularly irregular use of large doses of drug (Poole et al 1971; Aquinas et al 1972). No serious side effects have been given once weekly in relatively small doses under supervision (Girdhar, Sreevatsa and Desikan 1980). Two consecutive daily doses of the drug given once a month too have been found to be well tolerated (Girdhar and Desikan, 1979).
4.1.7.4.2 Clofazimine (Lamprene) : Is used as (1) an antileprosy drug (2) an anti inflammatory drug (anti reactional) and (3) an agent to stop an addiction to corticosteroid. It is never used in monotherapy. The cost is also high.

The drug has been in use since 1962, when Browne and Hogerzeil (1962) showed definite clinical and bacteriological improvement in lepromatous patients with its use. Further, it has been shown to have specific therapeutic effect on appearance of ENL and increases the tolerance of other drugs (Browne, 1965). This has been attributed to its anti-inflammatory effect (Hasting and Trautman 1968). Its use in cases of recurrent lepra reaction and those with steroid dependence has been well brought out in several studies (Iyer & Ramu 1976; Conalty et al 1971). It gets accumulated inside the macrophages and thus is able to act on intracellular organisms. A daily dose of over 200 to 300 mg continued for a long period specially in women, results in abdominal problems. It may be in the form of pain and / or diarrhoea. In severe cases hypokalaemia (Iyer and Ramu 1976) and death may occur.

4.1.8 Reactions in Leprosy

Reactions are episodes of acute increase (exacerbation) of the signs and symptoms in all types of leprosy except indeterminate type. The mechanism of reaction may however vary in different types due to immunological status (Waters, 1978). Reaction can occur spontaneously during the course of the disease (with or without chemotherapy) or may result from physical or mental stress, intercurrent infection, pregnancy and child-birth, administration of certain drugs or injudicious therapy. Sometimes no cause may be found.

There are two types of reactions.

1. Type 1 reaction i.e. Reversal reaction.
2. Type 2 reaction i.e. E.N.L. reaction
4.1.3.1 Reversal Reaction (Type 1 reaction)

Normally during the course of the disease in the absence of treatment there can be downgrading (decrease in immunity) with a shift from the tuberculoid towards the lepromatous end of the spectrum (TT → BT → BB → BL → LL). During Type 1 reaction this may be reversed and there may be upgrading (increase in immunity), with a shift from the lepromatous towards the tuberculoid end of the spectrum (LL → BL → BB → BT → TT). Hence Type 1 reaction is called reversal reaction or upgrading reaction. Type 1 reaction is a delayed hypersensitivity reaction. The antigens of M. leprae stimulate T lymphocytes causing a change in CMI; by enhancing their response.

4.1.3.2 Occurrence

The occurrence of reversal reaction while on therapy is normally considered to be increase in CMI which in turn in some cases could be due to reduction in antigenic load, while in others due to sudden release of antigen. Dapsone by killing the organisms, may result in some increase in CMI, thus resulting in upgrading reactions. Often there may be associated nerve damage. In contrast to the findings of Barnetson et al (1976) that there is no increase in nerve damage (and in fact nerve damage is less) with increase in DDS dose, Gupte (1979) has reported higher percentage of regular patients getting deformities. Before ascribing this to the neurotoxic effect of dapsone, it should be considered that immunological reactions in leprosy, whether cell mediated or humoral can cause nerve damage. This may be a silent phenomenon as shown by Srinivasan et al (1966) or follow over borderline reaction.

Reversal reaction occurs in borderline leprosy (BT, BB, BL). Because this type is immunologically unstable. The polar forms (LL and TT) are immunologically stable and reversal reaction does not occur in these cases. It
can occur in some tuberculoid patients. Onset is sudden or with a short history of one to few days. Duration may be short or prolonged for two to six months.

4.1.8.3 Erythema Nodosum Lepraeum (ENL) : Type II Reaction

This is seen only in Lepromatous cases and occasionally in Borderline cases close to Lepratomatous type (BL). Repeated ENL reactions result in several complications. This is more often seen after the treatment has been started for few months or in untreated cases of very long standing. The condition is associated with fever, pain in the inflamed nerves, joints, lymph nodes, eyes and testes. In several cases the nodules may ulcerate.

4.1.9 Neuritis in Leprosy

Nerve damage has a most important part to play in the clinical findings in leprosy patients and is frequently overlooked by clinicians. Leprosy neuritis may be defined as an acute or chronic inflammation in peripheral nerves, usually but not always painful, frequently resulting in partial or complete loss of function, and mainly affecting the nerve trunks which have a superficial course.

Nerves are frequently enlarged and painful in association with skin lesions, especially in borderline and sometimes in tuberculoid leprosy. Neuritis may be the presenting symptom of leprosy, or it may occur as the first sign of relapse after treatment has been stopped, or the first sign of incipient resistance to therapy in cases still on treatment. But, by far, the most common occurrence of neuritis in leprosy is as an accompaniment to reactions in borderline (reversal reaction) and lepromatous (ENL) cases.

4.1.9.1 Common Nerves Involved in Leprosy

Sensory, motor and autonomic functions may be equally involved but usually the sensory component is most commonly affected giving rise to
anaesthesia to light touch, pain, heat and cold. Autonomic loss seems to be most often related to advanced cases of lepromatous leprosy. Extensive sensory loss without motor weakness but motor involvement without any sensory loss is rare in leprosy.

Permanent damage to the nerve is not an inevitable consequence in leprosy. Examination of nerve function of all patients must be undertaken in early stages and at every clinic regularly. If we can detect leprosy and neuritis early and treat all cases efficiently both with drugs and physical therapy, the possibility of nerve damage will be minimised to great extent.

It has been established that early nerve damage is reversible with prompt and proper treatment. It is possible to detect leprosy before nerve damage takes place, in a large number of cases. This is primarily a responsibility of the doctors and paramedical staff working in leprosy. However the patients also need to be aware of the problem and know the signs and symptoms suggestive of early nerve involvement and they should know that such damage is reversible and seek prompt medical care (Lobo 1987).

4.1.10 Epidemiology of Deformities and Disabilities

The terms ‘deformity’ and ‘disability’ are used almost as synonyms, but they denote different states. Deformity is an alteration in the form, shape and appearance of the parts of the body. In otherwords, deformity is visible. Disability is, on the other hand, deterioration in one’s ability or capacity. It is felt only by the patient. Although deformity and disability may often go together, one need not necessarily be associated with the other. However, in organs like hands and feet, a deformity is often associated with disability because their form and function are intimately inter-related.
The disablities and deformities that occur in leprosy, affect the patient, his family and the community in several ways. One of the most important reasons for the fear, stigma and prejudices attached to leprosy, is due to the obvious and gross physical deformities that it produces. Patients with deformities carry a far greater stigma.

The diagnosis of leprosy by itself causes a certain amount of mental and emotional anguish. Deformities make the patient easily recognisable and branded as a leprosy patient. Often the entire family is branded as a leprosy family and is isolated and ostracised.

Of the estimated 4 million cases of leprosy in India, probably almost 6 lakh cases are handicapped due to the deformities. The severity of the deformity depends to a great extent on the accuracy and timely surveys of the leprosy population, as earlier the case is detected less shall be the deformity rate. But this is only one aspect of this multi-factorial condition.

4.1.10.1 Factors influencing the occurrence and progress of deformities

A number of factors influence the occurrence and progress of deformities in the leprosy patients. These are related to i) the patient, ii) the disease itself and iii) other environmental factors.

4.1.10.1.1 Factors relating to the patient

Age: Deformities are not common in children and young adults. Reason for this is that leprosy in children is often of the self limiting type and there is no general progress of the disease. Further, the disease is likely to be of shorter duration in children and young adults and so would not have spread widely in the body and damaged the skin and nerve to produce deformities. Deformity rate increases with increase in the age.
Sex: Deformities are more common in men than women. There are a number of reasons for this (1) the incidence of the disease is lower in women, (2) women tend to suffer more often non-lepromatous type of leprosy and (3) there seems to be a sex distinction in the matter of nerve trunk involvement, and women tend to suffer less nerve damage compared to men. The reason for the favoured position of women is not known.

Race: Yellow races are more prone to deformities than coloured one.

4.1.10.1.2 Factors relating to the disease

Duration: Deformities are more prevalent in patients with longer duration of the disease. Longer the duration of the disease, greater are the chances of extension of the disease and involvement of nerve trunks and so the chances of developing deformities also increase.

Type of disease: Non-lepromatous type of leprosy usually tends to be localised and is often self-healing. Therefore the deformity rate in patients with this type of disease is not very high. But in this type, when nerve trunks are involved, tissue damage is quite severe, because of the violence of tissue reaction, and so nerve damage occurs fairly early in the course of the disease and is often irreversible.

But lepromatous type is global in involvement and affects many nerve trunks. But damage to the nerve trunks occurs quite late in this type. Further, lepromatous leprosy takes longer to be controlled. For all these reasons deformities occur in a larger proportion of lepromatous patients, but much later in the course of the disease.
The intermediate forms of leprosy (indeterminate and borderline) are unstable forms in which flare-ups or reactional states are liable to be precipitated by injudicious treatment. Nerve damage is quite common during these acute states but there is a tendency for recovery if the condition is recognized and treated promptly. But inevitably there is some amount of residual nerve damage with resulting deformities. The deformity rates in patients with intermediate types of leprosy is also intermediate, neither so high as in the lepromatous nor low as in the non-lepromatous type of leprosy.

Number of nerve trunk involvement

Whatever the type of the disease, the greater the number of nerve trunks involved, the greater the chances of deformity. Involvement or even thickening of a nerve trunk does not necessarily lead to paralysis and consequent deformity. Paralysis and deformity depend on the extent to which the nerve fibre supplying the particular muscles are damaged. If many nerves are involved, the affection of some of them may produce deformity, while the affection of others may not have such an effect. Deformity is, therefore, seen more often in patients with involvement of many nerves than in those with involvement and thickening of a single nerve.

4.1.10.1.3 Other factors

a) Treatment: It can be visualised that early and regular the treatment is, less should be the deformities. But it has also been brought out (though controversial) that high doses of Dapsone given without close supervision may precipitate states of reaction in which paralytic and non-paralytic deformities can occur in a short time.

b) Occupation: Patients doing heavy manual work suffer with more and severe deformities than others. Injuries, single or repeated, often cause damage to the anaesthetic extremities of leprosy patients. Therefore heavy
manual labour and specific occupations causing repeated trauma to an anaesthetic part are likely to lead to ulceration, tissue damage and even mutilation of the part, hand or foot.

Women are likely to suffer from serious deformities for their occupation in the kitchen increases the chances of getting their anaesthetic extremities injured through burns or scalds.

4.1.10.2 Etiopathology of deformity in leprosy (Fig. 7)

As the *M. leprae* causes infiltration of the skin and mucous membranes we get "specific deformities" of the ear, nose, face, eyebrow and finger etc. On the other hand it also damages the peripheral nerve trunks. Depending upon the involvement of motor, sensory or secreto motor fibres of the nerve we get
motor palsy of the muscles, anaesthesia followed by ulceration due to neglected trauma in the limbs and cracks in the skin due to the dryness of the skin. (Fig.7).

The deformities can be prevented by early diagnosis, very early and regular anti-leprosy treatment before it reaches the stage of deformities. Early deformities can give good result if treated promptly by correct drug treatment, physiotherapy and surgical methods.

The chain of events that take place from the first sign of leprosy to the ultimate displacement and destitution of patients is as follows:

Leprosy → Nerve involvement → Nerve damage → Deformities → Displacement → Destitution

4.1.11 Physiotherapy

The social stigma attached to leprosy is caused by deformities. If a person is free from deformity whatever the stage of the disease, he/she is well accepted and is free from social stigma. Thus the prevention and correction of deformity is very important in leprosy control programme. Restoration of the function of the limbs brings about confidence and hope. The patient will be cured wholistically i.e., mentally, socially, economically, psychologically and physically. Physiotherapy in this regard is very important.

4.1.11.1 Definition

It is an external manipulation (treatment) to the internal tissues of the body. There are two ways of manipulation.

1. Through physical agents like heat, cold, water and electricity.
2. Through external manipulation like exercise, splints, plaster etc.
Physiotherapy is indispensable in reconstructive surgery. The early detection and early treatment cures leprosy without causing deformity. Thus the need for surgery is diminished. But the need of physiotherapy is still important. The physiotherapist attention is to be focussed on early diagnosis of nerve involvement and treatment. Every patient is to be examined for the thickening of nerves and weakness of muscles by the physiotherapist and other workers or it may go unnoticed by the patient. A patient realises the nerve damage only when he feels the disability such as claw hand, dropped foot or ulcer. If care is not taken to prevent the nerve damage, the patient will not appreciate the cure and society will not accept the patients and the problems caused by leprosy will remain unsolved.
PART II

4.2 SOCIAL ASPECTS OF LEPROSY

Social aspects of leprosy have been conventionally understood as socio-economic consequences of acquiring the disease. The problems arising out of social rejection, economic impoverishment and social and economic rehabilitation have been the identified social problems. Socio-economic factors for people's non-compliance with leprosy control activities have also been investigated. (Pontifical Academy of Sciences 1984). Human treatment of patients with love, sympathy and compassion have been recommended as the answers to social problems (Mexico Report, 1978).

Leprosy would not have been considered as a problem but for its social consequences, to a large extent. The social dimensions of leprosy are often tragic and frequently hinder leprosy control programmes. Social stigma attached to the disease is universal in all societies unlike stigma attached to racial and untouchable groups. Stigma of leprosy creates a brotherhood among patients which is distinct from such social groups as family, class or caste. In-groups are formed based on various stages of the disease as in other groups. There is no other disease, the stigma of which unites an individual from socially recognized groups and binds him with the stigmatized individuals.

4.2.1 Social Status

Statuses such as father, mother, son, daughter, teacher and priest are socially defined. Social system can be understood in terms of continuing structural relationship among individuals and groups. Family is a nuclear group in the relationships of members being personal, spontaneous, emotional and irreplaceable. Physical intimacy is prescribed with the society among these
groups. Each member performs certain role commensurate with his status and for which he is trained. If a person is unwell he is given the status of patient and he performs the sick role which is accepted in the society, family and work place. But a leprosy patient becomes no-person in the society. Even a medical man is reluctant to give a patients' status to him. The status given to the leprosy patients is social death with no role in society to perform.

4.2.2 Stigma of untouchability and Leprosy Stigma

Stigma based on caste system (untouchables) also suffers from civic, social, economic and religious disabilities in India. These groups get their stigmatized status by birth. However, these groups get their bio-psychic needs of affection and belonging satisfied in their own families. Whereas, in the case of leprosy patient, he may be driven to a stigmatized status at any period in his life after living a richer life in his social groups. In the life of any leprosy patient, there is sudden change in his status irrespective of whether he belongs to a particular caste or religious group. A leprosy patient rejected by society is deprived of satisfaction of his bio-psychic needs (Mutatkar, 1978).

4.2.3 Cultural Aspect

Every society considers health and disease, life and death in different ways and these influence the attitude taken by the community towards patients as a consequence of their illness. The social implications are closely interwoven with the cultural traditions of society. The patient is rejected on the basis of a belief that the disease is divine punishment, and is, hence incurable.

4.2.4 Reaction of Society

After identifying a leprosy patient, the society starts rejecting him; denies civic facilities such as transport, education, employment, etc., kith and
kin disown him. Society chooses to sacrifice few individuals, in the interest of majority by killing the leprosy patient socially and isolating him, because it is afraid of the spread of the disease.

The person with leprosy considers his future bleak. He starts believing that this is the punishment for the sins committed by him. He feels that he would degenerate in limbs and body and join the band of leprosy beggars. He tries to hide the disease and feels helpless. This brings changes in his/her personality and behaviour. He may become a social deviant and try to change society. He tries in vain to postpone social death. However, once isolated, he accepts his social condition and tries to mix with diseased brothers.

4.2.5 Society, Leprosy and the Law

Law makes an effort to generalize the prevailing social customs for social good. The law is expected to protect the rights of the people and help them to enjoy the benefits of their rights without interference. It is also supposed to be an expression of the existing social norms and public opinion. If one reviews the laws relating to leprosy and leprosy patients and also various legal enactments concerning leprosy patients, it is evident that they are fulfilling the above two functions. They do reflect the fear and prejudices existing in the society about leprosy, and their objective obviously, is to protect the society from infection of leprosy.

There are a number of laws and legal enactments which put numerous restrictions on the movement of a leprosy patient and severe legal impediments in his social mobility. For all practical purposes, a patient of leprosy, in the eyes of the law, is little short of a criminal who, at the slightest opportunity, should be hauled and put behind bars so that he does not pollute the social atmosphere.
The oldest enactment relating to leprosy is the Indian Leprosy Act of 1898. This Act was first enacted in Bengal and was later made applicable to the whole of India. The Act was passed in 1898, and one can well imagine the ignorance prevalent then, not only among the public but also among the legislators who passed the Act. The Act makes no distinction between infectious and non-infectious types of leprosy and presumes a leprosy patients to be a patient for life. It has also used the words 'leper' and 'pauper' as synonymous, as if every patient of leprosy is necessarily a pauper. (The word 'pauper' was however deleted by the Maharashtra Government in 1955 by Act No. XXVIII).

Section 9 of the Act prohibits leprosy patients from "preparing or selling of food or drinks or clothes, taking water from public wells, driving or travelling through public conveyance and any such other transactions which will affect public health". It imposes fine in cash and imprisonment for infringing any of its provisions. Section II holds the employer responsible for giving jobs to leprosy patients and provides for punishment to such employers. The Act provides for setting up segregation camps for those patients who are found to be in notified areas against prohibitory orders.

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

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

There are a number of "prevention of beggars" laws under which there is a separate provision for leprosy patients. In Maharashtra, in cities like Bombay, Poona and Nagpur, if any leprosy patient is found begging he/she is immediately arrested and sent to Begger Homes run by the Government.

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

These laws and legal provisions have been extremely harsh on leprosy patients through the years. It has been particularly hard on women leprosy patients who are married. In our male dominated society, the wife is expected to live faithfully with the husband in spite of all his faults and misdeeds, and hence there are few instances of wives applying for divorce against their patient-husbands. But woman-patients have been and are, even now, quickly divorced by their husbands on the ground of leprosy.

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

Leprosy workers all over the country have waged a relentless struggle, for over two decades, against these unjust laws. This has had some effect. The Indian Leper Act 1898 has been repealed in the State of Maharashtra from 2 October 1983 and the Government of India has also repealed its application to Union Territories from January 1984. The Railway Board is now not only allowing railway travel by leprosy patients but also giving them concessions for travel by railway from their residence to the place of their treatment. An effort to get a law passed by the Parliament in 1969 providing for compulsory sterilisation of leprosy patients was defeated in the Lok Sabha as a result of the campaign made by some leading leprosy workers. The High Court of Tamil Nadu has passed strong strictures against the decision given by a lower court where the statement of a witness was not recorded on the grounds that he was a patient of leprosy. The High Court issued a circular (No.251/1976, dated 9.12.1976) to all lower courts that patients appearing in courts as parties or witness should be treated with compassion and respect. Some courts in Maharashtra have accepted the expert medical advice in divorce cases where the wife-patient is taking regular treatment and is not in a position to spread infection, and have rejected the petition for divorce (Tare 1984).
The Working Group (Swaminathan Report 1982) appointed by the Government of India, in 1981, to draw up a Strategy Plan for the Eradication of Leprosy has made the following unambiguous recommendation.

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

4.3 SIGNIFICANCE OF HEALTH EDUCATION IN LEPROSY CONTROL

4.3.1 Introduction

The importance of health education in leprosy was anticipated long back before launching the control programme. When leprosy control programme was started we had no clear picture of the problem in our country. After thirty years of control programme though control of leprosy is still a far way off, the name of the programme has been changed as NLEP and is based on SET pattern of work. In fact these are the three pillars of the programmes. 'S' stands for Survey to detect all cases. 'E' stands for Education to remove misconceptions from the minds of the people, to make people conscious of leprosy, to make people aware of the early signs of the disease, to put under treatment all cases for early cure to prevent deformity and to join hands with the control programme.

At present there are 40 lakhs of estimated leprosy patients in India and out of them nearly 33 lakhs of leprosy have been registered but out of the registered cases hardly 50% are on the regular treatment. Thus inspite of all efforts two main problems remain: (1) 7 lakhs of leprosy patients are yet to be detected i.e. they are lying undetected in the society and some of them are spreading infection to others (2) out of the detected cases a larger number of patients are not taking regular treatment and thus posing a threat to the NLEP. The reason is the lack of importance given to health education.
4.3.2 Interrupting the transmission

Like any other communicable disease, in the case of leprosy also, it is the interplay of the following three factors which is responsible for the transmission of the disease: (1) Source of infection, (2) Mode of transmission and (3) Susceptible population.

In India infectious leprosy patients constitute 15 to 20% the total leprosy patients, who can spread infection to others. Early case detection and prompt treatment are the pillars of the edifice of the control programme of any disease. Health education can play an important role in case detection and case holding in such a way that the source of infection can be separated or made invalid in spreading the disease to the susceptible population.

Close contact with an infectious patient is the essential factor for the transmission. Skin to skin contact may be avoided but leprosy being an airborne infection, it is difficult to block the channel of transmission. However people can be educated regarding the risk of infections from highly infections cases and to take proper hygienic measures. Isolation of patients is neither feasible nor advisable as it can simply add to the stigma already prevailing in the society. Regarding increase in the resistance of the susceptible population, there is no effective vaccine available against leprosy till today. Thus for breaking the chain of transmission the only effective method is early diagnosis and prompt treatment of leprosy cases. Health education can play a very important role in this direction.

4.3.3 Diagnosis

Diagnosis is a job of a medical person. However, if people are conscious about the early signs of the disease then the patients will come forward for treatment in the early stage. The early signs of the disease should
be made known to the community through health education. If the common men are aware of the early signs of the disease and are not afraid to get exposed in the community as leprosy patients, the hidden cases in the society will come out and help in prompt diagnosis. Cases are exposed to the society only when they develop visible deformities. But awareness in the community about leprosy will definitely increase voluntary reporting of cases and thereby help in the diagnosis of more cases.

4.3.4 Treatment

Health education can play an important role not only in case detection but also in case holding. First of all the availability of the treatment should be made known to the people. Though treatment of leprosy is free all over the country even then ignorance and prejudices of the people prevent the patients many times from taking early and regular treatment. People should be convinced that leprosy is a curable disease like many other diseases, modern drugs (MDT) can cure leprosy within a short period and early and regular treatment ensures early cure with no deformity. Though MDT has been accepted in general as the more effective treatment than monotherapy, looking at different considerations monotherapy is still being continued in most of the places in our country. Regularity in treatment is absolutely necessary. But many times because of long duration of treatment the patient discontinues the treatment. Regular persuasion of patients and motivating them for regular treatment can solve the problem of dropout of leprosy patients to a large extent. Thus, educating the patients, their family members and community can make the patients to take early and regular treatment.

MDT was introduced in the treatment of leprosy to cure early and to prevent drug resistance. It has been found to be effective in shortening the
period of treatment. Rifampicin and Lamprène are costly drugs. This fact is
to be conveyed to the patients and also importance of the regularity in therapy.
Patients should be told very clearly that though the treatment period is reduced
to on an average 6 months in PB and 2 years in MB cases it is absolutely
essential to be very much regular in treatment. Otherwise it may cause harms
to the patients. Before giving MDT, the patients should be told that intake of
Rifampicin may make the colour of the urine a bit reddish about which the
patients should not worry. Thus both in Mono and MDT, health education can
play an important role.

4.3.5 Prevention of deformities and disabilities

Common people equate leprosy with deformities. But deformities are
not the early signs of the disease. Deformities occur at a late stage due to no
treatment in early stage, irregular intake of medicines on the part of the
patients, wrong treatment by the medical personnel (rare) and lack of care on
the part of the patients who develop anaesthesia. Deformities are preventable
if the patients take regular treatment from the early stage and they will not
develop deformities and will be cured within a short period. Thus health
education to the patients and the family members of the patients is very
important.

4.3.6 Rehabilitation

Leprosy patients were ostracised by the society when there was no
treatment available for leprosy. Some kind hearted people started colonies to
give shelter to leprosy patients. That was the old concept of rehabilitation. The
advent of DDS opened a new chapter in the history of leprosy. When the
control programme was started many people started thinking whether there is
any need for the colonies in the present set up. Though there are people even
today who favour continuation of colonies and consider colonisation as rehabilitation of leprosy patients, most of the people working in the field are on principle not in favour of colonisation. Rehabilitation is an essential process of decentralisation-keeping in or sending back the patients to their original prestigious position in the society. The old colonies, of course, may be reorganised and there should be different wings such as hospital with a good surgical, occupational, physiotherapy facilities, rehabilitation training centre and vocational training centre etc. Prevention of dehabilitation is the best solution of rehabilitation. Early case detection and early treatment is the real solution to the problem of rehabilitation and as mentioned earlier in the case of prevention of deformities. Health education can play a very important role in this direction. According to WHO, by 'rehabilitation is meant physical and mental restoration of whole treated cases as far as possible to their normal physical activities so that they can resume their place in home, society and industry. To achieve this, treatment of physical disabilities is obviously necessary. But it must be accompanied by the education of the patient, his family and the society so that not only can he regain his prestigious position in the society but the society also will be willing to accept and assist him in his complete rehabilitation'.

4.3.7 Conclusion

The word 'leprosy' used by the medical profession generally puts fear in the minds of new patients who do not like to accept the diagnosis, since patients' perception of leprosy is associated with gross deformities. It is advisable to use available local languages which would prevent confusion between early signs of leprosy with mutilation in the mind of patients and families. People are not afraid of physical death as much as of social death which is ensured by deformities. Man as a social animal, has to live in human
groups in which he seeks his life's fulfillment. The gap between 'what the
disease is' and 'what people believe it to be' needs to be understood by social
scientists, medical anthropologists and sociologists, educational psychologists,
management and communication experts. Social Science research should be
encouraged to find better tools for health education and attitudinal changes.

The social aspects of the fight against leprosy were not given their due
importance until 30 years later at the Congress of Mexico in 1978. There, for
the first time at these International Congresses, a workshop on the human
aspects in the treatment of leprosy patients took place (Mexico Report 1978).
With the development of social science theory and methodology, social aspects
should include besides social and economic, cultural, religious, management
and communication aspects. Since leprosy afflicts human and is transmitted by
humans amongst each other, understanding life styles of people such as mating
patterns of endogamy and exogamy, food habits, rules permitting physical
proximity and group interaction become relevant for understanding factors
favouring transmission of the disease.

People's participation in control programmes is essential for early
diagnosis and continued treatment. They have favoured multidrug therapy since
it reduces clinical manifestations of the disease in a short period. All control
programmes and tool development programmes should aim at reducing
def ormities to break the association of leprosy with deformity and social death
which is the root of social stigma. Stigma and fear hinder people's participation
in control activities. Health education should aim at the patient, his or her
family and community with an aim to transmit scientific knowledge to the
people's culture. Indicators of success of health education and community
participation would mean i) deformity rate reduction ii) voluntary reporting,
iii) utilization of services and iv) rehabilitation.
Leprosy is a disease with difference. The early signs of leprosy are trouble free. As a result many people do not understand the onset of the disease while some others neglect the disease in the early stages because it causes no trouble to them. There are misconceptions about the disease in the minds of people. All the misconceptions about the disease have created an age-old stigma and prejudice about the disease in the society. Effective health education can remove these misconceptions, stigma and prejudices from the minds of the peoples and help in overcoming problems associated with the case detection and case holding. Leprosy patients' well being and wholeness depends on the way we treat them and cure them. Love, dedication, and selfless service should accompany health education to all and they are the best means to achieve our goal of leprosy eradication.