Leprosy is one of the oldest and most dreaded diseases that has tormented humans throughout history, lasting impressions on religion, literature and art. It has been synonymous with stigma and discrimination due to the hideous deformities it produced, mystery around its etiology and transmission and lack of any effective remedy till recently¹.

II(a). SYMPTOMS OF LEPROSY

If there is one diagnosis that should not be established unless there is absolute certainty, it is that of leprosy. If there is the slightest doubt in the diagnosis, the patient should be put under observation for further evidence of confirmation of the disease. This will obliterate among the people the psychological, social and other damage that would be unnecessarily inflicted on them in the event of an incorrect diagnosis.

As in every diagnosis, all the positive or, in some instances, negative factors should be taken into account, for the confirmation of the disease. The following assist in the diagnosis of the leprosy disease.

1. Skin lesions such as infiltration, macules, papules, tubercles, and nodules usually appear gradually but in some cases suddenly on the limbs or face. They are less frequently found on the trunk. They differ in the size and configuration. They do not itch, and generally become anesthetic some time after their appearance. The progression is normally slow, having a tendency to be prolonged over years.

¹ Sunil Dogra, Tarun Narang & Bhushan Kumar, Leprosy – evolution of the Path of eradication, Indian Journal Medical Research, 137, Jan. 2013, P. 15.
2. There is loss of cutaneous sensibility to temperature, pain, and light touch. As a rule it can be detected in skin damage, but it may be slight or even absent in recent injuries. Loss of sensation in the extremities causes the loss of limbs, nose, fingers resulting the stumped hands and legs and ultimately produce grotesque figure.

3. Thickening of nerve trunks and of superficial nerves occurs. Because of neuritis nerve trunks often increase in volume, become more dense, and may change in form. The neuritis of their diseases is not accompanied by thickening of nerves, with the exception of interstitial hypertrophic neuritis, which is a familial disease and extremely rare. Muscular weakness and paralysis, atrophy, and anhidrosis may accompany the neuritis. Loss of hair is also frequent.

4. Another important diagnose criteria is that M. Laprae, in addition to skin and its adenexa, produce lesions in peripheral nerves, eyes, nose, larynx, month, hand and soft palate; organs of the reticuloen-dothenial system namely lymph nodes, liver, spleen and bone marrow, internal organs such as the testes, adrenal glands and kidneys. In rare instances bones and muscles are affected. The central nervous system, heart, lungs and organs of the gastro-intestinal systems are spared except for an occasional findings of bacilli in a macrophage in interstitial tissue or in endothelial cells of blood vessels of these organs.

Secondary amyloidosis, a sequel of long-standing chronic disease causing extensive tissue damage, is one of the common complications of leprosy.
II(b). ETYMOLOGY

The word leprosy comes from ancient Greek lepra “a disease which makes the skin scaly”, in turn a nominal derivation of the verb in ancient Greek means peel, or scale\(^2\). The word came into the English language via Latin and old French. The first attested English use is in the Ancrene Wisse, a 13\(^{th}\) Century manual for nuns. A roughly contemporaneous use is attested in the Anglo-Norman Dialogues of Saint Gregory.

The term Tzaraath from the Hebrew Bible was, erroneously, commonly translated as leprosy, although the symptoms of Tzaraath from the Hebrew Bible were not entirely consistent with leprosy and rather referred to a variety of disorders other than leprosy disease\(^3\). The first mention of leprosy recorded is found in Leviticus 13:2 – “when a man shall have in the skin of his flesh a rising, a scab, or bright spot, and it be in the skin of his flesh like the plague of leprosy; then he shall be brought unto Aaron the priest, or unto one of his sons the priests. “There is also the well known Bible story of the Syrian Naaman, “captain of the host of the king of Syria” (2 Kings 5:1), who suffered from this severe and savage skin disease.

In particular, fungal scalp infection and related infections on other body parts caused by the dermatophyte fungus Trichophyton violaceum are abundant throughout the Middle East and North Africa today and might also have been common in Biblical times. Similarly, the related agent of the disfiguring skin disease favus, Trichophyton

Schoenleinii, appears to have been common throughout Eurasia and Africa before the advent of modern medicine. Persons with severe favus and similar fungal diseases tended to be classed as having leprosy as late as the 17th Century in Europe.

ROME

In the west, the earliest known description of leprosy was made by the Roman encyclopaedist, Aulus Cornelius Celsus (25 BC – 37 AD), in his De Medicina. He called it leprosy “elephantiasis” The Roman author Pliny the Elder (23-79 AD) mentioned the same disease. Although Tzarath of Leviticus (Old Testament) is translated as “lepra” in the 5th century AD, Vulgate, the original term Tzarath found in Leviticus was not the elephantiasis described by Celsus and Pliny; infact Tzarath was used to describe a disease which could affect houses and clothing. McLeod Katrina C.D. and Robin D.S. Yates state that Tzarat “denotes a condition of ritual impurity or a temporary form of skin disease.

INDIA

The Oxford Illustrated Companion to Medicine holds that the mention of leprosy, as well as cures for it, were already described in the Hindu religious book Atharva-veda. Writing in the Encyclopaedia Britannica 2008, Kearns & Nash state that the first mention of leprosy is in the Indian medical treatise Sushruta Samhita.

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(6th century BC). The Cambridge Encyclopaedia of Human Paleopathology (1998) holds that: “That Sushruta Samhita from India describes the condition quite well and even offers therapeutic suggestions as early as about 600 BC”. The surgeon Sushruta lived in the Indian city of Kasi by the 6th century BC, and the medical treatise Sushruta Samhita attributed to him made appearance during the 1st millennium BC. The earliest surviving excavated written material which contains the works of Sushruta is the Bower Manuscript dated to the 4th century AD, almost a millennium after the original work. Despite the existence of these earlier works the first generally considered accurate description of the disease was that of Galen of Pergamum in 150 AD.

CHINA

Regarding ancient China, Katrina C. D. McLeod and Robin D. S. Yates identify the State of Qin’s Feng zhen shi dated 266-246 BC, as offering the earliest known unambiguous description of the symptoms of low-resistance leprosy, even though it was termed then under ‘li’, a general Chinese word for skin disorder. This 3rd century BC Chinese text on bamboo strip, found in an excavation of 1975 at Shuihudi, Yunmeng, Hubei province, not only described the destruction of the “pillar of the nose”, but also the

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8 Kutumbian, P., Ancient Indian Medicine, Orient Longman, Delhi, 2005, PP. XXXII – XXXIII.
“swelling of the eyebrows, loss of hair, absorption of nasal cartilage, affliction of knees and elbows, difficult and hoarse respiration, as well as anaesthesia”.

JAPAN

In a document written in 1833 in Japan, leprosy was described as “caused by a parasite which eats five organs of the body. The eyebrows and eyelashes come off, and the nose is deformed. The disease brings hoarseness, and necessitates amputations of the fingers and toes. Do not sleep with the patients, as the disease is transmittable to those nearby”. This was the first document concerning infectivity.

II(c). ACTIMOLOGY OF LEPROSY

Age distribution

Leprosy is known to occur to all ages ranging from early infancy to very old ages and its distribution is not uniform. In this connection, it may be noted that most studies of age distribution of leprosy are based on prevalence data, and only a few are based on incidence data. Further disease occurrence is often related to age at detection rather than age at onset of disease. In a chronic disease like leprosy, information based on prevalence data and data on age at onset may not fully reflect the age-specific risks. The youngest age reported for the occurrence of leprosy is three weeks. Incidence rates usually rise to a peak between 10 to 20 years as reported in endemic areas including South

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India with a first peak in the age group of 10 to 14 years and second peak in the age group of 30-40 years. It is slightly earlier in males than in females. Further, there are reports that the occurrence of leprosy, presumably for the first time, is not uncommon even after the age of seventy\textsuperscript{12}.

In spite of many high endemic areas showing a very similar age distribution pattern, there are still other areas where the patterns are different. In many of these, the occurrence of leprosy among children is often found to be higher than adults because they are more exposed to environment. A pattern is also observed in low endemic areas where the disease is dying out and there is the occurrence of the bulk of the cases among older adults. In the relatively rare situations the leprosy affects all ages equally. Further, in certain situations where it was possible to compare the age distribution of leprosy between natives and immigrants in the same country, it is found that the occurrence of leprosy among immigrants is higher in older ages, whereas among the natives it is not so\textsuperscript{13}.

Regarding age distribution by sex, the pattern is very similar between the two sexes, except for the fact that the levels are lower for females, the differences being more marked among adults. All these reviews indicate that the major factor that determines age distribution appears to be opportunities for exposure rather than age per se.

\textsuperscript{12} Ibid.
SEX DISTRIBUTION

Although leprosy affects both sexes, in most parts of the world, males are affected more frequently than females and often in the ratio of 2:1. This preponderance of males is observed in as diverse geographic situations as India, and certain parts of the world\textsuperscript{14}. In this connection, it may be noted that the male preponderance in leprosy is not universal and there are several areas, particularly in Africa, where there is either equal occurrence of leprosy in the two sexes, or occasionally even a higher prevalence among females as observed in Uganda, Nigeria, Thailand, Gambia, Upper Volta, Zambia and Japan\textsuperscript{15}.

The scientific studies have shown that where the sex distribution of leprosy is introduced for the first time into a community or where the disease is dying out as found in Northern Europe the prevalence of leprosy tended to be equal in the two sexes. A consistent finding in several parts of the world is that the male preponderance is much more pronounced in lepromatous leprosy than in tuberculoid leprosy\textsuperscript{16}. In areas where females benefit from low prevalence, they not only suffer from less serious disease, but their chances of developing deformities were also very much less, mainly due to less frequent involvement of nerve damage among the females.

\textsuperscript{15} Ibid.
The sex identification in leprosy is often attributed to ascertainment bias. It is possible that because leprosy workers are mostly men, the examination of women is less complete and less satisfactory, particularly in certain cultural situations, resulting in under-detection of leprosy among the females. There may also be selective concealment among girls and young women due to the intense social stigma against the disease\textsuperscript{17}.

The relatively low prevalence of leprosy among females may also be due to biological or environmental factors. The lower susceptibility of females is due to biological factors such as physiological or hormonal factors\textsuperscript{18}. As per the environmental factors are concerned the males in general expose themselves to greater risks of infection as a result of their life style. The differences in clothing habits among males and females is attributed as one of the reasons. Women in the East cover their bodies more than men and hence they are likely to have reduced opportunities for skin contact. But in many parts of Africa, men and women tend to dress alike and cover their bodies about the same extent, hence, the incidence difference is not prominently seen among the sexes\textsuperscript{19}. So it is difficult to state which of the two factors, environmental or biological, is more important, but in all likelihood, environmental factors are likely to play the greater role.

\textsuperscript{17} Thangaraj. R.H., \textit{A Manual of Leprosy}, New Delhi, P. 15.
\textsuperscript{18} Thangaraj. R.H. op.cit. P. 15.
\textsuperscript{19} Cochrane, R.G. op.cit. P. 16.
CLUSTERING

Leprosy is not uniform in its distribution. Its uneven skewed distribution extends to villages and even families. This has encouraged the view that genetics play an important role in determining susceptibility\(^2^0\).

It is not clear to what extent clustering may be:

a) Primary: Due to focus incidence patterns depending on shared environment, shared genes or both.

b) Secondary: Due to social forces tending to segregate leprosy patients to live together, due to intense social stigma.

c) Artificial: Due to non uniform case ascertainment, clustering is most obvious in areas of low prevalence and is not discernable in hyper-endemic areas.

MIGRATION

Leprosy is predominantly a rural disease. However, with rapid industrialization in many developing countries, migration from the country side to towns and cities continues to show a surging upward trend. In the process, the leprosy patients also migrate to towns and cities in search of employment, to seek their livelihood. The rural people thus migrated to urban areas usually settle down in unhygienic areas, especially slums where humid climatic conditions exist. The medical and scientific experiments conducted so far showed that the survival of

\(^2^0\) Tangaraj, R.H. op.cit. P. 16.
M. leprae outside the body is optimal under humid conditions. This might be one of the reasons to attribute the incidence of leprosy is more in humid regions of coastal areas such as South America i.e., Brazil, Venuzila, South Asia such as India and Burma; some parts of Africa such as Tanzania, Madagascar, Mozambique and western Pacific\textsuperscript{21}.

**Distribution of leprosy in time**

Just because leprosy as a disease has a chronic course, it is often assumed that the epidemiological situation in any area remains static. In fact, the epidemiological situation is capable of a considerable amount of dynamic changes, and the factors that influence these changes are many. Both long-term and short-term trends have been studied with regard to the occurrence of leprosy. Among the long-term trends the most striking is the rise and fall of leprosy in Europe, and among the short-term trends the epidemic of leprosy in the tropical and subtropical areas of Asia and Africa stands out prominently\textsuperscript{22}.

**The prevalence pool**

The prevalence pool of leprosy in a population in general is in a constant flux resulting from inflow and outflow. The inflow is contributed by the occurrence of new cases, relapse of cured cases, and immigration of cases. The outflow is mainly through cure or inactivation of cases, death of cases, and emigration of cases. Of the various


factors that influence the prevalence pool, the importance of inactivation of disease and mortality are less well recognized.

**Inactivation of disease**

Where leprosy treatment facilities exist, inactivation or cure due to specific treatment is an important mode of elimination of cases from the prevalence pool. Even in the absence of specific treatment, a majority of patients, particularly of the tuberculoid and indeterminate types, tend to get cured spontaneously. An earlier study in India had shown that over a period of 20 years, the extent of spontaneous regression among children with tuberculoid leprosy was about 90%. A more recent study in South India involving long-term follow-up of a high endemic population showed that among newly detected tuberculoid cases of all ages and both sexes, the rate of inactivation was 10.9% per year, the bulk of inactivation in the study being spontaneous\(^\text{23}\).

**Mortality in leprosy**

Mortality in leprosy is often not considered important since the disease rarely causes immediate death. The incubation period in a leprosy patient is very slow and in a few persons only it takes place in 3 to 5 years. But in majority of cases the incubation period is prolonged even upon 20 to 30 years and hence the death in a leprosy patient basing upon the immunity of an individual takes place in longer duration. However,

leprosy patients are exposed to increased mortality risks due to its indirect effects\textsuperscript{24}. The scientific studies in different parts of the Orient have shown that the mortality rate for lepromatous patients was four times more as compared with the general population, and that the situation for non-lepromatous patients was very similar to that of the general populations. A comparative study of lepromatous patients, non-lepromatous patients, and the general population from the same rural area in South India\textsuperscript{25} showed that the standardized death rate for lepromatous patients was three and a half times more than the general population, the non-lepromatous patients themselves having a mortality risk which was twice that of the general population. In that population, leprosy was found to contribute to about 1\% of all deaths.

II(d). IMMUNITY

It is a well-established fact that only 10\% persons exposed to leprosy infection develop the disease, while 90\% of population have natural immunity. A large proportion of early lesions that occur in leprosy heal spontaneously. Such abortive and self-healing lesions suggest immunity acquired through such lesions. Subclinical infections are far more common than was thought earlier; they are also believed to contribute to active immunity. A certain degree of immunity is also probable through infections with other related mycobacteria\textsuperscript{26}.

\textsuperscript{25} Noordeen, S.K., Mortality in Leprosy, \textit{Indian Journal of Medical Research} (60) 1972, PP. 439-445.
In the recent scientific studies it is identified that cell-mediated immunity (CMI) is responsible for resistance to infection with M. leprae. In lepromatous leprosy, there is a complete breakdown of CMI and hence in these cases the lepromin test is always negative. CMI does not however exclude the participation of humoral response. Antibodies have been demonstrated throughout the spectrum of leprosy that they are more pronounced at the lepromatous end. In a considerable number of leprosy patients it has been recently found that the energy of lepromatous leprosy is due to suppression of T cell production.

II(e). TRANSMISSION OF LEPROSY

There are several constraints in studying the transmission of leprosy. Unlike in many other communicable diseases, there is considerable difficulty in leprosy in identifying the three reference points that are involved in the transmission of leprosy, these being the onset points of exposure, infection and disease. The problem with the point of onset of exposure mainly relates to the clear identification of the source of the infection which is not always easy. The problem with the point of onset of the disease is mainly related to the insidious nature of the onset of the disease in most instances in leprosy. The identification of the point of onset of infection is the most important and difficult problem in the study of transmission. Although the future in this area appears to be very promising through development of specific tests, at present there is no dependable

test to measure sub-clinical infection with sufficient sensitivity and specificity for use in epidemiological studies\textsuperscript{29}. Until such a test becomes available the epidemiological picture of leprosy will remain incomplete.

**Incubation period**

In leprosy, both the reference points for measuring the incubation period, the time of infection and the time of onset of disease; are difficult to define; the former because of the lack of adequate immunological tools and the latter because of the insidious nature of the onset of leprosy. Even so, several investigators have attempted to measure the incubation period for leprosy. The minimum incubation period reported is as short as a few weeks and this is based on the occurrence very occasionally of leprosy among young infants and the maximum incubation period reported is as long as 30 years or over as observed among U.S. war veterans known to have been exposed for short periods in endemic areas in Vietnam and other countries but otherwise living in non-endemic areas. A detailed analysis of leprosy for short periods has shown that the incubation period varied between 2.9 and 5.3 years for tuberculoid leprosy, and 9.3 and 11.6 years for lepromatous leprosy\textsuperscript{30}. Bechelli and Martinez\textsuperscript{31} calculated the average incubation period as 8.4 years. Prasad & Ali found in South India that the mean

\textsuperscript{29} Ibid.
\textsuperscript{30} National Communicable disease center, New Delhi.
incubation period was 4.4 years\textsuperscript{32}. It can be concluded that the incubation period in leprosy is generally prolonged, that it shows considerable variation, and that in most instances the period falls between 2 and 5 years.

**Method of Transmission**

The exact mechanism of transmission of leprosy is properly not known. At least until recently, the most widely held belief was that the disease was transmitted by contact between cases of leprosy and healthy persons. More recently the possibility of transmission by the respiratory route is gaining ground. There are also other possibilities such as transmission through ingestion or through insects which cannot be completely ruled out.

**Transmission by contact**

The term ‘contact’ in leprosy is generally not clearly defined. All that we know at present is that the healthy individuals who are in close association or proximity with leprosy patients have a greater chance of acquiring the disease\textsuperscript{33}. However, it is the definition of contact by later workers with qualifications such as ‘skin to skin’, ‘intimate’, ‘repeated’, etc. that has made it appear as if the disease could be acquired only under such conditions, and that the transmission involved some kind of ‘inunction’ or rubbing in of the organisms from the skin of affected persons into the skin of healthy subjects\textsuperscript{34}.


\textsuperscript{33} Noordeen, S.K. oppo.cit. P. 25.

\textsuperscript{34} Ibid.
Certainly, there is no proof that transmission takes place only through such inunction. However, the entry of the organisms through broken skin appears to be more probable than through intact skin.

**Closeness of contact:**

In general, closeness of contact is related to the dose of infection which in turn is related to the occurrence of disease. Of the various situations that promote close contact, contact within the household is the one that is easily identified. The increased risk for household contacts of leprosy as compared with others as per studies conducted in South India has shown that the relative risk for contacts was about four times that of non-contacts.\(^3^5\).

Even within the family members of a household, the degree of intimacy appears to play an important role and the incidence was higher among contacts sharing the same bed by the diseased members and healthy individuals. The importance of closeness of contact has also been brought out by the observance of higher attack rates for child contacts when their mothers were the index cases of 6.8\% as compared with the situation when their fathers were the index cases of less than 3\% and the assumption being that the children are more close to their mothers than their fathers.\(^3^6\)

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Although in terms of risk the household contacts have a high risk, others who are less exposed than household contacts also get the disease. The follow-up of war veterans who return to their non-endemic countries after short spells of duty in endemic countries has clearly shown that leprosy can be acquired through casual contact. Thirty-six such occurrences from the Spanish American War, and 46 such occurrences from the Second World War, Korean War and Vietnam War have been reported\(^{37}\).

The observance of high risks for contacts in endemic areas should not lead to underestimation of the importance of the non-contact population in terms of their contribution to the total yield of new cases. Even with a relatively low risk, the non-contact population contributes a larger share of new cases solely because of its large size in comparison with the contact population. Even in highly endemic areas, the contact population make up less than 15% of the total population, and even with the increased risk its contribution to the total new cases is less than 25%, the rest of the 75% or so of new cases coming from the non-contact population which has a relatively low risk.

**Duration of contact**

In general, the longer the exposure of contacts among the healthy and diseased persons, there is greater the chances of getting the disease. However, in leprosy this appears to take several years as a result of the low levels of incidence of the disease. There are also considerable variations in different situations on this. In a follow-up of

child contacts in a study in South India, there was a decrease in incidence from 56.3 to 27.8 per 100 000 persons in a period of about 12 years\(^{38}\).

**Direct versus indirect contact** : While direct contact is expected to be more effective than indirect contact, the possibility of indirect contact playing an important role in transmission in leprosy cannot be ruled out. This is particularly because of the possibility of the survival of M. leprae outside the human host for 6 to 7 days in damp areas\(^{39}\) and the possibility of contamination of clothing and other fomites by nasal secretions.

**Transmission by inhalation**

The possibility of transmission of leprosy through the respiratory track of human beings is another route for the spread of leprosy. The possibility of transmission through the respiratory route is based on (a) the inability of the organisms to be found on the surface of the skin, (b) the demonstration of a large number of organisms in the nasal discharge, (c) the high proportion of morphologically intact bacilli in the nasal secretions, and (d) the evidence that M. leprae could survive outside the human host for several hours or days\(^{40}\).

Based on their experimental work, leprae could invade the body by the bloodstream through the lungs, apart from invading through the broken skin and the

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intestinal wall. Studies have also brought out the comparability between tuberculosis and leprosy with regard to the number of bacilli discharged in the sputum and the nasal secretions respectively, and also with regard to the attack rates among household contacts of tuberculosis and leprosy\textsuperscript{41}.

**Transmission by ingestion**

There is no direct evidence that leprosy is transmitted through ingestion, although some experimental evidence has suggested this possibility\textsuperscript{42}. The presence of M. leprae in the breast milk of mothers with lepromatous leprosy has also raised the possibility of infants acquiring infection through ingestion of breast milk. Pedley\textsuperscript{43} had calculated that through a four ounce feed of breast milk, an infant would ingest as many as 2 million bacilli. But however, in an infant, there exist more immunity and as such the disease usually won’t affect the health of infants.

**Transmission through insects**

With available evidence on intracutaneous inoculation as a successful method of transmission of M. leprae in the mouse footpad model and a similar situation possibly existing in human beings, the question arises whether insects could play any role in natural infection. Although a large number of experiments had been conducted in the past demonstrating AFB in biting insects, the question whether insects actually transmitted

\textsuperscript{42} Ibid.
infection had remained unanswered. In a study in South India, it was identified that laboratory bred Culex mosquitoes and bed bugs fed on lepromatous cases showed AFB in a high proportion, and that the AFB found were M. leprae as verified through mouse foodpad experiments. They also found M. leprae in pooled collections of insects found in the dwellings of leprosy patients. To some extent they were also able to transfer the infection from the insects to the mouse footpad by making the insects bite the footpads of mice.

II(f). GENETIC FACTORS

Genetic factors have been considered for a long time in leprosy. This is largely due to the observation of clustering of leprosy around certain families, and the failure to understand why certain individuals develop lepromatous leprosy while others develop non-lepromatous leprosy. Admittedly, it is the host factors that play a key role. However, what is not clear is the role of genetics vis-à-vis other factors in determining this clinical expression.

Route of infection

Recent studies have suggested that the route of entry of the organism may, to some extent, determine the occurrence of leprosy. This is based on the observation that while intradermal administration of killed M. leprae sensitizes the animal, intravenous administration of killed M. leprae tends to tolerize the animal as studied through skin test

Narayanan, E., Sreevatsa, Kirchheimer, W.F. and B.M.S. Bedi, Transfer of leprosy bacilli from patients to mouse foot-pads Leprosy in India (49) 1977, PP. 181-186.
reactivity. This also raises the possibility of tuberculoid and lepromatous leprosy being the result of different routes of entry of the organisms.

**Forms of the leprosy Disease**

The first signs of leprosy are detected as changes in the skin, mucous membranes, or the peripheral nerve system, caused by invasion of these tissues by the bacilli\(^45\). Skin changes involve the appearance of a non-itching spot or variety of spots on any part of the skin. These spots show a change in sensation; there may be a loss of sweating and absence of hair growth in the center of the spot. Thickening of certain nerves follows. Later, in certain types of the disease, nasal stuffiness or hoarseness may occur. The eyes may also be affected at this early stage\(^46\). The extent of signs of the disease is often influenced by the amount of body resistance. If body defenses cannot completely combat the bacilli invasion at this point, a tuberculod type of leprosy may develop. A more serious lepromatous type will progress if there is little or no resistance by the body’s immune system. A middle course of the disease is known as borderline type\(^47\). Leprosy is not in itself usually fatal, but the individual will succumb to some other sickness due to his weakened condition.

**Tuberculoid Leprosy**

The Tuberculoid and the lepromatous leprosy types differ in their progress. In tuberculoid leprosy, nerve changes dominate the disease manifestation, while skin

\(^{46}\) Ibid, pp. 3-4.
\(^{47}\) Ibid.
changes appear only as spots. First, pain and fever episodes occur and during these attacks brownish patches appear on the skin, lasting from a few days to years, and can disappear and reoccur. Ultimately the peripheral nerve branches and main trunk are attacked, with accompanying pain, paralysis, and muscle wasting. Fingers become clawed, ulcers may develop, and fingers, toes, or whole feet can be lost. Many victims of this type live to be very old, with death the result of kidney disease or other problems of advanced age. This type of leprosy lasts on the average twenty years at least.\textsuperscript{48}

**Lepromatous Leprosy**

In the Lepromatous leprosy is characterized by early skin changes and later, less prominent nerve changes. First, nodules, or swelling sores, appear in various locations, which slowly increase in size and number. The upper respiratory system is also affected, as are the eyes, and changes can occur in certain viscera such as the liver and spleen. Nerve changes also appear later in the form of periodic fevers. Patients sometimes die during these periods, while in others a period of stagnation may occur followed by recurrences of fever. Anaesthesia or loss of sensation occurs. Untreated lepromatous leprosy lasts on the average eight to ten years.\textsuperscript{49}


\textsuperscript{49} Ibid, P. 267.
Re-infection

The occurrence of leprosy, presumably for the first time, in older individuals in endemic areas has raised the possibility of re-infection in these individuals, since it is difficult to believe that they remained uninfected for such a long period in an endemic area. However, this occurrence in the older ages can also be explained by the possibility that the disease in these persons represents reactivation of old undetected primary disease following waning of previously acquired immunity. Since there is no evidence of a distinct primary disease occurring in leprosy as in tuberculosis, the hypothesis of re-infection gains some importance. Further, the occurrence of relapse in lepromatous leprosy also suggests, at least in a proportion of relapsed individuals, the possibility of re-infection. There is nothing to prevent these immune deficient inactive patients living in endemic areas from succumbing to fresh infection. In the absence of a method for the identification of strain variations of M. leprae, the hypothesis on re-infection will remain untested.

II(g). SOCIO – ECONOMIC ASPECTS OF LEPROSY

Social Problem

The leprosy is often called as social disease because it involves several sociological problems, which has been complicated by the traditional hostile attitude of society towards leprosy patients. This hostile attitude was not formed in a day but was acquired over centuries. Though notable advances are made in the treatment of leprosy, still the public understanding of the disease has not kept pace with these advantages. The
present day society is very much a product of the past and hence the beliefs, the values and the traditions have not changed much. Prejudices from the past have given birth to new ones. The attitude of the public is “once a leper, always a leper” is very much in vogue even today\textsuperscript{50}, no wonder the ugly social stigma of leprosy is very much part and parcel of the present society.

Sociologists say, the culture of a society is the way of life of its members, the collection of ideas and habits, which they learn, share and transmit from generation to generation\textsuperscript{51}. This is very much true with leprosy patients as well as with society. It is very difficult to change the social abhorrence towards leprosy patients on one hand, although there is considerable progress in science, technology and medicine with regard to leprosy. On the other hand, our cultural and traditional pattern of thought and behaviour did not change in pace with the new knowledge. People stick to their outdated and absurd ideas even though science has repeatedly proved them wrong. The cultural lag creates several disadvantages to the patients – not only they do not get modern scientific progress but also they keep facing social harassment, boycott and victimization\textsuperscript{52}.

When a patient suffers from leprosy sooner or later, he/she has to undergo the experience of segregation from people in home and society. People treat him/her as inhuman and also as an unwanted person because they fear that the disease is contagious and brings deformity.

\textsuperscript{50} Tangaraj, R.H. op.cit. P. 429.  
\textsuperscript{52} Mulalkar, K, \textit{Society and Leprosy}, Pune, Shuboda Srivatsava, 1979, P. 15.
A person who is recovered from leprosy also faces social exclusion in all human groups. It is an un-written law that they have to exclude themselves from the social life and activities. In the past, patients were admitted for a prolonged period in asylum and kept in a compulsory isolation. Society wanted them to be separated from family members, friends, colleagues and neighbours\(^{53}\).

To indicate social death for leprosy patients, the burial services were performed by religious people when they are still alive\(^{54}\). This fact reveals that leprosy patients are treated as dead people althrough their life time in the society.

Society considers them as social outcastes and treats them as inferior to human beings. They don’t have the normal relationship with society. They have to survive for the sake of existence without human values, freedom and dignity\(^{55}\).

**Leprosy and Family life**

If we look into the life of leprosy patients, it is tragic to understand that many do not have family relationships. Many a time, the members of the family simply neglect the patients just because of the disease. The patients experience rejection by their own spouses, parents and brothers and sisters. They are treated as unwanted persons and harmful to the other members of the family. They experience same kind of rejection in their day-to-day social life and the children of leprosy patients and/or their kith and kin.

\(^{53}\) Wadekar, R.V. *Protection against Leprosy*, Print Asia, Wardha, 1964, P. 52.

\(^{54}\) Thangaraj, R.H., op.cit. P. 29.

have no face value and also experience several sociological problems for their marriage settlement.

The Leprosy act of 1898 and the Railway Act of 1890 were promulgated in India when the people were under the assumption that the leprosy was incurable and the people know very little about the scientific aspects of the disease.

The Muslim Marriage Act of 1935 and the Hindu Marriage Act, 1955 are permitting divorce on grounds of incurability of disease\textsuperscript{56}, even though the medical and scientific knowledge with regard to leprosy strongly advocates that the disease is curable. But, however, these acts are still in force.

The Hindu Marriage Act, 1975, reads “A person living with an infected partner can seek judicial separation from him/her who is suffering from leprosy. It is also true in the society that the leprosy of the patient is a disqualification for marriage and family life”\textsuperscript{57}.

**PERSONAL PROBLEMS**

(a) Living with anaesthetic deformed limbs is a constant source of anxiety or irritation of leprosy patients. Cold insensitive hands and feet, and loss of protective reflexes of the extremities make patients more callous about life itself.

(b) Some of the stressful experiences of leprosy patients arise from facial lesions, such as unsightly patches, infiltrations and facial paralysis. The most detestable

\textsuperscript{56} Tangaraj, R.H., op.cit. P. 430.

\textsuperscript{57} Ibid. 431.
deformity, affecting the personality and image of the person is collapse of the nose.

(a) Disturbances of sweating, particularly the compensatory hyperhydrosis of face and body are a source of profound social embarrassment for a patient. The impact of a small muscle paralysis leading to inability to wash himself or tie dhoti or pants, or button his shirt is a serious matter of psychological stress for a patient.

(b) Blindness in leprosy is a tragedy. An insensitive foot needs the vision for its protection, but with onset of visual disturbances, the anxiety of leprosy patient is doubled.

(c) Nasal ulcers and the associated foul smell emanating from it in a lepromatous patient is a major cause of social embarrassment.

Stress of family life, problems of earning livelihood for dependants, future of the children in contact with the patient and their social relationship in community are all matters of serious concern for the patient. Depressive mental state, loss of will power to recover from the disease, loss of self-image and self-respect, persistent non co-operation for treatment are all common experiences of the emotional reactions of a leprosy patient.

Evils of prolonged institutionalized life had been mentioned with its social and psychological repercussions both for individual patients and general public.

However, it is no doubt, that during prolonged periods of illness or reactions, repeated trophic ulcers or paralysis and intercurrent infections, the leprosy patients need
institutional care. It is mandatory that no patient should be in an institution without the direct supervision of a health personnel. Their needs must be attended to and checked by a nurse, a paramedical worker or a social worker. The planning of management must be on the basis of mutual consultation between doctor, nurse, physiotherapist, occupational therapist, social worker and a health educator. Unsupervised admission into institution will create more socio-economic problems for the care of these patients.

Economic Problems

Economic standards and paying capacity of each individual patient must be ascertained carefully by the social worker. Wherever possible, patient must be encouraged to meet the expenses of the treatment prescribed, if not fully, atleast in part, according to his ability. It would be ideal to plan to make him an earning member of the society. If a person had been doing a job already, it becomes easier. If the person had been a rolling stone, never steady in his work or habits, it is difficult to make such a person work. It is a herculian task and a challenge to his kith and kin to motivate him to do something useful for himself and the society.

CARE OF PERMANENTLY DISABLED OR SEVERELY HANDICAPPED PEOPLE

One will be amazed to see how many (grade III deformities) totally crippled people regularly attend the village clinics. There are many, inspite of all their disabilities, well accepted into their folds in the village. Some of them constantly need the help of another person for their daily chores of life. There are others who are crippled, but without the assistance of anybody to help them. It is to meet this situation; the homes for
the crippled or handicapped will have to be established. There is a great need to train workers in this field. Social services and effective management of homes for the aged are essential needs of any modern society. There is no exception to the severely handicapped in leprosy too.

**PENSION SCHEME FOR OLD AND HANDICAPPED**

Certain State governments have introduced the old age pension schemes to the leprosy patients who are crippled or blind with a view that as long as there is a regular income to support them in the village, the relatives do not mind looking after these patients. Wherever possible, the monetary help from the government should be made available for the permanently disabled leprosy patients.

**Leprosy patients and poverty**

It is a fact in the life of leprosy patients, poverty plays an important role in making their lives very miserable. If the disease is identified to any one in the society the diseased is bound to loose his employment.

If the patients are bread winners for the family, it will directly affect his family life style and the whole family has to face the problems of starvation and financial crisis. When unemployment is a major problem, for even to well to do people, the agony and anxiety of the handicapped in leprosy is unimaginable. Thus many victims of leprosy turn to begging and in pleasure of begging, they continue to live in self derogatory style.

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59 Ibid, P. 90.
They become helpless and dependent and also face financial crisis that leads to permanent begging and unemployment. Further, the crippling and deformities often found in his body will not allow him to have any type of leprosy patients vocation and employment. So, it is clear that leprosy is not caused by poverty but it leads to poverty.

**The Leprosy patient and Religion**

It is to be admitted that most of the religions in our society play a very negative role with regard to leprosy patients. In general, religions associate leprosy with god’s punishment and sin.

T.A. Kaun, a 13th century Chinese traveler reported on leprosy patients “In India there has always been deep seated prejudice and fear that leprosy represents a divine curse”. The Hinduism believes that this affliction and suffering in the present day life is due to the his/her punishment for mislead and sins of previous birth. The Islam believes that leprosy is imposed by the will of Allah to be born obediently by the victims. Further, it also believes that leprosy provides a faithful heavenly credit for those who give alarms to the victims.60

In Biblical times, leprosy patients were treated as outcasted and Jews believed that the sins of the parents are the cause of suffering to their offsprings (John 9:1-5). So the Jews treated the leprosy patients as unclean.61 Therefore, the disease was not

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considered as only a disease, but an affliction placed upon men by God because of their sins.

Among the leprosy patients, the world statistics show that majority are from the rural areas. This clearly indicates that the majority of the leprosy patients are illiterates\textsuperscript{62}. Prejudice, superstition and ignorance are influencing illiterates more than literates. A majority of the leprosy patients become victims of these social evils. They may go for natural medicines, witchcraft, astrologers and religious physicians for the treatment of leprosy\textsuperscript{63}. As they are ignorant of medical science, they do not have much faith in medical treatment. This practice aggravates the situation and makes the patient to suffer more from the situation and makes the patient to suffer more from the disease, and suffer life long.

\textbf{II(h). PSYCHOLOGICAL PROBLEMS OF LEPROSY}

Leprosy is a disease of the mind as well as the body. The most cause of all psychological problems experienced by leprosy patients is the attitude of society towards the disease and persons suffering from it. This attitude is based on long held wrong beliefs regarding the causation of the disease\textsuperscript{64}.

In leprosy, the mental factor becomes more emphasized because of the fear and stigma that is associated with the disease. Every leprosy patient is under a heavy stress

\textsuperscript{62} \textit{Manorama}, 18\textsuperscript{th} year Publication, Manorama Publishing House, Kerala, 1983, P. 390.
\textsuperscript{63} Tangaraj, R.H. op.cit. P. 431.
\textsuperscript{64} Dharmendra, N.S., op.cit., P. 180.
due to emotional reaction, peculiar nature of the social and economic problems. It would be helpful for the researcher to take note of emotional reactions that the patient undergoes so that possible ways and means for the patients recovery through pastoral care and counseling may be developed.

1. **Fear** : The initial shock is the patient coming to know that he is suffering with leprosy. He considers himself as doomed and lost. The first reaction is fear of being rejected by family and society. There is fear of being left alone. There is also fear of impending mutilating deformities rendering him helpless. The helplessness makes him to act as a child.

2. **Guilt** : Along with fear, there often comes the sense of guilt and shame. This is often caused by the general belief of associating the disease with the sins of the patients. Guilt is subjective awareness of having offended against personal, family, religious or societal norms. The feeling of shame arises as the disease is considered as an affliction of God for him/her sins, Guilt moves patients to suffer mentally that they are sinners punished by God.

3. **Concealment** : The mental make up of any human being is to hide the problem that he has with regard to discolourisation of the skin of the body. It is true with leprosy effected persons. When disease is initially discovered, he feels fear and shame because of the disease and the rejection of the people. He feels himself different and

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65 Tangaraj, R.H. op.cit. P. 431.
he is ashamed to reveal himself to a physician. This often leads to unwillingness to seek treatment at a time when treatment is most effective and needed for the healing of the disease. Due to concealment by the persons, the disease goes on progressing till it becomes too apparent to be concealed\textsuperscript{68}.

4. **Isolation**: It is evident in the human relations that when a person fears that he will be rejected or cause harm to others, he may go into the cage of loneliness. He may develop strange feelings of being a stranger in society and want to be aloof. The painful experience of rejection makes him to feel he is alone, and has nobody in the world to care for him. They often find it difficult to relate himself to others. Relationship differ in quality or quantity or both. The situation makes him to suffer greatly in the world with a loan of negative feeling\textsuperscript{69}.

5. **Depression**: Depression is a common reaction when a leprosy patient looses parts of his body such as nose, fingers, eyes etc. Many times loss of employment, his identify and status leads to helplessness and depending on others. For some patients, this act is followed by a period of mourning. They feel an overwhelming sense of loss. A sense of great loss may lead to the impulse to end their lives because they feel that they are useless and unwanted. A person subject to repeated rejection is often depressed and looses faith in treatment\textsuperscript{70}.

\textsuperscript{69} Ibid.
\textsuperscript{70} Nancy C. Andersen, Understanding Mental Illness, *Religion and Medical Series*, Minnesota, Augsburg Pub. 1974, P. 22.
As a result, he looses interest in life and progressive detention occurs in his personality. His misery is so severe that often he contemplates suicidal thoughts or treats himself as a depressed person. Depression may also appear as a result of long suffering.

**Prostration & Anxiety**

Society is conditioned with the ideas of the contemporary age, some of which are harsh to leprosy patients. It requires so much courage to withstand these on-sloughts with endurance. Much of the frustration of leprosy patients arises from various deformalities which affects the image of the person. Living with anesthetic deformation is a constant source of anxiety and irritation. Stress of family life, problems of earning, livelihood, future of children in contact with the patients and their social relationship in community, all are serious concerns for patients leading to a depressive mental state, loss of will power to recover from the disease and loss of self image and self respect.

Further, the lengthy treatment contributes to the emotional reaction of leprosy patients. Leprosy patients sometimes become aggressive and try to seek revenge on society which they consider responsible for all his misery and agony.

**II(i). LEPROSY AND STIGMA**

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71 Tangaraj, R.H., op.cit. P. 432.
72 Ibid.
Goffman describes a stigmatized person as one with a “spoiled identity”. Stigma in the dictionary meaning is variously a stain, taint or defect, a sign of moral blemish, a reproach caused by dishonorable conduct or slavery or criminality. Stigma takes on differing degrees of intensity which vary from and within societies and situations. Stigma is attributed to physical and social characteristics as well as aberrations in character. The physically handicapped in general are less stigmatized than, say, the mentally ill. While most handicapped persons are viewed as some what less than normal, they remain within their own milieu, homes, vocations and environment. The leprosy-affected, on the other hand, have traditionally been ostracized to the extent of being excommunicated by society\(^73\).

That stigma has been attached to leprosy from early times because neither, causation nor cure were known till a hundred years ago and that stigma still persists in many countries, and community understanding and cooperation is far from satisfactory is a matter of deep concern. Community attitudes vary in different countries, and indeed even in different regions in the same country\(^74\). In some areas the occurrence of the earliest skin patches starts the cycle of fear, concealment, neglect and ultimately leads to deformity.

Leprosy therefore continues to be considered the most stigmatized disease of all, barring the recently developed disease, Acquired Immune Deficiency Syndrome (AIDS)\(^75\). It is because it is viewed as divine retribution that the Christian Missionary

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\(^73\) Navin Chawla, Vocational Rehabilitation and Social Reintegration of the Leprosy Affected in India, New Delhi, N.D., P. 23.

\(^74\) Ibid.

\(^75\) Ibid, P. 24.
activity applied itself to the “upliftment” of the leprosy-affected. Again, every society has its own concept of aesthetics, beauty and form. Into none of these could leprosy ever fit, “its victim altering with the advancement of the disease from normality into deformity. For much the same reasoning there is much less stigma attached to tuberculosis or cholera or smallpox. People also fear tuberculosis but there is little stigma, because there is available long-term cure, and there are no outward manifestations of the disease. Smallpox or Cholera in India are also dreaded, but viewed as a visitation of the Mother Goddess\textsuperscript{76}, a disease which is either fatal or cured within a specific time limit if proper treatment is taken in time. Although it left its mark behind, it is not viewed by traditional societies in India as a progression, the object of which needed to be distanced. In the case of leprosy, however, stigma continues to be perpetuated by ignorance and misapprehension, that assumes contagion or infectibility, whereas in most cases there is none. Even the literate equates deformity was infectivity\textsuperscript{77}.

When a person discovers that he (or she) has contracted leprosy, lie begins to view himself as he viewed the leprosy affected in general, that is, with some degree of dread or contempt. Upon discovery of the disease, his aspirations record a change. A defensive mechanism often develops in him in order to protect his immediate family from the humiliation of public discovery. There may be a daughter to marry, or a son to settle, a myriad of human accommodations yet incomplete. Too often to recount, he hides the disease until its outward manifestations became obvious, by which time conventional treatment cannot disguise deformity. Severe psychological damage, personality changes

\textsuperscript{76} Ibid.

\textsuperscript{77} Navin Chawla, op.cit., P. 24.
and deviancy often result. The logical end in which cases, happily less frequent now, was to leave home and as far as possible from known environs, to spare loved ones from ‘shame’\textsuperscript{78}, or to protect oneself from the humiliation of being outcasted by family, friends, neighbours and the community.

An important difference between the stigma attached to leprosy and that attached to human beings in the case of the latter, the incumbent is attached to his respective group or caste at birth\textsuperscript{79}. Moreover, his physical and emotional needs continue to be fulfilled within his own social grouping. The incumbent continues to play the familiar roles of father, mother, child or sibling. The person’s occupation or role in the family community or society remains undisturbed\textsuperscript{80}. He continues to derive a level of fulfillment from whatever job or task was being fulfilled.

But in the case of leprosy there is a marked change, from a comparatively higher status into which he was born, to a situation sans status. It can sometimes be a dramatic social death, which applies equally to the work situation and, often pitilessly, to the domestic situation. Ironic as it may seem, even practitioners of medicine are sometimes reticent to accord him the status of a patient, which is given to persons suffering from more “acceptable” diseases.

Several medical practitioners are unwilling to handle leprosy patients, sometimes for fear that this may not be tolerated by the bulk of their clientele. This too is stigma, and has the effect of strengthening society’s misapprehensions, instead of the

\textsuperscript{78} Ibid, P. 25
\textsuperscript{79} Tatkar, R.K. \textit{The Leprosy Affected and their Problems}.
\textsuperscript{80} Navin Chawla, op.cit., P. 25.
reverse. Conversely, fear of identification causes leprosy affected to shy away from specialized leprosy clinics and hospitals. With stigma being so deeply ingrained, a view has been taken that it is self-defeating to maintain special leprosy clinics and hospitals and hence leprologists advocate change in the use of terminology used, such as “leprosy hospitals”. Leprosy projects etc.  

Legislation too, in more countries than one continues to support stigma. Legislation concerning leprosy had its basic assumptions in the beliefs of incurability and infectivity. In many countries such legislation was enacted in the 19th century and sought to enforce compulsory segregation. In India, too, the Leprosy Act of 1898 reflected the social perceptions of the time, and was based on the premises that leprosy was incurable and that all cases were infectious. This Act and the Railway Act of 1890 as well as other legislation, affected a number of areas of segregation including the use of transport, presence of the leprosy affected in public places, as well as in the personal sphere affecting marriage, divorce, and inheritance. The Leprosy Act of 1898 has since been repealed by the Govt. of India in all Union Territories.

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