

CHAPTER – II

REVIEW OF LITERATURE

LEPROSY: HISTORICAL PERSPECTIVE

Leprosy as a disease is known since time immemorial. Availability of the description about leprosy in classic literature of different religions such as Christianity, Hinduism, and Islam etc. - proved the existence of the disease since very ancient time.

The earliest written records describing true leprosy, which were most probably preceded (perhaps by centuries) by orally transmitted traditions, come from India, in recessions brought together in about 600 BC. They are surprisingly full and accurate and testify to a high degree of observation and diagnostic skill from India, true leprosy spread to China in about 500 BC and then to Japan (Browne 1985).

In China the oldest reports of leprosy are found in the ancient medical text, the Nei Ching (Canon of internal medicine). They mention cutaneous lesions and anaesthesia, hoarseness and eye damage. As for causation, they mentioned overcrowding, promiscuity, lack of hygiene and dirt (Skinsnes and Chang 1985)

"No objective evidence of leprosy predates the findings of recent excavations in the Egyptian Oasis of Dakhleh, which have disclosed Four Leprous Skulls in white representatives of the ruling class buried there in the second century BC. No sign of leprosy has been found in Egyptian Skeletons from 600 BC onwards or in skeletons unearthed at Lachishm, dated 700-600 B. C. The earliest skeletal remains from the present era showing indubitable signs of Leprosy are of two mummies, Coptic Christians, found in a burial ground in El-Bigha in upper Egypt, which date from the six century AD. The hands and feet according to Smith and Dawson (1924) show clear evidence of mutilating leprosy, and Mollar christensen and Inkster (1965) confirmed the diagnosis of leprosy after examining the bones of the extremities and the skull. Anderson (1969) feels justified in ascribing to leprosy bony changes in a female skull from the same period"

(Cited from Browne 1985).

"Among the archaeological objects discovered during the excavation of the Amenophis III temple (1411 - 1314 BC) of Bethshan in Palestine, there was a clay jar, which has a human head moulded upon it. All the morphological changes of this head points to a "Leonine Facies" of lepromatous leprosy. A study of ancient Egyptian mummies done by the Royal Society of Medicine (1961) mention findings of one excellent specimen dating from Coptic time (400-500AD), of the hands and feet of a body affected by advanced leprosy" (Cited from Pannikar 1985).

An Egyptian record of 1350 BC refers to leprosy among Negro slaves from Sudan and Dafor. It has also been mentioned that leprosy has been described by the term "Uchedu" and "chon's swelling" in the Ebers papyrus written about 1550 BC. Lucretius, the Roman Poet (91-55 BC), in his "De Rerum Natura", makes reference to the birth of the disease, where he states -

*"High up the Nile Midst Egypt's central plain
Springs the dread Leprosy and there alone."*

(Cited from Pannikar 1985)

Evidence of the existence of leprosy in ancient time is available from study of archaeological objects. The literature cited gives examples of archaeological study that has been done and reveals the existence of leprosy in the ancient past.

THE ANCIENT LITERATURES AND LEPROSY

SWASTHANI BRATA KATHA

There is a particular kind of ritual, which is followed by fasting by women of Hindu families across Nepal during the month of January and February known as *Swasthani Brata*. This occasion a book "Swasthani" is read aloud every day for the whole month. In this book - in Chapters 26, 27 and 28 there is mention of leprosy.

In the story a queen on a journey, to meet her husband, was carried by porters. They rested in a forest. Porters were hungry and asked the queen if they could go a little away to get something to eat. As they went to a little distance from the queen, they saw some "Angels" of heaven who were worshipping and fasting for Shree *Swasthani* (goddess). The porters also participated in that ceremony. After that they returned to the queen who was very anxious to meet her husband quickly. They offered the queen sacred flowers. But she was angry and threw those flowers to the ground and discarded them. On the way while crossing a river, calamity struck and she fell into the river.

She was found afterwards by a fisherman using a net but she had already caught leprosy. Her hands and feet were damaged due to leprosy. She remained this way for a year and she eventually realized that it was a curse from a god, for her sin, of desecrating sacred offerings to her. Some Brahmans suggested that she should take fast and worship the goddess "*Shree Swasthani*." She at last learned how to rid herself of the curse. So she performed the religious ceremony, which made her clean and more beautiful than ever.

This story, which is repeatedly heard from childhood in Hindu communities, seems to be a source of social and cultural beliefs about leprosy.

LEPROSY IN THE BIBLE

There are many references in the Bible to leprosy. In the Old Testament the First recording is found in Leviticus, chapters 13 and 14. In these chapters leprosy is looked upon as an "unclean" disease and many regulations are laid out for those suffering from the disease. Initially the person must come to a priest. The priest will examine the skin and then the person will be announced "unclean" by the priest (Lev. 13 Ver - 2, 3, and 7). A person found in this condition had to wear 'torn clothes'; leave his hair unkempt, cover the lower part of his face and cry out "unclean, unclean". He must live alone out side the Camp (Lev 13 ver 45, 46). In Lev. chapt. 14 we can read what a leprosy sufferer must do if he is healed of his disease. The priest must announce him ceremonially clean and then many sacrifices must be carried out both by the priest and the cleaned person before he can enter back into 'the camp'.

The next account of leprosy in the Old Testament is the story of Naaman and how he was healed of leprosy. He was a commander of the army of the king and a great man in the sight of his master and highly regarded. He was said to be "a valiant Soldier but he had leprosy". Naaman's Servant girl told him of a man Elisha the prophet, who could cure his leprosy. Naaman's master did not disperse Naaman but gave him full permission to go to Elisha and sent a letter with Naaman and gave him money for the journey (2 kings 5, V - 4, 6). Elisha told Naaman to dip in the river Jordan seven times, which he did and was healed of his leprosy.

In the New Testament, there are many references of Jesus how healed people suffering from leprosy. Jesus cured ten sufferers (LU. 17 Ver 12-19 , Mt 8 V 2-3, Mk 1 V 40-42, LU 5 V 12-13). These references refer to times when men came to Jesus and asked to be healed and Jesus healed them, MK 1 V, 40 states "Jesus looked at the man and loved him". MK 14V 3 shows that Jesus had a friend 'Simon' who was a leprosy sufferer and he was happy to eat in his home. In Jesus time this disease was looked upon as a curse or as a result of sin.

In the Hebrew Bible, the word 'Tsaraath' was used to describe leprosy. The symptoms of 'Tsaraath' or biblical leprosy include a white or shining blister, a scar, ulcer, macule or tumor. It spreads rapidly and also contaminated clothes and houses. Through out the Bible it should be noted that the word for "leprosy" is a Greek word and was used for various diseases affecting the skin - not necessarily leprosy. (Noted from Bible 1978)

SUSHRUTA SAMHITA

The Sushruta - Samhita is an ancient medical treatise written by eminent Indian surgeon-Sushruta, which is believed to have been written in 600 BC and gives a reasonably good account of the clinical manifestations and treatment of the disease.

Some of the verses in chapter 5, entitled the section -"Nidansthanam" reads as follows:

Verse 18:

*Kushthe-shu tu tvakasankoch - swapa - swedashoph - bhedakounya swaropadhyata vaten,
paka-vadarannangu-lipatanakarna sabhanga- kshira - satvoptathya - ha pittan, kandvvarna
- medashophastravagour - vani sh-leshmana! tatra - dibal - pravrutam poundarikam
kakanan - chasadhyam //18//*

"Among 'Kushthas'. pain, wrinkling of skin, numbness, loss or excessive sweating, weakness and hoarseness of voice are due to 'Vaatham. Boils, loss of digits, falling of ears and nose, redness of eyes etc. are due to 'Pittam". Itching, red patches on the skin, swelling, discharge etc. are due to 'Kapham."

According to *tridosha* theory, the three humors present in the body are 'Vatam', 'Pittama' and 'Kapham'. The term, Vatam, is used in the sense of a nerve force dealing with sensory and motor functions. The term 'Pittam' is used to indicate all metabolic processes and 'Kapham' refers to that portion of lymph, which fills all the intercellular spaces of the body; any imbalance in these humors will produce disease

Verse 30:

*Mriyate yadi kushthane punarjate - sh - pl gachchati /
nata-ha kashthataro rogo yatha kushtham prakirti tam //30//*

When a person dies of 'Kushtha', then even to his next birth 'Kushtha' goes with him. Therefore it is said that there is no other trouble- some disease like this one.

Verse 32 and 33:

*Prasanga hadgatra - sansparshani - nishwatsama - bhojanat /
sama-shaiyasananyapi-vastra-malyanu-lepanat //32//*

*Kushtham jwarasch - shoshashch naitrabhishiyand evacha /
oupsargik - rogashch sankramanti narannaram //33//*

"By Sexual intercourse, by the breath, by eating with, by sleeping on the bed, by wearing clothes or -garlands of one suffering from 'Kushtham", other person will get diseases like 'Kushtham'.

A reference is found in "Sushruta Samhita" (chapter xii of the chikitsasthan verse 10) where 'Tugaraka' is mentioned as a potent remedy against leprosy. The oil (chaulmoogra oil) expressed from "Tugaraka" (*Hydnocarpus wightiana*) seed is to be taken by mouth and is to be used externally for rubbing the affected parts. Leprosy is described under the name "Kushtham" in different Ancient Hindu literature likes Manu-Smriti, believed to have been written between 500-1300 BC. and the book of Atharva-Veda (one of the Vedas dealing with medicine) written centuries before Manu-Smriti. All of the above mentioned references revealed that leprosy was known to man in the eastern culture from early times. (Cited from Pannikar 1985).

LEPROSY: MEDICAL PERSPECTIVE

DEFINITION OF LEPROSY

Leprosy (Hansen's disease; Hanseniasis) is a chronic disease caused by mycobacterium leprae (M. leprae), infectious in some cases, and affecting the peripheral nervous system, the skin and certain other tissues (Jopling and Mc Dougall 1995).

ETIOLOGY (CAUSE)

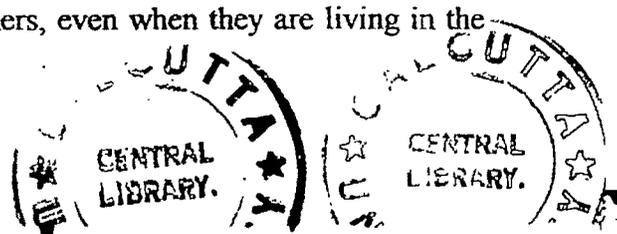
Leprosy is caused by Mycobacterium leprae, discovered in 1873 by G.A. Hansen at Bergen in Norway. M leprae is an obligate intracellular acid-fast bacillus (AFB) multiplying mainly inside the macrophages of the skin and of the nerves (Yawalkar 1992).

It is rod shaped bacteria, measuring 1-8 micro metre long and 0.3 micro metre widths. And M leprae have a generation (doubling) time of 11-13 days (Rees 1985).

EPIDEMIOLOGY

There are many gaps in our knowledge of the epidemiological aspects of leprosy. The occurrence or non-occurrence of the disease is closely associated with the cell-mediated immune response of the host to the challenge by the leprosy bacillus (Yawalkar 1992). Leprosy is generally believed to have originated in Asia, and the earliest records of a leprosy like disease come from China and India of the 6th century BC (Jopling and Mc Dougall 1995). Although leprosy is distributed world wide, in countries where leprosy is endemic, the prevalence rates show marked variations with rates ranging from below one per 1000 to over 50 or more per 1000 (Noordin 1985).

Leprosy is known to occur at all ages ranging from early infancy to very old ages. Although leprosy affects both sexes, in most parts of the world males are affected more frequently than females often in the ratio of 2:1 (Noordin 1985). Though leprosy has been reported from all over the world, the occurrence shows considerable variation among different ethnic groups living in different countries. These variations are more geographic than ethnic (Noordin 1985). Further frequency of lepromatous and severe forms of leprosy, is more in certain racial groups than in others, even when they are living in the



same country and apparently sharing the same environment (Noordin 1989). Although the prevalence of leprosy is high in hot and humid tropical countries, climate does not play a role in the epidemiology of this disease (Yawalkar 1992). The occurrence of leprosy more frequently in certain clusters, particularly family clusters, is well recognized. However, the most debated point is whether this is due to the clusters sharing the same environment or the same genetic predisposition, or a combination of both. The association between leprosy and certain other factors has been studied suggesting a possible causative or promotive association. One of the striking features of the decline of leprosy in many parts of the world is its association with improved socio-economic conditions (Noordin 1985). Although traditionally considered that the reservoir of infection is man alone, but natural *M. leprae* infection has now been identified in Chimpanzee, Mangabey monkey from West Africa and wild-armadillos (*Dasypus-novemcinctus*) in the Southern United States (Yawalkar 1992).

The exact mechanism of transmission of leprosy is not yet 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 (Noordin 1985).

CLINICAL PICTURE

There is no human infectious disease in which the clinical picture is as varied as that of leprosy (Bryceson and Pfaltzgraff 1985). Depending on the infected individual's resistance to the disease (cell-mediated immunity) and not on the humoral immune status of the patient, leprosy presents an astonishingly broad spectrum of symptom-less clinical lesions, ranging from a small solitary hazy macule to widespread multiple shiny nodules. Clinical manifestations of leprosy are so varied and divergent that it is hard to believe that they are caused by one and the same micro-organism (Yawalkar 1992). The commonest early lesion is an area of numbness on the skin or a visible skin lesion. Less commonly the presenting complaint is anaesthesia of part of the hand or foot or muscular weakness. Shooting pains may occur in the limb, trunk or face (Bryceson and Pfaltzgraff 1985). Secondary signs such as clawing of fingers and toes, absorption of digits due to repeated

injury and dry skin are due to impairment of motor, sensory and autonomic nerve function (Brakel 1994).

CLASSIFICATION AND TREATMENT

In 1982 World Health Organization (WHO) outlined a simple classification system for therapeutic purposes under field conditions based on the probable number of *M. leprae* being harbored by an individual. Patient harboring relatively few bacilli are called PB type (Paucibacillary) and patient harboring a relatively large number of bacilli are called MB type (Multibacillary) (Brakel 1994).

Until 1982, the chemotherapy of patients with leprosy has relied almost entirely on Dapsone monotherapy except in Malta; where in 1972 all the registered patient with leprosy were treated with a combined regimen, comprising Dapsone, rifampicin, prothionamide and isoniazid. In 1982 WHO study group recommended multi drug regimen for the treatment of patients suffering from PB type and MB type of leprosy (Yawalkar 1992). PB type of patient to be given a 6 months multi drug regimen (PB MDT) consisting daily dapsone (DDS 100 mg once daily) and monthly rifampicin (600 mg once a month). MB type of patient should be given at least for 12 months multi drug regimen (MB MDT) consisting rifampicin 600 mg once a month, Lamprone 300 mg once a month, DDS 100 mg daily and Lamprone 50 mg daily (Leprosy Manual 2001).

DEFORMITY AND LEPROSY

Deformity is defined as any deviation from the normal appearance of any part or parts of the body. As a single disease entity, leprosy is one of the foremost causes of deformities and crippling (Yawalkar 1992).

Deformity, however, is not inevitable in leprosy, and even where it is occurring, it may be lessened by early recognition and correct treatment. Deformities of leprosy are the logical results of damage to normal nerve supply in certain definite places (Hamilton 1989). Deformities in leprosy are of two main types: primary and secondary.

PRIMARY DEFORMITY

This is due to direct action of leprosy bacilli on the body tissues. *M. leprae* is the only bacillus, which is known to infect peripheral nerves. The peripheral nerve consists of sensory, motor and autonomic nerve fibres, damage to which results in anaesthesia (loss of sensation), muscle weakness or paralysis and lack of sweat and sebum, causing dry skin (Yawalkar 1992). Primary deformities includes claw hand and thumb, drop wrist, drop foot, claw toes, lagophthalmos (inability to close eye), and corneal anaesthesia, planter and the Palmer anaesthesia. Primary deformity is difficult to prevent or reverse. It can only be prevented by very early and regular treatment (Hamilton 1989).

SECONDARY DEFORMITY

This is not due to the action of the leprosy bacilli on the body. It comes only as a result of neglecting the primary deformity for example when feeling is lost mechanical factors cause constant minor injuries which are not painful and therefore neglected, and this leads soon to the familiar ulcers and tissue loss. Similarly stiffness of the joints and cracking of skin are the results of neglecting the paralyzed muscle and dry skin respectively (Hamilton 1989). Secondary deformity include burns, ulcers of hands and feet, stiffness of the joints in hands and feet, tight thumb webs, cracked skin, loss of fingers and toes and blindness. Its occurrence points to lack of effective teaching or failure to gain the patients interest and cooperation in caring about himself (Hamilton 1989). Thus the deformity in leprosy occurs in a sequence, which can be clearly understood by looking at the chart, which is placed in annexes (see sequence of deformity in leprosy in annex V).

STUDIES ON LEPROSY

Some studies have been undertaken in the field of leprosy in Nepal, which have looked at various aspects of leprosy. Most of the studies were conducted by foreigners. Since most of the studies were conducted by foreign scholars, there is a chance of a western cultural bias in the interpretation of the situation of people of a different culture. A very brief account of some of the studies conducted in Nepal has been presented below.

Provost K.J. (1991) has written a paper entitled "A search for physical and spiritual healing - The story of a kushtarogi" in the college year in Nepal programme. In this study

Provost has described the general perspective of leprosy in Nepal i.e. leprosy as a physical and as a social disease. Provost has done a case study of a patient, 'Maisani Ama', who is still a resident of Anandaban Hospital. It is an in-depth study of a single patient with an anthropological viewpoint. She has captured the real perception of the disease, she writes:

"A leprosy patient is released from treatment and is pronounced 'cured' by the doctor or paramedical workers. He no longer has the disease. Many patients might respond with " of course I am not cured. I still have leprosy! How can you say I do not have the disease? Look at my hands! Look at my feet! I'll always be a Kushtarogi!"

Deformity is the main problem in leprosy, otherwise it would not be a disease of fear and stigma, and in this regard Provost writes: -

Reconstructive surgery is now an option, correcting the problems that signify leprosy to society. This is not a solution. A better answer to the problem is prevention of permanent disability. Now that there is a cure for the disease, the focus of leprosy work can be turned toward the education of patients and the education of society about leprosy. Deformity is caused by wound after wound (from lost sensation) and the lack of the care given to the wounds when they do occur.

There seems a wide gap in the explanation of cure between medical eyes and social eyes. Medical service providers are concerned with the bug inside the patient and feel that work has been done by killing it. But on the other hand, patient is concerned with the residual effects of the disease (ulcer, deformity etc) which they think are the active signs of the disease.

Cardinalli R.J. (1982) has done an ethnographic study of leprosy in Nepal. He has studied leprosy in three villages of different castes and in different parts of Nepal. The studies were undertaken among the Newar of Bulu, Parbatiya of Dhime and Tharu of Koluwa. Separation of the leprosy patient from family or community is a significant phenomena. And this process to some extent is related to deformities. On this issue he writes:-

Intensive interviewing with each of the leprosy patients who was living separately at the time, revealed that in every case the patient had been expelled from his or her household (and community) when disability began to develop.

The result of disability or deformity due to leprosy brings problems with ability to maintain their livelihood. He further writes: "It was clear however, from extensive interviews and discussion with contractors and wealthy landowners that the policy not to hire leprosy patient was due to their physical disability.... This seemed to be borne out by the fact that any individual with a visible disability or ailment would be avoided during recruitment procedures."

In relation to deformity and its effects on the daily life of a patient he writes:

.... Basically they would avoid personal contact with him, not allow him to use public facilities e.g. water taps/wells/shrines and might begin to openly mock him. If traditional medicine failed repeatedly and the patient developed ulcers or facial/limb deformities the patient would be asked to keep himself out of the public arena.

An important in-depth socio-cultural study was conducted by Hyland (1993) in Nepal. This study seeks to understand socio-cultural influences affecting leprosy in general and leprosy in Nepal in particular. She writes

To understand leprosy in Nepal and its social consequences it is important to see it in context. The socio cultural factors involved in belief systems which surround every day life are essential to understanding, as well as those of geography and economics, of infrastructure and services, as they all affect the feasibility of travel to clinic.

Once a patient is diagnosed with leprosy he is most likely to be labeled for the whole span of his or her life, it is most often the case when visible deformities are present. So the definition of "Cure" in a medical sense doesn't make any sense to the patient himself and society as a whole. Patients or society can't see the germs are no longer within the body but they can see the remaining deformities as a result of disease. She further writes-

However we fly in the face of the nature of scientific medicine which excludes from the picture anything it doesn't see as fact. Would it make a difference to the notion of "cure" for scientific medical practice to acknowledge that they have only part of the answer to the problem..... After all, the present "Cure" available to scientific medicine is only part of the answer in relation to the medical problem of leprosy if the physical "Complications"" of reactions and nerve damage are recognized as part of the medical definition.

Deformity in leprosy is a crucial aspect of the disease medically as well as socially. In her study 44% of the respondents had the opinion that the deformity, particularly of the hands and feet are the signs to recognize leprosy. Her findings indicated that most people associate 'leprosy' with the deformity. The presence of deformity is an indication that the condition has been present for some time. There were very few who identified the type of skin lesions, which are characteristics of the leprosy in the early stages. This finding demonstrates that the general public is unlikely to recognize leprosy in its early stages, but may easily recognize it once deformity is present.

But in this present study, many people could recognize leprosy by skin lesions. It indicated that awareness about leprosy has been spreading in society and that people are aware of the early signs of leprosy. Therefore it can be said that the notion of association of leprosy with deformity has changed much compared to the past.

D.H. de Stigter et al. (2000) conducted a study in the Eastern Leprosy control Project area of Nepal, which describes community behaviour towards persons affected by leprosy in the eastern Terai districts of Nepal. Three hundred community members (148 male and 152 Female) were selected randomly in five communities. Respondents were asked about the behaviour other community members showed towards them to avoid if it was asked directly about his/her own behaviour can result in their giving social acceptable answer (positive answers). Respondents were asked to tell about community behaviour towards a particular person they knew was affected by leprosy. Respondents knew of 192 persons (144 Male, 48 Female) affected by leprosy. In this way 192 narratives were prepared to analyze the data. Community behaviour was categorized into 5 groups as: 1) Eating Limitations (people do not eat food touched by leprosy affected persons), 2) Individual Negative Behaviour (has to sit separately, not allowed in home, hated, ignored, people do not visit etc.), 3) Social - Public limitations (Not allowed in public places), 4) Segregation (Sent out of the village) and 5) Usual behaviour (Everything together, being treated well). They reported that negative behaviour seems to decrease while usual behaviour seems to increase during the last 20 years. It is interesting to note that they have found no difference between male and female. It is ironic to see that they have noted that in some cases (23 cases) negative behaviour only ended when a person affected by leprosy died. They have

reported that motives for rejection by the community is mainly due to the fear that leprosy is a very contagious disease, some are afraid of the curse of the god, whereas some community members mention both reason for their behaviour. They have also found that motives for acceptance depend on the benevolence of the community and on the characteristics of the person affected by leprosy. Their study concluded that fear of negative community behaviour is based on actual events and persons affected by leprosy still experience many limitations and restrictions in their social life, and segregation still occurs.

Linda M. Robertson, Nicholls and Butlin (2000) have conducted a study in Nepal to identify the risk factors for delay in presentation and start of treatment. The study was carried out at a leprosy referral clinic where 166 consecutive newly registered patients were studied using a structured interview. Delayed in presentation is a recognized risk factor for disability in leprosy and is the result of complex interactions among physical, social, economic and psychological factors. They reported that after discovering their first symptoms, 25% of the respondents had done nothing until coming to the clinic, 22% had consulted traditional healers, 21% had visited a private doctor, and 17% had attended a hospital and their local health post.

A number of studies of the various aspect of leprosy have been undertaken in other countries too. Most of the studies focus on the psychosocial world of the person with leprosy and on stigma (Gussow and Tracy, 1968, 1977, Volim 1983; Wheatley 1985).

T. Cakiner et al (1993) have studied leprosy in women in Turkey. They reported that the degree of disability of patients is high, as more than 50% had moderate to severe disabilities involving their eyes/hands/feet. They further mentioned that patients with a degree of disability constitute 54% of total for eyes, 55% for hands and 51% for feet. Insufficient self-care of patients due to low socio-economic and cultural status and failure of health personnel to control patients periodically may be among the reasons for such high ratios of moderate and severe disabilities.

Kartikeyan and Chaturvedi (1992) conducted a study in Laur district of Maharashtra State of India and this study tried to seek correlation between socio-demographic factors and the pattern of deformities in leprosy patients among agriculture labourers. They have reported that the patient's sex, type of disease, duration and educational status seemed to influence pattern of leprosy deformities. They reported that the percentage of deformity in male is 13.5 and in female is 10.3. Duration of the disease also seemed a responsible factor in the causation of deformities. They reported that the deformity rate is 2.66% for those patients having disease less than 2 years, 13.89% for the patient having disease 2 - 6 years and the rate jumps to 70.53% for the patients having disease 7 + years. In relation to educational status and deformity rate they found a significant difference. They reported illiterate patients had a higher deformity rate (14.5%) compared to literate (7.3%).

A Study conducted by Chan (1986) in Sarawak of Malaysia aimed to explore how leprosy is perceived by the people of major ethnic groups in this region (Chinese, Malay, Iban, Bidayuh and Orang Ulu). Cross - ethnic comparison of attitudes towards leprosy was carried out. He has noted that there are differences in beliefs about leprosy among these different ethnic groups. On the basis of his findings, he has proposed culture-specific health education model for each of the different ethnic groups. The models focused on influencing beliefs about the causation, mode of transmission, early signs and symptoms, the importance of early treatment and the consequences of delayed treatment.

Valecia (1984) conducted a research in the Province of Ilocos Sur and Ilocos Norte in the Philippines. This study aimed to understand traditional knowledge (cause, mode of transmission, signs and symptoms, treatment etc.) of leprosy patients and community's peoples attitudes towards disease to formulate recommendation for better management and control of leprosy in the Philippines. It is very interesting to note that, in this study, a majority of patients consulted traditional herbalists rather than government modern clinics as the main source of medical care for leprosy. It is ironic to note that the practice of these patients to consult traditional healers is not related to accessibility and scarcity of government clinics and trained personnel. The patient's decision to use traditional healers was found to be closely correlated with practice of self diagnosis based on their traditional

knowledge (explanatory model) of leprosy. Interestingly, they have noted that patients often return to their traditional healers for follow up care and treatment after aggravating symptoms have appeared as a result of their noncompliance with biomedical treatment.

In Israel, Meisel et al. (1980) conducted a study on how stigmatization of leprosy affects patients' self-image and their social attitudes and behaviour. This study applied the distinctive traditional anthropological method of participant-observation at the Jerusalem Hansen's Disease Hospital. The study reported that in comparison with out-patients, in-patients were found to have more negative self-image, more negative emotional responses and less social contacts.

Ashok and Anbalagan (1983) conducted a study at Central Leprosy Teaching and Research Institute, Tamil Nadu, India, during 1980 - 81 to find out the experiences of leprosy patients with regard to various aspects of their lives (reaction of family, spouse and society; effects on their marriage and married lives, occupation, economy etc.). The sample patients (225) were selected randomly, 171 were male and 54 were female. A pre tested scheduled questionnaire was used to collect necessary information. Authors have noted that 17.34%, 14.33% and 45.78% of families, spouses and society members respectively displayed negative attitude to them when the diagnosis became known. They also noted that 40.89% of the samples with advanced disfiguring deformities could not move freely in public places. Out of 225 patients studied 79 were unmarried. Among these 79 unmarried, (42 males, 11 Females), 53 attributed leprosy as the only reason for not getting a partner for marriage. Regarding change of residence, they have found that 19.55% of the patients had to shift to different places due to leprosy. Similarly their findings on the effects on occupation and economy, they have noted that the occupational status of 46.22% of samples were adversely affected due to leprosy (43 became totally dependent on their families, 17 became beggars and 44 changed to other occupation of less remunerations). This study concludes, by and large, the prejudice against leprosy has not changed much and the physical disabilities and deformities are important causes for the socio-economic deterioration of the patients.

Kumaresan and Maganu (1994) conducted a study to determine socio-cultural factors influencing knowledge and attitudes of the community toward leprosy in northwestern Botswana. The study was largely qualitative, using ethnographic approaches. The research was tailored in a way to capture the ethnic diversity of the region, in particular 2 ethnic groups, namely Bayei and Bambukushu. The name or symptom complex associated with leprosy was 'ngara' or 'lepero' and this was associated with bad blood. Knowledge of disease causation was lacking which in turn influenced health-seeking behavior of patients. Patients were well integrated and accepted into the social structure of communities. Women caring for these patients did experience some additional burden and identified time as their major constraint in care taking. It was apparent that the degree of rejection correlated with seriousness of the disease and extent of disabilities and dysfunction. The present pattern of health seeking behavior needs to be altered, so that an early diagnosis can be made at the health facility. This will aid appropriate management and prevent occurrence of deformities and disabilities, which in turn will reduce rejection and isolation of patients. Education of community, patients, traditional and religious healers on various aspects of the disease, especially causation, is essential to achieve a change in the health seeking behavior.

Amenu et al. (2000) did a case-control study for determining factors influencing the early reporting of leprosy patients to modern treatment units. The cases were 31 patients presenting with WHO disability grade 2, while controls were 48 patients presenting with grade 0. 77% of the cases waited more than 1 year before going to a leprosy clinic, whereas only 60% of the controls waited more than 1 year. On finding their first symptom, 68% of the cases and 23% of the controls went to a traditional healer. Ex-leprosy patients were found to be important advisors for early treatment. Compared with patients who sought traditional treatment, those whose initial contact was with the general health services had better outcomes. Worsening of symptoms was the final motivation for many of the patients to move from the traditional healer to the leprosy clinic. There were no significant differences between cases and controls with regard to sex, occupation, education or ethnic group. The study showed the need for intensive health education using different strategies to improve voluntary self-reporting of early cases of leprosy.

De Rojas et al. (1994) conducted a study to seek the reason of delay in leprosy diagnosis in Cuba. They interviewed all patients who were diagnosed during 1989-1990 in Guantanamo and Havana, where leprosy prevalence are respectively high and moderate. Data from the 2 cities in their study showed a significant difference in the average time passing between the first appearance of symptoms and definitive diagnosis, the time being 16.6 months in Havana and 10.7 months in Guantanamo ($p < 0.01$). Moreover, the patterns of delay were different. In Havana, the average patient sought medical advice relatively soon (a month after the first symptoms appeared), but one or more physicians consulted took an average of 15.6 months to arrive at the diagnosis. In contrast, the average Guantanamo physician reached a definitive diagnosis in 5 months, but the average Guantanamo patient waited 5.7 months before visiting the doctor. These observations demonstrate that delayed diagnosis can have quite different causes in different places, and that interventions seeking to reduce such delay need to consider the contributing causes in particular locale involved. In the case of leprosy diagnosis in Havana and Guantanamo, future interventions in Havana should aim at increasing the physician's level of clinical suspicion, while in Guantanamo they should encourage patients to seek medical care as soon as they begin to notice symptoms.

A review of literature suggests that further research in leprosy needs to be undertaken on the embedded social and cultural phenomena. Many studies showed the psychosocial and economic impact of the disease in an individual suggested a higher likelihood of debilitation. Literature revealed that there is a wide gap between the medical model and the social model of disease and this is hindering leprosy control activities. The failure in tracing the sufferers own perspective regarding the disease and it's consequences is also felt by the researcher. But there is no study that mentions the debilitation of leprosy-affected persons in particular. Therefore this would be the first study in Nepal, which has tried to measure the level of debilitation as a whole and also looked separately at the debilitation of self-esteem, social interaction, vocational condition and in family relationships and the influences of other factors in debilitation.