CHAPTER ONE

I. INTRODUCTION

Culture provides people with a distinctive way of viewing health and disease, deformity and normality, life and death, within its frame-work.

It shapes people's perceptions toward different episodes of disease and illness, on one hand, and maintenance of good health, on the other hand. "Culture defines the sickness and sick-role its causes and belief systems and practices associated with it. Within culture, the class, ethnic, religious and educational background also influence the meaning and perspective of health". (Polkarna: 1994: P-3)

Culture being an integrated holistic system, include health beliefs and practices. These give an insight into the other aspects of culture, like the social, political, economic, religious, educational and aesthetic.

It is in the early stages of life that the individual incorporates his first ideas about health and sickness and how to care for his body, mind and spirit. 'Learning process or socialization, does not include learning only of cultural habits, but tends to create certain attitudes towards health and illness.' (Kaufmann et al: 1982: 44). Learning is not confined to the early stages of life-cycle, but continues throughout the individual's life.

Through the processes of enculturation and socialization the individual learns to adapt himself to his group, norms, ideals and values.
I. Statement of Problem:

A) Socio-Cultural Context of Leprosy:

The present study is focused on "Cultural Explanation of a Chronic Disease: Leprosy, as provided by the three categories of people, namely: the community people, leprosy patients and providers of health in leprosy. It highlights on the change in perception towards leprosy by the community at Rajnandgaon district of Madhya Pradesh. The statement of problem is viewed in the context of the following two aspects:

"Every culture has its own ideas of personal body image. The deformity on account of leprosy goes against the normative pattern of life for which the individual is held responsible and is rejected when he poses a threat of communicating the disease or deformity to other members of the community" (Mutatkar and Patankar 1991:40).

Since antiquity, deformities and ulcers have been considered as visible symptoms and communicable aspects of the disease. Leprosy has been stigmatized on account of its "infectivity", "incurability" and "gross-deformities". People have lacked knowledge about the disease etiology and have harbored misconceptions and prejudices against the disease. Deformities have been "aesthetically displeasing" and "sight-polluting"; an aspect not easily tolerated by the community members. Physical disabilities on account of the disease have led the person to be a non-productive worker of the community.

No sick roles were assigned to persons suffering from leprosy, primarily, due to the absence of any physical discomfort in the initial stages. Secondly, they were not considered as patients in need of care and attention but as spiritual sinners and deviants.
of social norms. Leprosy was regarded more as an affliction (a cultural concept) rather than a disease (a pathological condition).

The untouchables, the deviants of norms and the poor were considered as the downtrodden in the society. The above mentioned groups, although underprivileged, yet enjoyed a social status and performed roles in the society. Their biological, emotional and social needs were derived from their own community. But a leprosy person was regarded as an outcast among the outcasts.

"Leprosy person is driven to a stigmatized status at any period in his life after living a richer life in his social group in which he was born. There is a sudden change in his status irrespective of whether he belongs to a particular class, caste or religious group". (Mutatkar 1978:1)

In the pre-dapsone era, community had sought to compulsory social isolation of the leprosy persons as the only preventive measure to check the spread of the disease. In the process of social isolation, a leprosy person lost not only his role and status in the society but lost his self-identity too. He experienced a "social death". As a consequence, the effected person resigned himself to fate, adopted low aspirations in life and experienced mental trauma.

"People are not afraid of physical death as much as of social death on account of social ostricism. Man is a social animal and seeks his life's fulfillment in human groups." (Working Group on Social Aspects of Leprosy, Pontifical Academy of Sciences, 1984:38).

"Death without suffering or with minimum suffering is preferred by people to suffering without death. Suffering is considered as
divine punishment and there can be no worse mental suffering than suffering due to leprosy". (Mutatkar: 1978:3)

B) Issues in a Leprosy Control Programme:

Deformity in leprosy has constituted the "Central-core" of the community's belief system.

According to Kleinman (1980), in any culture, there exists "health-related beliefs which form ideational component of culture and on the other hand, "health-related behaviors" which form the action component, and can be observed. (Kleinman 1980: 43). "The norms about chronic disease like leprosy which has had a weak curative technology have found place in the hard-core of culture, and are difficult to change with the weak tools of health Education". (Mutatkar and Patankar 1991: 41.)

Change in people's perception, beliefs and attitudes, do not occur in isolation but within the cultural whole. Change in one aspect leads to change in the other aspects of culture. Every new change has to fall within the scope of socialization in order to form the normative part of culture.

Most of the health programmes are directed toward the "disease" and the "diseased" and the Leprosy Control Programme is no exception. The National Leprosy Control Programme (NLCP) is based on the globally accepted blue-print model about the control of infection through early detection of cases, administration of drugs to detected cases and imparting health-education to the community on leprosy.

The programme has claimed success through chemotherapy in bringing down both prevalence and incidence rates of leprosy. But a question arises in a common man's mind as to what is cure in
leprosy when the normal functioning of the disabled or deformed, anaesthetized limbs has not been restored or the self-identity of the affected person not been regained.

The problem does not terminate with pill-swallowing or patient's compliance to treatment. People's prime concern in leprosy has been ulcers and deformities which incapacitates the affected person physically, psychologically and socially.

The beliefs and attitudes toward leprosy has been rooted deeply in the people's traditional culture, which cannot be easily changed. The mental image of leprosy affected person as deformed and disfigured beggar roaming in the streets of a town or a city, continues to linger in an average human being's mind. Thus, the question is asked: when does a community accept a change for a new technology introduced? Or what motivates people to change their attitudes and behavior toward leprosy and leprosy persons? Change in perception has been possible only when the community has experienced cure, gained confidence in the Leprosy Control Programme (LCP) and come forward to hold a dialogue with them. Community participation has resulted when the health services have shown more concern towards the correction and prevention of deformities and healing of ulcers. However, these aspects have been lacking in the Leprosy Control Programme.

The study undertaken at Rajnandgaon district of Madhya Pradesh reveals that the Leprosy workers' approach to leprosy control activities has been an innovative one, compared to the blue-print model.

The demystification of leprosy through the medium of Leprosy Camps like the Skin Diagnosis and Ulcer Care Camps have proved to be an important tool in fear-removal. One of the unique technique in fear-removal has been the administration of Hydro (water) Oleo
Physiotherapeutic (massage) Exercises (HOPE) to the ulcer and deformity cases by the health-workers. HOPE involved soaking of anaesthesised limbs in water, scrubbing off the dirt and application of oil on the limbs; medicines were locally applied to the person's wounds and ulcers by the leprosy-workers. The community members witnessing such activities underwent dissemination of fear towards the infectivity and incurability of the disease and were motivated to participate in the LCP.

In the process of community participation, certain non-medical roles of health-workers were shared by the community members. They developed partnership with leprosy workers and actively participated in early case-detections, case-holding and creating awareness about leprosy in the community.

Out of their own resources, community gave support in organizing leprosy camps, whereby leprosy-workers became autonomous from the hierarchical administrative structure of LCP for financial inputs. The leprosy-workers became accountable to the community for the health services. They achieved flexibility in their work pattern and launched innovative methods for leprosy control on the experimental basis.

Patients, on the other hand, were motivated to voluntarily report their cases for prevention of nerve-damage leading to deformities and ulcers.

The interactive relationships between the people, patients and health providers in leprosy have facilitated learning exercise in the contrast to educative process (or more aptly health-education) which was a top-down approach.
II. Significance of the study:

"Anthropology has been traditionally known as a study of tribal cultures... It is very recently that Anthropologists have been making efforts to understand culture from the standpoint of health systems of people." (Mutatkar: Society and Leprosy: 1979)

In recent years, the focus of western medicine has changed to community-based preventive, promotive and curative aspects of medicine. This has necessitated studies relating to understanding of community's way of life, particularly, for planning National Health Programmes.

The WHO Sixth Expert Committee Report on leprosy has emphasized that the "problem of leprosy extends beyond that of simply the number of cases, since it involves disabilities, economic loss, psychological trauma and social ostracism". (1988: 11)

The present study analyzes the dynamics of interactive relationships between the people, patients and health-providers in the Leprosy Control Programme which has evolved as People's Programme, what was earlier a Government Programme. The documentation of the dynamics of interactive relationships between the community, patients and health-providers in a National Leprosy Eradication Programme could help in planning and designing inputs, both medical and social, for better leprosy control programme, which could be made replicable (with modifications) in other Leprosy Control Units.

Leprosy, considered as a social problem, offers a good example in the field of Medical Anthropology.
III. Definitions of terms and concepts:

A) Concepts of Health and Disease:

"Health and disease are measures of the effectiveness with which human groups combining biological and cultural resources, adapt to their environment". (Lieban 1973: 1031)

From the functional or mechanical point of view, health can be defined as the "soundness of body, a condition in which its functions are duly and efficiently discharged". (Alland, A, 1970 : )

A social scientist defines health as "total fitness of an individual which would ensure performance of social roles to his optimum efficiency (Mutatkar 1981: 1). This reflection indicates that health is closely linked with the functional prerequisites of the social system. "Health is included in the functional needs of the individual member of the society, so that from the point of view of functioning of the social system, too low a general level of health, too high an incidence of illness, is dysfunctional" (Parsons 1951 : 430).

Disease on the other hand, is not a static entity, it is a process with a dramatic or insidious onset, a short or prolonged course and ending in recovery, death or disability.

At this juncture, it is important to distinguish between "disease", "illness" and "sickness" to understand the medical and social implications of the terminologies widely used in the present study. According to Young (1982) disease is what a medical professional would label as disordered physiology, whereas, illness refers to
perceptions and experiences of certain disvalued states of the affected person who is said to be ill. (Young, 1982:26 4-65).

Fabrega (1971), views illness as cultural category and a set of culturally related events; Disease is perceived as an abnormality in structure and function of any system of the body and evidence of biological malfunction serve as indicators of disease. (Fabrega 1971: 167,168)

According to Foster and Anderson (1978), "disease, with its pain and suffering, is the most predictable of human conditions; it is a biological and cultural universal". Illness is viewed as a product of having sinned or in some way offended the deities. It is also viewed as a social recognition that a person is unable to fulfill his normal roles adequately, and that something must be done about the situation. In contrast to plants and animals, man's diseases become "socially significant" only when they are identified as "illness" (a cultural concept) and as "physiological malfunctioning" that is seen to threaten the individual and the society. (Foster and Anderson 1978:33-40).

"A medical doctor wishes to cure disease but he treats illness, for it is usually the impairment of function and not the presence of disease pathogens that causes us to seek aid." (Ibid, 40).

Eisenberg (1977) puts in more aptly as "patients suffer 'illness'; physicians diagnose and treat 'disease'". (Quoted in Foster and Anderson 1978:47) Thus, disease is the pathological condition of the body, whereas, illness is a cultural concept.

Roemer (1960) attributes the occurrence of disease to sin: the consequence of which is punishment.
"Every disease is a punishment. Every suffering is a suffering for sin – for the sins of the individual himself, for those of his parents, or for those of his relatives ... As a consequence of this view of disease as punishment, the sick man was marked with certain stigma ... Through his sickness his sins became a matter of public knowledge". (Quoted in Foster and Anderson 1978:153) Thus, illness permits one to atone for wrongdoing. The moral slate is wiped clean, and the sufferer again has a valid claim on good health.

The concept that health depends on virtue and illness is related to misconduct, has been one of the early forms of social control in the development of human society. (Lieban 1973:1049). The attribution of illness to punishment for wrongdoing has been mandatory for social order within the community. A person failing to conform to social norms and expectations faced a threat to being exposed to illness. Thus, health is cherished and illness feared, primarily because it "incapacitates for effective performance of social roles". (Parsons 1951:430)

Sickness is a blanket term given to events involving disease and illness. Recent studies have redefined sickness as the process through which worrisome behavioral and biological signs, particularly ones originating in disease are given socially recognizable meanings. Sickness, in this context, is defined as a process for socializing disease and illness. (Young 1982:265,270).

The sick person lives both with the symptoms and consequences of disease in its physical and mental, medical and social aspects. In the act of alleviating his disease, the sick person becomes involved in numerous specific or non-specific, internal or external problem solving processes.
B) Concept of illness behavior:

Both behavioral scientists and medical anthropologists have been concerned with the social and psychological aspects of problem-solving processes and social roles of illness.

'The social aspect of illness, like the physical, mental and medical aspects, represents a time sequence. There is a beginning, an awareness of the early symptoms, its progression, the social and psychological processes that occur; and a termination through recovery or death.' (Foster and Anderson 1978:146)

Medical sociologists have coined the term "illness behavior" to describe the above sequential actions and have developed role models -- the "sick-role" and the "patient-role", to aid them in their analyses.

Illness behavior is concerned with how the symptoms are perceived, evaluated and acted upon by a person who recognizes some pain or discomfort in his body system.

C) The concept of Sick-Role:

Activities in all human societies are organized around age, sex and occupational specializations, which are termed as "roles".

Whatever the role, the person who fills it assumes certain rights and expects certain forms of behavior from those with whom he or she interacts: these are often reciprocal.

In contrast to the animal life, for human-beings, disease threatens not only the biological safety of the sufferer and his
fellowmen, but also affects the social and economic life of the group.

According to Rubin (1960), "By necessity man has undoubtedly always been concerned with questions of health and survival, and has sought, within the framework of his knowledge, solutions to problems of illness." (Quoted in Foster and Anderson 1978:34).

This concern is represented in many societies where there exists a strong urge to nurture the sick.

Furthermore, Jaco (1972) states that "When behavior related to illness is organized into a social role, the sick role becomes a meaningful mode of reacting to and coping with the existence and potential hazards of sickness by a society." (Ibid., 146).

A person assumes a sick role only when his illness is defined as sufficiently serious to exempt him from some or all of his normal roles, thereby altering the role behaviour of those around him.

According to Polkarna, the sick role is characterized by "inability to perform various roles due to bodily causes physical or psychosomatic" (Polkarna 1994: 3)

Sick role necessitates confinement, prescription or therapeutic measures like special diet or dietary restrictions, application or consumption of traditional or modern medicines, defining particular health-behavior pattern like refraining from strenuous activities, patient-care by family members etc.

Child-bearing and child rearing are believed to constitute a "cost" to the society, through pregnancy, child-care, socialization, formal training etc. Premature death would mean only partial "return" for this cost as the individual did not
have an opportunity to play out his full 'quota' of social roles (Parsons: 1951:430).

Thus, community members organize efforts to restore the state of normalcy of the sick persons by assigning sick roles to them in the community.

A sick human being signifies a condition distinct from a diseased animal. If the person is unable to fulfill his normal obligations to others, he jeopardizes the well-being of his group members since they depend on him for many things. Serious illness of one of their members drive the other members of the group to decide what to do. Polar choices are placed before them: like animals they can leave their sick comrade to his own resources, to recover or to die without their help. If he recovers, the victim can resume his former roles; if he dies, a substitute will be found for him, and the life of the group will continue on. Alternatively, the members of the group can attempt to restore the sick person to health so that he can again fulfill his normal role obligations. In human societies, the second alternative is the one that is usually selected, except in rare cases—as with leprosy in past centuries (Foster and Anderson 1978:35).

D) Parsons’ concept of Sick Role:

The view of illness as a social state originated with Parson’s functionalist analysis of the sick role. In his work "The Social System" (1951) he has described illness as deviant from the point of view of the social system because of its interference with the performance of normal social roles. Parsons viewed society as setting up mechanisms for channeling and controlling deviant behavior, so as to maintain a balance among the different elements and reduce stress on the social system as a whole.
Illness behaviors are not preventable and thus are controlled by assigning socially approved roles for the sick person.

Parsons has discussed about four aspects of the institutionalized expectation system relative to the sick role:

1) First, is the exemption from normal social role responsibilities, which is relative to the nature and security of the illness.

2) The second closely related aspect, is the institutionalized definition that the sick person cannot be expected by "pulling himself together" to get well by an act of decision or will... He is in a condition that must be taken care of.

3) The third element, is the definition of the state of being ill as itself undesirable with its obligation to want to 'get well'.

4) Finally, the fourth closely related element is the obligation - in proportion to the security of the condition - to seek technically competent help, namely, in the most usual case, that of a physician and to co-operate with him in the process of trying to get well.

The person is held responsible for the continuation of his diseased condition if he fails to fulfill the above mentioned expectations and obligations and may lead to termination or withdrawal of the rights or privileges of the sick role.

Parsonian Model of the Sick Role has been found most useful when applied to people who are suffering acute, self limiting diseases in which full recovery is the normal expectation. In chronic, degenerative diseases, which are not temporary conditions and in
which full recovery is not possible, the model has been less useful.

Parson's sick role model does not seem to apply to a number of conditions. For example, studies show that alcoholics are not accepted as "legitimate incumbents" of sick role. Patients defined as mentally ill are reluctant to accept sick role. The applicability of Parsons' sick role to pregnancy has been debatable. While illness are viewed as departure from norm, pregnancy is a "normal" state of affair necessary "biological function for the survival of the species". Furthermore, chronic illness also do not fall under the applicability of Parsons' sick role. By definition, these conditions are not temporary and sick person cannot be expected to get well. (Morgan et al 1985:48-49).

Chronic illness does not necessarily disrupt normal role performance, except in the case where the person is bed-ridden or suffering from physical disabilities.

A person who is physically ill, normally is not stigmatized by virtue of illness, as he is expected to lay aside his normal role obligations and will be assigned sick-roles.

However, a mental patient or a leprosy affected patient, must be prepared to face stigma and rejection because of his illness. He is denied even the sick-roles.

E) Perceptions, beliefs and attitudes:

According to the Oxford dictionary (1988), perception means, the ability to perceive or to become aware of, to see or notice. It is directed towards having or showing insight and sensitive understanding of a particular phenomena, belief or a social action.
Perception interprets sensation and relates it to experiences. For example, sensation makes us aware of the form, structure, colour, smell, taste or sound, but perception tells us the meaning of those components. Thus, perception involves both sensation and meaning, which are empirical.

Studies in social perception have been an area of interest to social scientists in the fields of health, social development, social welfare, public administration, etc. Though few studies have made attempts in this direction, the concept of social perception remains vague.

According to International Encyclopedia of Social Science, social perception is "generally concerned with the effects of social and cultural factors on man's cognitive structuring of his physical and social environment.

The term perception is associated with one's acquired knowledge, understanding, belief, attitudes, awareness about any specific aspect or phenomena within the cultural context.

Perception enables individual and group to form certain impression or understanding about objects, persons and events. Impressions, opinions and attitudes exist in person's mind and are referred to as beliefs.

The behavior of an individual as a member of a particular group is shaped by his belief system. The belief system is internalized in the process of socialization. "Belief system provides a large frame of reference which tends to control the more specific thoughts or actions of individuals and groups.... It is a social product, individual perception as well as group experience." (Polkarna 1994:111-112)
Beliefs influence behavior and attitudes of a group or individual. For example, the belief that smallpox was due to goddess Shitla's wrath (goddess of protection) has not been dispelled from the rural community despite the discovery of smallpox virus and its eradication from the world. Such beliefs have led to formation of certain customs relating to health beliefs practices amongst the people which have become the means to seek relief from diseases. In the process, cumulative experiences are socially transmitted and get institutionalized as belief systems within a particular culture.

F) Concept of Leprosy as a Chronic Disease:

"A chronic illness is one caused by a disease or condition that causes impairment or deviation with at least one of the following characteristics:

i) is a permanent condition
ii) leaves residual disability
iii) is caused by non-reversible pathologic alterations of a patient
iv) requires special training of the patient for rehabilitation
v) requires long period of supervision, observation or care".

Quoted in Phipps, W.J. et. al. 19 :252)

"Chronicity" has been derived from a Greek word "Chronos", referring to a condition which is constant, prolonged and lingering.

Leprosy is one of the chronic diseases. The chronicity of the disease generates general response of negative attitudes towards the affected person by the people. The negative attitudes and labeling of a leprosy affected person as a deviant of norms (which is a decrediting attribution) is referred to as stigma. On
account of the chronicity, the disease becomes stigmatized. Stigma is directed towards the deformity and ulcer component of leprosy, which are believed to be communicables.

G) Concept of Cultural Explanation:

According to Geertz (1973:5) the concept of culture is a semiotic one, that is, concerned with signs and symbols.

Human behavior is seen as symbolic action, like that of:

- Phonation in speech
- Pigment in colour
- Line in writing or
- Sonance in music

"As interwoven systems of construable signs and symbols, culture is not a power, something to which social events, behavior, institutions or processes can be causally attributed, it is a context, something within which they can be intelligibly thickly described". (Geertz, Clifford:1973:24.)

Understanding people's culture, exposes their "normalness" without reducing their "particularity". That is, seeing things from the actor's point of view: an emic analysis.

Through the flow of behavior and social actions, cultural forms find articulation in various artifacts and status of consciousness from which they draw their meaning from the role they play in an ongoing pattern of life. (Ibidi:90.)

What we perceive, as well as how we interpret what we perceive is influenced by the beliefs, social ideals, morals, cultural frames
of reference etc. These contribute to "cultural explanation" to that particular event or experience in the individual's life.

Popular beliefs concerning health and disease have had a rational basis, in the context of the particular world-view of those who hold it. Most cultures have an extremely complex theory of disease and misfortune, based on certain premises and its cultural aspects distinct from those of scientific medicine. Explanations offered by modern medicine hold no relevance in the existing culture. Even if the "germ theory" of disease is accepted, still an explanation as to why only some get diseases while others do not, is essential. "Explanations for them come from belief in witchcraft, evil spirits, evil eyes, anti-social action or a broken taboo." (Morgan et al. 1985:113).

Thus, cultural explanation articulates belief, knowledge and practices about the name, nature, cause, expected course of disease and the desired treatment for the different episodes of the disease, within its cultural frame-work.

Although many ethnographic and clinical studies have been written about the importance of cultural explanations in shaping illness behavior, there has been few attempts to examine directly the cognitive bases of cultural explanations of illness (White, 1982:1519).

In the present study, the concept of explanatory models developed by Arthur Kleinman (1980), has been utilized for studying the varying explanations given by the people, leprosy patients and health-providers towards a chronic, stigmatized disease as leprosy.
H) Explanatory Models:

Arthur Kleinman, a clinical psychologist and anthropologist, in his work, "Patients and Healers in the context of culture" (1980) has discussed about Explanatory Models (EM) he had developed for studying the differential explanations a patient on one hand, and the health-provider on the other, gave toward disease etiology and treatment, within their own cultural context. The study was conducted in a Chinese culture.

According to him, "Explanatory Models (EM) are notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process".

Kleinman utilized Explanatory Models to study the interactions between the practitioner EMs and patient EMs, which have led to the analysis of problem in clinical communications. Furthermore, investigating EMs in relation to the various sectors and subsectors of health-care systems (like the professional, popular and folk health-care systems), reveal mechanisms by which cultural and social structural context affect patient-practitioners and other health-care relationships.

Explanatory Models offer explanations about sickness and treatment and seek to explain five major questions for illness episodes:

(1) Etiology: (the progression of the disease)
(2) Time and mode of onset of symptoms
(3) Pathophysiology
(4) Course of sickness (including both degree of severity and type of sick-role-acute, chronic, impaired, etc.)
(5) Treatment.
Practitioners’ EM (even if they are not transmitted to patients), answer most or all the above questions, whereas, patients and family models address to their concern in the disease aspects. Lay EM discloses the significance of given health problem for the patient and the family, along with their treatment goals.

Kleinman’s study distinguishes between the practitioner’s, patients and laymen’s EMs, in terms of analytical power, level of abstraction, logical articulation, metaphor and idiom.

The layman’s EM report short, single-phase explanations because they are embarrassed about revealing their beliefs in a formal health-care setting. The patient and family EMs represent semantic networks that loosely link a variety of cultural concepts and experiences. Explanatory Models elicited from practitioners tend to be considerably different from those actually transmitted to patients or used to make day to day clinical judgments. Thus, practitioners EM is divided into theoretical and clinical types.

Kleinman and others (1978) view Explanatory Models as important instrument for teaching practitioners the meaning of illness to patients, and a tool for determining priorities and concerns of the sick.

Kleinman’s concept of Explanatory Models extends beyond the mere label that every culture has its particular explanations for sickness.

Firstly, it creates order and meaning, gives plans for purposive action. Secondly, he attributes EMs to individuals and not cultures, as EMs are unlikely to be homogeneous even within the same community. Furthermore, a person’s EM is likely to alter over time, in response to his particular medical experiences and
Kleinman distinguishes the various EMs of the patient, family members, practitioners and laymen along the three dimensions:

(1) In the first dimension, the EMs of practitioners and layman are distinguished.

(2) The second dimension portrays how a western practitioner's theoretical or scientific EM leads to his clinical EM (particularized by his clinical experiences) and how a layman's popular EM (shared by a community of laymen) leads to his family EM (particularized within a family) ends up as his individual EM.

(3) Along the third dimension, a clinical EM or individual EM passes through various editions.

Kleinman has proposed a 5-point scale for the analysis of EMs and applies it to measure cognitive distances between the EMs.

For example, for each of the five major questions, mentioned earlier in this section, the patients EM and the practitioners EM score "0" if they agree, "1" if they show a major discrepancy etc. A range of scores can be worked out for each comparision in which models that are maximally alike are scored "0", while those that are maximally discrepant are scored "10".

Limitations of the Kleinman's Explanatory Models:

According to Young (1982), "Kleinman employs the idea of explanatory models to show how the informants produce their
statements about sickness. EM emerge in his writing as sets of propositions or generalizations". (Young:1982:267).

Secondly, his interests in medical beliefs and practices are purely clinical. Clinical medical situations have formed the central part of Explanatory models referred to as "core clinical functions", that is, how systems of medical knowledge and practice enable people to :

(1) Construct illness as a psychosocial experience.

(2) Establish general criteria suitable for guiding the health-care seeking process and assessing the potential efficiency of different treatment approaches.

(3) Managing illness episodes through communicative operations such as labeling and explaining.

(4) Providing healing activities (therapeutic intervention, supportive care).

(5) Managing therapeutic outcomes (including chronic illness and death).

Social dimension of people's perception towards disease have been lacking.

Kleinman's study is based on the Doctor-Patient relationships in a clinical setting.

The present study utilizes the concept of Explanatory Models and adapts it to the study of interactive relationships between the three categories of the community members, namely, the people,
patients and health-providers, with regards to their change in perception towards leprosy.

IV. Aims and Objectives:

The present study aims to understand the process of change in people's perception towards a chronic, stigmatised disease like leprosy.

The objectives of the study have been:

1. To study the impact of intervention programs in leprosy control programme on:
   i) Patient-acceptance within the community.
   ii) Removal of fear and misconceptions from the minds of the community.
   iii) Deformity Prevention aspects.

2. To understand the factors which have motivated the leprosy workers to adopt innovative practices for community participation.

3. To examine the Explanatory Models of the community members, leprosy affected persons and leprosy-workers with respect to the following aspects in leprosy:
   i) early signs and symptoms
   ii) causation
   iii) transmission
   iv) treatment
   v) concept of cure
   vi) deformities and ulcers.
V. Hypotheses:

Hypotheses ensured the delimitation of the study and probed into four specific areas of investigation namely,

i) The process of community participation and community action in LCP.

ii) Change in Health-Care Delivery Services from drug-delivery to deformity prevention activities.

iii) Cultural and Medical Interventions in LCP.

iv) Cultural Explanation towards leprosy by the people, patients and health-providers.

The hypotheses of the study are as follows:

1. When community members and leprosy workers work together for deformity prevention and ulcer management, certain roles of the health-workers are shifted to the community members.

2. Community Participation has resulted when the health-services have shown more concern for deformity prevention.

3. Health services at the village level become more autonomous from the hierarchial administrative structure when community gives support.

4. Intervention programmes (both cultural and medical) have led to change in people’s perception towards leprosy.

5. Change in perception results in changes in Explanations provided by the leprosy-workers, patients and community members toward leprosy.
VI. The Chapterization Scheme of the Thesis:

PART ONE

I. Chapter One:

The Introduction of the thesis is sub-divided into different sections. The chapter begins with the statement of problem, significance of the study, aim and objectives and hypotheses. Next, it discusses certain terms and concepts used in the study, like concepts of health and disease, illness behavior, sick roles, perceptions, attitudes and beliefs, chronic disease, cultural explanation and explanatory models.

The organisation of the study is outlined followed by the limitations of the study included the end of the Chapter.

II. Chapter Two:

Chapter two provides a theoretical framework of the study through a comprehensive overview of literature conducted during the past decade (1980-1993).

III. Chapter Three:

Chapter three discusses the research methodology employed in the study. It elaborately outlines the tools and techniques of data collection, type of data collected, methods used in the analysis of data (both qualitative and quantitative), the different phases of field work and some of the methodological limitations faced during the field work.
IV. Chapter Four:

Chapter four gives a background information on scientific facts on leprosy, the infrastructure of the National Leprosy Eradication Programme and the magnitude of leprosy problem in India.

V. Chapter Five:

Chapter five focuses on the ethnographic details of the people of Ghumka (the area of the in-depth study conducted by the researcher).

PART TWO

The discussion and analysis of the data constitute the main body of the thesis. These include four major Chapters - Chapter Six to Chapter Ten.

Chapter Six:

Chapter six presents concepts about health and disease as viewed by the people of Ghumka.

The second section the chapter delves into the concept of personal body image and gives people's views toward it, with special reference to leprosy.

The third section gives a comparative picture of leprosy with other communicable and chronic diseases like tuberculoses, cancer, asthama, arthritis, small-pox, measles, typhoid and cholera, as perceived by the people. The last section of the chapter presents community's action towards leprosy prior to the implementation of multi drug therapy or the launching of the new
approach in community action, in the Leprosy Control Programme, at Rajnandgaon.

VII. Chapter Seven:

Chapter seven gives an insight into the Leprosy Control Programme, prior to multidrug therapy and the present infra-structure.

VIII Chapter Eight:

Chapter eight centres around a detailed discussion on the intervention processes in the present Leprosy Control Programme. The intervention processes are classified as medical, medio-social and socio-cultural.

The Chapter analyzes each of these processes as foci for change in demystification of leprosy and closing up of distances between the people, patient and providers of health in leprosy. This has resulted in interactive communication between the above three categories of people.

Furthermore, the chapter highlights on the innovative practices adopted by leprosy workers for better leprosy control. It gives a historical perspective of innovative practices, motivational factors underlying it, and its application in control activities, leading to community participation.

IX. Chapter Nine:

Chapter nine presents the results and findings of the analysis of interview schedules and questionnaires administered to people (community members and patients) of Ghumka sector and leprosy workers of the Rajnandgaon district, respectively.
The cultural explanation provided by the people, patients and providers of health (in leprosy) toward the early signs and symptoms, disease etiology, treatment, concept of cure, views toward deformity and ulcers, and the present leprosy control programme, constitute the Explanatory Models in the study. Arthur Kleinman’s Explanatory Models have been adapted in presenting the analysis of cultural explanation.

X. Chapter Ten:

Chapter ten focuses on selected case-studies of leprosy affected persons. Case-studies relate to areas concerning fear-removal, patient-compliance to treatment, patient-turned-educator, coping with crisis situation and patient-care.

SUMMARY

The Chapter on summary embodies data presentation, analysis and discussion of the study.

This chapter contains two major sections:

i) Summary of the entire data
ii) Summary of the major findings

The research findings relate to the hypotheses of the study and vividly explains each one of them in the context of the data presented.

CONCLUSION:

In this chapter, the inferences from the findings are drawn and its applications are viewed as valuable inputs in Leprosy Control Programme in areas where leprosy problem is of high magnitude.
VII. Limitations of the Study:

The study is basically exploratory in nature and hence, the data presented is descriptive. It investigates the unstructured field of inquiry in leprosy, whereby, the study is an attempt to document:

i) the process of change in people's perception towards leprosy, and

ii) the factors leading to innovative practices adopted by the leprosy workers in National Leprosy Eradication Programme.

The limitations of the study are as follows:

1. The hypotheses of the study have not been subjected to complex statistical testing.

Quantitative data, including the case-studies are employed to validate the hypotheses.

2. The sample size in the study is small and derived only from Ghumka sector of the Leprosy Control Unit, Rajnandgaon and hence, here again it is not subjected to complex statistical analysis. The purpose for small sample size was for an in-depth information to be gleaned from the respondents. The quantitative data was used to complement and validate the qualitative data.

3. Furthermore, the study has not employed any technique of quantifying people's perception towards leprosy, as utilized in other discipline of social sciences, like psychology. Perceptions are highly subjective and value oriented, hence, the quantification of such cultural values are not possible. However, a simple attitude scale has been formulated to project the community's attitudes toward leprosy affected persons.
4. Explanatory Models (EM) of Arthur Kleinman is not being directly applied to the study. Kleinman had used EM to study the doctor-patient relationship in a clinical setting (in a Chinese Culture). However, here the EM is adapted to analyse cultural explanations toward leprosy given by the people (Community members, and leprosy patients) of Ghumka and leprosy workers of the Rajnandgaon district.

5. Lastly, the researcher, for the first time was exposed to the field of leprosy through the present study. No prior knowledge about leprosy as a medico-social problem existed in the mind of the researcher. However, valuable insights into social aspects of leprosy were provided by the research supervisor of the research scholar.

Interactions with the DANLEP programme officers, leprosy workers, patients and community members in at Rajnandgaon, created an interest to investigate the unexplored area in leprosy.

Considerable time was spent in exploring the social aspects in leprosy, both in the literature and field.

Secondly, the vastness of the study made the delimitation of the study difficult. Time was a major constraint upon the researcher. Considerable amount of time was utilized in delimiting the area of study, crystallization of data from the base-line data, content analysis, quantitative analysis and finally, drafting of the manuscript. Thus, the thesis may not be a perfect literary piece of work.

However, with all these constraints the researcher has put in honest efforts to project the study in the most presentable way and asserts that the conclusions drawn from the study are valid.