CHAPTER I

INTRODUCTION

1.1 Background of the Study

Leprosy is a chronic disease caused by infection with Mycobacterium Leprae. It is characterized by the formation of nodules on the surface of the body and especially on the face and accompanied by the loss of sensation followed sooner or later in both types by the involvement of nerves with eventual paralysis, wasting muscles and production of deformities and mutilations. In 1873, Norwegien young physician Dr. G.H. Armauer Hansen found this bacillus. It is also called Hansen's disease, probably for reducing social stigma associated with it.

Religious notion of leprosy such as it appears as the result of divine curse, segregated practices of treatment in past, fear of contagion, supposed as inherited disease etc. made it a dreaded disease. Nowadays, leprosy can be medically cured. However, the sickness of it might have deep rooted in our society. Because of its chronic nature and causing deformities/mutilation of body parts, it has created its unique feature than other diseases. Still in this age of modernization, we may be veiling from those archaic values which can manifest in treatment seeking behavior. Inadequate bedding, contaminated water and insufficient diet enhance the risk factor so it may be labeled as the disease of poor/lower castes.

Nepal is a country within the category of top most seventeen around the world for the prevalence of leprosy. However, it had eliminated the leprosy (0.89/10,000) in Jan-2010 but it faces high rate of noncompliance more than (40%) in some region. This noncompliance is used as defense mechanism to conceal their disease and thus to maintain their social integrity (ELCP, 2004). The numbers of leprosy patients presenting to dermatologists in both private and teaching hospitals are increasing in the post elimination phase (Jha, 2012).

The latest data shows that 2,445 people are currently receiving treatment for leprosy in Nepal. Western Region has the lowest incidences (0.7/10,000), 8 percent of diagnosed people are children, 3 percent of the people diagnosed with leprosy have Grade 2 disability and around 68 percent of people diagnosed with leprosy are male (INF Pokhara, 2012).

In this study, researcher has tried to know the cultural world view of leprosy of community people (non-patients) around the periphery of rehabilitation center. In the same study participation restriction of leprosy patients and their lifelong experiences of suffering have tried to reveal. It was carried out in three different areas (Lamtara Rehabilitation Centre, Tutunga Camp and GPH of Pokhara). Total eighty respondents were taken for the interview. Fifty-five respondents who were non-patients but neighbors of leprosy patients were selected for cultural schema of leprosy. Twenty-five respondents (patients) were asked for participation restriction. Twenty respondents who were also involved in the study of participation restriction were asked for their lifelong experiences of leprosy.

1.2 Statement of the Problem

A disease may have constraints for the treatment in economic, technical, social and moral aspects. Stigmatized diseases may bear more social and moral constraints than other diseases. Due to chronic nature of leprosy from few weeks to 20 years, patients often require continuous support of family members, neighbors and state. A diagnosis of leprosy in a family can cause the loss of work and deterioration of social relationships even for distant relatives. Avoided by former friends, forced eating/sleeping, becoming the subject of gossip, refusing to marry, forced divorce by spouse, delaying treatment may be the consequences of stigma. It is said that some patients keep the matter of disease secrete even from family members. It may therefore dissipate the dignity, confidence and economic well being of leprosy patients. Disabilities and deformities may affect on marginalization and gender discrimination due to poor socio-economic status of people in underdeveloped country such as Nepal.

In India, Hindus consider deformity resulting from leprosy as divine punishment (Muthankar, 1979). In China, leprosy is considered to be sexually transmitted by contact with a prostitute and a punishment for the moral lapse (Skinsnes, 1964). In Africa, leprosy is referred to as 'ngara' or 'lepero'. In Botswwana, leprosy implies an association with 'bad blood' (Gussow, 1989). In Nepal, 25 percent had done nothing until coming to the clinic, 22 percent had gone to visit the faith healer *(Jhankri*) and 21% had visited a private doctor (Linda M. Robertson et al., 1995). In Far Western Development Region, overall delay was higher for women. Low literacy or none at all, a young marriage age, a heavy workload, poor knowledge, permission of mother in-law or husband to leave the homestead, the need for escort and money for transport and sometimes ways of treatment all these factors impeded women from reporting. (Varkevisser, 2009). J.H. Calcrafit's Study (2004) in LLSC, Janakpur Dhanusha of Maithili people revealed the more visible the leprosy, the greater the likelihood of stigma and income loss. In several cases, the person affected by leprosy was separated from the family because of stigma.

"Contemporary biomedical knowledge is socially produced and culturally specific. Western medicines are not merely characteristics of a scientific capacity to describe and to enumerate the natural world. They are dependent on certain fundamental features of medicine culture, which is itself produced and reproduced through processes of socialization (Atkinson, 1977). Therefore, explanations of diseases merely resting on the knowledge of health bureaucracies and foreign experts may be insufficient. Many programs launched by government and NGOS are facing serious cultural constraints. So, we might have ignored the social issues involved in leprosy. Study of leprosy through the aggregate of biomedical perceptions as well as social relations may complete our understanding.

Over the years, impact of education, awareness programs and media might have changed perceptions (cultural schema) of leprosy from fatalistic/religious explanation to germ theory. Similarly, perceptions (cultural schema) of lay people towards leprosy may be working in our context which may guide treatment seeking practices. Studies related with non-compliance (de Stigter et al., 2000), delay in diagnosis (Varkevisser, 2004), income generation (Calaraft, 2008) and mode of treatment (Burathoki et al.,

2008) have been done in Nepal. However, following questions are thought to be new and relevant.

- What are the perceptions (cultural schema) of lay people towards leprosy?
- Are these perceptions changing?
- What is the situation of stigma and discrimination against leprosy patients particularly at community level?
- What is the impact of leprosy in the lives of leprosy patients?

1.3 Objectives of the Study

General objective

The general objective of the study was to describe the schema of leprosy, types of stigmata and suffering of people by leprosy.

Specific Objectives

- To describe health beliefs (schema) of people (non-patients) towards leprosy.
- To measure the social participation/ostracize of leprosy affected people.
- To analyze the experiences (sufferings) of leprosy affected people.

1.4 Rationale of Study

Sociological/Anthropological study of diseases is a matter of new interest in our academic arena. Some studies were conducted by technical experts mostly related with treatment efficiency.

- Leprosy was a highly stigmatized disease in the past. Finding its situation in our context, may be fruitful in leprosy control.
- Sociological/Anthropological study of leprosy may be relevant in Nepal where many cultures coexist. It was thought that people adapt mode of treatment on the basis of perceptions they share from cultures.
- Understanding of the cultural stigma to leprosy can help to make a guideline for awareness program.

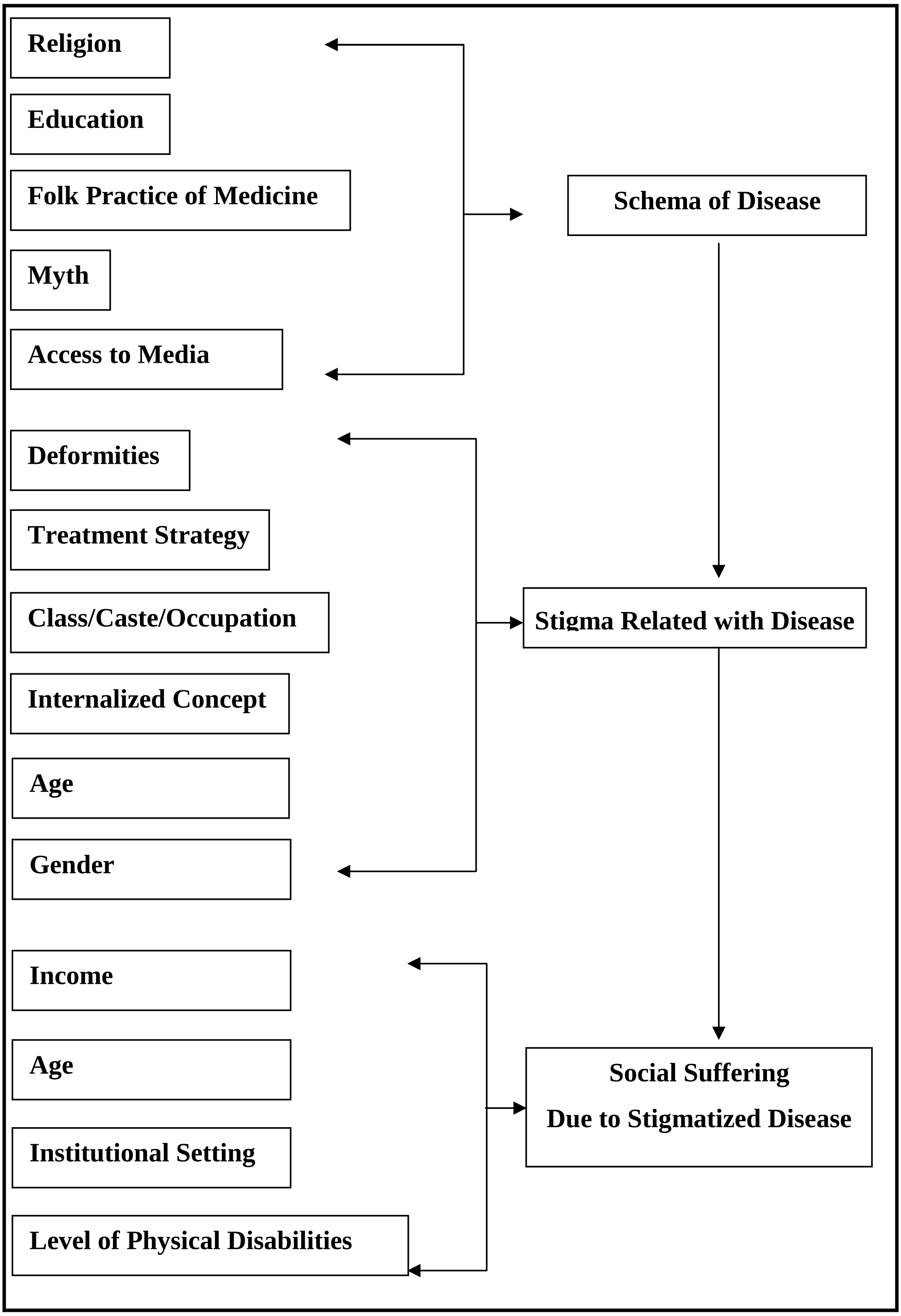
Some studies about stigmatized diseases such as TB, HIV/AIDS, and Prolapse etc. had been conducted in Nepal. Medicine may work effectively to treat physical pain, but for the treatment of psychological pain (a subset of suffering) it was supposed better to peep through the window of socio-cultural relation. Stigma to leprosy was thought to be the outcome of cultural understandings and its sociological /anthropological study was supposed as relevant in our context.

1.5 Limitation of Study

This study was limited mainly within the patients arriving in Green Pasture Hospital and Rehabilitation Centre, Pokhara-15, former leprosy patients in ‘Lamtara’ rehabilitation village Ritthepani-2, Lekhnath and ‘Tutunga’ camp, Pokhara-15. Some non-patients were taken from the neighboring community of ‘Lamtara’ rehabilitation village and ‘Tutunga’ camp.

The findings from this study may not generalize the whole Nepalese context. Dividing the whole respondents mainly into two categories (<40 years and >40 years) may be the next weakness. There were other difficulties such as measuring the ‘Schema’ and ‘Suffering’ quantitatively. Sampling was not purely random. Since it was quota sampling, that may prone to errors.

1.6 Conceptual Framework



In this study, consequent relations of schema to stigma and stigma to suffering were considered. People make sense of their worldview (schema) on the basis of sources of knowledge which they receive from their community. Negative schema may develop stigma to the disease. Higher the stigma to any disease can cause more sufferings.

Schema was considered to be affected by religion, education, and folk practices of medicine, local myths, and their access to media. Deformities, class/caste/occupation, internalized concept, age and gender were taken as factors related to stigma. Income, age, institutional setting, and level of physical disability were taken as factors to suffering.

1.7 Organization of the Study

The whole study is divided seven chapters. First chapter includes introduction of the study. Second chapter contains literature review. Third chapter is related about briefing of sampling and research methodology. Chapter four contains data for cultural schema and its analysis. Chapter five is related to data and analysis of participation restriction. Chapter six contains data and analysis for suffering and chapter seven contains summary, conclusion and recommendation of the study.

1.8 Definition of Key Terms

Leprosy: Leprosy is a chronic disease caused by infection with Mycobacterium leprae especially attacking on face, fingers and legs.

Participation restriction: It is a custom of any society in which an individual is avoided to take part in any opportunities say festivals, job or ceremonies.

Schema: It is a pattern of thoughts which is conceived by an individual from their surrounding for any specific event or entity.

Stigma: It is the way of treating to any individual by their peer group, family or society which in turn disposes the individual to an inferior hierarchy. It is also the concept felt by that individual by which he/she fells as inferior himself/herself.

Suffering: It is the unfavorable life condition of an individual where he/she is compelled to survive.

CHAPTER II

LITERATURE REVIEW

This chapter deals with the definitions of schema, stigma and suffering. Similarly, in the same chapter previous studies on schema, stigma and suffering which are related to leprosy have been mentioned.

2. 1 Theoretical/Conceptual Overview

2.1.1 Schema

Epistemological meaning of ‘schema’ is an outline of plan or theory. Its plural words are ‘schemata’ and ‘schemas’. Plato was the first philosopher to use the term 'schema' as the perfect circle that exists in the mind but which no one has ever seen. Immanuel Kant used the ’dog schema’ a mental pattern which can delineate the figure of a four footed animal in a general manner (D' Andrade, 1995).

A ‘schema’ may define in psychology of cognitive science in several ways viz. an organized pattern of thought or behavior, a structural cluster of pre-conceived ideas, a mental structure that represents some aspects of the world. Frederic Bartlett and R.C. Anderson used the term ‘schema’ in psychology.

Psychologist Eleanor Rosch (1970s) had used the word ‘Prototype’ which means "A category in our mind that these prototypes are perceived or remembrance not simply as a list of features, but as a configurational gestalt" e.g. one who identifies the schema of bird may refer to feather, wings and flying entity.

The decade of 70s was the hay days of schema theory. Mostly it was used in psychology and cognitive anthropology. It was used in cognitive field of psychology (1920's), linguistics (1960's) and anthropology (1950s). Good Enough (1956) and Harold Concklin (1954) had used it in Yale university nurturing their ethno-science.

Ronald Casson (1983), had divided the schema into three broad categories according as the number of people they share it. Cultural model lies elsewhere between the universal schema and idiosyncratic schema.

i. Universal Schema (known to all e.g. sound after lightening means raining soon)
ii. Cultural Schema (specific for any culture only e.g. in China leprosy is supposed as the result of moral lapse or incest relation)
iii. Idiosyncratic Schema (may differ from person to person on the basis of his/her level of understanding)

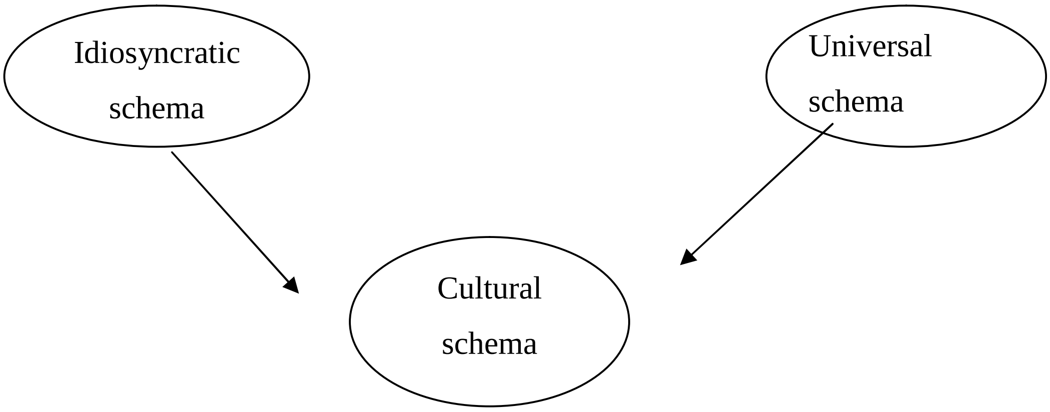


Fig. 2.1: Models of Schemata
Source: Ronald Casson (1983)

Similarly, according as the nature of schema he had divided it into five categories.

i. Object Schema (e.g. bird means feather, wings and flying entity)
ii Orientation Schema (e.g. guiding about route, go straight, above the bridge then right turn)
iii. Event Schema (e.g. suicide bombing, a white car rushed towards the post, blasted and ablazed)
iv. Metaphor Schema (Comparing illness as war, we fight colds, kill germs and are losing battles against AIDS)
v. Narrative Schema (It is the combined form of explanation of all the above schemas)

Cultural models are the shared cognitive schemas through which human realities are constructed and interpreted. These cultural models are "Culturally formed cognitive schemata that mediate the interpretation of on-going experiences and the reconstruction of memories" (De Andrade and Strauss 1992:3).

‘Cultural Model’ is defined as the shared, conventional ideas about how the world works that individuals learn by taking and acting with their fellows. Cultural model is the product of certain collective behaviour and is a producer of culture specific knowledge both (Holland, 1992).

People have 'Schemata' or unconscious mental structures that represent an individual’s generic knowledge about the world. It is through schemata that old knowledge influences new information (Bartlett, 1932).

Kessing (1987) sharply demarks between cultural model (I) as the collective and shared models about the way the world works and cultural model (II) as those models (Schemata) that are located in the individual and are used in forming the cognition of the individual.

Paul Farmer (1994) studied the development of cultural model (I) of HIV/AIDS in Haiti. He showed how the understandings of the cause of the disease shifted from a blame on 'microbes' to a blame placed upon the government for bad conditions which has led to the epidemic, a sort of political economy discourse.

Gussow and Tracy wrote about the importance of schema in the decade of seventy. “One cannot hope to understand the additional problems of patients without an understanding of the 'world view' of the people involved & their view of such concepts as health and illness” (Gussow and Tracy, 1970).

No one of the patients was able to attribute their illness to brain disease in case of Epilepsy. In Nepal, epilepsy is associated with weakness, possession by an evil spirit or the reflection of a red color. By standers who witness a 'Seizure' will often spray water on the forehead of the person experiencing the 'Seizure'. They allow him or her to smell a leather shoe (Rajbhandari, 2003).

A study was carried out by D.K. Baine (2003) in Gorkha district of Nepal found the cultural schema of AIDS as danger disease *(thulorog)*, irrelevant with bodily temperature (*sardi/garmi)*, transmittable *(saruwa)*, a fatal disease *(khattam)*, foreigner’s disease *(bidesi)*, a result of prostitution *(randi)*, blame over low places *(Terai/India)* with a concept of moral geography.

In our context, for example ‘Skin ailment’ can be interpreted by different causes such as by ring worms, touching plant's nettle *(Kauchho)*, allergy or by touching any insects. Similarly, sudden ‘Stomach Pain’ can explain as *Sul Chaleo*, appendicitis, indigestions or attack of evil eyes. Similarly, some diseases bear universal schema e.g. syphilis and gonorrhea are transmitted by sexual intercourse only and mumps are known as children’s disease.

In this study, researcher had tried to know the cultural model (II) that any patient or non-patient has acquainted about leprosy which may differ from one culture to another.

2.1.2 Stigmata

Stigmata are known as wounds or skin markings that match the wounds suffered by Jesus during his trial and crucifixion. The word 'Stigmata' is the plural of the Greek word "Stigma". This was an ancient name for marks that were pricked or branded into the bodies of slaves and soldiers for identification purpose. The word was also applied to religious symbols tattooed into the members of Pagan Religious Cults to show their devotion to particular gods and goddesses. Many Christians believe that the sudden appearance of stigmata is a divine sign that a person is very close to god and don't follow medical treatment.

Stigma is symbolically constructed when personal identities are associated metaphorically with ‘impure’ images raising doubts about his /her integrity, honesty, sexual purity etc. ‘polluting’ the moral essence of personhood (Douglas,1996).

"Stigma is best comprehended as moral experience, configured within a local world amidst danger and uncertainty. What is moral? That embodies our sense of right and wrong yet to be understood requires ethical scrutiny from the outside and from those on the inside who challenge accepted local values" (Kleinman, 2003).

Stigma is a phenomenon associated with many chronic health conditions, causing much suffering to those who are stigmatized (First, 1996, Kaur and Van Brakel, 2002, Nyblade et. al., 2003). In addition, stigma has indirect but strongly negative implication for public health efforts to combat the diseases or conditions concerned (Link and Phelan, 2001, Weiss and Ram Krishna, 2004).

Stigma is hard to define and measure being a complex reality made up as it is from a mixture of belief, attitudes and behaviors (Rafferty, 2005). Stigma is typically a social process, experienced or anticipated characterized by exclusion, rejection, blame or devaluation that result from experience, perception, or heath related condition, and the judgment is a person or group (Weiss, 2006). The social process of stigmatization is often connected to relations of class and command and the stigmatized are typically also exploited and oppressed (Scambler, 2004).

Following chart elaborates the distinction between enacted stigma and felt stigma to both patients and non-patients.

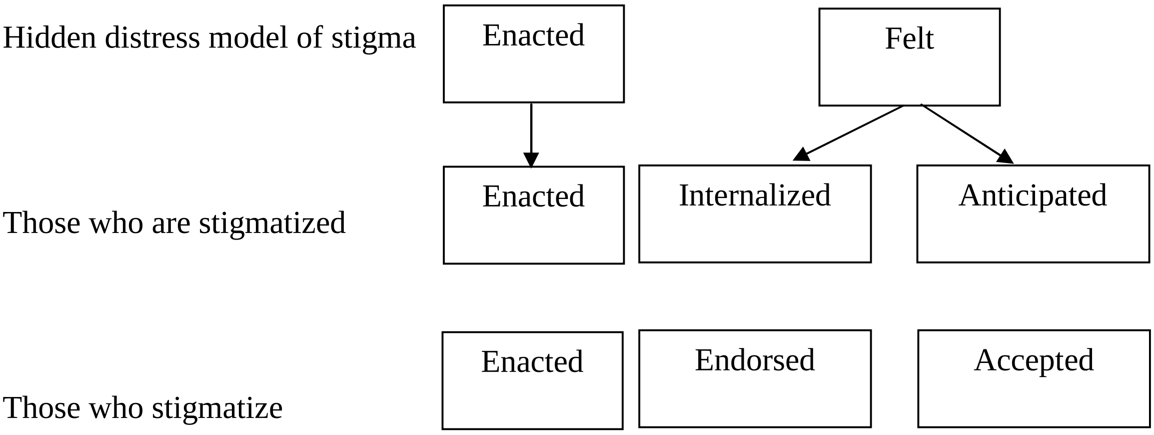


Fig. 2.2 : Scambler's Hidden Distress Model of Stigma

Source: Weiss (2008)

The paradigm shift of social stigma from archaic concepts of immorality to modern concepts of civil rights is mentioned in the paper of M.G. Weiss (2008).

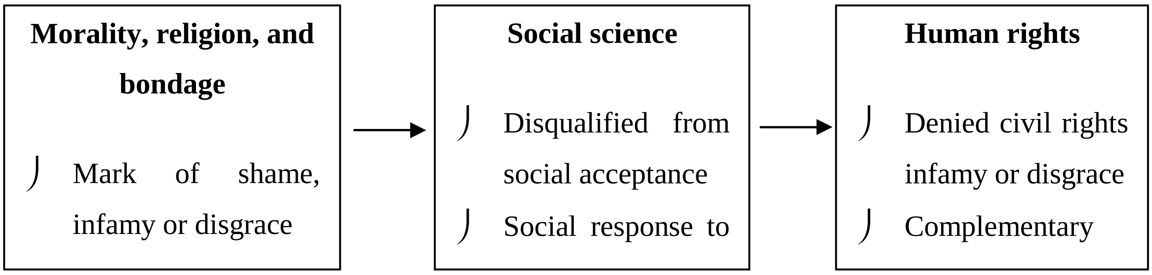


Fig. 2.3: Alternative Formulations of Social Stigma

Source: Weiss (2008)

Erving Goffman's work 'Notes on the Management of Spoiled Identity', (1963) elaborates the stigma as "An attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted and discounted one". He also coined the term ‘Courtesy Stigma’ which means the extension of a person’s stigma to people who are related through the social structure (such as saying leper’s son/daughter etc.).

Health related stigma has also led to the recognition of the synergistic relationship between stigma and other social factors such as poverty which increases vulnerability to disease (Darly and Virginina, 2006).

‘Sartorius Model’ (2004) of stigma is elaborated in cyclical process as follow.

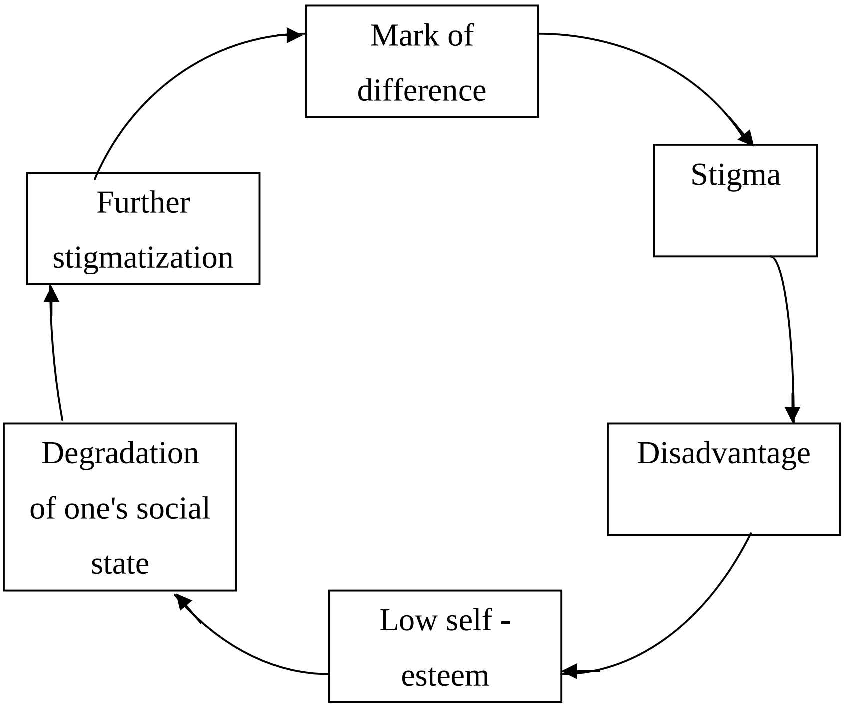


Fig. 2.4: Sartorius Model of Stigma

Source: Weiss (2008)

This model characterized stigma is an outcome of cyclic process in which a mark of difference that progresses forward stigma, disadvantage, low self-esteem to the degradation of one's social state which ultimately leads to further stigmatization. Stigma is a social process that exists when elements of labeling, stereotyping, separation, status loss and occur in a power situation that allows them.

General Categories of Stigma

1. Enacted stigma - Openly seen & enforced by others.
2. Perceived stigma - In view of patients (Shame, Secrecy)
3. Self Stigma - Felt by others and fear of discrimination

Heijnder’s study (2006) in Nepal considers two stages of stigmatization. He mentions stigma fosters the psychological morbidity, reduces the community interaction and delays the treatment seeking practice and increases the non-compliance.

1. Concealment phase (a stage when no visible deformities/disabilities appear)
2. Exposure Phase (a stage when clear deformities/disabilities appear)

W.H. Van Brakel (2006) put forward the following arenas of stigma.

1. Impact on the affected.
    i. Actual discrimination
    ii. Participation restriction
    iii. Self-esteem
2. Perceived stigma (fear of stigma by the patient)
3. Practices in health and social services (by institutional setting).
4. Legislation (excluding from opportunities).
5. Images of the affected in the media and the public domain.

Other Categories of Stigma

- Instrumental Stigma

Material advantages and disadvantages caused by the relationship between the discriminator and the sufferer. Leprosy patients may get low wage than the others and they may not be selected for institutional setting due to risk of infection.

- Symbolic Stigma

Saying poor, drunker, labeling as inferior, avoided by former friends, forced sleep/eat separately, treatment with isolation, becoming the subject of gossip or back-biting, marriage problem, forced divorce are included in this category.

In Hindu culture, where there is no strong concept of 'Self' an individual’s role is ritually and physically dependent on the bonds that exist within the close-knit, extended family, and the community from which the family draws his identity may have profound effect of stigma.

The phenomenon of 'Stigma' is also the product of social interaction which can better be understood by the tenets of social constructionist and social constructivist. In 'The Social Construction of Reality' (1967), Peter L. Berger and Thomas Luckmann argue that "All knowledge including the most basic are taken for granted common sense knowledge of everyday reality and is derived from and maintained by social interactions".

HIV/AIDS, mental illness, epilepsy, physical disability, TB, Buruli ulcer are other socially stigmatized diseases as like leprosy.

2.1.3 Labeling Theory

This theory concerns about deviant roles, stigmatic roles, or social stigma. It concerns with how the self-identity and behavior of individuals may be determined or influenced by the terms used to describe or classify them and is associated with the concept of a self-fulfilling prophecy and stereotyping. Society uses the stigmatic label to justify its condemnation but the deviant actor uses it to justify his actions.

Emile Durkheim’s work ’Suicide’ (1892) was the origin of this theory. He wrote that crime is not so much a violation of a penal code as it is an act that outrage society.

George Herbert Mead (1934) wrote that the 'Self' is socially constructed and reconstructed through the interaction which each person has with the community. This ‘Self’ determines one own position in social hierarchies.

In Frank Tannenbaum’s work ’Crime and Community' (1938), he used the concept of 'Tagging'. A negative 'Tag' or 'Label' often contributed to further involvement in delinquent activities.

Sociologist Edwin Lemert (1951) introduced the concept of 'Secondary Deviance'. According to him, the ‘Primary Deviance’ is the experience connected to the overt behaviour (say drug addiction and its practical demand) and its consequence is ‘Secondary Deviance’ which is the role created to deal with society’s condemnation of the behavior (e.g. shouting or scolding to them who try to stigmatize to him/her).

Labeling theory is closely related to social interaction and social construction theories. Labeling theory was developed by sociologists during the 1960s. Howard Saul Becker's books entitled 'Outsiders' (1963) was extremely influenced in the development of this theory and its rise to popularity.

In ‘Colonizer and the Colonized’ (1965), Albert Memmi describes the longer the oppression lasts, the more profoundly it affects the oppressed. It ends by becoming so familiar to him that he believes it is part of his own constitution, that he accepts it and could not image in his recovery from it.

David Matza elaborates the role of stigmatizer to create and impose the ‘Stigma’ upon the stigmatized. "To be cast as a thief, as a prostitute, or more generally, a deviant, is to further compound and hasten the process of becoming that very thing…. .In shocked discovery, the subject now concretely understands that there are serious people who really go around building his/her life around these activities... Stopping him/her, correcting him/her and devoted to him/her" (Matza, 1969).

Somebody may label it to the disease of poor, uneducated and powerless which further enhances the burden of stigmata. Lack of spoke persons, hurting by words such as 'leper', survival of biblical image are other causes of stigma (Waxler, 1981).

In 'Modified Labeling Theory' Bruce Link (1997) explains about the expectations of labeling can have a large negative effect that these expectations often cause patients to withdraw from society. Study of patients discharged from a mental hospital showed that stigma was a powerful and persistent force in their lives and those experiences of social rejection were a persistent source of social stress.

2.1.4 Suffering

'Suffering' refers to physical pain in narrow sense and mental or emotional pain in broad sense. This term can have similar meanings such as 'distress', 'sorrow', 'misery', 'unhappiness', 'affliction', 'woe', 'ill', 'discomfort', 'displeasure' etc.

Hinduism holds the notion that ‘Suffering’ follows naturally from personally negative behaviours in one's current life or in a past life. i.e. *'Karma'*. Buddhism considers liberation from ‘Suffering’ and the practice of compassion *(Karuna)* as basic for leading a holy life and attaining *'nirvana'*.

According to Arthur Kleinman (2003), social suffering is that "collective and individual human problems associated with life conditions shaped by powerful social forces". Suffering is the state of severe distress associated with events that threaten the intactness of the person (Eric Cassell, n.d.). Social suffering is the outcome of structural inequalities and power relations (Bourdieu, 2003).

Because of insensitive hands and feet, leprosy patients do heavy manual work eventually dysfunctioning these. Rejecting agro-product loses their income opportunity. Its chronic nature and mutilation of body parts becomes the burden to family members who are living at the bottom of poverty line. Persons affected by leprosy may experience unsympathetic reactions, insults, hate and rejection from society. Wrong perceptions about the leprosy may lead to divorce. The stigmatization in leprosy may frequently extend to the families having members suffering from leprosy.

It is also said that the image of leprosy patient presented to the public by donor agencies exploits them (donation at the cost of tear). The policy of segregation and faith on religious beliefs may have positive as well as negative consequences.

2.2 Review of Previous Studies

2.2.1 History of Leprosy

Leprosy is a disease as old as our knowledge of past. It is considered the oldest disease known to us. The earliest surviving excavated written material named 'Sushruta Samhita in Kashi, India before 600 B.C. has mentioned this disease. An excavated skeleton from a site Balathal, Rajasthan, in 2009 proved its presence before 4000 years. It has mentioned in Hindu literature 'Swasthani Brata Katha' as a result of divine curse.

Antiquity of leprosy in India and China goes as far back as 4000 B.C. A bamboo slip excavated in 1975 A.D. in China mentions the presence of leprosy around third century B.C and was called Li. One of the oldest leprosy-skeleton (1-50 AD) has found in Jerusalem. Leprosy was found in Sumerians, Babylonians and Mesopotamians during third millennium B.C. (Wilson, 1966). In Egyptian old Kingdom the term, 'Ukeda' synonymously used as leprosy around (Ca. 2700-2400 B.C.).

In pre-Buddhist Period, this disease was found to princess Priya (daughter of king Okak) and king Ram from Banaras. They met in forest of Eastern Nepal, did self treatment and marry. Their descendants are known as *Koliya* community today (Amritananda, n.d.).

In ancient Greece, it was known as *elephantiasis graecorum*. Blood was used for treatment either as beverage or a bath. Blood of virgin and children was considered to be especially potent. In China, people were murdered for their blood.

It had the dreaded history of stigmatization in the past such as forced segregation in Japan, Pointing gun to ‘Lepers’ in Medevial Europe to expel from society and thousands of leprosarium in India are some examples. In middle ages, 19000 Leprosaria were across the Europe and first 'Leper colony' was in Harble down.

Leprosy has mentioned in Hindu Atharva Veda. The Surgeon *Sushruta* lived in the Indian city of Kashi by the 6th century B.C. and he had started the treatment of this disease. In Hebrew Bible the word, *sara' at* was akin leprosy.

In a Legend king of Burma ate chaulmoogra fruit for the leprosy treatment. Some used injections of chaulmoogra oil which was very painful. Similarly, use of Cobra Venom, Bee Stings, Scorpions, frogs and excreta of Anabas were used in past for the treatment of leprosy.

Different medicines such as Promin was started to use in 1940s, Dapsone in 1950s Clofazimine in 1960s and Rifampicinin in 1970s. In 1940's use of Sulphone made a revolution in its treatment. In 1960, Charles Shepard (U.S.A.) grew the organism in the footpads of mice. In 1982, use of MDT (Multi Drug Therapy, Dapsone, Rifampicine and Clofazimine together) made another revolution.

Since 1995, leprosy patients in all countries have had access to free drug treatments, first through a donation by the Nippon Foundation and since 2000 through the Novartis Foundation for Sustainable Development. This highly effective MDT has contributed greatly to the success of bringing down the rates of leprosy infection around the world.

In Nepal, Leprosy Control Program was started in 1966, when it was estimated that there were 100,000 cases, MDT was introduced in 1982 and by 1996 it was expanded to all 75 districts.

Angola, Bangladesh, Brazil, China, D.R. of Congo, India, Ethiopia, Indonesia, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, Sri Lanka, Sudan, U. R. of Tanzania are the top seventeen countries where leprosy is endemic (2010, ILEP).

According to the 2010 WHO Weekly Epidemiological Record, a total to 2,27,849 new cases were identified worldwide, of those roughly half i.e. 133,717 were diagnosed in India. In Nepal, 80 percent of the leprosy patients are from Terai districts (READ Nepal, 2010).

According to official reports received during 2011 from 130 countries, the global registered prevalence of leprosy at the beginning of 2011 was 1,92,246 cases, while the number of new cases detected during 2010 was 2,28,474 (excluding the small number of cases in Europe) (ILEP). India, Brazil and Nepal have the serious concerns about leprosy. Today 90 percent of cases are found in India, Brazil, Nepal, Madagascar, Mozambique and Myanmar.

According to official reports, received from 105 countries and territories, the global registered prevalence of leprosy at the beginning of 2012 was 1,81,941 cases. The number of cases detected in 2011 was 2,19,075 compared with 2,28,474 in 2010 (WHO Fact Sheet No.101, Sept. 2012).

In 1985, in 122 countries Leprosy was endemic, in 1997 the number of leprosy patients reduced to less than 1 million and in 2005, 108 countries had less than 1 case per 10,000.

In 1991, World health assembly (WHA) passed a resolution to eliminate leprosy as a public health problem by the year 2000. Over the past 20 years, more than 14 million leprosy patients have been cured and about 4 million since 2000. Following data illustrates the facts of leprosy.

Table 2.1 Treatment Records of Leprosy

Years	Numbers of Patients
1985	5.2 million
1995	8,050,000
End of 1999	753,000
End of 2008	213,036

Source: ILEP (2012).

2.2.2 Schema

A study carried out by Rosalijn Both and et al. (2006) in Ethiopia found that "a blow from the devil, adultery by moonlight, intercourse during menstruation, spirit possession and heredity were the personalistic causes. Perceptions such as due to sun stroke, playing with mud and dirty water were the naturalistic causes of leprosy. They used to blame over non-Amhara people (*Buda*) who were landless tenants. In past, a strong concept about heredity of this disease was proved because they used to say "A leper is not born except from a leper". Even though, Ethiopian people had strong belief on Biblical ideas about leprosy, they were more sympathetic towards leprosy patients. Suffering from illness in general as well as those who help to leprosy patients was also thought to be rewarded in other world. Use of holy water (*tsebel)* in Amharic), tying leaves around arms, cutting skin and painting it, visiting to witch doctors were the traditional treatment".

In a study in the Kaduna State Nigeria, Muslim patients believed that leprosy is God's will, while Christians perceived it as a punishment of their sins. Nigerian people consider the disease is curable if deformities disappeared. Deformities and ulcers were considered highly infectious. They had the concept of heredity, witchcraft and breaking of taboos as possible causes of leprosy. Men discontinued sexual intercourse with their sick partners. Integration program failed in Nigeria in 1990 (Varkevisser, 2009).

Researches on stigmatized diseases such as HIV/AIDS (D.K. Baine, 2003), TB (Baral et al., 2007), Epilepsy (Rajbhandari, 2003) have been conducted in the context of Nepal relating with cultural schema, participation restriction and suffering.

Eastern Nepalese Communities held the belief that leprosy is contagious (64%), due to curse from God (9%) and due to both (18%) (de Stigter et al., 2000).

Most of the women patients interviewed in Achham district had visited a Dhami first. For women the biggest fear concerned the domestic group, their spouse and in-laws. Three quarters of the Nepalese patients resented their discharge fearing the return of the disease (Varkevisser, 2004).

A study carried out in Dhanusha district revealed that majority (73.7%) of non-compliance cases were illiterate, laborers by occupation and from poor economic class and (94.7 %) were having strong belief that the disappearance of sign/ symptoms has the only meaning of the cure of leprosy disease (as in Chalise, 2005).

A study was carried out by Marilyn K. N. and et al. in Southeast Brazil and found that leprosy was termed as ’Rat’s Disease’, 'Racist Skin Rash', 'Result of Biblical Curse' and 'Lethal Leukemia' (Marilyn, 2009).

2.2.3 Stigma

There are cases mentioned by William Jopling (1991) such as a shoulder discharged from British Army, people committed suicide, carelessness of doctor etc. Similarly, he wrote a case of explosion and murder in Kumamoto, Japan in 1951, the accused was a patient named Matsuo Fujimoto with leprosy. During the questioning and trial procedures, he received discrimination because he was a leprosy patient. He was executed in 1961.

In America in 1941, a blind patient, Stanley Stein, started the ‘Star’ a crusading international magazine against leprosy stigma. It remained till 60 years. From the 1920's to the late 1950's, citizens with leprosy were forcibly transported to Carville, America’s last leprosarium. They were abandoned by family and friend, stripped of their constitutional rights to vote, to get married and even to use the telephone (Anderson and Harrison, 1999).

Even today, social stigmatization is frequent so that leprosy affected persons with clear signs of chronic manifestations are often unable to work or to marry, they become dependent for care and financial support leading to insecurity, shame, isolation and consequent economic loss (British Leprosy Relief Association, 1999).

In Japan, in 1953 laws were passed allowing forced hospitalization of those with leprosy. This was abolished only in 1996. Japanese Leprosy patients received the compensation after winning their case against government’s discrimination.

Reservations were rejected by a hotel because of leprosy stigma in Kumamoto on Nov. 18, 2003 and many people protested against the hotel (Mc Curry, 2004).

In Brazil patients are more likely to be admitted to general hospital, which may be less stigmatizing than admission in a leprosy referral hospital (Nicholls. et. al. 2005).

People with leprosy suffer from losing employment, were expelled from housing, not accepted to reside with other in an institutional setting i.e. Jail (Brakel, 2006).

In India, longer the duration of disease, greater was the likelihood of restriction. The participation restriction was found to be negatively correlated with the education. (Armed Forces of Medical College, Pune, India, 2009).

R.M., Sijabat (2009), writes in Jakarta post (Indonesia) about the various discriminations to leprosy patients.

- A child left his school and stopped to play with his peer groups.
- A leprosy patient stole motorbike for the sake of money needed to purchase medicine and he was caught and beaten.

The effects on the affected individual include psychological stress and depression, fear, various participation restrictions and increased (risk of) disability and advanced disease. Roughly a quarter of a million new patients are diagnosed each year around the globe, but many more do not seek treatment early enough because of the terrible social stigma (leprosy news, 2010).

A study carried out by P.G. Nicholls et al. (2005) in Brazil, India and Nepal regarding risk factors of participation restriction found that "visibility was an important issue in India whereas lack of education, female gender and losing status within the family is prominent in Brazil".

Stigma affects not only patients but also families, groups, communities and even nations, as illustrated by the nationwide panic and a near international isolation of India" that followed alleged to be plague in Surat (Ramlingaswami, 2001).

A study in North-India showed 49 percent of the mothers with leprosy stopped breast feeding to their children (Tiwari, 2000). In Ethiopia, Leprosy patients delay their diagnosis due to discrimination (Bekri et al., 1998). Higher deformity is found in patients of Myanmar.

There are cases mentioned by William Jopling (1991) such as a shoulder discharged from British Army, people committed suicide, carelessness of doctor etc.

In Nepal, the situation of stigmatized disease such as ‘Mental Health’ is explained in the paper of Tausing and Subedi. “Modern mental health system has been established in Nepal but it is clearly inadequate to meet mental health need of the population which also not been clearly identified" (Tausing and Subedi, 1997).

Two studies were conducted by FHI in 2004 concerning with stigma and discrimination with HIV/AIDS taking respondents from Kathmandu, Patan, Makwanpur and Nawalparasi. The findings were those with HIV/AIDS were kept separately, facing physical and social restriction, fear of losing honor, separation and loss of contact with a family.

Stigma and marginalization seem to interfere with doctors and others health professionals' decisions to voluntarily treat persons who they perceive to be at high risk for HIV infections. Doctors and other health professionals appear suspicious, even unaware, of contemporary biomedical knowledge as it relates to HIV… ….Doctor was trying to squeeze his wound with bare hands ... I [said], "Please don't do that with open hands. Wear gloves." He asked me, "Why do you pretend knowing more?" I [said], "It's not a matter of knowing more .... he is HIV positive. If you have a wound in your hand, it might transmit [to] you too." The doctor said, "Why didn't you tell me before that he got AIDS? Do this dressing yourself." He threw medicines at me (Jha, and Madison, 2004).

De Stigter et al. (2000) conducted a research in eastern Nepal and found that people with leprosy were often ostracized by their communications, reporting insults, rejection, hate and the non-compliance rate for the leprosy control program is greater than 40 percent (as in Rafferty, 2005).

A study carried out in Achham district, Nepal showed strong traditions, the low status of women, their limited mobility, illiteracy and poor knowledge of leprosy appeared to be important socio-cultural factors explaining why women were under reported (Burathoki et al., 2008).

A study conducted by Ramchandra C. K. (2011) in Epilepsy found that "more than two-thirds (67%) of patients mentioned that they had not disclosed their condition to the community, suggesting an anticipation of stigma. However, the majority of patients (86%) mentioned that they had disclosed their condition to their family and many (64%) acknowledged support from their spouse".

2.2.4 Suffering

Leprosy is the only bacterial disease to be characterized by the invasion of peripheral nerves. This invasion and subsequent damage leads to peripheral neuropathy if treatment is delayed (Srinivason, 1990).

Many patients are affected mentally, not because of the disease, but because of society's rejection of them. One third of black patients studied in South Africa were found to have contemplated suicide after their diagnosis of leprosy. Similarly, one-third of the leprosy patients were left by their spouses. In this study, he summarizes the narration of one patient. "We can endure losing fingers and toes, eyes and nose but what we cannot endure is to be rejected by those nearest and dearest" (James Scott, 2000).

Kaur and Van Brakel (2002) in their study of leprosy affected beggars in India, point out that the combination of leprosy, physical impairments and social stigma leads to dehabilitation of the leprosy affected person which ends with the person becoming a beggar. In Rio de Janerio, Brazil about one quarter (25%) of the married women reported abandonment or divorce compared with 10 percent of men (Varkevisser, 2004).

Barrett's Study in North India (2005), proposed a concept of 'Self Mortification' which arises due to the cyclic relation of social discrimination to isolation leading to further impairment because of lack of treatment.

Stigma affects marriage, interpersonal relationships, mobility, employment, access to treatment and care, education, leisure activities and attendance at social and religious functions (Brakel, 2006).

In Ethiopia, members of community, family, and peers are the agents who stigmatize to leprosy patients. Diagnosis of leprosy was one of the strong causes of divorce. Many men left their spouse without any care. Feeling of hesitation to serve food, travel restriction and selected number of friends are the result of self-images. Still now low number of children per woman (patient) proves the correlation with fear of contagion among spouses (Rosalijn, 2006).

People suffered with skin lesion often hide their skin from other in Uganda. A respondent says “They are hiding their skin so that people cannot see them, I have not heard of anyone who wants others to know about it. No one will allow them to lead, and many people ignore them. They are considered dangerous and people fear to contact with them. I feel sorry for them. Even me, I feared that from staying, meeting with them and we could get the disease. They find it hard to marry and marriages can break because of this condition" (Weiss, 2008). Cases of relapse are also common in leprosy. Fifty nine percent of patients had positive slit skin smears on relapse (Shetty, 2011).

Despite having been diagnosed and receiving treatment, only 48% of adult cases knew their condition as leprosy, reflecting their poor knowledge of the disease and lack of communication between health service providers and patients. The symptom 'patch on the skin' seems to have percolated in the community. Despite approaching the private or public sector for help in the first instance, many patients and children remained undiagnosed and untreated for leprosy (Sachin, 2011).

2.2.5 Possible Causes of Stigma to Leprosy

Visibility, progressive nature, mystery of causes, fear of contagion and religious associations, stigmatizing attitudes in (community, media, health, and social services), the educational system and legislation may be the causes of leprosy stigma. Public attitudes, discriminatory practices, participation restrictions, perceived (felt) stigma, self (internalized) stigma may be the components of social stigma.

In medieval Europe, the climate of stigma to leprosy was in climax. Leprosy patients had to wear shroud dresses and were forbidden to enter churches, markets and other assemblies. The leper would carry a clapper and bell to warn of his approach, and this was as much to attract attention for charity.

In Old Testament, the story ‘God’ gave the punishment to Miriam and suffered from leprosy was the symbol of high stigma. In New Testament, “He ate at the home of Simon the leper…ordered his follower "Heal the sick and cleanse the leper" showed that the thought towards leprosy had changed. In Judeo-Christian era, we had the history that saints were kissing their wounds at least to relief their pain.

In ancient India, those with HD were ostracized and forbidden to have contact with others or to marry. They would punished by the law of Manu Circa (1800 B.C.). Suicide was a sin in Hinduism. However, it was not for those with leprosy.

In hay days of Christianity, Jews were constantly warned not to associate with the other people of Canaan or defiled persons. Concept of physical contagion, moral or cultural threats and ritual inferiority were strong. At that time, becoming beggars, forbidden by society, to work in manic jobs, depend on charity and waiting for gifts outside the worshipping places were serious issues in case of disables.

Stigma exists when a person is identified by a label that sets the person apart and links the person to undesirable stereotypes that result in unfair treatment and discrimination (Link and Phelan, 2002). The consequences of stigma often manifest in the form of participation restrictions (WHO, 2001).

CHAPTER III

RESEARCH METHODS AND MATERIALS

This chapter contains the brief explanation of research methods employed in this study. This includes location of study area, rationale of the study area, research design, sampling design, data collection techniques and modes of data analysis.

3.1 Rationale of the Selection of Study Area

The locations of this study were Green Pasture Hospital and Rehabilitation Centre, Pokhara, Lamtara rehabilitation village and Tutunga Camp. Green Pasture Hospital and Rehabilitation Centre lies on the outskirts of Pokhara sub-metropolitan-15. Lamtara rehabilitation village lies on Ritthepani-2, Lekhnath, and Tutunga Camp lies on NayaGaun, Pokhara sub-metropolitan-15. In addition to this, some respondents (non-patients) were taken from neighboring communities of ‘Lamtara’ rehabilitation village. Lamtara Village and Tutunga Camp were established in 2047 B. S. and 2049 respectively. Green Pastures Hospital was established in 1957 by the International Nepal Fellowship (INF).

In this study, it was thought that cultural schema (lay man's perception) can be elicited from non- patients and at the same time it could reflect the level of enacted stigma (stigma imposed by outsiders). It was also thought that these respondents were familiar to leprosy patients in some sort or had been workmate in some cases. Therefore, locality of respondents for cultural schema was neighboring community of 'Lamtara' village and 'Tutunga' camp which was selected purposively.

For participation restriction, it was supposed that people with different life conditions may have different experiences about leprosy. Therefore, they were taken from three places i.e. from GPH, 'Lamtara' village and 'Tutunga' camp. GPH is one of the oldest treatment centers in western Nepal where many referred patients are being treated. Patients arriving here may serve as good sample for study which encompasses the large territory. Former patients who were living in 'Lamtata' village were selected for the sake of their lifelong experiences where it could be noted change in their experiences if any. Similarly, patients from 'Tutunga Camp' were selected for the sake of experiences of those who were more disabled and remaining single.

3.2 Research Design

This study was carried out both qualitatively and quantitatively. This study was carried out under the exploratory research design and descriptive analysis. Cultural schema about leprosy may differ from place to place. For this, exploratory research design was selected. Stigma was measured quantitatively by using a standard scale (P-scale). Social suffering could best be understood with their life history rather than quantitative method. Therefore, descriptive method was used.

3.3 Nature and Sources of Data

Most of the data gathered were first hand, based on answers of pre-established semi-structured interview schedules. For cultural schema, opinions were collected in different headings and converted into tabular form. So, the data for cultural schema were quantitative. For participation restriction, a scale (P-Scale) was launched and the data were in quantitative form. For suffering, their life-long experiences were collected and the data were in qualitative form. Secondary data were collected from national and international journals published from different institutions working in the field of leprosy.

3.4 Data Collection Technique

For cultural schemas, opinions were collected by using a semi-structured interview schedule for 55 respondents (non-patients). For stigma, P-scale was launched for 25 respondents (patients). For suffering, in-depth interview were carried out to 20 respondents (patients) by using a checklist.

3.4.1 Interview Schedule

In this, 16 questions such as knowledge of leprosy, respondents' attitudes towards leprosy patients, and participation restriction to leprosy patients were included. Some of the questions were open-ended which were set for the sake of wide range of knowledge.

3.4.2 P-Scale

P-Scale is a set of 18 standard questions which was made and used by W.H. Van Brakel (2006) in Nepal, India, and Brazil. It was supposed as a high validity tool in the field of measuring social stigma. Different scores (1, 2, 3, 5) were given on the basis of answer provided by the respondents. The lower limit and upper limit of scores of participation restriction were 0 and 90 for each respondent. Following categories were proposed for the study of stigma for each individual.

Note: categories of scale

0-12 - Insignificant
13-22 - Minor
23-32 - Medium
33-52 - Serious
53-90 - Extremely high

3.5 Sampling Design

3.5.1 Sample Population

The population of the study was from three different places.

- The residents of Ritthepani-2, Lekhnath, and NayaGaun- Pokhara-15, (neighbors of Lamtara rehabilitation community and ‘Tutunga camp’ (around 200 households).
- Rehabilitated former leprosy patients from Lamtara rehabilitation community (13), from Tutunga camp (8).
- Whole admitted patients (50) of Green pasture Hospital and Rehabilitation centre.

3.5.2 Sample Size

The whole sample size was of 80 respondents. They were of three groups.

- Fifty five respondents (non-patients) were chosen for the opinion of cultural schema on the basis of availability. However, number of (male and female) and age groups were made more or less equal.
- Twenty five respondents (twenty patients also selected for life history and five others) were asked for participation restriction. It was thought that level of stigma/restriction can be measured from patients (victims).
- To draw different kinds of experiences about suffering, twenty respondents were selected from three different life conditions i.e. those who were rehabilitated in a Lamtara village (n=5), kept in Tutunga Camp (n=5) and admitted in hospital (n=10).

To study the Schemas, Stigma and Suffering related with leprosy, researcher had considered two generations.

- Respondents of the age <40 years were considered as new generation, who might have impact of some sort of education, awareness and modern technology (media etc.).
- Respondents >40 years were considered as old generation who might have little effect of awareness and might have different understanding.

3.6 Modes of Data Analysis

For cultural schema, analysis of data from semi-structured interview schedule was done in tabular form. For participation restriction, analysis of P-Scale was done. For social suffering conclusions were drawn from narrative information. Answers were converted into quantitative data if any in qualitative form. Raw data were processed manually using tally bar and converted into frequency table. Tabulated data were handled manually. Use of Percentage and Pie-chart were used for the demonstration of data. Qualitative data were managed descriptively. Unit of analysis was in individual level.

CHAPTER IV

CULTURAL SCHEMA OF LEPROSY

This chapter deals with the 'Cultural Schemas' about leprosy from the respondents who were from community i.e. non-patients. Perception of community people was supposed as the major factor of stigma generation in the study.

4.1 Respondent's Background

Respondents for cultural schema were taken from the neighboring community of 'Lamtara' rehabilitation village, Ritthepani-2, Lekhnath and Tutunga rehabilitation centre, Pokhara-15. They were mostly from ethnic groups such as Kumal, Newar, Gurung, Tamang etc. Number of male/female and two age groups were made more or less equal.

4.1.1 Gender and Age Background

In this study, cultural schema about leprosy of neighboring community of rehabilitation village and center was tried to understand. Respondents' (non-patients) attitudes towards leprosy patients were also the matter of study.

Cultural schema may differ for males and females because of their biological attitudes. Similarly it may be influenced by their age also. Respondents in younger age may expose to media, education etc. and have acquired different knowledge than old age.

Table 4.1: Percentage Distribution of Respondents by Gender and Age

Gender	Age Group						Grand Total	
	< 40 years			< 40 years				
	N	**%**	**Total %**	**N**	**%**	**Total %**	**N**	**%**
Men	15	60	27.27	17	56.66	30.90	32	58.18
Women	10	40	18.18	13	43.34	23.6	23	41.81
Total	**25**	**100.00**	**45.45**	**30**	**100.00**	**54.55**	**55**	**100.00**

Source: Field Survey, 2012.

Numbers of males (58.18%) were slightly higher than numbers of females (41.81%). Regarding to age group, respondents from old generation were (54.55%) and from new generation were (45.45%). So, number of males/females and younger/older respondents were made more or less similar.

4.1.2 Religious Background

In any society, people may indoctrinate by their religious values. Their perceptions to any disease may also be influenced by how they explain it from religious point of view. Stigma associated with leprosy was supposed as the result of its religious explanation in past.

Table 4.2: Percentage Distribution of Respondents by Religion

Types of Religion	Number	Percentage
Hindu	43	78.18
Buddhist	10	18.18
Christian	2	3.63
Total	**55**	**100.00**

Source: Field Survey, 2012.

Majority of respondents were Hindus (78.18%). The schema obtained from data represent Hindu notion of leprosy. Hindu considers the leprosy as the result of misdeeds in past life and concept of purity and pollution. This may be studied from the sample. Therefore, the data obtained from the study may not applicable for the ideas of Christians and Muslims.

4.1.3 Caste/Ethnicity Background

Type of caste in any society may determine cultural values. People may follow different kinds of perceptions and modes of treatment about any disease according as their cultural values. Therefore, cultural schema to leprosy may differ from caste to caste.

Table 4.3: Percentage Distribution of Respondents by Caste and Ethnicity

Castes	Number	Percentage
Brahmin/Giri/Thakuri	15	27.28
Gurung/Magar/Gharti	14	25.45
Kumal	9	16.36
Tamang	5	09.10
Newar	2	3.63
Kami/Sarki/Damai/Gandarva	10	18.18
Total	**55**	**100.00**

Source: Field Survey, 2012.

Respondents were taken from various castes. They were mostly from Janjati groups such as Kumal, Newar, Gurung, Tamang etc. In this study, respondents of so called high profiled castes, ethnic groups and scheduled castes were included. So, cultural schema may represent common ideas of these castes only.

4.2 Analysis of Schema

4.2.1 Source of Knowledge for Leprosy

Source of knowledge about leprosy may be a factor for cultural schema. Cultural schema about leprosy may differ whether the respondents is familiar with leprosy patient or not. This may be different whether they have accesses to media or not. All the tabulations in this section are categorized on the basis of generation also (<40 years and >40 years).

Table 4.4: Percentage Distribution of Respondents by Source of Knowledge

Source of Knowledge	**Age Group**				**Total**	
	<40years		**>40years**			
	N	**%**	**N**	**%**	**N**	**%**
Neighboring Community	14	56.00	17	56.66	31	56.36
Outside their Community	05	20.00	10	33.33	15	27.27
From Media	02	8.00	01	3.33	03	5.45
Total (Known)	**21**	**84.00**	**28**	**93.34**	**49**	**89.09**
Unknown	04	16.00	02	6.66	06	10.9
Grand Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Most of the respondents (89.09%) were familiar with leprosy**.** Leprosy being a rare disease around the study area, respondents from new generation was less familiar with leprosy patients. In old generation, they knew about leprosy when they saw leprosy patients in their former villages, outside their communities or in some cases in India also. Some had known about leprosy from media. Therefore, the schema obtained from the study can be interpretive for familiar respondents.

4.2.2 Prevalence of Leprosy Around the Community

Prevalence of leprosy around the periphery of study area may change their perceptions. Cultural schema of respondent who has interacted (living together/ being work mates etc.) with leprosy patient may differ to those who have heard about the disease only.

Table 4.5: Percentage Distribution of Respondents by Prevalence of Leprosy

Types of respondents	**Age group**				**Total**	
	<40years		**>40years**			
	N	**%**	**N**	**%**	**N**	**%**
Relatives not afflicted	23	92.00	22	73.33	45	81.81
Relatives afflicted	02	8.00	08	26.66	10	18.18
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Respondents hardly mentioned about their relatives who had contracted with leprosy. Only few (18.18%) had explained about this. This shows that leprosy is a rare disease around the periphery of Pokhara. Most of the respondents were neighbors of leprosy patients only.

4.2.3 Causes of Leprosy

Perception about the cause of leprosy is an important aspect of cultural schema. People may select the mode of treatment on the basis of their knowledge about it. For example, if they believe upon divine curse, they will worship their deities first before going to medical. If they perceive it as the result of personalistic cause it may develop more stigmata whereas if they believe upon naturalistic cause it may reduce stigmata.

Table 4.6: Percentage Distribution of Respondents by Causes of Leprosy

Causes of diseases	Age groups				Total	
	<40years		>40years			
	N	%	N	%	N	%
Poor blood	4	16.00	10	33.33	14	25.45
Water	5	20.00	3	10.00	8	14.54
Germ	2	8.00	3	10.00	5	9.09
By Person	1	4.00	1	3.33	3	5.45
Divine curse	1	4.00	1	3.33	2	3.63
Missing vaccination	0	0	2	6.66	2	3.63
By infection	2	8.00	1	3.33	2	3.63
Malnutrition	1	4.00	0	0	1	1.81
Unknown	9	36.00	9	30.00	18	32.72
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Respondents had different opinions about the causes of leprosy. Since large number of respondents (32.72%) couldn’t say about the cause of leprosy it shows that they were unfamiliar with leprosy or low level of awareness. Poor blood was considered as a cause of leprosy by (25.45 %) of respondents and it shows that community people blame over patients rather than microbes. Leprosy used to consider as a result of divine curse strongly in past but this concept was being so weak that only (3.63%) of respondents were in this category. Germ theory was weakly described by (9.09%) which shows very weak level of awareness. (14.54%) of respondents said leprosy appears due to water and they thought leprosy is communicable as other skin disease. Other concepts such as rise of leprosy by infection of wounds, missing vaccination, evil eyes, malnutrition were insignificant in the study.

4.2.4 Transmission of Leprosy

Leprosy became a highly stigmatized disease in past because people had the fear of contraction from leprosy patient. Some of the people still fear from ex-patients who were medically certified for stopping medicine. Knowledge of respondents about the transmission of leprosy can reveal the level of stigma also.

Table 4.7: Percentage Distribution of Respondents by Transmission

Transmission modes	Age groups				Total	
	<40years		>40years			
	N	%	N	%	N	%
Communicable	6	24.00	8	26.66	14	25.45
Non-communicable	14	56.00	17	56.66	31	56.36
Categorized	1	4.00	4	13.33	5	9.09
Unknown	4	16.00	1	3.33	5	9.09
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

About the transmission of leprosy, respondents had categorized it. They had explained mainly two broad classes such as red *(Rato)* leprosy and black *(Kalo)* leprosy, swelling one (*Fuluwa)* and mutilated one (*Jharuwa)*. They thought black leprosy was more dangerous than red one. Similarly swelling one was more communicable than mutilated one. Most of the respondents (56.36%) thought that leprosy is non-communicable disease. This view came strongly from new generation i.e. by (56%). Few of the respondents (25.45%) had said it as the communicable disease. Their concepts such as *Rato Leprosy* and *Fuluwa Leprosy* were related with preliminary stage and *Kalo Leprosy* and *Jharuwa Leprosy* were related with last stage of leprosy. Their concepts were set on the basis of severity of disease only.

4.2.5 Inheritance of Leprosy

In past, people used to think leprosy as an inherited disease. They would hesitate to live together, to marry and had fear even to their distance relatives. The reminiscent of this concept may deteriorate social relation and further delay the treatment seeking practices.

Table 4.8: Percentage Distribution of Respondents by Inheritance

Views	Age groups				Total	
	<40years		>40years			
	N	%	N	%	N	%
Inherited	14	56.00	20	66.66	34	61.81
Non-inherited	09	36.00	8	26.66	17	30.90
Unknown	02	8.00	02	6.66	04	7.27
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Leprosy was thought as the inherited disease by most of the respondents (61.81%). This belief was strong in old generation by (66.66%). This concept of inheritance has relation with weakness of blood as the cause of leprosy. It can therefore generate stigma in marital lives. Few of the respondents (30.90%) had mentioned it as the non-inherited disease.

4.2.6 Curability of Leprosy

In past, people used to think leprosy as a kind of non-curable disease. So, it had accompanied by strong stigma. Finding the knowledge of respondents about leprosy whether it is curable or not can give the measure of enacted stigma.

Table 4.9: Percentage Distribution of Respondents by Curability

Treatment	Age groups				Total	
	<40years		>40years			
	N	**%**	**N**	**%**	**N**	**%**
Curable	20	80.00	23	76.66	43	78.18
Non-curable	3	12.00	7	23.33	10	18.18
Unknown	2	8.00	0	0	02	3.63
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Most of the respondents (78.18%) were optimistic about the permanent treatment of leprosy. Most of the respondents (80%) from new generation said this disease is curable. Their thoughts of curability may reduce the fear of disease which was in past.

4.2.7 Transmission through Sexual Intercourse

In past, leprosy patients couldn't marry and most of the marriage prospects used to demolish where leprosy was thought to transmit through sexual intercourse. Finding the knowledge of respondents in this regard, we can speculate negative impact of stigma in marital lives at present.

Table 4.10: Percentage Distribution of Respondents by Sexual Transmission

Views	Age groups				Total	
	<40years		>40years			
	N	**%**	**N**	**%**	**N**	**%**
Can Transmit	5	20.00	13	43.33	18	32.72
Cannot Transmit	16	64.00	10	33.33	26	47.27
Unknown	4	16.00	7	23.33	11	20.00
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Majority of respondents (47.27%) said that leprosy is not transmitted by sexual intercourse. Belief about contraction by sexual intercourse was strong in old generation where (43.33%) reported it. It shows that leprosy patients can marry easily in coming days.

4.2.8 Knowledge about Free Medicine

In Nepal medicines for leprosy are being distributed out of cost. Finding the knowledge about free availability of medicine, we can know the awareness of respondents towards leprosy. Some of the patients may delay their treatment because of economic burden.

Table 4.11: Percentage Distribution of Respondents by Free Medicine

Views	Age groups				Total	
	<40years		>40years			
	N	%	N	%	N	%
Is free	21	84.00	21	70	42	76.36
Not free	2	8.00	3	10	5	9.09
Unknown	2	8.00	6	20	8	14.54
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Most of the respondents (76.36%) were aware of free availability medicine. Respondents who were exposed to media explained about free medicine but from old generation they were almost unknown. It showed that in new generation they had higher level of awareness.

4.2.9 Knowledge about Traditional Medicines

Knowledge about traditional medicines may be a measure of their closeness to leprosy in that locality. Types of medicines which they use may reflect the interpretation of leprosy also.

Table 4.12: Percentage Distribution of Respondents by Traditional Medicines

Knowledge	Age groups				Total	
	<40years		>40years			
	N	%	N	%	N	%
Known	0	0.00	03	10.00	03	94.54
Unknown	25	100.00	27	90.00	52	4.46
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Almost all (94.54%) couldn’t say about traditional treatment. Very few (4.46%) respondents mentioned about the traditional treatment. They mentioned the use of monkey flesh, Bhiringi Jhar, and urine of cow *(gaunt).* All they were from old generation. Respondents being from nearby city and from new generation they were unknown about the traditional treatment of leprosy. This showed that higher prevalence of biomedicine.

4.2.10 Interest to be the Friend of Leprosy Patients

Interest of respondents to be the friend of leprosy patients was thought as the measure of enacted stigma. Isolation from former friends/family members was a matter of serious concern in past.

Table 4.13: Percentage Distribution of Respondents by Interest to be the Friend

Interests	**Age groups**				**Total**	
	<40years		**>40years**			
	N	**%**	**N**	**%**	**N**	**%**
Happy	20	80.00	15	50	35	63.63
Unhappy	3	12.00	7	23.33	10	18.18
Hesitation	2	8.00	8	26.66	10	18.18
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Most of the respondents (63.63%) were happy to be the friend of former leprosy patients. Almost all respondents from new generation i.e. (80%) had this opinion. Some respondents who feel hesitation were from old generation. This was due to impact of media, education. But in old generation, discrimination was not effaced from their cognition. Those who could not reject leprosy patients but had some sort of fear were the borderline respondents (26.66 %) and they were from old generation.

4.2.11 Eating Limitation

Measurement of eating limitation may give the kindness between leprosy patients and community people. It can be supposed that those who were ready to eat together will not stigmatize leprosy patients.

Table 4.14 : Percentage Distribution of Respondents by Eating Limitation

Experiences	**Age groups**				**Total**	
	<40years		**>40 years**			
	N	**%**	**N**	**%**	**N**	**%**
Eating together	18	72.00	7	23.33	25	45.45
Annoying	5	20.00	13	43.33	18	32.72
Hesitation	2	8.00	10	33.33	12	21.81
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Majority of the respondents (54.53%) had eating limitation. Less than half of the respondents (45.45%) were ready to eat together with leprosy patients. To this category most of the respondents (72%) were from new generation. Eating limitation was too strong in old generation, i.e. by (43.33%). Respondents feeling hesitation to eat together with leprosy patients were mostly from old generation, i.e. by (33.33%). We can say that people are not still liberal towards the eating practices.

4.2.12 Similar Diseases to Leprosy

Respondents' view about the similarity of other disease to leprosy may be a clue how they categorize it in hierarchies of seriousness. The level of seriousness may reflect the extent of stigma.

Table 4.15: Percentage Distribution of Respondents by Similar Diseases

Diseases close to leprosy	**Age groups**				**Total**	
	<40years		**>40 years**			
	N	**%**	**N**	**%**	**N**	**%**
Ring worm	10	40.00	5	16.66	15	27.27
Cancer	4	16.00	8	26.66	12	21.81
Progression of infection	2	8.00	5	16.66	7	12.72
Borne internally	2	8.00	3	10	5	9.09
HIV/AIDS	2	8.00	0	0	2	3.63
Unknown	5	20.00	9	30	14	25.45
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Leprosy was thought as a kind of skin disease akin ringworm (*dadh)* by (27.27%) of respondents. This view was strong in new generation i.e. by (40%) and cancer was thought from old generation by (26.66%). Those who could not compare this disease with other diseases were also in substantial number i.e. by (25.45%). It showed that respondents were unfamiliar with symptoms. It was also considered as the secondary disease after the progression of infection by (12.12%). Leprosy was thought incomparable with other diseases by (09.09%). They said, "It appears due to loss of immunity". Very few of the respondents (3.63%) said, it was close to HIV/Diabetes. Those who couldn’t compare with other diseases were from old generation, i.e. by (30%).

4.2.13 Knowledge about Leprosy

Respondents’ knowledge about symptoms of leprosy may be a measurement for their level of awareness. Those who are unaware about symptoms may fear than others.

Table 4.16: Percentage Distribution of Respondents by Symptoms

Awareness	Age groups				Total	
	<40years		>40 years			
	N	%	N	%	N	%
Known	19	76.00	14	46.66	33	60
Unknown	6	24.00	16	53.33	22	40
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Respondents who were aware of symptoms of leprosy and unaware were (60%) and (40%). From new generation (76%) respondents had the knowledge of symptoms. Higher level of knowledge about leprosy was found in new generation. Those who were unaware about the symptoms were mostly from old generation i.e. by (53.33 %).

4.2.14 Ideas on Preventive Measures

Respondents' suggestions about preventive measures may be a measurement of level of awareness as well as their concept of stigma.

Table 4.17: Percentage Distribution of Respondents by Preventive Measures

Measures	Age groups				Total	
	<40years		>40 years			
	N	%	N	%	N	%
No physical contact	9	36.00	7	23.33	16	29.09
Increasing immunity	5	20.00	8	26.66	13	23.63
No sharing of food/cloth	4	16.00	3	10.00	7	12.72
Personal hygiene	5	20.00	2	6.66	7	12.72
Blood/semen	0	0	2	6.66	2	3.63
Unknown	2	8.00	8	26.66	10	18.18
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Large number of respondents (29.09%) suggested no physical contact for preventive measure. Concept about the need of self immunity was strong in old generation by (36.66%). It showed that people want to remain away from leprosy patients and preferred segregated mode of treatment. Nearly one fourth (23.63%) of respondents had suggested enhancement of immunity for preventive measures were. This had relation with the thought that leprosy was inherited. Prohibition to sharing food/cloth was suggested by (12.72%) and personal hygiene by (12.72%) of respondents. It can be said that leprosy was disease of non-cleanliness. Remarkable numbers of respondents (18.18%) were unknown about the preventive measure of leprosy which was the negative signal in leprosy control. Hindu considers purity and pollution which had manifested in the view that physical contact was suggested at most.

4.2.15 Preferences for Mode of Treatment

Respondents' preferences for mode of treatment may be a measurement for their level of stigma. In past, segregated mode of treatment was one of the causes of stigma generation.

Table 4.18: Percentage Distribution of Respondents by Mode of Treatment

Treatment Modes	**Age groups**				**Total**	
	<40years		**>40 years**			
	N	**%**	**N**	**%**	**N**	**%**
Integrated	19	76.00	11	36.66	30	54.54
Segregated	4	16.00	11	36.66	15	27.27
If possible separately	2	8.00	4	13.33	6	10.90
Unknown	0	0.00	4	13.33	4	7.27
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

In past, stigma related with this disease led to follow the segregated practice of treatment but in this era of modernization also treating them in separate hospitals can degrade their dignity. Majority of respondents (54.54%) were happy to accept integrated practice of treatment. Most of them (76 %) were from new generation. Segregated practice of treatment was preferred by (27.27%) respondents. In this group, almost all respondents were from old generation. It showed that new generation want to welcome leprosy patients nearby their beds in hospitals but respondents from old generation fear from them. Few respondents (0.90%) do not fear from leprosy patients but suggest the segregated mode of treatment.

4.2.16 Seriousness of Leprosy

Respondents' view on seriousness of leprosy may give the idea that how community people fear from leprosy and develop different kinds of stigmata.

Table 19: Percentage Distribution of Respondents by Seriousness of Leprosy

Seriousness	**Age groups**				**Total**	
	<40years		**>40years**			
	N	**%**	**N**	**%**	**N**	**%**
Very	7	28.00	23	76.66	30	54.54
Medium	9	36.00	4	13.33	13	23.63
Simple	9	36.00	3	10.0	12	21.81
Total	**25**	**100.00**	**30**	**100.00**	**55**	**100.00**

Source: Field Survey, 2012.

Most of the respondents (54.54%) thought it was very serious disease. Respondents from old generation (76.66%) said this disease was very serious. Prolonged treatment for complete recovery, disability and deformity adhered to this disease made it as very serious disease. This fear was strong in old generation. Most of the respondents from new generation had divided into two groups. They said that leprosy is not so serious and it can be cured in time if we have regular medicine and early diagnosis.

CHAPTER V

PARTICIPATION RESTRICTION OF LEPROSY PATIENTS

This chapter deals with the measurement of participation restriction. In this study, participation restriction was supposed as the major factor for different kinds of suffering faced by leprosy patients. For this, P-Scale was administered to 25 respondents and following categories were taken into consideration.

0-12	- Insignificant
13-22	- Minor
23-32	- Medium
33-52	- Serious
53-90	- Extremely high

5.1 Percentage Distribution of Participation Restriction

Analyzing the whole respondents on the basis of scores they had obtained by using P-Scale may measure the level of stigma upon leprosy patients.

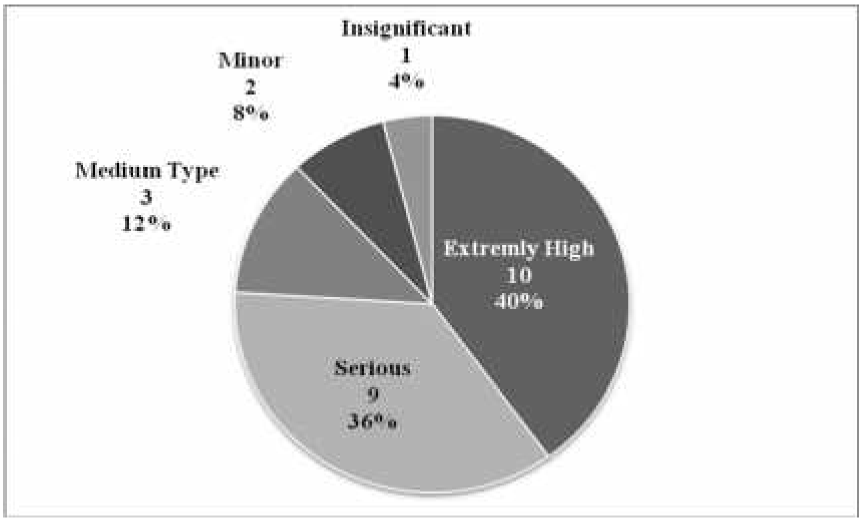


Figure 5.5: Percentage Distribution of Participation Restriction

Source: Field Survey, 2012.

Out of 25 respondents taken for P-scale measurement, 40 percent had experienced extremely high restriction, 36 percent had experienced serious restriction, 12 percent had experienced medium type restriction, 8 percent had experienced minor restriction and one had insignificant restriction. Most of the respondents fall on the categories of strong restrictions which showed participation restriction was hand-in-glove relation with leprosy.

5.2 Participation Restriction on the Basis of Age Group

Participation restriction may differ for different age groups. It was supposed that respondents from younger generation might have some impact of education as well as media than the respondents from old generation. It was supposed that among the age group, participation restriction was homogeneous. For each respondent, the limit of scores was 0 to 90. It was calculated in percentage also.

Table 5.1: Percentage Distribution of Participation Restriction by Age

Age group	**Number of Respondents (n)**	**Total Scores (ϕ X)**	**Average Score for Age Group (ϕ X/n)**	**Percent {(ϕ X/n) ÷90}×100**
25-40	5	143	28.6 (Medium)	31.77
40-55	5	247	49.4 (Serious)	54.88
55-70	9	435	48.3 (Serious)	53.66
70-above	6	306	51.0 (Serious)	56.66
Total	**25**	**1131**	**45.24**	**100.00**

Source: Field Survey, 2012.

From the data it was found that average score of participation restriction was very low in case of new generation i.e. <40 years but in higher age groups it was found more or less same. It showed that social ostracize was in the declining trend. The younger patients were less deformed/disabled which might be due to low level of participation restriction. It is more likely that less deformity contributed to lower restriction and vice-versa.

5.3 Participation Restriction in 18 Standard Questions

For participation restriction, 18 questions were asked to 25 respondents. Different grading such as 1, 2, 3 and 5 were given to answers on the basis of seriousness. If a question had top most score (i.e. 5) to all respondents (i.e. 25) its highest score would be 125. So, the lower limit and upper limit of each question were 0 and 125 respectively. It was calculated in percentage also.

Table 5.2: Participation Restriction in 18 Standard Questions

Types of Questions	Scores (X)	Percentage (X/125 ×100)
Eating limitation	33 (Serious)	26.40
Practices of back-biting	38 (Serious)	30.40
Internalized stigma	39 (Serious)	31.20
Travel restriction/difficulties	42 (Serious)	33.60
Visiting the public places	44 (Serious)	35.20
Caring their health	46 (Serious)	36.80
Performing household’s chores	52 (Serious)	41.60
Getting respect from other	52 (Serious)	41.60
Participation in festivals/ceremonies	56 (Ex. high)	44.80
Visits to relatives	68 (Ex. high)	54.40
Involvement in religious functions	69 (Ex. high)	55.20
Travel out of their community	71 (Ex. high)	56.80
Access to means of entertainment	77 (Ex. high)	61.60
Opportunity for job	83 (Ex. high)	66.40
Their help to other neighbors	84 (Ex. high)	67.20
Confidence to learn new things	85 (Ex. high)	68.00
Earning capacity	92 (Ex. high)	73.60
Working Capacity	94 (Ex. high)*	75.20

Source: Field Survey, 2012. * Ex. high – Extremely high

Questions related with eating limitation, practices of back-biting, internalized stigma, travel restriction/difficulties, visiting the public places, caring their health had insignificant restriction.

Most of the respondents said that utensils used in their families are not kept separate. In social functions they are using plates and cups like others. It was the indicator of decreasing eating limitation. Practices of back-biting were found low in their families. Respondents were not feeling shame when they meet new persons. It showed that low level of internalized stigma. Travel restriction/difficulties around their home or neighborhood had found higher to those who were severely disabled. Those who could travel had no restrictions. Most of the patients were visiting the public places such as schools, shops, temples and nearby markets. It showed that they were not discriminated in public places. Most of the patients were caring their health themselves.

They were performing household's chores as they could. Respondents in 'Tutunga' camp were cooking themselves. In 'Lamtara' village they were working for subsistence. They were getting respect from other friends. Most of the patients were taking part in festivals, marriage ceremonies, and death rituals.

Scores for questions related to their involvement to sports/ to means of entertainment/ visiting public gatherings, opportunity for job, their help to other neighbors and confidence to learn new things had significantly high. It showed that higher level of psychological morbidity and self mortification due to adverse effects of stigma.

Top most scores were found for the questions related with their capacities to earn for their family and to do work. Leprosy being a chronic disease and due to their insensitive/disabled hands/feet, they cannot earn like others. This earning had cyclic relationship with discrimination upon them.

From the scores of the questions, it was found that their visits to relatives had decreased and they had moved out of their community rarely and had taken part poorly in religious functions organized socially. Some of the respondents said that they do not want to welcome the invitation of friends/relatives due to the burden of reciprocity.

CHAPTER VI

SUFFERING OF LEPROSY PATIENTS

This chapter deals with the presentation of lifelong experiences of suffering from respondents of three groups. In-depth interviews were carried out at their homes and hospital. Total twenty cases were selected for the analysis. Their experiences were presented in their own words. Qualitative analysis of information was drawn from each respondent.

6.1 Respondents Background

First group was taken from 'Lamtara' rehabilitation village, Ritthepani-2, Lekhnath Municipality. Those respondents were bought in ‘Lamtara’ village by rehabilitation program in 2047 B.S. They are living here with their family or with their close relatives. In most of the families they were found without their sons/ daughters. They have a small house and a piece of land. In their old age, they are unable to earn. Plots provided to them are sufficient only for growing vegetables. They are getting Rs.570/month from the leprosy elimination program and Rs.500 /month (elder citizen allowance) from government in some cases is insignificant to manage their household. They are also suffering from other diseases and they need extra income. Most of the patients were weeping while interviewing and they were cursing to the village elites.

Second group was taken from Tutunga camp, Pokhara municipality-15. Most of the patients in Tutunga Camp were brought here in 2049 B.S. They have insensitive deformities and are unable to earn themselves. They are living with the food provided by leprosy elimination programme.

Third group was taken from GPH. All of them were admitted patients. Some of them had recently joined and some were being treated from several months. They were from Okhaldhunda district in east and Kailali district in west.

6.2 Dimensions of Sufferings

The word ‘Suffering’ can occupy broad range of definition or in other words, ‘Suffering’ may be the outcome of many social factors. In this study, only economic aspects, caste structure, level of deformities, age/gender, modes of treatment, role of son/daughter, traditional believes were taken into consideration for the dimensions of sufferings. These dimensions are listed in following ways.

6.2.1 Economic Aspects

Analyzing economic aspects of respondents, they had become disabled because of delayed treatment. They were trapped in the labyrinth of economic problems. Some had become beggars, cheater, Christians, disposed laborer, subject of headache for family and rebellion against government. Inabilities to early diagnosis, lack of easy access of treatment centre, transportation cost, several months of treatment, responsibility of family were the facts related with economy. Respondents in their late ages were unable to earn and had become burden for family. Those who had not their own children were suffering more than others.

Respondents from ‘Lamtara’ rehabilitation village were living with great economic deprivation. Some of them had not their children with them. They have been helpless because of earning hands. They were saying that money provided to them is not sufficient even for morning tea and have no money for the treatment of other diseases.

Respondents from ‘Tutunga’ camp were getting insufficient allowances. They had got some provisions for survival from Leprosy elimination program. They were more disabled persons and cannot earn anymore. They were saying that monthly allowance is not sufficient even for fire-wood. Other expenditures such as money for other diseases and bus fare were the matter of serious concern. Exposure to news, entertainment, visiting with relatives have almost seized from them because they were living in economic crisis. Many patients feared about future and were remaining single. Some of them had been burden for GPH (i.e. refusing discharge). They were deprived of welfare scheme of government where each disabled is liable for Rs.1000/month.

Some of them were living by begging. Some had taken shelter on the verandas of employers. They were compelled to work for low wages. One of the respondents cheated his employer for the sake of bus fare to come to GPH. One of the respondents became Christian for two times to save his life and could not continue his traditional occupation sewing. Because of economic constraints, one of the respondents left her three daughters came back to Leprosy Camp. One of the respondents was angry with government and don't want to receive elder citizen allowance. One of the respondents didn't ask money from his family but was borrowing from his friends. Similarly, many respondents had lost their parental property. Following case may exemplify this fact.

Case: 01

Bishu being a member of scheduled caste had the experience of extreme social discrimination. That couple had no children and begging was the strategy for subsistence. In his early days, villagers did not dare to touch him. He was harassed by village elites. Delay in diagnosis made him disabled. Now a day he is experiencing relief in social discrimination.

Bishu,50 years was born in Parbat. He has no palms on both hands and toes in both legs. His eyes have deformed and broke his left femur in an accident. For its recovery he has kept steel. His experience is as follows.

"I afflicted leprosy at six years and left that village at eleven years. At first, small blisters were seen on my knee. I had burned in fire at three years. Villagers had told that I was nearly died at that accident. I lost my father when I was of one month because of leprosy. He died in Malunga and my mother did marry with another person. In our village, traditional healer (Baidhya) diagnosed my disease and advised to keep me separate. Family kept me outside the house in a hut where I used to weep whole night. My mother used to leave me when I asleep.

When I was of eleven years, villagers suggested me to go to Baglung in a gathering of Chaite Dashain. I had long hairs and lice. I stayed there without food. Somebody picked me from the paddy farm (khet), took to health post, cut hairs, changed dress and gave medicine for one month. After fifteen days, our village headman (Jimmawal) *got letter for the management of treatment but he returned this letter refusing help because no one was ready to escort me. Later police came to my house and brought me to Pokhara. On the way, we had to cross ModiKhola. It was impossible for me, and the police carried me on his back. We came to Pokhara after two days of journey. I stayed in Hariyo Kharka for one year. They had suggested me to return to house but it was akin death sentence. I was not allowed to stand on the edge of my yard also. Therefore, I decided to go to Malunga following the friends from Ghandruk and Lamjung. In Malunga, I passed eighteen years and brought here in 2047 B.S.*

I married with a leprosy patient who had arrived in GPH from Nawalparasi district. We have no child. We are living with one of our son's (brother's) family. I am receiving Rs.570/month allowance which is not sufficient even for medicines for other diseases. I am living with begging in Chippledhunga. I thought it appears because of past deeds. Somebody says it as the result of incest relation. It is not communicable because my mother was not contracted.

In our old village, Kshtries would scold me while walking along the street. In early days of this village, neighbors would call us by bad name while traveling. Later a leader of youth club made a rule for not to call us in this way. Nowadays, they give us food in their own dishes. I am feeling easier than past. I do not participate in ceremonies because I have nothing to give them".

6.2.2 Caste/Ethnicity

In this study, correlation of caste structure and level of discrimination was found. Respondents who were from so called lower castes were surviving miserable life than others. They were not allowed to reside within the premises of house of villagers. Talim became sick but his neighbors did not help and he became Christian twice. He even did not get the compensation as other patients received. He had made a hut outside the Malunga Camp and lived there. One of the respondents being an orphan, female and from lower caste did not dare to return to her village after her diagnosis. One of the respondents had an exceptional case from new generation who was restricted less and said, "People are sympathetic upon me". Following story may highlight this heading.

Case: 02

Talim lost his traditional occupation (sewing) because of stigma. Even though he has son and his family, he is living alone in this camp. He became Christian twice for the support of life. As a traditional medicine ‘Human Flesh’ was feed to him. He suffered from deformity due to frequent non-compliance. He couldn’t claim his parental property and could not join in Malunga Camp. He couldn’t get shelter while travelling. He says, "Leprosy rises due to the impurity in blood. It is not communicable".

Talim was born in Parbat. He is now 72 years and was sewing clothes when I met him. He said his experiences as follows.

“I faced discrimination more than other leprosy patients because I was from lower caste and poor. This disease appeared me at the age of fifteen. I started its treatment since 2015 B.S. That year I came to GPH many times. I went to Palpa Mission Hospital in 2018 B.S. They had advised me to stay there but I refused and returned to home where I had to manage my household. I stayed at home for two/three years but disease spread more. I went to Gorakhpur, India and remained there for six months. I asked leave from there and returned to Nepal. After two/three years again my face became red and blue then I came to GPH. I went to Malunga in 2025 B.S. where I had made a small hut outside that Leprosarium. I used to work as an agro-labor around the village. I did not return to my old village because of severe discrimination. My son was of six years when I left home. He was grown up by my brother. I couldn’t claim my parental property because I was away from home.

I lost my fingers in 2049 B.S. My villagers had tried to keep me in an isolated hut but before their plan, I used to rush from house. Nowadays, no one is coming from my old village to visit me. I lost my traditional occupation (sewing). In past I was not allowed to touch public tap and even to go to cultivated land.

In 2032 B.S., I became Christian but faced untouchability among them and remained away from them. They stopped medicine for me. For continuous use of medicine they *asked me the recommendation letter from Gaun Panchayat. I went to Parbat district carrying a thermos with tea and bread of buckwheat. I did not get shelter in evening and slept in a cow shed. I could not handle thermos properly and it was broken.*

In my early days of treatment, we sacrificed five animals (Panch Bali) in village temple. We sacrificed a red goat to snake god (Nag) also. One day my father and one Brahmin man conspicuously gave me a medicine which was human flesh that I knew later.

Many patients having deformities as like me have got land and house but I did not get anything because I was from lower caste. Nowadays, I haven't faced such discrimination. I shouldn't wash cup after tea. I have son and grandsons near this camp but I am living here alone. Again at this age, I believe to Jesus because Christians saved my life last year providing blood".

6.2.3 Level of Deformities/Disabilities

Deformities may refer to disfigurement of visible parts (esp. skin, face, nose, eyes etc.) and disabilities may refer to mutilation of working parts or losing sense (hands and feet). Deformities/disabilities may act as a poor body capital for any individual. Respondents having low deformities had less experience (P-Scale scores) of social stigma. Higher restrictions (P-Scale scores) were found in those cases who had higher level of deformities. Their discrimination was found directly related with poverty. Exceptional cases were also found who were less stigmatized because of full support from family members.

Post modernists consider the subordination of society does not only base on the economic prosperity but is the combined effect of interpersonal relations such as age, gender, culture and economy or in other words, sum of cultural capital, symbolic capital and economic capital. Postmodernist's concept was well applicable in case of leprosy patients. The very low status of leprosy patients was due to lack of 'Symbolic Capital'. We can say, higher the deformities, they should face more discrimination.

In 'Distinctions', (1979) Pierre Bourdieu explains "Capital is the resource, command of which, enables one to exercise and resist domination in social relation". His concept of ‘Body Capital’ states that an individual can acquire or loss his/her status on the basis of physical fitness within his/her ‘Field’. This concept of ‘Body Capital’ was very useful to locate the identity of leprosy patients who were severely deformed or impaired were disposed to the lower strata of social hierarchies. Deformity/ disability was also related with income generation.

Case: 03

Hem was forcefully sent to Malugna by the villagers. His only one daughter had married and was in her husband's house. He was living with his wife. This couple had been helpless because of earning hands. He had been abandoned by his close relatives. He thinks leprosy is communicable and is inherited in some sort.

Hem, 66 years was born in Magdi. He has deformities on feet and hands. He stated his story as follows.

“In my family, my father had contracted by this disease. I contracted at the age of fourteen. Later my sister had also it. Villagers expelled me from the house and I stayed in a hut nearby an astrologist’s house who tried to heal me. No one was ready to touch me but he used to touch and had practiced the use of syringe also. I shifted to another hut at my own land where I passed three years. My mother used to bring food for me. After two years my sister also contracted and she was forced to keep in a cave. She left this cave without any information to family members because of frequent fear of fire in the forest. She had arrived in Pokhara herself. Only after six months later she told about my disease to foreign doctor. In winter she came in our village and brought me to Pokhara. I stayed in GPH for seven years where I had to sell milk in market. Later I got certificate to return to village. I had to submit this letter to our village headman. These elites had accepted me but other treacherous men exercised to broadcast rumor around the village. I stayed in my village for six months. At that period our neighbors would not come to my house.

I felt too difficult and left the village and set for Malunga in 2024 B.S. In the same year I did marry. We had a son and a daughter. We lost our son when he was of three years. Our daughter has married and now. We have become helpless. One of our grandsons (from uncle's house) is living with us. We have house to live in but no any means to collect bread.

Elaborating his experiences about past he said, "No one would come to visit me in Malunga". I haven't returned to Magdi. Sometimes my maternal uncle's son comes to visit me. This village was named as leprosarium (kodi khan) *in past but we have experienced relief now".*

6.2.4 Age and Gender

In his work, 'The Subject and Power' (1982) M. Foucault elaborates that "Power relations are rooted deep in the social nexus, not reconstituted 'above'. Society is a supplementary structure whose radical effacement one could perhaps dream off". This view was found true in the study where being as poor, from so called lower castes, female, widow, widower had greater suffering than others.

In this study, correlation of age/gender was found with the discrimination upon leprosy patients. In new generation, they were less suffered from enacted stigma but some sort of internalized stigmas were found. Because of their internalized stigma, they had reduced the visits to their relatives and around the periphery of community. Some of them were from new generation and had less tortured from society. In case of women, delay in diagnosis, lack of escorting person and financial access had caused the severity. Following case may represent the above heading.

Case: 04

Karma was living in her third life. She had passed her second life in a cave for three years. She was abandoned by her husband after the affliction of leprosy. She was chased away from her village and had arrived in GPH incidentally. Karma, 78 years was from, Myagdi. She has no clear deformity. She explained her history as follows.

"I afflicted leprosy after marriage. I had two sons but they left me from this world. I faced severe restriction from my villagers. They would not allow me to fill water from the tap. They even used to say it would transmit by smoke. I was expelled in a small hut nearby my husband's house. They threatened me that they will burn this hut. I came to my natal home. There was a cave at a distance of one morning walk from my mother's house. My mother and maternal uncle made a small wall there. It was the home for me where I passed three years.

I had cultivated around that cave but somebody opened fire there. I left this cave without informing anyone and walked towards unknown destitution to end my life.

Once I had reached to Baglung but feared to go there. Within the period of one month, I arrived to Pokhara. For many days I did not eat anymore.

In Pokhara, I meet one woman who told me about GPH. She took me there. They sent me to Bagar to check blood. I were sitting away from that clinic because of hesitation, one of the foreign lady doctor (Kanchhi) pulled me and checked. I told them about my brother who was also a leprosy patient only after six months. They had scolded me. I brought him in winter. We went to Malunga in 2022 B.S. We again returned to Pokhara in 2049 B.S. I have grand-son and grand-daughter from daughter's side. They use to come to visit me".

6.2.5 Modes of Treatment

Segregated mode of treatment in past had developed strong stigma to leprosy patients. Reminiscences of this practice and its results were found in the study. Segregated mode of treatment made them as people out of their society. Many have been out of contact to their family and relatives. Access to treatment centre and constraints for traveling (several days of walking) was the main cause for their deformities. Delay in treatment caused the suffering in some cases. Non-compliance was found in many cases and some had rushed from GPH because of fear from other patients or probably due to the stigma associated to this hospital. One of the respondents had contemplated for suicide because of fear adhered to this hospital.

Michael Foucault’s concept of ‘Bio-power’ tells us that state controls its subjects in the name of saving lives. It considers people as a species and imposes regulation of customs, habits, health, reproductive practices, family, blood and well-being. This was seen in leprosy patients where they were forcefully kept in 'Malunga Camp' even after the recovery from leprosy. They were brought in 'Lamtara' in their old ages and no means of survivals had provided. Many patients became the victim of forced sterilization because management of camp wanted to reduce the cost. Their several months of hospital admission had made them isolated from family. Many of hospital admitted were weeping at the time of interview because of home sickness.

Stigma resides within our deep core of cognition whose radical effacement is almost impossible. For this, one quotation of respondent (02) was very interesting *“Tiljogauna bar barnupurcha”*. We may say ‘stigmatizing people is an offence’ but in practice it is appearing in many forms. Following case can illustrate this fact.

Case: 05

Rima is an example of reincarnated leprosy patient. For some years, she had lived in a hut away from village. She lost her property and even her own ornaments were seized. She lost her daughter and two marriages also made her alone. Now she is angry with god. Escorting to treatment centre was a great problem for her. She is angry with villagers and don’t want to return. She is living by begging. Her husband was a drunkard and was also a leprosy patient.

Rima, 60 years is from Palpa. She is blind in one eye and the other is also suffering from itching problem. She has lost her night vision. Now she is having the treatment of her infected sole. She started her story as follows.

I was brought to my sister- in - law’s house in my childhood. I used to look after cattle on those days. Later my sister arranged my marriage to her husband’s younger brother. Only after 3 years of marriage we had sexual intercourse. When I was pregnant, I suffered from leprosy. At first we thought it as the disease caused by evil eye (boxi) or by serpents (Nag). I gave birth to a daughter. When she was of two years old, they separated me from her and kept me in a shed far from the village. After few *months my daughter died because of negligence. Later my husband’s brothers partitioned the land and I was moved further into the forest in a shed. Cows were kept on the lower floor and I used to sleep on the upper floor. Many days I was frightened by ghosts. My family did not support me to escort to Palpa. I quarreled with my family and went there myself. It was a challenging job for me to go to Palpa because I couldn’t speak Nepali* (khaskura).

My family used to give me some utensils and a mud pot (ghaito) *to carry water. I had to cut grass and work as labor daily. When my nose and ears were deformed, they took my ornaments and said that it can be used after refining in fire.*

When I reached to Palpa, they shouted at me for delaying to come for treatment. I used to come to Palpa for medicine but my family used to send me alone without money. I used to bring a basket (doko) *of ginger to* Aarebhanjayang. *In my return trip, I had to carry salt for the cow. I passed many years living together with the family of my sister. Later my husband asked me for the sake of cowherd and took me with him. I used to save some rice from each meal which was my pocket money for going to Palpa. No one would help me when I had suffered from a strong fever.*

I left that village 25 years ago and came to GPH. I married a leprosy patient called ‘Suke’ from Begnas. He used to drink too much. He took me to his village but I couldn’t work as agro-labor then went to Bhairahawa. He died in last year.

My relatives come to visit me rarely. My sister’s son comes here sometimes and requests me to go to Palpa but I am refusing his proposal. I have no interest to return to that village because villagers discriminated against me too much. I have a small hut made by Church in Jitgarg. It has no walls. Neighbors had helped to bring some fodder to make it.

I am living by begging in Bhairahawa. Sometimes food is provided by rich men. I arrived here 13 days ago. Sangita had given Rs.600 for bus fare. A woman from my neighbor is helping me to fetch water. Until now, I haven’t citizenship card and I don’t know where to go for it. Nowadays, I am asking god why it is so unsympathetic upon me (daiva le kina herdaina)”

6.2.6 Role of Sons/Daughters

Role of son and his family is very important in societies where patrilineal values work strongly. Their importance is closely related with income generation and special care in their late age. Most of the respondents were unmarried, childless, hadn’t had son and lost them and away from their sons and daughter. In that situation, they had greater suffering than others. Some of them were unmarried. Many of them were remaining single. Loss of only one son in case of many respondents made their life miserable and can be said "A ship drowned in their lives". They were weeping remembering their lost sons. Some of them had accepted the sons and daughters from their close relatives. Only few respondents were supported by and living with them. Following case can illustrate this fact.

Case: 06

Mallik was a father of one son and daughter but at that time, he was being alone in this world. He feared about the coming days, if this hospital discharges him. He was weeping at the time of interview. He lost his parental property.

Mallik, 65 years is from Kapilbastu. He had contracted leprosy 24 years ago. His right leg is severely disabled. He was weeping during the interview. He started his story as follows.

“I lost my mother in childhood. I am married and have one son and a daughter. I stopped sexual intercourse after getting this disease. My wife died 12 years ago thinking about my problem. After some years, father also died. My son left home after his marriage and birth to one daughter. This grand daughter was raised by her maternal uncle. Now my son is not in contact with me.

I could not visit hospital on time and suffered from this kind of severe disability. My village is 16 km far from the highway. Thakur Singh sir had advised me to come to Kapilbastu at first. He had given me the bus fare also. I could not get admission Sin hospital at my first visit because beds were not vacant. Within the period of 24 years, *I have traveled to Pokhara eight times. This time, I have been in GPH for four months.*

I am the youngest son of my father among three. My brothers did not give me a share in the parental property. They have died now and I couldn’t claim this from their sons. They turn their heads when we meet on the road. Sometimes I must sleep without food for one week also. They do not call me to join in festivals.

Nowadays, I am alone in my family. I can’t cook and collect food myself. I use to live with the food provided by villagers. I have difficulties even to go to toilet. It will be a great problem if this hospital discharges me. I am worried about how can I reach to village and who will take care me?

6.2.7 Traditional Belief

Nepal is a country where fatalism is a part of peoples' believes. In this study, misconceptions of respondents about this disease led to the faith healing practices which delayed the diagnosis and they had become disabled. Some of them had practiced traditional medicines. One of the respondents had eaten human flesh. One had used ear-secretion (*kaneguji)* and paste of house-fly (*makhha).* One said, "No one could dare to touch me but an astrologist had injected medicine. Many of them had believed upon evil eyes, local deities and had performed pacifying activities and had delayed the diagnosis. They had sacrificed animals for the recovery and were saying, "We had sacrificed many animals except human". One of the respondents had said this disease was the result of her fate *(bhuni chhunda payako).*

Case: 07

Tika was striving for her life in this camp since five years. No one escorted her when she had come at GPH and once contemplated for suicide. She lost her son at the age of 9 years. Even though, she has three daughters, but felt difficult to live with them. After many years of stopping her treatment, she came back to camp because of lack of care. She kept the matter of disease secrete even to her family.

Tika, 64 years was born in Tanahun. She couldn't remember her marriage because she did marry in very early age. Her husband's house was in Syanja. She lost her father before her birth and mother at the age of five years.

She said, "At first just below my left elbow spots were seen when I was of 26 years. I applied leaves of beans (Simi), ear secretion of buffalo (Kaneguji) and paste of housefly (Makha).One day when I had come to Waling, I met with Durga sir, a staff from GPH in his field visit. I was alone on the way. He said to me to rest for a while. I was afraid at first but he had seen my wounds already. He asked me about that wound and advised me to visit GPH anyhow. He wrote a letter to my village health post and suggested that I should take a tablet each day.

After that day, I feared too much whether it would transmit to my one son and three daughters. Similarly restrictions of villagers were so strong that I did not reveal to others. My husband did not believe that it was leprosy.

I came to Pokhara with my one son and one daughter. I had no idea about the way to Pokhara. I arrived Pokhara in the evening only. It was difficult for me to ask for shelter. One woman from Kshtri caste took me to her house. This woman brought me to GPH. When I had arrived near to Chor Sangu, I wept too much and tried to fell into the gorge. My daughter said not to do this. Passersby counseled me thereafter.

When I visited GPH, felt some relief because so many patients were there as like me. I stayed in GPH for six months. They did surgery of my leg which I had damaged in a lightening accident. After that I used to come in GPH in every six months. I had got Rs. 15,000 from this missionary to conduct small shop. I lost my husband in 2040 B.S. I passed my life with this shop for seven years. I used to carry light goods myself for shop.

I suffered from paralysis in Baishakh 2058 B.S. I had admitted in Western Regional Hospital but couldn't get recover. Later I was brought to Waling *Hospital where they used electric shock for 15 days. I had stopped to speak for six months. I lost my shop after this. I was carried at the back of my daughter-in law which was a matter of shame as per our custom.*

I felt hesitation to stay at the home of daughter-in-law. I finished my money and house was broken. I came to Pokhara to ask for grant before two years. At first they had advised me to go to Kathmandu but I did not accept.

I lost my only one son in 2045 B.S. Villagers couldn't know about my disease. If they had known, it would almost impossible for me to conduct shop. Villagers have advised me not to become Christian. I am living with food provided by leprosy elimination program. I am getting elder citizen allowance Rs.500/month and Rs. 400/month from this rehabilitation centre".

6.3 Consequences of Stigma

6.3.1 Marital Life

For the smooth conduction of marital lives, it requires the perpetual support or sympathy of one spouse to another. However, in case of leprosy patients it was seen as a major problem.

Demolition of first marriage prospects and initiation of next marital life was very common among many respondents. Many of them had married with leprosy patients. Forced separation or divorce was found in many cases. Some of them were ignored by their spouses. Some had been homeless and beggar even after two marriages. Many of them were remaining single because of stigma in married life. This shows that society has not yet liberal upon them.

French sociologist Pierre Bourdieu coins the term 'Symbolic Violence' in his writing Distinction (1979). He wrote 'Symbolic Violence' is the social/cultural domination occurring within the everyday social habits maintained over conscious subjects. It is a kind of 'Discipline' which is set forth to impose to any individual to confirm that individual's placement in a social hierarchy. He suggested that sometimes cultural roles become more dominant than economic forces in determining hierarchies of power within societies. In his view, 'Status' is also an important means of coercion necessary to maintain dominance in a system, rather than just having ownership to means of production.

In other words, 'Symbolic Violence' means "imposing self-interests, ignoring multiple choices and forcefully legitimizing social order to the subjects. Symbolic violence is in some senses much more powerful than physical violence in that sense where it is embedded in the very modes of action and structure of cognition of individuals and imposes the specter of legitimacy of the social order". This kind of violence is invisible by its nature but is manifested in social relations. Symbolic violence was found related with inability to run marital life.

In 'Discipline and Punishment', M. Foucault says, "Slavery is not a power relationship when man is in a chain". In our contexts, if would be spouse knows about the contraction of leprosy, he/she is not ready to marry with leprosy patients. Following case may be a good example of this fact.

Case: 08

Sharma is a homeless and alone in this world. He cheated his Rickshaw owner for the sake of bus fare to come to GPH. He is still facing discrimination. He is living with poor hope that this disease will be cured and he will marry after this. He uses the fraud report of diabetes to reduce the social stigma around his community. He said that impurity in blood is the cause of leprosy and blames over molasses *(velly)* which he had had prior to this disease.

Sharma, 47 years is from Bhairahawa and has been admitted here since three weeks. He had visited Bhim Hospital there and they had referred him to GPH. He is a rickshaw driver by occupation and is having treatment for his infected right sole. He says his trembling story as follows.

“I am alone and homeless person (sukumbasi). I am a single son of my father. I am married but my wife died after six years. We had no child. My mother suffered from cancer. I paid a lot of for her treatment. We sold our house and land for her treatment. My father also died three years after my mother’s death.

I started to take leprosy medicine three years ago and completed 20 months of treatment. I couldn't know the dropping of sandal. My fingers have become senseless and I have to eat food with the help of only three fingers.

I am feeling too much discrimination from my society. In my place, people used to say "Go away and have your food". I am living on the verandas of people homes. They do not provide me room for rent because I am the leprosy sufferer and single. I used to live in Bhairahawa making a fraud report of diabetes (sugar) to reduce the discrimination. I hardly earn Rs.200 per day. I must pay Rs.100 per day to rickshaw-owner. I don't get money for regular check up where they ask Rs.100 for ticket and Rs.500 for each time of diagnosis.

I had stayed here since October to December in previous admission. For this time, I had made Rs.400 and ran away without paying money to rickshaw-owner. I spent Rs.350 for bus fare. I cannot do hard labor as other because I suffer from headache due to strong sun. When I was strong, people used to give me work. I used to lift sacks of food. Now boss of agriculture firm is calling me for work but I can't work there.

One woman in Bhairahawa is willing to marry me. She has said, "You must be well before marriage". She is working as illegal transporter for sugarcane and tea packets from India to Nepal.

After my mother's death, I worked as a laborer to carry cement. We used to have too much molasses. It made my blood impure and leprosy appeared. I am praying to god, "Please! Take me with you otherwise make me fine".

6.3.2 Travel Restrictions

Travel restriction refers to rare visit of people out of their communities. This depends upon the inability of people to walk physically, lack of transportation cost, rare invitation from their relatives/friends and due to their own unwillingness because of internalized stigma.

Severely affected respondents had higher travel restriction. Some of them had not travel restriction because they had low level of disability. However, they had reduced the travel because of internalized stigma.

In 'Discipline and Punishment', (1975) M. Foucault says, "Modern forms of hospitals are the new forms of prisons where white coats' supremacy is rampant. Patients are treated as 'Cases' and measurements of bodily conditions are followed by charts and scales".

In this study, normalization of leprosy had not made yet. The same doses of medicine they could take at their homes but patients were admitted for several months in the name of complete recovery. In this sense, travel restriction was further increased from the side of treatment providing institution. Travel restrictions had relations with loss of income and psychological morbidity which can be termed as the side effects of stigma.

Case: 09

Even though being a responsible guardian of his family, Chaudhari is ignored by his wife and son. He is unhappy with his relatives who feel some hesitation to sit together. He shows his anger to villagers who school against him. He is being out of contact from his family when he came to GPH.

Chaudhari, 40 years is from Kanchanpur. His right sole is severely infected and his eyes have itching problems. He arrived in GPH one month ago for the surgery of this infected sole. He has two sons and two daughters. He has 8 members in his family along with his father. He explained his story as follows:

“I got leprosy at the age of fifteen. I did not care it because I was like a child. I had visited to different clinics in our area. They injected on both legs only. When I had arrived Dhangari hospital first, they shouted upon me for delaying the case and had visited that hospital many times. They referred me to GPH.

My father is also a local faith healer. We sacrificed many goats and cocks. My villagers have too much traditional beliefs. One day one of my mother’s sisters (sanima) blamed my father for performing magic (tunamuna). All villagers came to my house and hit him fiercely. They feed faeces of dog also.

I am in GPH for the fourth time. I am using crutches while walking and suffering from pain on my arms. I made wound on my hand and feet when I had drunk and slept nearby fire. I can care my body myself. I must stay here one month more.

I can do many of the farming activities except planting paddy seedlings. When I married, it was seen as white spots on legs only. My wife used to love me and bring medicine from market. Nowadays she does not care me. Many villagers and her natal families are schooling against me that I have suffered from cancer. My son in-law cooks rice and provide me. I do not ask money from them. They feel ashamed when a new guest comes to my house. They want to keep me away from home. I am saying to them it's my birthplace and where to go? Due to the discriminating behavior of my wife, I do not want to go her natal home (sasurali). I stopped medicine 15 years ago but still they have the fear of contraction. They are not saying dominating words in front of me but might have back-biting. Many years ago, my relatives had suggested to my mother to keep those utensils used by me separately. Later I knew it and told to those relatives not to come in my house.

I had worked as bonded labor (Haliya) in a house of landlord (kisanba) for 13 years. Now our family is living on unauthorized land (yelani). I lost a lot of money while coming to and returning from Dhangari. At this time, I arrived to Pokhara alone. I did not bring phone number and they are not calling me".

6.3.3 Deviance and Self-Mortification

Deviance refers to the violation of existing rules and customs of any society which are supposed to be confirmed by an individual. Self-mortification is the state of severe distress where an individual loses all of his/her hopes and lives without any ambition. Consequences of deviance will manifest in the form of habits such as drinking alcohol carelessly, involvement in cheating and criminal activities etc. People who are suffering from self-mortification do not have plans for future and live at the verge of hopelessness.

Concept of ‘Secondary Deviance’ as explained by Sociologist Edwin Lemert (1951) was found in some cases who want to drink carelessly. Concept of ‘Self-mortification’ was found in many patients who do not want to learn new things. No one was hoping for bright future. Only one respondent was saying that he will marry after his recovery.

Deviance and self-mortification are the negative tendencies of an individual which in sum can degrade the existing norms and values. The overall effect can be manifested in breaking up the intactness of ties between people and keeping the society as stable entity. Following case may serve as an example of this fact.

Case: 10

Hikmat was born in a family of bonded labor. He lost his parents in childhood and remaining single. He could not imagine the married life because of poverty. He faced strong discrimination in past but at the time of interview was feeling easier. He has been disposed for cheap labor. He has arrived in GPH with the bus fare provided by INF. He used to live without food for several days.

Hikmat, 35 years is from Chitwan. He has damaged sole of right leg and distorted toes. He is under the treatment for a leg infection. He started his experiences as below.

“I am the elder brother of the two sons of my father. Nowadays, I am living alone in a home made by INF in Sauraha. I lost my father when I was child and mother at the age of 10 years. My family was living as a bonded labor in a house of a landlord (Jamindar). Therefore, we had no parental property to share. We were brought up by our maternal uncle.

This disease appeared when I was ending my teenage years. Before that I had married but my wife left me after four months when I had come for the surgery of my leg in GPH. I had stayed in the hospital for one year at that time.

At first red spots were seen on my hands, body and face. I had gone to village health post but being immature, I discontinued medicine and regular check up. I used to be afraid when they would take blood from my ear and leg. Eventually I suffered from such kind of disability. I stopped taking medicine for leprosy many years ago but now I am suffering from wound infection.

I had come here before one month when my leg became senseless. I was suggested to come here by the staffs of INF who had visited my house. They provided bus fare also. I have no any means of subsistence. I am living with the wages (Rs.200/day) earned by carrying bricks, sand and stones in construction sites.

I faced strong discrimination from society. I had no home four months ago. I used to sleep in a school or the verandas of employer. They used to shout at me when I touched the tube well. I was not allowed even to spit around their house. Nowadays I am feeling it is little easier than in the past. My relatives come to visit me and I participate in public gathering also.

If I do work for five- six days regularly, then I become ill for two-three days. I must sleep without food for these days. I go to the house of my younger brother rarely. Sometimes they give me food but I must ask.

I want to marry and have children but it is only a dream for me. I must live on with one meal per day in the rainy season. I cannot travel very far from my village. I cannot do heavy work. Therefore, I earn less than other workers. Hikmat said, "This disease grows when we become very weak" and have some ideas about germs.

6.3.4 Social Distance

Social distance refers to closeness of relation among the people of society. Low level of interaction, rare visit to community people/their relatives and poor exchange of goods or labor increase the social distance. In fact, social distance hampers the livelihoods of people.

In this study, social distance was found a strong problem that had reduced social integrity. Even in small sample of 25 respondents, most of them had been isolated from their close relatives. Most of them had not returned to their birth places. They had rare visit to their relatives. Some of them were ignored by family members. In some cases they had come to Tutunga Camp leaving their sons and daughters. Some of them had been out of contact with family members. Only few respondents were living with their family and rest of them had moved from their birth places. Following case may be an ample example of this fact.

Case: 11

Siru was living in remote prison from her natal house. Her relatives rarely come to visit her. She was living with her husband before the contraction of leprosy. Her husband was helping to her when she was suffering from paralysis but after the contraction of leprosy she did not get his love and went to natal home. From natal home she came at GPH. Loss of her first son caused her brain stroke and she has been paralyzed now. She got threat from her neighbors.

Siru, 52 years is from Okhaldhunga. She arrived in GPH before 10 years. She mentioned her narration as below.

"My natal home and husband's home were around the same area. I did marry at the age of 22 years. I had one son at 23 years but he died after 15 days and I got brain stroke that caused my left part of the body functionless. I had lost speech at those days. My father and husband did treatment and I got well little bit. I was unable even to go to toilet at that period.

I afflicted leprosy at the age of 40 years. It appeared first in right leg. At first, hands and feet became senseless, frequent shaking, blisters appeared, paining inside and lastly small finger had mutilated. When I suffered from leprosy, they practiced the treatment of faith healers only and I lost my fingers. Villagers threatened my family if I wouldn't move away from house they would burn my house.

One of my villagers who was working in Lakeside told us about GPH. My father and elder brother brought me Pokhara. I took medicine for one year. I stayed in GPH for 2 years and in Naya Gaun for 2 years. I am living here since six years.

I cannot remember my mother. She had died when I were child. I became apart from my husband before fifteen years. Now he has married with another woman. He never comes to meet me. Sometimes my brothers come to visit but it is very far from here. I have very little contact with them.

I am cooking alone. It is very difficult me to burn fire and to wash dish because left hand couldn't catch and move properly. I am not getting any money other than Rs.400/month. We should pay Rs.250 for one bundle of firewood. You can imagine how we are surviving at this verge of deprivation".

CHAPTER VII

SUMMARY, CONCLUSION & RECOMMENDATIONS

This chapter summarizes the study and provides conclusion. Based on the findings some relevant suggestions are also made. Summary of schema and participation restriction were drawn from tabulated data whereas summary of suffering were taken from narrative information. To draw conclusions relations between schema and participation restriction as well as participation restriction and suffering have been considered.

7.1 Summary

This study was carried out in three different areas (Lamtara Rehabilition Centre, Tutunga Camp and Green Pasture Hospital of Pokhara). Total eighty respondents were selected for the interview. Non-probability sampling was used for the study. Fifty-five respondents who were non-patients but neighbors of leprosy patients were selected for the study of cultural schema of leprosy. Twenty-five respondents (patients) were selected for the study of participation restriction. Twenty respondents who were also involved in the study of participation restriction were asked for their lifelong experiences of leprosy. Semi-structured interview schedule were deployed for cultural schema, a standard scale (P-scale) was used for participation restriction and in-depth interviews were carried out for the description of suffering. In this way, this study uses both qualitative and quantitative data.

7.1.1 Schema

- Respondents had categorized the leprosy mainly into two broad classes such as red *(Rato)* leprosy and black *(Kalo)* leprosy, swelling one (*Fuluwa)* and mutilated one (*Jharuwa)*. They thought black leprosy is more dangerous than red one. Similarly swelling one is more communicable than mutilated one.

- Regarding the cause of leprosy, respondents poorly explained about the germ theory where they said it arises due to virus without saying bacteria. One fourth (25%) of the respondents explained the impurity in blood *(Khun bigreyear)* as the cause.
- Most of the respondents (56.36%) had the idea that it is non-communicable after having regular medicine. Similarly, there is paradoxical belief that almost two third (61.8%) believe that leprosy is inherited disease. It was thought non-transmit-able by sexual intercourse by (47.27%).
- Respondents said that leprosy is a kind of skin disease like ring worm *(Dadh)* which is not too serious as cancer and is more dangerous than small pox/chicken pox.
- About the preventive measures, they had the fear from leftover food *(Jutho),* sleeping together and those who were suffered by black leprosy (*Kalo core). A*voiding physical contact was suggested as the best preventive measure by (29.09%).
- Hesitation about becoming friends/workmates/neighbors with leprosy patients was still present in old generation. Many of them (63.63%) were ready to be friend with leprosy patients. Many of them (45.45%) were feeling easy to eat together. Many of the respondents (54.54%) had opinion that leprosy patients can be treated in a general hospital.

7.1.2 Stigma

- It was found that 10 (40%) of respondents had extremely high restriction and 9 (36%) of respondents had serious restriction. Average score of participation restriction was found very low in new generation i.e. <40 years age group.
- Out of 18 questions asked for participation restriction, questions related with their earning capacity and doing hard work had higher scores 92 (73.6%) and 94 (75.2%) respectively. It showed that their physical inabilities to work hard directly affected earning capacity.

7.1.3 Suffering

- Respondents having low economic status, being a member of scheduled caste, a woman, and couples without children, more disabled and having traditional beliefs were suffered more than others.
- Isolated mode of treatment made them apart from their families and relatives. In many cases they were first isolated for the sake of quarantine but this scheme detached them from their community forever. Some of the patients lost their parental properties, did not get citizenship card and government allowances.
- The main domain of stigma manifestation was seen in marital lives. Out of 20 respondents, one-fifth was remaining single, one-third had divorced, one-tenth was ignored by family and one-fifth had remarried.
- With regard to economic prosperity, those who were chronic sufferers were extremely suffered from economic constraints. Only one-fifth had no problems for daily subsistence but most of them four-fifth had the problems even for two times meal. They had lost their rights to entertainment, had become beggars, cheaters, disposed laborers and homeless. They had even the problem of bus fare and regular check up. They were suffering from home sickness, and psychological morbidity, had lost creativity, had contemplated for suicide and had rushed from hospital premises also. They were refusing discharge from hospital. They were forced for sterilization, had changed religion for two times and were refusing government allowances also.

7.2 Conclusion

Respondents' views such as leprosy appears due to the weakness of blood, no believe in divine curse, poor explanation of germ theory, transmission of leprosy through sexual intercourse and prohibition of physical contact all refer to personalistic cause (blame over person rather than microbes). This strong personality cause in old generation (>40 years) was the major influencing force for the origination of enacted stigma to this group. In new generation, explanation of leprosy from the point of view of naturalistic cause (faith on microbes/climate rather than germs) showed that biomedical perceptions working strongly. This naturalistic perception had relation with low level of enacted stigma with this group. Comparing the schemas on different aspects between two generations (i.e. < 40 years and 40 > years), some sort of positive changes (e.g. reduced enacted stigma) were noted in favor of leprosy patients. Respondent's view (non-patients) such as they are happy to be the friend of leprosy patients, willing to invite leprosy patients in religious and social functions and preference of integrated mode of treatment of treatment showed enacted stigma was being sharply reduced. Similarly, respondent's (patients) rare visit out of their community, poor attendance at religious and social functions and no interest of recreational activities showed internalized stigma was also working strongly. This internalized stigma had adversely affected marital lives (i.e. refusing marriage proposal and demolition of marriage prospects). Similarly, enacted stigma was found to be responsible for economic constraints (strong in new generation also). Earning had created all round effects in social relations. Travel restriction, degradation of self-confidence, increased social distance, psychological morbidity and deviance from social behavior showed that leprosy patients are being victimizing in many dimensions. High scores of participation restriction to most of the respondents showed that still stigma had hand-in-glove relation with leprosy.

Leprosy patients require more support than other patients but in practice it has been just opposite. Instead of providing further compensation, they were imprisoned either in hospitals or rehabilitation centers. They were left on the roads making them beggars, drunkards and thieves. They were surviving without any hope and ambition. Even though, leprosy is merely a skin disease, but still people bear some sort of hesitation towards leprosy patients. In sum, leprosy patients are being victimized by their family members/relatives (ignoring them), from community (disposing them) and state at large (disciplining them).

7.3 Recommendations

- In coming days, socio-cultural relation of leprosy and marriage/economic constraints should further be studied.

- As a part of providing culturally appropriate knowledge about leprosy it is important to include the topics of stigmatized diseases in our curricula which can guide for ways of treating stigmatized patients to new generation.
- Providing opportunities for jobs, motivating for skilled based training or funding for small business can relieve them from economic constraints.
- Providing them opportunities of recreational activities, engaging in social works, developing leadership can minimize the negative psychological effect of stigma.

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APPENDICES

APPENDIX: A

Interview Schedule

Date:

Name:

Code:

Age………… Male/Female………………

Marital status:

Married……. Single………. Divorced………. Widow(er)…….

Occupation: Education:

Religion:

a) Hindu	b) Buddhist	C) Christian	D) Muslim

1. Have you ever heard about leprosy before?
   If yes, where and what (short)?

2. Do you know people (friends/family/neighbor) who have been affected/ disabled with leprosy?
   If yes, specify relationship.

3. Do you know how leprosy is afflicted?
   If yes, how?

4. Is it communicable (from one person to the next) disease?
   If yes, how?

5. Do you think leprosy is inherited?

6. Do you think that leprosy is curable?
   If yes, how?

7. Does it transmit from sexual intercourse (from husband to wife)?

8. Do you know the medicine for leprosy is free?

9. Do you know the traditional (folk) medicines used for this disease?

10. Do you feel hesitation for becoming friends/neighbor/workmates with leprosy patients?

11. Have you participated for eating together/in festivals with leprosy patients?

12. Which diseases do you think very similar with leprosy?

13. Would you say symptoms of leprosy?

14. Would you explain about the preventive measures for this disease?

15. Can we treat leprosy as like any other disease i.e. in general hospital?

16. How serious do you think to leprosy?

APPENDIX: B

Checklist

Name/code:-

Date:-

Address:-

Age:-

Religion:-

Sex:-

Occupation:-

Education:-

Marital status:-

Date of symptoms:-

Date of diagnosis:-

Starting treatment:-

Level of disability/deformity:-

Financial burden:-

Family support:-

Community tolerance:-

Peer groups' behavior:-

Job opportunities/restrictions:-

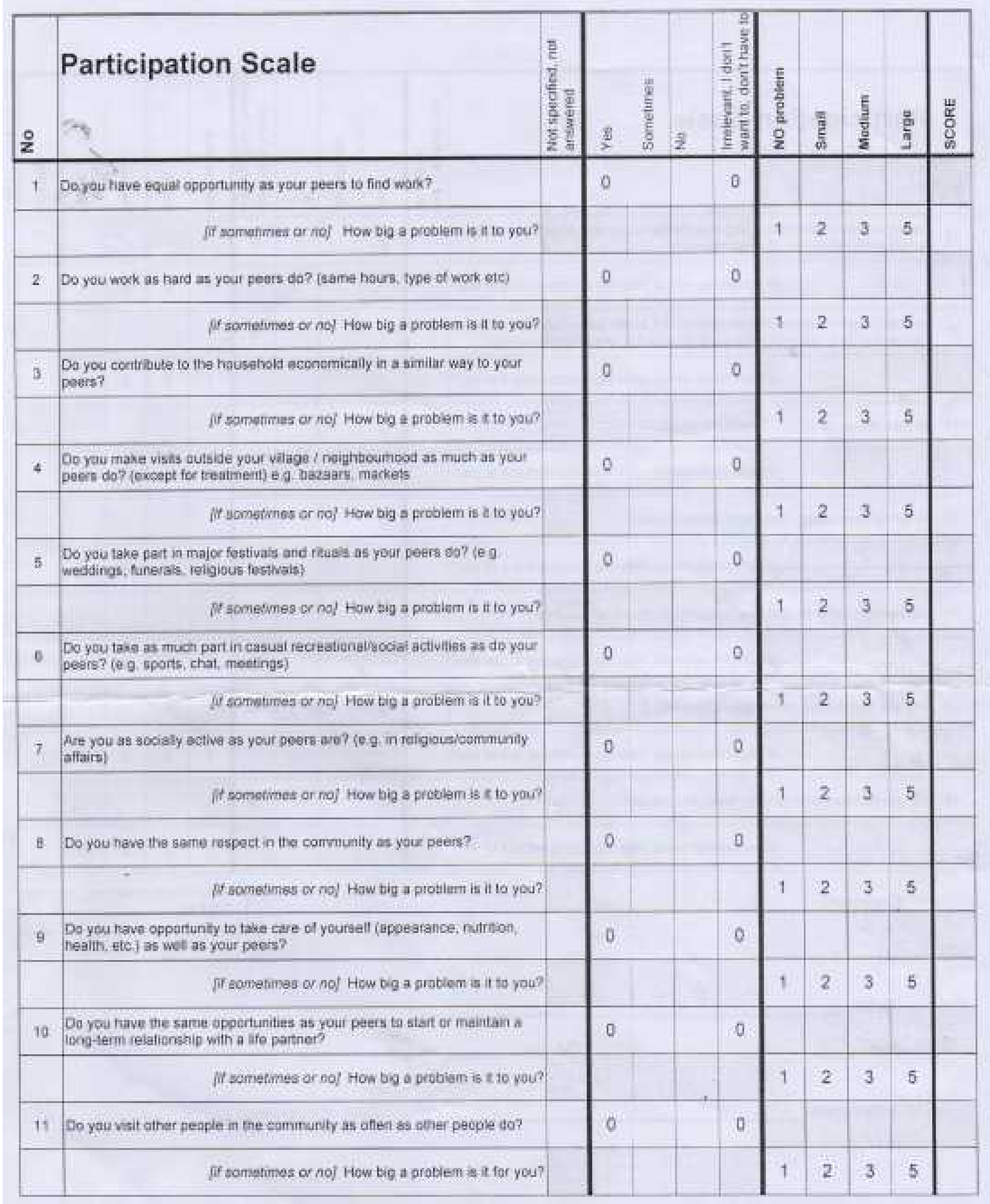
Travel restrictions/permissions:-

Participation in social functions:-

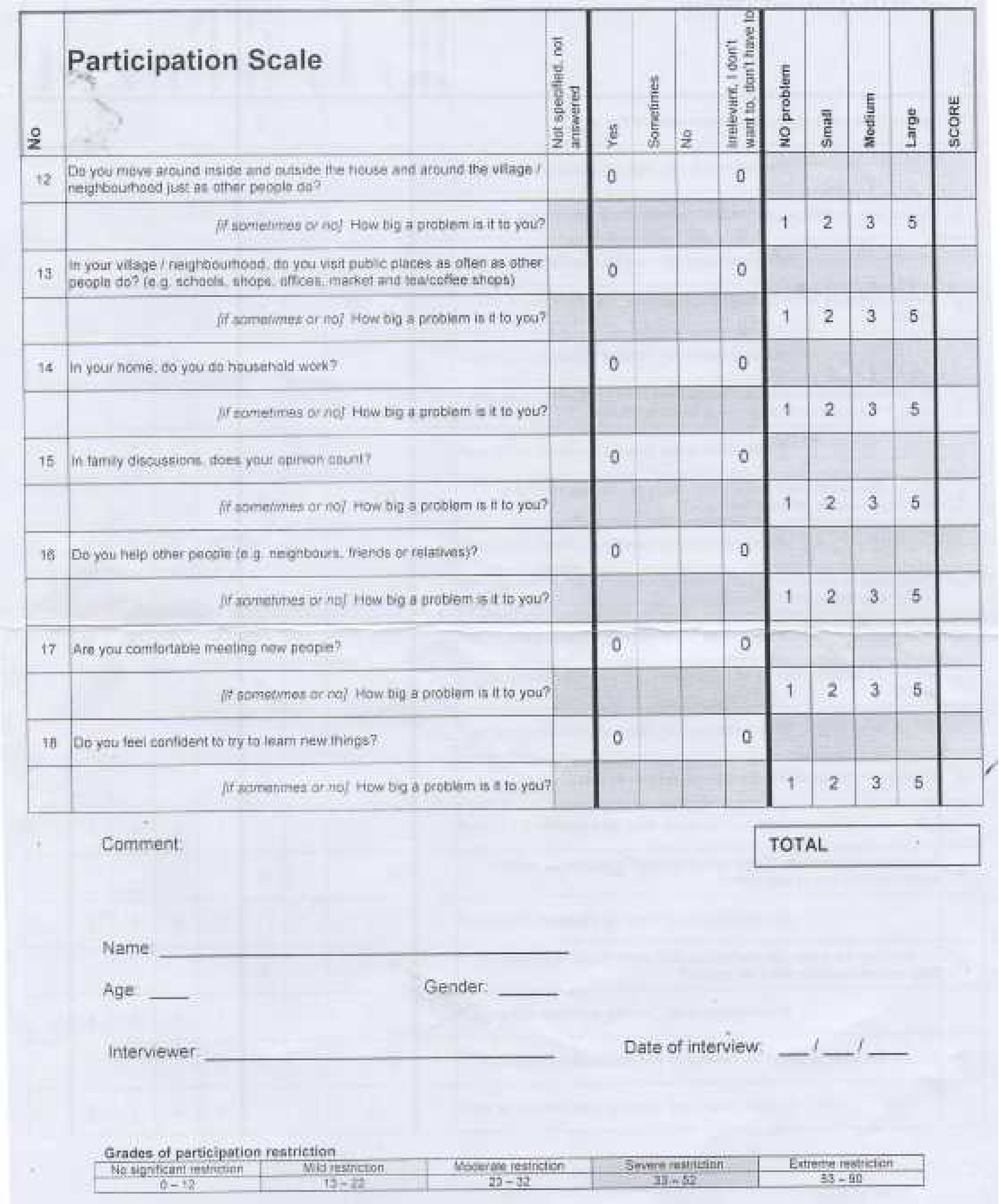
Causes of the disease:-

APPENDIX: C

P-Scale



No	Participation Scale	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't have to	NO problem	Small	Medium	Large	SCORE
1	Do you have equal opportunity as your peers to find work?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
2	Do you work as hard as your peers do? (same hours, type of work etc)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
3	Do you contribute to the household economically in a similar way to your peers?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
4	Do you make visits outside your village / neighbourhood as much as your peers do? (except for treatment) e.g. bazaars, markets		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
5	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
6	Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
7	Are you as socially active as your peers are? (e.g. in religious/community affairs)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
8	Do you have the same respect in the community as your peers?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
9	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
10	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
11	Do you visit other people in the community as often as other people do?		0			0					
	[if sometimes or no] How big a problem is it for you?						1	2	3	5	



APPENDIX: D

Case: 12

Subba had experienced the relief from social stigma but he was facing economic problems. In his early days, he was hatred by health professionals and village elites.

Subba, 69 year was from Shyanja. He has one son and one daughter. His daughter is remaining unmarried. He started his story as below.

“I am living here since 2047 B.S. I afflicted leprosy at 22 years. At first, my face became red and I was suggested to go to Palpa Mission Hospital. I am the youngest son among four brothers. At the time of diagnosis, even the doctor did not touch me. Doctor said me not to come in front of police when police were calling me for the compensation certificate. They suggested me to have medicine for five years. I requested to doctors not to reveal that case but immediately they scolded me. I faced severe discrimination by village elites (Pradhan Panch/Jimmawal) but other villagers used to accept easily. I used to participate in dancing but remaining isolated myself.

I did marry with a leprosy patient in 2025 B.S. in Malunga. We lived there from 2021 B.S. to 2047 B.S. Our relatives used to come to visit us but they had to stay in hotel. Nowadays, we take participation in ceremonies and they say 'Take yourself and eat as much you want'. I had thought life had ended when I arrived in Malunga. We took medicine for seven years. We have relieved from leprosy but financial burden is following us. The allowance (Rs.570/month) is not sufficient even for morning tea".

Subba does not suppose this disease is communicable. He gives the examples of his one son and daughter who are not contracted. He says this disease rises from the self-imbalance of bodily-fluids. His wife’s perception about leprosy is fatalistic. She says it’s the outcome of fate which we receive at the day on the earth (Bhuni Chhunda Paayako).

Case: 13

Rekha was an orphan. She had married with a leprosy patient and her only one son left her from this world. At that time, she had been widow and feared about the future. She did not dare to return her natal home after the diagnosis of leprosy.

Rekha, 60 years was born in Tanahun. She has no clear deformities. She starts her story as follows.

"I was of 15 years when this disease attacked me. My father and mother had already passed away when I were seeking for treatment. I came to Pokhara alone when a retired army in my village wrote a letter to GPH and advised me to go here. After the diagnosis of disease, I stayed in GPH for one week. Then I was said to return to my natal home but being an orphan I refused to go home and went to Malunga with other patients. In the same year I married with a leprosy patient. We had a son but he left us forever in 2050 B.S. Nowadays, I am living with grand-son of my husband's first wife. I don't think leprosy is communicable. It is not so dangerous if treated in early days. I haven't any experience of social discrimination because I didn't go to my old village after the diagnosis. I use to go to my husband's first wife's natal home as my relatives".

Case: 14

Lalu did not face the stigma from society. She had passed most of the part of her life in Malunga. Her husband had died. She was living with first wife of her husband at the great economic deprivation.

Lalu, 64 years is now widow. She was born in, Palpa. She said her experience as follows.

"My mother had left me at the age of one and half years and went to Malunga for the treatment of leprosy. I left that village at 13 years. Later I visited her there. She had married with another leprosy patient. I did marry with a leprosy patient at the age of twenty-two years. We had no children. I am the younger wife of my husband. His first

wife is 84 years and is living with me. I damaged one finger when frying corn in a mud pot (haandi). *I did not feel social stigma/restriction because most of the life spent inside the wall of leprosarium. I used to sleep inside my natal house while going there".*

*She says that this is not a communicable disease. It rises due to their past deeds (*karmas*). She has no own son and daughter to look for. Two old women were living with the poor support of Rs.570/month from rehabilitation program and Rs.500/month from government allowance for widow.*

Case: 15

Dambar could not live with his newly married wife because of stigma. He became victim of forced sterilization at the age of 28 years in Malunga. He was living there alone and was being out of contact with relatives since 20 years. He had vehemently rejected the allowance provided for elder citizens and become rebellion against government. He had lost his job from Indian Army. Two marriages also made him alone now. He has been out of contact from his close relatives.

Dambar, 70 years is from Palpa who afflicted leprosy at the age of 19 years. He started his story as below.

"I had joined in Indian army at the age of 18 years. I suffered from home sickness and lost my mental balance. They expelled me from the job. In next year, I suffered from this disease. I had married but had not had any child. She married with another man after two years when I left the village. We sacrificed many animals except man in my village.

I had come to Palpa in 2021 B.S. In Palpa I had to work as a sweeper and they had forced me to become Christian. I stayed there for four months and returned to my home. I could not remain at home because of stigma imposed by village elites. I came back to Malunga with other three villagers after one month.

I passed my 28 years in Malunga. I had married one leprosy patient there. She got an accident on the ladder while carrying a bucket of water. I had brought her in Western Regional Hospital where she passed away. I was alone at her death and hired four persons for cremation. Administration of Leprosarium forced me for vasectomy at the age of 28 years without my consensus. I had no option for this. If not so I had to leave the camp.

I took medicine for two years. I had returned to my old village only once for the death ritual of my mother. Daughter of father's sister (Phupu) *and small brother used to come to visit in Malunga but no one has come here since 2049 B.S. I am not receiving government allowance for elder citizen which I do not want to take".*

Case: 16

Puspa was not telling her blackness of face to her villagers. She was supported by her sons and had less experience of suffering. She was expressing home sickness and was weeping at the time of interview

Puspa, 70 years is from Tanahun. She had afflicted with leprosy two years ago. She visited district hospital at first. Her small son brought her to GPH. She has taken regular medicine for 23 months and one month is remaining for the treatment completion. She has an allergy to medicine causing her face black and reduced eye-vision. She is suffering from home sickness and was weeping while interviewing. Her narration is as follows:

"Because of the allergy to the medicine, I have been admitted for two weeks. I haven't told my neighbors about this diseased. They were surprised by the black color on my face. I don't know about the cause of leprosy, probably it may be due to weak blood.

I have three sons and one daughter. They have married and have children. I am not feeling discrimination from my family members. I am living with my second son's family. They do not allow me to work. I don't have financial problems. I don't know about back biting to me. Neighbors only ask about my black face. If I had revealed the fact, probably they would hate me. I can not work as before and do not go to market. I *had wept too much when it was diagnosed. Still I have some doubts about the permanent cure of leprosy".*

Case: 17

Shreenath was remaining bachelor in 45 years. He had no experience of social stigma. He was suspicious of whether he would be discriminated in future. He had not clear sign of leprosy. Once he had rushed from GPH.

Shreenath, 45 years is from Syanja. Eight months ago, he diagnosed his disease. Now he has no signs of leprosy. He explained his experience as follows:

"Four years ago, some spots were seen just below my right elbow but I ignored it. Probably I contracted leprosy in Aandrapradesh, India where I had worked as a laborer in a gas company. At first, I visited Charak Hospital and they had referred me to Kathmandu. My brother's daughter brought me here.

Nowadays, villagers know about my disease. They do not hate me. I can work with my neighbors. I have lost confidence to lift any load as before. I haven't married yet and I am living with my brother's family. I fear that they will hate me when I can not work as before.

Hospital counselor said, "He had left this hospital after one week of admission without any permission on his first visit". Shreenath says, "I must tolerate the discrimination because I can't do anything upon them".

Case: 18

Gautam did not have the feeling of enacted stigma but internalized stigma was found in his story. He had reduced visits to his relatives. At the time of interview, his wife was being out of contact which may be the reason of this disease. He had lost his recreation because of internalized stigma. He has reduced income because of insensitive hands.

Gautam, 35 years is from Tanahun. He had afflicted leprosy at the age of 11 years. His fingers of right hand have damaged. He was admitted in GPH two weeks ago. He said his suffering as follows.

"I had lived in Delhi and Bombay for many years. I had done blood test in India but they couldn't diagnose leprosy. At first, white spots were seen on my backbone and removed. Later granules appeared on my face. I thought it was an allergy and did not treat seriously. One of our sisters (Ramkali) told me about GPH. I was first admitted in 2066 B.S. for one and half months.

I did heavy work and suffered from muscles pain. I do a little agricultural work which can keep us only for three months. I should work all the time and have economic problem. I do not get time for entertainment and do not participate in social activities any more.

I am married and have one son of eight years. I am living with my mother. Recently my wife has been out of contact. Instead of hate, my villagers suggest me to have regular medicine. I feel difficult to go to my wife's natal home (Sasurali). They used to invite me but I stopped going. I think it appears due to the weakness of bodily power or lowering self confidence".

Case: 19

Chamu is living easier life with his family. He is unhappy about the difficulties for marriage. His family had kept utensils separately for him when they were suggested by one of the villager. He had kept the matter of disease secret from his villagers because of internalized stigma. Delay in diagnosis made him disabled. He lost his job and once had attempted to rush from GPH.

Chamu, 27 years is from Syanja. He afflicted leprosy in 2062 B.S. He has been admitted in GPH since 3 weeks. He revealed his experiences as follows.

"We are 13 members in our family. My father is working in Aasam. I am with my mother and brother's family in Syanja. Once I had a trip to Guhati College taking 60

nurses (sisters), probably I contracted leprosy from there. At first, on my right hand blisters were seen when I was working as guard in a hospital in India. At that time I was admitted in hospital for two months but they couldn't diagnose it. My fingers started to crumble, and they sent to me Diprikot Medical College. This college immediately diagnosed leprosy and referred me to GPH.

Two years ago I had surgery of fingers at GPH. Now these are becoming little bit straight. I took medicine from 2063 B. S. to 2064 B.S. continuously and stopped. My right leg is fully senseless and the left leg is functioning weakly. Recently I have suffered from infected ulcer on right leg.

I had not told to villagers about my disease when I discharged from GPH after my first admission. Later staff from GPH had visited my home and then they knew about it. In my early days, my mother and brother-in-law kept utensils separate for me as they were suggested by one of the neighbors. I felt humiliation (man saano vayo). Later we called that man in front of my family and all were counseled by educated men. Nowadays, I am not feeling discrimination from my villagers. On my first visit to GPH, I saw disabled patients and rushed from here. Next day, my mother and owner of hotel had brought me back again.

Because of this disease, I lost my job. They are calling me to join again but it's a four days journey from here. I haven't dared to go. I want to marry but no one wants to engage their daughters to a person like me. My small brother has already married but I am not sure that I can marry.

Case: 20

Lekha is living with her family with full support from past. She has some sort of internalized stigma that has reduced her travel around the village. Due to the delay in diagnosis of disease, she had lost her toes.

Lekha, 63 years is from Tanahun. She is living with her husband and son. Her right sole has ulcer and has arrived for the wound infection. She has passed two months in GPH in this visit. She says her experience as follows:

“In my first visit, I had stayed here for one and half year and had surgery on my right leg. This is my third visit to GPH”. “I grew up in India with my family. I was married there. One day I went to the river and a thorn was stabbed into my sole. I had taken it out but after 15 days this leg was swollen. My husband was working in the Indian army. He took me to many places of India for its treatment but we didn’t know it was leprosy. Later my son brought me Pokhara and a skin doctor referred me to GPH.

In my early days, I could not take off clothes. Each time doctors cut my fingers and dressed without giving medicine of leprosy. My elder son had also contracted with this disease but he got treatment in time and had become well.

I cannot walk long distances because of this leg. I am cooking food in kitchen and serving my family. I have no interest to go to my relatives’ houses. I do not participate in social functions. I feel difficult myself. I am not feeling discrimination from my villagers and family members. My husband supported fully for its treatment".