

ROLE OF STATE TO ELIMINATE STIGMA IN LEPROSY
A STUDY IN THE CONTEXT OF DADELDHURA DISTRICT, NEPAL



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DECLARATION

I hereby declare the work performed in this thesis entitled " Role of State to Eliminate Stigma in Leprosy: A Study in the Context of Dadeldhura District, Nepal" under faculty of Humanities & Social Sciences, Department of Political Science, and Tribhuwan University is my original work. It is done in the form of partial fulfillment of the Degree of Master of Arts in Political Science under the supervision and guidance of Dr. Mukund Ballabh Kalauni, Reader of Siddhnath Multiple Campus, Mahendranganj, Kanchanpur.

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ABBREVIATION

BCC= Behavior Change Communication
BBC=British Broadcasting Corporation
CBR= Community Based Rehabilitation
CDO= Chief District Officer
DEO= District Education Office/Officer
DDC= District Development committee
DTLO= District Tuberculosis and Leprosy Officer
DHO= District Health Office
DG= Disability Grade
FWR= Far Western Region
GoN= Government of Nepal
HDCS= Human Development and Community Services
INGO= International Non-government Organization
IEC= Information Education Communication
KAP= Knowledge Attitude and Practice
LDO = Local Development Officer
LCD= Leprosy Control Division
LAP/s= Leprosy Affected People
MP= Municipality
MB=Multi bacillary
MDT= Multi-drug Therapy
NGO= Non-government Organization
NLR=Netherlands Leprosy Relief
PB= Pauci bacillary
PHC= Primary Health Care
SLC=School Leaving Certificate
TLA = Tuberculosis and Leprosy Assistant
THD= Team Hospital Dadeldhura
VDC= Village Development Committee
WHO= World Health Organization

CHAPTER I

INTRODUCTION

1.1 General Background

A state is an organized communities living under one government which provides security and services to its citizens. Including services and security to its citizens and their rights are protected in the state. The state is responsible for well-being of its citizens and development of education, health and other sector.

In order to provide health service, for its development and secure people's health rights, Government of Nepal has set up different kinds of health polices services. However there are many kinds of drawback in health sector in Nepal. Only about 15% of Nepalese have access to health services. Leprosy is one of the major health challenges in Nepal.

Leprosy is known as "*kusthrog*", "*maharog*" (biggest disease) etc. in Nepal. Leprosy is the oldest disease in the world. Though it is oldest disease its consequences are still prevailed in our country. There are many kinds of negative attitudes and beliefs toward leprosy in Nepal. Leprosy is an infectious disease. It is the cause of *Mycobacterium Leprae*. But in Nepal people think that leprosy occurs due to bad habit or misdeed or curse of gods. People believe that it is *punarjanmako pap* (leprosy occurred due to sin done in previous life). Many people think that it is result of fate. There are lots of stigmas prevailed in the community related to leprosy.

People have not proper knowledge about leprosy in our society. And, people often behave negative toward leprosy affected people (LAPs). Government of Nepal (GoN) has provided free treatment service to LAPs but there are no specific programs launched for stigma reduction. LAPs are de-habilitated from their own family, own community within their own country. Many times LAPs and their family members are feeling unsafe and rejection in the community. Only the available free treatment is not enough to support them but it is necessary to rehabilitate them in the community and minimize stigma.

Some of the LAPs use to beg in India for living and some use to beg within the country. Many of LAPs, who are excluded from family or society, use to beg in India. Some of the patients are seen living by the side of the river or by the side of the jungle in a small hut which is not safe.

LAPs are facing social, political, economical problems in Nepal. They lack access to resources, job, education and their right to health facilities. They are rejected in public places. They are excluded from decision making process. They are occasionally rejected even from their own families. Their property rights are seized. They are ever living in anxiety, fear, sorrow and isolation. They lose their family, property and education opportunities due to leprosy.

Most of the leprosy patients have disability grade (DG) 2 in Nepal. Disability causes weaknesses and further it generates poverty or loss of their existing job. GoN has given less priority for reintegration and advocacy activities related to leprosy in Nepal. Only treatment for LAP is not solution but rehabilitation, awareness, advocacy, stigma reduction like activities should be promoted.

The study focused to understand the real situation of stigma in leprosy and seeking solutions.

1.2 Introduction about Dadeldhura district and leprosy situation:

Nepal is divided into 5 development regions, 75 Districts, 3,915 VDCs and 99 Municipalities. Dadeldhura district is one of the remote hilly districts out of 75 districts in Nepal. It lies in Far-western part of Nepal. Nepal is a federal democratic country. It is landlocked country in South Asia, between India and China. Dadeldhura district covers an area of 1,538 km² and had a

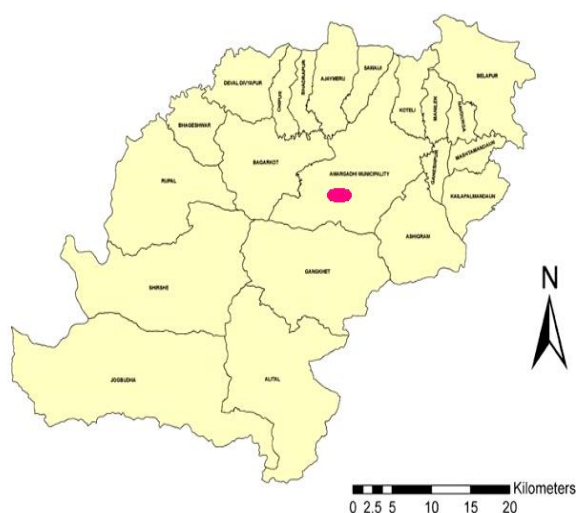


Figure 1 Map of Dadeldhura District

Source: DDC, Dadeldhura

population of 126,162 in 2001 and 142,094 in 2011. The district is entirely rural and has yet to be modernized. There are many kinds of problems in health education, agriculture and other sector. Since generations, leprosy disease has been one of the major health problems in Nepal. Team Hospital Dadeldhura (THD) provided services to LAPs at Dadeldhura and for people from surrounding areas more than 50 years. Leprosy is now controlled compared to past. However, the new cases are seen and the negative consequences of the disease are still prevailed. Mostly there is stigma and discrimination toward LAPs and their families in remote and rural area. The actual situation of the stigma in leprosy was hidden therefore the study has been done to understand the real situation of LAPs in this area.

Dadeldhura district is divided into 20 Village Development Committees (VDCs) and a Municipality (MP). The VDCs are- Ajaymeru, Alital, Ashigram, Bagarkot, Belapur, Bhadrapur, Bhageswar, Chipur, Dewal Dibyapur, Ganeshpur, Gankhet, Jogbuda, Kailpalmandau, Koteli, Manilek, Mastamandau, Navadurga, Rupal, Samaizi and Sirsha and Municipality is called Amargadhi.

According to Census 2011, at Ajaymeru VDC, there is population of 3,852, at Alital VDC there is population of 13461 and at Amargadhi, the municipal centre of Dadeldhura District center had population of 21,245. Accordingly, at Ashigram, VDC there is population of 3388, at Bagarkot VDC it is population of 4,632 and at Belapur VDC, it had population of 7,374. Likewise, at Bhadrapur VDC there is population of 2165, at Bhageswar VDC there is population of 3,717, at Chipur there is population of 2,724 and at Dewal VDC, and there is population of 5,879. In the same way, at Ganeshpur VDC, there is population of 3,592, at Gankhet VDC, there is population of 5,070. Similarly, at Jogbuda and Kailpalmandau, continually 21632, 4480 people live. Koteli VDC's population is 4,600. And, Manilek VDC 4,618 people use to live. Mastamandau and Navadurga VDC continually had population of 3,633 and 3,365. At Rupal, Samaizi and Sirsha VDCs, continually, there is population of 5780, 2,446 and 13,351. (Source: National Population and Housing Census 2011).

According to 2069/70 District Health Office (DHO), Dadeldhura, report the status of health facilities at Dadeldhura district: Hospital, Eye treatment Centre and PHC centre each are one and there are 16 health posts and 8 are sub-health posts (DHO Annual Report 2069/70).

Leprosy is one of the major health problems in this district. In the fiscal year 2012/13, 11 new leprosy cases were diagnosed at Dadeldhura hospital only from Dadeldhura district; and other cases often use to come to the hospital for having problems i.e. ulcers, reaction, regular medicine etc. (In the same year 3253 leprosy cases were diagnosed in Nepal, out of them 600 cases were from India.)

1.3 Statement of the Problem ,

Deformities and disabilities are consequences of leprosy. Loss of job, fear, isolation, rejection and sorrow are results leprosy and disability. Government of Nepal has not specific program for stigma reduction and behavior change toward leprosy affected people and their family members. Stigma is the result of the nature of disease, deformity, anesthesia, disability and other religious and cultural causes. LAPs and their family members have lot of social political problems in this region. They can't live freely like normal people, job security, participation in decision process who lose right to access resources etc.

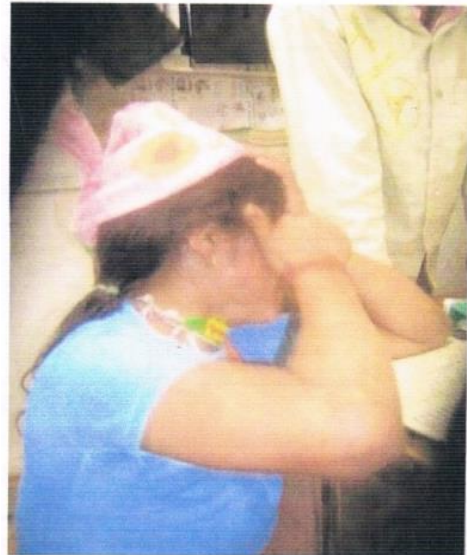


Figure 2 Patients feelings reflect their fear about the disease and discrimination they are facing in the communities; it's not easy to feel.

Source: TD Pant

Almost leprosy sufferers have only limit options to chose if excluded from the house either to go to leprosy colonies or go to beg.

The government provides free treatment to LAPs but has no specific activities conducted for stigma reduction and for protection of their fundamental rights. As well, there has not been sufficient study done in stigma reduction in this

region. People affected with disability (whether they are disabled due to leprosy) are getting services from the government whilst the moreover problems of stigma faced by LAPs are ignored.

1.3.1 Disability and Impairments Grading in Leprosy

As per World Health Organization (WHO), there are three types of disability related to Leprosy- DG 0, DG 1, and DG 2.

- i. Disability Grade (DG) 0: Normal eyes, hands and feet
- ii. DG 1: Loss of sensation but no visible deformities, legophthalmus on eye but vision power okay,
- iii. DG 2: Visible deformities on hands and feet, eyes affected by leprosy and vision power weak

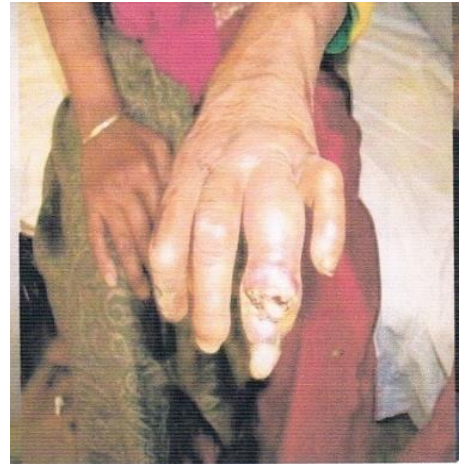


Figure 3 DG 2 Patient, visible deformities

Source: THD

1.4 Objective of the Study

The general objective of the study is "to understand and contribute to minimize stigma related to leprosy in the state, raise awareness in the community and contribute to effective national leprosy control program in Nepal."

Specific objective of the study are:-

- ❖ To understand the real situation of leprosy affected people and their families in the community.
- ❖ To identify the effectiveness of running program related to leprosy and stigma reduction in the state.
- ❖ To acknowledge knowledge attitude and practice (KAP) and behavior changed toward leprosy affected people and their family members in the community.

1.5 Significance of the Study

This study assists to understand the real situation of leprosy affected people and their families and problems they are facing. This study tries to explore the changed behavior and attitude toward LAPs and their family members. Study done in this field is not enough until this day. So it is hoped that this study will contribute to develop positive attitude toward LAPs and their families whilst it also realizes the real practices done in this sector by the government of Nepal.

Government of Nepal has set strategies for leprosy control 2011-15. One of the strategies is to enhance research activities in this field. Thus this study tries to assist in this national goal. This study is hoped to broaden knowledge about leprosy at national and local level. This study also enhance to increase political participation of leprosy affected people and disabled people due to this disease and support to empowerment. Furthermore this study will access to seek opportunities for them in decision making at both national and community level.

Through this study done on 'Role of State to Eliminate Stigma in Leprosy in the Context of Dadeldhura District', it is hoped that the finding of the study might resemble the situation of other districts in far western region as well. The study conducted here focuses especially remote and hilly areas. And, the finding of the study will contribute to Government's leprosy control program, rehabilitation of LAPs and stigma reduction.

1.6 Limitation of the Study

This study focuses leprosy related stigma only, but it doesn't cover other type of diseases or stigmas. This study is done in the context of Dadeldhura district whilst the general condition of national and regional is the sketch of this study. LAPs, local community people and local government non-government institutions were selected for interview; observation is held at field, questionnaire for related areas were incorporated. The conclusion of the study is generalized and recommended to apply in the study of Political Science in Nepal and furthermore it promotes the study of Political Science. The conclusion of the study may not generalize with other type of stigma in the state.

The study doesn't cover the whole state because it may differ from literacy level, geographical condition, different ethnic groups, beliefs and castes.

The data presented here is based on the received from sub-regional hospital Dadeldhura (previous HDCS-Team Hospital Dadeldhura). There might be other leprosy cases in the District if registered to another medical institutions i.e. patients from Jogbuda site may go nearby Dhangadhi NLR for treatment. If so, the number of patients may vary in the district.

1.7 Literature Review

'Leprosy' term in the context of world and national is tried to understand. It's medical and social aspect is reviewed and its consequences are explained. Government publications, WHO policies, newsletters, books and reports published related to leprosy are sources of literature here. Team Hospital Dadeldhura (THD) records and annual reports are reviewed. And, the notes and reports from local organizations working in leprosy and disability sector were studied during research. Social and political perspectives toward leprosy affected people; and leprosy stigma in the international, national and local context is obtained for the study.

1.8 Research Methodology

This study bases upon sociological and political aspects regarding leprosy affected people. This study explains about the state and social behavior and attitude toward LAPs. The study design is explorative and descriptive. The analytical design explains about social and political changes, beliefs toward LAPs. Interview is taken in the community in three categories:-

1. LAP and their family members, especially LAPs
2. Community people
3. Political parties, policy makers and service providers

Research tools are interviews, observation and questionnaire. Primary and secondary data are collected in the study. Sampling method is applied during primary data collection so that it may represent the population in general. All the collected data is verified, analyzed in statistical processing. Quantitative and

qualitative both kinds of data are analyzed. Data is presented in terms of frequency, percentage and distribution in graphs and tables.

1.9 Organization of the Study

This study is divided into five main chapters. The first chapter is introduction. Background of the study is located in the first chapter. Problem statement and objective of the study are in this chapter. Limitations of the study and significations of the study is included in this chapter. Importance of selection of the topic is justified in this chapter. In addition, relevant of the study is described in this part. Therefore this is the first part of the study.

The second chapter is about conceptual framework and study of literature. Literature review as received from books, articles, websites, and bulletins, government policies etc is reviewed and included in this chapter.

The third chapter is about research method used in the study. Research design is set in this part. Qualitative and quantitative data received from primary and secondary sources are integrated in this chapter. Population and sampling procedure is described in this chapter. Data collection techniques are defined in this part-interviews, observation, questionnaire etc. Reliability and validity of the data is ensured and research method is covered in this chapter.

The fourth chapter is data analysis and data presentation. Collected data from different sources regarding the leprosy problem is organized and presented in terms of graphs, bar-diagram, percentage, charts, etc. Ideas and concepts toward LAPs and their family members are presented in percentage of rational, dependent independent variables.

The fifth and last chapter is Summary, Conclusion and Recommendation. In this part, summary of the study, main finding and conclusion is covered and recommendation or further suggestion is presented. This chapter is brief but it is important. Therefore, it has been made clear, concise and specific oriented that presents the whole research.

CHAPTER II

CONCEPTUAL FRAMEWORK AND REVIEW OF LITERATURE

2.1 Introduction

Literature review used in this study is conducted with the previous studies on leprosy and political and social stigma. The literature review is used here aiming to fulfill the gap between periods and ages about history of leprosy, leprosy definitions, stigma and current situation of LAPs. Literature review provides information and guidance for further. Previous studies, objectives, findings and recommendations are deeply studied under this task. The main purpose of literature review is developing or searching new methods idea or information that are not conducted by the past researcher and it is supported by analyzing new data.

A literature review is a description of the literature relevant to a particular field or topic. It gives an overview of what has been said, who the key writers are, what are the prevailing theories and hypothesis, what questions are being asked and what methods and methodologies are appropriate and useful. Generally it is itself not primary and new research, but rather it reports on other findings. A literature review seeks to describe, summarize, evaluate, clarify and or integrate the content of primary reports." (Cooper, 1988)

A literature review may be purely descriptive, as an annotated bibliography or it may provide a critical assessment of the literature in particular area like in leprosy sector, starting where the weaknesses and gaps are contrasting, the view of particular authors, or rising questions. Such a review will not just be a summary but will also evaluate and show relationship between different materials so that key themes emerge.

2.2 Definition of State

A state is organized communities living under one government. Many human societies have been governed by the state; four essential elements that the state has: population, territory, government and sovereignty.

Harold Laski defines the State as "a territorial society divided into government and subjects claiming within its allotted physical area, a supremacy over all other institutions."

Robert Dahl says, "The political system made up of the residents of the territorial area and people living under one Government of the area is a 'State'.

According to above definitions of state, it has supreme power all over the institutions; it has allocated geographical area and people living under the government. State has extensive rule of law, citizenship rights and security and welfare of the people live in the place. A state is more than a government. Government changes but the state is constant. A state charges taxes, operates military and police forces. Some states are large, some are developed, somewhere there is violence, and some are in peace.

2.3 Responsibilities of the State toward its Citizens

States provide resources, facilities and protection to its citizens. Protect of human rights and provide freedom is responsibility of state to the people.

The state must be responsible for the well-being of the citizens. Residential rights, education facilities, health care, allocation of fair wages are arranged by the government. The state makes policy for the development of country to provide quality life of people. For this purpose, state makes different plans and policies. It performs different kinds of development activities such as education, health, transportation, safe drinking water etc. State makes rule and regulations; and it perform regular activities by the government which is formed through election. The Government should be responsible for providing good governance in the country.

Healthy people are wealth of the state. If everyone in the state has good health in the state they can perform each activity in better ways. Therefore it is responsibility of a state to provide good health facilities to people in the state and should focus for the development of health sector in the state.

For the development of health sector in Nepal, to provide health service to the people, Government established different level health institutions and hospitals all part of Nepal. Hospitals, primary health center, health post and sub health post are established and these provide health facilities to the people.

According to Greek philosopher Aristotle defines role of state, in his book 'The Politics', the role of state towards its citizens:" It provides all men's needs (material, social, religious, etc.) and offers them the fulfillment not only living but of living well in accordance with those virtues that are particularly human.

It is logical in the modern state too that state or its government should be ready to the assistance of its citizens when needs arise.

2.4 Definition of Leprosy

Leprosy is a chronic disease caused by micro-bacteria (*Mycobacterium Leprae*) affecting especially skin and peripheral nerves. It is characterized by the formation of nodules that enlarge and spread accompanied by loss of sensation with eventual paralysis, wasting of muscles and production of deformities. It is called Hansen's disease also. The disease mainly affects skin, peripheral nerves, nose, throat and eyes badly.



Leprosy has long history. Until the 20th Century, leprosy infected people were not accepted in

Figure 4 Leprosy patches over face and neck
Source: THD

the society rather segregated from society. They were compelled to live in isolated leper colonies. Today the disease is entirely curable through multi-drug therapy (MDT), still nearly 2.5 lakh new cases arise mostly in Asia, Africa, Central and South-America and the Pacific Islands every year. The dramatic decline in leprosy prevalence was attributed to a resolution passed in 1991 by WHO that the disease be eliminated by the year 2000. Disease elimination was defined as a reduction of prevalence to less than 1 case per 10,000 persons. The treatment is available though tissue damage before drug treatment cannot be reversed. In almost all cultures throughout history, leprosy has provoked horror about incurable disease and lifetime of progressive disfigurement.

In past leprosy was believed to be a hereditary disease. This made sense, leprosy frequently occurred in households among individuals who were members of the same family. In 1873, however, G.H. Armauer Hansen, a physician, in Norway, discovered the leprosy bacillus. Hansen was able to identify the organism under the microscope. His discovery became boon for the world that the dreadful condition due to leprosy in the world now is under control.

2.5 History of Leprosy

The disease is oldest disease in the world. It is believed to have originated on the Indian subcontinent. Indeed, the most ancient evidence of leprosy comes from a 4,000-year-old human skeleton uncovered in India in 2009. Thus, there is evidence that leprosy existed in India by 2000 BC (S. Sermitirong and WH Van Brakel, 2014).

Tradition has it that members of the army of Alexander the Great contracted the illness when they invaded India in the 4th Century BC and carried it into the Europe (Hussain T, 2007). On the other hand, genetic analysis of the leprosy bacillus indicates the *Mycobacterium Leprae* (Scientific name of leprosy) may have evolved some 100,000 years ago in eastern Africa or southwestern Asia. From there it seems to have migrated eastward and westward, developing one distinct subtype in Asia and another subtype in Europe and North Africa.

In the Holy book Bible there is description of the "leper king" of Jerusalem. In Nepal, in some of the hilly areas funeral services were not conducted like normal people from generations to generations. Leprosy was considered to be a form of divine punishment for sins, and the outward signs of the disease also are normally ugly due to deformities and effective of medicine, if used.

It was in Norway that Hansen identified the leprosy bacillus in 1873. His great discovery made possible the modern era of treating the disease itself and leprosy has been finally treatable disease. For centuries oil derived from the seeds of chaulmoogra tree had been used to treat leprosy and other skin conditions in India and China. In the early 1980s experts assembled by WHO

issued the recommendation that all leprosy patients receive combination multi-drug therapy and that all the leprosy treatment is strictly limited in duration.

2.6 Treatment of Leprosy

The current treatment of leprosy is extremely effective compared to past, halting the progress of the disease. The bacilli can be killed rapidly and multi-drug therapy- the use of two or more multi-drugs in combination prevents the development of drug-resistant strains. A multi-drug regimen developed by WHO is the current standard of treatment.

Currently treatment course of the disease is normally six months to 24 months. For patients with localized forms of leprosy and relatively few leprosy bacilli bodies, two drugs, dapson and rifampicin, are given for a total of six months. For patients with more widespread disease and relatively large number of bacilli, three drugs- dapson, clofazimine and rifampicin are given for 24 months. Most patients are able to tolerate the drugs well, but a few experience undesirable side effects. These disabilities can interfere with their ability to earn a living and otherwise lead a normal life.

2.7 Stigma in Leprosy: Concepts and Causes

2.7.1 Stigma in Leprosy

Stigma related to leprosy is caused by visible manifestations in people affected by leprosy, beliefs regarding causes of the disease and its treatment, fear of transmission, association of those affected with groups of people perceived as 'inferior', and public health measures that treated leprosy differently from other diseases.

There is evidence from different cultures that leprosy is registered as a punishment. For instance, among Christians, Hindus and Buddhists, leprosy may be regarded as a punishment for sin or misdeed in this or previous life. Some beliefs may gradually change, such as the belief that leprosy is god's punishment for sin, as people began to understand the biological cause of leprosy. Clearly, however, people may believe in several different causes operating at different levels. But it is a challenge to change the belief that

leprosy is incurable as people recognize leprosy by its impairments that cannot be hidden. And, it is challenging to change that belief that leprosy is hereditary, because people know from experience that leprosy occurs in particular families or groups of people.

Leprosy is a chronic disease that was recognized in the ancient civilizations of China, Egypt and India. (WHO,2014). At that time neither the biological cause nor treatment of the disease was known. Thus leprosy patients developed severe skin conditions and disabilities that terrified people. At present, the root cause of disease is discovered by GH Armauer Hansen and the treatment is also available, however, the stigma attached to leprosy still persists in most countries. (Idwani C, Yulizar M, Lever P, Varkevisser C, 2002)

Stigma is a serious obstacle to case finding and to effectiveness of treatment which are the major concern of disease control programs. Many attempts have been made to reduce the stigma attached to leprosy. For instance, leprosy services have been integrated into the general health care system to reduce the differences between people affected by leprosy and those suffering from other health conditions. Alternative terms have been used instead of 'leprosy', such as 'numbing skin disease', Hansen's disease' but still the stigma scale is not down.

In Thailand, leprosy affected people are still stigmatized by health providers and by their neighbors (Primkaew W, Supanant C, Rasameecham S et al, 2008). Some leprosy patients have been ignored and refused treatment of their ulcers by nurses (Predswat P, 1992). Before applying for certain types of work, applicant needs confirmation from a doctor that a doctor that he/she doesn't have leprosy (Sukhothai Thammathirat Open University, 2010).

2.7.2 The Concept of Stigma

Stigma is a Greek word that in its origins referred to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves or traitors, to visibly identify them as blemished or morally polluted people (Rebecca JF, 2003). These individuals were to be avoided, particularly in public places. The word was later applied to other personal attributes that are considered shameful or

discrediting. In relation to health, stigma was defined by Erving Goffman as an attribute that signifies that an individual is different from 'normal' people and, further that the person is 'of less desirable kind-in the extreme, a person who is bad, or dangerous or weak. (Goffman E. 1963)

Weiss and Ramakrishna defined stigma as 'a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular problem.'(Weiss MG, Ramakrishna J, Somma d, 2006)

Jones et al. defines stigma as 'a mark or attribute that links a person to undesirable characteristics or stereotypes' (Jones E, Farina A, Hastorf A et al, 1984). In some of the countries the government attempts to confine the transmission of leprosy by isolating people affected into leprosy colonies is likely to have helped to complete this separation of "us" from "them".

Link and Phelan referred to stigma as 'a dynamic process that is linked to competition of power and tied into existing social mechanism of exclusion and dominance (Link BG, Phelan JC, 2001).

From above definitions it is known that stigma is a concept that one person or group of people sees other person or group of people abnormal and the powerful one desire to dominate other one. Stigma can take on different 'faces'. It may be taken as understate other people, particularly in the early stages, for instance when people start asking questions of a person, or when they gossip about someone. As a result the stigmatized people may experience loss of self esteem and dignity, and or fear, shame, hopelessness and guilt.

2.7.3 The Causes of Stigma

2.7.3.1 Values and Beliefs

Values and beliefs can play a powerful role in creating or sustaining stigma such as the belief that leprosy is a divine curse or is caused by sin in a previous life.

In a study on Community Behavior in Eastern Nepal towards leprosy affected people, De Stiger et al shows that the person affected by leprosy tries to hide their disease out of fear for negative community behavior (stigma). They state that person affected by leprosy experience exclusion from social life. They have difficulties in getting employment or they are refused jobs. In general, persons affected by leprosy experience unsympathetic reactions likewise insults, hate, rejection etc.

2.7.3.2 Nature of Disease

Three studies held in Thailand also yielded similar results as those in Indonesia and in Nepal. Leerapun found that visibility of deformity was positively correlated with the level of stigmatization by the community (**Leerapun P. 1989**).

One problem in leprosy treatment is related with the late diagnosis of the disease. *Mycobacterium Leprae* multiplies lowly and the incubation period of the disease is about 5 years. Symptoms can take as long as 20 years to appear.

Some patients perceived rejection from their families and voluntarily left their homes for treatment in hospitals or colonies. After treatment, the ex-patients with visible deformities faced difficulty in adapting when they were back in their home. It is reported that most important attributes eliciting repulsion were the blood, puss from open wounds, disfigurements of the hands and feet. Some people with leprosy may have a distinctive odors caused by infected ulcers. This smell can be nauseating and was made worse in cases in which their communities don't allow people with leprosy to be in communal water like tap, river etc. And, people believe that leprosy is not curable because of its persisting external manifestations.

2.7.3.3 Religious and Cultural Beliefs

Since the ancient times, leprosy has been interpreted as god's punishment of the sinful act upon mankind. The Bible, particularly the book of Leviticus 13, is usually quoted in that context. Leprosy may have been used as a metaphor for sin. Leprosy is like sin in many ways. There are some good reasons. Leprosy is like sin in that it begins as nothing, its painless in its first stages, it grows slowly, it often remits for a while and then returns, it numbs the senses-one cannot feel in the afflicted area, it causes decay and deformity, it gives a person a repulsive appearance (The Church of Jesus Christ of Latter-day Saint, 2012). This particular stigma is not only in Christian religious traditions but it is described in other regions also. Entwistle describes how a belief which originated in Iran was transmitted to India. People afflicted with leprosy were considered to be sinners against the sun. Bathing in specified places like Suryakunds in Mathura was assumed to have healing power (Navon L, 1998)

According to Try and Brown, Hindus believe that impairments resulting from leprosy are a result of misdeeds in a previous life that caused bad *karma*, or a divine punishment, and the Chinese believed that leprosy was sexually transmitted by contact with a prostitute, and therefore a punishment for immoral behavior (Try L, 2006).

Try reported from a study in Nepal that communities held the belief that leprosy was a punishment from the gods for sins committed by patients or their relatives in present or previous lives (Idwani C, Yulizar M, Lever P, Varkevisser C, 2002). According to Budhathoki, this is usually attributed to failure to respect the gods by making appropriate offerings or serious violations of social norms (Brown W., 2006). Buddhist belief leprosy disease considered to be contagious and incurable (Predswat P, 1992). A man with leprosy was not allowed to enter the monkhood. The illness disqualified a person from becoming a monk, a position regarded with high respect by the people

Other causes of leprosy which people have been reported to traditionally believe are witchcraft, a curse, trespassing of food taboos, contagion and being hereditary (Stigter DH, de GL, Heynders ML, 2000). In Thailand, it was also

reported that leprosy was thought to be hereditary, because the community often saw many cases of leprosy in one family. Villagers were thus banned from allowing their children to marry people with leprosy (Predswat P, 1992). In the same country, many people with leprosy related disability were sent to a leprosy colony by their families as they were brought to be cursed or deserved social segregation (Pisuthipan A, 2007).

2.7.3.4 Fear of Disease

The fear of transmission is evidently one of the main reported causes of concern for people in a community. This fear is enhanced by the visible signs that make people want keep a safe distance and especially take care that their children, considered most vulnerable to infectious, stay away from a 'patient'. Fear has also been reported to be based on prevailing inaccurate belief.

In Brazil, traditional notions that leprosy is an incurable, disabling and highly infectious disease widely prevail and lead to unnecessary fears and stigmatization of patients (Moreira T, Varkevisser C, 2002). Villagers in Thailand believed that once the person with leprosy was deformed, there was no cure and that the patient cannot return to a normal state (Predswat P, 1992). In Nepal it was commonly believed that touch or close contact is the main cause of transmission. In Nepal people believe that transmission could occur through food, water, air, feces and patients excreta such as urine, sweat, pus from ulcers, semen and vaginal fluid. (Try L, 2006).

Predaswat commented that leprosy was seen as a loathsome disease rather than a contagious disease because people in advance stages of leprosy were characterized by bodily disfigurement, ulceration, excessive sweat and bad odors.

2.7.4 The Effects of Stigma

The effects of stigma may be psychological. For example, a stigmatized person can feel fear or shame, which can lead to anxiety and depression. Due to this, or because of discrimination or stigma, they may no longer take part in any social activities. This limits social participation and leads to social exclusion. Social exclusion or discrimination in turn may result in an economic burden for the affected person and their household and thus cause poverty. Because of stigma, almost leprosy suspected person do not seek help for diagnosis and early treatment. This may worsen the health condition. The risk of disability may also increase. Stigma thus hinders the effective treatment and care of the person.

Stigma can come from anyone; family members, neighbors, employers, classmates, fellow believers in church or at the mosque or temple, but, importantly also from health workers. Stigma from health workers can be particularly hurtful, since they may be the people a person turns to for help. People often do not realize that they stigmatize. People affected by leprosy don't feel safe attending in public places as they are insulted or rejected.

Overall, stigma is likely to have a negative impact on the quality of life of affected persons, their family members, health programs, and in society.

2.7.5 Key messages about leprosy

According to WHO guideline, there are 4 key messages about leprosy for the general public, which can be expressed in different ways and it further minimizes stigma in leprosy.

* **Curable:** leprosy is an infectious disease but the risk of developing the disease is low. It can be cured with drugs that are widely available and are free-of- charge.

* **Early signs** of leprosy are pale or reddish skin patches, with loss of sensation; early detection with appropriate treatment helps to prevent disability from leprosy.

* **No need to be feared:** the disease can be managed just like any other disease; affected people should not suffer any discrimination. Treated persons are no longer infectious.

* **Support:** Affected people need the support and encouragement of their family and community, firstly, to take MDT and any other treatment as prescribed, and secondly, to be able to live as normal life as possible.

(WHO South East Asia Office, New Delhi 2006)

2.8 Leprosy related Stigma in Nepal

Stigma in leprosy in Nepal is a major problem that affects directly to the leprosy affected people and their family members. There are many examples of LAPs are suffered due to highly prevailed stigma in the country throughout the history. In Rana's regime in Nepal, LAPs were not allowed to enter Kathmandu valley. Laws may be discriminatory, allowing divorce on grounds of the spouse having or developing a particular health condition or banning people from public offices, elections or land ownership. None of the Government cares the patient seen in the street or around the temple begging or in India.

Nepal has officially eliminated leprosy on 2009, but the challenges still remain. Even today, it is not easy to access available resources for LAPs. For example, A 65 year old man died drenched in his own urine and stool in western Nepal after he was infected by the raging diarrhea in his district but not get any medical aid because he was suffering from leprosy (Indo Asian News Service, July 29, 2009)

Throughout history, there has been a stigma shadowing leprosy. People affected with the disease were secluded and placed in 'leper colonies'. These people were placed in colonies that were isolated and far away from the rest of the population. Thus, leprosy not only led to physical disability, but also mental and emotional trauma (Spotlight News Sunday August 17, 2014)

Now days, there is evidence that Thai people use the terms- khi ruan and khi thut, which means translate as 'leprosy' and 'leprosy with disability'- to degrade another person. In Nepal also people use term 'kodi' to degrade another person.

2.8.1 Efforts of Government to eliminate leprosy and its stigma in Nepal

Khokana Leprosy Asylum was the first health institution established by the state in 1857 AD; actually it was to isolate the leprosy patients by the Government. As there was no treatment discovered for leprosy patients at that time, people with leprosy were just detained by the home department. Later on, leprosy hospital was established in Tripureswar. In 1935, the Leprosy Asylum in Khokana, Kathmandu was upgraded to sanatorium and new leprosy sanatorium constructed in Syangja also.

Likewise in earlier days, many other organizations established and they served in leprosy field in Nepal. They provided leprosy service through hospitals and rehabilitation centers. Anandaban Leprosy Hospital established in 1963, Kaski-Green Pasture Hospital established in 1957, Team Hospital Dadeldhura established in early 1960s. After the establishment of these hospitals and missions the dreadful condition of leprosy in Nepal is gradually controlled and such services, moreover played role in stigma reduction.

Leprosy disease was considered ruthless disease since generation in Nepal. But now the government has given priority to leprosy as a public health disease and it has initiated activities to control leprosy. After establishment of Leprosy Control Division (LCD) in 1966 by the Government of Nepal, it has played major role to eliminate out leprosy from nation. Thousands of cases have been treated and saved from disabilities and deformities. According to survey conducted in 1966, 100,000 leprosy cases were presented in Nepal. At that time dapson monotherapy treatment method was available. After 1982, Multi-drug therapy (MDT) was started in leprosy treatment to some districts and by 1996 it was expanded to all 75 districts through district hospital and health posts. Leprosy Elimination Campaigns were conducted in 1999 and in 2001 by the government in Nepal.

In 2009, government announced that leprosy has been eliminated in the country according to WHO measurement of less than 1 case per 10,000 populations. The prevalence rate of leprosy was 0.89 per 10,000 in the country in the year it was eliminated. And, 2,445 leprosy patients were on treatment at that time. The factors behind the achievement were keeping leprosy elimination program in high priority and rapid responses toward the disease were the helping factors to achieve the goal. Now the government is paving its path toward eradication of leprosy by setting strategies 2011-15 and further planning.

Progress toward the leprosy elimination is continuing in Nepal. Monitoring and supervision of the activities are undertaken. Local, national, regional and international coordination channel has been set up. Similarly, LCD has set up coordinated health system within the country. It works in close coordination with regional and district offices, district and zonal hospitals, supporting agencies and non-governmental organizations.

2.8.2 State Policies

National Leprosy Control Division Nepal has set the following goal and objectives for leprosy control in Nepal (2011-2015). One of the strategies the government has set is to eliminate stigma and discrimination against LAPs.

Goal: Further reduce the burden of leprosy and to break channel of transmission of leprosy from person to persons by providing quality services to all the affected community. Finally to make leprosy free Nepal and leprosy free World.

Objectives: The objectives are:

- To sustain elimination of leprosy (prevalence rate below 1 per 10,000 population) and further reduce disease burden
- To reduce disability due to leprosy
- Providing high quality service for all persons affected by leprosy through integrated set-up
- To eliminate stigma/discrimination against persons and families affected by leprosy

Government's policy focuses on- timely detection of new cases and their treatment so that no further lives suffer from deformities and disabilities; and to eliminate leprosy as public health problem and further reduce the burden of country. Government practices for stigma reduction focuses on leprosy diagnose and early treatment, community based rehabilitation, awareness and income generation through formation of self help groups, monitoring and supervision of the programs at central, district and local level. As well, GoN is playing leading role in coordination for leprosy service throughout the country. However, in 2009, government announced that leprosy has been eliminated leprosy in the country according to WHO measurement of prevalence rate less than 1 case per 10,000 populations; it doesn't mean that leprosy has been eradicated, in Nepal. Leprosy elimination is declared but lots of people suffering with its consequences (i.e. disability and deformity, exclusion) are ignored and the stigma scale is not down.

2.8.3 Equity, Social Justice and Rehabilitation for stigma reduction

Equity means that leprosy patients have the same opportunity to attend health services that are of sufficient quality to deal with their problems. It also implies that leprosy services should be neither worse nor better than other health services available in a given community. Social justice means an absence of discrimination for any reason, including type of disease, level of disability, race gender, social class or religion; it includes the principles of privacy and confidentiality as well.

The UN standard Rules for Equalization of Opportunities for person with Disabilities (PWD) defines 'rehabilitation that it includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence , social integration, a better quality of life and self actualization.

According to WHO, leprosy may lead to physical, functional, social and or economical problems. Social and economical rehabilitation aims at social integration, equal opportunities and economic advancement. Community based rehabilitation (CBR) is defined as a strategy for the rehabilitation, equalization

of opportunities and social inclusion of all people with disabilities in the person's own community. CBR is a team work and requires full participation of the clients, their families and communities in the rehabilitation process. Organizations of people with disability need to be involved actively in the planning and management of rehabilitation services. Persons affected by leprosy, who are in need of rehabilitation, should have access by the government to any existing (general) rehabilitation services. Similarly, where leprosy specific rehabilitation services are available, people with other disabilities should be given access. This facilities integration helps to break down stigma and promotes sustainability of rehabilitation service.

In past, government tried to rehabilitate leprosy patients to leprosarium Khokana and Syangja districts which are the institution based rehabilitation rather than rehabilitating them into their own family. The improved rehabilitation model is better; rehabilitating them into their own home, own village which is called CBR. The plan was more focused to change the attitude of people toward the leprosy affected people to inclusion them to their own family own community.

Equity, Social Justice breaks the cycle of stigma in leprosy and rehabilitation key that saves leprosy affected people from de-habilitation and stigma in the state.

2.8.4 State Services reducing stigma of leprosy in the context of Dadeldhura District

At Dadeldhura, through District Health Office (DHO), government provides leprosy service. It conducts coordination, supervision, awareness, advocacy, monitoring etc. DHO contributes in elimination of leprosy related stigma according to the national strategy at district level. To, support Government leprosy program, other different organizations also are important partners in stigma reduction in leprosy. Such organizations are Sub-regional hospital, District Disabled Welfare Committee, DDC, self help groups, etc.

Since last many decades, leprosy patients from surrounding areas used to come in larger scale at THD for treatment. According to the hospital data, there

is more than 35 thousands leprosy patients' record enrolled for treatment. The hospital not only provided medical treatment to leprosy patients but also provided them assistance in rehabilitation and stigma reduction in remote and hilly areas at Far Western Region.

After agreement with the Government of Nepal (GoN), foreign doctors came to Dadeldhura and established hospital which is known as Team Hospital Dadeldhura (THD), It was formally established to treat the leprosy affected people in this hilly area in early 1960s at Dadeldhura. At that time none of the health facility was available was in this region. During those days, leprosy disease was considered big problem in society. In past people who were affected from this disease had to leave their family and village. People believe this disease as a punishment of gods. Many doctors and organizations connected to the hospital served these people who lost hope in life.

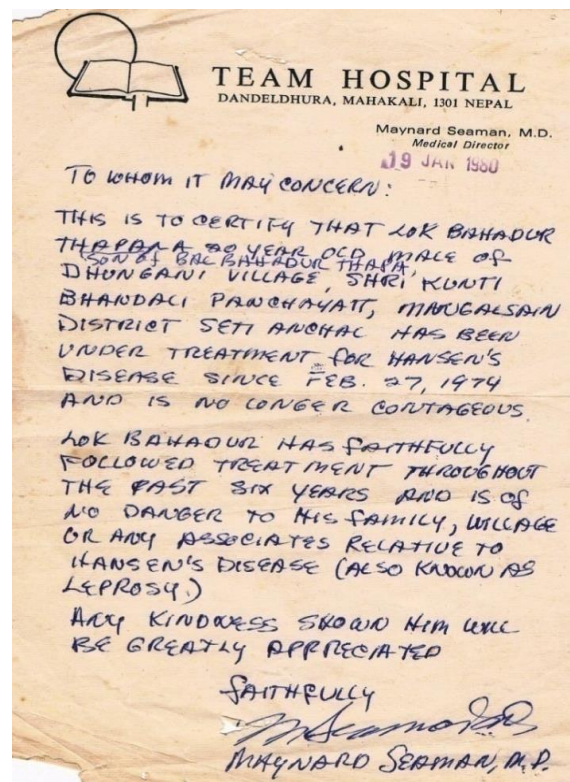


Figure 5 the letter written on 1980 (34 years ago) by the doctor, shows that the patient who got treatment at THD for 6 years can't easily go and live in the community. Therefore the doctor has written this letter for the community and patient's family for acceptance.

Source: Client

Even though thousands of patients were diagnosed of leprosy and given treatment service from this hospital from the beginning whilst the number of patients decreased now days. But still in many remote places new leprosy cases are being diagnosed. Taking a short glance at the data of past three years, patients are still being diagnosed with MB leprosy of disability grade two. It means there is still possibility of more hidden cases of leprosy in the community. The below chart shows 3 years record of new diagnosed at the hospital from Dadeldhura and surrounding districts. For example:

Table 2.1 Enrollment of new HD cases at THD during 2065/66-067/68

TYPE	Fiscal Year			Remarks
	2065-66	2066-67	2067-68	
MB	46	19	32	Multi-bacillary
PB	1	1	3	Pauci-bacillary
Total	47	20	35	

Source: HDCS-THD, 2011

Not only people suffer due to existence of disability in leprosy but also there is highly prevailed stigma in the Far Western Region especially in remote and hilly areas. Here is experience shared by one of a health staff ⁹ who is serving leprosy patients since last many years in this region. According to him, leprosy suspected people used to come at the hospital and after diagnosed leprosy many of them use to weep.

The disease (leprosy) still carries a great deal of social stigma, There are many heart touching stories of leprosy affected people in this region'. For example, once an old woman, about 85 came at the hospital; both hands and legs were badly affected with deep ulcers, bare feet. Her nephew, about fifty, was with her to care. After primary examination, she was waiting at the hall. Later on, she was found weeping alone there. Her nephew went away and left her alone there. Then, after counseling, she was admitted in the hospital. She was provided treatment and residential care. The incident became national news and later on, different organizations were ready to help her. (Source: Annual Report: HDCS-THD, 067/68)

It is felt that leprosy affected people cannot healed only by anti-drugs, they need lifelong support and encouragements. However, there have been changes in the situation but it is not said that leprosy is controlled and its consequences are managed.

One of the definitions by Mahatma Gandhi related to leprosy stigma is very popular. According to him, 'Leprosy work is not merely medical relief; it is transforming frustration of life into joy of dedication, personal ambition into

selfless service.' Most of the leprosy affected people not only need medical treatment but they also need counseling, encouragement, love and selfless care and service.

Although the leprosy incidence has plummeted in this region due to the great efforts of the public health service over the past 50 years, the problem still exists. However, due to raised awareness, proper counseling, early treatment, improved health system and effective rehabilitation, stigma-free society is possible.

2.9 Review of Books, Journals and Reports:

British Broadcasting Corporation (BBC), 1998: This is a report based on quantitative survey conducted by New Era, Kathmandu, and submitted to BBC. The data explains about different dimension of public perceptions about leprosy.

Brown W. 2006: Brown has prepared an essay on ' Can Social marketing approaches change community attitudes towards leprosy? It was published in the year 2006. This essay explores the stigma that people with leprosy and their family may face.

Cross H, Chaudhary R. 2005. An Intervention to address the issue of stigma related to leprosy in Southern Nepal. The writers have focused in the paper on the extent to which Stigma elimination program affected the social participation of people affected by leprosy in Southern Nepal.

Dadeldhura District Profile, 2067: The district profile is published by District Development Committee Dadeldhura for the purpose of providing brief information of social, religious, cultural, geographical situation and development activates. It also provides information about development status performed by DDC. Health sector and other development sectors are briefly described in it. It is a useful resource for them who like to know about Dadeldhura and development situation of the district.

De Stigter DH, de Geus L, Heynders ML. 2000. Leprosy: between acceptance and segregation: Community behavior towards persons affected by leprosy in eastern Nepal, Leprosy Review. The study describes community behavior towards LAPs in the eastern Terrain districts of Nepal. The result shows that negative community behaviors are mostly found in the fact that people fear infection and fear of a curse of god.

Floyd-Richard M, Gurung S, 2000: Stigma reduction through group counseling of persons affected by leprosy- a pilot study. The surveyors expressed about the experience they earned about the common effects of understanding through group counseling. .

Factors Affecting Perceived Stigma in Leprosy affected persons in Western Nepal, 2014. The book published by Bipin Adhikari, Nils Kaehler, Robert S. Chapman, Shristi Raut, Paul Roche is very useful book for the study of stigma in leprosy. In the book, it is maintained that there is urgent need to stigma reduction in leprosy and rehabilitation.

Global Strategy for Further Reducing the Leprosy burden and sustaining leprosy control activities (2006), published by WHO South East Asia, New Delhi: This book has provided technical guideline and treatment strategy for LAPs and it has also clearly mentioned how to minimize stigma in the community and prevent LAPs from de-habilitation. It also mention about the clear message for public about leprosy.

Hejinders ML. 2004. : The dynamics of stigma in leprosy. The write says that leprosy in Nepal is stigmatized disease.

HDCS-THD, 2011. Annual Report: Annual report prepared by the organization was reviewed and data were taken from that report. The report has focused about the leprosy case detection, treatment and need of stigma reduction and rehabilitation of patients in the community.

IDEA (International Association for Integration, Dignity and Economic Advancement) 1997: IDEA is an international association of LAPs which is fighting against stigma in the state and in the society. This association prepares a book in the title- Quest for dignity. And it has published many short life-stories

related to stigma toward LAPs. This organization has played major role in stigma reduction and for protection of rights of LAPs and stands up against prejudice.

Leprosy Control Program, Department of Health Services, Ministry of Health and Population, Government of Nepal Annual Report 2014: In this report data is presented and strategies prepared for stigma reduction.

Navon L.1998. Beggars, metaphors and stigma: This study is done by a student about leprosy situation in Thailand on 1998. She writes that progress in treatment is improved but patients keep their illness secret.

Van Brakel W. 2007. Disability and leprosy: The letter written by Van Brakel on 2007 provides an overview of recent findings and developments in research about leprosy-related stigma.

Weiss MG, Ramakrishna J. 2006. Stigma interventions and research for international health: Writers in this book described about stigma in many kinds of disease not only in leprosy.

Indo Asian News Service, July 29, 2009: This newspaper provided article on leprosy situation and stigma prevailed in the country during the time with examples.

Spotlight News Sunday August 17, 2014: The news published about stigma in leprosy is quite recent.

CHAPTER III

RESEARCH METHODOLOGY

Research methodology is a systematic way to solve a problem. It is a science of studying how research is to be carried out. Essentially, the procedures by which researchers go about their work of describing, explaining and predicting phenomena are called research methodology. It is also defined as the study of methods by which knowledge is gained. Its aim is to give the work plan of research.

Research methodology is concerned with the explanation of the following:

- (1) Why is a particular research study undertaken?
- (2) How is formula used in a research problem?
- (3) What types of data were collected?
- (4) What particular method has been used?
- (5) Why was a particular technique of analysis of data used?

The study of research methods gives training to apply them to a problem. The study of research methodology provides us the necessary training in choosing methods, materials, scientific tools and training in techniques relevant for the problem chosen.

The research methodology is applied in the study. Primary and secondary data are used in the study. Opinion survey technique was adopted while collecting primary data. Questionnaires were distributed to health staffs, leprosy affected people and their family members, community people and policy makers, service providers and political parties in order to know their opinion towards various aspects of leprosy and stigma. Numbers of leprosy affected people were taken interviews. For the analysis of data different statistical tools are applied. Mathematical tools are used to analysis the data. Out of different techniques percentage and Chi- square test of hypothesis are used for analysis.

3.1 Research Design

A research design encompasses the method and procedures employed to conduct scientific research. The design of a study defines the study type and sub-type, research question, hypotheses, independent and dependent variables, experimental design, and, if applicable, data collection methods and a statistical analysis plan.

When a particular research area has been identified, research problem defined and the related literature in the area have been reviewed. The next step is constructing the research design. Most of the material of this study was concerned with past phenomena of the performance in numerical or theoretical items and different people were interviewed in the field.

3.2 Area of Study

Nepal is divided into five development regions, 14 zones and 75 districts. Far-western region is least development region compare to other regions in Nepal. There are 9 districts in this region. Out of them, seven districts are hilly and mountainous and the rest two are plain areas. Dadeldhura District is situated in centre of the region which is a hilly district. The study done is held at Dadeldhura where there are 20 VDCs and a municipality. The researcher hoped that the selected district situation regarding stigma faced by LAPs resemble the situation of LAPs in other districts as well. Therefore, researcher conducted this study at Dadeldhura district.

3.3. Nature and Sources of Data

Both primary and secondary data have been collected in order to achieve the real and truthful result out of this study. All the possible and useful data as far as possible have been collected. The major sources of data's are as follows.

3.3.1 Primary source of Data

The major tools used for the collection of primary data was asking questionnaire to the related individuals. A set of questionnaires are developed and distributed to the selected respondents in order to get concrete and right information

related to the subject. The primary data's are collected from the following respondents.

- Leprosy affected people
- Community People
- Policy Makers, service providers and political parties

3.3.2 Secondary Source of Data

The secondary source of data has mostly has been collected through books, articles, newspapers and reports. The major source of secondary data's is listed below.

- Hospital Records
- Annual reports, news and articles
- Books related to leprosy
- Dissertation related to leprosy available at library of Siddhnath Multiple Campus
- Media resources

3.4 Population Sample

A sample is collection of items or elements from a population and universe. Hence a sample is only a portion or subject of the universe or population. It comprises some observations selected from the population. Here is the table that shows sample taken randomly from infinite population in different categories.

Table 3.1: Interview Categories

S.N.	Denomination of the Respondents	Sample
1	Leprosy Affected People	25
2	Community People	25
3	Policy makers, Service Providers and Political Parties	25
Total		75

Source: Opinion survey

The Leprosy affected people, people from community, policy makers and political parties and service providers in Nepal were considered as total population. Out of them, some of the respondents from Dadeldhura district were

considered as target sample. The denomination of the respondent has been presented in above table by random sampling method.

3.5 Data Collection Procedure:

As mentioned above, the study is done based upon primary and secondary data. The information of primary data was collected by developing a set of questionnaire and distributed it to the selected respondents in order to get actual information. Interview with concerned persons was taken separately. And sources of secondary were books, articles, websites, reports etc.

3.6 Data Analysis Procedure

Collected data from interview was classified into related groups. It has been tabulated, re-tabulated and presented into graph. To get more reliable information, required format has been used applied with mathematical tools and according to legal provisions.

The information received from primary and secondary sources was processed for tabulation and generally simple statistical tools have been used which are as follows.

- Percentage (%)
- Bar-diagram
- Trend line
- Test of hypothesis
Chi- square test (X^2 – test)

3.6.1 Test of Hypothesis

A hypothesis is a tentative statement about the relationship between two or more variables. A hypothesis is a specific, testable prediction about what is expected to happen in the study. It is measured in three bases:

- It is based on the topic
- It should be tested
- It includes independent and dependant variables

Therefore, hypothesis is used in this study and it is tested according to above measurement.

Variable is something that can be changed in characteristics or values. There are two types of main variable that are dependant and independent. Independent variable is affects the dependent variable.

A few examples:

Example 1: Social stigma occurs due to leprosy disease.

Table 3.2: Dependant and Independent variables.

Social stigma	leprosy disease
Dependant Variable	Independent Variable
Effect	Cause

Social stigma occurs (affect) due to leprosy disease (cause). Therefore, in this statement, leprosy disease is independent variable and social stigma is dependent variable.

Example 2: Leprosy can be healed after treatment.

Table 3.3: Dependant and Independent variables.

Leprosy patient healed	treatment
Dependant Variable	Independent Variable
Effect	Cause

Leprosy can be healed (effect) after treatment (cause). In this statement, treatment of disease is independent variable and healing from disease is dependant variable.

In the case of using hypothesis test chi-square test of hypothesis is used here. Chi – square test is a non parametric test because it depends only on the set of observed and expected frequencies, and degree of freedom. It describes the magnitude of discrepancy between theory and observation. It defines as

$$x^2 = \sum \left(\frac{(o - E)^2}{E} \right)$$

Where, O = Observed frequency,
 E = Expected frequency

For the application of chi-square distribution, chi-square test for goodness of fit is applied. If we are given set of observed frequencies obtained from respondent. As well, it is interest to know whether the experimental results support or not. A particular theory or hypothesis is said to be chi-square test for goodness of fit. It describes the magnitude of the difference between observed value and the expected value under some hypothesis.

If the observed values are close to the expected values under a hypothesis, the fit is said to be good. If, however the difference between the two set of figures are found to be significant otherwise the fit is not good. Similarly the further computation is made with $(r-1) (c-1)$ degree of freedom. Level of significance is assumed 5 %.

3.6.2 Trend-line

Trend line is used here to show registered data of leprosy patients in year-wise, age-wise and territory-wise. The number of leprosy patient is shown vertically and other related information is shown in horizontally. Prepared figures are described to identify re-search objectives.

3.6.3 Bar- diagram

Bar diagram is a chart that uses either horizontal or vertical bars to show comparisons among categories. One axis of the chart shows the specific categories being compared, and the other axis represents a discrete value. Some bar graphs present bars clustered in groups of more than one (grouped bar graphs), and others show the bars divided into sub-parts to show cumulate effect (stack bar graphs).

CHAPTER IV

DATA ANALYSIS & DATA PRESENTATION

This chapter includes the presentation, analysis and interpretation of the data of leprosy affected people in order to fulfill the objectives of the study. It is necessary to get feedback of research work by analysis of data. Analysis of data provides best result of research work, otherwise it may be worthless.

After collection of data, it should be processed and should be recorded properly according to research plan. This chapter helps to provide knowledge and quantitative data and the situation of leprosy in different VDCs at different time at Dadeldhura District

4.1 Leprosy Cases: Year-wise

Table 4.1.1 Leprosy Cases Year-wise from Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District

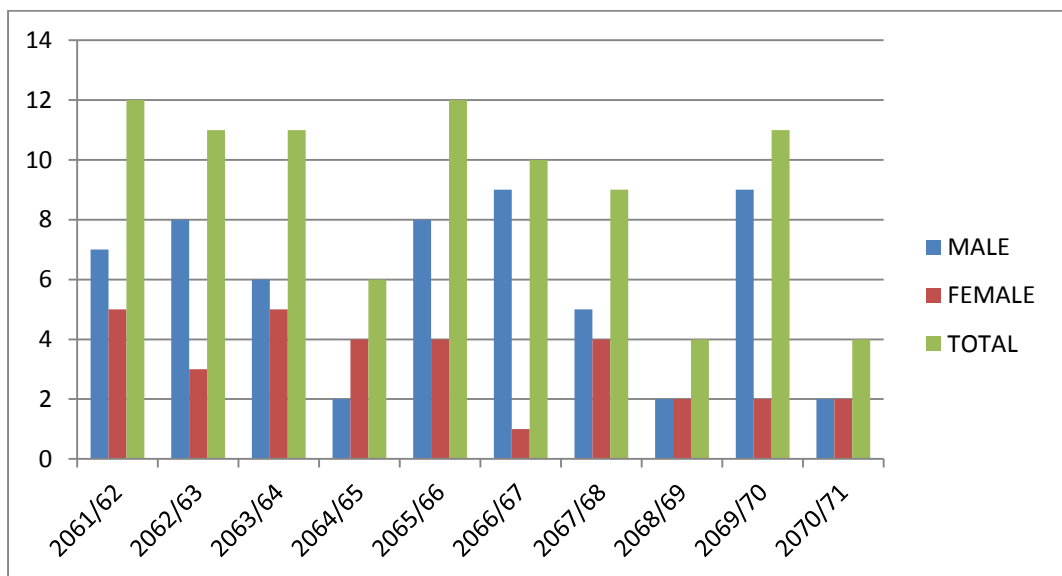
YEAR (FY)	MALE	FEMALE	TOTAL
2061/62	7	5	12
2062/63	8	3	11
2063/64	6	5	11
2064/65	2	4	6
2065/66	8	4	12
2066/67	9	1	10
2067/68	5	4	9
2068/69	2	2	4
2069/70	9	2	11
2070/71	2	2	4
TOTAL	58	32	90

Source: Sub-regional hospital Dadeldhura

Above table shows the situation of leprosy affected people registered for treatment at hospital in Dadeldhura district in the duration of fiscal year 2061/62 to 2070/71. In this period only 90 patients have taken health facility

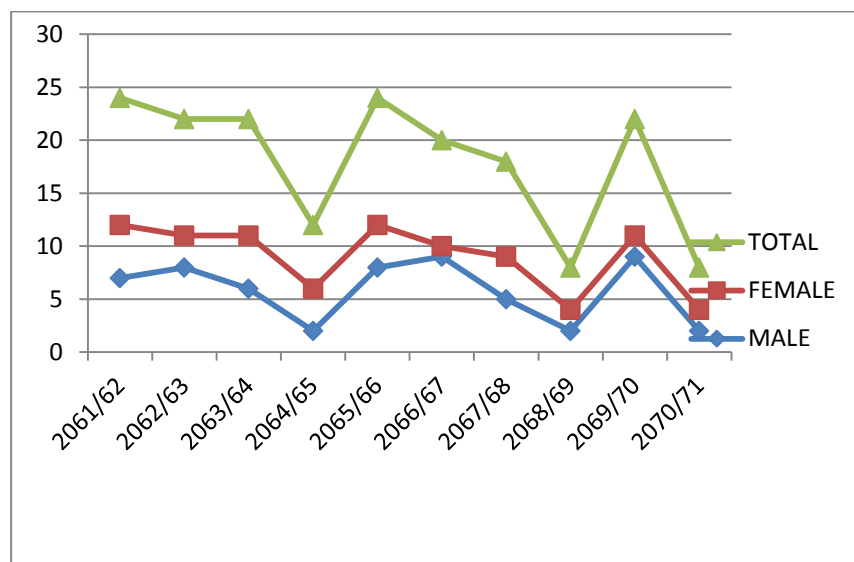
from the hospital; among them 58 male and 32 were female. In the year 2061/62, 7 male and 5 female took the health facility. Likewise in 2062/2063, 2063/64,2064/65,2065/66,2066/67, 2067/68, 2068/69, 2069/70, 2070/71 the number of male were continually 8,6,2,8,9,5,2,9 and 2 and the number of female were continually 3,5,4,4,1,4,2,2 and 2. This includes only enrollment of new cases.

Bar diagram 4.1.2 Leprosy Cases Year-wise from Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District



Above bar diagram shows the situation of leprosy diagnosis and treatment at Dadeldhura district in the duration of year 2061/062- 2070/071. It means leprosy case detection and treatment at Dadeldhura district is average similar. The bar-diagram shows that after five year from 2065/66 to 2069/70 the number of leprosy patients is near similar (increased).

Trend Line 4.1.3 Leprosy Cases Year-wise from Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District



Given trend line shows the enrollment of leprosy patients at the Dadeldhura for treatment service from the year 2061/062- 2070/71. The trend line shows that new detection cases are decreasing but in slow pace. Sometimes it's rising, i.e. in the year 2069/70 number of patients increased than precious year, but again in last year it decreased.

4.2 Leprosy Cases: VDC-wise

Table 4.2.1 Leprosy Cases VDC-wise from Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District

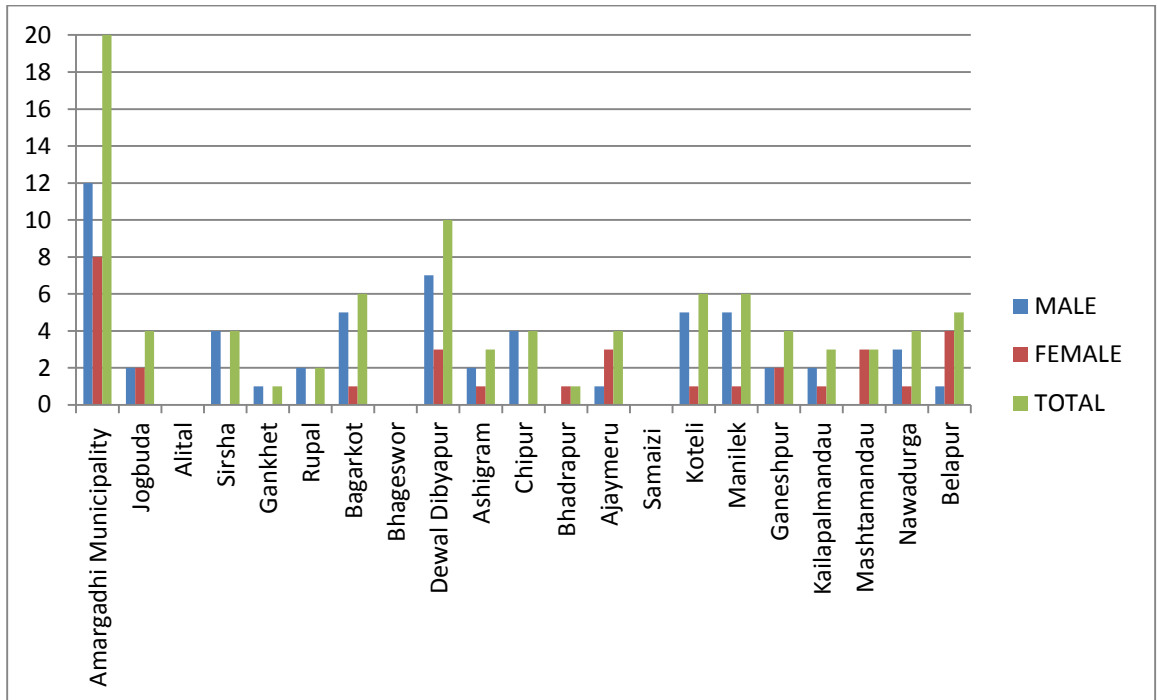
VDCs/MP	MALE	FEMALE	TOTAL
Amargadhi Municipality	12	8	20
Jogbuda	2	2	4
Alital	0	0	0
Sirsha	4	0	4
Gankhet	1	0	1
Rupal	2	0	2
Bagarkot	5	1	6
Bhageswar	0	0	0
Dewal Dibyapur	7	3	10
Ashigram	2	1	3

Chipur	4	0	4
Bhadrapur	0	1	1
Ajaymeru	1	3	4
Samaizi	0	0	0
Koteli	5	1	6
Manilek	5	1	6
Ganeshpur	2	2	4
Kailpalmandau	2	1	3
Mastamandau	0	3	3
Navadurga	3	1	4
Belapur	1	4	5
Total	58	32	90

Source: Sub-regional hospital, Dadeldhura

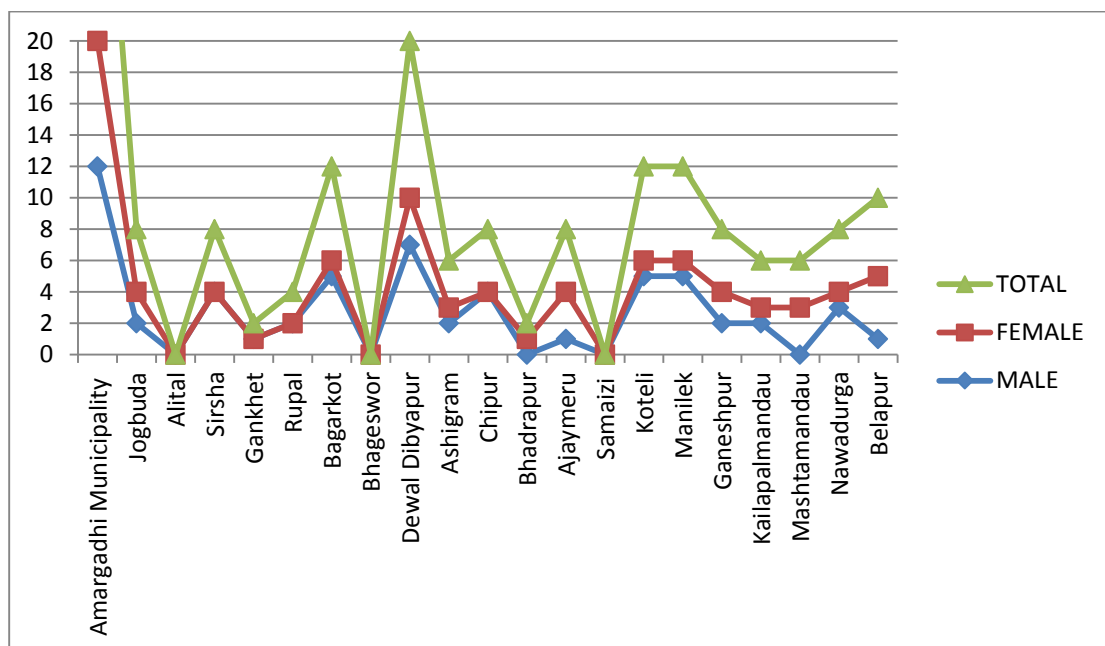
Given table shows the leprosy cases VDC-wise from fiscal year 2061/062 to fiscal year 2070/071 at Dadeldhura district. The highest number of leprosy patients are from Amargadhi municipality where male are 12 and female 8 , the total number of leprosy patient are 20. At Jogbuda 2 male and 2 female; Sirsha male 4, Gankhet male 1, Rupal male 2, Bagarkot male 5, female 1, Dewal Dibyapur male 7, female 3, Ashigram male 2 and female 1; at Chipur male 4, Bhadrapur female 1, Ajameru male 1 female 3 Koteli 5 male and 1 female , Manilek 5 male and 1 female, from Ganeshpur Male 2 and female 2; at Kailpalmandau male 2 and female 1, at Mastamandau female 3 , Navadurga male 3 female 4, and Belapur male 1 and female 4 new case of leprosy were found. There is no one leprosy patient registered at hospital from Alital, Bhageswar and Samaizi VDCs since past 10 years according to above data.

4.2.2 Bar diagram Leprosy Cases VDC-wise from Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District



Given bar-diagram shows the VDC-wise leprosy case detection in the duration from fiscal year 2061/062 to fiscal year 2070/071 at Dadeldhura district. The bar-diagram shows that the highest numbers of leprosy patient are from Amargadhi municipality but among VDCs the highest leprosy cases are registered from Dewal Dibyapur whilst from some VDCs there are no leprosy cases registered in this duration.

4.2.3 Trend-line of Leprosy Cases VDC-wise from Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District



Given trend line shows the VDC-wise leprosy case detection in the duration from fiscal year 2061/062 to fiscal year 2070/071 at Dadeldhura district. The trend line shows that the highest numbers of leprosy patient are from Amargadhi municipality but from VDCs Samaizi, Alital and Bhageswar VDCs, no leprosy cases registered in this duration.

4.3 Leprosy Cases: Age-wise

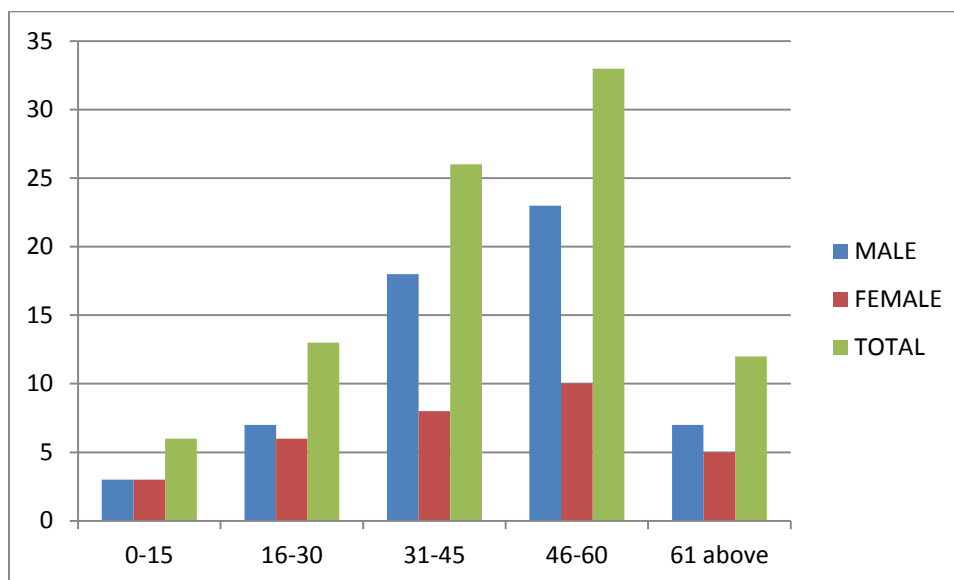
Table 4.3.1 Leprosy Cases Age-wise Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District

AGE GROUP	MALE	FEMALE	TOTAL
0-15	3	3	6
16-30	7	6	13
31-45	18	8	26
46-60	23	10	33
61 above	7	5	12
TOTAL	58	32	90

Source: Sub-regional hospital Dadeldhura

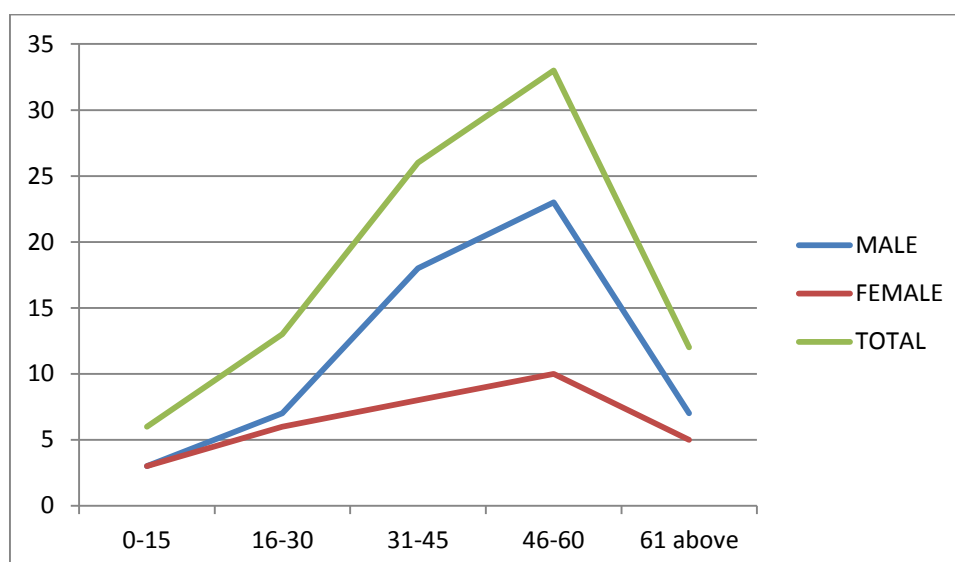
Above table shows the age-wise number of leprosy cases in fiscal year 2061/62 to fiscal year 2070/71. According to the data, the highest numbers of cases is 33 of the age group 46-60 and the least number of cases are 6 of the age group below 15. It is also shows that the male cases are more than female cases.

Table 4.3.2 Bar-diagram of leprosy Cases Age-wise Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District



Above bar diagram shows the number of leprosy cases age-wise from fiscal year 2061/62 to fiscal year 2070/71. According to the data the highest numbers of cases is 33 which is from age group between 46-60 and the least number of cases are 6 of the age below 15. It also shows that the male cases are more than female cases. Reasons may be different. Reasons might be female cases are hidden the community. They usually not allowed going outside for treatment or they are busy with household tasks or they feel uneasy to health checkup. In addition, bar-diagram shows that numbers of people after age 46 are increased. The reason might be that people hesitate to go to diagnosis and treatment in early ages. Normally after ages 40, when they get sever affects of leprosy in the body like deformities, ulcers, they step out for treatment.

Trend-line 4.3.3 of Leprosy Cases Age-wise Fiscal Year 2061/062 to Fiscal Year 2070/071 at Dadeldhura District



Above trend line shows that the number of leprosy cases age-wise in fiscal year 2061/62 to fiscal year 2070/71. According to the data the highest numbers of cases is 33 which are from the age group between 46 to 60; and the least number of cases are 6 which are from the age group below 15 years. It also shows that the male cases are more than female cases.

4.4 Situation of Government Health Services at Dadeldhura District:

Here is the table that shows the available health facilities at Dadeldhura District.

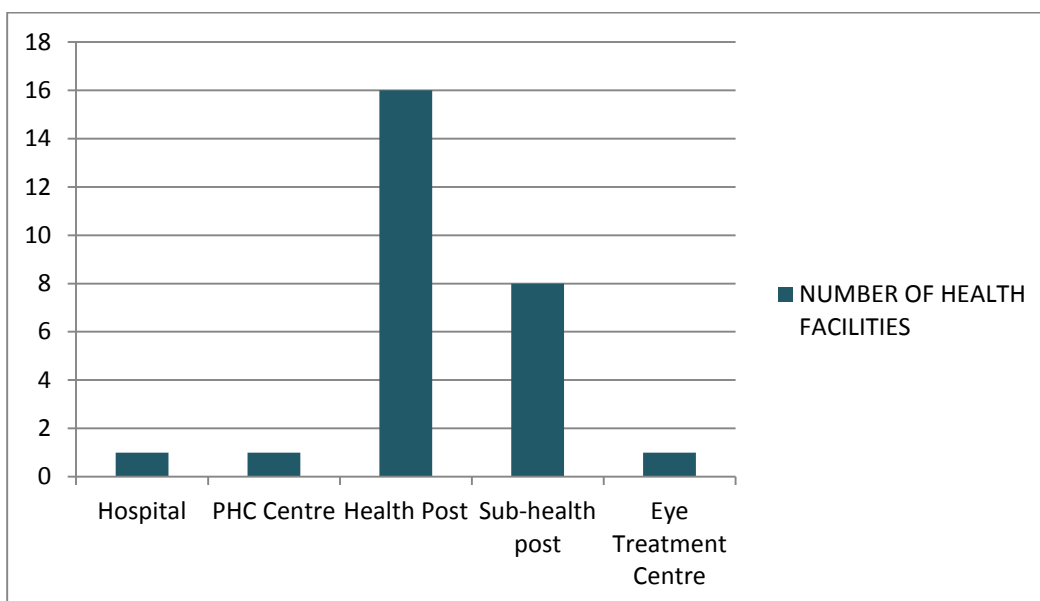
Table 4.4.1 Situation of Health Services at Dadeldhura District

SN	Particulars	Number of Health Institutions
1	Hospital	1
2	PHC Centre	1
3	Health Posts	16
4	Sub-health post	8
5	Eye Treatment Centre	1

Source: DHO Report

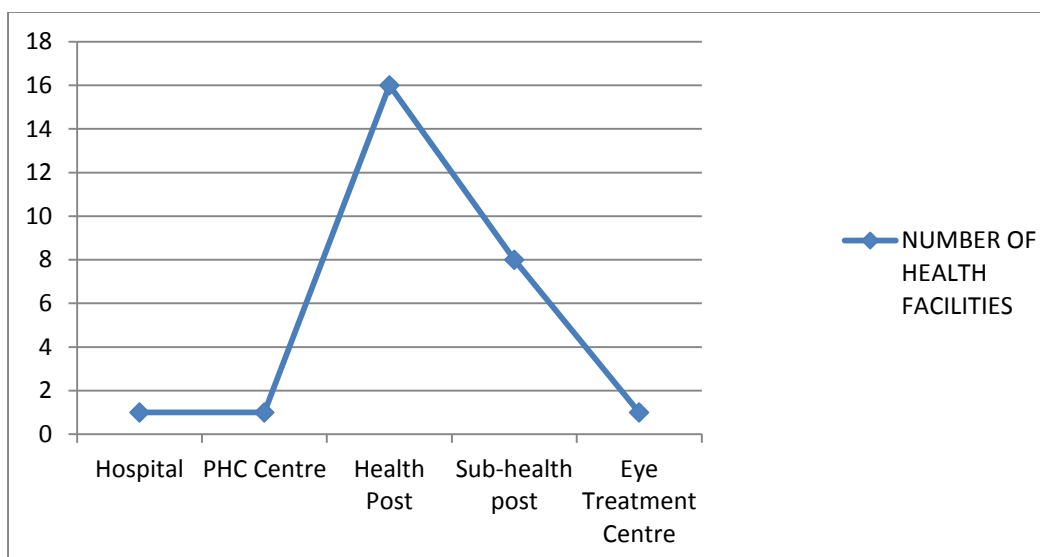
Given table shows the available health facilities at Dadeldhura District. There is one hospital, one PHC centre and one eye treatment centre; similarly health posts are 16 and sub-health post are 8 at Dadeldhura District.

4.4.2 Bar diagram of Situation of Health Services at Dadeldhura District



Given bar diagram shows the available health facilities at Dadeldhura District where there is one hospital, one PHC centre and one eye treatment centre; similarly health post are 16 and sub-health post are 8 at Dadeldhura District.

4.4.3 Trend-line of Situation of Health Services at Dadeldhura District



Given trend line shows the available health facilities at Dadeldhura District where there is one hospital, one PHC centre and one eye treatment centre; similarly health post are 16 and sub-health posts are 8 at Dadeldhura District.

4.5 Empirical Study

Empirical study is related with the investigation of condition of leprosy patients at Dadeldhura district. For the study, opinion survey is performed. A set of questioner is distributed among the leprosy affected people, community people, policy makers, service providers and political parties. And, then their collected opinion is arranged, classified, tabulated and used according to the research objective.

List of questionnaire are prepared to get 'yes' or 'no' answers (multiple choice) and some open questions also were asked. Highest choice answer gets high rank and least choice gets low rank. Rank is given between numbers 1-5. Then the number of respondents are converted into percentage and used as hypothesis test whether the response is significant or not given table shows the respondents nature as follows.

Table 4.5.1

Number of group and code used for respondents

SN.	Group of respondents	Sample Size	Code
1	Leprosy affected people	25	I
2	Community People	25	II
3	Policy makers, Service providers and political parties	25	III

Source: Result of Empirical Re-search.

4.5.1. Respondents Views:

4.5.1.1 Respondents View on Leprosy affected people are facing stigma and discrimination in the community

To know whether the LAPs are facing discrimination in the community or not, Yes No questions were asked to individuals. The question was "Do you think leprosy affected people are facing stigma and discrimination in the community?" Following answers were found from respondents.

Table 4.5.1.1

Leprosy affected people facing stigma and discrimination in the community

Respondents	Yes		No		Total	
	Number	%	Number	%	Number	%
I	16	64%	9	36%	25	100%
II	15	60%	10	40%	25	100%
III	18	72%	7	28%	25	100%

Source: Opinion Survey

From the above opinion survey most respondent have given answer 'yes'. I, II and III groups' opinion is respectively 64%, 60%, and 72%. Therefore, it is concluded that leprosy affected people are facing stigma in the community.

To know whether there is the significant difference between the views of community people and policy makers, service providers and political parties the Chi- square test of hypothesis is used and view of Leprosy affected people is assumed constant.

Table 4.5.1.2

Test of Chi-square

Respondent	Yes	No	Row total
II	15	10	25
III	18	7	25
Column total	33	17	50

Source: Opinion Survey

Step- I setting of hypothesis

Nul Hypothesis (H_0): There is no significant difference between policy makers, service providers; political parties and community people's view that leprosy affected people are facing stigma and discrimination in the community.

Alternative hypothesis (H_1): There is significant difference between community people and policy makers, service providers and political parties view that leprosy affected people are facing stigma and discrimination in the community.

Step II Computation of test statistics.

$$x^2 = \sum \left(\frac{(o - E)^2}{E} \right)$$

Where,

O = Observed frequency,

E = Expected frequency

$$= \frac{RT \times CT}{\text{Grand Total}}$$

Table 4.5.1.3

Row Column	O	E	(O - E)	(O - E) ²	$\frac{(O - E)^2}{E}$
1,1	15	(25 * 33)/50 =16.5	-1.5	2.25	0.14
1,2	10	(25 * 17)/50 =8.5	1.5	2.25	0.26
2,1	18	(25* 33)/50 = 16.5	1.5	2.25	0.14
2,2	7	(25 *17)/50 = 8.5	-1.5	2.25	0.26
				$\sum \frac{(o - E)^2}{E} = 0.8$	

Source: *Opinion Survey*

Step III Computation of degree of freedom and determination of level of significance.

$$d.f. = (r - 1), (c-1) = (2 -1) (2-1) = 1$$

Level of significance = 5 %

$$\text{Tabulated } x^2 = 0.05(1) = 3.841$$

Step IV – Decision

The calculated value of x^2 is < the tabulated value of x^2 (0.8 < 3.841). Therefore Null hypothesis (H₀) is accepted. It means there is no significant difference between community people and policy makers, service providers and political parties' view that leprosy affected people are facing stigma n the community.

4.5.1.2 Respondents View regarding the leprosy can be healed after treatment.

To know the opinion regarding the leprosy disease can be healed after treatment. A question "Whether the leprosy can be healed after treatment or not?" was asked. Then collected response is presented as follows.

Table 4.5.2.1

The leprosy can be healed after treatment.

Respondent	Yes		No		Total	
	Number	%	Number	%	Number	%
I	16	64%	9	36%	25	100
II	15	60%	10	40%	25	100
III	25	100%	0	0%	25	100

Source: opinion survey

Above table shows that 64% leprosy affected people gave 'yes' answer and only 36% gave 'no' answers in the given question. Similarly 60% community people gave answer 'yes' and all (100%) policy makers, service providers and political parties gave answers 'yes'; respectively, 36%, 40% and 0% was answers 'no' from community people and policy makers, service providers including political parties.

To know whether there is the significant difference between the views of leprosy affected people and community people (assumed policy makers, service providers and political parties constant) the Chi-square of hypothesis test is made below.

Table 4.5.2.2: Test of Chi-square(x^2)

Respondent	Yes	No	Row Total
I	16	9	25
II	15	10	25
Column total	31	19	50

Source: Opinion Survey

Step- I setting of hypothesis

Nul Hypothesis (H₀): There is no significant different between the view of leprosy affected people and community people regarding the leprosy can be healed after treatment

Alternative hypothesis (H₁): There is significant different between the view of leprosy affected people and community people regarding the leprosy can be healed after treatment

Step II Computation of test statistics.

$$x^2 = \sum \left[\frac{(O - E)^2}{E} \right]$$

Where, O= Observed frequency,
 E = Expected frequency
 $= \frac{RT \times CT}{\text{Grand Total}}$

Table 4.5.2.3

Row Column	O	E	(O - E)	(O - E) ²	$\frac{(O - E)^2}{E}$
1,1	16	(25 * 31)/50 = 15.5	0.5	0.25	0.02
1,2	9	(25 * 19)/50 = 9.5	- 0.5	0.25	0.03
2,1	15	(25 * 31)/50 = 15.5	- 0.5	2.25	0.02
2,2	10	(25 * 19)/50 = 9.5	0..5	0.25	0.03
				$\sum \frac{(o - E)^2}{E} = 0.1$	

Source: Opinion Survey

Step III Computation of degree of freedom and determination of level of significance.

$$d.f. = (r - 1), (c-1) = (2 -1) (2-1) = 1$$

Level of significance = 5 %

$$\text{Tabulated } x^2 = 0.05 (1) = 3,841$$

Step IV – Decision,

The calculated value of χ^2 is $<$ the tabulated value of χ^2 ($0.1 < 3.841$). Therefore Null hypothesis (H_0) is accepted. It means there is no significant different between the view of leprosy patient and community people regarding the leprosy disease can be healed after treatment.

4.5.1.3 Respondents View on Problems/ discrimination faced by LAPs

The respondents were asked to give their rank grading the situation of leprosy affected people and their family members. Questions were asked which problems are more serious than other. The answer of respondents is as follows:

Table 4.6.1

Problems faced by LAPs

SN	Problems/ discrimination	Group			Total Number	%	Rank
		I	II	III			
1	Leprosy affected people cannot contribute anything for the nation because of having leprosy	10	9	3	22	29.33%	V
2	People often patronize or treat them like a child, just because of having leprosy	14	13	8	35	46.67	III
3	People degrade their children and hate them	17	15	7	39	58.67%	II
4	Friends and neighbors make fun and patronize their family members	16	16	2	34	45.33%	IV
5	Negative effects in the family	21	17	15	53	70.67%	I
TOTAL		78	70	35	188	100%	

Source: *Opinion Survey*

Above rank grading shows that following are the major problems (situation) faced by the leprosy affected people and their family members.

- I. Negative effects in the family
- II. People degrade their children and hate them
- III. People often patronize or treat them like a child, just because of having leprosy
- IV. Friends and neighbors make fun and patronize their family members
- V. Leprosy affected people cannot contribute anything for the nation because of having leprosy

4.5.1.4 Respondents view on the role of state to eliminate stigma in leprosy

The respondents were asked to give their view on the role of state to minimizing the discrimination in the community. All the respondents were asked questions 'What should be the role of state to eliminate stigma in leprosy?' The answers given by respondents are shown in rank grading as follows:

Table 4.7.1

Role of State to eliminate stigma in leprosy

SN	Particulars	Group			Total No.	%	Rank
		I	II	III			
1	If special services and security be provided from the state	23	21	24	68	90.67%	I
2	If awareness raised and rehabilitation activities promoted	21	19	23	63	84%	II
3	If people affected with leprosy are encouraged to take part in political activities	15	16	10	41	54.67%	V
4	If they are encouraged and promoted to decision making level	22	22	17	61	81.33%	III

5	Promote media role	17	18	18	53	70.67%	IV
TOTAL							

Source: *Opinion Survey*

Above rank grading shows that following are the solution to minimize leprosy stigma and discrimination faced by leprosy affected people and their family members in the state. .

- I. If special services and security be provided from the state
- II. If awareness raised and rehabilitation activities promoted
- III. If they are encouraged and promoted to decision making level Promote media role
- IV. If people affected with leprosy are encouraged to take part in political activities

4.5.1.5 Response of people affected with leprosy in Some Separate Questions

Some questions were separately asked only to LAPs to know the real situation faced by them and their feelings toward themselves. These questions were not asked to respondents II and III. The result from LAPs is presented in given table.

Table 4.8.1

Response of people affected with leprosy in Some Separate Questions

SN	Particulars	Yes	%	No	%	Total
1	Having spoiled my life due to leprosy	16	64%	9	36%	25
2	I feel out of place in the world and feel inferior to others because I have leprosy	17	68%	8	32%	25
3.	Everywhere there is discrimination	15	60%	10	40%	25
4	Discrimination in the school toward children of leprosy affected people	13	52%	12	48%	25

Source: *Opinion survey*

5	Conflicts between husband and wife due to leprosy	8	32%	17	68%	25
6	Uneasy behavior done by relatives	22	88%	3	12%	25

Given table shows that 64 % and 36% respondents gave answer 'yes' and 'no' of the statement "having spoiled my life due to leprosy". At the same way, 68 % and 32% gave answer 'yes' and 'no' of the statement, "I feel out of place in the world and feel inferior to others because I have leprosy ". Likewise, 60 % and 40% gave answer 'yes' and 'no' of the statement, "everywhere there is discrimination". And, 52 % and 48% gave answer 'yes' and 'no' of the statement " Discrimination in the school toward children of leprosy affected people ". Similarly, 32 % and 68% gave answer 'yes' and 'no' of the statement " Conflicts between husband and wife due to leprosy. And, at last, 88 % and 12% gave answers 'yes' and 'no' on the statement, "uneasy behavior done by relatives ".

4.6 Main-findings from Interviews

4.6.1 Problems

People don't think that leprosy is also disease like other disease in the society. They think it is hereditary and there are many negative aspects. People often talk about LAPs negative in the community.

It is found that LAPs are kept away from the society and they cannot easily stay in society. They cannot be open, they are compelled to live secrete life. There is challenge for them to get married of their children too. There are not secured rights and opportunities for LAPs like *Dalits*, *Janjatis* and *Madhesis*. Government provides them free treatment service through health; however they don't get transportation (except one time support), lodging and food services during treatment period. But only it is not sufficient, therefore, the Government should focus about their rehabilitation and relief like activities.

Some of the interviewees agreed that living together, eating together, sleeping and behaving with each other, there is no problem; and, due to the previous

THD (current sub-regional hospital) services and services provided by Mr. Tara Datta Pant, leprosy is controlled in this region.

Old people have old concepts about leprosy but the concept of new generation is changed but patients still fear to live open life due to fear of society²¹. There is high fear and doubt in society about the disease. Patients hide or go to India fearing about their children could not get married if people know about the disease. Free treatment and other services (i.e. patients included in CBR) are provided for leprosy patients by the government but only clever and people from urban areas getting this kind of facility. Many people think that if a person gets sick, his/her whole generation and family are affected. ¹⁷.

4.6.2 Leprosy Services

Free diagnosis and treatment is provided to leprosy patients by the government. The people who are disabled due to leprosy are getting services likewise other disabled person. If LAPs are disabled, they are given priority like during election time etc.

Still patients are living hidden in rural areas. They don't come for treatment on time; they don't like to open because they fear of society. They fear about their children's marriage, and they fear that they will be rejected in society. Attempts for early treatment are done so that there should not be major loss and disability. Health education is provided to teachers as well so that stigma might minimize in remote areas ⁸.

4.6.3 Further Steps

In order to reduce the stigma and control the leprosy disease and its consequences; the government should focus the program in the remote areas not only in urban areas.

Media should play important role for minimizing leprosy stigma in society through spreading awareness and advocacy. If the government provides job (*Kota*) in offices and provides security them; politically if their seats be reserved, they'll get security and services. Laws should be maintained and be practicable

in case of discrimination and injustice toward these people. LAPs should be provided opportunities to take part in decision making process at each level. State should provide scholarships to their children's and employ them. It should not only be in papers. In order to reduce discrimination in society, special kind of training should be given to teachers also. And, state agencies should provide education about leprosy in the school,

Society also plays major role in rehabilitation of patients. Many educated people are also in fear and suspect about leprosy. Therefore in order to provide awareness and health education to the people in remote areas, political parties and the state jointly should make agenda to serve such people in remote areas. Some of the patients who are disable but don't have disability identity card and citizenship card should be provided as soon as possible.

In addition, If the government sure effective coordination channel and health system to address their issues, assists effectively in their rehabilitation, counseling, the discrimination might control.

4.7 Conclusion:

Respondent views are summed up in these points:

- Leprosy affected people and their family members are facing stigma and discrimination in the community.
- Leprosy can be healed after treatment.
- Integrated type method should be applied stigma reduction by the state.
- Almost leprosy affected people agreed that they feel different problems due to leprosy i.e. isolation, discrimination, uneasy behavior from relatives etc.

4.8 Political Parties View

State should be responsible for vulnerable and disabled people like leprosy sufferers. They should be provided residential care and employment opportunities. Their talents and skills should be promoted and protected by the government. The prevailed stigma and discrimination in leprosy can be

minimized through awareness and establishment of well equipped separate leprosy hospital in this region with provision of residential care and food support for such people. In the New Constitution, their rights should be preserved and secured.

4.9 Some Real Case Studies of Leprosy Affected People

Some of the case studies are collected and presented here.

4.9.1 Case Study No 1: Chandra

Chandra male of 31 lives in a remote village in Far Western Region. He was born normal but at the age of six or seven, his right leg started to become weak due to accident in the farm. His family spent much money seeking treatment; he could walk but not easily. He knew that he became disabling. Then, his life was tough to survive. He made disability identity card, but still he couldn't get any kind of support from the state or any other organizations as a disabled person.

Later on, he used to feel pain, tingling and burning and itching in the body. He stirred to different parts of Nepal and India seeking relief from it. His family spent lot money for diagnosis of the disease, consulted traditional healers, but nobody could diagnose the problem. At last when he came to THD, he was checked and diagnosed leprosy. He started MDT. After completing the course, he was encouraged for furniture making training. He took this training. After completing the training, he started a furniture shop at his own village. Now days, he is running it.

He feels encouraged and confidence that he is doing good job though he is leprosy affected person. He is now recovered but still he worries that so far he knows, no one in his family had such type of disease in his family before. He thinks that he shouldn't have leprosy. People at his village use to say that when the gods angry, leprosy occurs. He feels there are many other problems after leprosy. He goes for regular health checkup fearing that if again leprosy might be. He has to walk almost whole day to come for treatment. The disease has been main hindrance in his work. He feels that he couldn't study due to the

poverty, suffering from the disease and for seeking treatment. He thinks that if his children get education opportunity, their future would be better.

Still he is keeping his treatment secret even from his wife. (During treatment, his elder brother and he came to the hospital). He thinks if other people know about the disease, they would reject him in every sector, he might lose his work. Moreover, he fears about his children's marriage.

(Date: 2071/03/07)

4.9.2 Case Study No 2: Tek

Tek is man of 45. He thinks that his grandmother had leprosy. She died without taking medicine (MDT). She was kept away from home. A temporary hut was made for her far from the village and she used to live there. But this incident was before Tek was born. Then, his father got this disease. He came to THD, took treatment there. But later on he died of asthma.

In his opinion, leprosy is a hereditary disease. He thinks if one person in the family is leprosy affected then the disease transfers from one person to another, one generation to next. He thinks leprosy generally makes people like disable.

He says that at first, fifteen years ago, there were crack on feet, leg skin used to get dark, dry and red. He thought that it is because of gods. He concerned traditional healers, took herbal medicines but the problem was same. He went to Nepalganj and got some treatment of allergy and felt some relief for some days. Then he went to Lucknow (India) where he was told that it is leprosy. Later on, he went to the Sub-regional hospital Dadeldhura for treatment. Some health staffs suspected him another kind of disease and they sent him for blood check-up, He said that as he was going to lab room, he saw written in one corner 'Leprosy Clinic'. Then he concerned there. He was confirmed leprosy and admitted there for a week for sever reversal reaction neuritis.

He expressed that he suffered more than fifteen years due to this disease. He always worries that the disease has been callous for him and his family since generations.

(Date: 2071/03/12)

4.9.3 Case Study No 3: Ujeli

Ujeli is female of 40, living at Jogbuda. She has been diagnosed leprosy more than ten years ago, she got treatment of leprosy, but she is still suffering with ulcer. Therefore she always has to go to the hospital at Dhangadhi NLR or Sub-regional hospital Dadeldhura.

She use to run hotel at her own village but it has been tough job for her. Normal people often don't come. She says 'customers hesitate to buy food from my hotel'. She says 'If I go for water at public water tap, people don't allow me to carry water. Though I got rid of disease and my children and grandchildren but have no leprosy, still people suspect me leprosy. There is high stigma against this disease in the society.'

The government has made agenda and proclamation no discrimination in leprosy but it is only in papers. She shares 'In remote villages if people see ulcers at feet, disability or outward ugliness, they suspect that he/she is leprosy. But if they don't get timely treatment, the disease might transfer to other person too. Therefore the government has to take this disease seriously and launch more effective programs.'

(Date: 2071/01/10)

4.9.4 Case Study No 4: Shanti

Shanti is female of 30. Now days, she looks after cattle and busy with household works. She studied up to grade 10th but she couldn't pass SLC. Comparing to her friends, she worries that she could not study in life.

She thinks, she is having lost her life because when she got leprosy during her school days, her family members didn't allow her to go out of the house. They imprisoned her at her own house. She had to ever live to her own room all day and night. She stayed in this way more than a month. After being mentally sick and in high tension, she tried to suicide many times. Later on, one day, she was able to escape out of the house and went hospital Dadeldhura; she was counseled, got treatment and got rid of the disease. In this way, she was saved.

She thinks that there might be other women suffering due to leprosy in the community; they may be hidden and imprisoned at their own home like her. She thinks, if the government provides special care and supports such people in problem, situation might change. Otherwise, the problem is increasing entirely but leprosy is not controlled.

(Date: 2071/02/04)

4.9.5 Case Study No 5: Dhani Joshi

Dhani is male 60. Dhani thinks that leprosy occurs due to curse of gods. According to him, no one was suffered by leprosy on his family before. He said that only his elder father's son was leper many years ago who used to live nearby his house. He died 30 years ago and he was buried into pit. His funeral ceremony was not done as normal people. At that time people who died due to leprosy, people didn't take part in funeral ceremony. At that time he was 15 years old.

At the age of 45 he also suspected that he has some kind of signs and symptoms like leprosy. He didn't do any kind of treatment thinking that it might be curse of god. Only before a month ago, deformities started- both legs muscles gone dry and thin, hands and feet were swelling. He suspected leprosy and went to traditional healers but the problem was same. Then, he changed his idea and started to seek hospital. He went to local hospital and referred to THD at Dadeldhura where he got treatment.

He said *that* he heard about leprosy through radio that this disease can be healed, but actually he doesn't know more about the treatment process.

(Date: 2071/03/02)

4.10 Findings from the Case Studies:

From the case studies above, it is found that how people are struggling with their life e.g. seeking treatment, fear of job, fear of community, fear of disease. Leprosy affected people are facing exclusion even from their own family. It is known that still there are lots of blind beliefs toward disease. There are number of leprosy suspect people in unreached areas, who really need outside support.

A student's imprisonment by her own family members due to leprosy is measurable. Everywhere there is discrimination. And there is lack of trained manpower, health facilities and resources in leprosy diagnosis and treatment in this region.

(Name and place changed due to privacy in these case studies).

CHAPTER V

SUMMARY, CONCLUSION & RECOMMENATION

5.1 Summary

A state is responsible for welfare of its citizens. It provides services, security and opportunities to its citizens. Similarly a state can play vital role to eliminate leprosy related stigma.

Leprosy disease is the oldest disease in the world and its negative impact onto human civilizations is even today. As well, in Nepal, leprosy has been a major health challenge from generations. People from Dadeldhura and surrounding areas use to get leprosy diagnosis and treatment services through available government non-government health facilities before past 50 years. Leprosy is now controlled compared to past. However, the new cases are seen and the consequences of the disease are still prevailed in the society. Mostly there is stigma and discrimination toward leprosy affected persons in remote and rural area. But the actual situation of the stigmatized people due to leprosy is unknown. Therefore the study has been done to understand and contribute to minimize stigma related to leprosy in the state, raise awareness in the community and contribute to effective National Leprosy Control Program Nepal.

Literature sources for the study were books, newspapers, reports etc. Services provided by the government non-government agencies to leprosy affected people were studied. And the available data and materials were analyzed and presented in this report. This study is done according to the research procedures. Questionnaires were distributed in three categories to leprosy affected people, community people and policy makers, political parties and service providers in order to know their opinion in various aspects towards leprosy and it's affects upon the human being. Numbers of leprosy affected people were taken interviews. For the analysis of data different statistical tool are applied such as average, percentage and Chi- square test of hypothesis are used for data analysis.

From the study, it is found that though the dreadful situation of leprosy is improved compared to past, still there are various problems and discrimination faced by leprosy affected people in the communities i.e. de-habilitation. Therefore, the state has to increase stigma reduction activities.

5.2 Conclusion

Though leprosy is eliminated in Nepal through governmental and non-governmental services, still it has been highly stigmatized disease. As far western region is least developed region compared to other parts of Nepal; and due to poor health facilities, geographical difficulties and blind beliefs there is highly negative consequences of leprosy in this region. In addition, discriminating behaviors done toward LAPs and their families in society is higher than people suffer with other diseases. This is the stigma in leprosy.

5.3 Recommendation:

The vision of the small study is too seeing leprosy stigma-free state, thinking that this small effort might be base in stigma reduction in leprosy. Here is the recommendation in this regard:

- Government should maintain high level and sustainable commitment for elimination of stigma in leprosy developing appropriate policies, guidelines and strategies about it.
- Government and non-government sector should contribute in stigma reduction in leprosy though partnership with formed different disabled people's organizations, self-help groups and empowering them.
- Different political parties in Nepal has played key role for the development and protection of rights of people and sustaining democracy in Nepal. Similarly, the political parties should contribute to stigma reduction due to leprosy in Nepal. Moreover, the political parties should involve leprosy affected or their family members in political activities.
- Community should support in rehabilitation of leprosy sufferers accepting them and they should save them from de-habilitation and rejection.
- Community awareness about leprosy should be raised in effective way.

- Leprosy affected people themselves too try to be more conscious and they can provide peer education in stigma reduction. It is better to involve them in policy making. The state should empower them to overcome discrimination.
- If the media spread key messages about leprosy, stigma minimizes. So, the government should promote media role in stigma reduction.
- State should train health staffs to increase their role in leprosy service and stigma reduction.
- Education is a major part to reduce stigma. Therefore, the teachers should contribute in stigma reduction through awareness and education in the community.
- Traditional healers, religious leaders should teach scientific message about leprosy.
- Early case detection, early treatment and integrated set up of rehabilitation minimizes stigma in leprosy. Therefore, the state including these services should maintain proper coordination channel and improve health system to minimize stigma in leprosy.

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Appendix I
List of Interviewees

SN	Name of Interview	Profession/ Designation	Organization
1	Prem Raj Joshi,	Member	Ugratara Youth Club, Pokhara
2	Shankar Pd Bhatt	Teacher	Samaizi VDC
3	Yagyaraj Bhatt,	LDO	DDC, Dadeldhura
4	Gokul Bohara	Agriculture Information Officer	Agriculture Development Office, Dadeldhura
5	Uddhavdev Bhatt,	Admin Officer-ECN	Dadeldhura, Election Commission Nepal
6	Raisingh Dhami	General-Member	Alive-Nepal
7	Gaumati Upreti	Social Worker	Loo-Niva Child Concern Group Dadeldhura
8	Shyam Mandal	TLO	District Health Office Dadeldhura
9	Tara Datta Pant	TLA	Sub-regional Hospital Dadeldhura
10	Narad Prasad Joshi	DEO (<i>On Act</i>)	Dadeldhura
11	Prem Saud	Member Secretary	Nepal Communist Party Dadeldhura
12	Shivraj Joshi	CDO	District Admin Office Dadeldhura
13	Dambari Bhatt	Vice-Chairman	Disabled Welfare Regional Committee
14	Tika Subedi	G. Member	HCDP Dadeldhura
15	Tilak Hamal	Member	Red Cross Society, Dadeldhura
16	Shivraj Bhatt	<i>N.Subba</i>	Sub-Regional Hospital, Dadeldhura
17	Subas Saud	Chairman	Disabled Welfare Committee Dadeldhura
18	Laxmidatta Dhiktal	Vice-Secretary	Maoist (Integrated) Party Dadeldhura
19	Tirthraj Upreti	Member	Rastriya Prajatantra Party, Dadeldhura
20	Khagendra Pathak	Member	Amar Self-Help Group Dadeldhura
21	Puspraj Joshi	HP In-charge	Manilek VDC
22	Ram Bahadur	Secretary	Nepali Congress Party Dadeldhura
23	Chaturbhuj	Teacher	Belapur VDC
24	Dilli Raj Joshi	Officer	DDC, Dadeldhura
25	Indramani Awasthi	Teacher	Dadeldhura

3	If people affected with leprosy are encouraged to take part in political activities	
4	If they are encouraged and promoted to decision making level	
5	Promote media role	

5. Some Separate Questions for leprosy affected persons only (Please tick)

SN	Questionnaire	Yes	No
1	Having spoiled my life due to leprosy		
2	I feel out of place in the world and feel inferior to others because I have leprosy		
3.	Everywhere there is discrimination		
4	Discrimination in the school toward children of leprosy affected people		
5	Conflicts between husband and wife due to leprosy		
6	Uneasy behavior done by relatives		

6. Some open questions:

a) In your view, has the government provided any kind of special services and security to leprosy affected people?

b) (*Only for political parties*) what are the policies of your party toward them?

c) (*For policy makers and service providers only*) Are there any services the organization you belong, providing any kind of services to them and their family members?

d) If any experience, incidence or suggestion,

Appendix III

Format Used for Opinion Survey: Respondents

PART	Respondents	Yes		No		Total	
		Number	%	Number	%	Number	%
I	Leprosy affected people	XXX	XX	XXX	XX	XXX	XX
II	Community People	XXX	XX	XXX	XX	XXX	XX
III	Policy makers, service providers, Political Parties	XXX	XX	XXX	XX	XXX	XX
Total		XXX	XX	XXX	XX	XXX	XX

Note: PART I, II and III, were different respondents and asked separately. Interviews conclusion is summarized in Chapter IV. All questionnaires were translated and asked in Nepali language. And, list of (Part III) interviewees attached here with.

Glossary

Leprosy Affected People:	Person having leprosy clinical signs and symptoms in past or at present that needed MDT or treated
Stigma in leprosy	An attitude in society to reject the client or their family members from society for any kind of social contact/relationship
De-habilitation:	People excluded or rejected in the community from social activities, or in the state e.g. due to leprosy disease
Rehabilitation:	bring to previous condition
Equity:	leprosy affected people have the same opportunity as normal people
Deformity:	Changed structure of eye, feet and hands resulting from impairments of nerves, such as deformed nose or clawing hands
Disability:	A loss of restriction of functional ability or activity as a result of impairment of body or mind
Social justice:	an absence of discrimination for any reason
Blind beliefs:	Traditional and old concepts, beliefs that lack scientific base
Natural rights:	Inherent rights of an individual
Pauci bacillary:	A leprosy patient with up to five skin patches
Multi bacillary:	A leprosy patient with six or more skin patches